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HIV Infection and Schooling Experiences of Adolescents in Uganda

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1. 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% 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 formulated Education Sector Policies on HIV/AIDS that encompass all learners, employees, managers and administrators in all learning institutions at all levels of the education system (for example, Ministry of Education and Sports- Uganda, 2006; Ministry of Education- Kenya, 2004). The policies predominantly revolve 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.

In spite of the recognition of school-going HIV-positive young people as a vulnerable group, education sector responses to HIV/AIDS in the SSA region are predominantly curriculum-based. The focus is almost entirely on developing the capacity of learners in the areas of 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; Cohen, 2004; Kelly, 2000; Rugalema & Khanye, 2004). Insufficient attention has been paid to ways of supporting in-school HIV-positive young people partly because their needs in school are still largely unknown given that this is an emerging issue in the region. It could also be due to the dilemma of how to tackle the issue of HIV in schools based on fears that having specific programs targeting in-school HIV-positive young people could reinforce stigma and discrimination against them.

Whatever the reason for the lack of appropriate education sector responses in this area, a key issue that emerges is the need for evidence on in-school experiences of HIV-positive young people in the region. This should in turn inform appropriate interventions aimed at

ensuring an inclusive education system that adequately responds to the challenges in-school HIV-positive young people may face. This chapter therefore responds to the need for relevant evidence by exploring the experiences of HIV-positive adolescent boys and girls in primary and secondary schools in Uganda from the perspectives of school officials and teachers, the general student body, as well as adolescents perinatally infected with HIV. It specifically focuses on: (1) school attendance and experiences with class repetition; (2) experiences of stigma and discrimination within the school environment; and (3) availability of school-based health and psychosocial support programs and services for HIV-positive students. It ends with a discussion of the implications of these experiences for addressing the needs of in-school HIV-positive young people by the education sector not only in Uganda but in SSA countries affected by the pandemic.

2. Context

Uganda had an estimated population of 33.8 million people as of mid 2010 with the majority (87%) living in rural areas and nearly half (49%) being below 15 years of age (Population Reference Bureau, 2010). The first AIDS case was diagnosed in the country in 1982 and by 1986, it had reached the level of a generalized epidemic with the predominant mode of transmission being heterosexual contact (Ministry of Health & ORC Macro, 2006; Serwadda et al., 1985). The sentinel surveillance system from which national HIV prevalence estimates were initially derived was established in 1989 starting with six clinics in urban areas but later expanded to include clinics from peri-urban and rural areas (Garbus & Marseille, 2003). HIV prevalence was estimated at 15% among all adults (15-49 years) in 1991-1992 which was considered to be the peak of the epidemic in the country (Kirungi et al. 2006; Stoneburner & Low-Beer, 2004). This, however, declined to 7% in 2001 and was still at this level in 2009 (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2010; Kirungi et al. 2006; Stoneburner & Low-Beer, 2004). As in other sub-Saharan Africa countries affected by the epidemic, HIV prevalence is higher among women than among men and in the urban compared to rural areas. In 2004-2005, for example, 8% of women aged 15-49 years were HIV-positive compared to 5% of men of similar age groups while prevalence was nearly twice as high in the urban compared to rural areas (10% versus 6%; Ministry of Health & ORC Macro, 2006). Similarly in 2009, prevalence among young people aged 15-24 years was 5% for women and 2% for men (UNAIDS, 2010).

The first AIDS control program was set up in the country in 1987 with emphasis on abstinence, being faithful to one partner, and condom use (Ministry of Health & ORC Macro, 2006). This prevention strategy—referred to as ABC—has since been expanded to include voluntary counselling and testing (VCT), prevention of mother-to-child transmission (PMTCT) of the virus, antiretroviral treatment (ART), and HIV care and support services (Ministry of Health & ORC Macro, 2006). The Ministry of Health started a voluntary door-to-door HIV screening programme in 1999 and has also begun implementing provider-initiated testing and counselling (PITC) at health facilities (Menzies et al., 2009; Wanyeze et al., 2008). By 2009, HIV testing and counselling services were available in 1,215 health facilities representing an increase from 812 facilities in 2008 and 554 in 2007 (World Health Organization [WHO] et al., 2009, 2010). Free ART has been available since 2004 and by 2009, 39% of adults in need of treatment were receiving it (WHO et al., 2010). The Ministry of Health began offering free PMTCT services in 2000; the proportion of HIV-positive mothers receiving PMTCT services increased from 12% in 2005 to 53% in 2009

(WHO et al., 2009, 2010). However, challenges still remain with respect to reaching all those in need of treatment due to limited human resource capacity to provide the services, and lack of efficient management of funds and supplies (Onyango and Magoni, 2002).

With respect to education, Uganda implemented the Universal Primary Education (UPE) programme in 1997 which removed fees for enrolment in primary schools and resulted in substantial increases in enrolments (Deininger, 2003; Murphy, 2003; Nishimura et al., 2008; UBOS and Macro International, 2007). This was followed ten years later (in 2007) with the introduction of Universal Secondary Education (USE) whose impact is yet to be systematically evaluated (Chapman et al., 2010). Estimates of HIV prevalence among members of the school community (students and teachers) are unavailable. However, realizing the challenges posed by HIV to the education sector, the Ministry of Education and Sports issued the *Education and Sports Sector National Policy Guidelines on HIV/AIDS* in 2006 to provide a framework for responding to the epidemic within the sector. The objectives of the policy are to: (1) raise knowledge of students, education managers and other sector employees on HIV/AIDS; (2) ensure that students, education managers, and educators access prevention, treatment, care and support services; (3) eliminate all forms of stigma and discrimination; (4) mitigate the impact of HIV/AIDS that impede access to and provision of quality education; (5) strengthen the education sector's capacity to effectively respond to HIV/AIDS; and (6) contribute to the knowledge base on HIV/AIDS through research (Ministry of Education and Sports- Uganda, 2006).

3. Data

The data are 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 (of school-going age) who were perinatally infected with HIV (had been living with the virus since infancy) and who knew their sero-status. The sample members were identified and recruited through existing HIV/AIDS treatment, care and support programs/centres selected by The AIDS Support Organization (TASO)-Uganda in four districts (Kampala, Wakiso, Masaka and Jinja). Thirteen such centres participated in the study. All adolescents who received services from the centres and satisfied the eligibility criteria in terms age, perinatal infection, and awareness of sero-status were targeted for inclusion in the study. TASO counsellors assisted with the identification and mobilization of the eligible respondents. The process involved obtaining clearance from the management of the centres, identifying the target sample from the existing records, and making calls to their parents to request them to come to the centres or targeting days when they visit the centres 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 adolescents aged 12-17 years, written consent to

participate in the study was sought from parents/guardians and assent was sought from the adolescents themselves. However, for adolescents aged 18-19 years, the study obtained individual written consent only. The TASO Internal Review Board, the Uganda National Council for 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. There was, however, no significant difference in the distribution by sex according to 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). The majority (65%) of the respondents were aged below 18 years, hence considered minors while slightly more than one-third (37%) were from Kampala district. Besides, 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.

Characteristics	Male (N=294) %	Female (N=424) %	Both sexes (N=718) %
Age group			
12-14	31.0	38.4	35.4
15-17	31.0	28.1	29.3
18-19	37.4	33.3	35.0
Don't know	0.7	0.2*	0.4
District			
Jinja	21.1	27.6*	24.9
Kampala	40.1	34.0	36.5
Wakiso	7.1	5.2	6.0
Masaka	31.6	33.3	32.6
Lives with a biological parent			
Yes	39.8	39.4	39.6
No	58.8	58.0	58.4
Missing/no answer	1.4	2.6	2.1
Parents' living arrangements			
Married/living together	11.2	10.9	11.0
Divorced/separated	3.7	6.6	5.4
Mother dead	16.3	10.9	13.1
Father dead	27.2	24.3	25.5
Both parents dead	39.1	44.1	42.1
Don't know/missing	2.4	3.3	2.9

Notes: 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.

Table 1. Percent distribution of survey participants by various background characteristics

The second component of the study involved in-depth interviews with school officials to assess 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 operationalization of the 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 counsellor (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 peers 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 whose essays were analyzed 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.

4. Analysis

The first part of analysis involves cross-tabulations with Chi-square tests and significance tests of proportions to examine differences in schooling, experiences of stigma and discrimination, and availability of school-based support programs and services by various background characteristics of the respondents including age, sex, district, and whether the respondent lived with a biological parent. In the second part of the analysis, random-effects logistic regession models are estimated to predict the likelihood of HIV-positive adolescents being in school at the time of the survey, experiencing stigma and discrimination in school, and receiving any form of support from school. The choice of the analysis technique is guided by the need to account for unobserved characteristics of individuals identified from the same HIV/AIDS treatment, care and support program/centre. The model is of the form:

$$\log it(\pi_{ij}) \quad = \quad X_{ij}\beta + \mu_j \tag{1}$$

where π_{ij} is the probability of a given outcome for individual i identified from facility j; X_{ij} is the vector of covariates; β is the associated vector of parameter estimates; and μ_j is the

disturbance term due to unmeasured characteristics that may also affect the outcome for individuals identified from facility *j*.

The first dependent variable is measured by whether the respondent was still in school at the time of the survey conditional on having ever attended school. Stigma and discrimination, on the other hand, refer to whether those attending school had ever been teased, called nasty names, or suspected that rumours were spreading about them because of their HIV status. The third dependent variable is measured by whether the respondent received any support from groups, clubs or the school. The models control for age (single years), sex (male or female), district of residence (Kampala, Jinja, Masaka, Wakiso), and whether the respondent lived with a biological parent (yes or no).

5. Results

5.1 School attendance

Nearly all (99%) of adolescents perinatally infected with HIV had ever attended school with no significant difference between male and female respondents. In addition, 44% of those who had ever attended school reached secondary and above level of education (41% of male and 46% of female respondents; p=0.19). Most of those who had ever attended school (82%) were still in school at the time of the survey (81% of male and 83% of female respondents; p=0.49). As expected, current school attendance was significantly associated with age and whether the respondent lived with a biological parent (Table 2). In particular, older HIV-positive adolescents were significantly less likely to be in school compared to their younger counterparts (p<0.01) while those living with a biological parent were significantly more likely to be in school compared to those who did not live with a biological parent (p<0.05).

Covariates	Currently attending school[a]	Indicator of stigma/ discrimination[b]	Any support from groups/clubs/ school[b]
Age (single years)	-0.47** (0.06)	0.01 (0.05)	0.08 (0.06)
Sex (Female = 1)	0.04 (0.22)	-0.05 (0.18)	-0.27 (0.21)
District (ref = Kampala)			
Jinja	-0.51 (0.53)	0.08 (0.26)	-0.72 (0.41)
Wakiso	-0.71 (0.87)	-0.10 (0.42)	-0.03 (0.96)
Masaka	-0.84 (0.59)	0.84** (0.24)	0.21 (0.38)
Lives with any biological parent (Yes = 1)	0.62* (0.24)	0.04 (0.18)	0.28 (0.21)
Number of respondents	710	583	583

Notes: [a]Among those who ever attended school; [b]Among those currently attending school; Estimates are based on equation (1) in the text; Standard errors are in parentheses; ref: reference category; *p<0.05; **p<0.01.

Table 2. Coefficient estimates from random-effects logit models predicting current school attendance, experiences of stigma/discrimination, and receipt of any support from school

Slightly more than half (52%) of the respondents attending school at the time of the survey missed going to school the previous term (Table 3) with no significant variations by age, sex or whether the respondent lived with a biological parent. Nonetheless, the proportion that missed school the previous term was significantly lower in Jinja compared to other districts. Further analysis shows that illness was the major reason for missing school (cited by 57% of those who missed school) followed by lack of school fees or education materials (23%), and going for treatment/ medication (12%). There were also significant variations in the major reasons for missing school by sex and district of residence ($p<0.05$ in each case). For instance, 60% of female respondents cited illness as the major reason for missing school the previous term compared to 51% of male respondents. In contrast, slightly more than twice as many male as female respondents cited going for treatment/medication as the major reason for missing school (18% versus 8%). Similarly, the proportion mentioning illness was about 10 percentage points higher in Jinja and Masaka (61% in each case) compared to Kampala and Wakiso districts (52% and 50% respectively) while the proportion citing treatment/medication was nine times higher in Kampala compared to Jinja district (19% versus 2%).

Background characteristics	Missed school previous term (%)	Ever repeated a class (%)	Considers schooling very important (%)
Age group	p=0.24	p=0.42	p=0.46
12-14	55.3	56.1	96.2
15-17	48.5	59.1	93.6
18-19	50.3	50.3	95.4
Sex	p=0.32	p=0.66	p=0.39
Male	49.2	56.3	94.1
Female	53.3	54.5	95.7
District	p<0.01	p<0.01	p<0.01
Jinja	37.2	64.1	98.6
Kampala	58.7	45.8	95.6
Wakiso	52.9	52.9	79.4
Masaka	54.1	60.2	94.5
Lives with a biological parent	p=0.75	p=0.13	p=0.18
Yes	52.4	51.6	96.4
No	51.1	58.0	94.0
All respondents	51.6	55.2	95.2
Number of respondents	585	585	585

Notes: p-values are from Chi-square tests.

Table 3. Percentage of survey participants who missed school the previous term, percentage that ever repeated a class and percentage that considered schooling very important by background characteristics

More than half (55%) of the respondents who were still in school at the time of the survey reported ever repeating a class (Table 3). The proportion having repeated a class did not

significantly vary by age, sex or whether the respondent lived with a biological parent. It, however, significantly differed by district of residence with the lowest proportion being in Kampala (46%) and the highest in Jinja (64%). Results of further analysis show that poor performance and illness were the major reasons for repeating a class the last time (cited by 35% of the respondents in each case) followed by lack of fees or education materials (20%). There were also significant variations in the major reasons for repeating a class by age ($p<0.01$) and district of residence ($p<0.05$). For example, the proportion of adolescents aged 12-14 years who repeated a class because of poor performance was more than twice as high as that of those aged 18-19 years (49% versus 22%). In contrast, the proportion of those aged 18-19 years who cited lack of fees or education materials was about four times higher than that of those aged 12-14 years (35% compared to 9%). Similarly, the proportion that repeated a class because of poor performance was highest in Jinja (42%) and lowest in Kampala district (22%) while the proportion that repeated a class because of illness was highest in Kampala (41%) and lowest in Jinja district (28%).

Background characteristics	Future career prospects (%)	Encouraged by others (%)	Gain new knowledge (%)
Age group	p<0.05	p=0.49	p<0.01
12-14	64.6	16.9	16.5
15-17	67.3	20.5	10.5
18-19	77.1	21.1	5.7
Sex	p=0.72	p=0.13	p<0.01
Male	68.1	22.3	6.7
Female	69.5	17.3	15.0
District	p<0.01	p=0.14	p=0.08
Jinja	86.2	14.5	9.7
Kampala	74.7	19.1	9.8
Wakiso	64.7	14.7	5.9
Masaka	48.6	24.3	16.6
Lives with a biological parent	p=0.18	p=0.57	p=0.85
Yes	66.7	20.1	11.9
No	71.8	18.3	11.4
All respondents	68.9	19.3	11.6
Number of respondents	585	585	585

Notes: p-values are from Chi-square tests.

Table 4. Percent distribution of survey participants by three most commonly cited motivations for schooling according to background characteristics

In spite of the challenges with absenteeism and class repetition, nearly all respondents who were still in school (95%) considered education very important to them with no significant variations by age, sex or whether the respondent lived with a biological parent (Table 3). Nonetheless, a significantly lower proportion of respondents from Wakiso compared to those from the other districts recognized that education is very important to them ($p<0.01$). Their major motivations for continuing with education included future career prospects (mentioned by 69% of the respondents), encouragement from others (19%) and the urge to gain new knowledge (12%; Table 4). A significantly higher proportion of older (18-19 years) compared to younger respondents mentioned future career prospects as a motivation for schooling ($p<0.05$). In contrast, the proportion of respondents from Masaka district mentioning future career prospects was nearly half of that of respondents from Jinja district ($p<0.01$). There were, however, no significant variations in the proportion of respondents mentioning encouragement by others as a motivation for schooling by the background characteristics considered. But a significantly higher proportion of younger (12-17 years) and female respondents cited the urge to gain new knowledge as a motivation compared to older and male respondents respectively (Table 4).

Further analyses show that among respondents who had ever attended school but were out of school at the time of the survey, 63% cited lack of fees or education materials as the major reason for non-attendance followed by illness (16%) while 8% mentioned death of parent/guardian. There were no significant variations in the major reasons for non-attendance by age, sex or district of residence. However, the reasons differed significantly by whether the respondent lived with a biological parent ($p<0.05$). In particular, the proportion of those not living with a biological parent that cited lack of fees or education materials as the major reason for non-attendance was 24 percentage points higher than that of those who lived with such a parent (69% versus 45%). In contrast, the proportion of those living with a biological parent who mentioned illness as the major reason was more than three times higher than that of those not living with such a parent (32% versus 10%).

5.2 Stigma and discrimination

Findings from in-depth interviews with school officials indicate that students with full-blown AIDS face greater challenges in school compared to those who are HIV-positive but asymptomatic. The 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 was 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 5). 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 further supported by the following excerpts from the essays representing the perspectives of both male and female students:

Reactions	Possible reaction[a] (%)	Actual reaction[b] (%)
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**
Number of students	303	303

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 5. Distribution of most commonly cited possible and actual reactions as expressed in the essays by students who knew of a fellow student living with HIV in their school

"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' ['she has gone to get medication' but in a derogatory manner]." (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' [fever] 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).

Adolescents perinatally infected with HIV who participated in the survey and were still in school were asked whether they had been teased or called nasty names because of their HIV status and whether they suspected rumours spreading about their sero-status. Sixteen percent reported being teased because of their HIV status (similar proportions of male and female respondents), 19% reported being called nasty names (22% of male and 16% of female respondents; $p=0.07$), and close to a quarter (24%) suspected that rumours were spreading around in school about their sero-status (23% of male and 25% of female respondents; $p=0.56$). Results from the random-effects logit model predicting the likelihood of experiencing any of the three indicators of stigma and discrimination show no significant differences by age, sex, or whether the respondent lived with a biological parent (Table 2). District of residence is, however, significantly associated with experiencing stigma and discrimination ($p<0.01$) with those from Masaka being significantly more likely to report such experiences compared to their counterparts from Kampala ($p<0.01$), Jinja ($p<0.01$), and Wakiso districts ($p<0.05$).

5.3 School-based support

Only 16% of in-school HIV-positive adolescents reported having support groups or clubs for HIV-positive students in their learning institutions (18% of male and 14% of female respondents; $p=0.19$). Of those who had, 73% belonged to and received support from the groups/clubs (74% of male and 71% of female respondents; $p=0.75$). In addition, only 15% reported receiving any kind of support from school (19% of male and 13% of female respondents; $p<0.05$). Results from the random-effects logistic regression model predicting the likelihood of receiving any support from the groups, clubs or school show no significant differences by age, sex, district of residence, or whether the respondent lived with a biological parent (Table 2). However, nearly all those who received some kind of support from the groups/clubs (94%) or schools (92%)—where these exist—were satisfied with it. Additional analysis shows that the kind of support provided by the groups, clubs or schools mostly included taking medicine, counselling or moral support, basic needs, and life skills training.

School officials also reported during in-depth interviews that once they found out that a particular student had HIV or other chronic illness, they exempted them from engaging in heavy extra-curricular activities, provided them with special meals where possible, and

reminded them to take medicine in cases where they were aware that the children were on antiretroviral drugs (ARVs). Nonetheless, the interviews revealed that the support was mainly non-formal and a lot seemed to depend on the goodwill of particular head teachers, other teachers, and school nurses who sometimes use their own resources. In one school, for example, a teacher reportedly helped HIV-positive students to pick their monthly refill of ARVs so that they did not miss lessons while in another, the head teacher invited the guardian of one of the students to the school, counselled them, and connected them to a treatment centre. As one senior female teacher in one of the primary schools explained:

"Sometimes their guardians do not genuinely have the money but others [guardians] are just negligent they feel that 'after all the child may not have long to live'. In cases where the child knows that they are HIV positive this adds to their psychological stress. At school we ask them 'where are the materials we sent you for'; at home they are being told 'we do not have money'. When we do not know their special circumstances we think they are just being stubborn and not informing their parents. But when we find out, we try as a school to see how best to help them. Some teachers even buy them the materials using their own money but this is after they have found out the circumstances."

Findings from the in-depth interviews further show that HIV-positive young people in boarding institutions face additional challenges such as poor diet, adherence to ARVs, and taking cold showers. Whereas these have implications for their academic performance, schools lack formally established mechanisms for meeting these needs. For instance, sick-bays—where they exist in schools—are ill-equipped; they do not commonly stock antibiotics, have no full-time nurses while the available staff members are equipped to provide First Aid treatment only. Moreover, school-based caregivers (school nurses, guidance and counselling teachers, and senior teachers) are inadequately trained to handle the healthcare needs of HIV-positive students.

6. Discussion and implications

This chapter examined the schooling experiences of HIV-positive adolescent boys and girls in Uganda from the viewpoints of not only perinatally infected in-school young people but also school officials, teachers, and the general student body. As expected, most of the adolescents living with HIV are vulnerable on account of both their young age and the fact that the majority had lost one or both parents. Thus, although nearly all of them had ever attended school and most of them were still in school at the time of the survey, issues of absenteeism, class repetition, stigma and discrimination (by others or self-imposed) remain a challenge. These challenges cut across adolescents of various groups, that is, age, sex and whether they live with a biological parent. Moreover, the most commonly cited reasons for missing school and repeating a class are lack of fees or education materials, illness, going for treatment, and poor performance. Those who are in boarding institutions face additional challenges including poor diet, cold showers, and adherence to treatment for fear of being stigmatised.

The above challenges have implications for the academic performance and educational attainment of HIV-positive young people. Schools, however, lack formally established mechanisms for addressing these needs. Formal access to treatment, counselling, care and

support at school or through school is almost non-existent. Sick-bays—where they exist in schools—are not equipped with essential medicines while school-based caregivers (school nurses, guidance and counselling teachers, and senior teachers) are inadequately trained to handle the healthcare needs of HIV-positive students. Existing attempts at addressing the needs of in-school HIV-positive young people are ad hoc, at individual level, and crisis-driven. The absence of formally established mechanisms could also partly be due to non-disclosure of students' sero-status by parents/guardians during admission given that in certain cases, school authorities often discovered when the student became symptomatic while at school or because of continued absenteeism or seeking permission to go for treatment on specific days.[1]

These findings have important programmatic implications for the education sector not only in Uganda but other SSA countries affected by HIV/AIDS. Specifically, they suggest the need for: (1) school-based programs to assist orphans and other vulnerable children, including those living with HIV, so that they do not miss attending school for lack of essential materials; (2) strengthening the school-based healthcare program including treatment, care and support for HIV-positive students, encouraging in-school young people to undergo testing and counselling for HIV, and equipping sick-bays—where these exist—with essential medicines; (3) pre- or in-service training for school-based caregivers (school nurses, guidance and counselling teachers, and senior teachers) on HIV counselling, care and support; (4) putting in place psychosocial support mechanisms for HIV-positive young people, orphans and other vulnerable children in schools, which should be expanded to incorporate all students irrespective of their HIV status in order to reduce stigma and discrimination through innovative ways such as child-to-child communication; and (5) putting in place measures to discourage stigma and discrimination against HIV-positive students through sensitizing school officials and students on the consequences of the same on those who are exposed to them.

Although this chapter identifies possible responses by the education sector to the needs of in-school HIV-positive young people, its major limitation is that it does not consider acceptable, feasible and effective strategies for addressing these needs. This is largely because it relies on data from an exploratory study whose aim was to provide a better understanding of the schooling experiences of this subset of the population. Operations research is best suited for providing answers regarding acceptable, feasible and effective strategies for responding to these needs. Operations research can, for instance, provide answers to the following questions: What school-based support programs are appropriate and effective in meeting the education needs of orphaned and vulnerable children, including those living with HIV? How can school-based health care programs be strengthened to better meet the needs of in-school HIV-positive young people? Does training of school-based caregivers improve the provision and quality of care and support for HIV-positive learners? What strategies and psychosocial support mechanisms can

[1]In Uganda, parents/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/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.

effectively reduce stigma and discrimination in schools? These are questions which are beyond the scope of the present chapter.

7. Conclusion

In-school HIV-positive young people in Uganda face a number of challenges including: (1) high rates of absenteeism and class repetition because of illness, having to go for drug re-fills regularly for those on ART, or socio-economic hardships at home; (2) stigma and discrimination from fellow students, teachers or self-imposed; and (3) poor diet, cold showers, and non-adherence to ART because of fear of stigma and discrimination from fellow students among those in boarding institutions. At the same time, schools are not adequately prepared to respond to their special needs. Key actors in the education sector (government, private sector, non-governmental organizations, and donors) should therefore consider appropriate interventions aimed at enhancing the capacity of schools to respond to the unique needs of HIV-positive learners.

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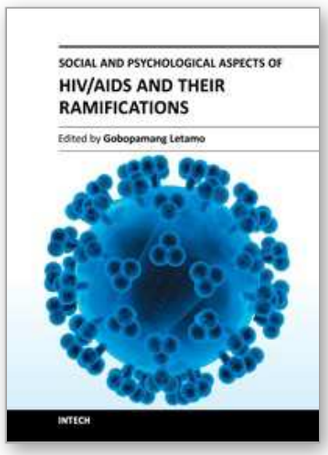

Social and Psychological Aspects of HIV/AIDS and their Ramifications

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This book has assembled an array of chapters on the social and psychosocial aspects of HIV/AIDS and their impact on HIV/AIDS and related behaviours. The book addresses key areas of HIV and AIDS, including, but not in any way limited to, care-seeking behaviour, adherence, access, psychosocial needs and support services, discrimination and the impact the epidemic has on various sectors of the economy. The book has seventeen chapters; seven chapters deal with social aspects of HIV/AIDS, four with psychosocial aspects of HIV/AIDS, and the remaining six chapters with the impact of social and psychosocial factors on HIV/AIDS and related behaviours. The book is an essential reading for academics, students and other people interested in the field of HIV and AIDS.

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