

# Transitioning to a Healthy Adulthood

## Lessons Learned from Adolescent Girls Living with HIV in Urban Zambia

Research Team:

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### BACKGROUND

Nearly six percent of Zambian girls aged 15-19 are living with HIV.<sup>1</sup> Many were infected at birth when antiretroviral therapy (ART) was not widely available for pregnant women. Others have acquired HIV through sexual relationships or abuse. Adolescent girls continue to be at high risk for acquiring HIV due to social factors, like harmful gender norms, and structural factors, such as a lack of youth-friendly health services.<sup>2</sup> Previous research in Zambia found that adolescents living with HIV often had difficulty adhering to treatment, disclosing their HIV status to family and friends and coping with stigma. They also had limited access to information about sexual and reproductive health.<sup>3</sup> Despite these challenges having been identified, very few community-based or clinic-based programs are designed to support healthy transitions to adulthood for adolescent girls living with HIV.

The International Center for Research on Women (ICRW) and Zambart conducted formative research between January and April 2015 to generate evidence-based ideas for services and programmatic interventions that support healthy transitions to adulthood among adolescent girls living with HIV in Zambia.

### METHODOLOGY

Twenty-four adolescent girls living with HIV between the ages of 15 and 19 were recruited to participate in the study from two urban health centers in Lusaka. Data were collected through a series of two participatory workshops with two groups of 10 and 14 participants each. Two rounds of in-depth interviews (IDIs) were then conducted with 17 participants. The characteristics of the participants are shown in Table 1.

Table 1. Participant Characteristics

	(N= 24)
<b>Age</b>	
15	10
16	5
17	5
18	4
<b>Socio Economic Status</b>	
Low	14
Mid	10
<b>Mode of Acquisition</b>	
Perinatally Infected	17
Non-consensual Sex	2
Not Specified	5
<b>Age Of HIV Disclosure to Participants</b>	
Under 11	5
11-12	4
13-14	5
15-16	3
Not Specified	7

In the workshops and IDIs, the girls discussed finding out about their HIV status, experiences with disclosure, experiences with treatment and at the ART clinic, support needs and gender differences. Data were collected through note-taking, digital recorders and through photos of workshop materials. Data were organized, coded and analyzed using ATLAS.ti Version 7. Ethical clearance was obtained from review boards in Washington, DC, USA and Lusaka, Zambia.

## KEY FINDINGS

A range of findings emerged from the research, including examples of resilience, support and creative mechanisms for coping with HIV. In this brief, we focus mainly on the challenges that emerged and the types of interventions that could be implemented to remove these hurdles to ensure a healthy transition to adulthood for adolescent girls living with HIV. We have organized the findings based on the following socio-ecological levels to inform the development of a multi-level intervention: the individual-level (adolescent girls), the interpersonal level (families, friends and social networks) and the organizational level (social institutions such as schools and clinics). The complete range of findings will be presented in a forthcoming publication.

### Individual level

The adolescent girls who participated in the research overwhelmingly asserted that living with HIV was not going to hold them back from achieving their dreams. The girls created collages during the first participatory workshop that clearly highlighted their aspirations of receiving a good education, having a career, having a family with children and living a comfortable life with nice possessions (see Fig. 1.)

*"I don't want anyone to think that because I am [HIV] positive I cannot do it – because I can" (Age 17)*

Despite their resilience and determination, all of the participants expressed some challenges about living with HIV. At the individual level, girls expressed the following concerns:

- Lack of support to cope with emotional needs.
- Lack of tools and advice to help with decisions around HIV disclosure.
- Fear of experiencing stigma if their status becomes known (anticipated stigma).
- Challenges around taking treatment, including confidentiality and side effects.
- Gaps in knowledge about HIV, including on treatment as prevention.

### Emotional needs

Most of the participants had limited opportunities to talk to others about their emotional needs, including around grief and loss, and appreciated the opportunities offered during research and clinic workshops to talk about their feelings.

*"Well speaking of support, I don't... So I've just realized that I rarely talk to people about stuff. I'm used to just keeping stuff to myself. I don't know whether it's cause I never really had anyone to talk to growing up, so I just got used to keeping everything in." (Age 17)*

### Disclosure

While disclosure of their HIV status was limited and treated with caution by most participants, there was a noted lack of support on how to approach the topic with friends, boyfriends or other trusted persons. The participants received mixed messages



Figure 1.

around disclosure from clinic staff, teachers and parents. For example, some clinic staff encouraged disclosure to boyfriends to limit risk of transmission, while some parents and guardians discouraged disclosure in order to minimize stigma both for the participant and her family. For the majority of participants, their parents or guardians decided whom to tell and then disclosed on behalf of the girl.

### Fear of stigma

Most of the participants expressed significant concern about what would happen if their HIV status were to become known to friends, boyfriends, teachers or family friends.

*"If I did tell them, maybe when I tell them they will start talking about me to people" (Age 15)*

### Treatment

While most participants reported good adherence to treatment, fear of others knowing their status sometimes led to challenges with taking ART. For example, when social events such as afterschool activities or camps coincided with medication times, some participants would skip doses. All participants understood the importance of adhering to treatment and many reported that taking the drugs made them look healthy and feel confident. Some noted that a healthy appearance was a useful tool that allowed them to deflect stigma and assumptions about their HIV status. As one girl put it, you could "use your appearance as a defense." Some side effects were experienced, however, particularly when drug regimens changed. Some participants recalled feeling dizzy, weak, having blurry vision and being unable to concentrate at school.

## Knowledge about HIV

While all participants had at least basic knowledge about HIV, there were specific gaps in their knowledge. In particular, participants were not aware that ART greatly reduced the risk of transmitting HIV to a sexual partner. It appeared that clinic staff and adolescent counselors were reluctant to share this information for fear that it might encourage adolescents to more readily engage in unprotected sex. There was also a clear gap in the provision of more neutral information on sexual health. Instead, counselors, clinicians and family members spoke about sex in moral terms of 'right' and 'wrong', often telling girls they shouldn't be having sex. Such framing made participants feel guilty about their curiosity and desires and discouraged them from speaking openly about sex.

## Interpersonal level

Many participants received significant and valued support from their family, friends and trusted community members. However, the girls mentioned a number of challenges, including:

- Fears of casual transmission and stigma from family.
- Lack of opportunities to discuss issues around HIV with family and peers.
- Harmful social norms that affect adolescent girls living with HIV more than they affect boys.

## Family

For all participants, family provided vital support and encouragement, including practical, financial and treatment support. However, family members often had a lack of detailed knowledge about HIV. For example, the types of stigma experienced by some of the girls at home (e.g. being moved away from other children in the family or being given separate cups, plates and clothes) stem from unfounded worries about HIV being transmitted via casual contact with others. Another common form of stigma was a family member bringing up a participant's HIV status during arguments to make the participant feel bad.

## Peers and social networks

While most participants had not disclosed to any friends, a few had disclosed to a limited number and were subsequently supported and encouraged by these friends. The main barrier to disclosure was anticipated stigma and fears about people telling others about their status. The participants placed particular importance on support from other people living with HIV, either friends from clinic workshops or family members, such as siblings or cousins. However, opportunities to talk openly with other people living with HIV are currently limited for most participants. Organized peer support groups are not available in most communities and many participants were hesitant to approach peers that they knew or suspected to be living with HIV, for fear of inadvertent disclosure.

*"I'd just go to my friends because we're closer and we're in the same age-group, so they'll likely understand more than my parents or other people" (Age 17)*

## Social norms around morality and gender

The participants were highly discouraged from having sex by their families, clinic staff and sometimes peers, partly based on social norms and morals around not having sex before marriage, and partly because they were viewed as 'infectious'. Some were chastised for having "bad [sexual] behaviors". There was an explicit view, even from some of the participants, that those who had acquired HIV at birth were more 'innocent' than those who had acquired HIV behaviorally. According to the participants, being a girl living with HIV was linked to prostitution and the participants considered themselves weaker than boys when it came to standing up to those stigmatizing them.

*"I think with girls if you are like HIV positive, then obviously they say that you are a prostitute or a whore or something like that. But for a guy, obviously they even like congratulate him for that" (Age 17)*

## Institutional level

### Clinic

The participants were generally satisfied with their clinical care and felt they were well taken care of. They received significant support from adolescent counselors, volunteers, nurses and clinicians and mostly felt comfortable asking questions about their care and treatment. The key concerns reported at the clinic included:

- Long waiting times and administrative challenges (e.g. lost files and test results).
- Fears around being seen by people they know.
- Limited access to neutral information about sexual and reproductive health.

Participants expressed a desire for procedural changes to reduce waiting times at the clinic. Girls often missed a whole day of school due to long waiting times. Participants from one health facility also reported that lost files and test results were commonplace. Participants were also concerned about inadvertent disclosure while at the clinic, mainly on their way through the health facility to reach the ART clinic, but also sometimes inside the ART clinic, where they could bump into people they knew.

Workshops at the clinic were an important source of information, support, and means to meet other adolescents living with HIV. However, information often focused heavily on adherence to treatment and moral messaging around abstinence, which often leads to feelings of guilt and secrecy. Access to neutral information and open, non-judgmental discussions around sexual relationships and health in the context of HIV was limited.

### School

While school was often a source of confidence for the participants, with many proudly referencing academic achievements, school also presented a range of challenges for many. These included:

- Fearing that students and teachers will inadvertently learn their HIV+ status.

- Feeling bad when students and teachers expressed negative or judgmental views about people living with HIV.

Most participants had never disclosed their status to anyone at school and expressed concerns over other students and teachers inadvertently learning their status. For the few who had disclosed to teachers, they felt supported by them. However, a few participants reported that some of their teachers had given incorrect information or judgmental messaging about HIV in class, which made them feel sad, uncomfortable and disinclined to disclose their status.

*"...at school they are teaching: HIV kills, even when you exchange clothes with your friend, you can get infected. Then I thought, where will I be getting clothes from when they are saying that HIV kills? I used to feel so bad. That's why I had to leave that school." (Age 15)*

*"She [the teacher] would say: 'If those who are born with it, you can't blame them. But those who have just had it after they were born without any problems, they just get it, then it's their fault... this is why I talk about fornication and all that'. Yes, I get it, she's trying to teach us, give us knowledge, but it's just in the wrong way." (Age 17)*

## INTERVENTION RECOMMENDATIONS

Our findings suggest that adolescent girls living with HIV in urban Zambia would benefit from a multi-level intervention. Recommendations for intervention components are summarized below by socio-ecological level:

### Individual level

- **Create opportunities for adolescents living with HIV to engage individually with other adolescents living with HIV**, either in person, or through technology, to support the girls' emotional and information needs over time. Both support group formats and peer-to-peer opportunities would be beneficial.
- **Disseminate new sources of information** on sexual health and HIV transmission that can be accessed discretely through the Internet or in the clinic waiting area. These materials could also be used in support groups to facilitate discussions. These could include: multimedia materials, videos, brochures, youth-oriented smart phone apps, help lines and more.

### Interpersonal level

- **Develop information sessions and counselling support for parents and guardians of adolescents living with HIV.** These would increase their knowledge about HIV and help them to talk to their children about issues around HIV, disclosure and sexual and reproductive health.

### Institutional level

- **Implement procedural changes at the clinic to reduce waiting times**, particularly to see clinicians.
- **Train adolescent counselors on discussing sex in a neutral way with adolescents**, which can include guidance on facilitating discussions following use of new multimedia tools and videos.
- **Train and supervise teachers to integrate existing curricula on sexual and reproductive health and HIV stigma-reduction in schools.** This would increase teachers' and children's knowledge around HIV and sexual health and ensure that teachers are confident to discuss HIV and stigma, foster non-judgmental attitudes and create a supportive environment for students living with HIV in their classrooms.
- **Implement school-wide campaigns promoting compassion and support for people living with HIV** to reduce judgmental attitudes and create a more supportive environment.

## REFERENCES

1. National AIDS Council, Zambia. *Zambia Country Report: Monitoring the Declaration of Commitment on HIV and AIDS and the Universal Access.* Lusaka, Zambia. 2014
2. WHO. *HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV.* 2013.
3. FHI 360. *ALHIV in Zambia. An examination of HIV care and treatment and family planning.* 2013

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