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# Fertility and HIV Infection

## Fertility Decision-making Challenges of Mutually-Disclosed Discordant Couples and Young People



**Jolly Beyeza-Kashesya**



**Makerere University**



**Karolinska  
Institutet**



From the Department of Obstetrics/Gynaecology, Makerere  
University College of Health sciences, Kampala, Uganda

and

The Division of Global Health (IHCAR), Department of Public  
Health Sciences, Karolinska Institutet, Stockholm, Sweden

# **Fertility and HIV Infection: Fertility Decision-making Challenges of Mutually- Disclosed Discordant Couples and Young People**

**Jolly Beyeza-Kashesya**



**Makerere University**



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*This thesis is dedicated to my mother with  
love and cherished memories*

## ABSTRACT

**Background:** Sexuality and reproduction in mature generalised HIV epidemics pose significant dilemma to both HIV infected and negative people. Sexually active young people and HIV sero-discordant couples are faced with difficult decision-making about procreation and HIV transmission. Insufficient data exists about fertility decision-making and how to handle sexuality and fertility among the HIV-infected youth and mutually disclosed discordant couples.

**Aim:** To explore the influence of HIV on fertility decision-making among young people and people in HIV-discordant relationship in Uganda

**Methods:** The four studies used qualitative (focus group discussions - study I, II, and III) and quantitative methods (semi-structured questionnaire - study III and IV). We explored the views of the youth on reasons for high fertility in Uganda and how decisions are made among the youth in the general population (study I) and among HIV-infected youth (study II). A cross sectional study (study III) assessed fertility decision-making among the discordant couples, and a prospective cohort (study IV) assessed how HIV-infected and negative youth sustain their fertility decisions over a period of one year. Thematic and content analysis were used for qualitative data and uni-variate, bi-variate and multivariate analysis for the quantitative data.

**Results** Patriarchy, culture and religion contribute to sustaining high fertility in Uganda (paper I). The majority (57%) would like to have children but have to grapple with the dilemma of HIV transmission to partner (paper II and III). Less than a half (44%) among the HIV-infected youth compared to two thirds (61%) among the HIV-negative youth made a consistent fertility decision, OR = 0.52 (0.38, 0.70). In total, 24% among the HIV-negative and 18% among the HIV-infected continued to use contraception throughout the year, OR 0.63 (0.41, 0.98), while 12% and 28% among the HIV-negative and infected respectively did not use contraception, OR 2.80 (1.80, 4.36) (paper IV).

**Conclusions:** Young people in central Uganda are still strongly influenced by the patriarchal, cultural and religious norms with the male gender enjoying a superior position. This compels women to desire many boys for their security and happiness (paper I). Many HIV sero-discordant couples in central Uganda desire to have children and are planning to conceive but the highest desire for children is among the young people (paper III, IV). The desire to have children hinders safe sex practice among HIV sero-discordant couples (paper II). The discordant couples committed to condom use have to risk HIV transmission, or look for a sero-concordant partner to get children. Others seek high-risk concurrent partnerships for children and sexual pleasure (paper II). HIV infected youth are not empowered to practice or sustain consistent contraceptive use or adopt preventive strategies” (paper I, IV). The current dialogue with health workers is not increasing contraceptive use, especially among the HIV-infected youth (paper IV).

**Implications:** Uganda’s cultural norms still favour high fertility and having HIV infection cannot remove the quest to fulfil patriarchal obligations. If not assisted, PLHIV will continue to practice high-risk sex to reproduce. A multi-sectoral approach uniting cultural, political and public institutions is needed to design programs that may stem the HIV epidemic. Strengthening family planning services should include planning for conception for the PLHIV. Critically, in addition to the need for the cultural re-learning processes to desire less children, we need to introduce low-cost harm reduction techniques for reproduction (timed intercourse, sperm washing) to assist PLHIV who want to have children to do so with minimal HIV transmission.

**Keywords:** Young people, HIV-infected, HIV discordant couples, Fertility decision-making, Uganda.

## LIST OF PUBLICATIONS

This doctoral thesis is based on the following papers, referred to in the text by their Roman numerals:

- I. Jolly Beyeza-Kashesya, Stella Neema, Anna Mia Ekström, Frank Kaharuza, Florence Mirembe and Asli Kulane.** “Not a boy, not a child”: A qualitative study on young people’s views on childbearing in Uganda.

*African Journal of Reproductive Health, March 2010; 14(1): 71-81*

- II. Jolly Beyeza-Kashesya, Frank Kaharuza, Florence Mirembe, Stella Neema, Anna Mia Ekström and Asli Kulane.** The dilemma of safe sex and having children: Challenges facing HIV sero-discordant couples in Uganda.

*African Health Sciences Vol. 9 (1) 2009: 2-12*

- III. Jolly Beyeza-Kashesya, Anna Mia Ekström, Frank Kaharuza, Florence Mirembe, Stella Neema, and Asli Kulane.** My partner wants a child: Determinants of the desire for children among mutually disclosed sero-discordant couples attending HIV/AIDS care in Uganda.

*BMC Public Health 2010, May 13; 10:247*

- IV. Jolly Beyeza-Kashesya, Frank Kaharuza, Anna Mia Ekström, Stella Neema, Asli Kulane and Florence Mirembe.** To use or not to use condoms: A comparison of contraceptive practices among HIV-infected and HIV-negative youths in Uganda.

*Manuscript submitted to BMC Infectious Diseases*

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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency syndrome
ANC	Antenatal care
ART	Anti- retroviral therapy
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
CPR	Contraceptive Prevalence Rate
FGD	Focus group discussion
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interviews
IUGR	Intra Uterine Growth Retardation
KII	Key Informant Interviews
LC	Local Council
MOH	Ministry of Health
PI	Principal Investigator
PLHIV	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission of HIV
MTCT	Mother to Child Transmission of HIV
RH	Reproductive Health
SEM	Social ecological model
STI	Sexually Transmitted Infections
TASO	The AIDS Support Organisation
TDIB	Traits, Desires –Intentions and Behaviour
TFR	Total Fertility Rate
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic and Health Survey
UHSBS	Uganda HIV sero-behavioural survey
UNAIDS	United Nations Programme on HIV/AIDS
UN	United Nations
UNFPA	United Nations Population Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

## **PREFACE**

Born fourth of the six siblings of mom and eighth of eighteen children of my dad meant that I was insignificant and voiceless. In addition, following the only boy child amongst five girls of my mother did not make things better. I would wonder as a child why mothers but especially fathers continue to beget children they are not interested in. I recall incidents when the old man (Dad) would forget names and start calling: Jeninah...Peninah/John...Ben.. *eeh "iwe nanka"* (meaning "you, the name not coming"). I would wonder whether all the many children mattered to him, and yet his younger wife was still giving birth. Later when I grew up, some explanations trickled in from the way mother referred to us as girls, but more so when she would once in a while say that she has only one child (meaning one boy) and five girls. My confusion did not stop at my mother's not getting boys as an explanation for my father's continued reproduction. His last wife continued to give birth even when she had several boys till she stopped at a whopping four boys and six girls!

Later during my medical training, I kept wondering why someone would not use contraception when they were sexually active but did not want to have children. My curiosity about fertility was increased when I lost two of my younger sisters to HIV. One had children the other did not. I vividly recall how the loss of these two girls affected our mother differently because one had left some children and the other had not. The grief of the first daughter leaving no children was stronger than the grief of having no one to look after the orphans left behind by the second one.

Working as an obstetrician and gynaecologist, working with Associate Prof. Florence Mirembe on adolescent sexual and reproductive health program for pre-service health personnel (many of them young people) rekindled my interest for fertility issues. The enthusiasm with which they discussed sexuality and reproduction was awesome. When I was offered a slot for PhD on the Makerere university-Karolinska Institutet collaboration, I felt I had the chance to enter into young people's lives but more especially to understand fertility from the young peoples' perspective.

Through this study, I have learned that it is not the decision-making that matters but the steps one takes to live-out those decisions. It situates me in a strategic position to discuss with policy makers, programme managers and cultural leaders, innovations to improve sexual, reproductive health and rights not only of PLHIV but also the youth and voiceless.

# 1.0 INTRODUCTION

HIV, sexuality and reproduction are overlapping challenges in the management of the HIV epidemic. As the HIV epidemic matures in predominantly heterosexual transmission populations, reproduction becomes a central issue that needs critical attention. A considerable amount of literature has been published about desires and intentions of child bearing among HIV-infected people (1-9). Proportions of those who desire to have children vary by age, gender, ethnicity and resource settings. During the past decade, there has been rapid development of innovations to mitigate the effects of HIV infection for people living with HIV (PLHIV). Harm reduction technologies and strategies are being developed to assist HIV-infected or affected couples that wish to reproduce to do so with minimal risk of horizontal and vertical HIV transmission (10). However, despite the efficacy and safety of the low-cost assisted reproductive technologies, child bearing among HIV-infected people in low-resource countries still suffer major drawbacks in access due to both availability and affordability of such services. Furthermore, while antiretroviral therapy (ART) undoubtedly reduces HIV transmission (through reducing viral load) (11-13), access is still sub-optimal (14-16).

The generalisability of most published research on fertility and HIV is also challenging. Most of the research on fertility among HIV-infected people in Uganda and Sub-Saharan Africa has included older people and yet most of the women in low-resource countries begin childbearing in their teens (17). Using these data underestimates the desire for childbearing and is misleading for making inferences for HIV programmes and reproductive health services. Furthermore, HIV infection among young people and among the increasing number of HIV sero-discordant couples present one of the most challenging phenomena in future HIV prevention. There is also insufficient data on fertility desires among HIV-infected youths and discordant couples who mutually know that they are HIV sero-discordant. Uncertainty exists about fertility decision-making and how to handle sexuality and fertility among the HIV-infected youth and discordant couples. The purpose of this thesis is to discuss the influence of HIV on fertility decision-making among HIV-infected people; especially the youth and people in HIV-discordant relationship in Uganda, a country with the second highest fertility rate in the world and a high burden of HIV. We explored the views of the youth on reasons for high fertility in Uganda and how decisions are made. In addition, we assessed fertility decision-making among the youth and discordant couples; and compared how HIV-infected and HIV-negative youth sustain their fertility decisions over a period of one year.

## *1.1 Global HIV Epidemiology*

Globally, the number of PLHIV is estimated to be 33.4 million (31.1 – 35.8 million). In 2008, about 430,000 new infections worldwide occurred in children and the majority were through mother to child transmission (16). Countries with mature epidemics have longevity of survival and some HIV-infected children are reaching adolescence and require special sexual and reproductive programming. Sub-Saharan Africa remains the most heavily affected region, with only 10% of the world's population but accounted for 71% of all new HIV infections in 2008 (16).

## ***1.2 HIV among the youth in Uganda***

Worldwide, there has been a slight reduction in the incidence of new HIV infections among the youth. However, HIV among the youth is still a growing concern because almost 40% of the new infections worldwide occurs among the youth (18). Some of the key determinants of vulnerability include high prevalence of intergenerational relationships. This leads young women to be disproportionately more affected than the young men. While 60% of the HIV-infected among adults are women, 75% among the infected youth are girls. (14)

## ***1.3 HIV sero-discordant couples***

In mature HIV endemics, HIV sero-discordance becomes an important issue for HIV prevention strategies. HIV discordance rate among stable relationships in many sub-Saharan countries is high (19). In Africa, between 5-31% of married or cohabitating couples live in a sero-discordant relationship (14, 20-23). In Uganda, 5% of married or cohabitating couples are discordant (14) and 49% of couples presenting for HIV-testing when one partner is HIV-infected, are sero-discordant (24). In addition, many cohabiting couples do not mutually know their HIV status (25). Incidence modelling estimates that 43% of all new HIV infections in adults (15-49 years) in 2008 were among people in discordant monogamous relationships (15). Most cohabiting couples do not know each other's HIV status, but, sexual relationships remain a challenge among mutually disclosed sero-discordant couples (25).

The process of rolling-out ART has made it possible for HIV-infected people to live a longer and healthier life and many will contemplate childbearing. However, sero-discordant couples face the dilemma of both possible horizontal and vertical HIV transmission. Moreover, only half of those in need of ART are able to have access to treatment (16).

## ***1.4 HIV and sexual and reproductive health and rights***

Most (82%) of the new HIV infections occur through heterosexual transmission. About 37% of all new infections result from multiple sexual partnerships, and 9% from transactional sex (15). Over 90% of these newly infected individuals are of reproductive age.

### **1.4.0 Reproductive health in Uganda**

Uganda's total fertility rate (TFR) remains unchanged and high for over the last six decades (6.9 children per woman in 1950, and 6.7 children per woman in 2007 (26, 27). This is the second highest TFR in the world after Niger's 7.7 children per woman (28). Although adolescent pregnancies have reduced significantly from 45% in the 1990s to 25% in 2006, childbearing in Uganda continues to start very early and end very late in life, with short birth intervals (17). Studies show that short birth intervals are associated with adverse child outcomes compared to those separated by a longer birth interval (29). In Uganda, 25% of non-first births occur within 24 months of the previous birth. The current growth rate of 3.2% translates into approximately 1.2 million additional people per year. Intimately related to high fertility are the high rates of maternal mortality (435/100,000 live births) and infant mortality (76/1,000 live births) (17). The unmet need for family planning has been steadily growing over the years. UDHS data show that

the unmet need for family planning was 29% in 1995, 35% in 2001 and 41% in 2006 (17) Table 1. Reducing the unmet need for family planning could directly contribute to reductions in Uganda's high maternal and child mortality. More important is the added benefit of reducing the high fertility rates and unintended pregnancies; but also it would avert the high rates of mother-to-child transmission (MTCT) of HIV/AIDS among the HIV-infected women. However, Uganda's contraceptive prevalence continues to be very low (24%). To this end, Uganda developed a strategy to improve reproductive health (2005-2010) which seeks to increase access to institutional deliveries and emergency obstetric care, strengthen provision of family planning services and implementation of goal-oriented antenatal care (ANC) (30). However, the majority (86%) of women (both HIV-infected and HIV-negative) find difficulties in accessing health care. The main reasons for not accessing care include: the lack of money to pay for treatment, transport and long distance to the health facility, no medicines at the health units and more than 1 in 4 also reported the lack of health workers at the health unit as a reason for not accessing health care (17).

#### **1.4.1 Reproductive health and the youth**

Initiation of reproduction in Uganda closely follows coitache, and the median age at first birth is 18 years (31). High adolescent pregnancy rates (25% among 15-19 year olds) contribute to the high fertility rates. In Uganda, 80% of young women already have children by 24 years and about 20% of them have 3 or more children (17). Moreover, only 5% of 15-19 year-old and 17% of 20-24 year-old women respectively are using modern methods of contraception (17). Yet adolescent pregnancies and births are associated with increased maternal and foetal complications (32, 33). In addition, studies among young people reported enormous obstacles to safe motherhood and parenting because of socio-economic and cultural factors (34, 35). Pregnant youth often lack basic needs of food, shelter and security (34), but more importantly, they have poor health seeking practices which puts them at even greater risk of fatal pregnancy related complications (36). Besides, few clinics are youth friendly enough to handle adolescents (37). Furthermore, an HIV infected woman has an increased risk and severity of maternal complications and adverse foetal/neonatal outcomes (38-40). A study among HIV-infected women from Uganda reported that sharper declines in CD4 cells may occur during pregnancy compared to the non-pregnant states although the study did not register excess mortality or progression to AIDS among the pregnant women compared to the non-pregnant (41).

**Table 1 Trends of selected SRH indicators: Uganda**

<b>Indicator</b>	<b>1991</b>	<b>1995</b>	<b>2002</b>	<b>2007</b>
Maternal Mortality Rate per 100,000 live births	527	506	505	435
Infant Mortality Rate per 1,000 live births	122	81	88	76
Adolescent pregnancy (%)	44	43	32	25
ANC attendance (four visits) %			42	47
Deliveries by skilled attendant (%)	38	38	38	41
Contraceptive prevalence	5	15	23	24
Unmet need for contraception	54	29	35	41
Total fertility rate	7.1	6.9	6.9	6.7
HIV prevalence (%)	30	15	6.1	6.4
Literacy rate (%)	54	65		69
Life expectancy (%)	48	46	51	51
Population below poverty line, < US\$1(%)	56	35	38	31

*Source: (UBOS, 2007; UNFPA, 2008; UNDP, 2009)*

### **1.4.2 HIV and multiple concurrent partnerships**

The “Abstain, Be faithful to one partner or use a Condom” (ABC) program has been applauded for reducing HIV/AIDS in Uganda. Neema et al report that about 69% and 72% of adolescent females and males respectively abstain from sex to avoid sexually transmitted infections (STI) or HIV while 64% and 34% respectively do so to avoid pregnancy. Furthermore, the report states that about half of adolescent girls and boys abstained from sex and or reverted to abstinence due to pressure from their mothers (42).

However, in 2005, more than two thirds of young women aged 15-24 years were married (14) therefore cannot abstain. Moreover, 45% of married men and 5% of married women have multiple concurrent sexual partners (43, 44). Sexually active young women and men are more likely to report multiple (not necessarily concurrent) partners with more than 35% adolescents reporting two or more lifetime sexual partners (42). There has been an increase in multiple partnering over the recent years. The proportion of women who reported having more than one partner increased from 2% in 2000-01 to 4% in 2004-05 and among the sexually active men, the proportion reporting multiple concurrent partners rose from 25% to 29% (14). Although, condom use with non-regular partners increased from 38% (in 2001) to 57% (in 2005) in women and from 59% to 67% in men, use with spouses and regular partners remained low (less than 10%) (14, 31). It is therefore not surprising that new infections are occurring among stable relationships (15).

### **1.4.3 HIV and fertility**

Studies in both low- and high-resource settings indicate that HIV adversely affects both the sexual health and fertility of men and women (45). A number of studies report a reduced fertility due to direct biological effects of HIV on the fecundity in HIV-infected (40, 46-50). However, tubal infertility due to STIs has been reported among HIV-infected women (51, 52).

Furthermore, studies show differences in the ability to produce a live birth among HIV-infected women who have very high viral loads (53). This reduced fertility may translate into increased quest for child bearing among those infected with HIV, and this may have implications for HIV transmission to partner. In addition, HIV decreases fertility because HIV-infected women get more miscarriages, premature babies, premature ruptures of membranes, abruptio placenta, Intra Uterine Growth Retardation (IUGR), Intra Uterine Foetal Death (IUFD), stillbirths, and unexplained early neonatal deaths (39, 40, 54). However, some studies report that most of the reduced fertility may be due to behavioural change after knowing one's positive status (55, 56).

#### **1.4.4 Fertility desires and intentions among HIV-infected people**

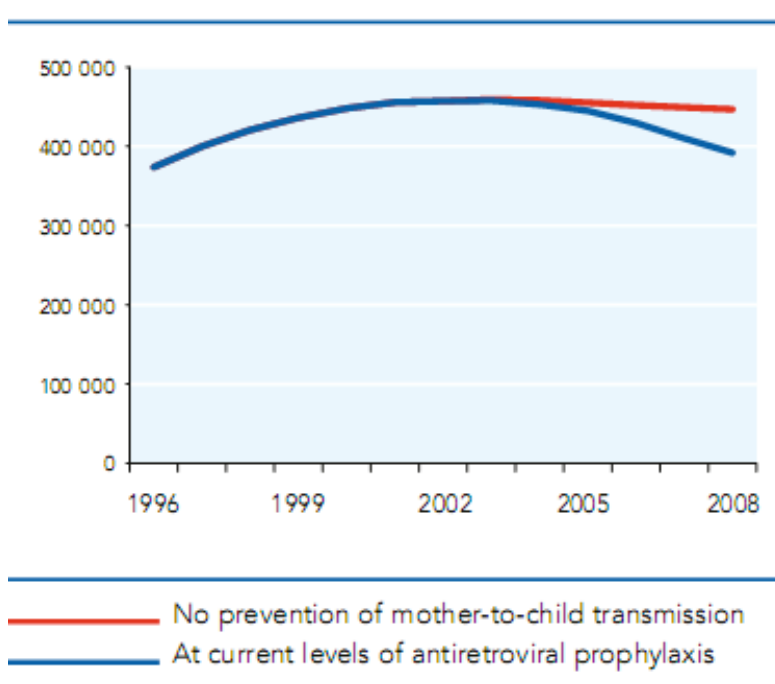
A large body of knowledge exists on desires and intentions to have children by HIV-infected people from both high and low-resource settings (1, 2, 5-7, 57). Fewer HIV-infected people in high-income countries desire parenthood compared to those in low-resource countries (2-4, 7). African men and women living in France and Canada were more likely to desire children than their native counterparts indicating the importance of reproduction among African populations (7, 57). Desire for children may be driven by the need if a person has no children, gets a new partner or not having children with the current partner. The younger people have a stronger desire for children because they are most likely to have fewer children (3, 5, 7, 57, 58). Improvement in assisted reproductive technologies, availability of various fertility options for couples living with HIV and effective prevention of mother-to-child transmission (PMTCT) have positively influenced HIV-infected people's decisions to have children (1, 59). Low-cost technologies such as teaching people about ovulation and timed intercourse, and self insemination for HIV-infected women with HIV-negative partners are viable options (10). Furthermore, improved access to ART (avoiding teratogenic drugs to women of fertile age because they may get unplanned pregnancy) provides sero-discordant couples with even more options since the reduction of viral load significantly reduces the risk of sexual HIV transmission to partners (10-13). Ironically, the knowledge and availability of various reproductive options is lowest in settings with the highest proportion of HIV-infected people, and in regions where procreation plays the biggest role and assisted reproduction is not affordable by the majority who would benefit from it (3, 4)

#### **1.4.5 Prevention of mother-to-child transmission of HIV**

Mother-to-child transmission of HIV infection occurs in utero (15-25%), intrapartum (50-60%) and through breastfeeding (15-25%) (60-62). It is possible to reduce HIV transmission from the estimated 30% to 35% with no intervention to around 1% to 2% if antiretroviral prophylaxis and replacement feeding are provided (16). Best practices in PMTCT includes: reduction in overall HIV among women and men of reproductive-age, the reduction of unwanted pregnancies among HIV-infected women, the provision of antiretroviral drugs to reduce the chance of infection to the foetus during pregnancy and delivery and availing appropriate treatment, care and support to mothers living with HIV, including infant feeding (16). Globally, the coverage of HIV pregnant women reached by PMTCT services has increased from 10% in 2004 to 45% in 2008. However, completion rates of the entire PMTCT ladder are lower. Thus, Uganda as the rest of Sub-Saharan

Africa still grapples with high rates of MTCT of HIV (16) Figure 1. Multiple factors including low access to ART services by pregnant women (14), inadequate obstetrical services and the sub-optimal access to skilled attendance at birth (17), contribute to this high rate of MTCT. In Uganda, only one third of the HIV-infected pregnant women accessed PMTCT services in 2005 (14). There was an increase to 51% women accessing ART for PMTCT services in 2009 but only 42% of their babies got ART prophylaxis (63). In addition, only 40% of pregnant women have access to skilled attendance at birth (17). Furthermore, the stigma associated with not breastfeeding infants among the HIV-infected mothers contribute to high rates of MTCT in Uganda and other countries with high regard for breastfeeding (64, 65). In 2008, peri-natally acquired infection accounted for 18% of new HIV infections in Uganda (15). While the drive for universal access to ART is very important, it has shifted the HIV response to care and treatment with limited focus on prevention. Over three quarters of all adults including PLHIV do not know their HIV sero-status therefore cannot access services to reduce paediatric HIV infections (15).

**Figure 1: Vertical transmission of HIV in Sub-Saharan Africa**



Source: UNAIDS, 2009 (16)



## **2.0 THEORETICAL UNDERPINNING OF FERTILITY DECISION-MAKING**

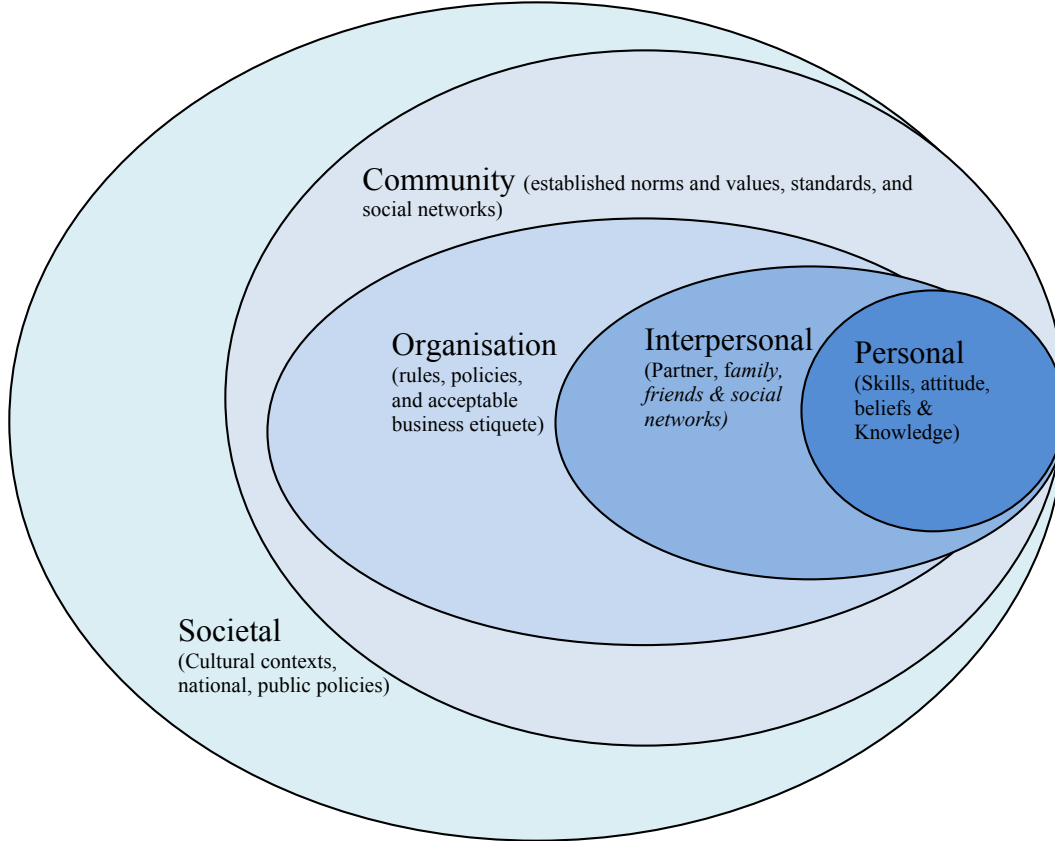
Decision-making is the mental cognitive process that results in the selection of an action, an opinion of choice or the course of action among several alternatives. Rational decision-making identifies all possible outcomes and determines their values (positive or negative) and weighs the options and analyses the opportunity cost *visa vie* the results of each course of action and then chooses the better option. Often one tries to be logical using relevant well thought through reasons and facts as other sane people see them when they are making decisions. However, sometimes the decision made is based on unsound judgment and groundless assumptions or poorly drawn inferences (66). In risky and uncertain decisions, the decision maker may think through their actions but sometimes they do not and the decision is instantaneous. The outcome of the decision-making process is, however, always influenced by the decision-makers' values and beliefs, attitudes, experiences, training, intentions, obligations and priorities. For example, wrong premises may inform decision-making; such as basing the decision on misconceptions, overestimating chance or even not evaluating the other available options. For example, using condoms in high HIV prevalent areas such as Uganda to prevent HIV transmission would absolutely be a rational expectation. However, this is not so because some people may think the condom is not effective and others may be hindered by the lack of sexual satisfaction attributed to condoms (67). Therefore, rational choices require that one is furnished with full information about the choices and the capacity to correctly evaluate the cost-benefit of each choice. More still, such a choice to be made assumes that all other things are taken care of and the only obstacle to making the choice is the individual's capability. Studies show that one's choices are influenced by many factors acting at different levels including personal, interpersonal, community and society (66, 68).

### ***2.1 Social Ecological Model***

The socio-ecological model (SEM) recognizes the intertwined relationship existing between an individual and the environment (69). The model further recognizes that individuals are responsible for instituting and maintaining the lifestyle changes necessary to reduce risk or improve health, but individual behaviour is influenced by factors at individual, interpersonal, organizational, community, and public policy level (70-72) Figure 2. Making choices is an art learnt through a socialisation process. It combines personal attributes with significant others' (role models, elders) and socio-environmental influence to shape or modify an individual's perceptions and choices. In addition, barriers and constraints to behaviour change also act at multiple levels. Therefore, it is unrealistic to expect individuals to change behaviour when barriers at higher levels are insurmountable. Barriers to healthy behaviours are shared among the community as a whole. As these barriers are lowered or removed, behaviour change becomes more achievable and sustainable. It becomes easier to "push the ball up the hill."

This thesis uses the SEM to explore factors that sustain high fertility (Paper I) and factors that hinder safe sexual practices among HIV sero-discordant couples (Paper II)

**Figure 2 A schematic drawing of SEM showing multiple level influence (modified from Sallis (69))**



## **2.2 Framework for modelling fertility motivation**

Sexual reproduction requires concerted action of two individuals. Fertility decisions are psychologically complex and commonly vary across the partners both in terms of the strength of their different desires and in terms of their relationship to other (often competing) issues. The challenge comes when one partner wishes to contracept while the other wants a child. Miller et al 2004 developed a framework for modelling fertility motivation from an individual level into a couple level model (73). This framework explains how the Traits-Desires-Intentions-Behaviour (TDIB) is a sequence through which the fertility motivations of an individual produces instrumental behaviours that are designed to promote or prevent childbearing. Its special feature is the cognitive capacity of individuals to perceive the partner's motivational structure. This is perceived through verbal and non-verbal communication between the partners. Each spouse communicates to his or her partner and reads his/her partner's verbal and non-verbal behaviour and makes deductions about the spouse's internal states such as desires and intentions. A number of factors can affect this communication-perception process. On the signalling side, there may be unclear or deceptive messages and on the receiving end there may be bias as a result of the receiver's own desires and intentions. HIV infection is such a factor especially among discordant couples that want to found a family because of the risk of transmission to the HIV-negative partner. Part of this thesis used the Miller model to assess couple communication about fertility among HIV sero-discordant couples. We explored how HIV status and gender influences the capacity to recognize partner's desires and intentions of wanting to have children. (Paper III).

### 3.0 RATIONALE

Little information exists on how to address sexuality and reproduction among HIV-infected youth and HIV sero-discordant couples. Uganda has been lauded as a success story in HIV incidence reduction from 25% in 1990 to the current 6.4%, even though the HIV prevalence is still unacceptably high (14). Moreover, about 40% of all new infections still occur among the youth (74, 75) yet this group generates momentum for population growth. In addition, 43% of new transmissions occur in HIV sero-discordant couples (15).

Desire for children among HIV-infected people is high especially in the young age group but they have to deal with the concern of both horizontal and vertical HIV transmission. Moreover, Uganda's ART and PMTCT programs are being rolled out but the access and completion rates are still limited with a substantial risk for peri-natal transmission.

For HIV and reproductive interventions to be effective, it is important to take into account socio-cultural explanations and people's perceptions of HIV disease and fertility. This would likely lead to better programming that addresses HIV sero-discordant and young people's concerns. While stigma and discrimination may hinder HIV disclosure, we need to understand how HIV-infected people "protect" their sexual partners when in sexual relationships, and negotiating for childbirth.

Available studies on fertility do not address fertility decision-making among young people because they mostly include older persons who have completed their childbearing, sometimes including people who have used permanent methods of contraception (1, 2). Yet initiating reproduction starts in the youth in many low-resource countries. Few studies have looked at the views of young people about fertility, the influence of HIV infection on fertility decision-making among young people or mutually disclosed HIV sero-discordant couples and whether fertility decisions made are followed through. There is therefore a need to understand how young people, especially the HIV-infected, deal with or manage fertility in the era of HIV and scaling up of ART. This thesis aims to identify factors that could help to design culturally appropriate programs for HIV prevention and sexual and reproductive health and rights (SRHR) programs targeting young people to reduce stigma towards HIV infected youth, support HIV discordant couples in their fertility decisions and also contribute to a reduction in HIV transmission between young people and MTCT through responsive and informed fertility decisions. The primary audiences for this research are policy makers, in particular the government of Uganda and the Ministry of Health, program managers, and clinical and counselling service providers who are interested in developing and implementing programs for HIV-infected young people and discordant couples in Uganda and other low resource settings.

## **4.0 AIM AND OBJECTIVES**

### ***4.1 Aim***

To establish the relationship between fertility decision-making and HIV infection among young people in Kampala and Wakiso districts.

### ***4.2 Objectives***

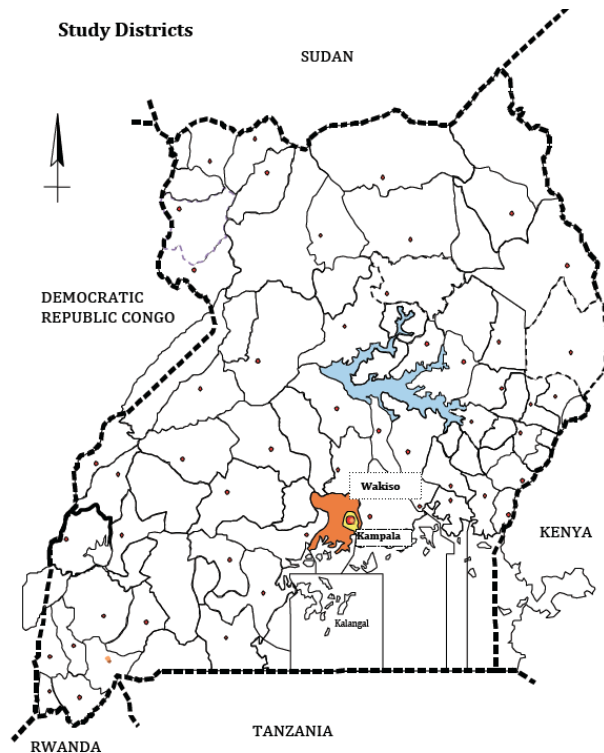
- I. To explore fertility decision-making norms in the general population of Kampala and Wakiso districts.
- II. To establish the determinants of fertility decision-making in HIV-infected young people.
- III. To assess fertility decision-making in HIV sero-discordant couples in Kampala and Wakiso districts.
- IV. To assess to what extent fertility decisions made by HIV-infected and HIV-negative young people are sustained over a period of one year.

## 5.0 METHODS

### 5.1 Study area and sites

The studies in this thesis were conducted in Kampala and Wakiso districts in the republic of Uganda.

**Figure 3. Map of Uganda showing study districts**



**Uganda:** The Republic of Uganda is a fertile, well-watered landlocked country in East Africa. It has an area of 241,038 square kilometres, 18% of which is open water and 12% forest and game parks. In 2010, the estimated total population is 33.4 million with a median age of 15 years. The country is divided into 112 political and administrative districts. Kampala and Wakiso districts are located in the central part of Uganda, Figure 3. Kampala district is also the capital city of Uganda and is predominantly urban with an estimated population of 1.2 million multi-cultural, multi-ethnic and socio-economically diverse residents. Wakiso is predominantly a rural district with about one million residents mainly from one ethnic group (77% Baganda) (31). We selected multi-cultural, multi-ethnic Kampala communities because fertility is culturally responsive and rural Wakiso communities with predominantly one ethnic group as a complement.

Uganda has the second highest 3.4% population growth rate after Niger's 3.7%, with a total fertility rate of (6.7 births per woman) (28). It is estimated that in 2004/5, Uganda had an HIV adult prevalence rate of 6.4%. The HIV prevalence among the youth in Uganda, overall, is 3% (4% among the females and 1% among males). The prevalence of HIV in the 15-24 year age

group in Kampala is ten times higher in females than in males (6.3% in females and 0.6% in males.). The prevalence of HIV in the 15-24 year age group in Wakiso is three times higher in females than males (4.8% in females and 1.7% in males) (14).

### **Study sites**

Study I was done in Bukasa parish communities of Wakiso Sub County in Wakiso district and Kamwokya a peri-urban subub of Kampala district. Sub-studies II, III and IV were done at TASO-Mulago but study III also included discordant couples from the ISS, AIC and JCRC clinics (see description below). In addition, study IV included the HIV-negative youth recruited from Naguru Teenage and Information Centre.

The AIDS Support Organization (TASO) is a non-governmental organization founded in 1987 to provide care and support for HIV/AIDS infected and affected people in Uganda. TASO has 11 dedicated centres and 34 outreach clinics throughout the country, one international and four national training centres, and a clientele of 200,000 by 2008, of which 70% are female and 30% male. TASO-Mulago is the main and oldest branch (76).

The Mulago Hospital immune suppressing syndrome clinic (ISS clinic), is an HIV/AIDS clinic at the Mulago national referral hospital. It cares for HIV infected patients referred from the main hospital clinics. Until 2008, the clinic has served a total of 13,000 clients

Joint Clinical Research Centre (JCRC), the Mengo unit, is a centre of excellence for AIDS care, treatment, research, and training. JCRC was founded at the height of the AIDS crisis in Uganda in 1990 to provide HIV/AIDS care for the Ugandan armed forces and for research. To date, JCRC has provided ART to about 30,000 clients (77).

AIDS Information Centre (AIC), at the Mengo branch. AIC started in February 1990 in response to a growing demand for HIV testing. AIC had provided HIV counselling and testing services to 337,500 clients as of 2008. AIC Kampala is one of the eight regional branches in Uganda (78). By 2003, over 5,000 discordant couples had sought voluntary counselling and testing at AIC.

All these units provide counselling services for individuals and families infected or affected by HIV/AIDS, and medical services that focus on treating opportunistic infections including ART. They, in addition, provide family planning services and those who need surgical contraception are referred to specialized units and pregnant mothers are referred for antenatal care and PMTCT. TASO, in addition, offers training to increase the capacity of its staff, grass-root communities and districts for basic HIV/AIDS management, and support other social services. These units, because of increasing number of HIV discordance among couples, have recently (2005-2006) started “discordant couples clubs” to support couples socially and psychologically. The units, in addition, provide education on treatment options and on how to prevent the infection to the HIV-negative partner, and they provide an environment for peer psychosocial support groups through the sharing of experiences and the promotion of positive living. These HIV/AIDS care units schedule visits for their clients to attend for follow up and for other activities, even when the clients are well. By June 2007, at the time of study recruitment, couples attending the HIV sero-discordant club at the ISS clinic were only 35, TASO-Mulago had 113 couples, 50 couples attended at JCRC and 150 couples at AIC.

Naguru Teenage and Information Centre (NTIC) is the biggest youth friendly clinic in Uganda. The centre is situated at about 3 km on Kampala-Jinja highway, and offers services to young people aged 10-24 years old. On average, the NTIC gives services to 60-80 youth per day. One half of these would be new patients, and one quarter is either not tested, or are newly tested. The services offered at NTIC include comprehensive counselling such as counselling for HIV, problems with relationships and STIs; consultations for contraception, antenatal and postnatal care, supply of condoms and other non-health related services like life skills meetings.

## ***5.2 Study design***

We use both qualitative and quantitative methods. Qualitative methods were used mainly to explore the norms, beliefs, and views; but also to get deeper understanding of people's behaviour and why they behave the way they do. We used focus group discussions (FGDs) and in-depth interviews (IDI) (study I, II and III). The quantitative study designs used were one cross-sectional and one prospective cohort (study III and IV) to assess proportions and the strength of association between exposures (HIV infection) and outcomes (fertility decisions, contraceptive use and condom use) Figure 4.

### **5.2.1 Data collection techniques**

#### **Qualitative methods**

##### **Focus group discussions (FGD)**

We used FGDs because they have the advantages when gathering information on people's talk exploring opinions, norms, values, experiences and practices, wishes and concerns (79). In addition, the social interaction of people and group dynamics help people in an FGD to build on each other's answers and give new insights on the topic to the researcher. Because participants build on each others' ideas and question each other, they generate more data within the same time than individual interviews (80, 81). The FGD, in addition, allows the researcher to access the different types of communication like jokes, teasing, arguing and anecdotes which may tell more than people ordinarily share (81). These strengths make them ideal to explore sensitive topics like sexuality among the youth (study I and II), as well as issues which do not have straight answers like safe sex and child-bearing for HIV discordant couples in low-resource settings (study III). In FGDs, sampling the participants depends on the area of research and topic being discussed. People in the FGDs do not have to have similar background or to be from the same organisation. However, gender and age may affect the quality of data collected because it affects the level of interaction of participants. In study I, II and the qualitative part of III, we used purposive sampling with maximum variation strategy to get participants with diverse views (82). Most of our FGDs consisted of 10-12 people and lasted 2 hours. Each group was same gender and similar age (15-19 and 20-24 years). The number and length of time of FGDs depends on the complexity of the topic. Usually 1 to 2 hours with groups of about 6-7 people, though in some circumstances, they may be as few as 3 people or as many as 12 people per group (81).

## **In-depth interviews (IDI)**

IDI enables one to access “people’s inside”, the *emic perspective* by collecting verbatim transcripts in order to understand people’s perceptions in their own words (83). IDI can also be used to interview people who have special knowledge in the topic/field being researched (the key informants) (80). In this thesis, we used IDI to capture, in their own words and terms (84), people’s understanding and perceptions of reasons for persistent high fertility in Uganda (paper I), and sexual practices and wanting children among discordant couples (paper II). We used a semi-structured interview guide because it ensures that all the important information is gathered while giving the researcher leeway to ask the same questions in different ways but also allowing the respondent to report their own thoughts and feelings (80). We combined in-depth interviews with FGDs to get a deeper understanding of the issues in question and for triangulation of the information. Specifically, the information from the FGDs were used to explore whether the issues are held as common knowledge but also informed the IDI which got more information on the issues raised. The IDI from key informants (KII) aimed to confirm or reject issues raised in the FGDs towards the end of data collection to “piece” the information together (82, 85). (Study I, II and III)

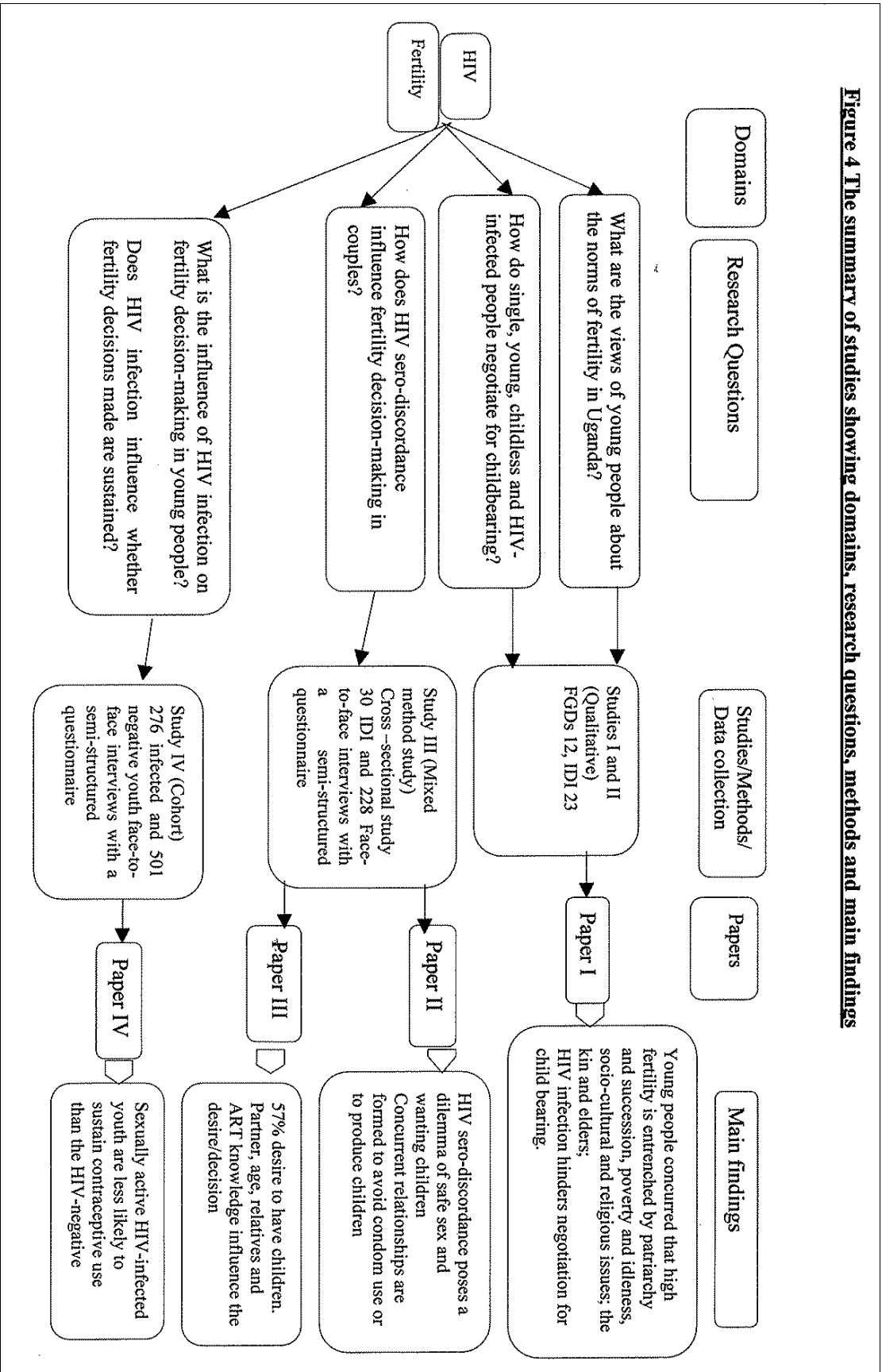
## **Quantitative methods**

### **Structured Interviews**

Collecting large volumes of data requires structuring the questions in order to collect data that will easily be grouped for analysis, e.g. through a standardised structured questionnaire. The strategy aims to get results from a sample that is representative of the population from which it is sampled (study III). However, cross-sectional studies are not ideal for assessing changes in behaviour and relationships. Therefore, we used a prospective cohort to determine how fertility decisions are sustained (study IV). To limit any potential bias and improve the power for statistical inference, emphasis was put on participant selection and recruitment, reaching an adequate sample size and data analysis. The structured questionnaire used previously validated questions from other surveys like the UDHS 2006 and the HIV sero-behavioural survey 2004/05 (14, 17) to allow for broader comparisons.



**Figure 4 The summary of studies showing domains, research questions, methods and main findings**



### 5.3 Individual study designs, recruitment of participants and data collection

#### 5.3.1. Exploring fertility decision-making norms and views of young people

For study I, the authors used multistage sampling technique to select a parish. Simple random sampling was used at: Stage 1 to select a county, stage 2 to select a sub-county, and stage 3 to select a parish. The research team conducted a pre-visit to the selected parishes to establish contact with local leaders of the villages. Local Council (LC) leaders were appraised about the objectives of the study, characteristics and qualities of participants needed and they collaborated with the principal investigator (PI) and the research team to select information-rich participants. For study II, the TASO counsellor identified by the clinic in-charge assisted the PI. The PI assessed and selected the information-rich youths by asking them questions about fertility, sexuality and condom use; and obtained informed consent for their study participation.

Altogether, the research team conducted twelve FGDs comprising of 126 participants (62 males and 64 females), 13 IDI and 10 KI interviews. We did four FGDs each in Wakiso, Kampala and TASO Mulago, grouped by age (15-19, and 20-24 years) and gender (Table 2).

**Table 2. Summary of qualitative methods**

Category of participants	Sex	Focus group discussions			IDI
		TASO	Kampala	Wakiso	
15 to 19 years old	Male	1	1	1	
15 to 19 years old	Female	1	1	1	
20 to 24 years old	Male	1	1	1	
20 to 24 years old	Female	1	1	1	
Youth leaders					2
Youth religious leaders					3
Youth living with HIV					8
Local council leaders					2
Teachers/school nurse					3
HIV counsellors					4
Shopkeeper					1
Total		4	4	4	23

The LC chairpersons, counsellor and participants approved interview venues. The first two interviews were used as a pre-test to adjust the interview guides for clarity of questions; and were not included in the final analysis. All FGDs and interviews were tape recorded after getting consent. Information gathered was on the following topics: childbearing practices, the key factors that influence fertility decision-making, negotiation for pregnancy, contraception; gender and power relations, socio-cultural context of high fertility and the influence of HIV infection was obtained using pretested interview guides (86).

### **5.3.2 Assess fertility decision-making in HIV sero-discordant couples**

Mutually disclosed HIV sero-discordant couples were sought to participate in the cross-sectional study (study III). Though more than 5000 discordant couples had tested at one of the units (AIC), by June 2007, 348 sero-discordant couples were registered with TASO, JCRC, the ISS clinic and AIC (113+50+35+150 respectively) in the discordant clubs. We included only couples where at least one partner in the dyad was  $\leq 40$  years so as to capture those who would have concerns about child-bearing because most Ugandan women would, by age 40 years, have completed childbearing (17). Other eligibility criteria included known sero-status for more than six months and not being involved in any behavioural studies that could affect fertility decisions. We identified a total of 150 eligible couples. Therefore we used the modified formula for the finite population:  $n / (1 + (n-1)/N)$ , Where  $N =$  Population size,  $=150$ , and  $n=384$  for an infinite population (desire for children among HIV discordant couples in Uganda is unknown and we therefore assumed a modest rate of 50%), and a 5% non-response rate, reaching a sample size of 114 couples.

From June to December 2007, we consecutively recruited and obtained informed consent from 114 sero-discordant couples attending care at the four HIV care units. Participants were interviewed separately as individuals not as couples. Data were collected using a structured questionnaire with closed and open-ended questions. The questionnaire had 8 sections according to themes as follows: socio-demographic information, general daily decision making, fertility intentions and decisions, ART and fertility decisions, stigma and discrimination, attitudes about sexual behaviour of PLHIV, risk of transmission and acquisition of HIV and support systems.

For study III, both men and women irrespective of the status had a lot to say which could not be contained in the coded response categories. We sought to understand their views more and did some complementary IDI with a sub-set of 15 couples that we considered to be key knowledgeable participants. We developed an unstructured interview guide with open-ended questions on safe sex, sexual practices, child bearing and HIV. The couples were purposively selected from the quantitative study population of discordant couples. The purpose of the second interview explained to them and a new informed consent was obtained before interview. The principal investigator (first author) conducted all the in-depth interviews with the 30 individuals making up 15 couples. Privacy was observed in all interview sessions that were held in English or *Luganda* (the local language mostly spoken) and audio tape-recorded.

### **5.3.3 Fertility decision-making among both HIV-infected and HIV-negative young people**

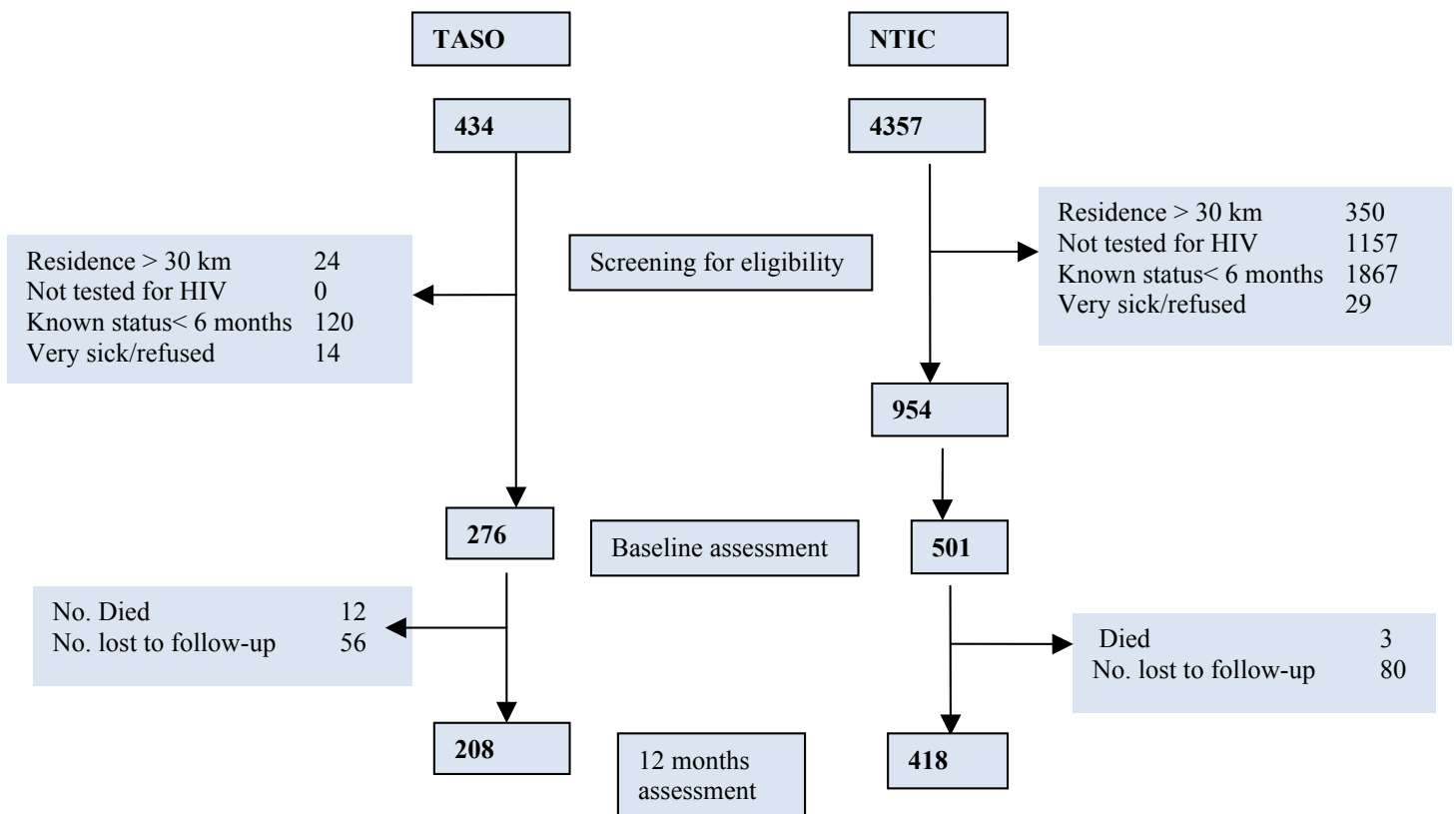
From July 2007 to April 2009 a prospective cohort of HIV-infected and HIV-negative youth aged 15-24 years was recruited and followed up for one year (study IV). The sample size was calculated using the formula for proportions (87). We considered a prevalence of modern contraception among sexually active women (15-49 years) of 18% (17), and wanted to detect a 10% contraceptive prevalence difference between the HIV-infected and HIV-negative youth, at 80% power and 5% significance. In a ratio of 1:2, and allowing for 15% loss to follow up, 250 HIV-infected and 500 HIV-negative youth were needed for the study.

The eligible HIV-infected youth were identified from TASO Mulago, a unit that cares for HIV/AIDS clients. At TASO, 434 were screened for eligibility and 276 were recruited. Data were collected using a pre-tested structured survey questionnaire. Study participants were interviewed at baseline, six months and at 12 months to determine the outcomes of the study.

The HIV-negative youth were recruited from NTIC. The study sought to recruit the youth with known HIV status for at least six months by the time of first interview, who resided within a radius of 30 km of the clinics, and who did not intend to relocate residence within two years. The counsellors identified the clients and referred them to the PI and the study team for screening for study eligibility at the end of their clinic visit. Informed consent was obtained. All eligible HIV-infected young people were consecutively recruited. A systematic random sampling technique was used for the selection of the HIV-negative youth. A total of 4,357 youth screened for eligibility at NTIC, 954 were found eligible and 501 were recruited using a systematic random sampling technique.

To identify participants for follow-up, a contact locator form with contact address and telephone numbers of respondent and their ‘significant other’, and head of household identification was recorded. This information helped to locate participants who did not return for their appointment for interview at the scheduled time. The PI or research assistant contacted the participants by phone or home visited after 4 weeks of the missed appointment. A lost to follow up when the client was not traced for 3 months either by four calls and/or one home visit and we failed to trace the home or found that he/she relocated to an inaccessible place (Figure 5).

**Figure 5. Flow-chart for patient recruitment and follow-up for prospective cohort study (study IV)**



## **5.4 Data Management and Analysis**

### **5.4.1 Qualitative data**

The majority of the interviews were done in *Luganda* –the most commonly spoken language in Kampala and Wakiso. Fewer were done in English in Kampala. The research assistants fluent in *Luganda* listened to and transcribed verbatim tape-recorded data (interviews, and FGDs). Research assistants who participated in interviews were involved in data transcription and translation. Reduction of data was done to remove vague, unclear or meaningless phrases and sentences. The PI and a social research expert from Makerere Institute of Social Research (Co-author) independently coded portions of the transcribed data and compared the coding for consistency and consensus on data interpretation. A codebook was generated for possible categories, patterns and themes of each study. In studies I and II, latent content analysis technique was used. First the inductive approach was done to identify the categories and themes. Later in the analysis, deductive analysis was done to test and affirm the authenticity and appropriateness of the categories earlier developed at induction (82). Finally, in-depth interpretation of the text to understand relationship aspects and underlying meanings was done (88). In study III, a thematic approach was used (89). Categories within the texts were identified and grouped together to form the emerging themes. We used NVivo 2 computer software package to assist in organizing the data (90).

### **5.4.2 Quantitative data**

Quantitative questionnaires were checked for completeness in the field every day after each interview. All quantitative data were double entered using Epi Info version 3.4, coded and cleaned. Analyses were done using STATA version 10. Uni-variate, and bi-variate analysis was done to describe the data and look at associations between the variables. Multivariate analysis was performed to adjust for confounding and to evaluate whether the association could be interpreted as a relationship. Non-conditional logistic regression analyses were performed to calculate odds ratios (OR) and their respective 95% confidence intervals (95% CI).

In study III, the main outcomes were consistent condom use (paper II) and fertility desire (paper III). Multivariate analysis was done to determine factors associated with consistent condom use. The factors included in the analysis were: socio-demographic characteristics, the perception that their partner desires children, discussion with spouse about pregnancy, number of children desired, use of ART and knowledge about PMTCT to decide about childbearing. In addition, the role of stigma, influence of significant others (family, friends and health workers), disclosure to relatives, whether they had had discussions with health workers about pregnancy, and contraception (Paper II.) In addition, we looked at possible explanatory variables that could influence fertility decision-making, and whether it was important whom in the couple (the man or the woman) was the HIV-infected partner. Analysis was stratified by whether the woman or the man was the HIV-infected partner in the sero-discordant couple dyad (HIV-infected men with their HIV-negative wives in one strata and HIV-infected women with their HIV-negative husbands in another). We did multivariate analysis to adjust for confounding and to assess factors independently associated with the desire for children (Paper III).

In study IV, descriptive statistics to compare the results from HIV-infected and HIV-negative young people were done using chi-square test for categorical data and Student t-test for continuous data. The outcome of interest was a fertility decision. The fertility decision was computed from three variables: a) desire for children, b) timing of pregnancy (wanting children now versus later) and c) contraceptive use. A good or consistent fertility decision was coded as 1 while an inconsistent decision was coded 0 as illustrated below:

- If the client desires children later but is not using contraception, this is an inconsistent fertility decision [0]
- If the client desires children later and is using contraception, this is a consistent fertility decision [1]
- If the client desires children now but is using contraception, this is an inconsistent fertility decision [0]
- If the client desires children now and is not using contraception, this is a consistent fertility decision [1]
- If the client does not desire children but is not using contraception, this is an inconsistent fertility decision [0]
- If the client does not desire children and is using contraception, this is a consistent fertility decision [1]

Other outcomes were desire for children, contraceptive use, and condom use. Bi-variate analysis compared desire for children, contraception, pregnancy, and condom use practices among HIV-infected and HIV-negative youth. Discussion with partner about fertility, religion, education level, sex, age and marital status and having discussed with health workers about contraception are very important factors in fertility decision-making and HIV transmission prevention among young people and were the explanatory variables.

In paper IV, we present the outcome of contraceptive behaviour as one of the fertility choices. We assessed the dynamics of contraceptive use during the one-year of follow-up by doing sub-analyses on participants who continued to use contraception and those who continued not to use contraception to assess factors that influence continued contraceptive use. We also analysed the determinants of resistance to the uptake of contraception among the youth. We created a new variable for consistent contraceptive users that combined use at baseline, six months and 12 months. We did not collect data on when exactly they started using contraception; therefore, we included those people who had started using contraception within the six months' follow-up and continued through to twelve months. Similarly, we created another new variable that combined non-use at baseline, six and twelve months. Factors associated with a sustained contraceptive use and non-use at a  $p < 0.20$  at bi-variate analysis were included in backward stepwise logistic regression models to assess for confounding and for the independent association between the variables and outcome of interest.

### ***5.5 Quality control for all sub studies***

Research assistants were trained to ensure that they fully understood the studies and the meaning of each question. Moreover, they all were young (23-26 years old) graduates from social sciences, social work and social administration, and education, with a diploma in counselling HIV-infected clients.

For qualitative studies, translation of the interview guides into the local language (*Luganda*) and back translation to English was done before data collection (91). The interview guides were pre-

tested with one FGD and IDI each and adjusted for clarity. To increase the validity of the information collected, purposive sampling using maximum variation sampling technique was adopted to gather different views (82). We used two methods of data collection, to complement each other, and for triangulation. The PI and two research assistants moderated all the FGDs, conducted all IDIs, and kept daily field notes and a field diary. Immediately after the FGD, the moderator and note-taker held debriefing sessions to expand the notes when the memory was still fresh; discussed any issues that could have arisen from the discussion groups and planned for the next activity. This helped us to focus our next interview by more probing for unclear questions but also allowed us to detect that no new information was forthcoming.

The quantitative studies had six research assistants and group training was necessary. The sessions involved understanding the study protocol, its objectives and the type of clients expected to be interviewed. Some of the questions about HIV and sexuality were sensitive; therefore the emphasis was put on being aware of this to avoid undue stress to the clients. The next session involved understanding the questionnaire, sampling procedures and imparting interview skills. The training lasted for one week. In addition, the questionnaires were pretested and adjusted for clarity before data collection. Moreover, we used validated questions from the previous surveys (UDHS 2006 and the sero-behavioral survey 2004/5). The principal investigator (first author) supervised data collection in all the study sites. Every evening, debrief meetings were held with research assistants and JBK to review some questionnaires and report on any incidents that occurred during the data collection. JBK would regularly hold discussions with the supervisors (FM and FK) to give guidance and strategic direction on the data collection.

### ***5.6 Ethical consideration***

The Makerere University College of Health Sciences Higher Degrees Research and Ethics Committee, and Uganda National Council of Science and Technology (UNCST) approved the study. Informed consent was handled according to the Uganda national guidelines where minors 15 to 17 years old seeking care were covered under the guideline that allows children 12 years and above to access care e.g. contraceptive services, HIV counselling, testing and could receive results without the parents' consent (92, 93). Parental consent and assent from minors (under 18 years) was obtained before the study because we recruited the young people from their homes.

This study involved sexuality and HIV, which are both sensitive topics especially in young people. Therefore careful handling of study subjects was our priority. The research assistants were trained counsellors with ability to handle and discuss sensitive topics such as sexuality and HIV with HIV-infected people.

The participants were informed that participation was totally voluntary; that they reserved the right to refuse to participate and could opt out of the study anytime. The participants, in addition, were told that non-participation would not deny them treatment or services they were seeking. Finally, the research team agreed with the participants how to do the follow-up. Some participants had not disclosed their status to relatives, friends and neighbours, and this was not a disclosure facilitation protocol. Therefore we asked each respondent to tell us what reason we would give to family if we called and someone else received the telephone or if we followed them up at their homes.

## 6.0 RESULTS

### 6.1 Views of young people about fertility (Paper I)

*“A woman who has not produced any boy is referred to by the society as someone who has no children.” Males, 15 to 19 years FGD*

Twelve FGDs comprising of 126 participants (62 males and 64 females), 13 IDI and 10 KII were conducted for paper I. We did four FGDs in Wakiso, 4 in Kampala and 4 at TASO Mulago unit grouped by age (15-19, and 20-24 years) and gender. Of the 139 FGD and IDI youth, 22% were under 18 years, about two thirds had more than eight years of formal education, and 44% were still single. Only six percent had skilled employment and one-third (34%) were not employed. Others had small businesses and wage jobs such as brick laying. Only 19% were in school.

#### **Factors that increase fertility rates**

Young people from the community and those from HIV/AIDS care units both identified the pro-fertility themes as:

1) Patriarchy and succession which can only be attained by producing boys. Young people concurred that having a male child would sustain the ‘men’s blood’ (the clan). Young people elaborated that the boy child had more value than the girl child. The need for the heir was crucial and girls cannot succeed their fathers. Most discussants agreed that not having a male child destabilizes homes. They noted that a home without a male child was like the home of an infertile couple, which is miserable, and the couple always quarrels. In the end, the man gets another wife and sometimes they (man and wife) both may end up practicing high-risk sex (concurrent relationships) to get the desired sex of the children. The only value attached to girls was to bring in bride price or dowry for the brothers use to get wives.

2) Poverty, joblessness were reported to increase child bearing because poor people were not able to plan for their fertility. The majority of young people observed that most poor families had many children and the rich had few. Some explanations offered were that poor people see children as a source of income (especially dowry from girls), a source of labour and old age insurance. In addition, young people suggested that those men who do not work get time to produce many children because they are not occupied; indicating that they use sex as a pastime. Others were reported to use sex in times of grief as a consolation, and in times of joy as a celebration.

*“The poor, when he gets money, they don't plan for it. They just go to the bedroom and when trouble encompasses them, they still go to the bedroom and what comes out are the many children. They say that they take their troubles to the bedroom and even their joy. .... he goes and when he gets money, he will buy for her a cloth, oh!!! Sweetheart, thank you! Then to the bedroom and they produce children.” Females, 20-24 years, FGD*

3) The socio-cultural issues such as religion, kin and elders were also identified as facilitators of big family sizes. Young people reported that both cultural norms and religious practices were responsible for high fertility. They cited that Catholics and Muslims are very different religions, yet they both believe that their religions direct them to produce as many children as God wants.



Sometimes, one in the couple wants more children. Discussants agreed that it would be problematic if it was the woman because women have no say in “*anything at home*” meaning the man is the decision-maker in everything. However, such disagreements were thought to bring violence in homes. Nonetheless, males groups agreed that it was difficult to force the woman to stop child bearing if they (women) wanted more children. Their suggestion was to sit with the woman and negotiate for a smaller family, because it would be useless for the man to appeal to the elders for redress, as the elders would support the person who wants more children.

### **Factors that could reduce fertility rates**

Factors, on the other hand, perceived to reduce fertility rates included “women emancipation, job security and couple fertility communication”. Young people described an emancipated woman as one who is educated, has a job and is able to stand up to the husband. In almost all discussions, young people concurred that education and income give women a “voice” - to talk, to communicate; or to challenge the husband’s decisions if she feels the demands are not favourable or realistic. Young women could reminisce that they would make their own decisions if they had a job or income to support them. Such women resort to guessing that the man wants more children and this may lead to large families. Young people reported that often women keep silent for fear of violence or the husband’s threats to send her away to fend for herself. Young people alluded to the challenges of starting and sustaining families faced by orphans of HIV infection. That being in unstable families makes them vulnerable to unplanned marriages and cannot negotiate fertility.

*They chase us because mum and dad, who were paying the rent, died; [and now] the landlord wants his house. I have nowhere to go with the property. Maybe I sell all of it. Then, when I get someone proposing for marriage, I just go. In my view, I see that [my] seventeen years [of age] are many. The guy can't tell me [to marry him] and I refuse because am going to be in my own home. ... since I don't have where to be. My uncle can't accept me [in his home] for he thinks that I also have HIV because my parents died of it. So when I get a guy and he tells me, "I love you; let's get married", I also go.*  
Females, 20-24 years FGD

## **6.2 HIV discordance and childbearing (Paper II and III)**

In this study, we recruited 114 HIV sero-discordant couples. The median age of participants was 33 years (inter-quartile range 28 - 40 years). Slightly more men (59/114) than women (55/114) were the HIV-infected partner. The lifetime number of sexual partners was reported to be much higher among males, eight (inter-quartile range, 5 –15 partners) and three (inter-quartile range 2-5 partners) among females. Most (86%) described their current relationship as monogamous. The median duration of the relationship with the primary partner was 7 years. Most participants were of low socio-economic status with 32% of the men being peasant farmers and 65% of women, housewives. A total of 41% (52% of men and 31% of women) got their income from temporary jobs or casual labour such as motorcycle transport services and small businesses such as market vending. The majority (83%) had secondary school education or less. Most, 212 (93%), of the participants had children. The median number of living children was 3 (inter-quartile range 1-5

children). More HIV-infected men couples had four or more children, 56 (48%) compared to the HIV-infected women couples 36 (33%),  $p$  value =0.024. Only 43% of HIV-infected individuals were taking ART. The median duration of taking ART was 2 years. Most participants were in good physical health.

### **Dilemma of safe sex and having children (Paper II)**

*“He brought the idea of another child; I brought the issue of HIV transmission. So we need advice. At first he would refuse condoms, I would refuse sex until he accepted condoms”* 30 year-old HIV-negative female

In this study, fifty six percent (56%) of participants used condoms consistently. Consistent condom use was less likely to occur among participants who desired to have children. In addition, having multiple sexual partners, and not having had discussions with health personnel about unwanted pregnancy and abortion, was also associated with inconsistent condom use. However, participants who were using contraception and had discussed pregnancy and HIV with health staff were more likely to use condoms consistently. The belief that ART gives high chances of an HIV-negative child was associated with inconsistent condom use but not significantly so in multivariate analysis. (Paper II)

From the qualitative data, two broader themes emerged which were sexual practices for HIV prevention, and desire for children with the dilemma of condom use. HIV sero-discordant couples reported struggles with sex and HIV transmission prevention. Five types of sexual practices were reported: 1) Abstinence, 2) Consistent condom use, 3) Practicing unsafe sex, 4) Alternative non-penetrative sexual practices and 5) Seeking for HIV concordant partners to avoid condom use. Those who wanted children had at least one of the following reasons for practicing unsafe sex: 1) Ensuring lineage and posterity 2) Pressure from relatives to reproduce 3) Securing the relationship through children and 4) Availability of antiretroviral therapy.

Four major challenges that HIV sero-discordant couples struggle with include the fear of transmitting HIV infection to partner and child, the HIV-negative (more often the females) partner’s lack of negotiating power for safer sex, failure of health systems to offer safe methods of reproduction, and whether to search for alternative sero-concordant partners or concurrent partnerships. One man reported that it is impossible to avoid getting HIV even if he wore a condom because he works with sharp metals. He observed that the manual labourers could fall in his category and condoms may not totally protect them.

*“You know how we do these things (sex). Do you also look for condom for the hands? You know the hands are involved in sex. They touch the fluids.... Some of us, the nature of our work, (manual) we get bruises in the hands. Are we going to put on gloves also?”*  
43 year- old HIV-negative male

Another hurdle was negotiating for condom use. Participants reported that in most issues, the man was the final decision maker and the woman had to obey. However, some men insisted that for sex, women could have more decision-making power if they so wanted as illustrated below.

*“Every creature has its own power. So women have power over men when in love [in bed]. Even the toughest and most feared man can become stupid like a goat being taken for slaughter. Actually the goat struggles; he becomes like a sheep being taken for slaughter.”* 28 year-old HIV-infected male

Men’s vulnerability about sexual performance came out strongly when discussing condom use. A man’s vitality seemed to be centred on his sexual performance. The fear of condom-associated impotence was raised as one major reason for unsafe sex that could be driving HIV transmission. Most participants concurred that if a man fears he may lose his erection, he will feel forced to rescue the situation by not using or removing the condom or else he will lose his status as a man.

*Respondent: If you lose an erection, can you perform? ... And at that point, you would rather die than lose face in front of a woman. That is why even the HIV-negative man can sleep with an HIV-infected woman live [without condom].*

*Interviewer: So in that case what do you do?*

*Respondent: You take off the condom of course.* 37 year-old HIV-infected male

Participants pointed out that practicing safer sex was hindered by the desire to have children. Many reported that HIV-infected people have learned how to go around their status. Some participants revealed that many discordant couples that had no children together separated to try new relationships in search for children. Some stayed together but strayed to concurrent/concordant relationships to get children. Discussions on why people still had unsafe sex with their partners when they knew they were discordant revealed that gender inequality, lack of communication between couples, fear of a “loose” partnership that could rather be secured or strengthened with a child, and myths about HIV discordance were responsible for the unsafe sexual practices.

Most participants applauded the advent of ART and saw it as an opportunity to produce HIV-negative children. However, others did not believe that ART reduced their own risk of being infected or the risk of infecting their partner. They reasoned that since ART is for life, then most likely infectivity is also lifelong necessitating lifelong safe sex.

*“It is HIV-infected women who benefit from ARVs to get HIV-negative babies. There are no ARVs to stop men from infecting women”* 34 year-old HIV-negative female

*“But it is him who is HIV-infected not me? Is there Nevirapine for men not to give us HIV? That is what I am waiting for. Otherwise, no more children.”* 30 year-old HIV-negative female

### **Desire for children among HIV Discordant couples (Paper III)**

Most participants (59%) desired to have children sometime in the future. Some participants, (12%), were currently pregnant or their partners were pregnant at the time of interview though three of them had not planned to get pregnant. The median number of more children planned was two. HIV-infected women couples were more likely to plan to have more children than HIV-infected men couples. Most of the participants wanted the next pregnancy later, on average: 1.6 years (SD 1.8) from the interview time.

The commonest type of contraceptive used was the condom (90%), and less than 4% were using dual methods, for example, condoms and injections. However, slightly over half (56%) of the participants reported using condoms consistently, 30% used condoms sometimes and 14% had never used condoms.

More than 67% of HIV-infected woman couples versus 57% in HIV-infected man couples perceived that their partner wanted children. This perception was confirmed as more than 80% correct when data was desegregated to compare individuals' desires. Overall, only 36% had discussed with their partner when to get pregnant. Though 55% in both strata reported that their relatives wanted them to have children, 82% thought that this would not be the case if the relatives knew that one in the couple was HIV-infected.

We assessed the effect of gender and HIV on fertility decisions. The two couple groups were analysed separately. Significant factors influencing decisions to have children in both groups included: younger age (less than 30 years), having three or less living children, perceiving that their partners wanted children, and that relatives wanted them to have a baby. However, not disclosing HIV status to relatives and partner discussion on when to get pregnant were significant in HIV-infected women couples while knowing that ART/PMTCT is more than 70% effective and discussions with health workers about contraception was significant in HIV-infected men couples. After analysing all factors considered important, factors that remained significant in the multivariate analysis were: perception that partner wanted children. In HIV-infected men couples, discussions with health workers on contraception and believing in high ART efficacy were important (Paper III, Table 2). Significant factors in HIV-infected women couples were perceiving that relatives want them to have children and young age of 30 years or less (Paper III, Table 3).

### ***6.3 Young people's fertility decisions (paper IV)***

Slightly more than one quarter (28%) of the HIV-negative youth and 22% of the HIV-infected youth were males. The median age was 21years (IQR; 17-23) years among the HIV-infected youth and 20 (IQR; 18-21) years among the HIV-negative youth with about 40% in both groups between 15 -19 years of age. At baseline, slightly more than half (52%) HIV-infected compared to 18% of the HIV-negative had children. The mean number of living children was 1.43 children (SD, 0.79) among the HIV-infected youth and 0.78 children (SD, 0.64) among the HIV-negative youth. Eleven percent of the HIV-negative youth and 5% of the HIV-infected youth were pregnant or their partner was pregnant. About two percent in both groups were not sure if they were pregnant. Ninety eight percent among the HIV-negative and 73% among the HIV-infected reported they desire to have some children in future. Over one year's follow-up, the proportion of those who desired to have children increased slightly in the HIV-infected group. Table 3. Furthermore, over 90% of both HIV-infected and HIV-negative youth wanted to have the children on average four years later.

**Table 3 Trends in the desire for children among HIV infected and HIV-negative youth over one year’s follow-up**

Months since recruitment	HIV-negative young people		HIV-infected young people		OR	95% CI	P-value
	No.	%*	No.	%*			
Month 0	487	97.6	201	72.6	0.07	0.03, 0.13	0.000
Month 0 – 6	334	97.7	124	77.0	0.08	0.03, 0.19	0.000
Month 7 – 12	399	98.0	156	77.2	0.07	0.03, 0.16	0.000

Less than a half (44%) among the HIV-infected youth compared to two thirds (61%) among the HIV-negative youth made a consistent fertility decision, OR = 0.52 (0.38, 0.70) Table 4. At multivariate analysis, HIV- infected youth were less likely (OR= 0.62 (0.44, 0.88) to make a consistent fertility decision than the HIV-negative youth. The older youth (20-24 years), being married or in a relationship, and those who had discussion with the partner about childbearing, were more likely to make consistent fertility decisions. On the contrary, the change in marital status, discussions with health workers on contraception, pregnancy and HIV prevention were not associated with a consistent fertility decision.

#### ***6.4 Contraceptive decisions among the youth (Paper IV)***

At baseline, there were significant differences in contraceptive behaviour among the HIV-infected and HIV-negative youths. HIV-infected youths were less likely to use contraception compared to HIV-negative youths, 84 (34%) vs. 206 (59%). The male condom was the most commonly used method of modern contraception in both groups (72% among the infected youth and 79% among the HIV-negative youth). Condom use should be consistent in order to be effective. HIV-infected youth were less likely to consistently use condoms compared to the HIV-negative youth. Using condoms and another method (dual methods) was 6% or less in both groups.

Compared to the HIV-negative youth, HIV-infected youth was less likely to use condoms with all sexual partners and less likely to have used condoms at the last sexual act. The youth were asked a question “If 100 HIV-infected people used the condom, how many would not transmit HIV to their partners?” HIV-infected youth reported that they thought that using a condom was only 60% effective in preventing HIV transmission (IQR; 40-95), while the HIV-negative youth reported that the condom was 80% effective (IQR; 50-99). T-test showed the difference in these two estimates was statistically significant, p value= 0.007. While the HIV-infected young people were less likely to discuss with partner about childbearing, they discussed with health workers about pregnancy, birth spacing and HIV prevention more than the HIV-negative youth did. Discussion with health workers about contraception was similar in both groups.

**Table 4 Young people's fertility decisions by baseline and some other characteristics**

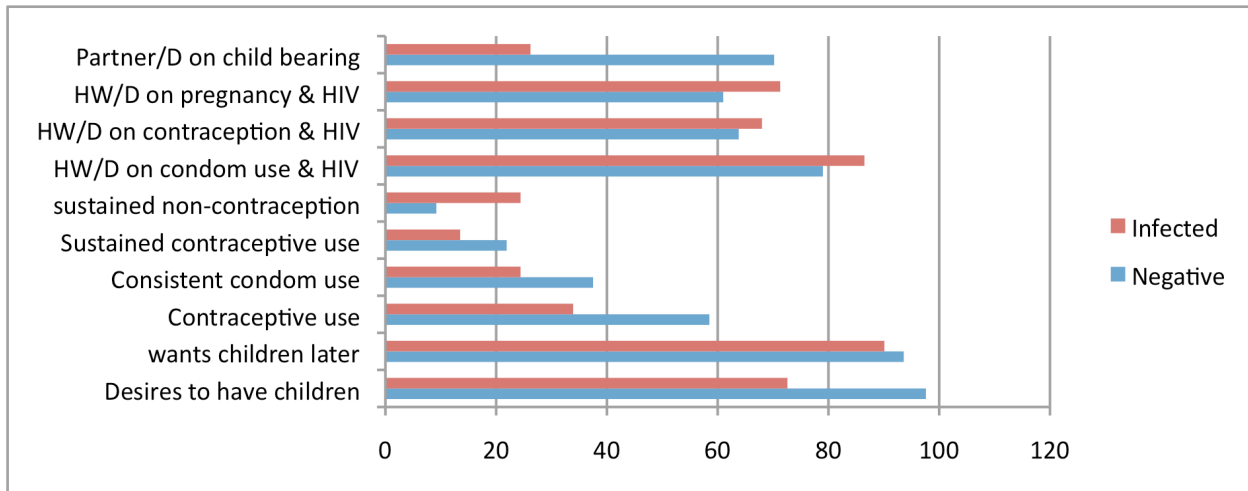
Characteristic	Consistent decision	P value	Crude OR	Adjusted OR	P value
HIV status of the youth					
HIV-negative	303 (60.5)				
Infected	122 (44.2)	0.000	0.52 (0.38, 0.70)	0.62 (0.44, 0.88)	0.007
Age of Respondent					
15-19 years	136 (42.8)				
20-24 years	289 (63.0)	0.000	2.28 (1.69, 3.07)	1.75 (1.25, 2.45)	0.001
Marital status					
Single	74 (29.4)				
Married /in a relationship	325 (67.9)	0.000	5.08 (3.55, 7.26)	2.46 (1.55, 3.89)	0.000
Separated/widowed	26 (56.5)	0.000	3.13 (1.62, 6.04)	2.67 (1.33, 5.36)	0.006
Education level					
Primary	102 (54.6)				
Secondary	137 (44.8)	0.035	0.68 (0.47, 0.98)	-	
Tertiary	185 (65.6)	0.016	1.59 (1.09, 2.33)	-	
Sex of the respondent					
Female	323 (55.9)				
Male	102 (51.3)	0.258	0.83 (0.60, 1.15)	0.89 (0.62, 1.29)	0.547
Religious affiliation					
Born-again (Pentecostal)	73 (45.6)				
Catholic	146 (55.3)	0.054	1.47 (0.99, 2.19)	1.43 (0.93, 2.20)	0.107
Protestant	137 (56.9)	0.028	1.57 (1.05, 2.35)	1.55 (0.99, 2.41)	0.054
Moslem	67 (61.5)	0.011	1.90 (1.15, 3.14)	2.00 (1.16, 3.44)	0.013
Reported their relatives wanted children	288 (54.4)	0.835	0.97 (0.71, 1.31)		
Discussed with partner about childbearing	270 (71.4)	0.000	3.94 (2.86, 5.41)	2.02 (1.33, 3.09)	0.001
Disclosed status to partner	295 (76.0)	0.000	6.32 (4.46, 8.95)		
Discussed with health workers about:					
Pregnancy and HIV prevention	275 (55.3)	0.806	1.04 (0.77, 1.40)		
Contraception and HIV	284 (56.5)	0.262	1.19 (0.88, 1.60)		
Changed marital status	132 (59.7)	0.076	1.33 (0.97, 1.83)	1.37 (0.97, 1.94)	0.078

### Trends in contraceptive use among young people

Throughout the one-year follow-up, HIV-infected youths were less likely to consistently use contraception compared to HIV-negative youths. The one-year follow-up showed no significant difference in discontinuing contraceptive use among both the HIV-infected and the HIV-negative youth. However, it showed that HIV-infected youth were less likely to start using contraception (contraceptive uptake) than the HIV-negative youth. In addition, contraceptive uptake was significantly more among the youth who were married or were in a relationship compared to those who considered themselves single but sexually active. Throughout the one-year follow-up, the 20-24 year olds were consistently more likely to uptake contraception than the 15-19 year age group. Those who discussed with partner were more likely to start using contraception. However, there was no difference in contraceptive uptake between those who discussed with health workers about contraception, pregnancy or birth spacing and those who did not. In total,

107 (24%) among the HIV-negative and 37 (18%) among the HIV-infected continued to use contraception throughout the year, OR 0.63 (0.41, 0.98), while 45 (12%) and 67 (28%) among the HIV-negative and infected respectively did not use contraception at all, OR 2.80 (1.80, 4.36). At multivariate analysis, the HIV-infected were less likely to sustain contraceptive use compared to the HIV-negative youth. Other factors independently associated with sustained contraceptive use included: age of the respondent, marital status and the male gender. Similarly, HIV-infected youth were more likely to continue not contracepting compared to the HIV-negative youth, and those in a relationship were less likely to continue not contracepting (Figure 6).

**Figure 6. Fertility behaviour among the HIV-infected and HIV-negative youth**



Note:

Partner/D on child bearing  
 HW/D on pregnancy & HIV  
 HW/D on contraception & HIV  
 HW/D on condom use & HIV

Discussed with partner on child bearing  
 Discussed with H/workers about pregnancy & HIV  
 Discussed with H/Workers about contraception & HIV  
 Discussed with H/workers about condom use & HIV

## **7.0 DISCUSSION**

### ***7.1 Discussion of findings***

This thesis discusses fertility decision-making in a country with both high rates of fertility and HIV infection. Factors that contribute to high fertility are entrenched in patriarchy and succession, the high poverty levels, religion and a culture that does not empower women to negotiate for the desired fertility (paper I). Young people also suggest that HIV infection hinders fertility negotiations especially among the HIV-infected and affected youth (paper I and IV). Compared to the negative youth, HIV-infected youth in care settings were more likely to make inconsistent fertility decisions and practice high-risk sexual behaviour. Furthermore, the desire for children, gender and myths about HIV sero-discordance hindered safe sexual practices among couples that mutually know they are discordant (paper II and III). The findings imply that the current health care system may not be meeting the reproductive needs of PLHIV, and call for a re-focus of policies and programmes.

#### **Views of young people about fertility**

Young people in Uganda believe that high fertility is sustained by patriarchy, poverty and religion. Patriarchy and succession are still the major determinants of family size in Uganda and can only be attained by producing boys. Patriarchal societies encourage male dominance and women are subordinates. The man has the last word on child bearing and stopping negotiations. However, the male groups agreed that it was difficult to force the woman to stop child bearing if they (women) wanted more children (paper I). Then men would have to use force or violence when their fertility decisions are not heeded. Only when the woman is educated or has a job, is she empowered to communicate her fertility preferences. The less educated use their ability to produce as many children as possible, hopefully boys, to gain power and status through their sons (94). Nonetheless, young people agreed that negotiation for fertility is still tilted in-favour of the man because even the women themselves desire to have boys to please their husbands. This phenomenon is reported in other studies that women make fertility decisions with their husband's preferences in mind (95). In countries with high son preferences, girl infanticide is carried out by women (96) and the son preference ideology is perpetuated by women (97).

Our study (paper I) agrees with other studies that poor people may want to have more children because they see them as a source of income (especially dowry from girls), or source of labour and old age insurance (98, 99). In Malawi, societies feel less poor if they have many children (100). The jobless were reported to produce many children because they used sex as a pastime and were not able to plan their fertility. The religious people were not on contraception because they believed that their religions directed them to produce the children, as God wants them to. This meant that God would decide for them the number of children to have. In Uganda, most women start their child bearing as teenagers (17). Therefore, if they do not use contraception and rely on God to manage their fertility, they may not complete their child bearing until they reach the menopause.



## Culture, behaviour and decision-making

*“Whenever you cross a border, the game will be the same but rules will be different.”*  
(Baker & McKenzie)

Behaviours are learned and also modified through a socialisation process that occurs through out a person’s life. The socio-cultural contexts, the relationships, family and community expectations shape a person’s choices and behaviour (101, 102). The best time to influence change in behaviours and norms of a society, is to target the young people in their formative years (103). Establishing norms is biased to favour the majority groups or sometimes to those who wield power in society like family, models, religion, politics and the law, economy and work, mass media and sometimes health care.

An important influence reported by discussants was that African societies, the kin and elders, prefer bigger families and this has a big impact on couples’ fertility decisions. One man narrated how his *senga* (paternal aunt) told him to marry many women to produce many children (boys) to expand the clan and also to get various talents from the children of different women (paper I). However, a review of child gender preferences in high income countries show that the boy child stabilizes marriages by reducing divorce rates; and it increases the father involvement in family and the parental time with the children (104). Furthermore, the gender composition of the already born children determines whether a couple should have another child or not (105). In addition, nowhere in the world do we find literature documenting sex selection and infanticide in favour of the girl child, which may indicate that son preference cuts across cultures but is expressed in different forms by different cultures.

HIV infection affects the individual, couple and societal fertility preferences (paper I, II, III, and IV). It conflicts with the norm when it makes powerful influences advocate for opposite values. For example, until recently, health workers advised that HIV-infected people should not have children. Even when the policies became accommodative, some health systems are still not responsive to HIV-infected peoples’ reproductive needs (106-108). The other powerful influence is the societal expectation that one should or must have children (109), but the HIV-infected people should not (paper III). “*When are you going to have a baby?*” is a common question, for the woman of childbearing age but the woman who is known to be HIV-infected gets a different one, “*Why would you have a baby?*” (56). This leaves the HIV-infected people in a double blind, rather between a rock (the society which wants them to have children) and a hard place (the health system which does not support HIV-infected people having children). Our study showed that HIV infection was an obstacle to negotiate fertility (paper I, and IV). The young people in our study cited the orphans of HIV who have been raised in unstable families as failing to negotiate for sex, marriage and childbearing because of the stigma of HIV (paper I). Other studies, in agreement, show a higher fertility rate among HIV-infected youth compared to their negative counterparts (50, 110).

Participants had a strong desire for children because they perceived that their spouses wanted children. They also felt pressured by relatives to have children though relatives had no knowledge that the participants/couple had HIV infection because they had not disclosed. The majority affirmed that the same relatives would not want them to have children if they knew that

they (participants) had HIV (paper III).

It is particularly important that health service providers should protect the reproductive rights of people living with HIV. The stigma and discrimination so often associated with HIV impinge on the right to access to sexual and reproductive health services and sexuality education even when they are available. HIV-infected people may have difficulties in choosing a partner, deciding whether to be sexually active or not and deciding freely and responsibly the number, spacing and timing of their children without discrimination, coercion and violence (45). HIV-discordant couples were looking up to health workers to assist them fulfil their reproductive dreams because by themselves they faced the dilemma of HIV infection to the HIV-negative partner. However, some feared approaching the health workers and tried to conceive without help (paper II).

### **Dilemma of safe sex and having children**

On the other hand, HIV infected or affected people were struggling with preventing HIV infection transmission especially to the partner during their quest for childbearing. Since they were in care, they learned that the hospitals are able to save the children from MTCT with Nevirapine tablets but believed they (hospitals) were not yet able to prevent horizontal transmission (paper I and II). Participants reported that HIV sero-discordant couples' sexual practices that are effective for HIV prevention (Consistent condom use, alternative non-penetrative sexual practices and abstinence) did not allow pregnancy to occur. Those couples that desired to have children had a dilemma of risking infection to the HIV-negative partner. In Uganda, assisted fertilisation techniques for discordant couples to avoid transmission for example like sperm washing when the man is infected, are not readily accessible. Such couples can only practice unsafe sex in order to conceive. Others sought for concurrent relationships (concordant partners) in order to fulfil their childbearing plans. However, seeking for HIV concordant partners outside of the relationship for sexual pleasure was also reported as a common practice to avoid condom use (paper II).

### **Fertility desires and HIV infection**

Our study reports a higher proportion of desire for children among HIV-infected people than previous researchers have found, likely because this study was conducted among the youth (paper IV). Studies done in older populations reported much lower proportions (ranging from 7%-16% of HIV-infected people desiring to have children (6, 8, 9). Heys' study, similarly, showed that the desire for children was much less in HIV-infected older participants than their HIV-negative counterparts (9). Studies done outside Uganda show similar results that young age increases the desire for children (2, 3, 5, 7, 57, 58, 111) of which the closest to our finding was the Nigeria study where 63% of the PLHIV desired to have children (3). Their study had a median age of 26 years and this may explain the high desire for children. A recent study from Canada had comparable proportions (69% desire and 58% intention to get children) with the results of our study among HIV sero-discordant couples (paper III) despite their participants having an older median age of 38 years (57).

## **ART and fertility desires**

Our study among the HIV-discordant couples did not show an increase in desire for children among those who were on ART (Paper III) in contrast to other studies that have found that ART may increase the desire for children (5, 57). Another study in western Uganda showed an increase in desire for pregnancy while on ART but no increase in pregnancy rates (112). We expected more desire since ART dramatically reduces the risk of both horizontal and vertical transmission of HIV, however, the awareness of the effectiveness of Art to reduce viral load and the risk of HIV transmission was surprisingly low and obviously not a prioritized topic for couple counsellors in this area. The HIV-negative partners reported they did not trust ART to protect them from horizontal HIV transmission (paper II). In the study by Homby et al. most participants had initiated ART but still reported very low (7%) levels of desire for children (8). Almost all participants in his study already had children and a big number (57%) were widows. Social desirability of answers on childbearing could have influenced the proportions responding that they want to have children. Besides, eventually (17%) got pregnant during follow-up; more than twice those who said they wanted more children. Another plausible explanation could be that these were unplanned pregnancies. However, a study from Kenya reported that women on ART quickly became pregnant even before their CD4 counts were optimal because they wanted to fulfil their womanhood roles but also they wanted to prove that they were healthy (113).

## **HIV transmission prevention strategy**

Our data shows that PLHIV would like to have children but need help to reduce transmission to partner and child (paper II and III), but others lack negotiation to practice their fertility preferences (paper IV). There are serious gaps in the implementation of the recommended four prongs approach for PMTCT: 1) the reduction in overall HIV among women and men of reproductive-age, 2) the reduction of unwanted pregnancies among HIV-infected women, 3) the provision of antiretroviral drugs to reduce the chance of infection to the foetus during pregnancy and delivery, and, 4) availing appropriate treatment, care and support to mothers living with HIV, including infant feeding (16). In reality, the only focus is on the third prong and this is also failing because combination treatment to all pregnant women from mid-term pregnancy is unfortunately still an exception, despite new WHO recommendations based on efficacy trials and comparably low cost (114). In addition, HIV prevention resources have increased from 13% in 2003–2004 to 33.6% in 2006–2007 (15), but the prevention strategies being implemented are still out-matched by the actual HIV prevention needs (16). Uganda, in an effort to reduce MTCT of HIV, has made commendable effort to avail mothers with PMTCT services, covering 80% of all health units. In 2009, 65% of all pregnant women were tested for HIV, 51% of those who needed ART/PMTCT accessed it and 24,554 (42%) of the babies got ART prophylaxis (63). However, this only constitutes 27% of the total number of babies exposed to HIV infection in Uganda if we assume an annual 1.5 million pregnant women and an HIV prevalence of 6%. This is a huge loss of PMTCT effectiveness due to health system failures. Furthermore, HIV-infected women very high viral loads are less likely to have a live-birth (115). This reduced fertility may translate into increased quest for child bearing among those infected with HIV, and this may have implications for HIV transmission to partner.

## **Fertility decision-making and unmet need for contraception**

A rational fertility decision is made when a person not intending to have children in that time period is using contraception, or is not contracepting because they would like to conceive. Decision-making may be affected by both internal (personal) and external factors (66, 68). According to Miller's model, once the desires turn into intentions (decisions), one has to negotiate with partner to effect conception or contraception (73). There are obstacles to negotiations and sometimes the intentions are not fulfilled. In our study, (paper IV), 90% of the young people interviewed wanted the children more than 4 years later, but about two thirds (66%) of the sexually active HIV-infected youth and slightly less than half (42%) on the HIV-negative youth were not using any contraception. Paper I reported that HIV-infected youth face difficulties when negotiating for their fertility preferences [13]. Moreover, other studies report an increase in births among 15-19 year-old HIV-infected adolescent women compared to their HIV-negative counterparts which points to an unmet need for contraception (50, 110). A possible explanation could be that the older youth are able to negotiate for contraceptive use with the partner. In paper IV, the older youth (20-24 years) were twice more likely to take up and sustain contraception use during the one-year follow-up than the younger youth (15-19 years). However, after controlling for age, gender and marital status (which all independently influenced contraceptive use), being HIV-infected was still significantly associated with lower likelihood of taking up or sustaining contraceptive use (paper IV). Studies report that young people rarely use condoms neither for contraception nor for HIV prevention because they fear condoms may reduce sexual pleasure and male potency [1, 37, 38]. Those who use condoms cite the fear of HIV acquisition as the main reason (116, 117). This is likely to be the logical explanation for the increased condom use among the HIV-negative youth in our study (paper IV).

Other factors associated with sustaining contraceptive use were being married or in a relationship and being male. From our data, the single youth were less likely to use contraception compared to those who were married or in a relationship. Moreover, during the follow-up period, the single youth were less likely to take up contraception or even sustain use compared to the married or those with a steady partner. It was not clear whether this ambivalence about pregnancy prevention was because of infrequent sexual activity as reported in other studies (118), inability to plan and control the next sexual encounter or fear of losing the new partners. Studies suggest infrequent sexual activity, changing new relationships, casual partnerships, alcohol or drugs, not having the condoms at the time they wanted sex and HIV-related stigma as major causes of non-use or inconsistent use of condoms among the youth (118-120). A lack of sex negotiation, gender and power relations and the adolescent's ability to communicate to partner about contraception are important factors that influence contraceptive use (121-123). One study reported that adolescents who were unfamiliar with the partner were less likely to use contraception (124). This is contrary to what is known that once a relationship is more intimate, condom use is stopped (119). In Uganda, another drawback to contraceptive use could be because the type of contraceptive method the youth prefer to use is male controlled (condom) and needs commitment of the male partner to be effectively and consistently used.

## 7.2 Discussion of methods

*“To present research as a smooth unblemished process of conception, exploration, analysis and discussion is not only unconvincing, it is fraudulent and dishonest” (125).*

### Selection bias

In sub-studies II, III and IV, we selected participants from care centres. Clients here get information about sexuality, contraception and HIV prevention. Their views and behaviour may be different from those who do not attend care. However, views of young people from the community about fertility were similar to those of young people from city suburbs and those from HIV/AIDS care (paper I). Moreover our results show that what the health workers said had minimal impact on fertility desires (paper II, III and IV). Yet paper II reports that participants were eagerly waiting for advice from health workers about how to manage child bearing in HIV sero-discordance. The fact that HIV-infected and affected people in care are still struggling with sexuality and fertility could imply that either, those who do not get information from health workers are worse off or we overestimate the ability of health workers to assist in childbearing decisions especially in low-resource settings. Moreover, many clients in care had low knowledge that ART reduces horizontal HIV transmission and this could reflect that the advice and counselling from health workers is inadequate. Therefore, the findings of this study could reflect the views and fertility decision-making norms of the population in the context of HIV infection.

The majority of our study groups were poor, yet the Uganda’s sero-behavioural survey showed that HIV is more prevalent in the wealthiest quartile of people. PLHIV that have higher incomes may be attending private clinics and thus be under-represented in our study. In addition, HIV sero-discordant couples (paper II and III) in the study were mutually disclosed which implies that their decisions may be different from those couples who do not mutually know each other’s HIV status or do not frequent the health services for counselling and support. This may indicate that the challenges may be greater for other PLHIV who do not access care. In addition, the experiences and decisions of this study group may not reflect the experiences and decisions of all PLHIV regarding childbearing. However, the socio-demographic characteristics, (median age, years of cohabitation and number of living children), of our study population are similar to those of other studies among discordant couples in Uganda and sub-Saharan Africa (24). Therefore our findings can be generalised to sero-discordant couples in stable relationships that know each other’s HIV status and are in similar socio-cultural situations and settings.

In the young people’s cohort, study IV, both the HIV infected and HIV-negative youth were attending some care facility where they both get education about sexuality, reproduction and HIV prevention. We selected only the youth who had known their HIV status for six months or more because HIV is a stress-related illness and those who find themselves infected need time to accommodate their status, settle psychologically and get on with life. Therefore, to get a clear picture of how HIV infection influences fertility decision-making, we needed to allow for this duration. Though we could have missed some important information by leaving out those who had not tested or had known their status for a short period. The results then would not represent all youth in the general population. However, we would then expect to get high levels of contraceptive use among this group attending care and receiving education about HIV and

pregnancy prevention. On the contrary, the results of contraception in our study are comparable to those from the UDHS 2006 among the youth in Kampala (17). Thus, the assumption is that the influence of any selection bias may be low in this study and that the results therefore may be generalised to the youth in other urban and peri-urban settings in Uganda and at least in sub-Saharan Africa with similar fertility norms and burdens of HIV.

### **Information bias**

Information collected was based on recalling the events like the time of starting or stopping contraceptive use, starting or ending relationships and the number of sexual partners. Participants were not able to accurately remember which day they started or stopped using contraception. We overcame this by taking blocks of six months. This may be inaccurate since we could have recorded those who used contraception for a shorter time as those who used it for the whole six months. In addition, participants could have told us what they thought we wanted to hear since they have been in care and are told to use contraception. However, this social desirability of answers was minimised by using research assistants who were trained and age appropriate. Information from FGDs depends on how well the moderator controls the group. When the researcher fails to control the group, dominant members sway the group to their opinions. Paper I and II, the principal researcher moderated all the FGDs and tried to encourage the non-dominant voices. In addition, the research team discussed the issue of dominant voices after every FGD to assess how balanced the discussion was. Results from qualitative studies (paper I and II) were not meant for generalization. We used purposive sampling with maximum variation strategy to get participants with diverse views, values, experiences and practices, wishes and concerns (79, 82). These were later explored in the quantitative studies (paper III and IV).

### **Reflexivity**

Researchers bring their own lived experiences into the research formulation, analysis and interpretation, therefore need to examine themselves and attempt to separate their own perceptions and interpretations from the phenomenon being studied. Nevertheless, the research process has the potential to transform both participants and researchers and may lead to personal analysis and internal reflection (126). I was anxious that my background from a high fertility and polygamous family would influence the research process but it helped me understand the cultural fertility connotations better. Listening to young people's stories about fertility and patriarchy deepened my understanding and unraveled the mysteries I had about my father marrying another wife yet calling my mother, *Keishekuura* (the one who got the clan from ridicule), the most prestigious pet name a wife can get from her husband. Nonetheless, we cannot rule out that another researcher from outside the culture would have got alternative interpretations.

I was referred to as a counsellor in one of the study sites and this could potentially have biased the results especially of the qualitative studies since I conducted all the interviews. I chose to ride on the counsellor title because I learnt from the clients that in the HIV care settings, counsellors were trusted and confidantes of clients. They feared doctors; therefore, the doctor-patient

relationship would have affected the quality of information I would get from the clients. However, results from the other three sites, where we introduced ourselves as researchers from Makerere Medical School, showed similar views and opinions. Most interviews were done at the health care premises, which could affect the responses. In all the studies, I was the only medical person; the research assistants were non-medical (sociological) counsellors. The trust built by the team was confirmed when participants in the study started confiding in the study team and sending them to tell the health care staff about changes they would like to have. For instance, some young people after one FGD on fertility among the HIV-infected youth (study II) suggested that we take the tape and play it to the health workers to hear their opinions. The general feeling was that we gained their trust. Furthermore, regular discussions of the findings with the other team members (FM, FK and SN) who were not in the field but had a lot of experience of the local contexts helped minimise potential bias. AK and AME were valuable resources providing an “outsider’s fresh eye”.

My challenge, as an Obstetrician/Gynaecologist, was holding back correct information when clients discussed grossly wrong misconceptions like “people with blood group O do not get infected with HIV” or “a man can get HIV virus from an infected woman and pass it on to his wife without he himself getting infected”. I had to hold back, be a researcher and seek to understand how they come to such ideas; but passed on feedback to their health caregivers for correction.

## 8.0 CONCLUSIONS

- The views of young people on childbearing in Uganda are still embedded and strongly influenced by the patriarchal cultural and religious norms with the male gender enjoying a superior position which compels women to desire to have many boys for their security and happiness (paper I).
- The youth form values and attitudes about fertility before they reach adolescence. This could imply a rooting of culture, mores and tradition rather than experiential learning (paper I).
- HIV infection hinders people's ability to negotiate for the preferred fertility (paper I and II).
- Many HIV sero-discordant couples in Uganda desire to have children and majority are planning to conceive but the highest desire for children is among the young people (paper III and IV).

The current dialogue with health workers is not increasing contraceptive use, especially among the HIV-infected youth (paper IV).

- The desire to have children hinders safe sex practice among HIV sero-discordant couples (paper II).
- The discordant couples committed to condom use have to trade the risk HIV transmission, or look for a sero-concordant partner to get children. To some the desire for children and sex for pleasure becomes a good excuse to look for concurrent partnerships (paper II).
- HIV infected youth are not empowered to practice or sustain consistent contraceptive use or adopt preventive strategies" (paper I, and IV).

### ***8.1 Implications of the findings***

The findings of this study show enormous implications regarding sexual practices and childbearing. They reveal that HIV infection has changed the context in which sexuality and fertility decision-making are lived-out among young PLHIV and sero-discordant couples. While the cultural norms still favour high fertility, HIV infection becomes a hurdle to surmount when planning for family size. Having HIV infection cannot remove the quest to fulfil patriarchal obligations especially if they also must look for boys. Moreover, having the stigma of "infertility", in the eyes of relatives, when one stops having children because of HIV, is too great a burden for those who already bear the challenges of living with HIV. Therefore, failing to program for PLHIV who want to have children will only continue to fuel the HIV epidemic.



The PMTCT policy is based on four pillars that include prevention of HIV infection among women of reproductive health, unwanted pregnancies, transmission from mother to child and provision of care to mother, child and families. However, the prong for prevention of unwanted pregnancies has not received attention both at policy and program levels. There are no activities in the established PMTCT program to cater for prevention of unwanted pregnancies. Furthermore, there are no policy or reproductive health programs for HIV-infected people who want to found a family. The fact that more than half on the PLHIV in our study (paper III and IV) want to have children calls for policy and programmatic evaluation to cater for the fertility needs of the PLHIV.

The lack of negotiating power has a potential to increase both fertility and HIV infection rates among the youth and discordant couples. Furthermore, the poor fertility behaviour reported in this thesis, and the concurrent concordant partnerships pursued outside of their main relationship for pleasure and childbearing, the lack of negotiation for safe sex and inconsistent contraceptive use have a potential to increase both HIV infection and unplanned pregnancies among young people but also in the population. However, the less immediate after effects of such behaviour is broken marriages, unstable families and the children may be the ones most severely affected.

The fact that the youth and couples we studied are in health care settings but are not consistently using protection for both HIV and pregnancy has both public and policy implications. As many as two thirds of the youth changed their fertility practices within one year, and this has significant implications for increasing unplanned pregnancy and HIV transmission unless programming for sexual and reproductive health critically considers the youth living with HIV and discordant couples as a special-needs group.

## 9.0 RECOMMENDATIONS

To minimize HIV transmission and unwanted fertility, a comprehensive approach to frame HIV-infected young people's sexuality is urgently needed. Programs that may stem the epidemic should target:

- Reduction of concurrent partnerships
- Consistent condom use among HIV infected people especially those in discordant and non-regular relationships
- Reduction of fertility could enhance motivation for safe sexual practices. Therefore we need innovations that could convince communities to desire fewer children.

Women empowerment alone will not suffice to reduce fertility rates if the society continues to look at the male child as having more value than the female child has. Young people need innovative cultural practices and programs that increase women's social respectability such as emphasis on respect for girl children, sensitize communities that a girl can be heir, and inherit her father's property. The gender and power re-learning process should start earlier in the pre-adolescent period.

Introducing adult education and income generating activities in poor communities to reduce idleness and raise socio-economic situation. This is empowering and reduces fertility.

In-depth understanding of the influence HIV infection has on young people's fertility and sexuality is critical for programming for their sexual and reproductive health needs.

Sexual and reproductive health programs tailored for HIV sero-discordant couples are critical but also for young people to help reduce the rapid change of fertility decisions which puts them at risk of both HIV and unwanted pregnancies. Furthermore, it is critical to include PLHIV and those in sero-discordant relationships as a group with special reproductive needs in the National Policy on Sexual and Reproductive Health and Rights, but also it is vital to include them to contribute to establishing programmes for their needs.

Health workers should stop imposing their own beliefs on clients and embrace ethics of care so that they assist couples to identify their reproductive options. In addition, health systems must be improved, to provide special sexual and reproductive health services tailored to PLHIV, particularly those in sero-discordant relationships. Furthermore, policies and guidelines that empower health workers with resources, information, skills and sensitivity training related to the specific needs of HIV-infected people cannot be over-emphasized. One possibility is to look at and modify the reproductive health counselling content to ensure that the youth receive counselling that stresses the importance of consistent fertility choices as a means of preventing both un wanted pregnancy and HIV transmission.

Mobilizing more political commitment and resources to strengthen family planning services to help women and couples have the number of children they want and when they want them. Further work must be carried out to determine whether the reported harm-reduction strategies, proposed as a strategy for discordant couples that want to conceive, are effective and feasible in low-resource settings before they can be adopted. These range from assisted reproduction (in-vitro fertilization) that require a lot of resources to sperm washing and practical advice based on the woman's reproductive cycle and HIV infectivity.

Policy-makers should also include in policy and HIV care programmes low-cost assisted reproductive technologies, such as teaching people about ovulation and timed intercourse, sperm washing for HIV-infected men and self-insemination for HIV-infected women with HIV-negative partners, to prevent HIV horizontal transmission of HIV.

Research to understand the content of reproductive discussions that occur between health workers and their clients, and also looking for new innovations to re-market the condom are critically needed.

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