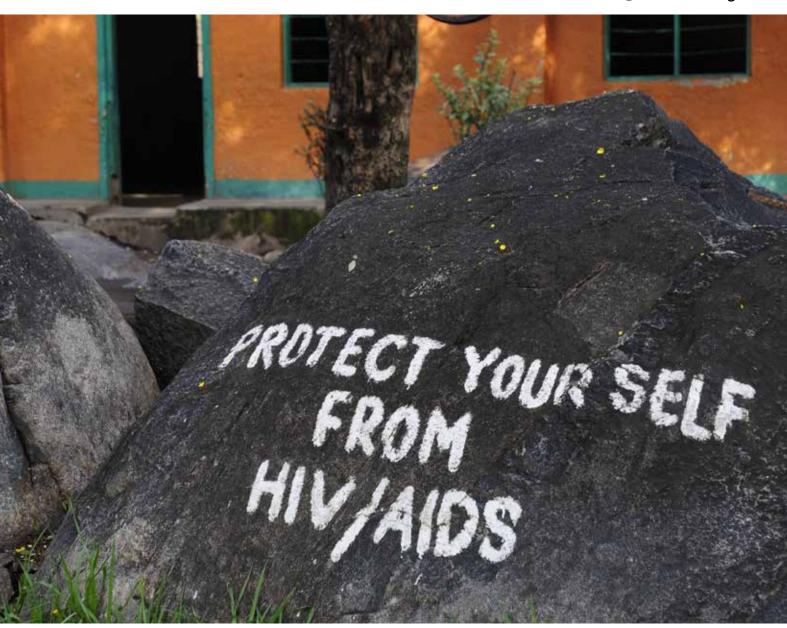


"YOU HAVE TO FEEL THAT BODY TOUCH"

ADOLESCENTS' PERCEPTION OF AND ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH AND HIV CARE IN KASESE, UGANDA

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Carrying out this study on adolescents' perception of sexual and reproductive health in Kasese municipality was an enormous experience for me. I was able to learn from the respondents in their social environment, which helped me to better understand adolescents' daily realities in relation to their health and sexuality.

I would like to thank all the people in Kasese who worked with me and talked to me to make this study possible and turn it into a constructive process. It was an enriching and touching experience to listen and learn from them. I would especially like to thank them for the openness with which they shared their personal experience in the realm of sexual and reproductive health. Personal life stories and stigmatisation, treatment experiences, their own sexual behaviour and that of their peers were all marked by their personal fears of and worries about getting infected with HIV.

A researcher cannot give immediate assistance but I hope that the information I gathered and the conclusions I have drawn will enable us to strengthen our interventions in order to create a successful dialogue with the adolescents, caregivers, families and health staff to improve access to comprehensive sexual and reproductive health and HIV care for adolescents in Kasese municipality.

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My experiences with MSF, my colleagues and the people of Kasese are precious to me; they have all my respect for their ability to cope with their difficult living conditions.

To all those who may continue to work in Uganda.

Cover picture: Messages painted on stones in a school yard in Kasese; ©Doris Burtscher/MSF.

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Executive summary

INTRODUCTION

This report provides an analysis of the perception of adolescents in Kasese municipality regarding their sexual and reproductive health. The data speaks of the socio-cultural dimension of everyday life of adolescents around Kasese town and explains the basic necessity for not only adolescent-friendly healthcare services but also for an intervention that helps adolescents reflect on the consequences of their risky sexual behaviour by promoting responsible sexual behaviour and condom use.

In this project in Kasese, MSF-OCP is focusing on reducing mortality and morbidity due to HIV and TB in the Kasese fishing communities/villages and adolescents' sexual and reproductive health and HIV care in Kasese town.

In a national assessment of HIV care in Uganda in late 2014, Kasese and Kabalo districts were found to be the most vulnerable in terms of prevention of mother-to-child transmission and paediatric HIV care. The most at risk/vulnerable population groups identified were the fishing communities of Lake George and Lake Edward, the districts' commercial sex workers, border post military personnel, transporters (boda-boda riders, commercial truckers, etc.), adolescents and children. HIV prevalence for the region stands at 8%.

The main objective of this study is to design and implement a methodology for an assessment of health-related behaviours of adolescents in Kasese town, particularly in the field of sexual and reproductive health and HIV.

SPECIFIC STUDY OBJECTIVES

This study set out to analyse and provide insights into the following topics:

- health-seeking behaviour of adolescents;
- risk perception and risk-taking;
- perceived and enhanced stigma;
- beliefs and perceptions related to sexual and reproductive health and HIV/AIDS;
- what messages and ways could be appropriate for raising awareness and enhancing attendance at the Kasese Adolescent-Friendly Centre;
- what adolescents would define as an adolescent-friendly centre: services, level of confidentiality,
 etc.:
- coaching of the community mobilisation officer on health promotion strategies, community mobilisation and general responsibilities.

METHODS

This qualitative study was conducted in Kasese municipality between November 3rd and December 2nd 2015. The primary target group were adolescents. In addition to adolescents – male and female, in- and out-of-school – peer supporters, commercial sex workers, *boda-boda* drivers, caretakers, coordinators of other NGOs working with adolescents and children and a few healthcare providers were interviewed. Data was collected through non-participant observation, field notes, and in-depth interviews guided by topic-led questions. Respondents were purposively selected with the help of MSF team members. Transcriptions were screened for relevant information, organised, coded, categorised and interpreted. Methodological triangulation was applied; individual in-depth interviews (37) were combined with group discussions (23), non-participant observations, document review and analysis of deviant cases.

FINDINGS

Awareness and knowledge about HIV/AIDS were quite good. In general, they depend on the level of education, however, and therefore differ among in- and out-of-school adolescents. Modes of transmission and prevention are quite well known among the youth of Kasese, even if their knowledge can be incomplete or theoretical and does not always translate into safe sex practices. Knowledge and perception about HIV/AIDS still tend to revolve around the ideas that HIV/AIDS kills and has no cure. The fact that people have started to refer to HIV/AIDS as 'OUR DISEASE' shows how concerned and touched they are by it.

Young people were clearly identified as the most-at-risk group, by themselves and by others. They are sexually active and often do not feel comfortable using condoms or have misconceptions about the consequences of condom use. Other identified most-at-risk groups were commercial sex workers because they have many different sexual partners and engage in unprotected sex, young men because they have multiple girlfriends and need 'live sex' and the so-called 'bad peer groups'.

The most vulnerable group are adolescent *girls*. Negligence and abandonment by their families and financial deprivations force them into a vicious circle of engaging in risky sexual relationships such as unprotected transactional and survival sex with multiple partners. Furthermore, gender inequalities lead to girls having little power in negotiating condom use.

HIV/AIDS is maybe the most stigmatised ill-health condition apart from TB. Stigma is prevalent on different levels and adolescents experience stigmatisation in most of their everyday environments. Stigma negatively influences the take-up of services like ARV treatment. The same stigmatisation is experienced by pregnant adolescents, which keeps them from seeking antenatal care.

Access to appropriate adolescent-friendly healthcare does currently not exist in Kasese. The HIV counselling and testing and antenatal care services in the health centres and hospitals have not been valued appropriate for adolescents because of a lack of confidentiality and an unfriendly reception. Adolescents expressed the wish and need for more information to be able to better deal with their health, particularly regarding sexual and reproductive health and HIV care.

Condoms are not used effectively and consistently enough. The barriers to condom use range from risky behaviour, multiple sexual relationships, certain perceptions and attitudes, (lack of) availability of and personal experience with condoms, to power relations and economic factors. From their environment, adolescents primarily receive the message that abstinence is the best method of HIV/AIDS and early pregnancy prevention and other ways of risk prevention receive less attention.

Adolescents wish to use testing services at the adolescent-friendly centre of MoH/MSF as they see the centre as a convenient place in terms of privacy. They want to be tested by medical professionals and get counselling from trained, older people and not from their adolescent peers.

KEY RECOMMENDATIONS

The recommendations are categorised and presented according to the study objectives. They are to be understood as general recommendations to achieve adolescent-friendly services, i.e. they are addressed to MSF and the Ministry of Health in Kasese.

General recommendations

- → Do not separate boys and girls but divide adolescents into age groups for information sessions.
- → Provide recreational activities like handicraft, tailoring and hairdressing for girls, and football, netball, watching movies, listening to music, dancing classes for all adolescents.

Educational and informational material at the Kasese Adolescent-Friendly Centre

Provide educational and informational material for girls and boys covering the male and female body, menstruation, conception, sexual intercourse, pregnancy, the baby in the womb (pictures), childbirth, ANC, breastfeeding, etc.

Discussing sexual and reproductive health and topics related to HIV/AIDS and abortion

- → For younger adolescents (age 10-13 or even up to age 15), the 'Auntie Stella' tools can be used; Certain subjects within the tool are also suitable for older adolescents:

 http://www.tarsc.org/auntiestella/index.php/site/frame/activity/topics/
 Other useful tools can be found through this Dropbox link:

 https://www.dropbox.com/s/k3hr610z3dtoouh/tools%20for%20sexuality%20education.zip?dl=0)
- → Provide a special room at the Kasese Adolescent-Friendly Centre where adolescents can come to address any problems, challenges or questions they might have and get advice in a confidential and youth-friendly atmosphere.

HIV testing and counselling

- → Select well-trained counsellors from an older age group (above 25), as adolescents prefer to be advised by persons who are educated and trained on health-related issues.
- Make sure that the counsellors respect confidentiality and have an adolescent-friendly attitude,
 - showing empathy;
 - understanding adolescents' problems;
 - being open, non-judgmental, respectful and authentic;
 - recognising individual differences, etc.
- → Have peer educators and counsellors in addition to the trained, older counsellors.

Family planning – contraceptives

→ Design and implement an advocacy strategy addressed to the MoH to promote family planning for adolescent girls at least from the age of 14 onwards.

Activities in the communities

- Involve the community to identify ways of linking adolescents to the Kasese Adolescent-Friendly Centre as the community knows best about the adolescents' healthcare needs and preferences.
- → Organise information sessions on different topics in the different areas ('villages') of Kasese town. Address the subject of how parents can protect their children and contribute to risk reduction by creating a supportive and positive environment.

Parents/teachers

→ Organise workshops on adolescents' sexual and reproductive health, needs and vulnerabilities, gender inequalities, etc. with parents and schoolteachers in their role as guardians for the adolescents in schools. Engage them in dialogue activities and together develop ideas how they can best support adolescents.

Boda-boda riders and other transporters

→ Sensitise boda-boda riders about the consequences of their behaviour for young girls. Instead of 'teaching' them how to behave, discuss WITH them about what 'we' (they and MSF) could do. A dialogue workshop would be most suitable to develop activities and messages together.

Sexual and gender-based violence

→ Provide mental health support for adolescents who have been raped or have experienced other forms of abuse and sexual and gender-based violence.

Condom use

- → Offer separate information and training on condom use for boys and girls at the Kasese Adolescent-Friendly Centre.
- → Train adolescent girls on condom negotiation skills.

Acronyms

AIS AIDS Indicator Survey

ALWHA Adolescents living with HIV/AIDS

ANC Antenatal Care

ART Antiretroviral Therapy

ARV Antiretroviral

CSW Commercial Sex Workers

DRC Democratic Republic of the Congo

eMTCT Elimination of Mother-to-Child Transmission (of HIV)

GD Group Discussion

HC Health Centre

HCT HIV Counselling and Testing

IPD Inpatient Department

LC Local Council

MARPs Most-At-Risk Populations

MO Medical Officer

MoH Ministry of Health

MoT Modes of Transmission

MTCT Mother-to-Child Transmission

NSP Uganda National HIV/AIDS Strategic Plan

PLHIV People living with HIV

PLWHA People living with HIV/AIDS

PMTCT Prevention of Mother-to-Child Transmission

SRH Sexual and Reproductive Health

STI Sexually Transmitted Infections

TBA Traditional Birth Attendants

USH Ugandan Shillings

VHT Village Health Team

WHO World Health Organization

1 Introduction

1.1 Brief description of the background

Uganda achieved remarkable progress in the control of HIV since the 1990s, bringing down HIV prevalence among adults aged 15-49 from a national average of 18.5% in 1992 to 7.3% in the 2011 AIDS Indicator Survey. The number of individuals accessing Antiretroviral Therapy (ART) based on the 2010 WHO treatment guidelines increased from 329,060 in 2011 to 569,298 by September 2013. There has been a decline in AIDS-related deaths between 2011 and 2013; from 72,928 in 2011, to 70,262 in 2012 and 61,298 in 2013. The life expectancy of 55 years in 2012 is nine years higher than life expectancy in 2000, which is likely to be a result of greater access to treatment for people living with HIV. An estimated 94% of pregnant women who attended antenatal clinics received counselling and testing for HIV in 2011.

However, several studies conducted in the country have shown high prevalence among the most-at-risk populations (MARPs): 37.1% in the fishing communities (MoH 2012, Kalangala district – 6 sampled landing sides) and 35.7% among sex workers in Kampala (Kampala, 2012 MARPs Network study). Moreover, adolescents – especially females – have historically constituted a large proportion of incident HIV cases in Uganda.

In line with the Uganda National HIV/AIDS Strategic Plan (NSP) 2011/12-2014/15, which defines several population groups that are important in the national AIDS response, more efforts still have to be made because of a combination of high HIV prevalence and extensive sexual networks.

Test kits and condoms can be difficult to obtain in several areas of the country; meanwhile it is estimated that one-third of women and half of men with HIV are not aware of their status. In addition, there are signs of an increase in risky sexual behaviours, and recent evidence indicates a significant increase in the number of sexual partners in Uganda, as well as a decline in condom use. While 71.7% of HIV positive mothers received ARV drugs for Elimination of Mother-to-Child Transmission (eMTCT), only 36.7% of the exposed infants received ARV drugs for eMTCT.

Since 2002, MSF teams have been supporting the MoH in the treatment and care of people affected with HIV and TB through a programme based at the Arua regional referral hospital. Most of the medical activities have been handed over to local authorities and their partner SUSTAIN in July 2014, while MSF is maintaining a laboratory activity (access to Point of Care viral load and early infant diagnosis) as well as a support for access to 3rd line regimes.

MSF is willing to continue supporting the Ugandan Ministry of Health (MoH) in the field of HIV care and treatment, particularly for the MARPs. Epicentre carried out a review of Ugandan national indicators in order to identify the challenges regarding HIV/AIDS care. The results of this evaluation indicated that Kasese district was one of the districts facing the biggest challenges in regard to HIV, leading to a 6-week assessment on-site between November 2014 and January 2015.⁶

¹ 2013 Uganda HIV/AIDS Country Progress Report, Uganda Aids Commission

² UNAIDS Global report 2012

³ Uganda: UNGASS country progress report (2012)

⁴ MSF international activity report 2013

⁵ 2013 Uganda HIV/AIDS Country Progress Report, Uganda Aids Commission

⁶ Please refer to the MSF assessment report.

1.2 Kasese district

1.2.1 General context

Kasese district is located in mid-western Uganda along the Equator and borders on the Democratic Republic of the Congo (DRC) in the west. The district has a total land area of 2,724 m², of which 885 m² are reserved for the Queen Elizabeth National Park and 652 m² for the Rwenzori Mountains National Park, leaving 1,187 m² for human habitation and economic utilisation. The district population was estimated to amount to 702,029 inhabitants in the national census of 2014.

Kasese district is prone to disasters, mainly floods and landslides, which hinder access to health facilities. In two consecutive years (May 2013 and May 2014), three rivers in Kasese district burst their banks leading to massive flooding and many displaced families in two main areas of the district: Kilembe and Kyarumba. In Kilembe, properties were destroyed as well as part of the hospital. In Kyarumba, the main bridge was washed away, making access to Kyarumba Health Centre (HC) III very difficult.

1.2.2 Background of HIV in Uganda

While Uganda has been cited as a good example of HIV/AIDS management, showing a significant reduction of the burden of the disease in the past years with large increases in the number of people being tested and treated for the virus, the number of people in Uganda living with HIV has continued to grow⁷. This is a result of the continued spread of HIV and the increased longevity among people living with HIV.

The 2011 Ugandan AIDS Indicator Survey (UAIS) reported that 7.3% of Ugandan adults aged 15-49 tested HIV positive. HIV prevalence was higher for women than men; overall, 8.3% of women have HIV compared with 6.1% of men. For both sexes, HIV infection levels are highest among people in their thirties and forties, and lowest in the 15-19 years age group (3.0% among women and 1.7% among men). Prevalence of HIV in both women and men increases with age until it reaches a peak, which for women is at age 35-39 (12.1%) and for men at age 40-44 (11.3%).

The Monitoring and Evaluation of the Emergency Plan Progress (MEEPP) reports an HIV prevalence of 8.2% for the mid-western region. District prevalence was calculated according to the different district antenatal care prevalence; prevalence for the three districts around Lake Edward and Lake George are reported to be 6.5%, 7.1% and 14.8% for Kasese, Kamwenge and Rubirizi districts, respectively.

1.2.3 Key drivers of HIV prevalence

The main drivers of HIV incidence in Uganda, as documented by Modes of Transmission (MoT) and other studies, are:

- level of knowledge and understanding of HIV, especially how it is related to the perceived personal risk of HIV infection, and its influence on negative and stigmatising attitudes towards people living with HIV (PLHIV);
- knowledge of one's HIV status, as established through HIV Counselling and Testing (HCT), and the associated willingness for mutual disclosure of the status between sexual partners;
- risky sexual behaviour including adolescent sex, multiple and concurrent sexual relationships, transactional and cross-generational sex and unprotected sex;
- level of male circumcision;
- alcohol consumption especially to the level of getting drunk, and closely associated with sexual activity⁸.

⁷ HIV/AIDS Uganda Country Progress Report, 2013

⁸ idem.

1.2.4 Adolescents' access to HIV testing care and treatment

An assessment of adolescents' access to HIV testing, care and treatment services was conducted in 1,020 facilities in 2013. The assessment revealed high acceptability for HIV testing among adolescents who enter HCT services, with 2.5% of those tested reported as HIV positive (similar to the 2.4% reported in the 2011 Aids Indicator Survey (ADIS) among 15-19 year old adolescents). Although there was good linkage to care among adolescents who test HIV positive (at 88%); only 17% of adolescent estimated to be living with HIV are currently in care, and just 29% of the estimated ART-eligible adolescents are receiving ART. Access to cotrimoxazole was good among adolescent (at 80%); but only 48% had accessed CD4 testing. These findings highlight the need to further strengthen HIV services for HIV positive adolescents.⁹

1.3 Rationale for the study

After a national assessment of HIV care in Uganda in late 2014, Kasese and Kabalo districts were found to be the most vulnerable in terms of Prevention of Mother-to-Child Transmission (PMTCT) and paediatric HIV care. The most at risk/vulnerable population groups identified were the fishing communities of Lake George and Lake Edward, the districts' commercial sex workers (CSW), border post military personnel, transporters (*boda-boda* riders, commercial truckers, etc.), adolescents and children. HIV prevalence for the region stands at 8%.

MSF proposed a community mobilisation programme with the primary objective of improving access to healthcare for the vulnerable populations of Kasese and the surrounding districts through the implementation of medical activities in Kasese municipality.

This anthropological study provides support for the community mobilisation programme laid out to improve access to comprehensive sexual and reproductive health (SRH) and HIV care for adolescents (10-19 y) in the municipality of Kasese.

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⁹ HIV/AIDS Uganda Country Progress Report, 2013

2 Objectives of the study

2.1 General objective

The aim of this qualitative study is to explore the experiences of adolescents accessing healthcare services and their perception of sexual and reproductive health.

The main objective is to design and implement a methodology for an assessment of health-related behaviours of adolescents in Kasese town, particularly in the field of SRH and HIV.

2.2 Specific objectives

This study set out to analyse and provide insights into the following topics:

- health-seeking behaviour of adolescents;
- risk perception and risk-taking;
- perceived and enhanced stigma;
- beliefs and perceptions related to sexual and reproductive health and HIV/AIDS;
- what messages and ways could be appropriate for raising awareness and enhancing attendance at the Kasese Adolescent-Friendly Centre (KAC);
- what adolescents would define as an adolescent-friendly centre: services, level of confidentiality, etc.;
- coaching of the community mobilisation officer on health promotion strategies, community mobilisation and general responsibilities.

3 Methods

3.1 Study setting and population

This qualitative study was conducted in Kasese municipality between November 3rd and December 2nd 2015.¹⁰ The primary audience were adolescents. Participants were identified with the help of a counsellor and a clinical officer from the health centre III in Kasese. At a later stage, the male translator engaged in identifying interview respondents from different schools and out-of-school youth. In addition to the adolescents – male and female, in and out of school – peer supporters, commercial sex workers, *boda-boda* drivers¹¹, caretakers, coordinators of other NGOs working with adolescents and children and a few healthcare providers were interviewed. As some areas in Kasese were identified as risky communities, we also carried out interviews in these communities, i.e. in Kilembe Mines, Railway and Kikonzo Village, Nyakazanga and Acholi Quarters, all located in the municipality of Kasese. One visit was done to the landing sites in Katwe, where four interviews were conducted.

3.2 Study design

This qualitative study is based on in-depth interviews to understand the perceptions and attitudes of adolescents aged 10-19 years related to SRH and HIV care.

This study followed a qualitative research design. Its aim requires an exploratory approach (Pope & Mays, 2006) to understand the knowledge and perceptions of SRH, HIV and access to healthcare services from the perspective of the adolescents in Kasese.

A flexible participatory technique was applied, i.e. the researcher gathered data using non-participant observation, field notes as well as in-depth interviews guided by topic-led questions. The questions were based on themes relevant to the research question and the literature research appraisal. Following standard qualitative interview procedures, the order of questions was driven by the nature of each participant's answers, which means that both the wording and the order of questions were likely to be modified during the interviews.

In addition to the individual interviews, group interviews were conducted with adolescents that felt comfortable to be interviewed together with others. All the interviews in schools were done in groups of 2-4 students, separated by gender in primary school. In secondary schools, two gender-mixed group interviews were conducted. Adolescents on ART were interviewed individually.¹²

A triangulation of findings was undertaken to enhance the interpretation of data. Triangulation enables an accurate representation of reality through the use of multiple methods or perspectives for data collection (Brikci, 2007). For this study, a methodological triangulation was used: in-depth individual interviews were combined with group discussions, non-participant observations and document reviews. Additionally, triangulation of the findings was applied through a validation workshop with some of the original participants and other key informants from Kasese such as government and non-government actors that have adolescent-related programming and/or services.

The qualitative study team consisted of the principal investigator, a medical anthropologist, a male and a female translator and a study assistant for the transcription of the interviews.

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¹⁰ Please refer to the anthropologists' work programme in the Annex.

¹¹ Boda-boda drivers are bicycle taxi riders; 'boda-boda' derives from 'border to border'.

¹² Please refer to the participants' characteristics list in the Annex.

3.3 Study sampling

A purposive sampling technique was applied. The sample size of purposive sampling is determined by the notion of saturation, which implies that the sample size cannot be planned beforehand. Our main target group were adolescents between the ages of 10 and 19 years. Additionally, key informants dealing with adolescents were interviewed. Categories for the choice of participants for the study included: age, sex, level of education, in and out of school, pregnant adolescent girls or teenage mothers.

Table 1: Target groups and respondent characteristics

Respondent characteristics	Total interviewees = 112; n
Adolescents female	38
Adolescents male	47
Healthcare providers female	3
Healthcare providers male	2
Peer supporters female	3
Peer supports male	3
CSW female	2
Street kid coordinator	1
Caretakers female	2
Boda-boda riders male	9
Fish boat owner	1
LC1 male	1

Table 2: Respondent characteristics

Respondent characteristics	Total interviewees = 112; n	
Age		
Adolescents 10-13	20	
Adolescents 14-16	24	
Adolescents 17-19	39	
Other	29	
Gender		
Male	64	
Female	48	
Education		
Educated low	51	
Education middle	48	
Education higher	13	

Table 3: Interview characteristics

Interview type	Total interviews = 60; n	
Individual interview	37	
Group Interview	23	

3.3.1 Interviews

For data collection related to adolescents' sexual and reproductive and HIV care, in-depth individual interviews were conducted. This qualitative method provides an emic perspective of adolescents who are sexually active, of their risk perception, their view of their daily life situation and future perspectives and their access to healthcare. Specific aspects related to the research question were explored through semi-structured interviews. In this case, the researcher followed a topic guide of open-ended questions. These were structured to build trust and rapport, encourage openness and honesty of respondents, with more emotive questions coming later on in the interview. This topic guide was kept flexible to prevent the conversation from taking on a 'vertical' nature. The researcher followed up on the answers and information the interviewees gave.

3.3.2 Participant observation

Observations were carried out as part of the data collection. Participant observation is a crucial qualitative method as it gives account of what people say and what they actually do (Burgess 1984). It is therefore an essential method in combination with interviews.

Participant observation allowed the researcher to learn about details that the participants themselves would not have come up with during the interview. This is the case when interviewees do not consider information worth speaking about or essential for the context. Thus, the strength of this method is that it provides an account of the "mundane and unremarkable features of everyday life" (Green and Thorogood 2004:148). To give an example, at the HC III, the researcher could observe conversations and behaviours among patients, feelings of patients when receiving treatment, communication between patients and healthcare providers, the condition of the health centre, etc. When conducting the conversation in the home of the adolescents, encounters between the young person and his or her guardians gave insight into how they behave with each other. In schools, students' conduct in front of their teachers could be observed.

Nevertheless, in some situations the presence of the interview team influenced the setting and people deviated from their 'normal' practices due to the presence of an 'outsider' who was conducting the study (Burgess 1984). For example, relatives and guardians were showing a friendly attitude towards the students when they saw us, which was sometimes a contrast to what adolescents described in the interviews.

3.4 Data management and analysis

The crucial first step was to fully transcribe all interviews and notes taken during the observations. Data has been stored without any information identifying the respondents and is only accessible to the principal investigator. The two research assistants who transcribed the recorded interviews signed a confidentiality agreement. At the end of the transcription process, all data was deleted from the assistants' computer and was stored only on the principal investigator's computer.

The manual analysis of the interviews was inspired by a qualitative content analysis by Mayring (2010): Transcriptions were screened for relevant information, which was then organised, coded, categorised and interpreted. This implies reducing the material to only those passages that are essential for the work and to generalise the statements. A category (label) was attached to the statements in order to structure the data (Mayring 2010:67f). The content was analysed in two ways: descriptively (describing data without reading anything into it) and interpretively (focusing on what might be meant by the responses) (Hancock 2002:17).

The empirical data was analysed in an inductive and a deductive way. This means that categories/codes were mainly generated on the basis of collected data. However, codes were also developed based on anthropological theory known prior to the research. Anthropological theoretical concepts that may appear as a code could, for example, be treatment-taking behaviour, illness perception, side effects, health-seeking behaviour, etc. (Munro et al:2007).

Continuous reflection on data is part of the creative process of analysis and necessary for contextualising and linking findings with anthropological theory. To follow the principles of good practice, the research process is clearly described in this report; validity of data is therefore ensured by a 'thick' description¹³ of the research context and also by presenting deviant cases.

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¹³ Originating from Geertz (1973), a 'thick' description of human behaviour is one that not only explains the behaviour but also its context, so that the behaviour becomes meaningful to an outsider.

3.5 Study limitations

This short-term study is designed to provide answers to current operational questions. Collected data will not amount to long-term or multi-sited¹⁴ anthropological fieldwork.

One limitation of this study might have been that the study focused mainly on the primary audience, i.e. adolescents. Additional important information could have been gathered from the secondary audience, i.e. parents, teacher, matrons and patrons in boarding schools, religious leaders, etc. Working with adolescents in the surrounding rural areas and comparing findings with those about urban adolescents could have added extra value to this study.

Another limiting element of data collection was the fact that the study team was connected to the MSF network. This bias was tried to be balanced out by carefully explaining the role of the anthropologist and her neutrality and strict assurance of anonymity and confidentiality.

Working with translators and transcribers can also be limiting since the quality of the translation and transcriptions depends very much on the translator's soft and hard skills. This limitation was reduced to a minimum by continuously reflecting on the interviews together with the translators and on the translation itself. Transcripts were read and feedback was given to the transcriber on what to focus on and improve in the transcription.

Finally, qualitative data is not a reflection of reality but always influenced by the presence of the researcher at the field site. In addition, the background of the researcher (gender, age, social status, origin, etc.) will shape the research process. The researcher is well aware of this factor and took a critical stance towards her own position in the data gathering process and during the analysis of the findings.

¹⁴ Multi-sited fieldwork uses a comparative approach and studies phenomena at different sites and time periods.

4 Ethical aspects

No official ethical approval was sought for this study. Nevertheless, essential and crucial ethical issues were taken into consideration.

The in-depth interviews covered several sensitive topics which may prompt negative feelings such as guilt or anxiety in the participants. Therefore, the primary investigator and her team ensured that interview techniques for sensitive subjects were applied and the feelings of interviewees were respected whichever way they appeared. Furthermore, participants were referred to existing counselling and support services if they expressed interest in additional psychosocial support at the end of the interview. They were also informed about the upcoming opening of the adolescent-friendly centre and its services.

It was guaranteed that participants' confidentiality is respected and all data obtained through in-depth interviews were anonymised and stored on password-protected computers without inclusion of personal identifiers such as names.

Verbatim quotations in dissemination materials like this report are referenced with the age-group, sex and category of the participant (e.g. male adolescent, aged 17, or female caregiver, aged 40).

Permission to interview participants under the age of 18 was sought from the caregiver as well as from the adolescents being interviewed. Interviews were tape recorded when permission was granted by the respondent, which was the case in 100% of the conversations. Additionally, the primary investigator took notes after the interview. Informed consent was obtained verbally. Each respondent was assured of the confidentiality and privacy of the interview and informed that s/he is free to stop the interview at any time or refuse to answer any question.

For the group discussions, informed consent was also obtained verbally. The facilitator introduced the aim and objective of the study. Participants were advised that they were free to leave the group at any time and that they could choose their level or participation throughout the session.

5 Major findings

This chapter concentrates on the major findings that will help to answer the following questions: How do adolescents deal with their sexual and reproductive health? What do they think about HIV/AIDS? How do they perceive themselves in regard to an infection? Do or can they protect themselves from an infection and from early pregnancy? How can they access healthcare? How would they view an adolescent-friendly centre and which services would they expect to receive?

Since all the collected information is analysed from the perspective of the adolescents and the people around them, the results will be presented according to these different understandings. The findings are underscored with quotations to give voice to the people interviewed during the field visit.

This study will help to better understand adolescents' SRH and to design and implement an adolescent-friendly centre adapted to the needs of these adolescents. The main question of how to better curb adolescents' risky sexual behaviour is to be answered and translated into appropriate action. In this sense, the study does not only benefit MSF's and the MoH's operations but also encourages discussions at the level of decision-makers' regarding governmental regulations that influence adolescents' health and a healthy future, such as access to information on SRH issues, family planning, safer sex practices, etc.

5.1 Background of HIV/AIDS

HIV/AIDS is a health issue that has attracted much attention and controversy. It has been the deadliest disease of the modern age for many years, but knowledge about and access to treatment have changed peoples' attitudes towards it and AIDS has become a chronic disease.

HIV/AIDS cannot be seen in isolation and as a personal affair of the affected people. The epidemic touches the society as a whole and affects people at every level, in urban and in rural settings, the rich as well as the poor. It is part of people's everyday lives; it changes their lives and influences their actions. The discussions about HIV/AIDS have to take place within the specific socio-cultural, economic and historical context. The adolescents' situation and their coping mechanisms are comprehensible only in their own context. In every society, regardless of where and how the epidemic enters, those who are marginalised, stigmatised and discriminated against are at greatest risk (Whiteside 2008:106).

Uganda has long been the pioneer for prevention and treatment strategies. In the year 2000, the country had achieved a remarkable reduction of infections.¹⁵ In recent years, the infection rates began to increase again which is due to the availability of treatment, the perception of the disease as a chronic disease and the rise of risky sexual behaviour still including poor condom use.¹⁶

The following quotation illustrates how certain adolescents talked about this issue:

"... that person who does not even mind about anything, and this is the situation where you find the girl who says to get pregnant I rather get HIV.

Why is it so that they don't fear HIV?

You find that there are some people who hear AIDS like a story, that it is not real and when you tell that person, he or she says that you are deceiving and they say I will swallow the drugs and finish my twenty years and you probably may die in the accident."¹⁷

¹⁵ Refer to: http://www.aidsuganda.org/images/documents/GARPR.pdf, accessed January 19th 2016

¹⁶ idem.

¹⁷ I 48: male adolescent, 19y, in college

5.2 Knowledge and perception of HIV/AIDS

When the adolescents speak about HIV/AIDS, they speak about SILIM, which is an adaptation of the English word 'slim'. This designation goes back to the early years of the disease when there was no treatment and people observed that HIV positive people got slim in the course of the disease. Other names and descriptions used in different local languages were:

- AKABONDE (Lukonjo) meaning HIV or AIDS; the word was derived from the word 'eribonda' which means 'becoming slim'
- MUKENENYA (Luganda) means slimming and is used for AIDS
- KAMUNYWENGYE (Runyankole) meaning AIDS
- "TO BECOME SMALL"
- "OUR DISEASE"
- "THIS DISEASE OF OURS"

These last two expressions were mentioned in a conversation at the landing sites where the respondent said that SILIM is an old-fashioned term and people would use 'our disease' nowadays.

"They no longer talk about **silimu** that is old fashion we now call it **obulhwere bwetu** (<u>our disease</u>) in lukonjo, they use to mean AIDS. And in luganda they say <u>obulwande bwaffe</u> (our disease). They use this to refer to HIV/AIDS."¹⁸

The respondent explained that people feel concerned and affected in saying that it is their disease. It means also that HIV positive people are not slim anymore because they take treatment.

Up to now, respondents spoke about the signs and symptoms when asked what an HIV positive person looked like or how they could recognise an HIV positive person. It was mentioned that the person gets slim, becomes small, loses weight, gets weak, has diarrhoea, has a dry cough, has a rough skin and skin rushes, etc. When asked about the changes they could see with the treatment, all respondents recognised that you cannot see that a person is HIV positive anymore when they take the drugs. Adolescents talked about these characteristics and would even propose not to provide treatment in order to discourage unprotected sex and to still be able to recognise an infected person.

"The drugs for HIV are ok but on one hand it has contributed a lot in the spread of the disease, because when someone goes out for the woman he has that feeling that tomorrow I will go for the drugs when I am tested positive and get better and when I get better I still go back for more women, so if it would be possible, it [the drugs] should not be manufactured any more. ... if this drug is stopped it would be better; if someone has already acquired that disease and you physically see that really this person is sick, by seeing the way how that person looks even if he comes and asks for that woman she will not accept only because of observing the person physically." ¹⁹

As observed in the interviews, awareness and knowledge about HIV/AIDS was quite good. In general, they depend on the level of education, however, and therefore differ among in- and out-of-school adolescents. For in-school students, they depend on the commitment of the schools, how much they invest into awareness raising activities and how much they encourage students to be active as peers, etc.

Although general knowledge about HIV/AIDS is quite good, many respondents did not differentiate between HIV and AIDS. Only some students from primary and secondary schools that had participated in more awareness raising activities spoke about the virus, its suppression with ARV drugs and transmission through blood, vaginal fluids and sperm. Some out-of-school respondents did not know

¹⁸ I 13: male adult, 53y

 $^{^{19}}$ I 40: male out-of-school, 18y, boda-boda rider

that the virus could also be transmitted through vaginal fluids and sperm; they emphasised that the only way of transmission via sexual intercourse was through blood. A common perception was observed among respondents above the age of 20; they seemed to believe that if a woman is well prepared for sexual intercourse through foreplay etc., she will have produced enough vaginal fluids so that there will not be any friction or blood in the vagina or on the penis, thus avoiding the risk of HIV transmission or infection.

"Someone will tell you that I go to that HIV positive lady, as long as I prepare her, the foreplay and make her so wet, the vagina will not get HIV because I would have not injured her and am circumcised so that virus will get nowhere to hide just in case if it's there. If she is well prepared and she is wet they think it washes out."

Additionally, other modes of transmission such as sharing sharp objects, mother-to-child transmission and unprotected sex with an infected person were mentioned.

The forms of protection the informants talked about reflected the ways of transmission they had named. Interestingly, the most frequently mentioned ways of protection were abstinence, being faithful to one's partner, not sharing sharp objects and avoiding sexual intercourse with an infected person; only very few respondents mentioned the use of a condom. In-school adolescents very well repeated what they have learned in the curriculum or in awareness raising activities, but when they mentioned abstinence and we asked for more details to explain how they would abstain, it became clear that abstinence is only possible for very few, devout individuals. One respondent mentioned that it is practicable for those (girls) from better families, as these girls do not need to engage in transactional sex.

"Someone who abstains is from a good family that gives her everything.

Why would they engage in sexual relationships?

When you ask a young girl from the good family she will tell you my father can give me everything why is it pushing you to men there is one thing which he cannot give, like the father cannot fall in love with the daughter, and having sex.

What includes boy love?

There is sex, words, having fun, hugging, having feeling when you are home you find that you end up having a boyfriend." 20

Adolescent respondents expressed that the church, being religious and a close relationship to a religious leader helps them to abstain. They said they would wait until they get married to start having sexual intercourse with their girlfriends or boyfriends. Churches also encourage that couples go for an HIV test together before getting married. The adolescents who mentioned religion as an important factor in their lives knew their girlfriends or boyfriends from church.

It seems that the *boda-boda* drivers play a major role in transactional relations with young girls. In several group discussions, participants mentioned that saying no to lifts from *boda-boda* drivers was a way of protecting yourself.

"They give them [the girls] free lifts and then ask for sex, so the girls should not accept the free lifts. They are saying that these people who take drugs like marijuana, and they eat these herbals things and when they get disorganized in their brains they get involved in the bad." ²¹

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²⁰ I 35: pregnant girl, 17y, out-of-school

²¹ I 51: GD (group discussion) in-school boys, 13y

5.3 Risk perception and risk-taking

Risk perception of the interviewed adolescents can be viewed as a rather positive characteristic, meaning that they all feel at high risk. All respondents said that they feel jeopardised and are afraid of getting infected with HIV because it is a "deadly disease and it has no cure". Their risk perception was never linked to the idea that they could protect themselves with condoms, etc. hence would not fear infection. However, respondents asserted that they knew that treatment is available but taking the medicine every day and for the rest of their lives would be difficult. Adolescent girls feel an additional risk of getting pregnant. Girls and young women are not able to reduce the risk of an infection as they do not have the power to negotiate condom use. Some girls said that they count their days (menstrual cycle) to prevent pregnancy but that does not prevent an HIV infection.

Young people were clearly considered the most at risk group, by themselves and by others around them: adolescent boys and girls because they are sexually active and often do not feel comfortable using condoms; commercial sex workers because they have many different sexual partners and engage in unprotected sex; young men because they have multiple girlfriends and need 'live sex'; and the so called 'bad peer groups'. Adolescents use the expression 'bad peer groups' to describe people who use alcohol and drugs (marihuana) and to refer to young people who have started sexual relations with 'sugar daddies or mummies' or any other practice of transactional sex.

"Joining bad peer groups like when you have free time you go to discos, bad peer groups like taking alcohol, smoking things that can destroy your quality as human being, and if you do good things people will respect, but don't tell me that when you are taking alcohol people can respect you.

If you go and take alcohol, smoking, people will not like you, me I dislikes in appearing in bad groups, like your friends may deceive you to come, we join them and me I refuse and say these are bad groups am still young.

Me I hate to join bad peer groups e.g. the group which takes alcohol, those who join the boys, and you may end up having sex with the boys who have AIDS and you also get infected and you even get pregnant, finally you may be chased from home or school."²⁴

Some respondents brought up other situations that could put individuals at risk of getting infected; they mainly mentioned sharing sharp objects but also caring for an infected person.

According to the interviews, risky sexual behaviours are still practised, mainly among individuals who have been tested HIV positive. In many interviews, respondents said that HIV positive individuals would rather engage in unprotected sex than people who have been tested HIV negative. First, because they would say 'I am anyway positive so no need to care anymore', 'I will die anyway'; second, the rumour is spread that they would not want to die alone; and third, that they intentionally want to spread the virus.

"Those ones who are positive will always be free with live sex, but those who feel they are ok [HIV negative] they want to use the condom.

But those with HIV, do you think they want to spread HIV?

It is vice versa, one their aim is to spread the infection, the same applies to the men those who know they are positive, when they go there [to the CSW], they don't want to use the condom they want to use live sex.

Why do you think they want to spread?

Because they have belief that they are already dead, they don't want to die alone."25

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 $^{^{\}rm 22}$ Refer to the chapter 'Dynamics of sexual relations' for further remarks.

^{&#}x27;Sugar mummies' and 'sugar daddies' are women and men who provide money or other favours in exchange for sexual relations.

²⁴ I 16: GD in-school girls 11, 13 and 14y

²⁵ I 33: GD *boda-boda* riders, 19-30y

5.4 Condom perception and condom use

The use of condoms is a form of 'behaviour' and constitutes an active coping mechanism. Correct and consistent condom use reduces the chances of HIV infection. In a context like Kasese and for adolescents, condom use has a limited chance of being a successful prevention strategy. It is a one-dimensional way of active coping that allows mainly men and male adolescents to decide if condoms are used or not.

Condom use in general seems to be inconsistent. In most of the conversations, it was said that men usually prefer 'live sex' and, as mentioned above, women do not have the power and negotiation skills to impose condom use for different reasons. One of them is that women have to find a way to survive and need money at the present moment. In such a situation, an HIV infection and a disease like AIDS seem far from the women's daily struggle. Another factor influencing condom use is that women receive more money for unprotected sex. Moreover, the younger a woman is, the less power she has and the more inferior she is seen compared to the man.

Condom use among married couples or with the 'real' girlfriend is not accepted and seen as mistrust. In longer-term relationships, condoms are used at the beginning; when the couple knows each other better, most of them continue with unprotected sex.

Since many people in Uganda engage in multiple concurrent sexual relationships, the risk of infection increases with the number of partners and inconsistent condom use.

5.4.1 Condom perception

Condoms are perceived as an uncomfortable but necessary means of HIV prevention, which does not mean that they are necessarily used. Attitudes towards condoms are mixed among adults and adolescents. Most of the adults think that it is not appropriate for the younger adolescents to use condoms. The pioneers among them are the churches that promote abstinence and faithfulness. In general, however, it was said that churches avoid talking about sexual matters.

"The church does not talk about the diseases or the condom, this traditional perception that foreign thing [condom] is inserted in a human being with those fluids that is traditional thing [vagina], but the church wants to promote faithfulness, for them they don't talk about medical things they talk about faithfulness partner."²⁶

Parents, guardians and teachers would also react negatively when they discover that their children and students carry or use condoms.

Many adolescents question the safety and security of condoms. Rumours are spread that condoms cause cervical cancer, contain diseases, can burst or stay inside the woman or girl and move to the heart. A man who does not want to use a condom will just tell the girl that the condom contains diseases, which negatively influences and intimidates the girl, who will then not insist on its use.

"He said for him he couldn't use the condom because it brings diseases." 27

Female condoms, when known, were perceived very negatively in all interviews. They are seen as inconvenient, difficult to use, not well manufactured and designed; the woman would need to hold the female condom and control it during intercourse to prevent it from slipping into the vagina or the man might penetrate outside of it.

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²⁶ I 26: male peer supporter

²⁷ I 34: teenage mother, 17y, out-of-school

"The female condoms they inconvenience them, they prefer male condoms. When you are having sex you have to support it, partly hold it, because a man may go beside it when you are thinking that you are putting on a condom and he is inside that condom yet he has passed behind it that's what they tell me, several times yeah, the fact you are holding it that the man will not enjoy the exercise, so they don't like female condoms, now if this young lady gets a man who tells her me I cannot put on a condom. Because some men say when they put it on they don't function. The erection goes stop. If a man has refused to put on a condom and this one doesn't want to be inconvenienced with the supporting of female condom, then they will have 'live sex'."²⁸

5.4.2 Availability of condoms

The price of condoms is not a problem; free condoms are available at the clinics and in many other places, e.g. in public dispensers at a landing site (Fig. 2). In one interview, it was mentioned that free condoms are distributed during funeral ceremonies. The question, especially for adolescents, is not if you get a free condom at all but how to get it in a discrete way. Respondents did not complain about the free condoms, their appearance and their quality as people did in other countries like Swaziland, Zimbabwe and Kenya.





Figure 1: Poster for Protector condoms

Figure 2: Public dispenser of Protector condoms

Nevertheless, older respondents such as *boda-boda* riders said packed condoms were safer because of the little box and that people could not easily recognise them as condoms. *Trust* condoms were said to be harder, *Life Guard* condoms to be soft and a shop seller said that people complain that *Protector* condoms have a bad smell. In general, opinions were mixed about which ones are the best.

Nicely packed condoms can be purchased at many places, in shops and pharmacies, and they are also available in bars and lodges. A box of three *Trust*, *Protector* or *Life Guard* condoms cost 1000 USH (€0,26), the luxury condom brands like *Rough Rider* and *Wet'n Wild* and "O" cost 5000 USH (€1.30).





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²⁸ I 2: female healthcare provider, 25y

Respondents used the following terms to describe condoms. Most of the words are nicknames (password) used to indirectly refer to condoms and to ask for them (in drug stores or pharmacies) in a discrete way.

- CDS (abbreviation for condoms)
- BULLETS (as you symbolically kill the virus)
- AKAPIRA (Lukonjo) it can also mean a ball; it is used to describe condoms because of the round form
- HELMET, GLOVES, STOCKINGS (referring to protection)
- KALINDA BWOMEZI (Rutoro) (meaning life protection)
- PROTECTOR (this comes from the condom brand *Protector*)
- PASSPORT (with a condom you can pass)
- BISCUITS or CHAPATTI (something nice and sweet)
- RUBBER (adapted from the texture of the condom)

5.4.3 Condom use among adolescents

Adolescents are in a vulnerable stage in terms of puberty. They are in the epitaxial period, in a learning period about the body, sex and interpersonal relations and they feel uncomfortable, uncertain and unconfident about using condoms. Their doubts range from how safe condoms are, the fear that it contains diseases or that it can remain in the body of the girl or burst to its practical use.

"The condoms are not 100% safe because they also have toxic. When they are inserted they will automatically move to the body especially they will negatively affect the female reproductive system, so the womb and the ovaries. ... some reverend at the church he talked about it that people should avoid using them [condoms]." ²⁹

Male adolescents expressed their fears of the practical use of condoms; they are simply worried that the condom would not fit their penises.

"The fear comes when you have small size of the penis and it can easily roll off into the woman." 30

Incorrect use was mentioned as well: one adolescent said that he puts on two condoms to protect himself from an HIV infection. In a group discussion with boys, it was mentioned that it is the girls who are afraid that the condom could remain in her bodies and that they would also question the boys' love when they used a condom.

"The fear is mostly on the girls, so if you the boys propose to use the condom the girls refuse and say no am afraid please am afraid? Yes the girls refuse and the girl says if you agreed to love me why you use the condom. But this is for the girlfriend not the one you are going to give the money."³¹

Male condoms look simple but they are not easy to use. The boy must have an erection to put it on and he must withdraw his penis immediately after ejaculation so that semen does not leak. Male adolescents in particular feel embarrassed and out of control when they first try condoms, finding them difficult to use. A bad experience such as losing their erection and not being able to complete sexual intercourse may make them reluctant to try it again.

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²⁹ I 4: male adolescent, 19y, in-school

³⁰ I 32: *boda-boda* rider, 18y

³¹ I 32: *boda-boda* rider, 18y

Among in-school adolescents sexual intercourse might take place quickly and they might not have time to look for or think about a condom. This form of intercourse is called "stolen sex" as it happens clandestinely and in a rush.

5.5 Adolescents' family values

In the interviews, it did not seem that the adolescents highly valued their families in terms of emotional support and care. This does not mean that they do not appreciate their families but rather that the families could not support the children for a variety of reasons mainly related to their economic and financial situation. Families who are better off can provide more support to their children, such as school fees, food, clothes, transportation, etc. Adolescents from poorer families reported not having very close ties with their parents, resulting in early marriage and transactional sexual activities for both girls and boys.

"You find that many families are vulnerable, and trying to force their children into early marriages. You said force you mean the family is the one which forces it?

Yes it's the family, you find that they have no option and they force her to marry when she is still young."³²

Only in a few cases, interviewees reported a positive and supporting environment in their families, which helped them to deal with their lives in general, their HIV status and especially treatment intake.

It was also mentioned that numerous adolescents do not live with their fathers and mothers but with relatives; in such a situation the young person is always the last to receive emotional, physical and financial care. Some of these adolescents are HIV positive orphans, born with HIV, living with relatives; others are HIV negative, but do not live with their parents because of other problems in the relationships with their stepparents.

"Some of us our father died and the mother got married by another man so we are just stuck there, and others we are just at home." 33

Stigmatisation around HIV also leads to a lack of support from friends and family. They are afraid of getting infected when they care for HIV positive people, but they also do not want to be associated with someone living with HIV because of the gossip that surrounds them.

"That day I knew I was positive they started fearing me, this was for the children, neighbours and the family members, they don't want even to sit next to me.

How did they know that you are HIV positive?

Because I told my mum and the mum told the brothers, they also fear me, but our brothers don't fear me only those children from my step mother."³⁴

There are still many supportive and caring families, however; they are the ones who have most of their children in schools and face fewer financial difficulties. All adolescents acknowledged that family, friends and peers are a crucial social and emotional assistance for them. If adolescents lack such care and support, they are more likely to engage in transactional sex.

5.6 Dynamics of sexual relations

In order to be able to understand why, how and when sexual intercourse takes place, we have to understand sexual relationships. It is important to explore and analyse who has sex with whom, when,

³³ I 43: GD, male out-of-school boys, 14-18y

³² I 48: GD, male school boys, 18 and 19y

³⁴ I 46: female out-of-school girl on ART, 19y

why and how. In all the conversations, people talked about the manifold dynamics of sexual intercourse. Individuals engage in multiple, mostly concurrent sexual relations that have different meanings for them.

"Even me myself I have many girlfriends because it helps someone not to be heartbroken even though someone says am done with you. I will just say its ok and I feel ok because I will be having many like 10 or 12; by the way having many it is tradition because for us Africans that's our culture and that's not big problem.

And the women don't complain?

Yes, they know but others complain, I am a man if you complain you complain and if you want to go you can go after all they [the women] are very many and I will get another one, the man says to the lady. Yes, it hurts the ladies more than the man, for example you find that I know that I have three girlfriends, and everyone will do her best to make sure that she wins your heart, so there is stiff competition."³⁵

5.6.1 Sex to show off

Adolescents feel peer pressure to have a girlfriend or a boyfriend. Girls engage in sexual relationships to show off, to feel 'older' and mature in front of their peers. They want to belong to their peers who have boyfriends or girlfriends. These are also the peers that were mentioned as 'bad peer groups' as explored in Chapter 5.3.

Having many partners is a 'must' for a young sexual active man. Young boys compete among each other when talking about how many girlfriends they have. It is mainly the out-of-school boys who boast about the number of girlfriends.

"Those young boys are proud that they have six girlfriends. When I am with my friends you begin I have six girlfriends discussing that this one is good and this one is not good but to me this one is sweet and this on is not sweet like that. ... Being proud to have many I want to be known that I have many girlfriends and the boys you feel you have that power that you are better than the other one, so you find all of us to have many girlfriends." ³⁶

5.6.2 Men 'need' sex

In the interviews with older adolescents and young men, they frequently mentioned that men need sexual intercourse to satisfy their sexual pressure. Some have their wives and partners in the village and work in town. Many say they are tempted and cannot do anything about it. In a workshop, men described why and how they think that the first intercourse with a woman is the best and they already start thinking about another woman when they have intercourse with the same woman for the second time.

"Men tend to run away from women after having the first sex. We were in a workshop, men confessed that the second round is enjoyed when you are thinking about another women not necessarily the one you are with. The first round is when am still mad the second round is when I have realized that she is like other women." "37

Men's interpretation of masculinity in terms of male strength means that a man has to be sexually active, strong and powerful. This understanding implies frequently having sexual intercourse and preferably with many different partners.

Male adolescents are not only in the middle of puberty and feeling their sex drive; they also grow up observing and learning these attitudes from their parents and role models and then apply a similar

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³⁵ I 48: GD, male in-school, 18 and 19y

 $^{^{36}}$ I 48: GD, male in school, 18 and 19y

³⁷ I 38: Peer, educator 43y

behaviour. All male adolescents, even younger ones, talked about these dynamics and also mentioned that a boy might look for another girl because he does not have a beautiful girl, is not sexually satisfied with her, the girl could be in a bad mood or they might have a dispute.

"There is nature, I may not have a beautiful girl but when I look around and then see someone who is more beautiful, then I go to the one who is more beautiful, some guys say that their ladies do not satisfy them, they try to search for others and they normally say that these ladies are dry, so you find they are trying to force them and look for more.

You are saying that the girls do not satisfy them what do you mean?

This means the girl does not satisfy them in sexual intercourse, you find her lazy not active, not taking care and then very dry.

You said that they are dry what does this mean?

You know ladies they have their natural fluids, you find some don't have and the man fails to have appetite for her."³⁸

Younger and older respondents mentioned the physical condition of a woman of being 'dry' or 'wet' in many interviews. However, it was referred to as a personal trait of the woman rather than an indicator of the woman's state of sexual arousal. 'Wetness' is considered a positive characteristic that makes sexual intercourse more joyful. 'Dryness' was used to describe that a woman is not experienced and skilled in sexual matters. Moreover, dryness was attributed to ethnic affiliation, nutrition and wealth of a person, e.g. the Bakonzo are said to be dry, the Batoro to be wet.³⁹ This finding contrasts with what was found in various Southern African countries, where women are expected to be 'dry' for sexual intercourse to be considered pleasant (Burtscher 2004, 2011).

5.6.3 Transactional sex

Generally, the dynamics of transactional sex differ from commercial sex in that transactional sex relationships last longer, tend to be inter-generational and are not only caused by poverty and destitution, which is often the case for commercial sex. Specifically, young adolescent girls get involved in relationships with a number of older men in exchange for basic needs support or as a means of survival, but also for school funding, gifts, desired items or contributions to their living expenses.

Boys and girls both engage in transactional sex: adolescent girls need the money, boys and men they have the money. Likewise, some boys have sex with women and receive goods or money in return. In Kasese, transactional sex was viewed to be mainly related to poverty and in most cases it concerns young girls. Adolescents frequently blame the families, claiming that they abuse the adolescents, force the girls in early marriage or mistreat the children so they run away or the families chase them away. A discussion with street kids revealed that some of them had their families in Kasese but would not go home as the parents would not care for them.

"The child will run away from the home and when he will find the man reaches there a man will take her and she will be impregnated and will be neglected. There at times when the children make mistakes and the parents get fire and burn the hands of the child, and when they are burnt, she will fear to tell her fellow pupils and starts going to the bush. ...there are some schools who release their students very late [when it is already dark] and a group of men will try to get the girl. There are some families in the village they send the child to get money, this comes after lacking what to eat, and when the child will go to the bar in order to get money to eat." 40

³⁸ I 51: GD in-school-boys, 12 and 13y

³⁹ Historically, it was said that the Batoro looked down on the Bakonzo (Stacey 2003). The Bakonzo belong to the Bantu, they originally came from Katanga, DRC.

⁴⁰ I 19: GD in-school-boys, 12y

'Sugar mummies' and 'sugar daddies' are among those who engage in transactional sex with adolescents. Men state that they are tempted by 'beautiful' young girls and propose sexual intercourse. These men are found among the *boda-boda* riders (bicycle and motorbikes), truck drivers, businessmen, teachers or any men that have (little) income or can afford it.

The boda-boda riders belong to the most-at-risk population. They are the ones who try to seduce young girls to give them their phone numbers, or they give them a free ride and ask for sexual intercourse in return. Some also deviate from the road and rape the girls; others make appointments and sleep with the girls in return for some small gifts or money. The boda-boda riders seem to subconsciously perceive themselves as 'failures' because most of them dropped out of school. They do not own their bikes but rent them from someone who owns one or more. Bicycle boda-bodas have to pay 2000 USH to the owner for a day, most of them said they earned around 5000 USH. The moto boda-boda riders have to pay 5000 USH to the owner of the bike and can earn around 15,000 in a day.

There are girls who engage in transactional sex to be able to buy nice clothes or luxury items to compete with their peers and not because of poverty; however, in most cases the causes are a lack of financial means and economic deprivation.

One 18-year-old out-of-school boy talked about having 15 girlfriends in front of three of his friends in the interview. He was laughing himself when he said it, but at the same time he was very sure of himself and explained why he was doing it and how it happened. He said he was having 'sugar mummies' who financed him. These women have beauty salons or other small businesses. He explained that some of them come with condoms. These sexual relationships happen in lodges, at the sugar mummy's or sugar daddy's place or at any place they can find such as toilettes, street corners, etc. depending on the financial possibilities of the person.

5.6.4 Commercial sex workers

When speaking about the commercial sex workers, we need to differentiate between the most-at-risk population and the most vulnerable individuals. Commercial sex workers are the most-at-risk group while adolescent girls are the most vulnerable group in general given their life circumstances.

A typical case of a commercial sex worker would be a girl that was abandoned by her family, had to drop out of school, lived with relatives or other guardians who abused her, or a girl that is left to her own devices to survive. If such a girl does not find any other job, she might end up working as a maid in a family, where again she might be sexually abused by the sons of the family. After that, she might work in a bar and finally end up as a commercial sex workers. Commercial sex workers 'sell their bodies' as they do not have any other option to survive – they practice 'survival sex'. Apart from the sex workers who were interviewed, it was observed that there were also women who were still living in their families or even had a partner. There were young and older women among the commercial sex workers; some are married, some are not; some live with their husbands and when he is away (for work) they receive clients. Some are with children, some are single young girls, but what they ALL have in common is their need of money to survive.

Many of the younger girls are homeless; they try to find a job and a place where they can stay and sleep and work. This is how they start to first engage in transactional sex and eventually end up in commercial sex work. There were also girls who had come from the villages in the surrounding areas of Kasese to make a living. The same was observed at the landing sites.

The commercial sex workers prefer to see themselves as girls working in a bar. This is what they tell their parents or other people when they leave their home (if they still have one). Then they change their clothes before reaching the place where they will work.

In the interviews, references were made to different categories of commercial sex workers. The 'highest' category refers to women who stay inside the bars and who can afford a drink. They are the ones who are able to negotiate a better price and request certain conditions for the sexual intercourse such as going to a certain hotel or lodge and using a condom. These women can ask up to 50,000 USH

(13€) compared to girls who stand in the streets or under the trees in a small park near Mariana Street⁴¹ and who might have to accept a proposal of 5,000 USH (1,3€). The latter belong to the lowest category of commercial sex workers. In between, there is the category of women who can be found in corridors (at corners between buildings) and outside the bars; they are still able to negotiate the price some extent or go to a simple lodge.

Some respondents in the interviews said that that commercial sex workers use drugs, otherwise they would not be able to bear this kind of job.

Payment ranges from 5,000 (1,30€) up to 50,000 (13€) USH, depending on the 'category' of commercial sex workers, the beauty of the girl or woman, the time she spends with the man and the number of rounds the man will ask for.

One interesting feature came up in the interviews with older informants. When a woman stays and works in a certain area for some time, she becomes known by the men and loses her value. This is why women move from different areas in Kasese town to other towns in Uganda like Fort Portal. After some time, they return to the place where they initially started and continue the cycle.

5.6.5 'Real love sex' with your 'real' girlfriend or boyfriend

After some time of interviewing it became clear that the term 'girlfriend' has to be understood in different ways. Boys and men referred to the term 'girlfriend' when they spoke about any woman they had sex with but had a complete different perception of their relationship with the 'real' girlfriend. With the real girlfriend they experience real love. They treat her differently and do not give her money but presents. With the real girlfriend, they take care of family planning and try to have safer sex.

"You said you have five girlfriend can you explain why you have five girlfriends? We boys we are still young and when someone beautiful passes then you say I can't manage to stay with one girl and another day you see another one so you end up 'coning' [running after girls]. But are you still with the one at school, which you said is your real girlfriend? Yes, that one I love her she is my best, but the others I don't love them."

"If you really love the girl you can take her to family planning method called injector plan so that she is not able to become pregnant or you can use withdraw method when you have sex." 43

5.7 HIV counselling and testing

In contrast to findings in Zimbabwe and Swaziland where testing was related to stigma, the majority of adolescents asserted that they would not have any problems going for a test either to the clinic or during outreach activities. Many of the interviewed adolescents had already done several HIV tests. The ones who had not yet been tested had avoided testing because they had already engaged in unprotected sex; this group of adolescents expressed their fears of going for a test.

It was observed that among out-of-school adolescents, HIV testing outreach activities (organised by Baylor) are well accepted, but it was not clear if they receive anything in exchange for the test. When the HC III together with Baylor organises moonlight outreach, the peer educators mobilise the people to come for the test; we were told that they receive 2000 USH to buy a drink. Moonlight outreach happens in bars at Mariana Street or in other risky quarters in Kasese like Nyakazanga.

For in-school adolescent, access to testing depends very much on how much information and awareness raising sessions the authorities of the individual schools provide for the students.

⁴¹ Mariana Street is the hotspot for commercial sex workers in Kasese; there are many bars and most of them have small rooms attached.

⁴² I 37: GD out-of-school, 17y and 19y

⁴³ I 33: GD *boda-boda* riders, 19-30y

Attendance for such testing activities is said to be high as social conventions play a role ('When the friends or others are going, I am going too'). A certain lack of knowledge was observed regarding the 'window period' for testing; older students said they had heard about it, but did not really know what it refers to. Others did not understand what it means.

In two schools consulted for interviews, students stated that they had already been tested several times and that it had been compulsory for them.

In-school testing was considered acceptable in terms of location and practice, but confidentiality was not fully respected in the schools. The interviews suggested that the students know who is positive; likewise, the teachers and head teachers had knowledge about the HIV status of their students. The same was reported about the health centres; the lack of confidentiality seems to be a major problem.

All interviewed adolescents expressed the wish to receive testing services in the adolescent centre of MoH/MSF as they see the centre as a convenient place for them in terms of privacy. It was emphasised that they want to be tested by medical professionals and get the counselling from trained, older people and not from their adolescent peers.

A common practice in Uganda also known to the government is that HIV positive individuals can obtain a negative test result if they pay for it. A young 18-year-old woman who had had a boyfriend for one year explained such a case. They had used condoms at the beginning of their relationship, but when the boy asked for sex without a condom, the girl requested to go for an HIV test. The boy accepted but organised the testing in a private clinic. The girl received negative test results but never saw the boyfriend's results. Both the 'doctor' and her boyfriend told her that everything was fine. Later on, when they had unprotected sex and she discovered that she was pregnant, the boy disappeared and abandoned her. She lost her job and went to live with her mother's sister. During antenatal care she was tested HIV positive.

The stress and pressure to obtain a negative HIV test result mainly affects people who know that they are HIV positive but want to marry, and who fear that their relationship will fall apart when the partner finds out that they are HIV positive.

At the landing site in Katwe, respondents expressed the wish to have testing opportunities closer to their location as the health centre is very far away.

5.8 Sexual and reproductive health

Sexual and reproductive health includes all features that adolescents link with their health related to their physical, mental and social well-being. This report focuses especially on their experiences with sexuality, feelings, desires and (risky) behaviours.

5.8.1 Traditional features related to a women's body

Traditionally, women have to follow certain rules and regulations during pregnancy to make sure that there are no negative consequences for her during pregnancy or the delivery. Some of the norms are related to the woman's nutrition or behaviour, others are symbolic perceptions. Usually, it is the grandmothers or aunts who pass this information on to the girls during puberty. The following are some of the most important rules:

- It is not allowed to 'expose' the pregnancy and to touch a pregnant belly, as one does not know the other person's intention.
- The pregnant woman is not allowed to hold, look at or buy certain objects such as teddy bears or cartoons because the baby might look like this teddy bear or the characters in the cartoon.
- When a woman gives birth to a child with disabilities, one explanation used is that the child
 does not belong to the husband's family, and his family will start to search for something the
 woman has done wrong during the pregnancy.

- The woman is not allowed to eat mudfish; the fish is slippery and has a lot of saliva, which means that the baby will show the same features.
- A woman should be careful not to kill a chameleon as the child might die or be very slim.
- Once a woman or a girl is married into a family, she has to adopt and respect the rules of the husband's family because "once you are married you are for the husband and you must follow what is there"⁴⁵. Every family has its totem animal, which is there to protect the individuals. The members of this family are not allowed to eat it and they will never desire it. If a pregnant woman admires the animal that is taboo for her husband's family, the relatives will claim that she is pregnant by another man.
- Pregnant women should not walk to the bush and the forest as bad spirits could attack her. They are supposed to stay near their homes.
- Some traditional healing practices encourage a man to have sex with a pregnant woman to transmit his disease to the baby in the womb.

5.8.2 Information about sexual and reproductive health

How do young people access information on topics related to sexual and reproductive health? Inschool boys and girls learn about the human body in Natural Sciences class in primary and secondary school. These respondents had a more detailed knowledge about the reproductive health system, but usually adolescents do not ask questions related to sexuality in the classroom. They rather discuss these issues with their friends and peers.

All the girls interviewed expressed the wish to get further information and education on SRH. The knowledge they gained in school was considered insufficient. Girls said that they wanted to learn more about their menstrual cycle, family planning, how a woman can get pregnant, about pregnancy, the baby in the womb, giving birth and about how to care for a child. Antenatal care (ANC) and postnatal care (PNC) were mentioned as important services they hope to receive at the MoH/MSF adolescent-friendly centre.

Some girls mentioned that their mothers informed them about menstruation and advised them not accept if a man proposed sexual intercourse to them. Both girls and boys mentioned that they watch porn videos together either at home or in video clubs. This is another way they learn about sexuality.

5.8.3 First experience with sexual intercourse

It was said that adolescents start having sex around the age of 12, when they are still in primary school. Some adolescents explained that they had their first experience with sexuality in their childhood. However, this was not perceived as a real sexual experience or as sexual intercourse as they were just playing and imitating what they had seen with their parents, relatives or other adults. For many girls, their first sexual experience comes with domestic sexual violence and rape.

5.8.4 Early pregnancy and abortion

Early pregnancy is perceived as a shame, by the girl herself and by others around her. Some young girls talked about this topic in a way that suggests that they believe it is the pregnant girl's fault that she got pregnant at an early age. When asked further questions, they mentioned that negligence and lack of care from the parents, financial needs and poverty had pushed the girls into accepting to sleep with a boy or a man. In Uganda, family planning is illegal up to the age of 18. Therefore, the only way to prevent pregnancy is using a condom.

⁴⁴ An explanation for a malnourished child which relieves the mother of the guilt of not having taken proper care of her child.

⁴⁵ I 15: pregnant woman, 26y

In most cases, the boy or man who has gotten a girl pregnant does not accept the pregnancy and 'disappears'. The girl is left to her own devices. She is worried about informing her parents and stressed about figuring out how she can continue her life. Usually, it is not the pregnant girl who informs her parents or guardians; she talks to a third person like an aunt who will then inform the parents. When the adolescent girl has no support from her family, she is forced to find her living elsewhere. In such cases, girls often try to abort using herbs (which they receive from an aunt, friends or from a traditional midwife), swallowing pills or − if they have or get financial support − they have a clandestine abortion at a private clinic. Clinics charge between 150,000 (39€) and 250,000 (65€) USH; an abortion with an herbalist or a traditional midwife costs around 50,000 USH (13€). Self-induced abortions quite often end up causing problems:

"When you go there [to the traditional midwife or herbalist] you say can you help me to abort, so they feel comfortable to talk to them because they know they will help them.

So they are not afraid to go there? No

And these herbs can they help? The problem with them they may not terminate all the products resulting into septic abortion and sometimes this adolescent remains at home, and by the time she comes seek for the health services the uterus is eaten up, rotten up."⁴⁶

"We sometimes find thrown kids after abortion and we know when the abortion exercise has failed and then the girl is dead.

But how can you recognize that it is abortion when there is no way to do it?

You may see the girl when she is very smart but after few days she has come slimy, you can easily identify this baby alongside the road in a way that some parts are not yet fixed that's the way how you can easily identify the baby. Others do normal delivery and then eventually throw the baby on the dustbin."

Schools organize regular pregnancy screenings for the female students after holidays. These screenings are not announced and take place in all (private and government-aided) schools. The interviews revealed that it is a shame and a traumatising experience for the girls to be sent home from school in front of all the others when the screening shows they are pregnant. Pregnant girls are stigmatised and do not feel comfortable coming back to school to continue their studies after they have delivered. When the pregnant girls are in S4 (secondary 4, where they have a final school exam), they are allowed to attend the final exam but not the classes during the year before.

For delivery, the girls in Kasese town go to the health centre or the hospital; usually, they do not go to the traditional birth attendants (TBA). The government and the village health team (VHT) discourage delivery with a traditional midwife. A delivery at Kilembe Hospital is said to cost 300,000 USH (78 \in) at Kagando Hospital, it is 350,000 USH (92 \in). At the health centre, a woman pays 20,000 USH (5 \in). For a traditional midwife, a woman gives two bars of soap, sugar and some money, depending on the financial means of the woman.

5.9 Antiretroviral therapy

All respondents knew that treatment exists and is available for free at the hospitals and health centres. The question is how much stigma is attached to taking drugs every day and how taking drugs for the rest of one's life is perceived in general.

Nearly all adolescents knew about ARVs and confirmed that ARVs do not cure. In-school adolescents specified that the drugs do not cure but suppress the development of the virus and that they had

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⁴⁶ I 2: female healthcare provider, 25y

⁴⁷ I 33: GD *boda-boda* riders, 18-30y

observed physical changes in people taking ARVs. A person that was slim before would gain weight, look fat/healthy and could not be recognised as HIV positive anymore.

"I know about TASO (THE AIDS SUPPORT ORGANISATION) [ARVs] that does not cure. The ARVs are there to cool and it doesn't cure the HIV. When you take the ARVs and you miss a day your body does not move on well. What I know about those drugs is that it gives hard time because it's big in size."

Some adolescents asserted that they had seen people dying even if they took the drugs. Some assumed it would be difficult to follow lifelong treatment; others thought that you will die anyway if you are HIV positive so there was no point in taking drugs.

Already the initiation of treatment poses problems, as the new clients receive a kit with a mosquito net, a jerry can and other items. Respondents explained that when people are seen with these objects, one can easily deduct that they are HIV positive. Similarly, if someone swallows pills, he or she is presumed to be HIV positive. Any larger pill is perceived to be an ARV.

"There are classes of ARVs that there is young HIV and mature HIV, so for young HIV they give Septrin [cotrimocazole], for matures they give you a tablet that is big in size [ARVs]." ⁴⁹

Respondents did not name ARVs as such but referred to ARVs as the 'big drugs' or 'big pills'. Many were able to describe what the pills looked like (shape, size and colour). Another problem is the noise the pills make in their container. To avoid the noise, some of the clients empty the boxes and put the pills into a plastic bag. Adolescents taking ARVs mentioned that it is a problem for them to swallow the drugs in a discrete place when they are at schools or in boarding schools.

For many respondents, the biggest challenge of being on ARVs is the fact that they do not have enough to eat. Nearly all HIV positive respondents on ARVs complained about a lack of food and having to swallow drugs on the empty stomach:

"At times they swallow drugs on empty stomach, when they have eaten, that's there challenge. Because after swallowing they get dizziness, they feel bad in way that they can't walk, and hunger continues." ⁵⁰

To remember taking the ARV drugs, many clients use a mobile phone, the radio or take them at a certain time in the morning and in the evening. In families with several members on ARVs, they remind each other to take the drugs and generally take them together.

5.10 Stigma and discrimination

Stigma is a fundamental problem that arises from social interaction when a person or a group of people experience exclusion, rejection, blame or devaluation by their social environment in reaction to a health problem or health-related condition. It can be experienced (enacted) or anticipated both by the patient/client itself (self-stigmatisation) and the family. Numerous factors such as isolation or separation of the infected person enhance and reinforce stigma.

Stigmatisation occurs on different levels. It happens when people have certain symptoms that are perceived to be caused by an HIV infection; it takes place when people get tested, when they go to the clinic for their drugs and when they swallow their drugs. Pregnant adolescent girls feel stigmatised when they are seen pregnant; that is why they try to hide their condition as long as possible.

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⁴⁸ I 10: GD male out-of-school, 16-18y; TASO is used to refer to ARVs. TASO has been active in Uganda since 1987.

⁴⁹ I 9: GD male out-of-school, 16v

⁵⁰ I 2: female healthcare provider, 25y

HIV is not an easily transmittable disease. When you are infected with HIV, you first ask yourself the question of how you got infected. There was a clear distinction in how respondents discussed the different modes of transmission. Transmission through blood or sharp objects or month-to-child transmission were more easily discussed, as these modes of transmission are not related to behaviour and unprotected sex. Transmission through sexual intercourse was mostly mentioned as a last priority. Accepting that people behave in a way that spreads HIV creates moral dilemmas. And this is the point where stigma comes in.

If a child was born with the disease, they are stigmatised less because the child is not considered blameworthy. A person who got HIV through sexual intercourse is found guilty and blamed for having 'indulged in immoral behaviour'. This does not only apply to HIV infections but also to early pregnancies, as a group discussion with primary school girls indicated:

"What is the reason why they get pregnant?

They play sex; they don't use family planning methods.

What do you think about these girls?

They may lose life when giving birth, they may drop out of school.

Does it mean that if a girl is pregnant she is not allowed at school? Yes

Can they be allowed back to school after delivering? Yes.

Do you think these girls are guilty that they got pregnant? Yes

What about the girls who are raped?

They should go to the chairperson to report the person who impregnated her, but it will be too late because he has impregnated her already. After the girl is pregnant they should give her to the man.

What could have protected these girls from getting pregnant?

Abstain from sex.

How can you abstain if someone has forced you?

I can kick him, or stone him."51

This conversation reflects what the primary school girls have learned about HIV prevention and behaviour and how to avoid early pregnancy. Abstinence can protect from an HIV infection and early pregnancy but not when the girl is forced into sex. In all the interviews with female and male adolescents, they talked about the 'bad peer' groups that are already sexually active, drink alcohol, use drugs or dropped out of school and engage in transactional sex.

"I advise my fellow friends not to put themselves in 'bad peer groups' going on streets, they are going to sell themselves, as they reach there selling themselves acting as whores, prostitutes, you lose your life when you have not yet reached the year of dying and you end up creating shame in your family." ⁵²

5.10.1 Self-stigma

HIV positive individuals stigmatise themselves. Among younger adolescents it was observed that they mainly speak about friends in their peer groups, i.e. about other HIV positive adolescents on treatment. Some of the adolescents who have already participated in the peer groups of ART clients for some time have a good, friendly and open-minded relationship with their counsellors and show a positive attitude towards life. But again, the environment they live in plays a critical role in how they face the challenge of living a life on ART.

⁵¹ I 55: GD female primary school students, 12y old

⁵² I 5: out-of-school girl, 18y

Younger HIV positive adolescents (10-15y) do not want to mix with other adolescents who are not HIV positive. They rather stay at home in their free time, and all said that they did not want the others to know that they are HIV positive. Older adolescents (16-19y) are more self-confident and do not limit themselves in their movements. On the contrary, as mentioned earlier, many older out-of-school adolescents do not care about their HIV positive status.

5.10.2 Enhanced stigma

All respondents explained that HIV positive individuals are stigmatised. In the course of arguments, people might address a person's HIV status and blame them for the infection.

"In most cases if someone picks a quarrel with a friend or neighbour and that neighbour gets to observe that that person has any sign then he will automatically say, take away your AIDS from me. When an infected person is your friend and you happen to move around together and those people who know that person and they are aware that he is sick and they will say, you have started moving with that person, that person will also make you sick." 53

It is also common to label a person HIV positive when they are seen swallowing drugs, carrying a jerry can back home from the health centre or bringing home the drugs from the health centre because they make a certain sound in the box when they are carried and shaken in the bag. These are reasons why clients throw the jerry cans away or take the pills out of the box and put them into a sachet. Jerry cans that are distributed to HIV positive clients at HC III are white; even if clients carry them home in a bag, they can still be identified as HIV positive because of the colour since jerry cans in Uganda are usually yellow.

In-school adolescents, and particularly the ones in boarding schools, described the challenge of swallowing the drugs in a discrete atmosphere. First, they have to keep the medication somewhere and secondly they have to take them. Confidentiality does not seem to be guaranteed in schools; it was observed that teachers, matrons and patrons do know who is HIV positive. This would not be a problem if they respected confidentiality. Sometimes they assume the role of the guardian and remind the students to take their drugs.

Confidentiality is a general problem; in all interviews, it was understood that people knew PLWHA (people living with HIV/AIDS) in their communities without knowing them personally. They identify them based on their appearance, because they take big pills, because they are sickly people and frequently go to the clinics, etc.

Another concern adolescents have is confidentiality during testing activities. Going for a test is not a problem; the difficulty is that testing sites do not guarantee a discrete atmosphere. This concern was mentioned mainly in relation to testing in schools, which entails stigmatisation when someone is tested HIV positive.

5.11 Health-seeking behaviour

Many different factors influence the individual health-seeking behaviour. These factors include social and cultural aspects (how patients and others around them perceive the problem), practical aspects (if medical care is available), economic and financial factors (whether patients can and want to afford it), empirical factors which determine the failure or success of treatment within the popular (self-treatment) or folk sector (traditional healer)⁵⁴ as well as qualitative aspects (which explain if the quality of care is adequate and appropriate in the patient's perception).

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⁵³ I 40: GD male out-of-school, 18-19y

⁵⁴ Arthur Kleinman (1981) defined three healthcare sectors that influence health-seeking behaviour:

Popular sector: lay, non-professional, non-specialist domain of society. Where ill health is first recognised and defined and healthcare activities are initiated. The main area is the family where ill health is recognised and treated first.

Nearly all respondents stated that they have access to healthcare when needed. The real question is if healthcare is adolescent-friendly. Young people do not want to be mixed with adults and, most of all, they are afraid of running into relatives at the clinics when they would like to get condoms.

Before starting any treatment or approaching any pharmacy or health facility adolescents would go home to consult their parents, guardians or foster parents. All adolescents would talk to their parents first, if they still have them. In most of the cases, the mother would be the one to speak to, but some also prefer speaking to the father first. In-school adolescents have to first ask the teacher for permission to leave the school. Normally boarding school students are not allowed to leave the school compound at all and would need permission for any visit to the health centre or the MoH/MSF adolescent centre.

5.11.1 Self-treatment

For minor health conditions such as headaches, stomach aches, diarrhoea, etc., respondents trust the traditional healthcare sector and use herbs for treatment. There is no need to see a herbalist as the parents or guardians or even the adolescents themselves know what remedy to use. For malaria, it is very common to treat it in a traditional way with herbal medicine; the person is supposed to take a steam bath.

"For which kind of condition is herbal medicine helpful?

When you are sick of malaria, they cook some herbs they put them in the saucepan after they are ready, then they bring the saucepan near you and they bring the blankets and cover you, such that you inhale the steam and that steam helps the germs to get out of the body."⁵⁵

"When I get diarrhoea, the grandmother makes some herbs, so I do not go to the clinic." 56

5.11.2 Health centre or hospital

Another factor why many use herbal medicine is the perception of the health centre and the reception they would face there:

"We don't prefer going to the health centre because of inadequate services. You may go there early morning, and you find nothing there, besides that they may give you a list of drugs to buy, and you are not having the money to buy. Those are the challenges. That at times the grandmother says it's not necessary to go to the hospital and fail to get drugs. It's better to remain home and prepare for you the herbs."⁵⁷

In most cases, people first try the traditional healthcare system or buy medication directly at a pharmacy before going to a western health facility. Apart from social factors, financial and practical factors also prevent people from going to the health centre. Only when their health condition does not improve do they finally approach a western health facility. Distance was not mentioned to be a factor preventing people from going to a western health centre.

5.11.3 Early pregnancy and antenatal care

Access to appropriate and adolescent-friendly antenatal care poses a considerable problem. In the interviews, there were many complaints about how midwives and employees treat young pregnant

Folk sector: healers, TBAs that are not part of the official medical system, but have networks like healer associations. The WHO stated in 1978 that traditional medicine should be promoted, developed and integrated.

Professional sector: modern Western scientific medicine.

⁵⁵ I 51: GD male in-school, 12-13y

⁵⁶ I 9: GD male out-of-school, 16y

⁵⁷ I 9: GD male out-of-school, 16v

girls at the health centres. These concerns were not only voiced by the young girls themselves but also by caretakers and healthcare providers.

Young girls already feel uncomfortable and ashamed because they are pregnant; in addition to the traumatising experience of being expelled from school, they face unfriendly behaviour by the midwives at the governmental health facilities, who blame them and make them feel guilty. These are reasons why some girls prefer to give birth with a traditional midwife, where they receive a more empathic treatment.

The village health teams are trained to encourage the girls to deliver in the health centres. The government put a ban on the traditional midwives and prohibits them from doing deliveries.

All respondents, adolescents, caretakers and healthcare providers alike, expressed the wish and the need for adolescent-friendly services. Lack of privacy, confidentiality and empathy, inappropriate language and vocabulary and HIV status disclosure without consent are only some of the numerous fears adolescents have.

6 Discussion and recommendations

6.1 Discussion

This study focuses on the perception of adolescents in Kasese municipality regarding their sexual and reproductive health. It is one of the few studies representing the perspective of adolescents and their ways of dealing with sexuality and their behavioural patterns in this specific geographical area that mainly used in-depth interviews. The data speaks of the socio-cultural dimension of everyday life of adolescents around Kasese town. It explains not only the basic necessity for adolescent-friendly healthcare services but also for an intervention that helps adolescents reflect on the consequences of their risky sexual behaviour by promoting responsible sexual behaviour and condom use.

According to the UNFPA "[g]ood sexual and reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system. It implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so. To maintain one's sexual and reproductive health, people need access to accurate information and the safe, effective, affordable and acceptable contraception method of their choice. They must be informed and empowered to protect themselves from sexually transmitted infections. And when they decide to have children, women must have access to services that can help them have a fit pregnancy, safe delivery and healthy baby." Findings of this study suggest that these conditions are not given for most of the adolescents in Kasese municipality.

During this study, we found that knowledge and perception about HIV/AIDS still tend to revolve around the idea that 'SILIM' kills and has no cure. The fact that people start to name it 'OUR DISEASE' shows how concerned and touched they are by it. A study on the adolescents' discourse about ART in Tanzania reached similar findings and showed that HIV/AIDS appears to maintain the label of a 'deadly and incurable' disease and that ART does not rule out death (Ezekiel et al. 2009). In Kasese, adolescents continue to refer to the visible signs and symptoms when speaking about individuals who they suspect of being HIV positive; at the same time, they acknowledge that treatment has an impact on the physical appearance in that they cannot recognise an HIV positive person anymore.

Modes of transmission and prevention are quite well known among the youth of Kasese, even if their knowledge can be incomplete or theoretical and does not always translate into safe sex practices. "For people to accept HIV has the potential to spread, they must acknowledge the behaviours that allow its spread – unprotected sex and risky sexual behaviours, engaging in transactional sex, men visiting commercial sex workers, sex outside of marriage and etc." (Whiteside 2008:118). Adolescents tend to primarily receive the message that abstinence is the best method of HIV/AIDS and early pregnancy prevention, as also stated by Birungi et al.; other ways of risk prevention such as a reduction of risky sexual behaviour or condom and contraceptive use receive less attention (Birungi et al. 2009). Active coping with the situation would imply that adolescents are capable of making decisions themselves and of taking care of their sexual and reproductive health. However, especially in the case of girls, this is often not the case in Kasese as the social and economic context is one of the main determinants of sexual behaviour and autonomy.

Condoms are only effective when used consistently and properly to prevent unintended pregnancy and HIV infection by avoidance of breakage, slippage or leakage. Condom use increases with effectiveness and positive experiences adolescents have when using them. This study revealed a variety of reasons and barriers why adolescents do not use condoms rigorously enough to prevent infections or pregnancy. They range from risky behaviour, multiple sexual relationships, certain perceptions and attitudes, availability of and personal experience with condoms to power relations

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⁵⁸ See more at: http://www.unfpa.org/sexual-reproductive-health#sthash.CbLTyUNR.dpuf (accessed January 27, 2016)

and economic factors. MacPhail & Campbell's study on adolescents' condom use in a Southern African township revealed similar motivations (MacPhail & Campbell 2001). Adolescents believe that condoms reduce sexual pleasure, they need 'live sex' and do not like condoms, as various other studies in comparable contexts suggest (Campbell 2003, Skovdal et al. 2011, Winskell 2011, Ezekiel et al 2009).

The question of condom use affects boys and girls quite differently. For the boys and men, it is also related to the concept of masculinity. Not only do they decide on whether condoms are used or not; for them, not using condoms also means to be a 'real man' as a real man needs 'real sex'. Girls do not have the power to negotiate the use of a condom and are therefore in the most vulnerable situation. For active coping, girls must feel able to negotiate which requires a consenting relationship between them and their partners, which is often not the case in the Kasese region. Moreover, adolescents of both sexes have misconceptions about the effectiveness and consequences of condom use, thinking that they provoke diseases or remain inside the body. They do not know how to use condoms or feel uncomfortable with their practical use and finally do not always have one readily available. Some do not use condoms because they are already HIV positive. Another study on contraceptive use in Uganda also indicated that HIV positive young people used fewer contraceptives than HIV negative adolescents (Beyeza-Kashesya et al. 2011).

The lack of social acceptability of condoms also hinders its purchase and consequently its use. Adults' attitudes towards condoms and sex, their insistence on abstinence and the abuse and punishment used to sanction adolescents' sexual activities increase the barrier. Peer norms constitute an additional influence. Adolescents tend to follow the negative attitudes their peers express about condoms. However, adolescents in Kasese also influence each other in how they copy sexual behaviours of others in watching pornographic films, as similarly mentioned in a Rwandan study on adolescents' views on sex and HIV (Van Nuil et al. 2014).

Finally and foremost, the economic context in which sexual intercourse takes place will dictate the use (or lack) of protection measures, as girls accept having sex without a condom in return for more money. Girls face economic disempowerment and therefore expose themselves to unprotected sex (Winskell 2011). Survival at that present moment is more important for them than a potential HIV infection that can appear later in their future. Young adolescent girls are often forced into transactional sex and commercial sex. In her study on young people's engagement in transactional sex in northern Tanzania, Wamoyi explored that transactional sex was not only offered to cover material needs and guarantee financial survival but also for beauty products and other luxury items (Wamoyi et al. 2010). In the present context, such reasons and motivations were only discussed in few occasions. Transactional sex puts adolescent girls most at risk and makes them most vulnerable for an HIV infection and earl pregnancy. It is a way of survival for most of the adolescent girls that engage in it and it is viewed as immoral. It was not observed that girls had any negotiation power for condom use as this would jeopardise their financial gain, as suggested in Wamoyi's study (Wamoyi et al. 2010). Boda-boda riders and other transporters are the counterparts of these vulnerable girls because of gender and economic power relations. They are the ones who have some money and either propose unsafe sexual practices or force girls into unprotected sex.

HIV/AIDS is maybe the most stigmatised ill-health condition apart from TB. Stigma is prevalent on different levels: when people show symptoms, when they get tested, when they go for the drugs and when they take the drugs. Our findings show that adolescents experience stigmatisation in most of their everyday environments: in school, among peers, in families, in church, in the community per se and even with staff at healthcare centres. HIV positive adolescents, when not born with the disease, feel that being infected is a shame and should not be shared with others, as similarly explored by Simbayi in her study on internalised stigma in Cape Town (Simbayi et al. 2007). As HIV is not an easily transmittable disease, a common interpretation is that people with HIV have either done something that caused the infection – having sex with an infected person, using a contaminated sharp object, suffering a needlestick injury – or have had something done to them – having been raped, born to an infected mother or receiving infected blood. This leads to concepts of innocence and guilt. "Stigma and

blame is further compounded because many of the behaviours that lead to HIV transmission are circumscribed by society" (Whiteside 2008:117). Venables in her exploration of stigma in Kwa Zulu Natal, South Africa also refers to morality when analysing the causes of stigma (Venables 2013). The feeling of guilt and of having done something they should not have done leads to self-stigmatisation and feelings of shame.

Stigma negatively influences the take-up of ARV treatment because on the one hand, treatment is not seen as a cure and on the other hand, swallowing drugs is seen as a sign of being infected. Almost ironically, stigma may even have positive side effects. As Green notes "fear of stigma can keep people from engaging in risky sexual behaviour, to their own benefit, if by that we mean decreased morbidity and mortality" (Green 2011). Riley supports the idea of a positive correlation of stigma with safer sex practices because young people perceive themselves as vulnerable (Riley et al 2010). Stigma related to children born with the virus is less prevalent as they are not found blameworthy; however, apart from self-stigmatisation, they might experience stigma in that other parents may not want their children to play with an HIV infected child (Campbell 2010).

Access to appropriate adolescent-friendly healthcare does currently not exist in Kasese although the need is apparent and has been expressed in other studies as well (Atuyambe et al. 2009, Baryamutuma 2011). Minor ill-health conditions are treated at home within the popular and folk sector. The HIV testing and counselling and antenatal care services in the health centres and hospitals have not been deemed appropriate for adolescents because of a lack of confidentiality and unfriendly reception. Confidentiality is an important factor in relation to stigmatisation. Our interviews revealed concerns about a lack of confidentiality both about HIV test results and about consultations at healthcare centres. Privacy as well as non-judgemental interactions are important for young patients when seeking healthcare and shape their willingness to show up for testing, treatment and counselling.

In the conversations held for this study, adolescents expressed the wish and need for more information to be able to better deal with their health, particularly regarding sexual and reproductive health and HIV care. Specifically for HIV, our study reveals that more efforts are needed to inform adolescents about the use and benefits of ART as lifelong treatment in order to improve health-seeking behaviour, take-up and adherence to treatment. Suitable settings are necessary for adolescents to feel comfortable to seek such information. They voiced the desire to be trained and counselled by elders, not by their own peers. Especially young (pregnant) girls spoke emphatically about the inhospitable reception at the health facilities. It is considered unacceptable for a young girl to be pregnant, so the girl is first judged by herself, then in school when found pregnant, then again in the family when she has to disclose and finally at the health centre for ANC and childbirth. Boys and men in the great majority deny paternity and girls feel left alone and powerless. Abortion under these circumstances is often the last solution.

The Adolescent Girls Vulnerability Index states that "[v]erbal or written consent is not required from a parent or guardian before a minor client can be given family planning services." (Amin et al. 2013). This statement contradicts the information collected in Kasese. Under Ugandan law, adolescents are not allowed to use any family planning methods except condoms until the age of 18. In her study, Atuyambe found that girls look for safety and empathy which, on an institutional level, should be provided at schools and at health facilities and, on a social level, in the families and among their peers (Atuyambe et al. 2009).

6.2 Recommendations

The following recommendations are drawn from the analysis of the field research, exchanges with national and international MSF staff working in Kasese and discussions and debriefings with the HoM. Informal discussions with colleagues at project level and discussions with other medical anthropologists have also been integrated into the analysis. An extended literature review of articles and books related to HIV/AIDS, sexual and reproductive health, adolescents, and health-seeking behaviour was carried out prior to the field research and was continued after the mission. Finally, the anthropologist's own field experience with MSF, especially in contexts of HIV/AIDS and sexual and reproductive health, and particularly in Zimbabwe, Swaziland and Kenya, influenced the data analysis and the elaboration of these recommendations.

Our primary target group are adolescents. This report shows that among adolescents it is the adolescent girls who are most vulnerable to contracting an HIV infection and who also face the additional risk of an early pregnancy. Often, these girls' problems begin at home, where they lack support and protection, are forced into early marriage or have to leave their homes because of poverty. Because of these underlying causes, an intervention that targets adolescent girls and boys is not sufficient. Adolescents live in an environment that can be beneficial or detrimental to their health. This social environment comprises initially and primarily parents or guardians and later school teachers, matrons and patrons, religious leaders, *boda-boda* riders and other transporters.

As we have explored and know about the difficulties that adolescents face, a more preventive approach should shift to the key questions "What do girls (and boys) need?" and not "What problems do girls have?".

There is a wide spectrum of areas where general improvements should be made:

- family planning;
- emergency contraception;
- maternal care;
- STI/HIV/AIDS testing and care;
- protection against harmful traditional practices like widow inheritance (primarily in rural areas);
- and information, education and communication (IEC) activities with parents/guardians, service providers, school teachers, NGOs, religious bodies, high-risk male groups, and community leaders on sex, life skills, substance abuse, nutrition and hygiene, etc., working on the attitudes, risk perception, risky behaviours and protection.

PRIORITISED KEY RECOMMENDATIONS⁵⁹

Recommendations are categorised and presented according to the study objectives. They are to be understood as general recommendations to achieve adolescent-friendly services, i.e. they are directed at MSF and the Ministry of Health in Kasese.

General recommendations

→ Do not separate boys and girls but divide adolescents into age groups for information sessions.

→ Provide recreational activities like handicraft, tailoring and hairdressing for girls, and football, netball, watching movies, listening to music or dancing classes for all adolescents.

Educational and informational material at the Kasese Adolescent-Friendly Centre

Provide educational and informational material for girls and boys covering the male and female body, menstruation, conception, sexual intercourse, pregnancy, the baby in the womb (pictures), childbirth, ANC, breastfeeding, etc.

⁵⁹ These recommendations should be seens as a priority. More detailed recommendations follow below.

Discussing sexual and reproductive health and topics related to HIV/AIDS and abortion

- → For younger adolescents (age 10-13 or even up to age 15), the 'Auntie Stella' tools can be used. Certain subjects within the tool are also suitable for older adolescents: http://www.tarsc.org/auntiestella/index.php/site/frame/activity/topics/
 Other useful tools can be found through this Dropbox link: https://www.dropbox.com/s/k3hr610z3dtoouh/tools%20for%20sexuality%20education.zip?dl=0)
- → Provide a special room at the Kasese Adolescent-Friendly Centre where adolescents can come to address any problems, challenges or questions they might have and get advice in a confidential and youth-friendly atmosphere.

HIV testing and counselling

- → Select well-trained counsellors from an older age group (above 25), as adolescents prefer to be advised on health-related issues by educated and well-trained people.
- Make sure that the counsellors respect confidentiality and have an adolescent-friendly attitude,
 - showing empathy;
 - understanding adolescents' problems;
 - being open, non-judgmental, respectful and authentic;
 - recognising individual differences, etc.
- → Have peer educators and counsellors in addition to the trained, older counsellors.

Family planning – contraceptives

→ Design and implement an advocacy strategy addressed to the MoH to promote family planning for adolescent girls at least from the age of 14 onwards.

Activities in the communities

- Involve the community to identify ways of linking adolescents to the Kasese Adolescent-Friendly Centre as the community knows best about the adolescents' healthcare needs and preferences.
- → Organise information sessions on different topics in the different areas ('villages') of Kasese town. Address the subject of how parents can protect their children and contribute to risk reduction by creating a supportive and positive environment.

Parents/teachers

→ Organise workshops on adolescents' sexual and reproductive health, needs and vulnerabilities, gender inequalities, etc. with parents and schoolteachers in their role as guardians for the adolescents in schools. Engage them in dialogue activities and together develop ideas how they can best support adolescents.

Boda-boda riders and other transporters

→ Sensitise boda-boda riders about the consequences of their behaviour for young girls. Instead of 'teaching' them how to behave, discuss WITH them about what 'we' (they and MSF) could do. A dialogue workshop would be most suitable to develop activities and messages together.

Sexual and gender-based violence

Provide mental health support for adolescents who have been raped or have experienced other forms of abuse and sexual and gender-based violence.

Condom use

- → Offer separate information and training on condom use for boys and girls at the Kasese Adolescent-Friendly Centre.
- → Train adolescent girls on condom negotiation skills

THE ADOLESCENT-FRIENDLY CENTRE - KAC

The MoH/MSF centre is currently set up to offer comprehensive healthcare comprising multi-disease diagnosis for Malaria and waterborne diseases, HIV testing and counselling and linkage to care, TB screening, testing and linkage to care, laboratory support for viral load point-of-care testing and Early Infant Diagnosis (EID), ANC and general medical consultations. To broaden its spectrum of services, paramedical and non-medical activities should be taken up in the future as well.

General recommendations

In the interviews, adolescents made some suggestions on which offers they would appreciate apart from the healthcare services.

- → Do not separate boys and girls but separate them in age groups for information sessions.
- Provide recreational activities like handicraft, tailoring and hairdressing for girls, and football, netball, watching movies, listening to music or dancing classes for all adolescents.
- → Discuss opening hours with the adolescents (taking into account darkness, weekends, church visits, boarding school students, etc.).
- → Make sure you can provide food and drinks for HIV positive adolescents coming for their drugs, while they are waiting for their turn.
- → Have a corner with computers and internet access for adolescents.
- → Have a small library with books and journals.

Educational and informational material at the KAC

All adolescents, but mainly the girls, expressed the wish to get more information about the human body with regard to SRH and HIV care.

- → Provide educational and informational material for girls about the female body, menstruation, conception, sexual intercourse, pregnancy, the baby in the womb (pictures), childbirth, ANC, breastfeeding, etc. Offer an opportunity for the girls to discuss these issues and ask questions.
- → Provide educational and informational material for boys and inform them about the male and the female body, about conception, family planning, etc.
- → Provide education sessions with specific information about the female body and the male body.
- → Talk about human rights for women/girls, the value of a woman/girl and about why a society needs healthy women.
- Sensitise the adolescent about gender inequalities, discuss the causes and formulate solutions together with them.

Discussing sexual and reproductive health and topics related to HIV/AIDS and abortion

Different age groups have to be addressed differently and the topics have to be adjusted to each group.

- Provide play therapy.
- → For younger adolescents (age 10-13 or even up to age 15), the 'Auntie Stella' tools can be used. Certain subjects within the tool could also be used for discussions with older adolescents. http://www.tarsc.org/auntiestella/index.php/site/frame/activity/topics/. Other useful tools can be found in the Dropbox link:
- https://www.dropbox.com/s/k3hr610z3dtoouh/tools%20for%20sexuality%20education.zip?dl=0)
- → Another participatory working tool is to let the younger (HIV positive) adolescent make drawings to explore their subjective experience with their health in general and with HIV/AIDS specifically (see also Campbell et al. 2010).

- → Provide a special room where adolescents can come to address any problems, challenges or questions they might have and get advice in a confidential and youth-friendly atmosphere. The adolescents themselves suggested that this room could be called:
 - Adolescent Expressions
 - Adolescents Login
 - Comfort Zone
 - Adolescents Unit
 - Comfort Voice
 - Adolescents Care
 - Adolescents Express

HIV testing and counselling

Confidentiality and privacy is a burning issue mentioned in almost all interviews and should be addressed adequately at the MoH/MSF centre.

- → Make sure that HIV testing and counselling takes place in a discrete, private room to avoid that others point their fingers at adolescents using these services.
- → Select well-trained counsellors from an older age group as adolescents prefer to be trained by their elders on health-related issues.
- → Have peer educators and counsellors in addition to the trained, older counsellors.
- → Make sure that the counsellors respect confidentiality and have an adolescent-friendly attitude,
 - showing empathy;
 - understanding adolescents' problems;
 - being open, non-judgmental, respectful and authentic;
 - recognising individual differences, etc.
- → For couple counselling, talk to the male and female adolescents individually for preparation and then bring them together for couple counselling.

Family planning - contraceptives

Knowledge and information about family planning, contraceptives and emergency contraception is lacking.

- → Design and implement an advocacy strategy addressed to the MoH to promote family planning for adolescent girls at least from the age of 14 onwards.
- → Raise awareness about contraceptives in general, and particularly about condoms through health promotion sessions.
- → Train adolescent girls on condom negotiation skills.
- → Inform adolescents about emergency contraception.

Adolescents living with HIV/AIDS

→ Make sure to create a stigma-free environment with other adolescents.

→ Develop a PhotoVoice project⁶⁰ with HIV positive adolescents. The participants are trained in the use of photography as a way to communicate what is important to them. They are encouraged to capture the details of their lives as ALWHA and of their homes that they feel others may not be aware of, but which affect their well-being and happiness.

 $^{^{60}}$ Get more information from Wang & Burris 1997 and Wilson et al.,2007.

ACTIVITIES IN THE COMMUNITIES⁶¹

Apart from the services and activities in the centre, MSF should organise activities in the communities to build a strong relationship with the adolescents and to link them to care. Community work and community outreach is based on the assumption that people in the communities know their members best, but some are afraid to talk to someone from their community because of the lack of confidentiality and stigma.

- → Show what MSF is doing and explain the services MSF provides at the KAC to create links with the community.
- → MSF should involve the community to identify ways of linking adolescents to the KAC as the community knows best about the adolescents' healthcare needs and preferences.
- → Assess the perception, conduct and acceptance of the village health teams (VHT) before linking them with the adolescents. 62
- → Organise information sessions on different topics in the different areas ('villages') of Kasese town. Provide information about HIV/AIDS but also try to address the subject of how parents can protect their children and contribute to risk reduction by creating a supportive and positive environment for their children.
- → Organise sensitisation sessions on reducing stigma and discussing why it is important to accept people living with HIV and taking ARVs in the community
- → Organise day outreach in the different areas of Kasese using existing networks and meeting places to communicate about HIV/AIDS and the related stigma. Outreach measures may include:
 - health talks (on different subjects like transmission and prevention, ARVs and the stigma related to these topics);
 - HIV counselling and testing outreach, ensuring confidentiality;
 - drama groups (create dramas proposed and provided by the adolescents coming to the KAC);
 - showing films with a positive story, with different subjects and for different audiences; moving cinema can be used, for example, moving from one area in Kasese to another one;
 - football and netball matches with MSF teams (teams from the community as they will go back to the community);
 - dancing and singing activities in the communities with songs created by the adolescents and dancing performances with a dancing group;
 - debates on certain subjects among the students in schools, also including the teacher; promote participation of the teachers and give them an important role.
- → Organise special awareness activities in the areas in Kasese that are considered more vulnerable such as Nyakasanga Village, Kisungu Village, Kilembe Mines, Railway Station and Acholi Quarters. In these areas, awareness raising activities should take place together with drama and role plays.

Parents/Teacher

MSF should include parents, teacher and matrons/patrons and sensitise them on the positive impact they can have on the health and well-being of adolescents. Moreover, schools have been defined as key arenas for stigma reduction. They can be supportive social spaces for adolescents, and teachers can help promote anti-discriminatory behaviours.

→ Discuss with adolescents from primary and secondary schools separately the subjects they think are the most important to tackle in order to improve their relationship with parents and teachers.

⁶¹ Since the MSF project is more focused on the adolescent-friendly centre, the recommendations/community mobilisation and preventive interventions will be prioritised taking into account the feasibility and the potential impact of the interventions on the adolescents' problems.

⁶² Confidentiality issues regarding the VHT were reported.

- → Have separate activities such as workshops on adolescents' SRH, needs and vulnerabilities, gender inequalities, etc. with parents and schoolteachers in their role as guardians for the adolescents in schools. Engage them in dialogue activities and together develop ideas how they can best support adolescents.
- → Attribute importance and responsibility to parents and teachers and empower them to assume the role of protectors of the adolescents. The main objective is that parents and teachers create a supportive rather than a punitive environment for adolescents.

Boda-boda riders and other transporters

Boda-boda riders should be targeted because they are at great risk of getting infected with HIV and spreading the virus to their sexual partners, particularly to adolescent girls.

- → Sensitise boda-boda riders about the consequences of their behaviour for young girls. Instead of 'teaching' them how to behave, there should be a discussion WITH them on what 'we' (they and MSF) could do. A dialogue workshop would be most suitable to develop activities and messages together.
- → Consider founding a *boda-boda* football club of positive and responsible out-of-school adolescents. Messages such as 'I am responsible, I care' could be used, referring to their interaction with young female adolescents and the fact that they get them pregnant.
- Promote condom use for their own protection and to protect the girls.
- → Address the problems and challenges with them in workshops and collectively work on an approach they own and accept.
- → Provide *boda-boda* riders who want to participate in such awareness raising activities with shirts with a positive slogan they have created themselves. The slogan should help strengthen their selfesteem and present them as responsible men.

Sexual and gender-based violence

For many girls, the first sexual experience comes with domestic sexual violence and rape.

- → Provide mental health support for adolescents who were raped or have experienced other forms of abuse and SGBV.
- → Together with adolescents, find an appropriate name for the room where such support is provided to avoid stigmatisation. Ensure that the name does not evoke the idea of HCT counselling.

Condom use

To achieve effective condoms use, adolescents have to be trained on consistent and correct use:

- using a new condom for each act of intercourse;
- putting the condom on correctly before any genital contact;
- withdrawing while the penis is still erect and holding the condom firmly to keep it from slipping off;
- using only water-based and not petroleum-based lubricants (because condoms can be damaged by petroleum jelly, mineral oil, vegetable oil, cold creams, body lotions, and several antifungal medications).

The most important errors that lead to disappointment are breakage, slippage, and failure to use throughout intercourse.

- Offer information and training on condom use for girls and boys separately at the KAC.
- → Provide additional dialogue workshops with parents and teacher on attitudes towards condoms.
- Practice condom use with adolescents.
- → Encourage adolescents to train and practice condom use through masturbation.
- Provide adolescent-friendly condoms (appealing colours, packaging and taste).
- → Promote the idea that condom use is 'manly', using messages such as 'I am a strong and responsible man, I do not harm'.
- → Train adolescent girls on condom use and condom negotiation skills.

Socio-economic context

Adolescents and especially girls face economic deprivation and are forced into risky sexual and multipartner relationships.

- → Provide income-generating activities such as gardening, chicken breeding, handicraft, etc. to create a more supportive and secure environment to reduce poverty and transactional sex for adolescent girls.
- → Cooperate with another NGO who provides such activities (if MSF will not do it).

7 Conclusion

In this project in Kasese, MSF-OCP has initiated a community mobilisation program with the primary objective of improving access to comprehensive sexual and reproductive health care, including HIV care for adolescents in Kasese town. A qualitative study was conducted to better understand adolescents' health-seeking behaviours and their subjective experience with SRH and HIV care and to provide input for an adolescent-friendly community mobilisation program.

Adolescents are the population most at risk of contracting an HIV infection. Although they recognise HIV/AIDS as a major threat to their health, they still accept and engage in high-risk behaviour. They neglect the use of condoms as they feel uncomfortable with them or have misconceptions about the consequences of their use. The most vulnerable group are adolescent *girls*. Negligence and abandonment by their families and financial deprivations force them into a vicious circle of engaging in risky sexual relationships such as transactional and survival sex.

Adolescent-friendly healthcare services should focus on an intervention that helps adolescents to reflect on the consequences of their risky sexual practices by promoting responsible sexual behaviour and condom use. Specific attention should be given to strengthening their life skills related to HIV transmission/prevention and prevention of early pregnancy. The MSF community mobilisation programme will address gender inequalities and emphasise behavioural interventions that empower boys and especially girls to practice safer sex.

8 Annex

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8.2 Anthropologist's work programme in Kasese

week 1

Tuesday	03 November	Arrival in Kampala
Wednesday	04 November	Briefings at Coordination
Thursday	05 November	Travel to Kasese, briefings
Friday	06 November	1 HIV counsellor, 2 clinical officer, 3 HIV positive boy on ART
Saturday	07 November	4 HIV negative boy, 5 HIV negative girls, 6 HIV positive boy
Sunday	08 November	

week 2

Monday	09 November	7 GD adolescent girls out-of-school			
Tuesday	10 November	8 peers CSW, 9 GD 2 boys out-of-school, 10 GD 4 boys out-of-school			
Wednesday	11 November	11 fisherman, 12 fisherman, 13 LC1, 14 clinical officer			
Thursday	12 November	15 caretaker female, 16 GD 3 girls in-school (PS), 17 GD 3 boys in-schoo (PS), 18 GD 2 boys 2 girls in-school (SS)			
Friday	13 November	19 GD 3 boys in-school (PS), 20 GD 3 girls in-school (PS), 21 HIV positive girl on ART, 22 HIV positive boy on ART, 23 peer CSW, 24 CSW			
Saturday	14 November	25 CSW, 26 peer CSW, 27 boy in-school			
Sunday	15 November				

week 3

Monday	16 November	28 HIV positive girl, 29 GD street kids, 30 street kid coordinator, 31 caretaker female			
Tuesday	17 November	32 GD <i>boda-boda</i> rider, 33 GD <i>boda-boda</i> rider			
Wednesday	18 November	34 teenage mother, 35 young girls pregnant			
Thursday	19 November	36 GD 2 boys out-of-school, 37 2 boys out-of-school, 38 peer educator, 39 HIV positive girl on ART			
Friday	20 November	40 GD 3 boys out-of-school, 41 young boy in-school, 42 HIV positive girl on ART, 43 GD 4 boys out-of-school, 44 GD 2 girls (1 on ART), 45 young girls on ART, 46 young girl on ART			
Saturday	21 November				
Sunday	22 November				

week 4

Monday	23 November	47 peer educator, 48 GD 2 boys in-school, 49 GD 2 girls in-school, 5			
		girls in-school			
Tuesday	24 November	51 GD 2 boys in-school (PS), 52 2 boys in-school (SS), 53 teenage			
		mother, 54 teenage mother			
Wednesday	25 November	55 GD 2 girls in-school (SS), 56 girl in-school (SS), 57 boy in-school (SS)			
Thursday	26 November	58 HIV positive girl pregnant, 59 visit private clinic			
Friday	27 November	Presentation of first findings to Kasese team			
Saturday	28 November	60 healthcare provider/midwife			
Sunday	29 November				

week 5

Monday	30 November	Travel from Kasese to Kampala
Tuesday	01 December	Debriefings, departure from Kampala
Wednesday	02 December	Arrival in Vienna

8.3 Interviewees' profiles

Interview code	Date	Interviewee profile	Sex	Age	education
1_IDI_HCP_F	FR 06/11	Healthcare provider HIV counsellor	F	35	higher
2_IDI_HCP_F		Healthcare provider clinical officer	F	25	higher
3_IDI_ADO_M		HIV positive adolescent on ART, out of school	M	16	middle
4_IDI_ADO_M	SA 07/11	Adolescent in-school Form 4	M	19	middle
5_IDI_ADO_F		Adolescent out-of-school	F	18	middle
6_IDI_ADO_M		Adolescent in-school Form 3	M	15	middle
7_GD_ADO_F	MO 09/11	Adolescent out-of-school girl 1	F	16	low
		Adolescent out-of-school girl 2	F	13	low
		Adolescent out-of-school girl 3	F	13	low
		Adolescent out-of-school girl 4	F	14	low
		Adolescent out-of-school girl 5	F	17	middle
		Adolescent out-of-school girl 6, pregnant	F	17	low
		Adolescent out-of-school girl 7, has a baby	F	17	low
8_GD_PEER_F	TUE 10/11	Peer for commercial sex workers	F	28	middle
		Peer for commercial sex workers	F	32	middle
9_GD_ADO_M		Adolescent out-of-school boy 1	M	16	low
		Adolescent out-of-school boy 2	M	16	low
10_GD_ADO_M		Adolescent out-of-school boy 1	M	17	low
		Adolescent out-of-school boy 2	M	18	middle
		Adolescent out-of-school boy 3	M	18	middle
		Adolescent out-of-school boy 4	M	18	middle
11_IDI_ADO_M	WE 11/11	Fisherman	M	19	low
12_IDI_Fisherman_M		Fish boat owner	M	28	middle
13_IDI_LC1_M		Local council 1	M	53	middle
14_IDI_HCP_M		Healthcare provider clinical officer	M	35	higher
15_IDI_CT_F	THU 12/11	Caretaker, pregnant woman	F	26	higher
16_GD_ADO_PS_F		Adolescent in-school girl 1 Primary school	F	10	middle
		Adolescent in-school girl 2 Primary school	F	13	middle
		Adolescent in-school girl 3 Primary school	F	14	middle

		T	T		
17_GD_ADO_PS_M		Adolescent in-school boy 1 Primary school	М		middle
		Adolescent in-school boy 2 Primary school	М	-	middle
		Adolescent in-school boy 3 Primary school	M	-	middle
18_GD_ADO_SC_M+F		Adolescent in-school boy 1 Secondary School	M	18	middle
		Adolescent in-school girl 1 Secondary School	F	16	middle
		Adolescent in-school girl 2 Secondary School	F	18	middle
		Adolescent in-school boy 2 Secondary School	M	18	middle
19_GD_ADO_PS_M	FR 13/11	Adolescent in-school boy 1 Primary School	M	12	middle
		Adolescent in-school boy 2 Primary School	М	12	middle
		Adolescent in-school boy 3 Primary School	М	12	middle
20_GD_ADO_F		Adolescent in-school girl 1 Primary School	F	11	middle
		Adolescent in-school girl 2 Primary School	F	15	middle
		Adolescent in-school girl 3 Primary School	F	13	middle
21_IDI_ADO_F		Adolescent in-school girl, raped, HIV positive on ART	F	12	middle
22_IDI_ADO_M		Adolescent in-school boy, HIV positive on ART	M	12	middle
23_IDI_PEER_CSW_F		Peer at Baylor for commercial sex worker	F	32	middle
24_IDI_CSW_F		Commercial sex worker at the Moonlight outreach with Baylor	F	27	low
25_IDI_CSW_F	SA 14/11	Commercial sex worker at the Moonlight outreach with Baylor	F	29	low
26_IDI_PEER_CSW_M		Peer at Baylor for commercial sex worker	М	43	higher
27_IDI_ADO_M		Adolescent at moonlight outreach in school Senior 4	M	18	middle
28_IDI_ADO_F	MO 16/11	Adolescent girl HIV positive, raped at IPD	F	17	low
29_GD_ADO_SK_M+F		Adolescent street kid 1	F	14	low
		Adolescent street kid 2	М	10	low
		Adolescent street kid 3	М	10	low
		Adolescent street kid 4	М	15	low
		Adolescent street kid 5	М	19	low
		Adolescent street kid 6	М	25	low
		Adolescent street kid 7	М	12	low
		Adolescent street kid 8	М	17	low
		Adolescent street kid 9	М	16	low
30_IDI_Coord_SK_M		Coordinator of the street kids	М	38	middle
31_IDI_CT_F		Caretaker of HIV + girl at the IPD	F	40	low
	I	<u> </u>			

32_GD_boda-boda_M TUE 17/11	Boda-Boda bicycle driver 1 out-of-school	М	18	middle
	Boda-Boda bicycle driver 2 in school	М	22	higher
	Boda-Boda bicycle driver 3	М	22	middle
33_GD_boda-boda_M	Boda-Boda motor bike driver 1	М	25	middle
	Boda-Boda motor bike driver 2	М	19	middle
	Boda-Boda motor bike driver 3	М	30	middle
	Boda-Boda motor bike driver 4	М	24	middle
	Boda-Boda motor bike driver 5	М	25	middle
	Boda-Boda motor bike driver 6	М	18	middle
34_IDI_ADO_F WE 18/11	Young girl with a baby, out of school	F	17	low
35_IDI_ADO_F	Young pregnant girl, out of school	F	17	low
36_GD_ADO_M THU 19/11	Adolescent out-of-school boy 1	М	18	middle
	Adolescent out-of-school boy 2	М	17	middle
37_GD_ADO_M	Adolescent out-of-school boy 1	М	19	low
	Adolescent out-of-school boy 2	М	17	middle
38_IDI_PEER_M	Project officer at Nacwola and peer educator for Baylor	М	43	higher
39_IDI_ADO_F	Adolescent out-of-school girl on ART	F	18	low
40_GD_ADO_M FR 20/11	Adolescent out-of-school boy 1	М	19	low
	Adolescent out-of-school boy 2	М	18	middle
	Adolescent out-of-school boy 3	М	18	low
41_IDI_ADO_M	Adolescent in school at Kilembe Mines	М	17	middle
42_IDI_ADO_F	Adolescent out-of-school girl on ART	F	18	low
43_GD_ADO_M	Adolescent out-of-school boy 1	М	14	low
	Adolescent out-of-school boy 2	М	18	low
	Adolescent out-of-school boy 3	М	16	low
	Adolescent out-of-school boy 4	М	16	low
44_GD_ADO_F	Adolescent out-of-school girl 1	F	14	low
	Adolescent in-school girl 2	F	10	low
45_IDI_ADO_F	Adolescent in-school girl on ART	F	15	low
46_IDI_ADO_F	Adolescent out-of-school girl on ART	F	19	low
47_IDI_PEER_M MO 23/11	Project coordinator at Reach the Youth	М	35	higher
48_GD_ADO_M	Adolescent in-school boy 1	М		higher

		Adolescent in-school boy 2	М	18	higher
49_GD_ADO_F		Adolescent in-school girl 1	F	15	low
		Adolescent in-school girl 2	F	15	low
50_GD_ADO_F		Adolescent in-school girl 1	F	13	low
		Adolescent in-school girl 2	F	15	low
		Adoelscent in-school girl 3	F	15	low
51_GD_ADO_M	TUE 24/11	Adolescent in-school boy 1	M	12	low
		Adolescent in-school boy 2	M	13	low
52_GD_ADO_M		Adolescent in-school boy 1	M	15	higher
		Adolescent in-school boy 2	M	15	low
53_IDI_ADO_F		Adolescent out-of-school girl, 2 children	F	18	low
54_ADI_ADO_F		Adolescent out-of-school girl, 1 child	F	18	low
55_GD_ADO_F	WE 25/11	Adolescent in-school girl 1	F	12	low
		Adolescent in-school girl 2	F	12	low
56_IDI_ADO_F		Adolescent in-school girl	F	16	middle
57_IDI_ADO_M		Adolescent in-school boy	M	19	middle
58_IDI_ADO_F	THU 25/11	Adolescent out-of-school girl on ART, pregnant	F	18	low
59_IDI_NURSE_M		Visit to a private clinic in Kasese	М	35	higher
60_IDI_MIDWIFE_F	SA 27/11	Healthcare provider midwife	F	42	higher

8.4 Map of Uganda



8.5 Map of Kasese district

