HAL
open science

AIDS IMPACT Special Issue: Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting

Sabrina Bakeera-Kitaka, Christiana Maria Nöstlinger, Nicolette Nabukeera-Barungi, Addy Kekitiinwa, Robert Colebunders

To cite this version:

Sabrina Bakeera-Kitaka, Christiana Maria Nöstlinger, Nicolette Nabukeera- Barungi, Addy Kekitiinwa, Robert Colebunders. AIDS IMPACT Special Issue: Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting. AIDS Care, 2008, 20 (04), pp.426-433. 10.1080/09540120701867099 . hal-00513450

HAL Id: hal-00513450

https://hal.science/hal-00513450

Submitted on 1 Sep 2010

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

AIDS IMPACT Special Issue: Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting

Journal:	*AIDS Care - Psychology, Health & Medicine - Vulnerable Children and Youth Studies*
Manuscript ID:	AC-2007-08-0419.R1
Journal Selection:	AIDS Care
Keywords:	Adolescents, HIV/AIDS, Sexual and reproductive health, Sexuality, Secondary prevention

scholarONE™
Manuscript Central

For Peer Review Only

Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting

ABSTRACT

As anti-retroviral therapy becomes increasingly available, young people living with HIV need tailored support to adopt healthy sexual behaviors. There has been a gap in the availability of culturally appropriate techniques for secondary prevention and sexual risk reduction in this target-group.

This formative study assessed sexual and reproductive health needs and problems, as well as determinants of sexual risk taking among young people living with HIV aged 11 to 21 years attending the Paediatric Infectious Disease Clinic in Kampala, Uganda. Theoretical guidance was provided by the Information-Motivation-Behavioral Skills Model. Socio-demographic and selected psychosexual data were assessed using a brief anonymous questionnaire. *A total of* 75 young people living with HIV participated in 8 focus group discussions. In addition, one focus group was conducted with adult key informants (service providers). About a quarter of the young participants reported prior or current sexual experience. The study revealed knowledge gaps relating to reproductive health, HIV transmission and contraceptive methods. Motivations for protection included hope for the future, good counseling, and fear of the consequences of sexual activity such as unwanted pregnancies. Barriers to adopting preventive behaviors included peer pressure, poverty, HIV-related stigma, ignorance of their partners, alcohol use, and a desire to have children for the older ones. Young sero-positive people in this setting lacked specific

Deleted: *Background:*
Deleted: (YPLH) will
Deleted: reduce
Deleted: risk
Deleted: This study assessed the sexual risk reduction needs as well as determinants of sexual risk taking for adolescents living with HIV in a clinical care setting.
Deleted: *Methods:*
Deleted: qualitative
Deleted: carried out among
Formatted: Font: Not Bold
Deleted: adolescents
Deleted: (PIDC),
Deleted: used grounded theory as the methodological approach and
Deleted: focus group discussions (FGD) as data collection technique. Eight FGD were conducted with adolescents along the
Deleted: dimensions of the I
Deleted: .
Deleted: e
Deleted: One FGD involved health care providers.¶ *Findings*
Deleted: Seventy five
Deleted: YPLH aged 11 to 21 years (median=16) were
Deleted: recruited (47% females, 53% males). Nineteen (25.4%)
Deleted: FGD
Deleted: Adolescents'
Deleted: m
Deleted: to protect themselves
Deleted: and others

For Peer Review Only

behavioral skills, such as disclosure of HIV-status to their sexual partners; the latter closely linked to fear of rejection and stigma.

HIV-positive youths need support in developing the appropriate behavioural skills to adopt healthy sexual behaviours. Interventions in this field need to be developmentally appropriate and tailored to young people's specific needs. Structural interventions should at the same time address and reduce HIV-related stigma and socio-economic needs of young people living with HIV.

Deleted: D
Deleted: sero
Deleted: was reported to be very difficult because of fear of
Deleted: Conclusion: YPLH face potential risks relating to their SRH, they still have considerable knowledge gaps and challenges
Formatted: Font: Not Bold, Not Italic
Formatted: Font: Not Italic
Deleted: which are barriers to secondary prevention.
Deleted: to support youth living with HIV for sexual risk reduction
Deleted: be
Deleted: their
Deleted: .

Key Words

Adolescents, HIV, Sexuality, Sexual and reproductive health, Secondary prevention

Word count: 287

For Peer Review Only

Introduction

HIV remains a global problem, with about 6000 young people being HIV infected worldwide each day. Almost two thirds of all young people living with HIV (YPLH) live in sub Saharan Africa (YouthNet, 2004). In Uganda, about 100,000 children under 15 years are infected with HIV and 67% of newly infected individuals were aged between 15 and 24 years (UNAIDS, 2006).

About 5% of perinatally infected children are slow progressors, who reach adolescence even without antiretroviral treatment (ART) (ANECCA, 2006). With the help of effective ART, however, growing numbers of young people living with HIV (YPLH) will reach adulthood and become sexually active during their adolescence (Mellins et al., 2003; Levine et al., 2006; Rice et al., 2006). They may have multiple protection needs that differ from their uninfected counterparts (Boonstra, 2006). Among their particular sexual and reproductive health (SRH) risks, unwanted pregnancies, infection with other sexually transmitted diseases (STDs), subsequent infertility, and the risk of HIV re-infection may be mentioned. In addition, there is also the possibility of transmitting HIV to sexual partners.

The Pediatric Infectious Disease Institute (PIDC) in Kampala (Uganda) follows a cohort of more than 600 YPLH (10-24 years), with about 300 patients being enrolled in ART programs. With the increased efficacy of ART, a growing number of them have been observed to experience unwanted consequences of sexual activity. Clinic data (from June 2004 -June 2007) confirmed 21 pregnancies among female adolescents.

Deleted: youths

Deleted: L

Deleted: W

Deleted:

Deleted: Mellins et al., 2003;

Deleted: ,

Deleted: the

Deleted: s

For Peer Review Only

These clinical observations as well as a body of scientific evidence (Futterman et al., 2000; Elkavich et al., 2006) shows that YPLH are in need of secondary prevention, in particular with respect to their SRH. Dual protection has been recognized as a high priority among adolescents' secondary prevention needs (Berer, 1997; Crosby et al., 2001; Cates et al., 2002; UNDP, 2002; Adeokun et al., 2003; Anderson et al., 2003; Kleinschmidt et al., 2003; Mantell et al., 2003; Berer, 2006). Given the complex dynamics of sexual identity building in adolescence (Bearinger et al., 2007), interventions should consider the diverse needs of this target group. However, most of the interventions available to reduce sexual risk behavior have been developed in a western context (Butler et al., 2003; Lyon et al., 2003; Rotheram-Borus, 2004; Lightfoot et al., 2007). There has been a gap in the development of culturally appropriate techniques in particular for clinical care settings.

Deleted: Elkavich et al., 2006;

Formatted: English U.S.

Deleted: Berer, 1997, 2006; Cates et al., 2002; Crosby et al., 2001;

Deleted: UNDP, 2002

Formatted: English U.S.

Deleted: Lightfoot et al., 2007;

This study aimed at collecting baseline data for developing a targeted intervention for sexual risk reduction with YPLH. Specifically, we set out to identify their SRH-related problems and needs. Using the Information-Motivation-Behavioral skills model (Fisher & Fisher, 2000; Fisher et al., 2004), which has received empirical support in intervention research, as theoretical guidance, needs were assessed along the IMB-model's 3 relevant dimensions: information deficits, motivations to behavior change, and behavioral skills shown to be determinants of effective behavioral change.

Deleted:)

For Peer Review Only

Methods

Guiding principle for the methodological approach was grounded theory (Charmaz, 2006; Strauss & Corbin, 1990; Glaser & Strauss, 1967). We employed the method of analytic induction and comparative analysis to define common patterns in the data, i. e. scanning the FGD transcripts for common themes and developing a working scheme with the categories found.

The analysis aimed at delineating complex social phenomena surrounding the SRH-related needs of YPLH. Data were collected using focus group discussions (FGD) according to standard techniques (Morgan & Kruger, 1998).

The study population were adolescents aged 11 to 21 years attending the PIDC, who knew their HIV status. They were consecutively enrolled until saturation of data was achieved (Barbour & Kitzinger, 1999). Brief anonymous self administered questionnaires were filled in before the FGDs to assess additional socio-demographic and selected psychosexual data.

A total of 8 FGDs with same sex, similar age-group adolescents (4 for each sex) were held using a pre-tested focus group topic guide. Each FGD had about 10 participants, one trained moderator and an observer. FGD were conducted in *Luganda*, audio taped, transcribed and translated into English

One additional FGD involved 12 health care providers (HCP) working with YPLH in various centers around Kampala to assess their perceptions on the SRH-related problems and needs of YPLH.

Formatted: Line spacing: Double

Deleted: The

Deleted: for this qualitative study

Deleted: Strauss & Corbin, 1990)

Deleted: to

Deleted: e

Deleted: some of the

Deleted: .

For Peer Review Only

Study participation was voluntary, and confidentiality was ensured. Informed consent (or assent, if applicable) was obtained from adolescents and/or their caregivers, as well as institutional consent from all relevant agencies involved.

Deleted:

Deleted: ¶

Statistical analysis

Qualitative data were available as verbatim transcripts of the FGD. Two independent raters assigned the first codes manually. Transcripts were repeatedly scrutinized for common items, which formed the basis of categorization. Common codes were identified inductively, refined and sub-grouped as themes. These second codes and a description of their contents were grouped under the theoretically pre-defined dimensions of the IMB model. Quantitative data were summarized in descriptive tables.

Results

From October 2006 to December 2006, 75 HIV infected adolescents participated in the study. Thirty five (46.7%) of them were female. The age range was 11 to 21 years, with a mean and median age of 16 years. Table 1 provides an overview of the study participants' main characteristics.

→ *Insert table 1 here!*

About a quarter of the study participants reported to have experienced sexual intercourse. Table 2 shows some details relating to their sexual activity.

→ *Insert table 2 here!*

For Peer Review Only

Information and misconceptions about sexual and reproductive health

The FGD revealed some important misconceptions. In relation to pregnancy, some adolescents thought they could not conceive since they have HIV. One 13 year old girl said for instance, *"It is not possible for us to become pregnant because we are sick. We cannot produce."* Some thought that the first semen in boys cannot render girls pregnant. Others thought that if they engaged in sexual relationships only for a short period of time, pregnancy was impossible.

With respect to HIV transmission, misconceptions were present in all age groups. For instance, 18 to 20 year old boys in one FGD thought that semen did not carry the virus, only blood. The younger ones (below 16 years) believed that young children could not get HIV by having sex with an adult. They believed that a boy who had not started "sperming" could not get infected with HIV. Some girls thought that HIV would be reduced over time as they loose blood during menstruation. Many adolescents were knowledgeable of the risk HIV re-infection and they expressed strong fears of getting worse because of re-infection. They had some information about STDs like Syphilis, Gonorrhea, and Genital Warts, and many feared to get infected by them.

Most of the adolescents considered abstaining from sex and using condoms as primary means of protection against HIV. They had some knowledge about available contraceptive methods, such as condoms and oral contraceptives, and had many fears relating to the latter. They believed that they may not produce children in future or that the pill would damage the health of their children. Some believed that if they used the pill just before sex, it would prevent pregnancy. One 16 year

For Peer Review Only

old boy was convinced that if he got overwhelmed by sexual desires, he could have sex with a girl and then ask an adult for removing the sperms.

Adolescents' motivations for adopting protective behaviors

Hope was identified as an important motivation for protection. Many hoped that if they continued to adhere to their treatment, they would be able to live long enough to finish school, get a good job, get married, and have their own children. Some hoped that finally a cure for HIV might be found. Adolescents, who perceived the counseling at the clinic as supportive, appeared to be more motivated to protect themselves and their partners.

Younger adolescents below 16 years tended to have a stronger believe in sexual abstinence than their older peers. Younger ones reported to be convinced about what they have been taught at PIDC's peer support group, i.e. that they should wait to engage in sex. Others opted to abstain because they believed condoms were not 100% protective: *"Even protected sex is risky because there are accidents like the condom can burst."* They feared that condoms could have a hole, rapture or come off during sex.

In general, fear of consequences of unwanted pregnancy was the strongest motivation for protection. Girls feared dropping out of school, rejection from parents or caregivers or from the boy/man by whom they got pregnant. They also feared difficult delivery, early marriage and parenthood with no financial assistance. Feared consequences of abortion included death, abnormal children and failure to produce children in future.

Deleted: go ahead having

Deleted: ¶

Deleted: Some

Deleted: by

Deleted: responsible

Deleted: when being

For Peer Review Only

Perceived barriers for adopting protective behaviors

Adolescence in itself was perceived as a time of sexual experimenting and having to deal with peer influence. Peer pressure was reported as a main barrier to protection. YPLH desired to be like their friends who were already involved in sexual relationships. Some said they desired to have sex at least once before they die: *"Maybe I might not reach that age; I try to have sex before I die."* Some older adolescents desired to have children as they had concerns about who would inherit their riches or wanted to leave a lineage: *"Some of us feel you cannot leave this world without a child, your lineage ends."*

Many of the adolescents were orphans and therefore poor and vulnerable. In spite of their knowledge about the consequences of unprotected sex, some adolescents engaged in sex in exchange for money or other benefits. Some agreed to sexual relationships to find the love which they have missed for most of their lives. Ignorance of their sexual partners was confirmed as another barrier. Disclosure of HIV was perceived as a difficult and ambivalent issue. When YPLH disclosed to their sexual partners, they often would not believe them because they did not look sick.

Use of alcohol was reported as a further barrier. Some of them remembered losing their sense of judgment when drinking alcohol or watching pornographic movies with male peers.

Behavioral skills adopted by adolescents for protective behaviors

YPLH perceived sexual communication as an important prerequisite for using protection. However, HIV-related stigma was perceived as a hindrance to disclosure

For Peer Review Only

to their partners because of the anticipated discrimination and rejection. As one young male put it: "*It is very difficult to tell someone that you have the virus. People will tell everyone in the village.*" Some young boys said that they would only disclose to HIV-positive partners because they would not reject them. Others said they would only go for HIV-negative partners without disclosing their own HIV-status, because of the fear of re-infection.

Avoidance and refusal were often described as coping strategies. Some of the younger adolescents were determined to avoid environments that could lead to sex like romantic situations, or bad peer groups. Some YPLH were determined to refuse any sexual activity. If a person insisted on getting sexually active, they tried to resist, to either leave or to raise alarm. Some denied sexual activities on the ground of religious reasons or by disclosing HIV.

Younger adolescents believed more strongly in abstinence than the older ones. The following comments were made by participants from a FGD with male adolescents aged 16 and older: *"You cannot abstain because it is nature,"* or: *"If you say HIV infected people should abstain from sex it is like condemning us to die."*

Older YPLH opted for condom use to prevent both unwanted pregnancies and the spread of HIV, but difficulties with consistent use were reported. Some described difficulties to get condoms or to get the right ones. If condoms were too big, they tied a rubber band around them to achieve a better fit. Others did not like the feeling of condoms mainly because, *"sweets cannot be eaten in wrappers."*

Deleted: *s*

Masturbation was also mentioned in one FGD as a strategy to avoid sexual activity with a partner, however, this was not acceptable to most of the participants.

For Peer Review Only

Health care providers' perceptions on SRH-related needs of YPLH

HCP stressed that issues relating to SRH needs of YPLH were complex. Their views were similar to the adolescents' perceptions with a few remarkable differences. For instance, adolescents did not bring up the role of peer counseling which HCP thought was vital. While adolescents rarely mentioned the issue of sexual exploitation by caregivers, HCP said that many YPLH were vulnerable in that respect. HCP stressed that SRH of YPLH had to be tackled from various angles including caregivers, religious leaders, teachers and health staff using a coherent approach. They also emphasized the need for specific tools to identify sexual risk behavior, and to counsel them accordingly. HCP suggested that they needed proper training on SRH issues to better meet the needs of their young clients.

Deleted: out

Deleted: brought up

Deleted: approach YPLH with non-judgmental attitudes so that clients would open up to them.

Discussion

While the results of this qualitative study are not representative for the general population of YPLH, their theoretical generalizability is valuable, i.e. their contribution to theory-building in intervention research. Our results confirm the dimensions of the IMB-model revealing some of the factors that influence protective behavior among YPLH. Study results may also be limited in that we assessed perceptions of a clinical sample, and voluntary participants may have been more educated than other YPLH, for instance those who are not on treatment. The perceptions of YPLH were corroborated by the results of the FGD with service providers, which allowed for integrating a broad range of services in the field.

For Peer Review Only

The knowledge gaps concerning SRH and transmission of HIV among YPLH were remarkable, even among the post-adolescents. YPLH are a diverse group including long term survivors of MTCT or HIV positive youths infected during adolescence due to unprotected sex. This group is heterogeneous with respect to a variety of factors: being in or out of school, being orphaned, being under different care arrangements, having different experiences with sexual activity (ANECCA, 2006). Our findings concerning the onset and the level of sexual activity was not surprising as the Uganda HIV/AIDS sero-behavioral survey 2004/05 showed that 14% of female and male respondents reported their first sex below the age of 15 years (MOH, 2006).

Adolescents' motivation for protection was identified on a continuum between hope and fear. However, the latter seemed to be more prevalent in al age groups. Adolescents' fears relating to SRH and sexuality in general where omnipresent, relating from realistic fears of unwanted consequences of unprotected sex (such as unintended pregnancy) to general taboos and shame tied to sexuality. Some of the misconceptions pointed to developmentally inappropriate magical thinking (e.g. the idea that *"an adult would remove sperm from a sexual partner after sex"*), which may also be interpreted as a sign of immature cognitive functioning.

Pregnancy was the most feared consequence across all age groups, and was more prevalent among girls than among boys. This is similar to uninfected adolescents (Bankole et al., 2004; IPPF, 2005; Kirby et al., 1991; WHO, 2006), and reasonable given the higher chance to get pregnant than to transmit HIV at one single unprotected intercourse (Dryfoos, 1990; Varghese et al., 2002). This finding calls for the need to address all unwanted consequences of sexual activity in a broad

Deleted: We found some important

Deleted: .

Deleted: older ones

Deleted:

Deleted: and

Deleted: different levels

Deleted: of

Formatted: Font: Italic

Deleted:

For Peer Review Only

context of SRH. In addition, public health messages that are mainly fear evoking have been shown to be less effective (Johnson, 2002), which is another reason for addressing the SRH-related needs in a positive manner.

Because of the fear of re-infection with HIV, many of the adolescents preferred HIV negative partners, which may constitute an unintended effect of prevention prioritizing the risk of HIV re-infection (Sengh, 2006).

Our data show that procreation and safe motherhood were major desires of YPLH, thus the concept of triple protection (Brady, 2003) as a public health message may be of benefit in this target group. At the same time, adolescents need to be protected from adverse consequences of early parenthood, which makes dual protection crucial for any targeted interventions (Harvey et al., 2004; Hawken et al., 2002).

While we could not elaborate on the many gender-differences prevalent in the FGD given the limited length of this analysis, they certainly have to be taken into consideration when tailoring specific interventions for YPLH (Schoeberlein et al. 1999; Wingood et al., 2004).

This study took place in a public health context favoring the ABC prevention approach (**A**bstinence - **B**eing faithful - **C**ondom use) (Cohen, 2003). We found strong age differences in the way how YPLH accepted abstinence-only messages. This is a very relevant finding from a policy point of view, and congruent with findings by intervention research (Jemmott et al., 1998). While recent research has shown that abstinence only approaches are of limited efficacy (Santelli et al., 2006), our findings stress that the delay of onset of sexual activity should still be objective of preventive efforts with younger adolescents, even more relevant in the context of coercive sex. Studies have shown that it is difficult to return to abstinence once

Deleted: particularly

For Peer Review Only

adolescents have become sexually active (Jemmott et al., 2005), and our data stress that a developmentally appropriate approach to correct and consistent condom-use would be more promising for those already being sexually active (Pedlow & Carey, 2004).

Being confronted at a young age with one's own mortality also shaped the culturally relevant wish to procreate and therefore to become sexually active. Given the complex psychodynamics that may drive such wishes, we can assume that such motivations may be stronger than information targeting the cognitive level. This finding highlights the specific needs of YPLH compared to their uninfected counterparts, and shows that primary prevention initiatives need to be scrutinized carefully for their potential transferability to this target group.

Our results show that major socio-economic characteristics shape the factors that constitute barriers to protection behavior to a large extent. This is in line with findings on the overall impact of the HIV/AIDS on affected children, adolescent, and family systems (Sengenedo & Nambi, 1997; Stein et al., 2003). Children who were orphaned, or had experienced poverty and stigma came were put at risk of exchanging sex for money. Protecting themselves and others became less likely in such a context, which made them vulnerable even when having access to correct information.

In the light of tailored interventions to be developed on the grounds of these findings, it is encouraging that the HCP participating in the FGD agreed that children need to be told early, i.e. before adolescence about sexuality and prevention. HCP stressed that YPLH need to be given correct, consistent, and

Deleted: on

Deleted: a

Deleted: Whether

Deleted: children

Deleted: out as major barriers to protecting themselves and others, which

Deleted: them

Deleted: These made them

For Peer Review Only

developmentally appropriate information. Caregivers need to be involved, trained and encouraged to be open and to demystify sex. In addition, for any success of targeted SRH interventions, the underlying socio-economic issues should be addressed on a structural level to reduce adolescents' vulnerability.

Deleted: specific

Deleted: ¶
¶

Acknowledgements

We wish to acknowledge the individual anonymous donor from Antwerp, Belgium, for the financial contribution to this study. We would like to expand our special thanks to the Finance and Administrative Department of the Infectious Disease Institute for their support, and the research assistants who worked so tirelessly, in particular Mr. Fred Sebuuma, Ms.Cissy Ssuuna, Mr.Caleb Twijukye, Ms.Esther Kangavve, and Mr. Julian Nkuraija, and Mrs.Stella.B.Ssali for data transcription. Last but not least, all the adolescents who participated enthusiastically in this study.

For Peer Review Only

References

ANECCA, African Network for the Care of Children Affected by AIDS (2006). *Handbook on Pædiatric AIDS in Africa.* Revised version. USAID. Accessed at: http://www.fhi.org/en/HIVAIDS/pub/guide/mans1.htm.

Adeokun, L., Mantell, J.E., Weiss, E., Ebun Delan, G., Jagha, T., Olaturegun, J., Udo, D., Akinso, S. & Weiss, E. (2003). Promoting dual protection in family planning clinics in Ibadan, Nigeria. *International Family Planning Perspectives, 28* (2): 87-95.

Anderson, J.E., Santell, J. & Gilbert, B.C. (2003). Adolescent dual use of condoms and hormonal contraception: trends and correlates 1991 – 2001. *Sexually Transmitted Diseases, 30*(9): 719-722.

Bankole, A., Singh, S., Woog, V. & Wulf, D. (2004). Risk and protection: Youth and HIV/AIDS in Sub Saharan Africa. The Alan Guttmacher Institute, New York. Accessed at: http://www.guttmacher.org/pubs/riskandprotection.pdf.

Barbour, R., & Kitzinger, J. (1999). *Developing focus group research. Politics, theory, and practice.* London: Sage

Bearinger, L.H., Sieving, R.E., Ferguson, J., & Sharma, V. (2007). Global Perspectives on the sexual and reproductive health of adolescents: patterns,

Formatted: Font: Italic

Deleted: ,

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Dutch Belgium

Deleted: ,

Deleted:

For Peer Review Only

prevention, and potential. *The Lancet, 369*, 1220-31. DOI: 10.1016/S1040-6736 (07)60367-5.

Berer, M. (1997). Dual protection: making sex safer for women. In: T. K.S. Ravindran, M. Berer, J. Cottingham (Eds), *Beyond Acceptability: Users' Perspectives on Contraception*(pp. 109-21). London: Reproductive Health Matters for World Health Organization.

Berer, M. (2006). Dual protection: more needed than practised or understood. *Reproductive Health Matters*, 14(28):162–70.

Boonstra, H. (2006). Meeting the Sexual and reproductive health needs of people living with HIV. *Guttmacher Policy Brief* , nr. 6. The Guttmacher Institute, Accessed at: http://www.guttmacher.org/pubs/IB_HIV.html.

Brady, M. (2003). Preventing sexually transmitted infections and unintended pregnancy, and safeguarding fertility: triple protection needs of young women. *Reproductive Health Matters, 11* (22):134-141.

Butler, R.B., Schultz, J.R., Brown, L.K. et al. (2003). Promoting safer sex among HIV-positive youth with haemophilia: theory, intervention, and outcome. *Haemophilia, 9*(2):214-222.

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

For Peer Review Only

Cates, W. & Steiner, M.J. (2002). Dual protection against unintended pregnancy and sexually transmitted infections: what is the best contraceptive approach? *Sexually Transmitted Diseases*, *29*(3):168-174.

Charmaz, K. (2006). *Constructing Grounded Theory. A Practical guide through qualitative analysis*. London: Sage.

Cohen, S.A. (2003). Beyond Slogans: Lessons From Uganda's Experience With ABC and HIV/AIDS. *The Guttmacher Report on Public Policy*, *6* (5); accessed at: http://www.guttmacher.org/pubs/tgr/06/5/gr060501.html.

Crosby, R.A., Di Clemente, R., Wingood, G.M., Sionean, C., Cobb, B., Harrington, K., Davies, S.L., Hook, E.W. & Oh, M.K. (2001). Correlates and dual method use for sexually transmitted diseases and pregnancy prevention among high-risk african-american female teens. *Journal of Adolescent Health*, *28*(5):410-414.

Dryfoos, J.G. (1990). *Adolescents at risk: prevalence and prevention*. Oxford University Press, London.

Elkavich, A., Rotheram-Borus, M.J., Goldstein, R. et al. (2006). Young People living with HIV. In: S.C. Kalichman (Ed.): *Positive Prevention. Reducing HIV transmissions among people living with HIV/AIDS.* (pp. 163-92). Kluwer Academic/Plenum Publishers, New York.

Formatted: Font: Italic

Formatted: Font: Italic

Deleted: ,

Formatted: Font: Italic

For Peer Review Only

Fisher, J.D. & Fisher, W.A. (2000). Theoretical approaches to individual-level change in HIV risk behaviour. In: J.L. Peterson & R. DiClemente (Eds.). *HIV prevention handbook* (pp. 3 -55). New York, Kluwer Academic.

Fisher, J.D., Cornman, D., Osborn, C.Y., Rive Amico, K., Fisher, A. & Friedland, G.A. (2004). Clinician-initiated HIV risk reduction intervention for HIV positive persons. Formative research, acceptability, and fidelity of the OPTIONS project. *Journal of Acquired Immune Deficiency Syndrome, 37* (S2): S78-87.

Futterman, D., Chabon, B. & Hoffman, N. (2000). Adolescents and HIV Infection. *Pediatric Clinics of North America.* M. Rogers, (Ed.), 47:171-88.

Harvey, S.M., Henderson, J.T. & Branch, M.R. (2004). Protecting against both pregnancy and disease: predictors of dual method use among a sample of women. *Women Health*, *39*(1):25-34

Glaser, B. & Strauss, A. (1967). *The discovery of grunded theory: strategies for qualitative research.* Chicago: De Gruyther.

Hawken, M.P., Melis, R.D., Ngombo, D.T., Mandaliya, K.N., Ng'ang'a, L.W., Price, J., Dallabatta, G., & Temmerman, M. (2002). Opportunity for prevention of HIV and sexually transmitted diseases in Kenyan youth: results of a population based survey. *Journal of Acquired Immune Deficiency Syndrome*, *31*(5):529-525

Formatted: Font: Italic

Formatted: Font: Italic

Deleted: ,

Formatted: Font: Italic

Formatted: Font: Italic

Deleted:

Formatted: Font: Italic

For Peer Review Only

International Planned Parenthood Federation (2005). Gender, Youth, and AIDS. Azerbaijan, 7-10 February 2005. EGM/BPFA-MD-MDG/2005/EP.4. Accessed at: http://www.un.org/womenwatch/daw/egm/bpfamd2005/experts-papers/EGM-BPFA-MD-MDG-2005-EP.4.pdf.

Jemmott, J.B., Jemmott, L.S. & Fong, GT. (1998). Abstinence and safer sex HIV risk reduction interventions for African American adolescents: a randomized controlled clinical trial. *Journal of the American Medical Association JAMA*, *279* (19):1529-36.

Jemmott, J.B., Jemmott, L.S., Bravermann, P.K. & Fong, G.T. (2005). HIV/STD risk reduction intervention for African American and Latino adolescent girls at an adolescent medicine clinic: a randomized controlled trial. *Archives of Pediatric and Adolescent Medicine, 159*(5):440-9.

Johnson, B.B. (2002). Risk Communication: A Mental Models Approach. *Risk Analysis* 22 (4), 813–814. doi:10.1111/0272-4332.0007.1

Kirby, D., Barth, R.P., Leland, N. & Fetro, J.V. (1991). Reducing the Risk: Impact of a new curriculum on sexual risk-taking. *Family Planning Perspectives*, *23* (6):253-263. doi:10.2307/2135776.

Formatted: Font: Italic

Deleted: ,

Deleted: Afrivcan

Formatted: Font: Italic

Deleted:

Deleted: ,

Deleted: N

Deleted: C

Deleted: S

Deleted: e

Deleted: R

Deleted: T

Deleted: *Vol.*

Formatted: Font: Italic

For Peer Review Only

Kleinschmidt, I., Maggwa, B., Smit, J, Beksinska, M.E. & Ree, H. (2003). Dual protection in sexually active women. *South African Medical Journal, 93*(11):845-847.

Levine, A.B., Aaron, E. & Foster, J. (2006). Pregnancy in perinatally HIV-infected adolescents. Clinical observation. *Journal of Adolescent Health, 38*:765-68.

Lightfoot, M., Rotherham-Borus, M.J. & Tevendale, H. (2007). An HIV-preventive intervention for Youth Living with HIV. *Behavior Modification, 31*(3):345-363. DOI: 10.1177/0145445506293787

Lyon, M.E., Trexler, C., Akpan-Townsend, C. et al. (2003). A family-group approach to increasing adherence to therapy in HIV-infected youths: results of a pilot project. *AIDS Patient Care and STDs, 17*(6):299-308.

Mantell, J.E., Hoffman, S., Exner, T., Stein, Z.A., Atkins, K (2003). Family planning providers' perspectives on dual protection. *Perspectives on Sexual and Reproductive Health,* 35(2):71-78.

Mellins, C.A., Smith, R., O' Driscoll, P. et al. (2003). High rates of behavioural problems in perinatally infected children are not linked to HIV disease. *Pediatrics*, 111:384-93.

Deleted: ,

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

Formatted: Font: Italic

For Peer Review Only

Ministry of Health (MOH), Uganda & ORC Macro. (2006). *Uganda HIV/AIDS Sero-behavioural Survey 2004-2005.* Calverton, Maryland, USA: Ministry of Health and ORC Macro.

Morgan, D.L. & Kruger, R.A. (1998). *The focus group tool kit.* Thousand Oaks, CA: Sage.

Pedlow, C.T. & Carey, M.P. (2004). Developmentally appropriate sexual risk reduction intervention for adolescents: Rationale, review of interventions, and recommendations for research and practice. *Annuals of Behavioral Medicine, 27*(3):172-184.

Rice, E., Batterham, P. & Rotherham-Borus, M.J. (2006). Unprotected Sex Among Youth Living with HIV Before and After the Advent Of Highly Active Antiretroviral Therapy. *Perspectives on Sexual and Reproductive Health, 38*(3), 162–167. doi:10.1363/3816206.

Rotheram-Borus, M.J., Swendeman, D., Comulada, W., Scott, M.S., Weiss, R.E. Lee, M. & Lightfoot, M. (2004). Prevention for Substance-Using HIV-Positive Young People: Telephone and In-Person Delivery. *Journal of Acquired Immune Deficiency Syndromes. 37*, Suppl; 2:S68-S77.

Santelli, J., Ott, M., Lyon, M., Rogers, J., Summers, D. & Schleifer, R. (2006). Abstinence and abstinence-only education: A review of U.S. policies and programs. *Journal of Adolescent Health*, *38* (1): 72-81.

Deleted: ,

Formatted: Font: Italic

Deleted:

Formatted: Font: Italic

Formatted: Font: Not Italic

Formatted: Font: Not Italic

Formatted: Font: Not Italic

Formatted: Font: Not Italic

Formatted: Font: Not Italic

Formatted: Font: Not Bold

Formatted: Font: Italic

Formatted: Font: Bold, Italic

Deleted: ,

Formatted: Font: Italic

For Peer Review Only

Schoeberlein, D.R., Blezer, M.E. & Woolston, J.L. (1999). HIV-prevention for teenage girls: relationships are the medium and the message. *AIDS Reader, 9*(2):113-121.

Seng, R. (2006). Sexual behaviour at risk for HIV superinfection and HIV-RNA levels progression in women followed in the SEROCO and PRIMO cohorts. Thirteenth Conference on Retroviruses and Opportunistic Infections, Denver, abstract 731.

Sengendo, J. & Nambi, J. (1997). The psychological effect of orphanhood: a study of orphans in Rakai district. *Health transition review*, *7*: S105-S24.

Strauss, A. & Corbin J. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Stein, J. (2003). Sorrow makes children of us all: A literature review on the psychosocial impact of HIV/AIDS on children. *Working paper no. 47;* Centre for social science research, University of Cape Town.

UNDP/UNFPA/WHO/World Bank Special Program of Research and Development and Research Training in Human Reproduction. (2002). HIV/AIDS makes dual protection a must. *Progress in Reproductive Health Research, 59*. Accessed at: http://www.who.int/reproductivehealth/hrp/progress/59/news59.html.

Deleted: ,
Formatted: Dutch Belgium
Formatted: Font: Italic
Deleted:
Formatted: Font: Italic
Formatted: Font: Italic
Deleted: *2002 (*
Formatted: Font: Italic
Deleted:)
Formatted: Font: Italic

For Peer Review Only

WHO/UNAIDS/UNFPA/UNODC (2004). YouthNet. Protecting Young People from HIV and AIDS: the role of health services. Geneva: World Health Organization.

UNAIDS/WHO (2006). AIDS epidemic Update 2006. Special report on HIV/AIDS. December 2006. Geneva. Accessed at: http://www.unaids.org/en/HIV_data/epi2006/.

Varghese, B., Mahler, J., Julie, E., Peterman, T., Thomas, A., Branson, B. & Steketee, R. (2002). Reducing the Risk of Sexual HIV Transmission: Quantifying the Per-Act Risk for HIV on the Basis of Choice of Partner, Sex Act, and Condom Use. *Sexually Transmitted Diseases*, *29*(1):38-43.

Wingood, G.M., DiClemente, R.J., Mikhail, I., Lang, D.L., McCree, D.H., Davies, S.L., Hardin, J.W., Hook, E.W. & Saag, M. (2004). A randomized controlled trial to reduce HIV transmission and sexually transmitted diseases among women living with HIV: the WILLOW program. *Journal of Acquired Immune Deficiency Syndrome*, *37*(S2):S58-67.

Deleted: ,
Deleted: ,
Deleted: ,
Deleted: .
Formatted: Font: Not Italic
Deleted: ,
Formatted: Font: Italic
Deleted: ,
Formatted: Font: Italic

For Peer Review Only

Table 1. Study participants' main characteristics (YPLH)

Characteristics		Frequency (n=75)	Percentage (%)
Residence	Urban	26	34.7
	Peri-urban	39	52.0
	Rural	10	13.3
Highest education	Primary education	33	44.0
	O level	35	46.7
	A level	6	8.0
	Tertiary education	1	1.3
Mode of HIV transmission	MTCT	64	85.6
	Blood transfusion	2	2.6
	Injection	1	1.3
	Heterosexual sex	1	1.3
	Do not know	7	9.3
On ART	Yes	66	88
	No	9	12
Relationship status	Single	58	77.3
	In relationship	17	22.7
Prior or current sexual intercourse	No	56	74.6
	Yes	19	25.4
Primary caregiver	Parent	29	38.7
	Grandparent	18	24.0
	Older sibling	11	14.7
	Aunt/uncle	9	12.0
	Other	6	8.0
	Self	2	2.6
Primary caregiver's source of income*	Employed	42	56.0
	External support	21	28.0
	No support	10	13.3

* 2 of them were independent and therefore had no primary caregiver

For Peer Review Only

Table 2: Characteristics of YPLH reporting sexual experience

Characteristics		Frequency (n=19)	Percentage (%)
Age at first sex	Below 15	8	42.1
	Above 15	8	42.1
	Unknown	3	15.8
Gender	Female	9	47.4
	Male	10	52.6
Number of sexual partners	1	9	47.4
	2 - 7	6	31.7
	13	1	5.3
	Unknown	3	15.8
Currently having a boyfriend/girlfriend	Yes	9	47.4
	No	10	52.6
Residence	Urban	7	36.8
	Periurban	11	57.9
	Rural	1	5.3

For Peer Review Only

Sexual Risk Reduction Needs of Adolescents Living with HIV in a Clinical Care Setting

ABSTRACT

As anti-retroviral therapy becomes increasingly available, young people living with HIV need tailored support to adopt healthy sexual behaviors. There has been a gap in the availability of culturally appropriate techniques for secondary prevention and sexual risk reduction in this target-group.

This formative study assessed sexual and reproductive health needs and problems, as well as determinants of sexual risk taking among young people living with HIV aged 11 to 21 years attending the Paediatric Infectious Disease Clinic in Kampala, Uganda. Theoretical guidance was provided by the Information-Motivation-Behavioral Skills Model . Socio-demographic and selected psychosexual data were assessed using a brief anonymous questionnaire. *A total of* 75 young people living with HIV participated in 8 focus group discussions. In addition, one focus group was conducted with adult key informants (service providers). About a quarter of the young participants reported prior or current sexual experience. The study revealed knowledge gaps relating to reproductive health, HIV transmission and contraceptive methods. Motivations for protection included hope for the future, good counseling, and fear of the consequences of sexual activity such as unwanted pregnancies. Barriers to adopting preventive behaviors included peer pressure, poverty, HIV-related stigma, ignorance of their partners, alcohol use, and a desire to have children for the older ones. Young sero-positive people in this setting lacked specific

For Peer Review Only

behavioral skills, such as disclosure of HIV-status to their sexual partners; the latter closely linked to fear of rejection and stigma.

HIV-positive youths need support in developing the appropriate behavioural skills to adopt healthy sexual behaviours. Interventions in this field need to be developmentally appropriate and tailored to young people's specific needs. Structural interventions should at the same time address and reduce HIV-related stigma and socio-economic needs of young people living with HIV.

Key Words

Adolescents, HIV, Sexuality, Sexual and reproductive health, Secondary prevention

Word count: 287

For Peer Review Only

Introduction

HIV remains a global problem, with about 6000 young people being HIV infected worldwide each day. Almost two thirds of all young people living with HIV (YPLH) live in sub Saharan Africa (YouthNet, 2004). In Uganda, about 100,000 children under 15 years are infected with HIV and 67% of newly infected individuals were aged between 15 and 24 years (UNAIDS, 2006).

About 5% of perinatally infected children are slow progressors, who reach adolescence even without antiretroviral treatment (ART) (ANECCA, 2006). With the help of effective ART, however, growing numbers of young people living with HIV (YPLH) will reach adulthood and become sexually active during their adolescence (Mellins et al., 2003; Levine et al., 2006; Rice et al., 2006). They may have multiple protection needs that differ from their uninfected counterparts (Boonstra, 2006). Among their particular sexual and reproductive health (SRH) risks, unwanted pregnancies, infection with other sexually transmitted diseases (STDs), subsequent infertility, and the risk of HIV re-infection may be mentioned. In addition, there is also the possibility of transmitting HIV to sexual partners.

The Pediatric Infectious Disease Institute (PIDC) in Kampala (Uganda) follows a cohort of more than 600 YPLH (10-24 years), with about 300 patients being enrolled in ART programs. With the increased efficacy of ART, a growing number of them have been observed to experience unwanted consequences of sexual activity. Clinic data (from June 2004 -June 2007) confirmed 21 pregnancies among female adolescents.

For Peer Review Only

These clinical observations as well as a body of scientific evidence (Futterman et al., 2000; Elkavich et al., 2006) shows that YPLH are in need of secondary prevention, in particular with respect to their SRH. Dual protection has been recognized as a high priority among adolescents' secondary prevention needs (Berer, 1997; Crosby et al., 2001; Cates et al., 2002; UNDP, 2002; Adeokun et al., 2003; Anderson et al., 2003; Kleinschmidt et al., 2003; Mantell et al., 2003; Berer, 2006.). Given the complex dynamics of sexual identity building in adolescence (Bearinger et al., 2007), interventions should consider the diverse needs of this target group. However, most of the interventions available to reduce sexual risk behavior have been developed in a western context (Butler et al., 2003; Lyon et al., 2003; Rotheram-Borus, 2004; Lightfoot et al., 2007). There has been a gap in the development of culturally appropriate techniques in particular for clinical care settings.

This study aimed at collecting baseline data for developing a targeted intervention for sexual risk reduction with YPLH. Specifically, we set out to identify their SRH-related problems and needs. Using the Information-Motivation-Behavioral skills model (Fisher & Fisher, 2000; Fisher et al., 2004), which has received empirical support in intervention research, as theoretical guidance, needs were assessed along the IMB-model's 3 relevant dimensions: information deficits, motivations to behavior change, and behavioral skills shown to be determinants of effective behavioral change.

For Peer Review Only

Methods

Guiding principle for the methodological approach was grounded theory (Charmaz, 2006; Strauss & Corbin, 1990; Glaser & Strauss, 1967). We employed the method of analytic induction and comparative analysis to define common patterns in the data, i. e. scanning the FGD transcripts for common themes and developing a working scheme with the categories found.

The analysis aimed at delineating complex social phenomena surrounding the SRH-related needs of YPLH. Data were collected using focus group discussions (FGD) according to standard techniques (Morgan & Kruger, 1998).

The study population were adolescents aged 11 to 21 years attending the PIDC, who knew their HIV status. They were consecutively enrolled until saturation of data was achieved (Barbour & Kitzinger, 1999). Brief anonymous self administered questionnaires were filled in before the FGDs to assess additional socio-demographic and selected psychosexual data.

A total of 8 FGDs with same sex, similar age-group adolescents (4 for each sex) were held using a pre-tested focus group topic guide. Each FGD had about 10 participants, one trained moderator and an observer. FGD were conducted in *Luganda*, audio taped, transcribed and translated into English

One additional FGD involved 12 health care providers (HCP) working with YPLH in various centers around Kampala to assess their perceptions on the SRH-related problems and needs of YPLH.

For Peer Review Only

Study participation was voluntary, and confidentiality was ensured. Informed consent (or assent, if applicable) was obtained from adolescents and/or their caregivers, as well as institutional consent from all relevant agencies involved.

Statistical analysis

Qualitative data were available as verbatim transcripts of the FGD. Two independent raters assigned the first codes manually. Transcripts were repeatedly scrutinized for common items, which formed the basis of categorization. Common codes were identified inductively, refined and sub-grouped as themes. These second codes and a description of their contents were grouped under the theoretically pre-defined dimensions of the IMB model. Quantitative data were summarized in descriptive tables.

Results

From October 2006 to December 2006, 75 HIV infected adolescents participated in the study. Thirty five (46.7%) of them were female. The age range was 11 to 21 years, with a mean and median age of 16 years. Table 1 provides an overview of the study participants' main characteristics.

→ *Insert table 1 here!*

About a quarter of the study participants reported to have experienced sexual intercourse. Table 2 shows some details relating to their sexual activity.

→ *Insert table 2 here!*

http://mc.manuscriptcentral.com/ac-phm-vcy
For Peer Review Only

Information and misconceptions about sexual and reproductive health

The FGD revealed some important misconceptions. In relation to pregnancy, some adolescents thought they could not conceive since they have HIV. One 13 year old girl said for instance, *"It is not possible for us to become pregnant because we are sick. We cannot produce."* Some thought that the first semen in boys cannot render girls pregnant. Others thought that if they engaged in sexual relationships only for a short period of time, pregnancy was impossible.

With respect to HIV transmission, misconceptions were present in all age groups. For instance, 18 to 20 year old boys in one FGD thought that semen did not carry the virus, only blood. The younger ones (below 16 years) believed that young children could not get HIV by having sex with an adult. They believed that a boy who had not started "sperming" could not get infected with HIV. Some girls thought that HIV would be reduced over time as they loose blood during menstruation. Many adolescents were knowledgeable of the risk HIV re-infection and they expressed strong fears of getting worse because of re-infection. They had some information about STDs like Syphilis, Gonorrhea, and Genital Warts, and many feared to get infected by them.

Most of the adolescents considered abstaining from sex and using condoms as primary means of protection against HIV. They had some knowledge about available contraceptive methods, such as condoms and oral contraceptives, and had many fears relating to the latter. They believed that they may not produce children in future or that the pill would damage the health of their children. Some believed that if they used the pill just before sex, it would prevent pregnancy. One 16 year

For Peer Review Only

old boy was convinced that if he got overwhelmed by sexual desires, he could have sex with a girl and then ask an adult for removing the sperms.

Adolescents' motivations for adopting protective behaviors

Hope was identified as an important motivation for protection. Many hoped that if they continued to adhere to their treatment, they would be able to live long enough to finish school, get a good job, get married, and have their own children. Some hoped that finally a cure for HIV might be found. Adolescents, who perceived the counseling at the clinic as supportive, appeared to be more motivated to protect themselves and their partners.

Younger adolescents below 16 years tended to have a stronger believe in sexual abstinence than their older peers. Younger ones reported to be convinced about what they have been taught at PIDC's peer support group, i.e. that they should wait to engage in sex. Others opted to abstain because they believed condoms were not 100% protective: *"Even protected sex is risky because there are accidents like the condom can burst."* They feared that condoms could have a hole, rapture or come off during sex.

In general, fear of consequences of unwanted pregnancy was the strongest motivation for protection. Girls feared dropping out of school, rejection from parents or caregivers or from the boy/man by whom they got pregnant. They also feared difficult delivery, early marriage and parenthood with no financial assistance. Feared consequences of abortion included death, abnormal children and failure to produce children in future.

For Peer Review Only

Perceived barriers for adopting protective behaviors

Adolescence in itself was perceived as a time of sexual experimenting and having to deal with peer influence. Peer pressure was reported as a main barrier to protection. YPLH desired to be like their friends who were already involved in sexual relationships. Some said they desired to have sex at least once before they die: *"Maybe I might not reach that age; I try to have sex before I die."* Some older adolescents desired to have children as they had concerns about who would inherit their riches or wanted to leave a lineage: *"Some of us feel you cannot leave this world without a child, your lineage ends."*

Many of the adolescents were orphans and therefore poor and vulnerable. In spite of their knowledge about the consequences of unprotected sex, some adolescents engaged in sex in exchange for money or other benefits. Some agreed to sexual relationships to find the love which they have missed for most of their lives. Ignorance of their sexual partners was confirmed as another barrier. Disclosure of HIV was perceived as a difficult and ambivalent issue. When YPLH disclosed to their sexual partners, they often would not believe them because they did not look sick.

Use of alcohol was reported as a further barrier. Some of them remembered losing their sense of judgment when drinking alcohol or watching pornographic movies with male peers.

Behavioral skills adopted by adolescents for protective behaviors

YPLH perceived sexual communication as an important prerequisite for using protection. However, HIV-related stigma was perceived as a hindrance to disclosure

For Peer Review Only

to their partners because of the anticipated discrimination and rejection. As one young male put it: "*It is very difficult to tell someone that you have the virus. People will tell everyone in the village.*" Some young boys said that they would only disclose to HIV-positive partners because they would not reject them. Others said they would only go for HIV-negative partners without disclosing their own HIV-status, because of the fear of re-infection.

Avoidance and refusal were often described as coping strategies. Some of the younger adolescents were determined to avoid environments that could lead to sex like romantic situations, or bad peer groups. Some YPLH were determined to refuse any sexual activity. If a person insisted on getting sexually active, they tried to resist, to either leave or to raise alarm. Some denied sexual activities on the ground of religious reasons or by disclosing HIV.

Younger adolescents believed more strongly in abstinence than the older ones. The following comments were made by participants from a FGD with male adolescents aged 16 and older: *"You cannot abstain because it is nature,"* or: *"If you say HIV infected people should abstain from sex it is like condemning us to die."*

Older YPLH opted for condom use to prevent both unwanted pregnancies and the spread of HIV, but difficulties with consistent use were reported. Some described difficulties to get condoms or to get the right ones. If condoms were too big, they tied a rubber band around them to achieve a better fit. Others did not like the feeling of condoms mainly because, *"sweets cannot be eaten in wrappers."*

Masturbation was also mentioned in one FGD as a strategy to avoid sexual activity with a partner, however, this was not acceptable to most of the participants.

http://mc.manuscriptcentral.com/ac-phm-vcy
For Peer Review Only

Health care providers' perceptions on SRH-related needs of YPLH

HCP stressed that issues relating to SRH needs of YPLH were complex. Their views were similar to the adolescents' perceptions with a few remarkable differences. For instance, adolescents did not bring up the role of peer counseling which HCP thought was vital. While adolescents rarely mentioned the issue of sexual exploitation by caregivers, HCP said that many YPLH were vulnerable in that respect. HCP stressed that SRH of YPLH had to be tackled from various angles including caregivers, religious leaders, teachers and health staff using a coherent approach. They also emphasized the need for specific tools to identify sexual risk behavior, and to counsel them accordingly. HCP suggested that they needed proper training on SRH issues to better meet the needs of their young clients.

Discussion

While the results of this qualitative study are not representative for the general population of YPLH, their theoretical generalizability is valuable, i.e. their contribution to theory-building in intervention research. Our results confirm the dimensions of the IMB-model revealing some of the factors that influence protective behavior among YPLH. Study results may also be limited in that we assessed perceptions of a clinical sample, and voluntary participants may have been more educated than other YPLH, for instance those who are not on treatment. The perceptions of YPLH were corroborated by the results of the FGD with service providers, which allowed for integrating a broad range of services in the field.

For Peer Review Only

The knowledge gaps concerning SRH and transmission of HIV among YPLH were remarkable, even among the post-adolescents. YPLH are a diverse group including long term survivors of MTCT or HIV positive youths infected during adolescence due to unprotected sex. This group is heterogeneous with respect to a variety of factors: being in or out of school, being orphaned, being under different care arrangements, having different experiences with sexual activity (ANECCA, 2006). Our findings concerning the onset and the level of sexual activity was not surprising as the Uganda HIV/AIDS sero-behavioral survey 2004/05 showed that 14% of female and male respondents reported their first sex below the age of 15 years (MOH, 2006).

Adolescents' motivation for protection was identified on a continuum between hope and fear. However, the latter seemed to be more prevalent in al age groups. Adolescents' fears relating to SRH and sexuality in general where omnipresent, relating from realistic fears of unwanted consequences of unprotected sex (such as unintended pregnancy) to general taboos and shame tied to sexuality. Some of the misconceptions pointed to developmentally inappropriate magical thinking (e.g. the idea that *"an adult would remove sperm from a sexual partner after sex"*), which may also be interpreted as a sign of immature cognitive functioning.

Pregnancy was the most feared consequence across all age groups, and was more prevalent among girls than among boys. This is similar to uninfected adolescents (Bankole et al., 2004; IPPF, 2005; Kirby et al., 1991; WHO, 2006), and reasonable given the higher chance to get pregnant than to transmit HIV at one single unprotected intercourse (Dryfoos, 1990; Varghese et al., 2002). This finding calls for the need to address all unwanted consequences of sexual activity in a broad

http://mc.manuscriptcentral.com/ac-phm-vcy
For Peer Review Only

context of SRH. In addition, public health messages that are mainly fear evoking have been shown to be less effective (Johnson, 2002), which is another reason for addressing the SRH-related needs in a positive manner.

Because of the fear of re-infection with HIV, many of the adolescents preferred HIV negative partners, which may constitute an unintended effect of prevention prioritizing the risk of HIV re-infection (Sengh, 2006).

Our data show that procreation and safe motherhood were major desires of YPLH, thus the concept of triple protection (Brady, 2003) as a public health message may be of benefit in this target group. At the same time, adolescents need to be protected from adverse consequences of early parenthood, which makes dual protection crucial for any targeted interventions (Harvey et al., 2004; Hawken et al., 2002).

While we could not elaborate on the many gender-differences prevalent in the FGD given the limited length of this analysis, they certainly have to be taken into consideration when tailoring specific interventions for YPLH (Schoeberlein et al. 1999; Wingood et al., 2004).

This study took place in a public health context favoring the ABC prevention approach (**A**bstinence - **B**eing faithful - **C**ondom use) (Cohen, 2003). We found strong age differences in the way how YPLH accepted abstinence-only messages. This is a very relevant finding from a policy point of view, and congruent with findings by intervention research (Jemmott et al., 1998). While recent research has shown that abstinence only approaches are of limited efficacy (Santelli et al., 2006), our findings stress that the delay of onset of sexual activity should still be objective of preventive efforts with younger adolescents, even more relevant in the context of coercive sex. Studies have shown that it is difficult to return to abstinence once

http://mc.manuscriptcentral.com/ac-phm-vcy
For Peer Review Only

adolescents have become sexually active (Jemmott et al., 2005), and our data stress that a developmentally appropriate approach to correct and consistent condom-use would be more promising for those already being sexually active (Pedlow & Carey, 2004).

Being confronted at a young age with one's own mortality also shaped the culturally relevant wish to procreate and therefore to become sexually active. Given the complex psychodynamics that may drive such wishes, we can assume that such motivations may be stronger than information targeting the cognitive level. This finding highlights the specific needs of YPLH compared to their uninfected counterparts, and shows that primary prevention initiatives need to be scrutinized carefully for their potential transferability to this target group.

Our results show that major socio-economic characteristics shape the factors that constitute barriers to protection behavior to a large extent. This is in line with findings on the overall impact of the HIV/AIDS on affected children, adolescent, and family systems (Sengenedo & Nambi, 1997; Stein et al., 2003). Children who were orphaned, or had experienced poverty and stigma came were put at risk of exchanging sex for money. Protecting themselves and others became less likely in such a context, which made them vulnerable even when having access to correct information.

In the light of tailored interventions to be developed on the grounds of these findings, it is encouraging that the HCP participating in the FGD agreed that children need to be told early, i.e. before adolescence about sexuality and prevention. HCP stressed that YPLH need to be given correct, consistent, and

For Peer Review Only

developmentally appropriate information. Caregivers need to be involved, trained and encouraged to be open and to demystify sex. In addition, for any success of targeted SRH interventions, the underlying socio-economic issues should be addressed on a structural level to reduce adolescents' vulnerability.

Acknowledgements

We wish to acknowledge the individual anonymous donor from Antwerp, Belgium, for the financial contribution to this study. We would like to expand our special thanks to the Finance and Administrative Department of the Infectious Disease Institute for their support, and the research assistants who worked so tirelessly, in particular Mr. Fred Sebuuma, Ms.Cissy Ssuuna, Mr.Caleb Twijukye, Ms.Esther Kangavve, and Mr. Julian Nkuraija, and Mrs.Stella.B.Ssali for data transcription. Last but not least, all the adolescents who participated enthusiastically in this study.

For Peer Review Only

References

ANECCA, African Network for the Care of Children Affected by AIDS (2006). *Handbook on Pædiatric AIDS in Africa.* Revised version. USAID. Accessed at: http://www.fhi.org/en/HIVAIDS/pub/guide/mans1.htm.

Adeokun, L., Mantell, J.E., Weiss, E., Ebun Delan, G., Jagha, T., Olaturegun, J., Udo, D., Akinso, S. & Weiss, E. (2003). Promoting dual protection in family planning clinics in Ibadan, Nigeria. *International Family Planning Perspectives, 28* (2): 87-95.

Anderson, J.E., Santell, J. & Gilbert, B.C. (2003). Adolescent dual use of condoms and hormonal contraception: trends and correlates 1991 – 2001. *Sexually Transmitted Diseases, 30*(9): 719-722.

Bankole, A., Singh, S., Woog, V. & Wulf, D. (2004). Risk and protection: Youth and HIV/AIDS in Sub Saharan Africa. The Alan Guttmacher Institute, New York. Accessed at: http://www.guttmacher.org/pubs/riskandprotection.pdf.

Barbour, R., & Kitzinger, J. (1999). *Developing focus group research. Politics, theory, and practice.* London: Sage

Bearinger, L.H., Sieving, R.E., Ferguson, J., & Sharma, V. (2007). Global Perspectives on the sexual and reproductive health of adolescents: patterns,

For Peer Review Only

prevention, and potential. *The Lancet, 369*, 1220-31. DOI: 10.1016/S1040-6736 (07)60367-5.

Berer, M. (1997). Dual protection: making sex safer for women. In: T. K.S. Ravindran, M. Berer, J. Cottingham (Eds), *Beyond Acceptability: Users' Perspectives on Contraception*(pp. 109-21). London: Reproductive Health Matters for World Health Organization.

Berer, M. (2006). Dual protection: more needed than practised or understood. *Reproductive Health Matters*, 14(28):162–70.

Boonstra, H. (2006). Meeting the Sexual and reproductive health needs of people living with HIV. *Guttmacher Policy Brief* , nr. 6. The Guttmacher Institute, Accessed at: http://www.guttmacher.org/pubs/IB_HIV.html.

Brady, M. (2003). Preventing sexually transmitted infections and unintended pregnancy, and safeguarding fertility: triple protection needs of young women. *Reproductive Health Matters, 11* (22):134-141.

Butler, R.B., Schultz, J.R., Brown, L.K. et al. (2003). Promoting safer sex among HIV-positive youth with haemophilia: theory, intervention, and outcome. *Haemophilia, 9*(2):214-222.

For Peer Review Only

Cates, W. & Steiner, M.J. (2002). Dual protection against unintended pregnancy and sexually transmitted infections: what is the best contraceptive approach? *Sexually Transmitted Diseases*, *29*(3):168-174.

Charmaz, K. (2006). *Constructing Grounded Theory. A Practical guide through qualitative analysis.* London: Sage.

Cohen, S.A. (2003). Beyond Slogans: Lessons From Uganda's Experience With ABC and HIV/AIDS. *The Guttmacher Report on Public Policy, 6* (5); accessed at: http://www.guttmacher.org/pubs/tgr/06/5/gr060501.html.

Crosby, R.A., Di Clemente, R., Wingood, G.M., Sionean, C., Cobb, B., Harrington, K., Davies, S.L., Hook, E.W. & Oh, M.K. (2001). Correlates and dual method use for sexually transmitted diseases and pregnancy prevention among high-risk african-american female teens. *Journal of Adolescent Health*, *28*(5):410-414.

Dryfoos, J.G. (1990). *Adolescents at risk: prevalence and prevention*. Oxford University Press, London.

Elkavich, A., Rotheram-Borus, M.J., Goldstein, R. et al. (2006). Young People living with HIV. In: S.C. Kalichman (Ed.): *Positive Prevention. Reducing HIV transmissions among people living with HIV/AIDS.* (pp. 163-92). Kluwer Academic/Plenum Publishers, New York.

For Peer Review Only

Fisher, J.D. & Fisher, W.A. (2000). Theoretical approaches to individual-level change in HIV risk behaviour. In: J.L. Peterson & R. DiClemente (Eds.). *HIV prevention handbook* (pp. 3 -55). New York, Kluwer Academic.

Fisher, J.D., Cornman, D., Osborn, C.Y., Rive Amico, K., Fisher, A. & Friedland, G.A. (2004). Clinician-initiated HIV risk reduction intervention for HIV positive persons. Formative research, acceptability, and fidelity of the OPTIONS project. *Journal of Acquired Immune Deficiency Syndrome, 37* (S2): S78-87.

Futterman, D., Chabon, B. & Hoffman, N. (2000). Adolescents and HIV Infection. *Pediatric Clinics of North America.* M. Rogers, (Ed.), 47:171-88.

Harvey, S.M., Henderson, J.T. & Branch, M.R. (2004). Protecting against both pregnancy and disease: predictors of dual method use among a sample of women. *Women Health*, *39*(1):25-34

Glaser, B. & Strauss, A. (1967). *The discovery of grunded theory: strategies for qualitative research.* Chicago: De Gruyther.

Hawken, M.P., Melis, R.D., Ngombo, D.T., Mandaliya, K.N., Ng'ang'a, L.W., Price, J., Dallabatta, G., & Temmerman, M. (2002). Opportunity for prevention of HIV and sexually transmitted diseases in Kenyan youth: results of a population based survey. *Journal of Acquired Immune Deficiency Syndrome*, *31*(5):529-525

For Peer Review Only

International Planned Parenthood Federation (2005). Gender, Youth, and AIDS. Azerbaijan, 7-10 February 2005. EGM/BPFA-MD-MDG/2005/EP.4. Accessed at: http://www.un.org/womenwatch/daw/egm/bpfamd2005/experts-papers/EGM-BPFA-MD-MDG-2005-EP.4.pdf.

Jemmott, J.B., Jemmott, L.S. & Fong, GT. (1998). Abstinence and safer sex HIV risk reduction interventions for African American adolescents: a randomized controlled clinical trial. *Journal of the American Medical Association JAMA*, *279* (19):1529-36.

Jemmott, J.B., Jemmott, L.S., Bravermann, P.K. & Fong, G.T. (2005). HIV/STD risk reduction intervention for African American and Latino adolescent girls at an adolescent medicine clinic: a randomized controlled trial. *Archives of Pediatric and Adolescent Medicine, 159*(5):440-9.

Johnson, B.B. (2002). Risk Communication: A Mental Models Approach. *Risk Analysis* 22 (4), 813–814. doi:10.1111/0272-4332.0007.1

Kirby, D., Barth, R.P., Leland, N. & Fetro, J.V. (1991). Reducing the Risk: Impact of a new curriculum on sexual risk-taking. *Family Planning Perspectives*, *23* (6):253-263. doi:10.2307/2135776.

For Peer Review Only

Kleinschmidt, I., Maggwa, B., Smit, J, Beksinska, M.E. & Ree, H. (2003). Dual protection in sexually active women. *South African Medical Journal, 93*(11):845-847.

Levine, A.B., Aaron, E. & Foster, J. (2006). Pregnancy in perinatally HIV-infected adolescents. Clinical observation. *Journal of Adolescent Health*, *3*8:765-68.

Lightfoot, M., Rotherham-Borus, M.J. & Tevendale, H. (2007). An HIV-preventive intervention for Youth Living with HIV. *Behavior Modification, 31*(3):345-363. DOI: 10.1177/0145445506293787

Lyon, M.E., Trexler, C., Akpan-Townsend, C. et al. (2003). A family-group approach to increasing adherence to therapy in HIV-infected youths: results of a pilot project. *AIDS Patient Care and STDs*, *17*(6):299-308.

Mantell, J.E., Hoffman, S., Exner, T., Stein, Z.A., Atkins, K (2003). Family planning providers' perspectives on dual protection. *Perspectives on Sexual and Reproductive Health,* 35(2):71-78.

Mellins, C.A., Smith, R., O' Driscoll, P. et al. (2003). High rates of behavioural problems in perinatally infected children are not linked to HIV disease. *Pediatrics*, 111:384-93.

For Peer Review Only

Ministry of Health (MOH), Uganda & ORC Macro. (2006). *Uganda HIV/AIDS Sero-behavioural Survey 2004-2005.* Calverton, Maryland, USA: Ministry of Health and ORC Macro.

Morgan, D.L. & Kruger, R.A. (1998). *The focus group tool kit.* Thousand Oaks, CA: Sage.

Pedlow, C.T. & Carey, M.P. (2004). Developmentally appropriate sexual risk reduction intervention for adolescents: Rationale, review of interventions, and recommendations for research and practice. *Annuals of Behavioral Medicine, 27*(3):172-184.

Rice, E., Batterham, P. & Rotherham-Borus, M.J. (2006). Unprotected Sex Among Youth Living with HIV Before and After the Advent Of Highly Active Antiretroviral Therapy. *Perspectives on Sexual and Reproductive Health, 38*(3), 162–167. doi:10.1363/3816206.

Rotheram-Borus, M.J., Swendeman, D., Comulada, W., Scott, M.S., Weiss, R.E. Lee, M. & Lightfoot, M. (2004). Prevention for Substance-Using HIV-Positive Young People: Telephone and In-Person Delivery. *Journal of Acquired Immune Deficiency Syndromes. 37*, Suppl; 2:S68-S77.

Santelli, J., Ott, M., Lyon, M., Rogers, J., Summers, D. & Schleifer, R. (2006). Abstinence and abstinence-only education: A review of U.S. policies and programs. *Journal of Adolescent Health*, *38* (1): 72-81.

For Peer Review Only

Schoeberlein, D.R., Blezer, M.E. & Woolston, J.L. (1999). HIV-prevention for teenage girls: relationships are the medium and the message. *AIDS Reader, 9*(2):113-121.

Seng, R. (2006). Sexual behaviour at risk for HIV superinfection and HIV-RNA levels progression in women followed in the SEROCO and PRIMO cohorts. Thirteenth Conference on Retroviruses and Opportunistic Infections, Denver, abstract 731.

Sengendo, J. & Nambi, J. (1997). The psychological effect of orphanhood: a study of orphans in Rakai district. *Health transition review*, *7*: S105-S24.

Strauss, A. & Corbin J. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Stein, J. (2003). Sorrow makes children of us all: A literature review on the psychosocial impact of HIV/AIDS on children. *Working paper no. 47;* Centre for social science research, University of Cape Town.

UNDP/UNFPA/WHO/World Bank Special Program of Research and Development and Research Training in Human Reproduction. (2002). HIV/AIDS makes dual protection a must. *Progress in Reproductive Health Research*, *59.* Accessed at: http://www.who.int/reproductivehealth/hrp/progress/59/news59.html.

For Peer Review Only

WHO/UNAIDS/UNFPA/UNODC (2004). YouthNet. Protecting Young People from HIV and AIDS: the role of health services. Geneva: World Health Organization.

UNAIDS/WHO (2006). AIDS epidemic Update 2006. Special report on HIV/AIDS. December 2006. Geneva. Accessed at: http://www.unaids.org/en/HIV_data/epi2006/.

Varghese, B., Mahler, J., Julie, E., Peterman, T., Thomas, A., Branson, B. & Steketee, R. (2002). Reducing the Risk of Sexual HIV Transmission: Quantifying the Per-Act Risk for HIV on the Basis of Choice of Partner, Sex Act, and Condom Use. *Sexually Transmitted Diseases, 29*(1):38-43.

Wingood, G.M., DiClemente, R.J., Mikhail, I., Lang, D.L., McCree, D.H., Davies, S.L., Hardin, J.W., Hook, E.W. & Saag, M. (2004). A randomized controlled trial to reduce HIV transmission and sexually transmitted diseases among women living with HIV: the WILLOW program. *Journal of Acquired Immune Deficiency Syndrome*, *37*(S2):S58-67.

For Peer Review Only