Knowledge, attitude and practices of young people, regarding HIV positive prevention - a mixed method study at the Infectious Diseases Institute Kampala Uganda


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ABSTRACT
Background
HIV remains a high priority global health problem. An estimated 33.2 million people were living with HIV/AIDS in 2007, of which 22.5 million live in Sub-Saharan Africa. An approximated 67% of newly infected individuals are aged 15 to 24 years. Despite the existence of HIV control programmes that have been targeting HIV negative people, the AIDS pandemic has continued to grow. Current efforts in the fight against HIV/AIDS are tailored towards positive prevention with people living with an HIV/AIDS diagnosis. However, the effect of these efforts has not been evaluated among young people who continue to bear the highest brunt of transmission risk.

Objective
The objective of the study was to assess the knowledge, attitude and practices of young people living with HIV in terms of sexual behaviour, motivation and consequences of unprotected sex.

Design
A cross sectional survey complemented with a qualitative component based on focus group discussions.

Study setting
Infectious Disease Institute Clinic, Makerere University College of Health Sciences, Mulago, Kampala, Uganda

Study subjects
A total of 126 young people aged 18 to 24 years attending the Infectious Disease Clinic in Mulago Hospital with an additional 35 subjects participating in focus group discussions.

Methods
Quantitative data were collected through administered structured questionnaires. Five focus group discussions were conducted in order to understand young people’s attitudes and practices better and thus interpret the survey findings better.
Results

126 participants were studied, with a median age of 23 yrs, range 6 yrs and male to female ratio 1:4 and 52% were taking ART. The study revealed deficits in knowledge and positive prevention tailored behaviour. One year prior to time of the study 16% of the participants practiced abstinence and 16% had multiple sexual partners. Percent knowledge of at least one method of STI transmission was 78%. Failure to identify modes of STI transmission was found in 12% of the participants. Whilst disclosure of HIV status to significant others is common, disclosure to spouses is relatively low (36%). There was an 8% prevalence of pregnancy, 44% of all the pregnancies acquired after acquisition of HIV and knowledge of HIV status are unwanted. 58% women and 78% men wanted to have children in future. The themes that emerged under behavioral beliefs included, avoiding infecting others, improved personal wellbeing and reduction of risky behaviour. Normative beliefs arose from expectations of family members, peers and healthcare workers. Subsequent positive prevention behaviour ranged from consistent condom use to disuse, mutual disclosure of HIV status to serosorting, abstinence and faithfulness to multiple sexual partners. It also varied from felt stigma to being pioneers of prevention and seeking and compliance to medical expert advice.

Conclusion

The success of positive prevention programmes dealing with HIV infected young people will greatly depend on; a) Promotion of mutual partner serostatus disclosure through equipping young people with disclosure skills b) Ensuring that altruistic behaviour and leadership among young people living with HIV is reinforced c) Prevention of unwanted pregnancies among young women while explicitly targeting men’s cooperation d) Addressing stigma and shame e) Addressing the difficult choices that surround condom use and sex and f) Improvement of the wider socio-economic conditions in which young people live.
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LIST OF ABBREVIATIONS

AIDS Acquired Immunodeficiency Syndrome
ART Antiretroviral Therapy
FGD Focus Group Discussion
HIV Human immune deficiency virus
IDI Infectious Disease Institute
MoH Ministry of Health
PLWA people living with HIV/AIDS
PMTCT Prevention of Mother to Child Transmission
PP Positive prevention
SCOT Strengthening of Counselor Training
STD Sexually Transmitted Diseases
STI Sexually Transmitted Infections
UNAIDS Joint United Nations Programme on HIV/AIDS
WHO World Health Organization
YPLWA Young people living with HIV/AIDS
OPERATIONAL DEFINITIONS

**Young people:** Age group 10 to 24 years

**Sexual risk behaviour:** Activities in which young people get involved that increase the risk of HIV acquisition.

**Disclosure:** A patient revealing his or her HIV serostatus to his or her spouse, significant family members or significant others.

**Change agent:** A person living with HIV who is reasonably well informed about his or her HIV status and can in turn educate people living with HIV/AIDS and or the community in which he or she lives.

**Unintended pregnancy:** Pregnancy that was not earlier planned by the person.

**Positive prevention:** HIV prevention that focuses on the behavioral activities of people living with an HIV diagnosis. It aims to increase the self-esteem, confidence and ability of HIV positive people to protect their own health and to avoid passing on the infection to others.

**Serosorting:** A process through which HIV positive people search for fellow HIV positive partners.
INTRODUCTION AND LITERATURE REVIEW

1.1 Epidemiological background

HIV remains a high priority global health problem. An estimated 33 million people living with HIV/AIDS (PLWA) were reported in 2007 (UNAIDS/WHO report), with 23 million living in Sub-Saharan Africa. Globally, approximately 67% of newly infected individuals were aged between 15 and 24 years in 2003. By the end of 2005, adult HIV prevalence in Uganda was estimated to be 6.7% translating into an estimated one million Ugandans living with HIV/AIDS [1].

The currently existing prevention strategies have been designed to target HIV negative people or people who are unaware of their HIV status with the hope of preventing them from getting new HIV infections. Moreover, for every new HIV infection there is a negative and positive party involved [2-5, 6]. The abstinence, being faithful and condom use (ABC) strategy adopted by Uganda in the early 1980’s, resulted in a tremendous reduction in HIV prevalence in the 1990’s [7]. However, stagnant HIV rates have been observed since 2007 with threats of upsurges in some urban areas.

No single HIV prevention strategy has been proven to work efficiently in solitude. However, a combination of prevention strategies increases the chances of reducing new transmissions [2-6]. In the past, very few or no prevention strategies have addressed prevention from the perspective of involving HIV infected individuals. This is probably due to the fear of overburdening an already marginalized group with new responsibilities and sparking off a new wave of stigma. Yet HIV positive people have sexual needs and issues concerning sex and sexuality, disclosure, condom use, child birth, and contraception that still remain ethically complex in different sub groups and ages [2,3,8]

In Uganda and other East African countries estimated discordance rates as high as 40-50% have been reported [6]. The fact that discordance couples are more frequent than HIV positive concordant couples in some areas poses a crucial prevention challenge. The proportion of HIV negative people at a daily risk of acquiring HIV infection through discordant relationships cannot be ignored [9]. Misconceptions about discordance remain wide spread not only among the discordant couples but also among some health workers [10,11]. It is therefore evident that HIV positive people have a role to play and a responsibility to take when it comes to containing the HIV epidemic through controlling
new HIV transmissions. This role and ethical responsibility can no longer be handled lightly [2-5, 12].

Recent increase in access to antiretroviral therapy (ART) programmes has led to improved quality of life for HIV positive people who have subsequently lived longer and healthier lives. It is therefore not surprising that they resume normal sexual activity. However, difficult choices concerning disclosure and condom use surround sexual encounters of HIV positive people every day. HIV infected persons might not have protection as the priority during sexual affairs and sometimes, they may transfer the protection responsibility to their partners. There is also a possibility that disclosure of one’s HIV status may be complicated by rejection and feelings of fear and anxiety. It has also been described as not fitting with the exciting and spontaneous sexual encounters with new partners [2-4, 10, 13].

It has been argued that most new HIV infections are spread by people who are unaware of their HIV status. This has redirected HIV prevention efforts to massive campaigns for timely HIV diagnosis with subsequent referral of those who are found to be seropositive to health care services. Since treatment and prevention are indispensable, the integration of HIV prevention services into HIV treatment facilities has been advocated for [2-4,6,8,14].

There is growing evidence from more recent studies suggesting, that when HIV positive people are treated holistically, the resulting improved mental, physical and sexual health might in fact lead to change in risky sexual behaviour. However, the exact effect of ART introduction on HIV transmission remains partially unclear. The efficiency of interventions targeting behaviours of people living with HIV/AIDS has also been demonstrated [4, 15-20].

1.2 Positive prevention

The term ‘positive prevention’ was coined to depict HIV prevention that revolves around activities of people living with an HIV diagnosis [10]. A more elaborate definition has been developed by the International Alliance on HIV Prevention for People Living with HIV, where positive prevention (PP) refers to activities by and with people living with HIV/AIDS to reduce new infections, maintain well being, delay disease progression
and reduce vulnerability to different infections [21]. It aims to increase the self-esteem, confidence and ability of HIV positive people to protect their own health and to avoid passing on the infection to others. It also addresses the dual needs of HIV infected people by simultaneously preventing HIV/STI and unintended pregnancies. According to WHO 2002, dual protection has been defined as such and can be achieved in various ways:
— By consistent use of a male (or female) condom alone
— By consistent use of a non-barrier contraceptive method together with a male (or female) condom (i.e. dual method use)
— By avoidance of penetrative sex, particularly in high risk situations
— By use of effective contraception in the context of long-term mutual monogamy.
Positive prevention has also been referred to as “prevention for positives” but this terminology has been dismissed by some organizations e.g. The British Columbia persons with AIDS Society. This organisation belongs to a school of thought that believes the terminology is rather imposing and does not bring out the sense of ownership and potential role of HIV positive persons in designing HIV prevention programmes [2,14].
In a paper from 1999 King-Spooner comments;
“Preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, resources, than preventive interventions focused on negative individuals. A change in the risky behaviour of an HIV positive person will, on average, and in almost all affected populations, have a much bigger impact on the spread of the virus than an equivalent change in the behaviour of an HIV negative person.” [5].
It is therefore not surprising that positive prevention has been recommended by the UNAIDS (the Joint United Nations Programme on HIV/AIDS) in the industrialized countries and is also currently being encouraged in Uganda. Organisations like SCOT Uganda (Strengthening of HIV Counseling and Training in Uganda) have been training HIV positive people in aspects of positive prevention in order to empower them to become “change agents”, (HIV positive patients who are reasonably well informed about HIV and can in turn educate fellow patients). The overall motive of positive prevention and all these efforts is to ensure that HIV positive persons live fulfilling lives whilst maximizing harm reduction [8,12,21].
1.3 Young people living with HIV/AIDS (YPLWA)

HIV infection rates have continued to grow with 67% of new HIV infections being young people between the ages of 15-24. The growth is more evident in young women and girls who make up 64% of young people living with HIV/AIDS. Although women are twice as likely as men to contract HIV, they have to depend on their male counterparts to protect themselves against the virus (UNAIDS 2004).

In Uganda young people infected with AIDS form a small, but very important group with unique behavior and special needs. They are a diverse group with different sexual practices ranging from abstinence to serial unprotected sexual relations. They have an evolving and rapidly changing sense of identity that is influenced by many factors including biological and social economic factors. Late adolescents have a sense of vulnerability and are more prone to engaging in risk-taking behavior i.e. unsafe sexual activities, not following treatment regimens, and resisting authority figures. This age group is also rather insecure, and as a result they are especially vulnerable to peer-pressure [22].

With unprotected sex come many complications such as sexually transmitted infections (STI’s), unwanted pregnancies, septic abortions and infertility. These consequences are usually more evident and severe in young women. Pre-existing power imbalances between the genders are also reflected in intimate relationships that young people have. This necessitates health care programme involvement in addressing the special reproductive health needs of young women with HIV. The reproductive health services should be tailored towards dual protection for women, including protection of fertility whilst addressing HIV transmission issues. There is also a necessity to explicitly target young men in reproductive health services since dual protection depends on consistent use of the male condom [8,21,22].

In circumstances where an individual’s fear of getting pregnant out ways the individuals motivation to avoid HIV transmission, a method with higher effectiveness in pregnancy prevention may decrease the likelihood of consistent condom use as a second method [23]. Protection of fertility through avoided STI’s may then serve as a major motivation
factor for condom use. It is therefore extremely important that interventions targeting young people living with HIV/AIDS consider the special characteristics and needs of this particular age group.

1.4 Ajzen and Fishbein’s Theory of Reasoned Action and HIV

According to the Theory of Reasoned Action, the two main factors that influence a person’s intention to perform certain behaviour are attitude and subjective norms. A person holds a belief that a particular behaviour leads to a particular outcome and evaluates the outcome and consequently forms an attitude towards the behaviour. Subjective norms on the other hand arise from normative beliefs which in turn shape a persons’ perception of social pressure to perform certain behaviour. This is important because it makes it possible for persuasive campaigns and other interventions to be more target oriented through evaluation of the beliefs i.e. (subjective and normative beliefs) that underlie performance of certain behaviours. These beliefs, however, need not be necessarily rational in themselves but are acquired as one learns about ones world. The theory has also been found to predict attitude behaviour relationships effectively and is thus an important theoretic frame work for HIV sexual risk reduction interventions [24, 25].

2.1 Rationale and justification

The increase in accessibility to antiretroviral ART has led to improved quality of life for young people living with HIV/AIDS who have either resumed or continued to have sex. In Uganda, much emphasis has been put on strategies that encourage HIV negative people to remain negative through abstinence, being faithful and negotiation for safer sex. A general plateauing of HIV rates since 2003 has been observed, and threats of surges have been reported in areas where prevalence and incidence had previously gone down (e.g. rural areas in Masaka) [9]. This calls for a reform in the HIV prevention strategies with emphasis on newer and more effective prevention strategies recommended by UNAIDS. Young people infected with HIV are more often than not likely, to engage
in high risk sexual behaviour which puts them at risk of acquiring STI, resistant HIV strains and unwanted pregnancies.

There is an unpublished study conducted at the Infectious Diseases Institute (IDI) assessing the transition needs of young patients between the ages of 17 and 24. Over 150 individuals participated in the study. More than 60% of the participants had contracted HIV through sexual intercourse but only 25% of the participants felt comfortable with disclosing their HIV status to their spouses or family members. Positive prevention was recommended as one of the interventions that should be incorporated into the prospective transition clinic for paediatric patients transiting into adulthood. In another study, conducted at the Paediatric Infectious Disease Institute, late adolescents were found to be likely to engage in risky sexual behaviour [22]. Since there is no well structured positive prevention intervention at the Infectious Diseases Institute, it would be worthwhile to explore the baseline knowledge, attitudes and practice of the youth that will be attending the transition clinic. This will help the facility to create more focused interventions for the age group.

2.2 Overall goal and objectives

The overall goal of the study was to identify ways through which young people living with HIV/AIDS could be motivated to practice positive prevention behaviours.

The general objective of the study was to assess the knowledge, attitude and practices of young people living with HIV in terms of sexual behaviour, motivation and consequences of unprotected sex.

The specific objectives of the study were:

1. To identify existing information and knowledge deficits among young people living with HIV/AIDS regarding positive prevention.
2. To determine prevalence of pregnancies among young people living with HIV/AIDS at Infectious Diseases Institute
3. To establish if the pregnancies were wanted pregnancies.
4. To establish if young people felt committed to use condoms as means of reducing STI infection, reducing transmission of HIV and avoiding re-infection.
To discover the attitude that young people living with HIV/AIDS had towards being responsible for the protection of their sexual partners who are HIV negative.

METHODOLOGY

3.1 Study design
A cross sectional survey of young people attending the Infectious Disease Institute complemented with a qualitative component based on focus group discussions. The study consisted of two cycles. The first cycle comprised of a three week quantitative study involving all young people whose clinic visits were scheduled for the first 3 weeks of August 2008. The second cycle consisted of a qualitative study of young people whose clinic visits were scheduled for the last week of August. Preliminary quantitative data analysis was carried out between the two cycles to guide the qualitative phase. Quantitative data were obtained using validated questionnaires. An emergent study design was adopted while collecting qualitative data through FGDs. Quantitative data were used to quantify the knowledge attitudes and practices while qualitative data were used to create a deeper understanding of attitudes and practices in order to better interpret the survey findings.

3.2 Study setting
The study was done at Infectious Diseases Institute’s clinic in August 2008. It is an HIV/AIDS care and research centre of excellence based at Makerere University Medical School and the National referral hospital (Mulago Hospital). It offers specialized outpatient care to over 20,000 people living with HIV/AIDS. Enrolled patients are usually referred to the clinic from health centers or other voluntary and counseling units. The patients usually returned to the clinic on a monthly basis for review. There were only 160 young people actively participating in the clinic at the time of the study, although 375 young persons had been entered into the clinic registry by August 2008. Young people, who had not been actively attending the clinic for the last six months, could not
be traced and were therefore not freely available for the study. During the study period, the clinic had four clinic days a week which included Monday to Friday excluding Wednesdays. Young people were allowed to attend the clinic on any of the clinic days but efforts were in progress to establish a specialized clinic day for only young people living with AIDS on Wednesdays. Adults beyond the age of 24 would not participate in clinic activities on Wednesdays.

3.3 Study population
Young people living with HIV/AIDS attending the Infectious Diseases Clinic in Mulago Hospital.

3.4 Sampling of participants
Cross sectional survey

Inclusion criteria
• Young HIV positive person attending the clinic (ages 18-24)
• Being able to give informed consent to participate in the study
• Ability to fill in a self-administered questionnaire

Exclusion criteria
• Very sick patients were not included in the study.
• Young people who were unable to write Luganda or English (Because the focus groups were conducted in either Luganda or English on the basis that they are some of the commonly spoken languages.)

Sample size estimation
Sample size estimation was initially guided by and based on the random sample assumption. It was calculated using the formula $[c^2\cdot p\cdot q/d^2/1+c^2\cdot p \cdot q/d^2*N]$.
Where $c$ is the confidence interval
$p$ is the sample proportion
$q$ is $(1-p)$ and $N$ is the source population.

In a knowledge attitude and practice study (KAP), on positive prevention, the expected outcome measure would be people who obtain positive knowledge, attitude and practices of positive prevention. Since there are no conclusive previous Knowledge Attitude
Practice studies on positive prevention, using a sample proportion of 50% and a source population size of 375 (young people living with HIV/AIDS attending or previously registered in the clinic under study) and a sample error of 10%, a sample size of 114 participants, would be representative of the young people attending the clinic.

**Sampling method**

In view of the study setting, which constituted a small number of young attendees among adults and large number of previously inactive yet registered patients, it was not possible to obtain an adequate random sample of participants. Convenience sampling techniques were then used with the intent to obtain a total sample of the participants attending the clinic in the first cycle of the study.

**Focus group discussions**

Five focus group discussion groups consisting of 5-8 participants were conducted to create a deeper understanding of attitudes and practices in order to better interpret the survey findings. Ideally one should conduct as many focus group discussions as possible until saturation is attained [26, 27].

**Sampling methods**

Purposive sampling techniques were used to recruit informants into the focus group discussions. Purposive sampling was used because there are few young people attending the clinic. Yet only participants who had not participated in the cross sectional survey were targeted for the focus group discussions with the intent to increase trustworthiness of the study.

**3.5 Study instruments**

A standardized questionnaire was administered for the quantitative survey. A thematic guide was used for the focus group discussion.
3.6 Study procedure

On arrival at the clinic, potential study participants were identified from a daily clinic attendance registry. They were provided with information concerning the study. Those who fulfilled the inclusion criteria and were willing to consent were recruited into the study. They were either provided with self administered questionnaires (during the first cycle of the study) or invited to a focus group discussion (during the second cycle of the study.)

3.7 Data collection

Cross sectional survey

Participants were required to complete a self administered questionnaire that was written in English. Most of the questions that were used in the questionnaire were borrowed from previously validated questionnaires.

Focus group discussions

Adopting grounded theory and maximum variation sampling techniques [27-29] Qualitative data were collected through 5 homogenous focus group discussions (FGD) each consisting of four to eight participants. Female and male participants were interviewed differently by a moderator who was the same sex as the participants. A pre-tested thematic FGD guide was used by the moderator conducting the discussions. The focus groups were also stratified according to literacy, and whether participants had previously had any children. Discussions were audiotaped and later on transcribed. Focus group discussions conducted in Luganda were then translated into English. Three of the focus group discussions had female participants (females in school, out of school, and those who have previously had a child) and two of the focus groups had male participants. The FGD were transcribed and preliminarily analyzed on the same day as they were conducted. Modifications were then made for the subsequent FGD’s depending on the findings.
3.8 Ethical considerations

Written and verbal informed consent was obtained from participants who were willing to participate in the study. The questionnaires were anonymous and all data were kept confidential. Sensitive questions were limited to sexual habits. Institutional consent was sought from the Department of Public Health and Clinical Medicine Umeå University, Makerere Faculty of Medicine, Research and Ethics Committee and the Uganda National Council of Science and Technology. Permission was also obtained from the management and senior Research Committee of Infectious Diseases Institute.

3.9 Statistical methods

Data were cleaned, coded and entered into epidata version 3.1. They were exported to STATA version 10. Simple descriptive statistics in form of frequencies and percentages were generated. The Chi square test was used to test for any significant associations. When significant chi tests were found, binary logistic regression was used to generate odds ratios. Missing values were excluded from the analysis.

3.10 Qualitative data analysis

Data were transcribed and exported into open code software. Applying analytical induction and comparative analysis, data were coded. The codes were scrutinized for common patterns to form categories. The analysis sought barriers and facilitators of behaviour tailored towards positive prevention. The categories and their defining codes were sub grouped as themes. These themes were eventually grouped together through selective coding under theoretically pre-defined dimensions of the theory of reasoned action, [24-28].

RESULTS

4.1.1 Background characteristics

This was a cross sectional survey conducted in August 2008. A total of 126 subjects aged 18-24 yrs with a median age 23 yrs were enrolled. The majority were
female 82% (103/126), and the male to female ratio was 1:4. At least 40% (50/126) had completed primary school or secondary school (48%). Most of the female participants were either married or cohabiting (47%) versus (47%) males who were never married. More than half of the female participants were unemployed (58%) versus (35%) males and 52% participants were taking ART. Nearly all participants had disclosed their HIV status to at least one significant other (93%). Main reasons for none disclosure included fear of rejection and assumption that other people obviously knew. 44% (55/126); [39% males versus 45% females] of the participants had had children within the last two years. The main characteristics of the participants are summarized in Table 1 below.

**Table 1**
Main characteristics of study subjects

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-20</td>
<td>5</td>
<td>30</td>
<td>35</td>
<td>28</td>
</tr>
<tr>
<td>21-24</td>
<td>18</td>
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<td>91</td>
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</tr>
<tr>
<td><strong>Highest level of education</strong></td>
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<td>1</td>
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<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Primary</td>
<td>7</td>
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<td>40</td>
</tr>
<tr>
<td>Secondary</td>
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<td>47</td>
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<td>48</td>
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<tr>
<td>Post-Secondary</td>
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<td>10</td>
<td>8</td>
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<tr>
<td><strong>Marital status</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>26</td>
<td>37</td>
<td>29</td>
</tr>
<tr>
<td>Married/cohabiting</td>
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<td>56</td>
<td>44</td>
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<tr>
<td>Separated</td>
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<td><strong>Occupation</strong></td>
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<td><strong>On ART</strong></td>
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<td>No</td>
<td>11</td>
<td>49</td>
<td>60</td>
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<tr>
<td><strong>HIV status disclosure to significant others</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>21</td>
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<td>No</td>
<td>2</td>
<td>7</td>
<td>9</td>
<td>7</td>
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<tr>
<td><strong>Children in last 2 yrs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>Yes</td>
<td>9</td>
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<td>56</td>
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</table>
Figure 1
A graph reflecting on the year when the participants learnt about their HIV status

![Graph showing the distribution of HIV diagnosis years.](image)

Table 2
Table of distribution of years under specialized HIV/AIDS care for the participants

<table>
<thead>
<tr>
<th>Number of yrs Under care</th>
<th>Frequency</th>
<th>Percent</th>
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<tbody>
<tr>
<td>&lt;1</td>
<td>39</td>
<td>31.2</td>
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<tr>
<td>1</td>
<td>35</td>
<td>28.0</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
<td>16.0</td>
</tr>
<tr>
<td>3</td>
<td>21</td>
<td>16.8</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>4.8</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Total</td>
<td>125</td>
<td>100.0</td>
</tr>
</tbody>
</table>
The first participant to know his or her HIV status did so in 1989. The participant came into care of the clinic under study, 17 years later or in 2006. The mean duration from knowledge of HIV status to enrollment into the clinic for our study participants was 0.8 yrs, standard deviation +/- 2.3yrs. Duration under specialized HIV/AIDS care ranged from <1 to 5yrs, mean duration 1.5yrs and standard duration +/- 1.4yrs.

Table 3
Table illustrating the duration between time of knowledge of diagnosis to time of enrollment into the HIV/AIDS care clinic

<table>
<thead>
<tr>
<th>Year of HIV diagnosis</th>
<th>&lt;1</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>9</th>
<th>10</th>
<th>13</th>
<th>17</th>
<th>Total number diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989-2001</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>2003</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>2004</td>
<td>4</td>
<td>6</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>2005</td>
<td>12</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>2006</td>
<td>12</td>
<td>8</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>24</td>
</tr>
<tr>
<td>2007</td>
<td>23</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>25</td>
</tr>
<tr>
<td>2008</td>
<td>31</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>32</td>
</tr>
<tr>
<td>Total enrolled within specified duration from diagnosis time</td>
<td>85</td>
<td>21</td>
<td>8</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>125</td>
</tr>
</tbody>
</table>

4.1.2 Recent sexual behavior of study participants
Despite the fact that the majority of the participants or 75% (96/124) had known their HIV status for at least one year, a mere 17% (20/119); [17% females versus 21% males] of the participants abstained from sex. Among those who continued to have sex, 67% (80/119); [71% female versus 47% male] had one sexual partner within the past one year, 13% (16/119); [12% female versus 21% male] had 2 sexual partners and 2.5% had had at least 3 to 5 partners. The highest number of sexual partners reported was 5 and this
was reported by 2 of the participants. Over half of the participants, 65%, had had their last sexual encounter within 3 months from the time of the study and 55% had done so within the last month. There was, however, no statistically significant association between taking ART and number of sexual partners or last sexual encounter, (P>0.05).

When asked about the change in sex frequency since they learnt of their HIV status, 77% of the study subjects reported that they were having sex less frequently, 20% had no change in sex frequency while 4% [3% females versus 6% males] reported an increased frequency.

### 4.1.3 Condom Use

Among the 115 sexually active patients at the time of the study, 38% (44/115); [32% females versus 75% males] were using condoms consistently, 39% (45/115); [41% females versus 29% males] used condoms inconsistently and 23% (26/115); [25% females versus 13% males] never used condoms at all during sexual intercourse. Among participants reporting condom use, over half or 51% (55/107); [56% females versus 28% males] had problems convincing their partners to use condoms. The main reasons for partner refusal of condoms included unpleasant sexual experiences, beliefs that condoms should be used in relationships were two partners trust each other, belief that condoms cause candida infection, reports of penile rashes after condom use and at least one participant reported that he or she and his or her partner did not know what condoms are exactly and a number of participants simply did not know why their partners refused condoms.

A big proportion of participants or 78% (97/124); [75% females versus 95% males] believed they had easy access to condoms. The remainder who believed otherwise or who were not sure of condom accessibility consisted mainly of females who thought that issues concerning condom accessibility were their partners business. The other group consisted of students who feared to be seen collecting condoms and those who were currently not sexually active. No statistically significant association was observed between consistent condom use and education level attained, sex, or being on ART, (p > 0.05).
Cohabiting couples were less likely to use condoms consistently (OR= 1.5, 95% CI= [-2.89- -0.25], p=0.02) compared to married couples with no statistically significant condom use differences.

4.1.4 STI knowledge and treatment seeking behaviour

Regarding STIs, 33% [25% females versus 70% males] participants were able to correctly identify at least one symptom of STIs, 45% [53% females versus 9% males] identified two or more symptoms of STIs while 22% (28/126) did not know any symptoms of STIs. Of the 104 participants who knew how STIs are transmitted, 88% (92); [85% males versus 100% males] correctly identified STIs as being transmitted through unprotected sex or sex. The other methods of STI transmission incorrectly identified by study subjects included sharing bathrooms, toilets and basins.

More than half (58%) of the female participants versus 40% males reported having suffered from STIs 6 months prior to the study. Participants, who reported having suffered from an STI or those who were not certain they had suffered from an STI, were asked about the symptoms they had experienced in the last 6 months. The vast majority, 53% (37/70); [78% males versus 49% females] reported at least one symptom, 23% reported at least 2 symptoms and 24% [28% females versus 0% males] reported 3 or more symptoms. Nearly all participants, 94% (115/122) felt comfortable seeking treatment if any of the STI symptoms occurred and majority of participants felt comfortable disclosing a STI to their partners. Main reasons for disclosure of STI included, seeking treatment together and preventing partners from demanding sex while the affected is undergoing STI treatment. Those who did not feel comfortable disclosing STIs to their partners reported the fact, that it is difficult to disclose a STI, fear of accusation that they have not been faithful and poor communication in relationships. In addition to this 50% and 55% of men and women respectively, who were aware they had suffered from an STI, in the last 6 months, disclosed the STI to their sexual partners and subsequently 37% (22/60); [37% female versus 33% male] of partners sought treatment. Most of YPLWA or 67% (84) were able to mention or identify at least one of the dangers of untreated STIs. The reported dangers of untreated STIs included, damage to the reproductive organs (34%), death (46%), infertility (12%), and infecting others (8%). Furthermore, 105 (84%) participants correctly identified at least one of the STI
prevention methods included condom use (90%). The other methods reported included, seeking treatment when symptoms appear (14%), having ones partners treated (10%) and being faithful (7%). No statistically significant association was established between STIs and education level, marital status, condom use or number of sex partners, all p values were >0.05.

4.1.5 HIV/AIDS, disclosure and discordance

Nearly all participants had disclosed their HIV status to at least one significant other. However, only 36% (41); [36% female versus 50% male] had disclosed their HIV status to their sexual partner or spouses. Half of those who disclosed HIV status to their partners had informed at least one more significant other about their HIV status. The rest had disclosed their HIV status to at least one or more family members in 54% (62), or to friends in 10% (12). Of the 112 subjects having relatively stable partners, 52% (58); [52% women versus 66% men] were certain that their partners had tested for HIV, 28% (31/112) of the partners had not undergone an HIV test while 21% (23/112) were not aware if their partners had undergone HIV testing. Among those who were certain that their partners had undergone HIV testing, 55% (32/58); [65% females versus 16% males] of partners were HIV positive, 35% (20); [28% females versus 58% males] were negative and 10% (6/58); [7% females versus 21% males] did not know the test result. The main reasons for partner’s not being tested included, non disclosure, fear of a positive result and having no current HIV symptoms. Married people were generally more likely to disclose their HIV status to their partners (OR=3, 95% CI= [1.96-4.21], p=0.00) versus cohabiting (OR=2, 95% CI= [1.1-3.4], p=0.00).There was however no association between being on ART and disclosure to spouse or discordance. There was also no statistically significant association between discordance and other factors like consistent condom use, sex.

4.1.6 HIV, pregnancy and desire for children among women.

At the time of the study, 43% (43/100) of young women living with HIV admitted to having become pregnant after learning their HIV status. More than half of the pregnancies or 57% (24/43) were intended while 44% were unintended pregnancies. The
three main reasons for previously unintended pregnancies included; 1) Not being on appropriate family planning methods even though they did not like the idea of having children while HIV positive (27%) . 2) Husband refused to use condoms, yet they were not using other family planning methods 13.6%, and 3) 59% said it was simply an accident.

Eight participants were pregnant at the time of the study. This translates into a prevalence of 8%. Three of them had recently been diagnosed with HIV while attending the routine antenatal clinic. The rest became pregnant after being aware of their HIV status.

Fifty seven percent (59/102) of participants reported that they would consider both giving birth or giving birth again, 31% would not consider either of the two and 11% (11/102) could not surely say they would consider giving birth in future. The main reasons given for the wish to have children in the future included; a) having no child or having only one child, b) being too young to leave no legacy, c) being envious of peers with babies, d) having children of a sex other than the desired one, e) availability of mother to child transmission prevention services, f) possibility of having an HIV negative baby and g) hope for having an HIV cure in the future. The reasons for not desiring to have children in the future included, fear of having an HIV positive baby and fear that the pregnancy might make HIV symptoms worse.

The majority of female participants (60%) believed that HIV positive women should have children, as compared to the 23% and 17% who believed that they should not have children or who were not sure, respectively. There was a significant association between being on ART and desire to have children, (OR=2.6, 95% CI= [1.1-6.2] p=0.021) However, education level, employment, marital status, and previously having children were not statistically associated with desire for children among women.

4.1.7 HIV and desire for children among men

Among the male participants 30% (7/23) had children after being aware of their HIV status. A similar proportion felt pressurized to have children. Most of the pressure was from within themselves, spouses and other relatives. Most of the male participants or 78 % (18/24) believed that HIV positive men should have children. The rest believed that they should not have children in future except for one participant who was uncertain.
Table 4
A table showing the summary of recent sexual behavior and characteristics of YPLWA

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Men</th>
<th>Women</th>
<th>Total frequency</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of sexual partners</strong></td>
<td>4</td>
<td>16</td>
<td><strong>n=119</strong></td>
<td><strong>17</strong></td>
</tr>
<tr>
<td>0 (abstinent)</td>
<td>9</td>
<td>71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>4</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Last sexual encounters</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within last week</td>
<td>6</td>
<td>30</td>
<td><strong>n=115</strong></td>
<td><strong>31</strong></td>
</tr>
<tr>
<td>Within last month</td>
<td>3</td>
<td>25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 3 months</td>
<td>3</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 6 months</td>
<td>1</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;6 months ago</td>
<td>5</td>
<td>27</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Change in sex frequency after knowing HIV status</strong></td>
<td></td>
<td></td>
<td><strong>n=116</strong></td>
<td><strong>77</strong></td>
</tr>
<tr>
<td>Having sex more frequently</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having sex less frequently</td>
<td>14</td>
<td>75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No change</td>
<td>3</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Condom Use</strong></td>
<td></td>
<td></td>
<td><strong>n=115</strong></td>
<td><strong>38</strong></td>
</tr>
<tr>
<td>Consistently</td>
<td>12</td>
<td>32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inconsistently</td>
<td>4</td>
<td>41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never (might include secondary abstainers)</td>
<td>2</td>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HIV status of partner</strong></td>
<td></td>
<td></td>
<td><strong>n=112</strong></td>
<td><strong>52</strong></td>
</tr>
<tr>
<td>Partner tested</td>
<td>12</td>
<td>46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Result 1. Positive</td>
<td>2</td>
<td>30</td>
<td>(32)</td>
<td>(55)</td>
</tr>
<tr>
<td>2. Negative</td>
<td>7</td>
<td>13</td>
<td>(20)</td>
<td>(35)</td>
</tr>
<tr>
<td>3. Result not known</td>
<td>3</td>
<td>3</td>
<td>(6)</td>
<td>(10)</td>
</tr>
<tr>
<td>Partner not tested</td>
<td>5</td>
<td>26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure if partner tested</td>
<td>4</td>
<td>19</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ability to identify STI symptoms</strong></td>
<td></td>
<td></td>
<td><strong>N=126</strong></td>
<td><strong>33</strong></td>
</tr>
<tr>
<td>At least one symptom</td>
<td>16</td>
<td>25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 2 symptoms</td>
<td>2</td>
<td>55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>STIs in the last 6 months</strong></td>
<td></td>
<td></td>
<td><strong>n=118</strong></td>
<td><strong>41</strong></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>11</td>
<td>37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>1</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>STI symptoms if yes or not sure</strong></td>
<td></td>
<td></td>
<td><strong>n=70</strong></td>
<td>53</td>
</tr>
<tr>
<td>1</td>
<td>7</td>
<td>30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 3</td>
<td>0</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge of STI transmission</strong></td>
<td></td>
<td></td>
<td><strong>n=104</strong></td>
<td>73</td>
</tr>
<tr>
<td>Un protected sex</td>
<td>19</td>
<td>57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>3</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>other</td>
<td>0</td>
<td>12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.2.1 Behaviour of young people modeled using the theory of reasoned action

According to the “Theory of Reasoned Action” the two main factors influencing a person’s intention to perform certain behaviour are attitude and subjective norms. A person holds a belief that a particular behaviour leads to a particular outcome and evaluates the outcome and consequently forms an attitude towards the behaviour. Subjective norms, on the other hand arise from normative beliefs which in turn shape a persons’ perception of social pressure to perform certain behaviour, [24]. During focus group analysis, barriers and facilitators of behaviour tailored towards positive prevention were sought. The categories that emerged and their defining codes were sub-grouped as themes. These themes or secondary codes were eventually grouped together through selective coding under theoretically pre-defined dimensions of the theory of reasoned action, [24-28].

Figure 2 below is a diagrammatic representation of theory of reasoned action model applied to the data

**Figure 2**
4.2. 2 Behavioral beliefs affecting young people living with HIV/AIDS’ attitude towards HIV positive prevention

Overall, a total of 35 individuals participated in 5 focus group discussions. Focus group discussion analysis revealed beliefs ranging from those based on good knowledge of the components of positive prevention and a desire to prevent spread of HIV, to beliefs based on lack of accurate knowledge of pp and indifference about the spread of HIV. These beliefs were shaped by previous experiences.

Desire to avoid infecting other persons

Disclosure of one’s serostatus was pointed out as a preventive strategy. In regards to the disclosure, YPLWA believed that it was not good to have a sexual relationship without disclosing ones HIV status to the partner for example; one of the participants in the female FGD said “The boy who infected me with HIV knew he was HIV positive. After infecting me he told me that he knew he was HIV positive and that his parents had died a long time ago. This made me feel very bad.”

Overall, the participants said they were willing to disclose their HIV status to their partners before having stable relationships with them, for instance, a participant from the female FGD said “When my first husband died and I met someone who loved me, I told him I was HIV positive and we decided to use condoms and up to now he is still negative.”

Fear of being left alone seemed to drive the smaller degree of hesitancy in willingness to disclose HIV status to sexual partners expressed by some of the participants. This can be exemplified by a participant from the male FGD who said “I would like to disclose my HIV status to my girlfriend but I fear discussing HIV with her, she might leave me.”

Condom use was often mentioned by the participants as an effective way of reducing HIV transmission. Some thought condoms were suitable for occasional, but not daily use. Other beliefs about condoms included misconceptions that HIV is an infection for condemned people and therefore the use of a condom cannot save anyone from acquiring HIV. Other beliefs were that the HIV virus is too small to be avoided using condoms and that condoms should principally be used to prevent unwanted pregnancies
and may be other STIs, but not HIV. There was also a general misconception among female participants that condoms cause candida and cancer.

It was often expressed that young people living with HIV/AIDS should be responsible for their HIV negative counterparts. Some young people even believed that it was their responsibility to sensitize other youth about HIV.

There was an atmosphere of both a wish to be honest and the pressure to be honest. Young people strongly believed in being truthful, honest and being faithful to ones partner. Some young people believed that they should disclose their HIV status to as many people as they can, while others disagreed and thought that this would be stigmatizing.

Challenges of facing a difficult reality were often identified as an influential factor in hindering preventive behaviour. Young people said that they have heard other HIV infected peers say, “HIV did not come to infect trees.” “Did I get HIV from an animal?” and “Now that ARVs are available, we do not have to be that careful.” Some female participants however thought that it was only possible to avoid HIV transmissions if they got good paying jobs so that they were not tempted into sex for money. For example, a participant in the female FGD said “when I got a partner, he used to give 50,000 shillings every time we met, I used to get this kind of money after working for 5 months, when I got pregnant he left me, I then aborted and looked for another one, it is lack of money which forces us into these things.”

There was a general struggle between a desire to have loving sexually fulfilling lives and the responsibility to protect HIV negative partners. Young people expressed different opinions about discordant relationships. Some thought that it is like killing an innocent person knowingly, while others believed that it was alright to be in a discordant relationship as long as one disclosed ones HIV status the partner. Others believed that HIV positive people should only have relationships with fellow HIV positive people.
**Desire to improve personal wellbeing and to reduce risky behaviour**

Importance of reducing the number of sexual partners and the use of condoms as a way of avoiding re-infections and other STIs, was often mentioned by the participants as a way of maintaining one's health status.

Avoidance of situations that impair one's sense of judgment was identified by the participants as a strategy to protect health status and avoid risky behaviour. Both male and female participants believed that they had to stay away from alcohol and social drinking because it makes them lose control and have unprotected sex. Women expressed concern of potential rape under the influence of alcohol.

The room for abstinence was pointed out as a possible strategy to avoid risky behaviour. Some of the YPLWA believed that they were still in the abstinence age group and were still considering abstinence as their only possible option in avoiding risky behaviour.

Transparency in seeking medical care was identified as another way of preserving health. The participants were of the opinion that hiding medical ailments from healthcare workers and not following instructions would cause deterioration in their health status. This was expressed by female participant in this way, "*HIV people should value their lives, if you get any infection tell the doctor, you will get treatment. You do not want to have a low CD4 count and to lose weight.*"

Misconceptions about certain family planning methods were identified in the focus group discussions as barriers to behaviour tailored towards positive prevention. Both male and female participants were aware of some family planning methods. The methods of family planning motioned in the FGDs included; condoms, pills, injectables, and withdrawal methods. There were however some misconceptions about certain family planning methods among female participants who believed that swallowing oral contraceptives reduces CD4 counts.
4.2.3 Normative beliefs held by YPLWA

Influence from family and friends

Pressure from extended family members was identified as a factor affecting normative beliefs. Orphaned young people said they were being encouraged by other family members to behave in irresponsible ways. One of the participants said “I do not understand my auntie, when I asked her for transport to come to the clinic she said to me: have I not already told you to look for rich men with Pajeros who can never fail to give you transport to the clinic? She did not even care that I was bringing her kids along to get tested”

Bad older models influenced young people’s normative beliefs towards positive prevention. They felt disgusted by what they had seen other older people living with HIV doing. A young woman expressed how she was disgusted by an uncle who was deliberately and gladly spreading HIV to other people.

Poor communication with parents and fear of an undesired parental reaction hindered adaption of positive prevention behaviour. Non orphaned participants expressed concern over the poor communication they had with their parents. This made it quite difficult for them to disclose their situation to their parents in order to get parental support. They particularly feared harsh judgment from the parents.

Influence from the experience of being a YPLWH and partners

Poor communication with partners shaped young people’s normative beliefs towards positive prevention. Young people experienced a number of communication problems with their partners. Female participants were particularly concerned about men who got violent when asked to use condoms.

A wish to deny the difficult truth characterized young people’s normative beliefs towards HIV prevention strategies. Participants were concerned about being accused of being unfaithful and not trusting if they used condoms in the relationships. They also reported that when they made efforts to disclose to their partners and people who approached them for sex they were not believed.
Turning to God served as a motivation for adopting of preventive behaviour. Female participants strongly believed that they should turn to God and stop trusting men.

A desire to leave a legacy was identified as barrier to practicing preventive behaviour, more specifically condom used. Male participants reported that they would want to have a child or more of their own and leave a legacy. They specified that this would be in future after they have fully pursued their careers and made more money. Some believed that it was not a good idea to have children and leave them as orphans since HIV positive people have a reduced life span.

Influence from healthcare workers

Previous medical advice shaped normative beliefs to behaviour tailored towards positive prevention. It also served to raise female participant’s hope of leaving a legacy behind. Female participants reported that if they were on ART, and if there was no objection from a doctor, they would have a child. Others said that if they wanted to have a child they would take a CD4 count and if it was good then they would go ahead and have a child.

Trust in healthcare workers was identified as a vital factor affecting young people’s general outlook on life. They strongly believed that health care workers were able to help them with disputes concerning safer sex negotiations such as counseling men who refuse to use condoms, and equipping them with disclosure techniques.

Male participants expressed strong desire to follow the advice given to them by healthcare workers regarding positive prevention. One male participant said “It is better we listen to what the doctors and counselors tell us. When we get other partners we can get different types of HIV virus, this will make us more sick. The clinic will be congested yet the staffs have already been good to us. Let us not over burden them.”

4.2.4 Subsequent behaviours adapted by young people towards HIV positive prevention.

The behaviours adapted by young people towards HIV positive prevention lay between a strong desire to protect others and oneself from HIV infection and re-infection respectively, to ambivalence.
Regarding disclosure, practices of young people ranged from being willing to disclose HIV status to sexual partners in order to protect them from HIV, to being afraid of disclosing HIV status due to fear of unfavorable consequences. Some study participants suggested that they would at least write a letter of disclosure to their partners if they were afraid of disclosing their HIV status face to face. Others were very determined to convince people who did not believe them when they say they are HIV positive. This range seemed to be a reflection of how well the YPLWA had learnt to cope with HIV associated stigma.

Participants, who did not perceive being in a discordant relationship as being problematic, were willing to have or stay in one, while those who perceived it as being problematic, were likely to look for partners of the same HIV status in HIV clinics. There was a general belief that partners from HIV clinics were more understanding and better counseled to cope with HIV compared to those who are not attending an HIV clinic. This shows, that the meaning the young people attached to being HIV positive, determined their subsequent sense of fear of the consequences of passing on a serious infection to their partners.

Analysis from FGD also revealed that some HIV infected young people had resorted to not using condoms at all, while others were more determined to use condoms consistently no matter what the cost may be. Some of them expressed willingness to divorce spouses who do not use condoms and a desire to take spouses who refuse condom use for counseling. This finding suggests the differences in power of negotiation for safer sex acquired by different individuals under different circumstances. It also shows that YPLWA are cautious about having good health and are concerned about protecting their HIV negative partners.

Nevertheless, many young people viewed abstinence as the only way to avoid the spread of HIV and re-infection. Adopted strategies for abstinence among female participants include viewing all men as enemies, refusal of any sexual advances from men, and avoiding friendly conversations with men. Their male counterparts, on the other hand, opted to stay away from their partners as much as possible to avoid sex. One of the participants in the male FGD said for example “When I tested HIV positive I encouraged my girlfriend to test as well. She tested negative. Since we could not separate, I now go
home only on weekends so that we do not have sex often but when we have sex we use condoms.” Others were more committed to being faithful in their relationships and reducing number of sexual partners.

Practices centered on felt stigma ranged from, complete acceptance of one’s HIV status and desire to protect other young people from HIV by sharing experiences of living with HIV, to extreme protection of one’s HIV status. This is a reflection of the various coping strategies that are employed by different YPLWA experiencing different forms of stigma in various circumstances.

**DISCUSSION AND RECOMMENDATIONS**

**5.1 Information and knowledge deficits**

One of the cornerstones of positive prevention is ensuring that individuals with HIV learn their serostatus so that they are able to disclose it to their sexual partners. It is presumed, that their partners would then be motivated to test for HIV and subsequently take the necessary measures to avoid new infections [6, 12]. This study revealed major gaps in knowledge and behaviour tailored towards positive prevention. There was a substantial lack of partner testing with 28% (31/112) of study subjects having untested partners. Lack of mutual partner disclosure, fear of a positive test and absence of HIV symptoms were implicated as the driving forces. Whilst disclosure rates to partners, remained low among the study participants, 35% (20/58), [28% females versus 58% males] of participants with tested partners were sero-discordant. This finding is consistent with studies done elsewhere in Africa. It also poses a major prevention challenge in view of the fact that this study was performed in a setting where counselor facilitated disclosure is already being practiced. The argument is that this form of counseling could be complimented with peer counselors or change agents who through sharing their experiences with disclosure could make it easier for their younger counterparts to disclose. This would mean further investment of resources in training of peer counselors [6, 12, 30].

The existence of gaps in knowledge of STIs and their transmission was of paramount importance. Despite high prevalence of STI related symptoms among study
subjects, 22% (28/126) could not correctly identify any of the symptoms of STIs and 12% (12/104) were still unable to correctly identify methods of transmission of STIs. This should be critically looked into in the light that the impact of public health efforts to control STIs on the reduction of HIV-transmission in developing countries, remains unclear [31]. Yet, for individuals already infected with HIV, an acute sexually transmitted infection may influence several immunologic parameters contributing to a deterioration of the infected person’s health status and to an acceleration of the progression from HIV to AIDS [32]. The above findings call for provision of more STI education and information to YPLWA both in and out of school.

5.2 Pregnancy

Another key element of positive prevention is ensuring that unintended pregnancies are prevented in couples were one or both partners are infected with HIV. This has potential benefits of preventing HIV transmission through PMTC and reducing HIV transmission risk in couples where the woman is the uninfected party [6]. Of the pregnancies acquired after Knowledge of HIV serostatus, 44% were unintended. This represents an unmet sexual reproductive health need. Young people living with HIV need to be given information about different family planning alternatives available to them and counter discourses about certain forms of family planning e.g. the oral contraceptive pill need to be addressed. Women, in particular, should be equipped with safer sex negotiation skills since they rely on their male counterparts for cooperation for dual protection. Moreover, dual protection has been recommended by most authors and WHO as the ideal method to reach simultaneous prevention of STIs and unwanted pregnancies [11, 23].

There was also a remarkable desire for children among both male and female participants. There was a general belief in HIV positive people having children which was more pronounced in men and women on ART. This is not surprising given that the study subjects are in the most reproductive age group. The finding is in line with other studies conducted among PLWA elsewhere in Uganda, where the desire for children was more profound in men than women [34]. Protection of fertility, while safeguarding against STIs, becomes a crucial element of positive prevention with this respect [33]. There is a need to integrate PMTC services into HIV/AIDS care services [6, 34].
5.3 Condom use

The results demonstrate that access to condoms might not always translate into condom use. This was evident as the majority of study participants (78%) had easy access to free condoms but only 38% [32% females versus 75% males] used them consistently. Perceived barriers to condom use included intimate partner violence that was directed towards women, reduced tactile pleasure, misconceptions that condoms should not be used in trusting relationships and belief that condoms cause candida and cancer. The suitability of condoms for daily use was dismissed by some of the participants. Folk beliefs portraying the HIV virus as too small to be avoided by condom use and beliefs that HIV is an infection for condemned people were expressed in the study. Students feared to be seen collecting condoms. This depicts the diversity of needs of YPLWA who cannot be confined to one common group. Interventions aimed at improving condom use in this age group should take into account the complex issues surrounding condom use for the different subgroups. Both men and women will need to be equipped with skills for negotiating safer sex. Social factors surrounding intimate partner violence will need to be addressed. Better and less stigmatizing ways of condom distribution will have to be identified targeting the young person in school. The folk counter discourses regarding condom use will also need to be abandoned.

5.4 Young people’s attitudes towards positive prevention

Motivation for accepting behaviour tailored towards positive prevention included a desire to protect others from HIV infection, a desire for improved general wellbeing, a desire to reduce risky behaviour and a desire not to disappoint healthcare providers. The above findings represent avenues through which positive prevention behavioral skills could be reinforced and should be scrutinized in view of the fact that it is more difficult to change a negative behaviour than to reinforce a positive one [10,16,35]. The altruism, shown by YPLWA towards protecting others, was so strong that they wanted to take on the responsibility of sensitizing other youth through sharing their experiences. Such altruistic behaviour should be encouraged through promotion of leadership by PLWA [6, 16, 35]. These findings would also call for interventions that are aimed at acquainting YPLWA with techniques for safer sex negotiation and mutual partner disclosure [35]. The expressed wishes not to disappoint healthcare providers provide an opportunity to
exploit the trusting relationships and continuous follow up that exist between patients and healthcare providers. Such a relationship could be of benefit in reinforcing positive prevention behaviour and communication of prevention messages [20].

Behavioral skills adopted by YPLWA to prevent HIV transmission included; abstinence, condom use, serosorting, faithfulness to partners and reduction of the number of sexual partners. These findings highlight that the ABC strategy, despite the many criticisms it has received, is still an appropriate strategy for Ugandan youth. Prevention of new HIV transmission through serosorting, however, is at the expense of acquiring re-infection and STIs in the absence of condom use [12].

Barriers to uptake of preventive behaviour are shaped by previous experiences and the socio-economic conditions in which young people infected with HIV live. The focus group discussion analysis showed, that under circumstances of poverty, an individual’s main priority may not be protecting others or reducing risky behaviour. The preference changes from protecting oneself and others, to searching for money in various difficult ways including exchanging sex for money. This finding is line with other studies that have shown an association between poverty and likelihood of exchange of sex for money in Ugandan settings [22].

It is therefore, likely that in some situations like the one mentioned above, risky behaviour may only be interpreted as risky retrospectively. Attempts should be made to design interventions that suspend risky behaviour before it actually happens [11, 16].

Faced with difficult choices surrounding sexual relations of HIV infected people, individuals do a mini cost benefit evaluation of immediate versus long time effects of certain behaviours such as condom use or disclosure [16]. Immediate effects may take the form of fulfilling pleasurable sex and perceived intimate partner violence potential, while long term effects may take the form of avoiding re-infection and avoiding infecting others. Altruistic behaviour has been described to be the driving force behind sacrificing immediate gratification for long term benefits. Prevention programmes ought to strengthen altruistic concern that HIV infected individuals have towards their sexual partners by equipping them with necessary mutual disclosure skills [16, 35].

Gender imbalances were also reflected as a potential barrier to preventive behaviour such condom use. Violence directed towards women was echoed in the focus
group discussions when the young women expressed their concern over partners who got violent at the mere suggestion of condom use. Increased condom use and adopting other preventive behavioral skills will therefore rely on addressing gender imbalances through women empowerment both socially and financially.

Stigma and shame were major hindrances to adopting positive prevention measures. Some young people expressed fear of rejection and being stigmatized if they disclosed their HIV status while others had come to terms with managing stigma and shame. Issues of stigma and shame should continue to be addressed in health centers dealing with young people infected with HIV. Patients, who have already come to terms with managing stigma and shame, may be valuable resources in helping others come to the same through self-help groups.

5.5 Study limitations

Although these results are not representative of all YPLWA in Uganda in that they were obtained from a clinical sample, and quantitative data was obtained through convenient sampling techniques, their generalizability is still relevant. The young people attending the clinic under study were referred from different areas and as such they are truly representative of the source population which is the different referral centers. Efforts were made to recruit an adequate sample size comprising of the total sample (161/160) of YPLWA approximated to have been attending the clinic under study in the given study cycles. Nine of the subjects that were not enrolled into the study had either failed to keep the clinic appointment or had declined to consent to the study but their absence was offset by newly registered participants. In order to ensure dependability maximum variation sampling methods were utilized. Both young people in and out of school were targeted. Educated and uneducated participants were recruited into focus group discussions and those with and without children were also enrolled into the study. It is noteworthy that although 8 participants were invited to each focus group discussion, sometimes fewer participants attended the discussion. This coupled with the small number of male clinic attendees, may have made it harder to capture all the ideas of the male study population. The study was unable to establish why there were few male YPLWA attending the clinic. It has however been speculated that this is due to the fact that HIV disproportionately
affects women and young girls or to the Machismo behaviour of men that hinders health seeking behaviour.

Another possible limitation of the study is reporting bias. Measures were however put in place to reduce this bias. It was ensured that questionnaires were anonymous. Yet the likelihood of risky behaviour being reported has been previously described by other authors [15, 16].

Whilst causal associations cannot be ascertained through a cross sectional study, this study did not explicitly seek to find causal associations, it sought to explore knowledge, attitudes and practices. Establishing causal association would therefore be a secondary objective.

Finally it has been argued that KAP methodology is a poor study approach due to the complexity of health related behaviour and the inevitable difficulty in the quantification of the elements measured by KAP studies. This thesis has to some extent provided useful information in determining the existing knowledge, attitude and practices of YPLWA in relation to positive prevention. The information may be a relevant stepping stone for designing future positive prevention interventions in a Ugandan setting.

**CONCLUSION**

The study has clearly illustrated that success of positive prevention programmes dealing with HIV infected young people will greatly depend on: 1. Promotion of mutual partner serostatus disclosure through equipping young people with disclosure skills, 2. Ensuring that altruistic behaviour and leadership among young people living with HIV is reinforced, 3. Prevention of unwanted pregnancies among young women while explicitly targeting men’s cooperation, 4. Addressing stigma and shame, 5. Addressing the difficult choices that surround condom use and sex and, 6. Improvement of the socio-economic conditions in which young people live.
REFERENCES:


Acknowledgements

I wish to express my sincere gratitude to the following people:

1. All the young people who participated in the study,
2. To my supervisors Drs. Ellinor Ädelroth, Sabrina Bakeere-Kitaka and Andrew Kambugu- I am grateful for all the inspiration you offered and all the scientific knowledge and skills you shared with me.
3. To the peer counselors who tirelessly distributed the questionnaires
4. To Adelline Twimukye, Rachael and Julian Nkuraija- You did a very good job with the focus group discussions. I am so grateful
5. To Dr. Christine Kihembo- I cannot find the words to express how glad I was when you accepted to submit in my proposal on my behalf.
6. Drs Timothy Muwonge and Tina Katusiime and all the IDI staff who tirelessly referred all the young people to me.
7. To the Swedish centre party- The stipend you offered made this research a reality.
8. To Civil Society Fund- The young people now have a clinic of their own, thanks to your funding.
9. To Phoebe Berglund Mugerwa- I appreciate everything you did for me. God bless you.
10. To Mr and Mrs Simon Mulera- I appreciate everything you did for me. God bless you.
11. To my special friends and” parents” in Umea, Allan and Gunilla Karbassi- I do not know how life in Umea would have been without you. I will always treasure the moments I shared with you, God bless you.
12. To my dear parents and siblings- Thanks for all the support and prayers. I made it.
13. To all my friends not mentioned not individually mentioned- It was an experience of a life time getting to know each and every one of you. You remain my gold and silver.