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Preventive service needs of young people perinatally infected with HIV in Uganda

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The sexual and reproductive health needs of young people perinatally infected with HIV in Uganda remain largely unaddressed by existing HIV/AIDS programs mostly because, such programs encourage young HIV-positive clients to refrain from or postpone sexual activity. This study examines the sexual expressions and experiences as well as the preventive practices of 732 adolescent boys and girls aged 15–19 years who were born with HIV with a view to identifying the preventive service needs of these young people and the implications of these needs for HIV/AIDS programs. The data come from a project on the sexuality of young people perinatally infected with HIV conducted in 2007 in four districts of Uganda, that is, Kampala, Wakiso, Masaka, and Jinja. The analysis involves both quantitative and qualitative approaches: the quantitative approach entails cross-tabulations with chi-square tests as well as significance tests of proportions while the qualitative approach involves an analysis of individual case stories, in-depth probes and focus group discussions for content. The findings show disconnect between: (1) the information the service providers give to the young people and their actual needs and desires; (2) the fears of the adolescents and their actual preventive practices; and (3) the high level of reported condom use and the frequency of use. Programs will therefore need to recognize that young people perinatally infected with HIV are sexually active or anticipate being so in future. Thus, both sexually active and non-sexually active young people require information and services on prevention of unwanted pregnancies as well as avoiding infecting their sexual partners with HIV and re-infecting themselves. Programs will need to devise ways of responding to these needs which should include emphasizing the disclosure of HIV status to the partner as well as the need to accompany such disclosure with consistent condom use.

Keywords: young people; perinatally HIV-infected; sexual experiences; preventive service needs; Uganda

Introduction

The Joint United Nations Programme on HIV/AIDS (UNAIDS) notes that while young people aged under 25 years account for over 40% of all new HIV infections worldwide, HIV prevention efforts remain notably inadequate for this segment of the population (UNAIDS, 2006). In sub-Saharan Africa – the region most affected by the HIV/AIDS epidemic – the roll-out of anti-retroviral treatment (ART) programs has led to a small but steadily growing population of young people perinatally infected with HIV and who are transitioning into adolescence and adulthood. Whereas actual trends are not available, indications from Uganda show that the oldest surviving perinatally HIV-infected client of The AIDS Support Organization (TASO) turned 23 years old in 2006. In addition, TASO has recorded some 5000 young people living with HIV since infancy while the Paediatric Infectious Disease Clinic (PIDC) in Mulago Hospital in Uganda has over 600 young people between the ages of 10 and 19 years living with HIV.

As they grow into adolescence and adulthood, these young people develop sexual needs and desires, yet their sexual and reproductive health (SRH) needs remain largely unaddressed by existing HIV/AIDS programs. SRH issues discussed during counselling of young HIV-positive clients tend to be about refraining from or postponing sexual initiation (Birungi et al., 2008). Moreover, HIV treatment, care and support programs in the country are organized around paediatric and adult care (Birungi, Mugisha, & Nyombi, 2007). Thus, young HIV-positive clients are treated under paediatric care and are not being adequately prepared for adult life. This implies that, first, service providers seem un-prepared to find out whether their clients are sexually active in order to provide appropriate information and services on prevention of pregnancy, re-infection and infecting others with HIV. Second, sexually active adolescents living with HIV are left un-prepared and unable to negotiate contraceptive use or access contraceptive methods and other preventive services. This puts them at risk of engaging in sexual practices that

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may lead to further transmission of HIV/AIDS and/or unwanted pregnancies.

Existing studies have documented poor preventive sexual practices among HIV-positive persons which include having unprotected sex especially with concordant (HIV-positive) partners and non-disclosure of HIV status to the partner (Bell, Atkinson, Mosier, Riley, & Brown, 2007; Golden, Wood, Buskin, Fleming, & Harrington, 2007; Johnson & Buzducea, 2007; Kalichman, 2000; Marks & Crepaz, 2001; Rice, Batterham, & Rotheram-Borus, 2006). These studies are, however, mostly based on clinics or intervention sites in the West. This paper examines the sexual expressions and experiences of adolescents born with HIV in Uganda, one of the first sub-Saharan African countries to experience high HIV prevalence. In the process, it identifies the preventive service needs of these young people and discusses the implications of these needs for HIV/AIDS programs. It builds on the initial work by Birungi et al. (2007, 2008) by presenting evidence based on detailed analysis of the available information.

Methods

Data for this paper come from a diagnostic study that was conducted in Uganda between April and July 2007 by TASO through support from the Population Council. The study targeted a sample of adolescents aged 15–19 years who had been living with HIV since infancy (that is, presumed to be perinatally infected) and who were aware of their HIV sero-status. The sample members were identified and recruited through existing HIV/AIDS treatment, care and support programs/centres (20 sites/centres in all) in four districts in Uganda (Kampala, Wakiso, Masaka, and Jinja).

The management of the centres/facilities granted the research team access to the client registers and permitted their data clerks/officers to help with identifying clients aged 15–19 years. From these clients, the counsellors identified those who were presumed to be or recorded as perinatally infected with HIV and who were aware of their sero-status. For the non-emancipated adolescents (those with parents/guardians) aged 15–17 years, written consent to participate in the study was sought at two levels: from the parents/guardians first followed by the individual adolescents. However, only individual written consent was sought from those aged 18–19 years (both with and without parents/guardians) and from emancipated minors (i.e. those aged below 18 years and who had no parent/guardian). It is worth noting that the Ugandan constitution defines a child as anybody aged below 18 years and that the Uganda National Council of Science and Technology (UNCST) allows emancipated minors to consent to participate in research except that they have to be thoroughly informed about the risks involved. Ethical clearance for the study was granted by TASO Internal Review Board (IRB), UNCST, and the Population Council Ethical Research Review Committee.

Out of a total of 740 young people identified for inclusion in the survey, two refused to participate while six participated but did not complete the interviews. Of those who completed the interviews, 64% were female. Table 1 shows the distribution of the study participants by various background characteristics. A structured questionnaire was used to collect information on background characteristics, access to information and support, sexual behaviour and practices, preventive knowledge and practices, contraceptive knowledge and use, pregnancy and childbearing experiences, and issues relating to self-esteem, worries as well as experiences of sexual and physical violence. Data were also collected through ethnographic methods consisting of extended interactions, listening, and ethnographic interviews (conversational and narrative approaches and in-depth probes) with 12 adolescents (four of whom had participated in the survey). In addition, focus group discussions (FGDs) were held with the adolescents living with HIV to determine group opinions, perceptions, attitudes around their sexuality as well as their SRH education and service needs. There were a total of six FGDs comprising 6–8 participants. During survey interviews, there were specific counsellors in each facility whom the adolescents kept referring to. These counsellors (one from each district) were purposively selected for in-depth interviews as well.

Analysis for this paper involves both quantitative and qualitative approaches. The quantitative approach entails cross-tabulations with chi-square tests as well as significance tests of proportions to examine differences in sexual expressions and experiences as well as in preventive practices of young people living with HIV by background characteristics of the respondents. Sexual expressions in this context refer to whether the individual had ever engaged in kissing, touching, fondling, masturbation, hugging, or fantasizing about love and sex. The qualitative approach involves analysing the in-depth interviews, ethnographic case stories, and FGDs for content.

Table 1. Percent distribution of survey respondents by background characteristics.

Characteristics	Female (%) ($N=469$)	Male (%) ($N=263$)	Both sexes (%) ($N=732$)
Age group			
15–17 years	60	57	59
18–19 years	40	43	41
District			
Jinja	21	32**	25
Kampala	29	24	27
Wakiso	35	18**	29
Masaka	15	26**	19
School attendance			
In-school	71	71	71
Out of school	29	29	29
Living arrangements			
Lives with biological parents	31	35	33
Doesn't live with parents/N/A	69	65	67
Biological parents' living arrangements			
Living together	9	11	9
Divorced/separated	7	4	6
Mother dead	14	16	15
Father dead	23	21	22
Both parents dead	47	48	47
Lives with siblings in HH			
No	28	25	27
Yes	64	62	64
No siblings	8	13	10

Notes: HH – Household; N/A – not applicable because parents died; Percentages may not add up to exactly 100 in some cases due to rounding; Significance test of difference between male and female proportions: *$p<0.05$; **$p<0.01$.

Results

Sexual expressions and experiences

Service providers encourage young people perinatally infected with HIV to refrain from or postpone sexual initiation. Nonetheless, the results of this study show that these young people are beginning to explore their sexuality by dating and engaging in sexual relationships. Qualitative interviews with counsellors and the adolescents best illustrate the disconnect between the service providers' messages and the actions of these young people:

> You are already stigmatized and not supposed to have any sexual feeling and it is wrong for you to have that because you are going to infect all the others. (Counsellor, Kampala)

> We still emphasize abstinence but these girls come here when they are pregnant and sometimes disappear for fear of facing their counsellors. (Counsellor, Masaka)

> My mother and the counsellors always tell me what to do but I listen to them and later do my own things because I believe I am old enough to make my own decisions…It is all about love now. (Ethnographic Case Study No. 10, Masaka)

Quantitative data further indicate that almost two-thirds (62%) of the respondents had ever engaged in at least one form of sexual expression such as kissing, touching, fondling, masturbation, or fantasizing about love and sex (Table 2). In addition, 44% reported a desire to have sex while 41% felt that there is no reason why someone who is living with HIV should not have sexual intercourse. Significantly more older adolescents (those aged 18–19 years) than younger ones (those aged 15–17 years) had engaged in at least one of the forms of sexual expressions considered. In addition, significantly more male than female and more out-of-school than in-school adolescents had engaged in at least one form of sexual expression (Table 2).

Table 2. Percent distribution of respondents by sexual expression, desires and preventive practices, and by background characteristics.

Characteristics	Ever engaged in particular sexual expressions[a] ($N=732$)%	Ever desires having sex ($N=732$)%	No reason why an HIV+ person should not have sex ($N=732$)%	Ever had boyfriend/ girlfriend ($N=732$)%	Ever had sex ($N=732$)%	Willing/ wanted to have first sex ($N=242$)%	Used a method to prevent infection/ re-infection at first sex ($N=236$)%	Used any form of contraception in current/previous relationship ($N=239$)%	Disclosed HIV status to current boy/ girlfriend/ partner ($N=158$)%
Age (years)	**	**	**	**	**	ns	*	*	ns
15–17	46	28	30	30	15	65	27	37	29
18–19	84	67	57	69	60	76	41	55	42
Gender	**	**	**	*	**	**	ns	*	ns
Male	78	55	54	46	89	89	35	58	42
Female	52	38	34	37	63	63	39	45	35
Attending school	**	**	**	**	ns	ns	ns	ns	ns
No	75	57	50	62	76	76	36	51	42
Yes	56	39	38	32	70	70	39	50	35
Lives with at least one parent	ns	ns	*	ns	ns	ns	ns	ns	ns
No	60	42	38	41	40	73	40	50	42
Yes	35	48	47	39	34	74	34	51	32
Lives with siblings in HH	**	ns	ns	ns	*	ns	*	ns	ns
No	65	43	41	43	32	70	32	41	44
Yes	58	43	41	39	35	75	35	54	34
No siblings	76	46	46	44	65	74	65	57	45
All respondents	62	44	41	41	37	73	37	50	38

[a]These include kissing, touching, fondling, masturbation, hugging, or fantasizing about love and sex; HH – household; Chi-square tests: *$p<0.05$; **$p<0.01$; ns – not significant.

Qualitative data also indicate that many adolescents felt that having sex is unavoidable and abstinence from sexual intercourse is nearly unsustainable. The following examples from FGDs illustrate this feeling:

> Sex is something everyone would go for, very few can avoid it. . .One cannot pretend that come-what-may I will never have sex because it is natural. It is not easy to avoid it. (FGD No. 1, Mildmay Centre, 15-year old)

> It is natural. Anyone who has grown to the age of having sex, he or she has to have it or seek to have it...When one has grown to the age of 16, he or she starts feeling the need to have sex. The body simply demands it. Then what follows is to learn how to get somebody to do it with and how to do it. . . .When one is growing up and his or her peers do not see him or her dating, then they start scorning him or her. (FGD No. 2, TASO, Entebbe)

With respect to experiences with dating, 41% of the respondents reported ever having had a boyfriend or girlfriend (Table 2). In addition, one-third of the respondents (33%) had ever had sex. Of these, 73% reported that they were both willing or wanted to have first sex (consensual first sex). The remainder reported having been forced or raped (10%), tricked into having sex (8%), or persuaded with money or gift (9%). The median age at first sex among male respondents who had consensual sex was 15 years, two years younger than the median age for men from the 2006 Uganda Demographic and Health Survey (UDHS). The corresponding figure for female respondents was 16 years, similar to that of the UDHS (UBOS & Macro International, 2007). The results further show that significantly more older than younger adolescents had ever dated (that is, ever had a boyfriend or girlfriend), had sex, or were willing or wanted to have first sex. In addition, significantly more male than female respondents had ever dated, had sex, or were willing or wanted to have first sex. Similarly, significantly more out-of-school than in-school respondents had ever dated or had ever had sex. These patterns are consistent with those of other studies among young people in general (e.g. Erulkar & Matheka, 2007).

Further analysis shows that among those who had never dated, 26% reported having had a desire to have sex while 74% said that they had no desire for sex ($p < 0.01$). Similarly, among those who had never had sex, 29% reported having had a desire to have sex while 71% said that they had no desire for sex ($p < 0.01$). Some of the major reasons for not having sex were the fear of infecting others or self re-infection with HIV, fear of becoming pregnant or impregnating someone, not being ready for sex, as well as discouragement from parents/guardians/health care providers/counsellors (Table 3). However, further analysis indicates that 86% of those who had never had sex anticipated having sex at some point. The majority of those who anticipate having sex intended to wait until marriage (82%) with only a small proportion intending to wait until they find someone to love (14%) or when the opportunity to have sex occurs (4%).

Preventive practices

In terms of preventive practices, only 37% of the respondents who had ever had sex reported using a preventive method at the time of first sex to prevent HIV infection or re-infection (Table 2). In addition, one-half of those who had ever had sex used any form of contraception in their current or previous relationship. The results from further analysis show that among those who had ever had sex, 47% reported that they were currently using condoms. These are relatively high rates of contraceptive use in general and condom use in particular for an adolescent population, perhaps suggesting more careful behavior among the HIV-infected adolescents. Estimates from the 2006 UDHS, for instance, show that among those aged 15–19 years and who had ever had sex, a slightly lower proportion (44%) had ever used any form of contraception while only 11% reported that they were currently using condoms.

Despite the high level of condom use among adolescents perinatally infected with HIV compared to that of adolescents in the UDHS, qualitative data point to some level of inconsistent use:

> It's hard. . .I used to use a condom with my boyfriend at first but he got tired; after some time we tried sex

Table 3. Percent distribution of respondents who had never had sex by the major reasons for not having sex.

Reason for not having sex	Percentage[a] ($N = 490$)
Fears infecting others with HIV	39
Fears self re-infection	34
Does not feel ready to have sex	32
Discouraged by health care providers/ counsellors	22
Afraid of becoming pregnant/impregnating someone	21
Discouraged by parents/guardians	20
Wants to wait until older	13
Fears having sex	12
Feels sex before marriage is wrong	7

[a]The question on the reason for not having sex allowed for multiple responses – the percentages therefore do not add upto 100.

> without a condom. I think that's when I got pregnant. (Ethnographic Case Study No. 3, Nsambya Home Care)
>
> You know men (after using condoms over time) he asked me that after all that time, couldn't I trust him! I also said I would use the monthly calendar for family planning but I wasn't serious with this, that is how I became pregnant. (Ethnographic Case Study No. 4, TASO, Mulago)
>
> I insist on using a condom with him, but most times he refuses. He forces me to have sex when am weak or not feeling well and sometimes I end up with infections. (Ethnographic Case study No. 12, Entebbe)

Disclosure of HIV status to the partner might also be relevant as a prevention strategy because it can foster the adoption of protective measures. Despite this, just over one-third of the respondents who were in a relationship (38%) disclosed their HIV status to their partners with no significant differences in the proportion of individuals who did so by the background characteristics considered (Table 2). Disclosing their HIV status to their friends was also one of the major fears of the adolescents (Table 4). Further analysis shows that only 33% of those in a relationship reported knowing the HIV status of the partner. Of these, 39% had HIV-negative partners (discordant relationships).

It, however, remains an open question whether disclosure of HIV status does encourage more careful behavior. For one, among those who were currently in a relationship, there was no significant difference in the proportion of individuals who reported using condoms by whether they had disclosed their sero-status to the partner or not (55% among those who had disclosed versus 58% among those who had not). There was also no significant difference in the proportion using condoms by whether the individual knew the HIV status of the partner or not (57% among those who knew versus 58% among those who did not). In addition, among those who knew the HIV status of the partner, the proportion reporting condom use was higher among those in concordant than among those in discordant relationships though the difference was not statistically significant (65% versus 45%; $p = 0.16$). Qualitative data further suggest that even in circumstances where the respondents disclosed their HIV status to their partners, most were willing to continue with the relationship regardless of whether they were concordant or discordant. These patterns are indicative of poor preventive practices among sexually active young people perinatally infected with HIV in Uganda. However, the adolescents reported becoming pregnant or impregnating someone as well as infecting someone else with HIV as some of their major fears (Table 4).

Discussion and implications

Understanding the SRH needs of young people perinatally infected with HIV is critical for informing programs aimed at addressing the unwanted consequences of sexual behaviours and practices among this group. The results of this study suggest three areas of disconnect in addressing the SRH needs of this segment of the population in Uganda. First, whereas service providers emphasize refraining from or postponing sexual activity, the young people themselves desire otherwise. This may lead to lack and/or denial of appropriate information on safe sexual practices for this group. Moreover, the majority of those who had never had sex also anticipate being sexually active at some point in future despite worrying more about pregnancy, infecting someone with HIV and having sex compared to those who had already had sex. It is therefore critical that HIV/AIDS programs devise ways of responding to the real sexual practices, desires and worries of young people perinatally infected with HIV other than just emphasizing self-restraint. This should include updating, reorganizing and/or redesigning the existing counsel-

Table 4. Percentage of respondents who were worried about specific issues by sexual experience.

	Ever had sex (%) ($N = 242$)	Never had sex (%) ($N = 490$)	All respondents (%) ($N = 732$)
Infecting someone else with HIV	69	86**	80
Becoming pregnant/impregnating someone	59	82**	74
People knowing their sero-status	54	53^{ns}	54
Disclosing HIV status to friends	53	49^{ns}	51
Having sex	23	62**	49

Notes: The question on the respondent worries allowed for multiple responses – the percentages therefore do not add upto 100. Significance test of difference between the proportions pertaining to those who had ever had sex and those who had not: $*p < 0.05$; $**p < 0.01$; ^{ns} – not significant.

ling and support packages on sexuality counselling and related services. It should also entail training and re-orienting service providers to enable them effectively offer these services. Programs should further consider setting up transition clinics to address the needs of these young people who are inadequately prepared to obtain services from the adult care centres and yet no longer fit in the paediatric clinic setting.

Second, the majority of young people expressed fears about becoming pregnant/impregnating someone or infecting someone else with HIV. Nonetheless, the level of use of preventive methods is not concomitant with the degree of fears about these negative consequences of having sex. Third, whereas the level of reported contraceptive use (including condom use) among this segment of the population is relatively high for an adolescent population, qualitative interviews reveal inconsistent use of condoms. There is also lack of any significant difference in condom use between those who knew the HIV status of their partners and those who did not. Moreover, though not significant, condom use was higher among those in concordant than among those in discordant relationships. The implication is that HIV/AIDS programs will need to strengthen preventive services for both sexually active and non-sexually active young people perinatally infected with HIV. These should include emphasizing disclosure of HIV status to the partner as well as the need to accompany such disclosure with consistent condom use.

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