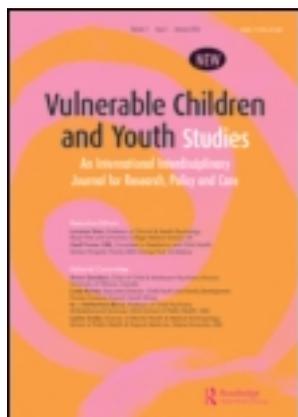


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### Having sex, becoming somebody: A qualitative study assessing (sexual) identity development of adolescents living with HIV/AIDS

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## Having sex, becoming somebody: A qualitative study assessing (sexual) identity development of adolescents living with HIV/AIDS

Jasna Loos<sup>a\*</sup>, Christiana Nöstlinger<sup>a</sup>, Irene Murungi<sup>b</sup>, Daniel Adipo<sup>c</sup>, Brenda Amimo<sup>c</sup>, Sabrina Bakeera-Kitaka<sup>b,d</sup>, Dorothy Oluoch<sup>c</sup>, Phyllis Mboi<sup>c</sup>, Eric Wobudeya<sup>d</sup>, Hilde Vandenhoudt<sup>a</sup> and Anne Buvé<sup>a</sup>

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A growing number of adolescents are living with HIV/AIDS. For their well-being and for prevention, age- and culturally appropriate interventions become increasingly important. This qualitative study was conducted as the first step to develop a sexual and reproductive health (SRH) intervention. The study's objective was to assess the impact of HIV and related contextual conditions on identity formation of adolescents living with HIV/AIDS (ALH) in the domains of physical, cognitive, social, and sexual development. Data were collected using focus group discussions (FGDs). Through HIV care centers in western Kenya and Greater Kampala, Uganda, we recruited 119 ALH aged 10–19 years, 54 of their caregivers, and 55 service providers for 28 FGDs. Following analytic induction principles, data analysis showed that many ALH had grown up in HIV-affected families in poverty. They reported experiencing long histories of illness and HIV-related stigma and discrimination, affecting their self-esteem. The physical changes of puberty, fueled by effective HIV treatment, symbolized a new start in life. The cognitive changes typical for adolescence enhanced their self-esteem, resilience, and belief in the future, particularly among older adolescents. In discovering their new social identity, ALH experimented with behaviors and norms, especially related to sexuality. ALH carefully examined the contrasting sexual norms of their peers, caregivers, and service providers and balanced them when developing their own sexual identity. For many ALH, sex is the way to become a social “somebody.” For some, having sex served to cope with the emotional pains of growing up with HIV. Sexual relationships also enabled some ALH to gain financial and emotional independence. This study shows how ALH's identity development is influenced by the individual and social consequences of HIV. Multiple factors contribute to the importance that ALH attribute to sexuality, which calls for comprehensive interventions addressing the broader context of positive living and SRH rights.

**Keywords:** adolescents; HIV; identity development; sexuality; interventions

### Introduction

Worldwide, an increasing number of adolescents are living with HIV/AIDS. Eighty percent of the approximately seven million HIV-positive young people below the age of

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24 worldwide are living in sub-Saharan Africa (UNAIDS, 2010). In Kenya and Uganda, perinatally infected children (under 15 years) comprise 12% of all reported HIV infections (UNICEF, 2009). Among adolescents and young adults aged 15–24 years, HIV prevalence was 2.9% in Kenya and 3.6% in Uganda in 2009 (UNICEF, 2009).

Improved access to antiretroviral treatment (ART) has resulted in increasing numbers of children living with HIV who reach adolescence and adulthood (Foster & Fidler, 2010). A growing number of studies conducted among adolescents living with HIV/AIDS (ALH) in Eastern Africa show that this transition goes along with specific sexual and reproductive health (SRH) challenges, such as unmet contraceptive needs, unintended pregnancies (Beyeza-Kashesya et al., 2011), and unsafe sexual behavior (Bakeera-Kitaka, Nabukeera-Barungia, Nöstlinger, Kekitiinwa, & Colebunders, 2008; Birungi, Obare, Mugisha, Evelia, & Nyombia, 2009). These studies all underline the need for evidence-based interventions supporting ALH in their SRH. Apart from a few exemptions (Lightfoot, Rotheram-Borus, & Tevendale, 2007), the existing interventions have been designed and evaluated in resource-rich settings only (Elkavich, Rotheram-Borus, Goldstein, Flannery, & Jones, 2005; Michielsen et al., 2010). To address this gap, the study team aimed to develop a tailored SRH intervention for ALH in Uganda and Kenya.

In their review identifying 17 characteristics of effective sex and HIV education programs for youths, Kirby, Laris, and Rolleri (2007) found that programs should address the multiple psychosocial risk and protective factors underlying the targeted risk behavior. Clear messages, appropriate to the youth culture, developmental stage, and sexual experience should be given. This translates into SRH interventions targeting ALH to be comprehensive, culturally sensitive, and developmentally appropriate. Apart from managing HIV-specific challenges, ALH are confronted with the developmental challenges of adolescence, just like their uninfected peers. The formation of a personal and social identity becomes a central task during adolescence. During this period, adolescents undergo puberty, develop new cognitive skills, and learn to negotiate intimate relationships (Kang, Mellins, Kee Ng, Robinson, & Abrams, 2008). The smoothness of adolescents' transition is determined by personal, economic, social, cultural, and health conditions (Steinberg & Morris, 2001). Most theories also positively link family influences and parenting processes with the development of identity (Mullis, Brailsford, & Mullis, 2003). These findings suggest that the individual and social consequences of HIV will affect the identity formation of ALH, including their sexual socialization. Few qualitative studies have reported on aspects of ALH's identity formation. Aka Dago-Akribi and Cacou Adjoua (2004) described the importance ALH in Abidjan attributed to their bodily development. They reported on how HIV-induced delayed puberty brought up worries about social position (e.g., participation in traditional rituals) and their future (e.g., getting married and having children). A qualitative study of Hosek, Harper, and Robinson (2002) described adolescent relationships and psychological burdens of ALH aged 17–21 in the United States. Other studies have documented the impact of HIV-related stigma on ALH, e.g., on adherence and health-care utilization (Birungi, Obare, van der Kwaak, & Namwebye, 2011; Martinez et al., 2012). Yet, few studies applied an integrated approach to identity development of ALH and no studies were carried out in Eastern Africa. Since understanding the impact of HIV and the related contextual conditions on adolescents' identity formation in the interlinked domains of physical, cognitive, social, and sexual development is essential for the development of an SRH intervention, we conducted this qualitative formative study.

## Methods

We used an inductive methodological approach and focus group discussions (FGDs) as data collection technique (Morgan & Krueger, 1998). Between July and November 2009, 28 FGDs were held.

To ensure assessing diverse insights and perceptions, three distinct groups of participants were included, i.e., ALH aged 10–19 years, caregivers of ALH, and providers of HIV support services. A convenience sample was recruited via HIV care and support centers collaborating in the intervention development: Baylor College of Medicine Children's Foundation – Uganda (Kampala, Uganda), Tuungane (in Kisumu, western Kenya), and YESHICA (based in Kamito and Wagai, rural villages about 50 km from Kisumu). Written informed consent was obtained before participation. Caregivers of ALH provided consent before minors gave assent. The study received ethical approval from Institutional Review Boards of all collaborating institutions, namely Baylor College of Medicine, Centers for Disease Control – Texas, Makerere University, Kenya Medical Research Institute (KEMRI), Institute of Tropical Medicine (ITM), and the University of Antwerp.

Sociodemographic and medical data were collected prior to the FGDs using a brief face-to-face questionnaire. Trained moderator conducted the FGDs assisted by one or two observers/note takers. To inform the intervention under development, an open-ended topic guide on seven themes was used: puberty, cognitive changes, personal and community perception of life with HIV, medical aspects, relationships, sexuality, SRH-related needs, and expectations toward a SRH intervention. Discussions took on average two hours and were held in the local language (Luganda or Dholuo) or English depending on the participants' preference.

FGDs were tape-recorded, transcribed verbatim, translated in English, randomly checked for quality control, and coded with N-VIVO 8 software (QSR International, Melbourne, Australia) following a codebook. Coders of the different research teams independently proposed data-driven codes, establishing a consensus codebook after comparison and discussions. Transcripts were divided and coding continued independently with regular review meetings lead by the first author. Four of the coders conducted the analysis. Separately, they applied analytic induction principles to assess the impact of HIV and related contextual influences on identity development of ALH along the dimensions of gender and age differences. The codes were categorized into themes relevant to this specific research question. Differences in findings were compared and discussed to reach consensus.

## Results

### *Participants' characteristics*

The 16 FGDs with ALH were organized homogenously according to age and gender. Eight FGDs were organized with 64 girls and another eight with 55 boys. To yield developmentally appropriate results, participants were subdivided in eight FGDs with 10–12-year-olds, four FGDs with 13- and 15-year-olds, and four with 16–19-year-olds. As shown in Table 1, most of the participants had acquired HIV through vertical transmission, and many who were orphaned were currently living with extended family or siblings. While the majority was in school, many had performance problems. Eighty percent of ALH were in medical follow-up, more than 80% were on ART, and the majority participated in a peer support group.

Table 1. Sociodemographic and medical characteristics of the participating ALH.

Adolescents living with HIV		Females 64 (53.8%)	Males 55 (46.2%)	Total 119 (100%)
Residence	Kampala District (Uganda)	28 (43.8%)	30 (54.6%)	58 (48.7%)
	Kisumu Town (Nyanza Province, Kenya)	12 (18.7%)	18 (32.7%)	30 (25.2%)
	Kamito and Wagai (rural towns, Nyanza)	24 (37.5%)	7 (12.7%)	31 (26.1%)
Age (mean)		12.9 years	14.1 years	13.5 years
School	In school	54 (84.4%)	48 (87.3%)	102 (85.7%)
	Two years behind in school*	15 (30.6%)	10 (25.6%)	25 (28.4%)
	Three years or more behind in school*	11 (22.4%)	9 (23.1%)	20 (22.7%)
Parents*	Not in school	10 (15.6%)	7 (12.7%)	17 (14.3%)
	Both parents died	23 (35.9%)	23 (42.6%)	46 (39.0%)
	Father or mother died	22 (34.4%)	17 (31.5%)	39 (33.0%)
Living situation	Both parents alive	19 (29.7%)	14 (25.9%)	33 (28.0%)
	With both or one biological parent(s)	29 (45.3%)	17 (30.9%)	46 (38.7%)
	With extended family	25 (39.1%)	24 (43.6%)	49 (41.2%)
	With siblings	9 (14.1%)	9 (16.4%)	18 (15.1%)
HIV transmission	Other (alone, homeless, or with partner)	1 (1.5%)	5 (9.1%)	6 (5.0%)
	Do not know the transmission route	29 (45.3%)	22 (40%)	51 (42.9%)
	Know the transmission route	35 (54.7%)	33 (60%)	68 (57.1%)
	Mother-to-child transmission	29 (82.9%)	24 (72.7%)	53 (77.9%)
	Sexual transmission	2 (5.7%)	5 (15.1%)	7 (10.3%)
	Blood	2 (5.7%)	2 (6.1%)	4 (5.9%)
Medical follow-up*	Preferred not to answer	2 (5.7%)	2 (6.1%)	4 (5.9%)
	Part of peer support group*	54 (84.4%)	47 (85.5%)	101 (85.6%)
	On ART*	52 (81.2%)	48 (87.3%)	100 (84.7%)

\*Variables with missing data.

Six FGDs with caregivers were gender mixed and consisted mainly of parents and relatives of ALH (76%), the remaining were acquaintances and friends taking on the caregiver role. Many of the caregivers were also living with HIV and about half were widowed or separated/divorced. They cared for an average of five children.

Six FGDs with service providers were also gender mixed and consisted of HIV service providers having worked on average three-and-a-half years with ALH. Most of them were nurses (59%) (Table 2).

### **Qualitative analysis: emerging themes**

#### *Changes in puberty: "healthy body image"*

Most participants reported long histories of HIV-related illness, growth retardation, and visible medical problems, such as sores and rashes. Many said people's stigmatizing reactions to their physical appearance had undermined their self-esteem. The bodily changes of puberty attributed to effective ART resulted in the development of a new body image and increased self-confidence. The younger ones in particular perceived their growth spurt as a sign of hope and accomplishment.

I never thought I would grow, but look at me, I look beautiful, now I am somebody. (Girl, 10–12 years, Kisumu)

Girls and boys cherished their newly acquired self-esteem by caring about their hygiene and appearance, like dressing up and showing off:

They shine and they are not dull as before. Their buttocks shake when they are walking and they are conscious of the way they are walking. (Caregiver of ALH aged 13–17, Kisumu)

Table 2. Characteristics of participating caregivers of ALH and service providers of ALH.

Caregivers of ALH		N = 54	Percentage
Residence	Kampala District (Uganda)	18	33.3%
	Kisumu Town (Nyanza Province, Kenya)	18	33.3%
	Kamito and Wagai (rural towns, Nyanza, Kenya)	18	33.3%
Gender	Female	47	87%
	Male	7	13%
Age (mean; range)		41.7 years (20–69 years)	
Marital status	Married	25	46.3%
	Widowed	22	40.7%
	Single (divorced/separated)	7	13.0%
Occupation	Self-employed	19	35.2%
	Farmer	11	20.4%
	Other (regular/casual employment, housewife)	20	37.0%
	Unemployed	4	7.4%
Relationship with ALH	Parent	24	44.4%
	Relative (grandparent, aunt, sibling, wife)	17	31.5%
	Other (acquaintance, friend)	13	24.1%
ALH sleeps in the same house as the caregiver		48	88.9%
Caregivers' HIV status	HIV-positive	21	38.9%
	HIV-negative	30	55.6%
	Preferred not to answer/unknown	3	5.5%
Service providers of ALH		N = 55	Percentage
Residence	Kampala District (Uganda)	23	41.8%
	Kisumu Town (Nyanza Province, Kenya)	17	30.9%
	Kamito and Wagai (rural towns, Nyanza, Kenya)	15	27.3%
Gender	Female	34	61.8%
	Male	21	38.2%
Age (mean; range)		33.4 years (24–54 years)	
Profession	Nurse	32	58.2%
	Doctor	9	16.4%
	Other (social worker, counselor, nutritionist, etc.)	14	25.4%
Experience working with ALH (mean, range)		3.5 years (five months, 24 years)	

Many participants remembered vividly the social isolation when they were ill. They could not contribute to household chores, missed school and felt isolated, insulted, and abused. Changing physically into healthy adolescents offered a new social position:

People will start respecting us. They will say: “so and so’s son has grown . . .” and they will start thinking that I will be respectable. (Boy, 13–15 years, Kampala)

### *Cognitive changes and coping with HIV*

At 12 years I feel like I have grown and my thoughts have also grown. (Boy, 10–12 years, Kampala)

This quote illustrates how in particular participants younger than 15 years consciously observed changes in their cognitions. Accounts of the very young adolescents (up to 12 years of age) were very concrete, while the discussions of the older adolescents (especially 16–19 years) accounted for hypothetical reasoning and more complex analyses of actions and emotions. Older participants showed increasing resilience in coping with HIV. They took their lives more actively in their own hands, developing positive perspectives toward their future and fulfilling role-modeling tasks for younger HIV patients.

Like they say age is wisdom and you start giving advice. I will also start giving my fellow HIV positive young ones advice, I will say “you see I was also once like you”. (Boy, 16–19 years, Kampala)

This resilience of older participants stood in sharp contrast to younger participants’ avoidance to think about and discuss HIV:

Most of them, by the time they are ten, are starting to understand that they have HIV. Usually [before that] they were very open with you, but at this time they start being shy ( . . . ) and sometimes they refuse to open up. (Service provider about ALH aged 10–12, Kisumu)

Almost all participants mentioned having been confronted with HIV-related stigma and discrimination. They had been isolated at home and at school due to of fear of infection, they were insulted and labeled, sometimes even abandoned. Many said this made them withdraw from social interactions, thereby internalizing the stigma. They realized that they were different from their uninfected peers and questioned their ability to ever become “normal.” They looked for a reason why HIV was afflicted upon them, often blaming their parents.

They are always asking “why me, why me?” and sometimes they blame and resent their parents. (Caregiver of ALH aged 13–17, Kampala)

Although many participants mentioned fearing a premature death, they also dreamt of a better life with a good job offering financial security and status (for instance, becoming a doctor), getting married (about half preferred an HIV-negative partner), and having healthy children. In particular, the younger ones (i.e., up to 15 years) wondered if these hopes were realistic. They balanced between their own confidence in the future, their fear of premature death, and the sometimes tainted expectations of their surroundings because of HIV:

They also begin relationships with HIV negative boys and their partners have no idea of their status and they . . . keep it a secret. I was once joking with her that she will get married to my friend's son who is also positive and she told me that she cannot get married to one who is HIV positive – she has to get a healthy one. She is only 13! (Caregiver of ALH aged 13–17, Kampala)

*Social identity: from outsiders to insiders*

HIV stigma within their families and caregivers' exhausted care capacities forced many participants prematurely into detachment from caregivers and economic independence. Many participants had lost one or both parents, leaving them to live with extended family, acquaintances, or on their own. They mentioned having been moved around between family members, who often perceived them as a financial, social, and/or emotional burden. Some of their caregivers feared HIV transmission due to physical contact and stigma by being associated with an HIV-positive adolescent living in their house. Although service providers reported on cases of, what they called, "enlightened caregivers" (i.e., actively supporting ALH to live positively by monitoring their adherence and hospital visits, providing an adapted diet, and emotional support), ALHs accounts of being treated as the "lesser child" were common. They felt they were the ones poverty-ridden families would invest little in, e.g., providing insufficient food, unsuitable clothing, and giving little or no emotional care, thus often becoming victims of psychological and physical abuse.

You are hated. They send you away from the sitting room saying that they have not given birth to an HIV child ( . . . ) They want you to use your own cup and plate and you are isolated from the others. (Girl, 10–12 years, Kampala)

Adolescents' reactions to such discrimination were diverse and context, age, and personality specific. Some adolescents, particularly those between 10 and 12 years, reported psychological problems (such as self-stigma, being depressed, distressed, or fatalistic) and adverse social reactions (mistrusting people and isolating themselves). Older ones in particular were more defiant. While girls said they argued with words, boys rather used physical force. They strived for emotional independence by detaching from their caregivers and seeking constructive relationships with their age mates.

The difference that I have seen is that I like making friends of the same age group. I don't want to associate with euh . . . younger ones. (Boy, 16–19 years, Kisumu)

You can get friends who can be helpful like if you have forgotten to take your medication, they may remind you . . . (Girl, 16–19 years, Kampala)

The youngest adolescents aged 10–12 often mentioned feeling like outsiders because "their school mates and the children from the neighborhood ran away from them." Older adolescents were happy with newly established peer groups, but also mentioned new challenges. Having felt like outsiders most of their life, they were eager to reinforce their peer relationship. Peer norms in terms of looks and behaviors became imperative.

You may see a friend dressed well and you also want the same dress, so there will be admiration. (Girl, 16–19 years, Kampala)

Shifts in autonomy were also reflected in changing relationships with service providers. Many participants perceived them to be of life-changing help and trust, but there was also

some criticism. ALH said service providers were too focused on medical problems, particularly on improving adherence, while for adolescents medical issues were only part of the many problems they had to deal with. Failure to address the multifaceted challenges faced by ALH made providers' prevention messages less effective. An older boy complained:

In some hospitals it are the medical workers who are the problem. They give the patients a hard time; it is as if the patient is at fault for having HIV. The client eventually fails to go back to the clinic. (Boy, 16–19 years, Kampala)

*Sexual feelings and identity: becoming somebody*

Only a smaller group of mostly (older) boys reported about their own sexual experiences. However, when asked about their peers, accounts were more recurrent. Yet, most ALH described how they were confronted with sexual feelings. Boys portrayed them to be overwhelming, illustrated by the typical quote “my body rules me.” Girls were more discrete, but both genders mentioned being confused about how to cope with these feelings, especially with respect to HIV.

At this age we get experiences we do not clearly understand, like you can see a girl - then your brain gets confused ( . . . ) you may forget you are already infected. (Boy, 16–19 years, Kampala)

ALH's accounts showed that they were carefully examining the diverse sexual norms of their environments. Their caregivers, service providers, and by extension society promoted abstinence. Adults generally cautioned about the consequences of sex, with service providers focusing on the medical aspects and caregivers on how sexual activity might jeopardize the future:

We tell them the dangers they may face when they involve themselves into sexual activities, like re-infection and early pregnancies and any other infections like STIs. (Service provider about ALH aged 10–12, Kisumu)

I do talk to my children and tell them that my life is full of suffering because I did not work hard at school, I got married when young. If they do not want to get married early, they should work hard at school and not play around with boys. Boys will get you pregnant and you will then drop out of school and just get married. (Caregiver of ALH aged 10–12, Kisumu)

The sexual norms of peers, however, were perceived as being quite different. Many ALH reasoned that having the bodies and thoughts of adults, they could act like them and have sex. There was also a clear gender effect: boys reported feeling the pressure to prove their ability to seduce girls, and many reported sexual experiences as proof of their masculinity.

You may have your friends who tell you that you may not be functioning. They then ask you to prove if you can really have an erection. So out of pressure you go. (Boy, 16–19 years, Kampala)

Girls reported the pressure to be able to be feminine and seductive. Looking attractive, wearing the right clothes, and using hair and beauty products increased their value in

the courting market. Given economic shortages in their families, this was perceived as an opportunity to improve their social position in the future by later marrying someone with a higher social status. In this competition, female friends became opponents, and there was increased pressure on some participants to engage in transactional relationships.

Someone may tell her friend that: “Do you see what I am having? It is my partner who bought it for me.” Such things may make someone want to do what the other friend is doing. Peer groups may influence. (Girl, 16–19 years, Kamito and Wagai)

Some participants reported other ALH engaged in sexual relationships for survival:

At times they [other ALH] don’t have parents or others to provide for them, this makes them go into relationships for assistance. (Girl, 16–19 years, Kamito and Wagai)

Some participants facing emotional neglect also said to be ready to maintain relationships by having sex on pressure of their partners, because “at least somebody will love you.” They said the absence of parental monitoring enabled them to take their own sexual decisions, because “nobody really cares.”

For some, sex also meant experimenting and having fun, a way of coping with the distress they felt in relation to living with HIV. Fear of dying emerged as an additional topic when discussing sexual debut. Participants expressed the need to experience everything in life before dying and to accomplish the big steps in life, including procreation and having a family:

You can’t die without having had sex! (Boy, 13–15 years, Kamito and Wagai)

Especially those who are HIV-positive, they get pregnant to get an heir. (Boy, 16–19 years, Kisumu)

## Discussion

Our study showed vividly how adolescents’ identity development is influenced by the individual and social consequences of HIV. The participants were growing up in HIV-affected families, in poverty-ridden contexts, and had to deal with stigma and self-stigma. These findings are in line with the literature review conducted by Brown, Lourie, and Pao (2000), who showed that ALH have to cope with emotional pain related to social stigma, isolation and hopelessness, forced disclosure, anxiety about their medical prognosis, loss and bereavement, abuse, and a body image affected by wasting and dermatological conditions. However, ALH welcome their puberty growth and improved physical appearance as a new start, which boosts their self-esteem and gives them a new social position and hope for a better future. The cognitive changes enable ALH to actively explore life with HIV and increase their resilience as they become older. Having been victims of HIV-related discrimination and social exclusion, ALH are specifically eager to become somebody and to belong to a peer group. This urge for a new sense of belonging facilitates experimentation with new behaviors, including sexual behaviors. It is remarkable how the focus on sexuality cuts across all areas of ALH’s identity formation. ALH are becoming sexually active during their teen years, just like their HIV-negative counterparts (Baryamutuma & Baingana, 2011). Their bodily development in combination with the effectiveness of antiretroviral (ARV) drugs stimulates them in their sexuality. This was also found in other studies (Aka

Dago-Akiribi & Cacou Adjoua, 2004; Wamoyi, Mbonye, Seeley, Birungi, & Jaffar, 2011). ALH have not yet internalized stable sexual values and norms, which may increase their vulnerability when they are confronted with diverging sexual norms, for instance, between peers and adults. Yet, our data show their subjective importance of sexuality for their social status. For some of our participants, sex was a way to finally become “somebody.” Sexuality may also be part of their coping strategies. It enables them to cope with the emotional pains of living with HIV, the experienced social exclusion, and the anxiety of a premature death without having lived their life to the fullest. The environmental context enhances the importance of sexuality and sexual relationships. Aka Dago-Akiribi and Cacou Adjoua’s (2004) study described sexual relationships as a means of gaining independence from difficult family situations. In our study, emotional neglect due to the in-family stigma was found to be the basis of this strive. Stemming from poor backgrounds, improving their social position becomes a vital need. For many girls, sex is perceived as a means for improving their social position through transactional sex. This is in line with what has been found in studies on this topic (Kaufman & Stavrou, 2004; Morrow, Sweat, & Morrow, 2004). As shown by Nobelius et al. (2010), these tokens for sexual relationships were not perceived as immoral but served the self-respect of ALH.

Our study showed that multiple intertwined factors contribute to the importance that ALH attribute to their sexual identity and gave evidence of how it is impacted by distal contextual factors, such as culture, social norms, and poverty. While these factors are difficult to disentangle, ALH in our study clearly faced many identity challenges linked to their serious chronic condition. In comparison, ALH from resource-rich settings describe very positive self-images because they live in highly supportive personal and social environments (Di Risio, Ballantyne, Read, & Bandayan, 2011). This stresses the crucial role of youth-friendly HIV care and support.

Our study highlighted that clinic-based prevention counseling does not effectively respond to these challenges. ALH accounts showed that service providers often reduce SRH information to the negative medical consequences of having sex, thereby enforcing their sexual moral of abstinence (Birungi, Mugisha, Obare, & Nvombi, 2009). Yet, their HIV status is only one of many considerations ALH balance when making sexual decisions. Clinic-based interventions should therefore address SRH in a comprehensive way and should link SRH to adolescents’ identity development and positive living (e.g., coping with stigma, mental health, treatment adherence, disclosure, and increasing social support). Providing only (medical) information is not enough; interventions must also pay attention to the psychological needs of ALH, build motivation and skills, and increase social support for protective behaviors in a developmentally appropriate way (Pedlow & Carey, 2004). Our study illustrated age-specific differences in ALH’s identity development, which interventions should consider by anticipating future developmental challenges. This should go along with an investment in the training of clinical counselors (Bharat & Sharma Mahendra, 2007).

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