HIV sero-status disclosure in the school context: Experiences of adolescents perinatally infected with HIV in Uganda

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Introduction

The increased availability of anti-retroviral treatment (ART) for HIV in parts of sub-Saharan Africa (SSA) has enabled many children who were perinatally infected to survive to school-going age and even longer. For instance, a study conducted in 2007 in Uganda among adolescents aged 15-19 years who were perinatally infected with HIV found that about 70 per cent of them were attending school at the time of the survey and many desired to be in school to avoid social isolation (Birungi et al. 2008). With an increasing number of HIV-positive young people attending school, most governments in SSA have begun to recognize the challenges this situation presents to the education sector (Kelly 2003). Many governments have moved to formulate Education Sector Policies on HIV/AIDS, whose scope of application includes all learners, employees, managers and administrators in all public and private, formal and non-formal learning institutions at all levels of the education system (see for instance, Ministry of Education and Sports 2004). The policies have predominantly evolved around a legal framework that recognizes and upholds the rights of all people with a special focus on marginalized and vulnerable groups and those with special needs. They also recognize the need for universal access to HIV/AIDS information, access to treatment and care, protection from discrimination and stigma, and care for orphans and vulnerable in-school young people.

Although the policies recognize school-going HIV-positive young people as a vulnerable group, education sector policy responses to HIV/AIDS are predominantly curriculum-based, focusing almost entirely on developing the capacity of learners in three areas: better knowledge about the diseases, skills that enhance the ability to protect oneself against infection, and approaches that acknowledge the rights and dignities of those infected and affected (Bennell et al. 2002). Insufficient attention has been paid to ways of supporting in-school HIV-positive

young people, a problem compounded by the fact that their needs are largely unknown, perhaps because very few have disclosed their sero-status to school officials. In Uganda, for instance, parents and guardians complete medical forms upon student admission so that the information can be used to identify those with needs that might require special attention. However, most parents and guardians tend to conceal certain ailments including HIV, perhaps, for fear that their children might not be admitted if their conditions are known or to protect them from stigma and discrimination. This limits the kind of support such children obtain from school if their conditions are concealed.

Therein lies the dilemma: on the one hand, insufficient attention has been paid to putting in place adequate support mechanisms for in-school HIV-positive young people partly due to non-disclosure of sero-status, and on the other, there is non-disclosure that is based on fear that the children might be stigmatized and discriminated against by their colleagues and school officials. In this paper, we use data from Uganda to examine disclosure of HIV sero-status in the school context by adolescents perinatally infected with HIV. We begin by presenting evidence of the existence of stigma and discrimination in schools from the perspectives of school officials, in-school young people perinatally infected with HIV, and other students. We then examine the level of disclosure of sero-status to school officials and friends by adolescents perinatally infected with HIV. We end by examining the reactions of the school officials and friends to the disclosure as reported by the adolescents.

Data and methods

This paper uses data from a study conducted in Uganda in 2009 whose objective was to understand the needs of in-school HIV-positive young people. The study involved two major components. The first component was a survey among 718 young people aged 12-19 years (that is, of school-going age) who were perinatally infected with HIV and who knew their sero-status. The sample members were identified and recruited through existing HIV/AIDS treatment, care and support programs/centers selected by The AIDS Support Organization (TASO)-Uganda in four districts (Kampala, Wakiso, Masaka and Jinja). Thirteen such centers participated in the study. TASO counselors assisted with the identification and mobilization of the respondents. The process involved obtaining clearance from the management of the centers, identifying the target sample from the existing records, and making calls to their parents to request them to come to the centers or targeting days when they visit the centers for routine reviews or drug re-fills.

Information was collected using a structured questionnaire which was translated into *Luganda* and *Lusoga*, the two dominant local languages. Interviews were partially completed with 6 of the participants. Information was gathered on the respondents' background characteristics, educational attainment, school attendance (absenteeism, repetition, changing of schools, and drop-out), motivations for being in school or dropping out, disclosure of HIV status within the school environment and the reactions of others to the disclosure, availability of support programs for HIV-positive young people within schools, psychosocial feelings in school and whether these affected school attendance, and experiences of physical or verbal abuse, discrimination and stigma in school. For non-emancipated adolescents aged 12-17 years, written consent to participate in the study was sought from parents/guardians and the adolescents themselves. However, for adolescents aged 18-19 years and emancipated minors aged 12-17

years, the study obtained individual written consent only. The TASO Internal Review Board, the Uganda National Council of Science and Technology (UNCST), and the Population Council's Institutional Review Board granted ethical clearance for the study.

Female respondents comprised more than half (59%) of the survey participants, although there was no significant difference in the distribution by sex in most of the background characteristics such as age, district of residence, whether the respondent lived with a biological parent, and the living arrangements of the biological parents (Table 1). Nearly two-thirds (65%) of the respondents were aged below 18 years, hence considered minors while slightly more than one-third (36%) were from Kampala district. Four-in-five (80%) of the respondents reported that one or both parents had died, which suggests that the majority of them might lack proper support not only in school but also at home.

<Table 1 about here>

The second component of the study involved an in-depth assessment of the school environment and their preparedness to support in-school HIV-positive young people. A total of eight schools (four primary and four secondary) in five districts (Kampala, Jinja, Wakiso, Mukono and Iganga) were included in the assessment. Two of the primary and two of the secondary schools were mixed day while one school in each category was a boys' only and the other a girls' only boarding institution. The schools were purposively selected in consultation with the Ministry of Education and Sports. The Ministry granted the research team permission to visit the schools and talk to the officials. The research team obtained oral consent for participation in the study from the school officials. Information was collected through in-depth interviews to determine the existence and operationalization of HIV/AIDS policies in schools, perceptions and practices of teachers and school management towards in-school HIV-positive

young people, the existence of support programs, and possible responses by the education sector to the needs of infected students. A total of 52 in-depth interviews were conducted with head teachers (7), deputy head teachers (4), director of studies (1), deans of students (2), senior teachers (12), Presidential Initiative on AIDS Strategy for Communication to Youth (PIASCY) teachers (3), school nurses/clinical officers (8), school matron (1), peer counselor (1), health prefects (8), and club patrons and members (5) from the selected schools.

In addition, a total 1,012 students in Senior Three and Five from the four secondary schools wrote essays on specified themes. These included the perceived and actual attitudes and practices of students towards colleagues who are HIV-positive as well as possible responses by fellow students and the school administration to the needs of HIV-positive students. The essays were anonymous-- students were asked to indicate only their age, sex, and class but not their names-- and were administered to the students as a class exercise. It was explained to them that the exercise was voluntary and that they had the freedom not to participate in it if they did not wish to. Twenty nine (3%) of these essays were, however, discarded because it was apparent the students did not understand the nature of information required. Participants in the remaining essays were aged between 11 and 25 years, 71% of them were females (1% of the students did not indicate their sex), and about two-thirds (63%) were in Senior Three.

The student essays are analyzed in two ways: qualitatively (for content) and quantitatively. For the quantitative analysis, each essay was first assigned a unique identifying number, then a code ‘1’ was assigned for each particular theme that appeared in the essay and ‘0’ otherwise. Analysis of the quantitative data from the essays and the survey entails cross-tabulations with Chi-square tests as well as significance tests of proportions to examine

differences in experiences with disclosure, stigma and discrimination by various background characteristics of the respondents such as *age, sex, highest education level,* and *district*.

Results

Stigma and discrimination in schools

In-depth interviews with school officials revealed that students with full-blown AIDS face greater challenges in school compared to those who are HIV-positive but asymptomatic. Such challenges include being isolated and withdrawn as well as being shunned and stigmatized by other students. The existence of self-imposed stigma and discrimination as well as discrimination by others was also evident from the student essays. For instance, among students who knew a fellow student in their school who is HIV-positive, the reported actual reactions by students and teachers towards the HIV-positive students is at variance with reports of how they would react in the hypothetical case (Table 2). In most cases, the proportions reporting actual positive reactions towards HIV-positive students are significantly lower than those reporting similar possible reactions to a hypothetical case. In contrast, whereas only 2% reported that they would discriminate, isolate or stigmatize a fellow student who is HIV-positive, nearly half (47%) acknowledged that such students face considerable discrimination, isolation and stigmatization not only from fellow students and teachers but also self-imposed. This is supported by the following excerpts from the essays representing the perspectives of both male and female students:

> *"Yes we have someone in our school who is HIV-positive. I don't like to even touch her I think I can even get tempted to loving her and get infected. Other students don't want to talk to her."* (17-year old male student).

"At first I did not like her and any person around her because I thought they also had the virus." (14-year old female student).

"Yes I know someone in the school with AIDS … some students isolate him some are friendly to him. But even some do not share with him, some beat him up, some do not want to be nearer to him." (20-year old male student).

"Students always feel disgusted with her sickness and tend to keep a distance from her." (17-year old female student).

"Students tend to nickname such student for example there's a boy who was nicknamed 'woliru woofira' (poison)." (18-year old male student).

"Her dormitory mates normally insult her when they see her going back home on a monthly basis for treatment, for example they say 'kigenze kuleta biweke'." (19-year old female student).

"They don't associate with us and always make insulting comments... Even teachers should stop back-biting us." (17-year old HIV-positive male student).

"Teachers have also resorted to nick-naming him like for example 'Musuja' and rebuke him in public." (18-year old male student).

"I know of a boy in our school who is HIV-positive… However much other students try to comfort him, he always wants to be alone." (18-year old female student).

"Yes, I know one boy with HIV and he is not always healthy. He does not associate with others. Every time he is in a bad mood." (16-year old male student).

<**Table 2 about here**>

Participants in the survey who were still in school were asked whether they had been teased or called nasty names at school because of their HIV status and whether they suspected rumors spreading about their sero-status. Sixteen percent reported being teased because of their HIV status with no significant difference between male and female respondents (similar proportions of male and female respondents). A slightly higher proportion of male than female respondents reported being called nasty names because of their sero-status with the difference being on the borderline of statistical significance (22% versus 16%; $p = 0.05$). Close to a quarter (24%) of the respondents suspected that rumors were spreading around in school about their status with no significant difference between male and female respondents (23% versus 25%; $p = 0.56$).

Disclosure of HIV status in schools

Among survey participants who were still in school at the time of the survey, 66% reported disclosing their HIV status to school friends, teachers or school nurses with no significant difference by age, education level, district, or whether the individual lived with a biological parent (Table 3). However, a significantly higher proportion of male than female respondents reported having disclosed their sero-status to at least one of the significant others within the school environment (71% versus 62%; $p<0.05$). Disclosure of HIV status was mostly to school friends (56% of those who had friends) followed by teachers (47%) and school nurses (17%). There are significant variations by age and district in the proportion of respondents who had disclosed their sero-status to school friends with the highest proportions being aged 18-19 years and from Kampala district. With respect to disclosing to teachers and school nurses, significant variations are noted by district and age respectively, again with the highest proportion being recorded in Kampala and among those aged 18-19 years (Table 3).

<Table 3 about here>

Respondents who had not disclosed their HIV status to school friends reported that the main reasons for this were fear of discrimination/stigma (38%), friends telling others (34%), losing friends (22%), or being ridiculed (17%). Those who had not disclosed to teachers feared that the latter might tell others (33%), discriminate/stigmatize them (25%), or ridicule them (13%). Similarly, those who had not disclosed their HIV status to the school nurse believed that the nurse could tell others (19%), could not help even if they disclosed (17%), or could discriminate or stigmatize them (12%). A significantly higher proportion of female than male participants believed that the school nurse could tell others if they disclosed their HIV status to

them (22% versus 10%; $p<0.05$). However, there are no significant differences by sex in the other major reasons for non-disclosure to school friends, teachers or school nurses.

Survey participants who had disclosed their HIV status to others in school were asked about the person who made the decision. Disclosure to school friends was largely an individual decision (78%) with a significantly higher proportion of male than female respondents reporting that they made the decision themselves (85% versus 73%; $p<0.05$). The decision to disclose to teachers and the school nurse was, however, partly made by the respondent him/herself and partly by the parent/guardian with no significant difference between and female respondents. For instance, 40% of the respondents who had disclosed their HIV status to teachers reported that it was an individual decision and 49% reported that it was the parent/guardian who made the decision. The figures for who made the decision to disclose to the school nurse are 51% and 30% for individual and parent/guardian respectively. Health providers/counselors, other family members/relatives, teachers, and other friends played minimal roles in influencing the decision to disclose HIV status.

Reactions to disclosure

Most respondents who had disclosed their HIV status to school friends, teachers and school nurses reported positive reactions from them. The school friends mostly showed compassion/sympathy (65%), counseled them (31%), or kept the information confidential (24%; Table 4). The teachers also mostly showed compassion/sympathy (70%) or counseled the respondents (38%). In addition to showing compassion/sympathy and offering counseling the respondent, the school nurses further reminded, gave, or helped respondents with medication. In most cases, the differences between male and female respondents with respect to the reactions of

others are not statistically significant except for showing compassion/sympathy by the school nurse (Table 4).

<Table 4 about here>

The other indication that disclosure of HIV status in schools might not necessarily reinforce stigma and discrimination is with respect to the existence of support groups or clubs for HIV-positive young people in the institutions. Participants in the survey who were still in school were asked whether they had such groups/clubs in their learning institutions. Although only 16% reported that their institutions had such groups/clubs, nearly three-quarters (73%) of them were members (Table 5). The kind of support provided by the groups/clubs mainly included taking medicine (38%), counseling and moral support (29%), basic needs (27%), and life skills training (18%). Nearly all respondents (94%) who were members of these groups/clubs expressed satisfaction with the kind of support they received with no significant difference between male and female participants. In addition, about three-in-four (78%) of the respondents attending school at the time of the survey felt that it is useful to have such support groups/clubs in schools.

<Table 5 about here>

Discussion and implications

In a school setting, non-disclosure of students' HIV status to school authorities has implications for the institutions' ability to respond to the needs of such students in a timely manner assuming that the institutional capacity to do so exists. However, one of the barriers to disclosure of HIV status is the fear of stigma and discrimination (Antelman et al. 2001; Medley et al. 2004; Nsabagasani and Yoder 2006; Varga et al. 2006; Kadowa and Nuwaha 2009). The findings from

this study show that school officials, students, and adolescents living with HIV acknowledge the existence of some level of stigma and discrimination towards in-school HIV-positive young people although part of this is self-imposed. In essence, there is still need for measures that discourage stigma and discrimination in schools. This can be achieved, for instance, through programs aimed at sensitizing school officials and students on the consequences of discrimination and stigmatization on those who are exposed to them as well as advocacy to have school management allocate resources for anti-AIDS campaigns within the school budget. This could, in turn, increase the propensity to disclose one's sero-status, and ensure appropriate and timely response to the needs of HIV-positive students by school officials. In addition, having HIV/AIDS counselors in schools could help reduce self-imposed stigma.

With respect to the outcomes of disclosure of HIV sero-status to school friends, teachers and school nurses by in-school HIV-positive students, the study finds that this mostly elicits positive reactions from those disclosed to. This is consistent with previous studies among adults which found low rates of negative reactions from partners (ranging from 4% to 15%) after disclosure (Maman et al. 2003; Medley et al. 2004). The largely positive reaction to disclosure from school friends, teachers and school nurses is also supported by the finding that nearly all respondents with support groups/clubs for HIV-positive young people in their schools and are members are satisfied with the kind of support they receive. This suggests that the groups/clubs could be a means of discouraging rather than reinforcing stigma and discrimination since such groups/clubs promote acceptance and being open about one's sero-status. Expanding the groups/clubs to incorporate all students irrespective of their HIV status but with the objective of supporting those who are HIV-positive could further discourage stigmatization and

discrimination of HIV-positive students through the use of innovative ways such as child-to-child education and communication.

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Table 1: Distribution of survey participants by various background characteristics

Characteristics	Male (N=294) %	Female (N=424) %	Both sexes (N=718) %
Age group			
12-14	31.0	38.4[ns]	35.4
15-17	31.0	28.4[ns]	29.3
18-19	37.4	33.3[ns]	35.0
Don't know	0.7	0.2[*]	0.4
Ever attended school			
Yes	99.7	99.1[ns]	99.3
No	0.3	0.9[ns]	0.7
Currently attending school[a]			
Yes	81.2	82.6[ns]	82.1
No	18.8	17.4[ns]	18.0
Highest education level			
No schooling	0.3	0.9[ns]	0.7
Primary education	45.0	42.9[ns]	43.8
Secondary education	48.4	48.0[ns]	48.2
Tertiary/University	6.3	8.2[ns]	7.4
District			
Jinja	21.1	27.6[*]	24.9
Kampala	40.1	34.0[ns]	36.5
Wakiso	7.1	5.2[ns]	6.0
Masaka	31.6	33.3[ns]	33.6
Lives with a biological parent			
Yes	39.8	39.4[ns]	39.6
No	58.8	58.0[ns]	58.4
Missing/no answer	1.4	2.6[ns]	2.1
Parents' living arrangements			
Married/living together	11.2	10.9[ns]	11.0
Divorced/separated	3.7	6.6[ns]	5.4
Mother dead	16.3	10.9[ns]	13.1
Father dead	27.2	24.3[ns]	25.5
Both parents dead	39.1	44.1[ns]	42.1
Don't know/missing	2.4	3.3[ns]	2.9

Notes: [a]Among those who had ever attended school; Percentages may not add up to exactly 100 in some cases due to rounding; Differences between male and female proportions are statistically significant at: [**]$p<0.01$; [*]$p<0.05$; [ns]- not significant.

Table 2: Distribution of most commonly cited possible and actual reactions in the essays by students who knew of a fellow student living with HIV in their school

Reactions	Possible reaction[a] (N=303) %	Actual reaction[b] (N=303) %
Show love, compassion, friendship, kindness	60.7	56.4[ns]
Provide hope, encouragement, advice & counsel for positive living	46.9	12.9[**]
Show pity, sympathy, feel bad, sad or sorry	43.9	56.8[**]
Discourage sexual activity/relationships	32.3	5.0[**]
Encourage to pray and/or trust in God	22.8	5.6[**]
Encourage/remind to take ARVs and other medicines always	23.1	6.3[**]
Encourage balanced diet	17.2	0.3[**]
Encourage/support to seek medical treatment including lab tests	15.2	0.7[**]
Stop sharing sharp instruments and other things	13.2	2.6[**]
Assist with class or house work	11.9	4.3[**]
Keep information confidential/secret	11.6	4.0[**]
Discriminate, isolate, stop friendship, stigmatize	2.0	46.9[**]
Tell others/gossip about it	1.7	5.9[**]

Notes: [a]Possible reaction refers to the hypothetical case whereby students were asked how they would react if they found out that a fellow student was HIV-positive; [b]Actual reaction refers to how the students themselves, other students, and teachers react to the presence of an HIV-positive student; ARVs- antiretroviral drugs; Differences between proportions for possible and actual reactions are statistically significant at: [**]$p<0.01$; [*]$p<0.05$; [ns]- not significant.

Table 3: Distribution of respondents attending school at the time of the survey by whether they have disclosed their HIV status to school friends, teachers, or school nurses

	Percentage of respondents that have disclosed their HIV status to			
Characteristics	School friends[a]	School teachers[b]	School nurse[b]	Any one of the three
Age group	**	ns	*	ns
12-14	45.4	49.0	11.8	62.0
15-17	57.0	46.2	18.1	69.6
18-19	68.3	45.1	21.7	67.4
Don't know	0.0	0.0	0.0	0.0
Sex	ns	ns	ns	*
Male	55.7	50.0	18.9	71.4
Female	54.0	44.7	15.0	61.7
Highest education level	ns	ns	ns	ns
Primary	49.8	49.8	14.1	65.3
Secondary	60.0	43.4	19.4	65.9
Tertiary/University	71.4	45.5	18.2	68.2
District	**	*	ns	ns
Jinja	41.6	49.0	18.6	64.8
Kampala	72.3	38.7	20.0	63.6
Wakiso	26.3	55.9	11.8	58.8
Masaka	55.4	53.6	11.6	70.1
Lives with a biological parent	ns	ns	ns	ns
Yes	52.5	48.0	15.5	66.6
No	58.4	45.2	17.9	64.7
Missing/no answer	33.3	50.0	25.0	50.0
Total	54.7	46.8	16.6	65.6

Notes: [a]Among those who had school friends; [b]Among all respondents attending school at the time of the survey; Chi-square tests show significance at: **p<0.01; *p<0.05; ns- not statistically significant.

Table 4: Distribution of survey participants who disclosed their HIV status to school friends, teachers or school nurses by the most commonly cited reactions to the disclosure

Reactions of those disclosed to	Male %	Female %	Both sexes %
School friends	(N=98)	(N=127)	(N=225)
Showed compassion/sympathy	63.3	66.1^{ns}	64.9
Counseled me	36.7	26.0^{ns}	30.7
Kept it confidential/secret	26.5	22.1^{ns}	24.0
No reaction	9.2	16.5^{ns}	13.3
Turned unfriendly/avoided me	4.1	5.5^{ns}	4.9
Told others	1.0	4.7^{ns}	3.1
Other	9.2	3.9^{ns}	6.2
Teachers	(N=119)	(N=155)	(N=274)
Showed compassion/sympathy	66.4	72.3^{ns}	69.7
Counseled me	37.0	39.4^{ns}	38.3
Stopped punishment/hard labor	2.5	3.9^{ns}	3.3
No reaction	0.8	4.5^{ns}	2.9
Turned unfriendly/avoided me	2.5	1.3^{ns}	1.8
Told others	0.0	3.2^{ns}	1.8
Don't know	9.2	5.2^{ns}	6.9
Other	7.6	4.5^{ns}	5.8
School nurse	(N=45)	(N=52)	(N=97)
Showed compassion/sympathy	53.3	76.9*	66.0
Counseled me	60.0	44.2^{ns}	51.6
Reminded/gave/helped with medication	13.3	7.7^{ns}	10.3
Told others	0.0	1.9^{ns}	1.0
Don't know	2.2	3.9^{ns}	3.1
Other	2.2	7.7^{ns}	5.2

Notes: Questions allowed for multiple responses, percentages do not therefore sum up to 100; Differences between male and female proportions are statistically significant at: $^{**}p<0.01$; $^{*}p<0.05$; ^{ns}- not significant.

Table 5: Distribution of respondents attending school at the time of the survey by the availability of support groups or clubs for in-school HIV-positive young people

	Support groups/clubs for HIV-positive young people		
	Male	Female	Both sexes
Support groups/services	%	%	%
Have support groups/clubs in school[a]	18.1	13.8[ns]	15.6
Is a member of such groups/clubs[b]	74.4	70.8[ns]	72.5
Kind of support received from the groups/clubs[c]	(N=32)	(N=34)	(N=66)
Taking medicine	46.9	29.4[ns]	37.9
Counseling/moral support	18.8	38.2[ns]	28.8
Basic needs	28.1	26.5[ns]	27.3
Life skills training	18.8	17.7[ns]	18.2
Other	21.9	17.7[ns]	19.7
Satisfied with support received from groups/clubs	96.7	91.2[ns]	93.9
Useful to have support groups in schools for HIV-positives[a]	75.6	79.8[ns]	78.1

Notes: [a]Among participants currently attending school (238 male and 347 female respondents); [b]Among those who reported having support groups/clubs for HIV-positive young people in school (43 male and 48 female respondents); [c]Questions allowed for multiple responses, percentages do not therefore sum up to 100; Differences between male and female proportions are statistically significant at: [**]$p<0.01$; [*]$p<0.05$; [ns]- not significant.