research brief

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS AMONG YOUNG PEOPLE LIVING WITH HIV IN UGANDA: FINDINGS FROM THE LINK UP BASELINE SURVEY

An estimated 3.7 percent of young people between the ages of 15 to 24 years old are living with HIV in Uganda.[1] Young people living with HIV face unique challenges in navigating a wide array of social, health, and developmental challenges as they transition to adulthood. Like all young people, those who live with HIV are starting to learn about their sexuality, often beginning to have intimate relationships or marry. In addition, they confront a myriad of complex issues associated with HIV status disclosure, initiation of and adherence to antiretroviral therapy (ART), and deeply entrenched HIV-related stigma and discrimination. Young women bear a disproportionate share of this burden. Compared with men in their age cohort, young Ugandan women are more than twice as likely to be living with HIV (4.9 percent versus 2.1 percent).[1]

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Programs aimed at supporting young people living with HIV must address not only their immediate HIV-specific needs, but also their holistic sexual and reproductive health rights needs.

KEY MESSAGES

Like most young people, young people living with HIV in Uganda are sexually active and have a desire to have children in the future. Programs and providers need to address their holistic sexual and reproductive health needs, including comprehensive contraceptive and preconception counseling.

Young people living with HIV face significant stigma, discrimination, and violence. They need respectful and responsive psychosocial support and medical care. Stigma reduction training and other sensitization efforts among young people living with HIV, providers and communities are needed.

Many young people living with HIV have unprotected sex. In addition, they hold misperceptions about HIV transmission, despite having regular contact with health facilities for treatment. Psychosocial support and behavioral interventions are needed that reinforce basic education about modes of transmission and condom use.

Efforts to link young people living with HIV to routine care, ART, and PMTCT should be strengthened.

Integration of family planning and safe conception into ART services may present an opportunity to improve access to family planning and PMTCT services for young women living with HIV.

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LINKUP

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Previous research repeatedly indicates that young people living with HIV wish to lead their lives just like any other young person—including enjoying healthy sex lives, having boyfriends or girlfriends, and eventually having children. Nevertheless, programs and health care providers frequently neglect the needs and desires of these young people, many of whom may be too old to be served by pediatric services, yet may feel uncomfortable in existing adult services. Lacking respectful and trustworthy sources of information, many Ugandan young people living with HIV have knowledge gaps about HIV transmission, and they use condoms inconsistently as well as engage in other risky behaviors that may put them and others at risk for sexually transmitted infections, including HIV.[2]

Furthermore, among young women living with HIV—who comprise a large majority of people living with HIV in this age group—most desire children, but wish to delay pregnancy.[2] These women often are not using contraception, despite the fact that they wish to avoid pregnancy at this time. In a recent survey of Ugandan women living with HIV, one-third of 15- to 19-year-olds wanted to avoid becoming pregnant, but were not using family planning (FP).[3] Another study found that 36 percent of pregnancies among Ugandan HIV-positive mothers under age 20 were either mistimed or unwanted.[4]

Programs that aim to meet the comprehensive sexual and reproductive health and rights (SRHR) needs of young people living with HIV should also consider how stigma and discrimination can affect their health outcomes. Perceptions of external stigma, particularly in health care settings, are linked to many negative outcomes, including delay of care and non-adherence to ART.[5] People with greater internalized stigmatizing beliefs (i.e., feelings of shame and "self-stigma") are less likely to disclose their status to others, and have poorer self-reported health status.[5,6] Conversely, simply utilizing ART services may help reduce perceptions of internalized stigma.[7]

As access to ART improves, young people living with HIV are living longer and healthier lives. Thus, programs aimed at supporting young people living with HIV must address not only their immediate HIV-specific needs, but also their holistic SRHR needs. Link Up, a global consortium led by the International HIV/AIDS Alliance, intends to meet these needs by integrating SRHR and HIV in community- and facility-based programs.

Under the Link Up project in Uganda, the Community Health Alliance Uganda (CHAU) and Marie Stopes Uganda (MSU) will lead the implementation of peer-outreach activities designed to increase access to HIV and SRHR services among young people living with HIV in Luwero and Nakasongola districts in Uganda. Link Up HIV-positive peer educators will counsel young people living with HIV in community-based support groups, providing referrals to facilities that offer HIV and reproductive health services.

A peer outreach campaign under the Link Up project in Uganda, "Stay on Top of Your Game," addressed SRHR issues such as menstruation, sexually transmitted diseases, pregnancy, violence, rights, and stigma and discrimination.

The Population Council and Makerere University's Child Health and Development Centre are leading an evaluation of these activities to assess how they affect the SRHR knowledge, attitudes, and practices of young Ugandans living with HIV. This brief presents preliminary baseline findings from this evaluation study.

METHODS

Between October and November 2014, the research team conducted a baseline survey of young people living with HIV who participate in community-based peer support groups in Uganda's Luweero and Nakasongola districts. First, the research team informed the leaders of the peer support groups about the study and its objectives. Then, group leaders shared this information with their group members. Trained data collectors then attended support group meetings and recruited all eligible attendees (young people living with HIV, ages 15 to 24 years, who lived in the study districts) who agreed to participate and provided written informed consent. Ultimately, the data collectors administered an hour-long questionnaire to 473 young people living with HIV. The structured interview covered socio-demographic characteristics, HIV knowledge, status disclosure, condom use, reproductive history, and FP utilization. We conducted chi-square tests and t-tests to assess differences between men and women on variables of interest.

STUDY POPULATION

More than two-thirds (70.2 percent) of participants were women. Participant median age was 20 years, 47 percent had completed some primary education, and 46 percent had completed some secondary education. Although 67 percent of participants had never been married, women were significantly more likely than men to be married or cohabitating with a partner (27 percent versus 8 percent, $p < 0.001$). Most men (83 percent) had no children, whereas over half of women (55 percent) had at least one child; 28 percent had two or more children (Table 1).

TABLE 1 PARTICIPANT CHARACTERISTICS (N = 473)

Variable	Male (N=141) % (n)	Female (N=332) % (n)	Total (N=473) % (n)
District			
Luwero	63.8 (90)	67.5 (224)	66.4 (314)
Nakasongola	36.2 (51)	32.5 (108)	33.6 (159)
Age*			
15–19 yrs	57.5 (81)	44.6 (148)	48.4 (229)
20–24 yrs	42.5 (60)	55.4 (184)	51.6 (244)
Median (min-max)	18 yrs (15, 24)	20 yrs (15, 24)	20 yrs (15, 24)
Education			
No education	0.7 (1)	3.0 (10)	2.3 (11)
Some primary	44.7 (63)	48.2 (160)	47.1 (223)
Some secondary	48.2 (68)	45.2 (150)	46.1 (218)
Any tertiary	6.4 (9)	3.6 (12)	4.4 (21)
Marital status*			
Never married/ single	89.4 (126)	58.1 (193)	67.4 (319)
Married or co-habitating	7.8 (11)	27.1 (90)	21.4 (101)
Widowed/ divorced	2.8 (4)	14.8 (49)	11.2 (53)
Number of children*			
None	82.6 (114)	44.5 (145)	55.8 (259)
1	12.3 (17)	27.9 (91)	23.3 (108)
2 or more	5.1 (7)	27.6 (90)	20.9 (97)

Note: Cell frequencies may not sum to the total sample size due to missing values.
*Significant difference between male and female proportions: $p<0.05$.

KEY FINDINGS

Learning HIV status

On average, participants reported that they had been living with HIV for about five years. Most participants (78 percent) learned of their HIV status either through an HIV counseling and testing (HCT) center or after being tested at a health facility. Seventeen percent reported being told by a parent/ guardian that they had been born with HIV, while nearly 30 percent reported that they had first tested positive within the past 12 months.

Self-efficacy to engage in healthy behaviors

In general, survey participants reported a high sense of self-efficacy; 91 percent felt confident in their ability to engage in positive sexual and reproductive health behaviors such as condom use. Women were significantly more likely than men to agree that a partner might reject them if they suggested using condoms (36.7 percent versus 24.8 percent, p = 0.01). Of all measures of self-efficacy assessed, both men and women felt least confident that they would be able to convince an unwilling partner to use condoms (66 percent).

Among the 45 women who wanted to limit or delay pregnancies, but were not using a contraceptive method, most felt that they could obtain contraceptive methods if needed (78 percent). Similarly, 71 percent of these women felt that, if they wanted to, they could use a contraceptive method continuously for a year.

HIV treatment

Sixty-eight percent of young people living with HIV were receiving ART, 72 percent were taking medication to prevent opportunistic infections, and 68 percent had received a CD4 test in the past 12 months. Although most participants reported taking their medication at the prescribed intervals, adhering to their drug regimen was a concern for a many. Twenty-two percent had missed at least one ART dose in the past four weeks; 16 percent had missed a dose within the past two weeks.

Knowledge of HIV transmission

Although 94 percent knew that condoms can prevent disease transmission, and 90 percent knew that a person with HIV can look healthy, many participants still had misconceptions. Sixteen percent of survey respondents incorrectly believed that HIV can be transmitted by sharing a meal with another person, and over 30 percent indicated that HIV can be transmitted through mosquito bites.

Stigma and violence

Internalized stigma was quite prevalent; over one-third of the 473 participants reported feeling ashamed, disgusting, or guilty because they live with HIV. Many reported feeling external stigma—that they were stigmatized by those around them. Over three-quarters felt that people living with HIV are often rejected when others learn of their status (78 percent), and two-thirds (66 percent) felt that people living with HIV are treated differently than those not living with HIV.

Because of their HIV status, a considerable proportion decided not to get married (13 percent), not to have sex (17 percent), or not to have children (15 percent). Nearly one-quarter (24 percent) were aware that others were gossiping about them because of their HIV status. Other young PLHIV (8 percent) indicated that their HIV status resulted in rejection by a sex partner.

About 21 percent of the sample reported being sexually (8 percent) or physically (16 percent) abused within the past 12 months. About 35 percent of men and women reported experiencing verbal abuse. More women reported being physically or sexually abuse, but these differences were not statistically significant between men and women.

Sexual activity

Table 2 describes sexual activity among young people living with HIV. About 76 percent reported having ever had sex, among whom 53 percent had been sexually active within the past three months. Approximately 9 percent of those who had ever had sex reported having two or more sexual partners during the past three months.

HIV status disclosure

Although 80 percent of young people living with HIV stated that they had disclosed their HIV status to someone other than a health care provider,

TABLE 2 SEXUAL BEHAVIOR AND CONDOM USE (N = 473)

Variable	Male (N = 141) % (n)	Female (N = 332) % (n)	Total (N = 473) % (n)
Has ever had sex*	68.8 (97)	78.9 (262)	75.9 (359)
Had sex in past 12 mos.*	66.0 (64)	80.2 (210)	76.3 (274)
Had sex in past 3 mos.*	41.2 (40)	58.4 (153)	53.8 (193)
Had more than one partner in past 3 mos.*	14.4 (14)	6.9 (18)	8.9 (32)
Median age at sexual debut (min-max)*	15.7 yrs (8, 24)	16.2 yrs (6, 22)	16.1 yrs (6, 24)
Ever used condoms	88.7 (86)	77.9 (204)	80.8 (290)
Used condom at last sex with primary partner (n=260)	67.5 (52)	45.3 (83)	51.9 (135)
Used condom at last sex with non-primary partner (n=52)	73.1 (19)	61.5 (16)	67.3 (35)

Cell frequencies may not sum to the total sample size due to missing values.

*Significant difference between male and female proportions: $p < 0.05$.

comparatively few had disclosed their status to their sexual partners. Among the 250 respondents who had a primary partner—such as a spouse, boyfriend, or girlfriend—approximately one-half (48 percent) had disclosed their HIV status to this partner. Of the 50 participants who reported having one or more casual sex partners in the past six months, 17 (32 percent) reported disclosing their status to their last casual partner.

Condom use

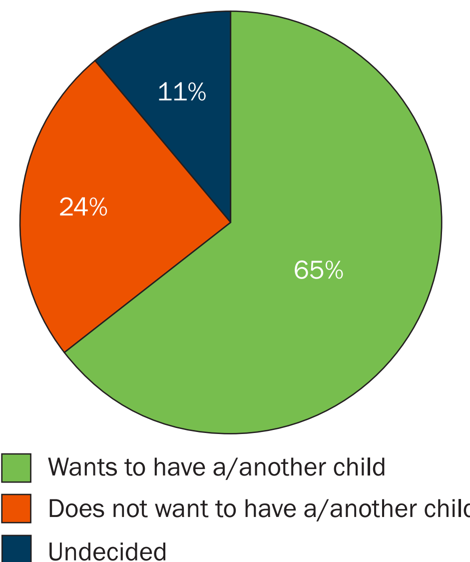
Over 80 percent of participants who ever had sex reported having used a condom at least once before. The reasons for non-use most frequently given by those who had never used condoms were partner refusal (36 percent), not liking condoms (35 percent), lack of availability (16 percent), and partner also living with HIV (13 percent). About 48 and 71 percent reported using a condom at last sex with a primary partner or a casual/non-primary partner, respectively. Men were significantly more likely than women to report using condoms at last sex (72.5 percent versus 48.7 percent, $p < 0.001$). Among the 352 participants who either did not know their partner's HIV status or who knew their partner to be HIV-negative, 40 percent did not use condoms at last sex.

Pregnancy and desire for children

As shown in Figure 1, nearly two-thirds of the 332 young women want to have a/another child in the future. Overall, 64 percent of young women living with HIV reported that they had been pregnant before, among whom 60 percent had been pregnant since learning that they were living with HIV; 19 percent were currently pregnant.

Among the 212 women who had been pregnant, 33 percent reported that their most recent pregnancy was unintended. Although abortion is legally restricted in Uganda, 19 percent of women who had been pregnant also reported having previously terminated a pregnancy.

FIGURE 1 DESIRE TO HAVE CHILDREN AMONG YOUNG WOMEN LIVING WITH HIV



Wants to have a/another child
Does not want to have a/another child
Undecided

PMTCT

In 2012, Uganda adopted the Option B+ PMTCT guidelines as part of its national HIV prevention strategy.[8] Option B+ guidelines specify that all HIV-positive pregnant women are eligible to initiate ART and remain on treatment for life.[9] Nevertheless, over a quarter (27 percent) of the 41 women who were pregnant at the time of the interview were not receiving ART.

Family planning

Among the 151 women with need for contraception—which excludes those who had not had sex in the past 12 months, those who were currently pregnant or unable to get pregnant, and those who wished to have a child within the next 12 months—68 percent reported that they were currently using at least one contraceptive method to prevent pregnancy. Injectable contraceptives were the most popular method (47 percent), followed by male condoms (26 percent) and the pill (17 percent). Overall, 69 percent of contraceptive users used a non-barrier modern contraceptive method, and 34 percent used either male condoms, female condoms, or both (Table 3).

TABLE 3 CONTRACEPTIVE USE AMONG WOMEN LIVING WITH HIV (N = 151)*

Variable	% (n)
Any FP method used (n=151)	72.2 (109)
Modern FP method used (n=151)	68.2 (106)
Male condom	25.6 (28)
Female condom	11.9 (13)
Pill	16.5 (18)
Injectable	47.7 (52)
Implant	6.4 (7)
Intrauterine device	1.8 (2)
Lactational amenorrhea method	3.7 (4)
Withdrawal	0.9 (1)

Note: Cell frequencies may not sum to the total sample size due women using multiple contraceptive methods, or missing values.

*Among women who were able to become pregnant, had been sexually active in past year, were not pregnant, and did not want a child in next 12 months.

DISCUSSION

These findings indicate that young people living with HIV have a broad range of SRHR needs. Many are sexually active, and despite high levels of basic HIV prevention knowledge, misconceptions about how HIV can be transmitted persist and condom use is inconsistent. This indicates a critical need for targeted HIV prevention and risk reduction messaging among adolescents. However, simply improving access to health education is insufficient. Young people living with HIV need help developing strategies to disclose their HIV status to their sex partners. Peer support and respectful health care play important roles in supporting them to do so.

Participants were selected for this study based on their involvement with peer-support groups. Thus, they likely have stronger social support networks than other young people living with HIV. Nevertheless, their consistent feelings of internal and external stigmatization underscore the need that young people living with HIV have for greater access to psychosocial support and counseling services. Furthermore, the fact that many participants—both men and women—reported physical and sexual violence highlights the need for programs and policies to focus on addressing stigma, discrimination, and violence toward young people living with HIV. To foster a respectful and welcome environment in facilities and communities, stigma reduction trainings and programs should be guided by a rights-based approach.

The heavily skewed gender ratio in this convenience sample of young people living with HIV is consistent with national surveillance data on HIV among men and women ages 15 to 24: twice as many participants were women as men.[1] Consistent with previous studies among Ugandan young women living with HIV, levels of unintended pregnancy and abortion were high and contraceptive use was low. Among those women who were pregnant at the time of the interview, many were not on ART, despite the fact that all pregnant women living with HIV are eligible for treatment in Uganda. For these young

women, it is especially important that programs such as Link Up continue to work to increase knowledge of and access to PMTCT services during antenatal care, following World Health Organization guidelines.[9] Another potential integration strategy that could reduce unmet need for FP among the two-thirds of women who were enrolled in ART would be to incorporate FP counseling and commodities into ART service delivery points.

Even with recent shifts in governmental and donor funding priorities from HIV prevention towards care and treatment, a notable proportion of young people are not being adequately linked to HIV care and treatment services, including routine HIV management and PMTCT services. Similar to other settings, weak linkages between HTC and follow-on services—whether for prevention or for care and treatment—is a key challenge in many HIV programs.[10] This is particularly important when consistent condom use is low. Programs should link them to supportive services to meet their diverse needs, including improving and maintaining dignity, protecting human rights, and enhancing the individual's physical, mental, emotional and sexual health.

These baseline data provide vital information that can be used to tailor program interventions to the needs of young people living with HIV. These are young people who face stigma and discrimination, who want to plan the timing and spacing of having children, and who need support to improve their SRHR. Programs like Link Up should continue to train healthcare providers, counselors, and peer outreach workers to engage young people in a manner that acknowledges their transition into adulthood: they are no longer children, yet they face different social challenges than most adults.

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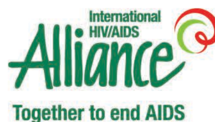
LINKUP

Link Up aims to improve the sexual and reproductive health and rights (SRHR) of one million young people affected by HIV across five countries in Africa and Asia. The project is being implemented by a consortium of partners led by the International HIV/AIDS Alliance. For more information, visit www.link-up.org



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