The Social Context of Prevention of Mother to Child Transmission of HIV (PMTCT) in Uganda:

Mothers' and health care providers' experiences and lessons for programme improvement

Joseph Rujumba

Dissertation for the degree philosophiae doctor (PhD)
at the University of Bergen

2012

To all mothers and their health care providers

Contributors

The study was funded by the Norwegian Programme for Development, Research and education (NUFU), *Essential nutrition and child health in Uganda,* grant number NUFU PRO-2007/10119, a collaborative project between the Department of Paediatrics and Child Health, Makerere University, Uganda and the Centre for International Health (CIH), University of Bergen, Norway.

This PhD thesis is a result of the above collaboration. The main supervision of the candidate was done by Professor H. Kristian Heggenhougen, CIH, and the co-supervision was done by Professor James K Tumwine, Dept of Paediatrics and Child Health, Makerere University, Dr. Stella Neema (PhD), Department of Sociology and Anthropology, College of Humanities and Social Sciences, Makerere University and Professor Thorkild Tylleskär, CIH.

Table of contents

List of Appendices

1. Consent form
2. Interview guide for pregnant women
3. Interview guide for health workers
4. Interview guide for key informants
5. Ethical clearance letters

Abbreviations

ABC	Abstinence, Being Faithful and using Condoms
AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
AIDS	Acquired immune deficiency syndrome
ANC	Antenatal Care
ARVs	Antiretroviral drugs
AZT	Zidovudine
CSDH	the Commission on the Social Determinants of Health
eMTCT	Elimination of mother-to child transmission of HIV
HAART	Highly Active Antiretroviral Therapy
HC	Health Centre
HIV	Human immune-deficiency virus
HSSIP	Health Sector Strategic Investment Plan
IDIs	In-depth interviews
MOH	Ministry of Health, Uganda
MTCT	Mother-to-child transmission
NVP	Nevirapine
PHC	Primary Health Care
PMTCT	Prevention of mother-to-child transmission of HIV
RCT	Routine Counselling and Testing
SDH	Social Determinants of Health
sdNVP	single dose nevirapine
TASO	the AIDS Support Organisation
UAIS	Uganda AIDS Indicator Survey
UBOS	Uganda Bureau of Statistics
UNAIDS	Joint United Nations Programme on AIDS
UNICEF	United Nations International Children’s Emergency Fund
VCT	Voluntary Counselling and Testing
VHT	Village Health Teams
WHO	World Health Organization

Abstract

Introduction: The prevention of mother-to-child transmission of HIV (PMTCT) programme has been operational in Uganda since the year 2000, but its performance remains sub-optimal. The objective of this thesis is to increase understanding of the role of the social context in the delivery and utilization of PMTCT services, focusing on how pregnant women experience routine HIV counselling and testing as part of antenatal care, HIV status disclosure to partners and lessons leant by health care providers, to inform strategies for improving the effectiveness of the programme.
Methods: This was a qualitative study conducted in 2010 in Eastern Uganda. We conducted 1) in-depth interviews with 30 pregnant women (15 HIV positive and 15 HIV negative) attending the antenatal clinic at Mbale Regional Referral Hospital, 2) key informant interviews with 6 health workers involved in providing antenatal care and HIV counselling and testing at the same hospital; and 3) 24 individual interviews with health workers involved in the PMTCT programmes at 10 health care facilities and 4 key informant interviews with district officials and The AIDS Support Organisation Mbale (TASO). We did observations at the antenatal clinics at 2 TASO clinics and at Mbale Hospital. The content thematic approach was used for data analysis.
Results: Most women knew that the hospital provided HIV counselling and testing services as part of antenatal care (ANC) prior to attending the current ANC visit. Most women perceived HIV testing within the ANC as a compulsory procedure, a belief that was re-enforced by health workers' downplay of the opt-out option during health education and counselling sessions. In general, most women viewed routine HIV testing as beneficial by enabling those who test HIV positive to access PMTCT services and HIV treatment. Most women who tested HIV positive were satisfied with the immediate counselling they received. However, they identified the need for follow-up and supportive counselling to cope with the fears and the stigma of living with HIV. Some HIV negative women mentioned that the post-test counselling they received was inadequate.
All HIV negative women reported that they had disclosed their HIV status to their sexual partners but expressed need for support to convince their partners to undergo HIV testing. Women reported that their partners often assumed that they were equally HIV negative (*testing by proxy*). Most of the HIV positive women had not disclosed their HIV status to their sexual partners for fear of abandonment, violence and accusation of bringing HIV infection into the family. However, the few positive women who disclosed their status generally experienced positive responses from their sexual partners. The key lessons for programme improvement were: ensuring constant availability of critical PMTCT supplies, regular in-service training of health workers to keep them abreast with the rapidly changing knowledge and guidelines for PMTCT, ensuring that lower level health centres provide maternity services and ARVs for women in the PMTCT programme and that they had adequate facilities for effective follow-up and support for mothers.
Conclusion: In this setting, routine HIV counselling and testing services are known and acceptable to mothers. There is need to strengthen post-test and follow-up counselling for both HIV positive and negative women to maximize opportunities for primary and post exposure HIV prevention. Most women who tested HIV positive found disclosure of their HIV status to partners extremely difficult. Such women should be identified and supported. Pregnant HIV negative women and their unborn babies remained at risk of HIV infection owing to the resistance of their partners to go for HIV testing on the assumption that they were equally HIV negative. This notion of HIV testing by proxy requires further investigation but also should be addressed in health education and counselling sessions. The voices of health workers in this study revealed that it is imperative for government, civil society organizations and donors that the PMTCT programme addresses the challenges of shortage of critical PMTCT supplies, continuous health worker training and follow-up, and support for mothers as urgent needs to strengthen the PMTCT programme. Attaining the global and national goal to eliminate new HIV infections in children requires strengthening the health system as part of the social context to better deliver the PMTCT programme interventions.

Original papers

The thesis is based on the following papers:

Paper I

Joseph Rujumba, Stella Neema, James K. Tumwine, Thorkild Tylleskär, Harald K. Heggenhougen: Pregnant women's experiences of routine counselling and testing for HIV in Eastern Uganda: A qualitative study *(Submitted)*

Paper II

Joseph Rujumba, Stella Neema, Robert Byamugisha, Thorkild Tylleskär, James K.Tumwine Harald K. Heggenhougen: "Telling my husband I have HIV is too heavy to come out of my mouth": pregnant women's disclosure experiences and support needs following antenatal HIV testing in Eastern Uganda. *Journal for the International AIDS Society 2012,* **15**:17429

Paper III

Joseph Rujumba, James K.Tumwine, Thorkild Tylleskär, Stella Neema, Harald K. Heggenhougen: Listening to health workers: lessons for strengthening the programme for the prevention of mother-to-child transmission of HIV in Mbale District, Eastern Uganda. *BMC Health Services Research 2012,* ***12**:3*

The original papers are reproduced with the permission of the respective publishers.

Acknowledgements

I am very grateful to God for the opportunity to undertake this study programme and for His grace that has carried me through this journey.

I am extremely indebted to my supervisors who guided me throughout my study period. Prof. H. Kristian Heggenhougen, I am very grateful for your day to day guidance and encouragement in this journey. I am fortunate to have been under your guidance and mentorship. You have broadened my understanding of the social determinants of health and qualitative research. Prof. Thorkild Tylleskar, thank you for your support in both the technical and practical elements of my study. Prof. James K. Tumwine, thank you for the ever timely advice and insights in my work. Dr Stella Neema, I am grateful for your support, encouragement and always being available for me whenever I needed your input. I am privileged to have been supervised by a team of multi-disciplinary and experienced researchers. Thank you for the constructive comments and advice throughout my study period. The skills I have learnt will be a building block for my future research and mentoring engagements.

I thank the academic and administrative staff at the Centre for International Health, University of Bergen, for all the support you rendered to me and for making my stay in Bergen enjoyable. Special gratitude to all my colleagues and friends at the Centre for International Health and the Department of Health Promotion and Development, University of Bergen and the Ugandan Community in Bergen; I am grateful for all the support and encouragement.

The mothers and health workers who participated in this study, I am grateful for your experiences and insights that made this research possible. Special thanks to the management and staff of all the study health facilities, and our research assistants, for the practical help during data collection.

I thank Makerere University, my employer for granting me study leave. The head and staff Department of Paediatrics and Child Health, Makerere University, thank you for the continued support and encouragement. Special thanks to Mr William Barugahare Department of Social Work, Mulago National Referral Hospital and Dr Herbert Muyinda Child Health and Development Centre, Makerere University for taking on my teaching roles whenever I was away. Special thanks to the Government of Norway-QUOTA programme for the sponsorship and the NUFU grant PRO-2007/10119 for covering research costs.

To my parents, thank you for the foundation you laid for me in my education. Mum Atwooki, I cannot forget the continuous encouragement and prayers that have kept me going. To my brothers, sisters and in-laws thank you for the prayers and practical support that kept me going when being away from home was challenging. Special thanks to my wife, Sharon Ahumuza Rujumba for the continued support, encouragement, patience and taking on the challenging roles of work and managing our family while I was a way. To our beloved children, Henry, Hillary and Hannah, I cannot express enough how we have missed each other, I am very grateful for your love and patience.

Introduction

Global overview of HIV and mother-to-child transmission

HIV/AIDS remains a global challenge, affecting both adults and children. At the end of 2010, there were 34 million people living with HIV globally, of whom 3.4 million were children under 15 years of age [1]. Sub-Saharan Africa, with only 12% of the global population, continues to be the region most affected by HIV/AIDS [1-3]. In 2010, about 70 % of all people living with HIV resided in sub-Saharan Africa. In the same year, 1.2 million AIDS deaths accounting for 67% of the total AIDS related deaths in the world occurred in the region [1]. Similarly, of the 2.7 million people who became infected in 2010 worldwide, about 70% were in sub-Saharan Africa [1]. This represents an addition of 1.9 million people living with HIV in the region. However, a reduction in HIV incidence has been reported in 22 Sub-Saharan African countries between 2001 and 2009 [1, 4].

In 2010, about 390 000 children were newly infected with HIV, 90% from sub-Saharan Africa [1]. Over 90% of HIV infections in children below 15 years are due to mother-to-child transmission (MTCT) [5]. MTCT refers to HIV infection transmitted from an HIV-infected mother to her offspring during pregnancy, delivery or breastfeeding [5]. The risk of mother-to-child transmission of HIV without any intervention is estimated to be 5-10% during pregnancy, 10-20% during delivery, and 10-20% during breastfeeding [6]. In response, a number of interventions have been initiated to reduce this transmission, often under the umbrella: the prevention of mother-to-child transmission of HIV (PMTCT) programme. In high income countries with well-functioning PMTCT programmes, MTCT has almost been eliminated but remains a challenge in many low income countries.

The HIV situation in Uganda

The first cases of HIV/AIDS in Uganda were suspected in 1982 among businessmen in fishing communities along the shores of Lake Victoria [7]. Most of the early cases were concentrated among the young, sexually active and mobile population groups. About 70% of the early cases were between 20 and 40 years [7]. In the early years, HIV/AIDS took on a social interpretation. It was initially linked to witchcraft or a punishment to some traders who were thought to have stolen [8] goods from their suppliers. As the epidemic evolved, HIV/AIDS elicited fear, secrecy, stigma and discrimination owing to being associated with sexual promiscuity, long time of illness and death [9].

Currently in 2012, the national HIV prevalence stands at 7.3% [10], an increase from 6.4% documented in the 2004/05 survey [11] among adults aged 15-49 years. In the early days [7], as is the case today, HIV prevalence remains disproportionately higher in urban (8.3%) than in rural (6.5%) areas [12] where the majority of the people live. These variations suggest the existence of differences in exposures among urban and rural dwellers, an indication of the role played by social determinants, like variations in sexual practices and the norms that regulate sexual behaviour, [7] and the predominance of the cash based survival mechanisms in urban areas. The HIV prevalence is higher among women (8.3%) than men (6.1%) and highest among the widowed women (32.4%) and men (31.4%) [10], followed by those who were divorced or separated (16%) [12]. The HIV prevalence increases with age and it peaks for women at the age of 35-39 (12%) and at age 40-44 for men (11%) [10]. HIV prevalence is lower in groups with higher education attainment [12] also reflecting the underlying social determinants in the spread of HIV.

There are regional variations with Central I region having the highest HIV prevalence of 10.6% while the Mid Eastern region, where Mbale District is located, has the lowest prevalence of 4.1% [10]. The 2004/05 survey documented higher prevalence in the conflict affected areas of Mid Northern Uganda relative to other regions, (8.2%) [13]. The 2011 Uganda AIDS Indicator Survey (UAIS) reported a stable HIV prevalence at 8.3 % in that region similar to prevalence in the Mid Western and South Western regions. The actual reasons for the stable HIV prevalence in the Northern region are not easy to discern, but in part it could be due to the return of peace to the region and people moving away from internally displaced people's camps to villages. It should be noted that the rebel group led by the notorious Joseph Kony, relocated to Darfur Southern Sudan, The Democratic Republic of Congo and the Central African Republic and has, thus, not been active in the northern region of Uganda since 2005. The stability in HIV prevalence in this region compared to other rural regions may be a reflection of the reduced interrelated effects of social determinants of health like displacement, poverty, breakdown in social norms and networks, prostitution, excessive use of alcohol [14, 15] and the abduction of children to become child soldiers or girls to become concubines for the rebels. Overall, the 2011 UAIS showed a reduction in HIV prevalence in three regions (Kampala, Mid Eastern and East Central) between 2004/05 and 2011 while the prevalence increased in the remaining seven regions **(Figure 1 and 2).**

Uganda is often cited as a success story on the African continent ravaged by the HIV crisis. Uganda registered significant gains in the reduction of HIV prevalence from about 18% in the 1990s to 6.4% in 2005 [13]. This has been attributed to strong political commitment, partnerships, openness in the public education campaigns and the Abstinence, Being Faithful and using Condoms (ABC) model [16, 17]. The reduction of the HIV prevalence might also be attributed to the numerous deaths due to AIDS since there was no treatment at the time until 1998. It might also be attributed to the demographic transition with the young uninfected growing up [18].

Table 1: Annual estimated HIV incidence in Uganda 2007 to 2010

	Estimated annual HIV incidence			
Category of population	**2007**	**2008**	**2009**	**2010**
Adults	87,727	91,967	97,163	102,157
Children < 15 years	25,746	24,878	24,548	24,142
Adults and children	113,473	116,845	121,711	126,299

Source: UAC 2012 [19]

The HIV prevalence is the sum effect of 1) new HIV infections and 2) number of HIV related deaths. Thus, when ARV treatment decreases the number of HIV related deaths, the HIV prevalence tends to lose its importance as an easy tool to assess the epidemic. For instance an increase in prevalence may be the result of a higher number of new infections (which is negative) or the decrease in HIV related deaths (which is positive). In this regard, HIV incidence which denotes the number of new HIV infections is a better measure to assess the epidemic. Over the years, new HIV infections in Uganda have remained considerably high **(Table 1).**

Recent estimates by the Ugandan Ministry of Health revealed that the new HIV infections have been increasing annually. For instance the annual number of new HIV infections increased by 11% from 113,473 in 2007 to 126,299 in 2010 [19]. As shown in table 1, the new HIV infections among adults increased throughout the four year period while new HIV infections among children below 15 years declined by 6% from 25,746 in 2007 to 24, 142 in 2010, possibly as an effect of the PMTCT programme [19]. This reduction in HIV infections in children is insufficient to achieve elimination of mother-to-child transmission of HIV, a national [20] and global target [21]. Overall, the high number of new HIV infections in the country implies that more effort is needed to scale-up HIV prevention interventions. The high number of new HIV infections together with more people accessing HIV treatment contributes to an increase in HIV prevalence in the country documented in the 2011 Uganda AIDS Indicator Survey [10]. Currently in 2012, about 60% of the eligible adults and children living with HIV are receiving ARVs [19]. Indeed, there are concerns that the decline in HIV prevalence in Uganda may have ended in 2000 [13, 20], around the same time ARVs became available. It is important that HIV prevention interventions are strengthened to compliment care and treatment interventions. An increase in HIV prevalence in Uganda reflects a reversal in the gains the country had made in the fight against HIV. Of the total new HIV infections, 43% are estimated to occur among people in mutually supposed monogamous relationships [22]. In 2009, a total of 1,200,000 people in Uganda were estimated to be living with HIV, of whom 610,000 were women aged 15 years and more [23]. Heterosexual contact and mother-to-child transmission are the major routes of HIV transmission in Uganda [24].

Mbale

District

located in

Mid

Eastern

Figure 1: Map of Uganda showing the statistical sub-regions used is the 2004/05 and 2011 Surveys [25]

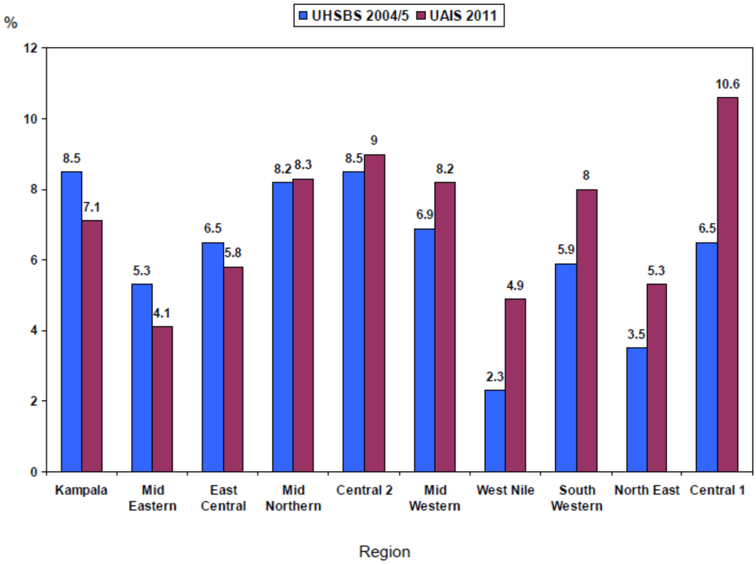

Figure 2: Variations in HIV prevalence by region, 2004/05 and 2011 [10, 19]

The health system in Uganda

Health services in Uganda are provided by both public and private actors, each sub-group covering about 50% [26]. Public health services in Uganda are provided at district, regional, and national level (**Table 2).** At district level, services are organized at community and health facility levels. The community level services are provided mainly by village health teams (VHT) which constitutes Health Centre one (HC I). This level has no physical location. The HC I level is followed by HC II up to hospital level. A health centre II provides outpatient services, antenatal care, immunization and community outreach services; HC III provides all the services provided at HC II, plus maternity and laboratory services, and has a general ward for inpatients. Health Centre IV provides all services at HC III and surgical services. Hospitals offer all services provided at HC IV and specialized care. The main challenge, however, is that most of the health facilities are not operating at optimal levels. For instance, in 2008 only 28% of the 154 HC IVs were fully operational [27]. Low funding limits a steady supply of essential health commodities and the recruitment and retention of the essential number of health workers [28].

Except for the General and Regional Referral hospitals, all levels of health facilities currently provide services for more people than they are supposed to, table 2. This situation is likely to constrain health facility infrastructure and staff in the delivery of health services including maternal and child health services like PMTCT.

Regional Referral Hospitals provide all services at a district hospital level and more specialized care. At the end of 2010, there were 13 regional hospitals in Uganda [30]. At the national level of health care delivery, there are two National Referral hospitals. Whereas the district health services are managed by the district local governments, the regional and national referral hospitals are semi-autonomous [26] with their own institutional budgets and accounting procedures. Districts are responsible for the management and supervision of public and private health service providers within their areas of jurisdiction while the supervision of national referral and regional referral hospitals is the responsibility of the Ministry of Health headquarters [26].

Table 2: The structure of the health system in Uganda

Level	Planned population to serve	Actual average population served	Difference between planned and actual	Location	Services provided
Health centre (HC 1)	1000	1000	0	Village level, no physical structure	Community mobilization, health education, basic curative care and referral
HC II	5000	15,000	+10,000	Parish	Outpatient, antenatal care, immunization and outreach services
HC III	20,000	85,000	+65,000	Sub-county	All services provided at HC II, and maternity, general ward and laboratory services
HC IV	100,000	188,000	+88,000	County	All services provided at HC III, and wards, theatre and blood transfusion
General Hospital	500,000	263,000	-237,000	District	All services at HC IV, and more wards, surgery, consultation and laboratory and X-ray
Regional Referral Hospital	3,000,000	2,308,000	-692,000	Regional (3-5 districts)	Specialist clinical services such as psychiatry, Ear Nose and Throat, higher level surgical and medical services, teaching.
National Referral Hospitals	10,000,000	34,000,000	+24,000,000	National	Provide comprehensive specialist services and care, teaching, research in addition to services provided by general and regional hospitals.

(Adapted from): MOH, HSSIP II [29], MOH, 2nd National Health Policy [26], UBOS [25].

The burden of mother-to-child transmission of HIV and the PMTCT programme in Uganda

In Uganda, 10% of the people living with HIV are children below 15 years of age [13]. Mother-to-child transmission of HIV accounts for about 18-22% of the total annual new HIV infections [13, 22] and remains the major source of HIV infection among children. In 2010, a total of 94,000 women living with HIV were estimated to have given birth in Uganda and 28,000 new HIV infections occurred in children due to mother-to-child transmission in the same period [1].

The PMTCT programme in Uganda began in the year 2000 on a pilot basis, in a few districts as a collaborative effort by the Government of Uganda, the World Health Organization (WHO), the Joint United Nations Programme on AIDS (UNAIDS) and other development partners. The programme was later extended to all districts by the end of 2004 [24]. Over the years, the PMTCT programme has continued to evolve benefiting from the experience gained, the emerging evidence and guidance from the international agencies, especially WHO and UNAIDS. Currently, Uganda implements a comprehensive PMTCT programme under the leadership of the Ministry of Health (MoH). The main pillars of the PMTCT programme are: 1) preventing HIV infection in women of child-bearing age, 2) preventing unwanted pregnancies among women living with HIV, 3) reducing HIV transmission from women living with HIV to their infants, and 4) providing care and support for women living with HIV, their children and families [21, 24]. By June 2009, 77% of all health facilities in Uganda, from hospitals down to Health Centre (HC) III, were offering PMTCT services, compared to 53% of the health facilities in the same categories in 2008 [13].

Despite the scale-up of the PMTCT programme, marked differences exist in the availability of PMTCT services by level of health facility. In 2009, PMTCT services were available at 87% of hospitals, 93.2% HC IVs, 73.2% HC IIIs and only 12.4% of the HC IIs [13]. The uneven and incomplete coverage of the PMTCT programme reflects structural barriers and the potential for unequal access to these services which, in part, may explain the undesired performance of the programme [13]. In 2009, only 52% of pregnant women living with HIV in Uganda received antiretroviral drugs for preventing mother-to-child transmission of HIV [13]. In 2010, it was estimated that 42% of the pregnant women living with HIV received the most effective ARVs for PMTCT [1]. Low rates of PMTCT coverage have also been documented in other African countries [31]. A review of PMTCT data at Mbale Regional Referral Hospital in eastern Uganda covering 8 years of PMTCT implementation revealed that only 33% of the infants born of HIV positive mothers were given ARVs for PMTCT under the VCT approach but this proportion increased to about 40% when routine HIV testing was introduced within the antenatal clinic [32]. This trend depicts some improvement in the programme, but coverage remains too low to guarantee elimination of HIV infection in children.

The PMTCT programme in Uganda, like the world over, has been characterized by constant changes, especially in the guidelines, keeping pace with the international recommendations, especially by the WHO and UNAIDS **(Figure 3).** Common subjects for change have related to drugs used, infant feeding and the mode of counselling and testing. All these have implications for the implementation of the programme and how it is experienced by service users and providers. The programme involves HIV counselling and testing of mothers during pregnancy, antiretroviral prophylaxis, safer delivery practices, and counselling and support on infant feeding [33]. The first PMTCT guidelines in Uganda were launched in 2002 informed by the pilot phase of the programme that started in 2000. The main drug was single dose nevirapine for women during labour and single dose nevirapine for babies within 72 hours after birth. Zidovudine (AZT) from 36 weeks of gestation, during labour and post-partum was available at a few sites. Replacement feeding was recommended for HIV positive women. In 2006, Uganda revised her PMTCT guidelines and introduced use of more effective PMTCT drugs, antiretroviral treatment for eligible women and exclusive breastfeeding for 3-6 months for HIV positive women. Exclusive replacement feeding was recommended if it was deemed to be acceptable, feasible, affordable, sustainable and safe (AFASS) [24].

Since 2006, Uganda has been rolling out the use of Combivir [zidovudine (AZT) 300 mg/lamivudine (3TC) 150 mg] twice a day starting from 32 weeks of pregnancy throughout labour and boosted by single dose nevirapine 200 mg at the onset of labour. The women continue with Combivir twice a day for one week after delivery [24]. The baby receives a single dose of nevirapine (2 mg/kg body weight) within 72 hours and zidovudine (4 mg/kg body weight) twice a day for one week [24]. At lower level health facilities, with constraints in human resources, they continue to use nevirapine single dose for women during labour and the single dose nevirapine for babies within 72 hours after birth [34]. While single dose nevirapine is no longer recommended for PMTCT by WHO, in 2009, over half (58%) of the women who received ARVs for PMTCT in Uganda received single dose nevirapine while 25% received combination drugs for PMTCT [13]. The implication here is that even among the women who receive ARVs for PMTCT, many still receive less effective drugs unlikely to guarantee elimination of new HIV infections in children. In 2010, the proportion of women who received effective drugs for PMTCT increased to 42% [1]. This trend depicts an improvement in programme coverage, but more needs to be done and the views of health workers are important in this endeavour.

During the initial phases of the PMTCT programme, focus was on protecting infants from HIV infection with little regard to the mothers' health. This presented challenges for mothers who had to deal with the fear of knowing they had HIV but needed to protect their babies from being infected [35]. There has been a considerable shift in policy guidelines since 2006 in favour of more effective and long-term use of ARVs for PMTCT and ensuring the health of HIV positive women, children and other family members [5, 36]. Currently, in 2012, Uganda is implementing a revised set of PMTCT guidelines adopting option B-plus which involves providing Highly Active Antiretroviral Therapy (HAART) for life to all HIV positive pregnant women irrespective of CD4 count [20].

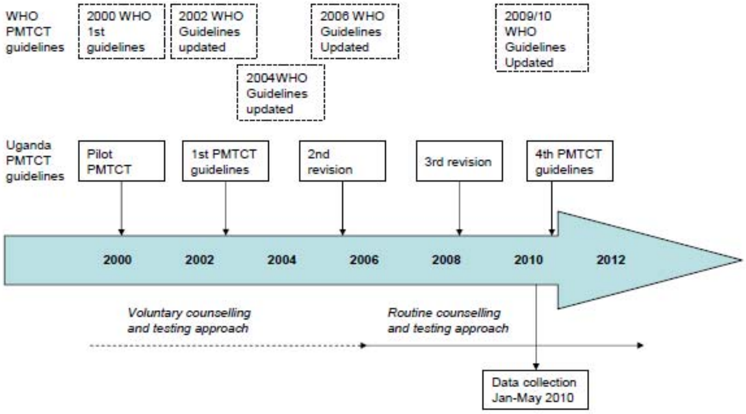

Figure 3: Key policy changes in PMTCT guidelines in Uganda (Source: MoH 2003, 2006, 2008, 2010 and 2012 [20, 24, 37-39] and WHO 2002, 2006 & 2009 [40-42] guidelines.

HIV Counselling and testing as a key component of PMTCT

HIV counselling and testing is a critical entry point for HIV prevention (including PMTCT), treatment and support. Uganda began providing HIV counselling and testing services in 1990 using the voluntary counselling and testing (VCT) approach [43] also called the client-initiated approach or opt-in approach. Between 2000 and 2005, the PMTCT programme in Uganda used VCT as a dominant model for HIV testing. Under this approach, women would be offered an HIV test if they requested it and were provided individual pre-test and post-test counselling [43]. While VCT offered greater autonomy for women in deciding whether to take the test, it has been criticized for making HIV/AIDS an exceptional disease and generally having low testing rates. Since 2006, HIV counselling and testing for PMTCT in Uganda has been offered as a routine service integrated within the antenatal, maternal and child health clinics [24, 43]. This new model of HIV testing is also called routine counselling and testing (RCT) or provider-initiated counselling and testing.

The major changes in this model include: introduction of group pre-test counselling/education, and the routine offer of the HIV test to all clients with a possibility to decline the test (opt-out) if the client so desires. Whereas routine provision of HIV testing as part of the antenatal clinic has been part of the standard of care in many high income countries, for instance Sweden and Norway since 1987 [44, 45] and France since 1993 [46, 47], this mode of service provision is relatively new in most African countries [48]. The RCT was introduced following a UNAIDS and WHO recommendation in 2004 [49]. In Africa, Botswana was the first country to implement this model of HIV testing in 2004 [50]. Routine counselling and testing has been associated with increased HIV testing rates, use of PMTCT services and early access to treatment for women who test HIV positive in many African settings [32, 50-53].

In 2010, it was estimated that 63% of all pregnant women in Uganda tested for HIV, a substantial increase from 18% in 2005 when HIV testing was being provided as a voluntary service [1]. Similarly, over 90% of pregnant women who attend ANC at health facilities that provide the service in Uganda are counselled and tested for HIV [13], a likely indication of high acceptability. While this new mode of HIV testing is being rolled-out to more health facilities, there are concerns about reduced autonomy among women, the inadequate counselling received and that HIV testing exposes women to stigma [54, 55]. However, information on how pregnant women experience HIV counselling and testing under this new mode of delivery (RCT), especially in low income countries, remains limited yet could help to improve the programme.

Disclosure of HIV status to sexual partner in the context of PMTCT

Disclosure of HIV status to sexual partners among women who test for HIV as part of the PMTCT programme is important to facilitate adherence to PMTCT recommendations and is critical for the success of each of the four pillars of the PMTCT programme including primary prevention among women who test HIV negative [21, 24]. Moreover, if the woman got infected during pregnancy or breast feeding, there is an elevated risk of mother-to-child-transmission due to the initial high viral load [24]. While some studies in the African setting have documented fear of stigma, accusation of infidelity, violence and loss of support [56-58] as some barriers to women's disclosure of their HIV status to their partners, most of the studies focused on people who test HIV positive [59, 60]. Thus there is a lack of views and experiences of HIV negative women who, in fact, are the majority.

Health workers, health system and the PMTCT programme

The design and implementation of successful health programmes, including PMTCT, revolves around having a well-functioning health system, including adequate numbers of well-trained health workers. The World Health Organization defines a health system as constituting all activities whose primary purpose is to promote, restore or maintain health [61]. WHO further contends that health systems are a vital part of the social fabric of any society [62]. Thus any public health intervention like the PMTCT programme could only perform to the level and functionality of the health system, of which it is part. Some of the health system constraints in relation to the PMTCT programme include: scarcity of staff, limited skills and stock-out of medical supplies among others. A recent Ugandan Ministry of Health sector performance report indicates that service delivery is constrained by too few and inadequately skilled staff. Overall, only 56% of the staff positions are filled while stock-out for drugs remains an ongoing challenge [30]. Within this setting, insights and lessons learnt by health workers are important to inform programme improvement.

Social determinants/social context: do they matter for PMTCT?

The main theme of this thesis, “the social context”, addresses the question: do social determinants/social context matter in the performance of the PMTCT programme? Interest in the relationship between health and social determinants has increased greatly in recent years. The social context relates to factors such as gender, ethnicity, socio-economic status, education [63] among others. Focus on the social context/social determinants of health has gained increased visibility and interest following the two major documents by the World Health Organization, that is, the 2008 report of the Commission on Social Determinants of Health (CSDH) [64] and the World Health Report 2008 on Primary Health Care (PHC) [65]. The CSDH defines social determinants of health (SDH) as “the structural determinants and conditions of daily life responsible for a major part of health inequalities between and within countries” [64]. Social determinants thus represent the broad and complex facets of social, political, economic, environmental and cultural factors that impact on health [63]. They include the distribution of power, income, goods and services, and the circumstances of people’s lives such as their access to health care and education [64].

In this thesis we use the term social context to mean the social determinants or conditions under which the components of the PMTCT programme are provided and utilized. Social determinants of health like education, religion, beliefs about illness presentation and treatment, gender roles and power relations, beliefs on illness as source of punishment, disparities in income, stigma among others, shape how health is promoted, restored or maintained. In our case, the social context determines how women encounter HIV counselling and testing, disclosure of HIV status to their partners and the utilization of PMTCT services in general. For instance, limited staff, and shortage of supplies at health facilities in the context characterized by poverty and gender inequality are some of the broader forces that may constrain HIV prevention among women [66] including MTCT [67]. Family practices such as polygamy, common in many Ugandan societies, may have a bearing on couple communication and relationships especially about sensitive issues such as disclosure of HIV test results or encouraging male partners to go for HIV testing.

In Uganda, HIV/AIDS remains a stigmatized condition [68], associated with sexual promiscuity and denial. Stigma hinders access to HIV testing, treatment and support but also disclosure of HIV status to sexual partner which has a direct effect on women’s access and utilization of PMTCT services. While the PMTCT programme has been integrated in maternal and child health clinics, this process constitutes a structural barrier to male involvement in the programme as these clinics are perceived as female spaces [67, 69]. Poor socio-economic conditions have been documented as barriers to infant follow-up [70] and account for the many women who drop-out of the PMTCT programme [67].

Theoretical framework

This thesis was guided by the Critical Theory orientation as used in Medical Anthropology sometimes called the political economy of health [71]. Proponents of this orientation contend that health and well-being are fundamentally linked to the social, economic and political realities at both macro and micro levels of society [71]. This theoretical underpinning emphasizes the social and structural forces that underlie the production of ill-health and the constraints to restore health, including access and utilization of health care interventions [71]. In this regard, discussion of health problems, separate from their social context downplays the social relations underlying such problems [71]. The Critical Theory tradition, involves paying attention to social structures and relations that generate the patterns of human behaviour, beliefs and attitudes [72] that may be associated with ill-health or limited use of health services and resources, in our case PMTCT services. With regard to the PMTCT programme in Uganda, the social context where women live and access these services is influenced by the interface between macro and micro level factors. At macro level, the international and national PMTCT guidelines and how these are implemented at health system level often characterized by few staff and stock-out of medical supplies will impact the programme. In addition, the other contextual issues like poverty, stigma, and gender and power relations and marriage structures may also play out as structural forces limiting women's ability to prevent transmission of HIV to their babies for both women who test HIV positive and those who test HIV negative. Access to information by women before attending ANC, the value attached to children, knowledge of ARVs, beliefs about illness, as some examples of the social context, may also have a bearing on women's understanding of HIV testing and disclosure of HIV status to their partners as key elements for a successful PMTCT programme. In particular, the use of the critical theory perspective was intended to aid in the understanding of women's experiences of HIV testing and the meaning assigned to the HIV test results **(Paper I)** as well as the lessons learnt by health care workers on how to improve the PMTCT programme in Eastern Uganda **(Paper III).**

Gender and power relations emerge as central concepts in the Critical Theory tradition and this perspective is relevant in our study. To better understand women's experiences of disclosure of HIV status to their sexual partners **(paper II),** we draw upon gender intersectionality theory [73, 74] to comprehend how the varied social positions that are assigned to women played out as barriers or facilitators to women's disclosure of their HIV status to their sexual partners. Proponents of this theoretical perspective argue that considering women as a homogeneous group, marginalizes categories of oppression [73, 74]. Thus the basis for intersectionality theory is that various dimensions of social stratification, for example socio-economic status, gender and age, can add up to great disadvantage or advantage [75, 76]. In our case, gender intersectionality theory was relevant to explain how gender interacts with other social positions to influence disclosure or non-disclosure and the implications this has for the PMTCT programme.

Explanatory models

We also draw on concepts of explanatory models advanced by Kleinman [77] to explain some aspects of our study participants' interpretation and understanding of HIV results. According to Kleinman a clinical encounter denotes a transaction between patient's and doctor's explanatory models [77] and this reality emerged in our study, especially with regard to the meaning some of our study participants attached to their HIV test results. The patients' explanatory models were particularly relevant in understanding the views of our study participants which were in disagreement with the medical model and the implications such opposing perspectives may have for the PMTCT programme.

Rationale and focus of the study

Despite the implementation of the PMTCT programme in Uganda for over a decade, its performance remains inadequate [13] to meet the national target of eliminating paediatric HIV. In Uganda, MTCT accounts for about 20% of the total annual HIV infections [22, 78] and remains the second major source of HIV infection after heterosexual transmission [24, 38]. Within this context, the perspectives of health care providers and pregnant women as service users are important to better understand what needs to be done to improve the PMTCT programme. In this regard, the focus for each of the three papers included in this thesis is described in the following sections.

Though relatively new in Uganda, RCT has been practiced in high income countries as early as 1987[44, 45]. There is still insufficient information on how pregnant women perceive and experience this new approach of HIV testing and the implications these experiences may have for the PMTCT programme. Understanding women's experiences of RCT was particularly important, given the low coverage of HIV testing in the general Ugandan population [13] and the fact that RCT is being expanded to lower level health facilities. Some studies have indicated that HIV testing is perceived as mandatory [57, 79, 80] and that women do not fully understand the reasons for being tested [57]. **Paper I** documents pregnant HIV positive and negative women's experiences of routine HIV counselling and testing within a typical antenatal care setting and formulated suggestions for programme improvement.

One of the challenges encountered by women after antenatal HIV testing is disclosure of their HIV status to their sexual partners. With low male partner attendance of the ANC, estimated at about 5% in Mbale District [69] where this study was conducted, disclosure could be a huge challenge for women to undertake especially those who test HIV positive. In addition, most studies on disclosure have focused on women who test HIV positive, thus we know little about the experiences and the support women who test HIV negative may require before and after disclosure. Understanding women's disclosure experiences including the role of the social context in which women live could provide insights on how best they can be supported to improve success for the PMTCT programme. In **paper II,** we document HIV positive and negative women's experiences of HIV status disclosure to their partners and the support women require before and after disclosure.

Health workers are important stakeholders in the design, implementation and improvement of health programmes; although in many instances they have been depicted as the weak link in health care delivery [69, 81-84]. An evaluation of PMTCT services in Uganda done in 2003, when HIV testing was being offered as a voluntary service, documented challenges related to staff, space and reluctance of women to test for HIV [85]. Today, when the programme has operated for a decade, one would anticipate that these challenges could have been addressed. However, given the sub-optimal performance of the PMTCT programme [13], the views of, and lessons learnt by, health workers involved in programme implementation are important in generating ideas on how to improve the effectiveness of the programme. Thus **paper III** explores the lessons learnt by heath care workers in the delivery of PMTCT services.

Study objectives

General objective

To increase understanding of the social context in which PMTCT services are delivered and utilized in Eastern Uganda so as to make suggestions for improvement of these services.

Specific objectives

1) To explore pregnant HIV positive and negative women's experiences of routine HIV counselling and testing in Mbale District, Eastern Uganda **(Paper I).**

2) To explore pregnant HIV positive and negative women's experiences of disclosing their HIV status to their sexual partners in Mbale District, Eastern Uganda. **(Paper II).**

3) To document experiences and lessons learnt by health care workers involved in the delivery of PMTCT services in rural Uganda to better understand what more needs to be done to strengthen the programme **(paper III).**

Study subjects and methods

Study area

The study was conducted in Mbale District, Eastern Uganda from January to May 2010. Uganda is located in East Africa bordering Kenya in the east, Tanzania in the south, Rwanda in the southwest, the Democratic Republic of Congo in the west and the Republic of South Sudan in the north **(Figure 4).**

Figure 4: Map of Uganda showing the location of study area

Uganda has an estimated population of 34 million people, 56% of whom are below 18 years, implying that the country has predominantly a young population. Uganda's population growth rate averaged at 3.2 between 1990 and 2000 [25, 86] and it was estimated at 3.6 between 2000 and 2009 [87]. Uganda's population has doubled in the last 20 years (from 16.7 million in 1990 to the 34 million in 2012). The majority of Uganda's population (85%) live in rural areas [25] and depend on subsistence farming. Trends of selected health and demographic indicators are shown in table 2.

Table 3: Trends of selected health and demographic indicators for Uganda

Indicator	**1990/1**	**2002/3**	**2005/6**	**2011/12**
Total population (millions)	16.7	24.2	30	34
Total fertility rate (children per woman)	6.9	6.9	6.7	6.2
Life expectancy (years)	47	50	50	54**
Infant Mortality Rate (per 1000 live births)	106	87	76	54
Under 5 Mortality Rate (per 1000 live births)	175	156	137	90
Maternal mortality ratio (per 100,000 live births)	510	505	435	310
ANC attendance (one visit) (%)	92	92	94	95
ANC attendance (four visits) (%)	30	42	47	47
Urban population (%)	10	12	13	15
Literacy rate, persons aged 10 years and above (%)	54	70	69	73**
Health facility deliveries (%)	35	37	41	57
HIV prevalence (%)	18	6.1	6.4	7.3
Population below the poverty line (below USD 1) (%)	56	38	31	25

** Currently in 2012, the literacy rate is estimated at 79% for men and 66% for women while life expectancy is estimated at 55 years for women and 54 years for men. Sources**:** UNICEF 2004, 2008 & 2012 [23, 88, 89], UDHS 2006 and 2011[90, 91], UBOS 2011 and 2012 [25, 86], UNFPA 2011 [92], MOH 2012 [1].

Mbale District – study site

Mbale District is about 245 km from Kampala, the capital. The district has an estimated population of 416,600 people [93], with the vast majority residing in rural areas [94]. Mbale District has one regional referral hospital, which doubles as the district hospital, and 40 health centres all providing HIV services at different levels [93]. In 2005, the HIV prevalence in Mbale was estimated at 5.3% in the general population and 6.3% among women aged 15-49 years [11]. In 2011, HIV prevalence in Mid Eastern Uganda where Mbale District is located, was reported at 4.1% which is lower than the national prevalence of 7.3% [10]. The people of Mbale are predominantly Bagisu, alternately referred to as

Bamasaba or Gisu. In this thesis we use Bagisu as the description for the people of Mbale District. Lumasaba is a dominant language spoken in the district, though some people speak and understand Luganda, a language from Central Uganda. The Bagisu, inhabit other districts neighboring Mbale, such as Sironko, Bududa and Manafwa. Among the Bagisu, traditional male circumcision is a dominant cultural practice that marks transition from boyhood to manhood, and is highly publicized through dancing, running around villages and streets and instilling courage in candidates to be strong and demonstrate that they are ready to become men. With regard to marriage, Mbale, like many parts of Uganda, is a patri-lineal society whereby, upon marriage, a woman moves to the husband's clan and children belong to the man's lineage. Customarily, the man is the head of the household. In Eastern Uganda, where Mbale is located, 72% of the households are headed by men [95]. Thus the majority of the women depend on their husbands to meet the family needs while women are responsible for the domestic spheres but also much of the agricultural work is done by women. Polygamy, though declining, is still practiced in Mbale district. In 2005, almost 29% of women and 20% of the men in Eastern Uganda were in polygamous unions [11].

Mbale Regional Referral Hospital

The study was conducted at the antenatal clinic, Mbale Regional Referral Hospital **(paper I-III)**, at seven selected health centres in Mbale District, at The AIDS Support Organisatition Mbale (TASO) and at an outreach site at Bukedea HC IV in Bukedea District **(paper III)**. Mbale Regional Referral Hospital has an estimated tertiary catchment population of 1.9 million people [32] and serves the districts of Budaka, Bududa, Bukedea, Bukwo, Bulambuli, Busia, Butaleja, Kapchorwa, Kibuku, Kumi, Kween, Manafwa, Mbale, Pallisa, Sironko and Tororo in eastern Uganda. Antenatal care services at the hospital are provided daily on weekdays, and on average 60 pregnant women attend the antenatal clinic per day, most are new attendees. The study health facilities were selected purposively on the basis of providing PMTCT services and length of time they had provided these services.

The PMTCT programme at Mbale hospital started in 2002 at a time when HIV testing was being offered under the voluntary counselling and testing (VCT) approach. In 2006, Mbale hospital started providing HIV counselling and testing for PMTCT as a routine service (RCT) [43] and this approach has led to high testing rates among ANC attendees [52].

Inclusion of Mbale hospital in the study was done purposively for serving predominantly a rural population and being one of the oldest PMTCT sites in Uganda. The AIDS Support Organisation (TASO) Mbale, one of the 11 TASO Uganda service centres was studied for being one of oldest (since 1992) and a major HIV prevention, care and support centre in the district [96]. By the end of 2009, TASO Mbale had registered a cumulative number of 22 500 clients out of which 3 893 were on ART [97] and had started providing PMTCT services on a monthly basis at the centre and during outreach services.

Study design

A qualitative study design was adopted to facilitate an in-depth exploration and understanding of women's experiences of HIV counselling and testing, as integrated services within the antenatal care clinic **(paper I)** and women's experiences of HIV status disclosure to sexual partners **(paper II)**, as well as the lessons learnt by health workers for improving the PMTCT programme **(paper III)**. Indeed qualitative research has the strength of describing the complexity and breadth of a phenomenon of concern in a natural setting [98]. Qualitative research facilitates understanding of social processes and concepts from the perspectives of study participants (pregnant women and health workers), informed by their lived experiences [99, 100] and the meaning mothers and health workers attach to such experiences [101, 102]. In-depth interviews (IDIs) with pregnant women and health workers were conducted to enable study participants to share their experiences with regard to the PMTCT programme [102]. Talking to people in depth and allowing them to tell their own stories, provided access to their world-view [100]. In-depth interviews with women were preferred to focus group discussions since HIV-infection is still a sensitive and stigmatizing condition in the study setting. The qualitative approach was appropriate to enhance our understanding of both the process and the outcome of health care policies and initiatives [103], in this case routine HIV counselling and testing as well as the PMTCT programme in general. In table 4, the issues explored per group of study participants are summarised.

Table 4: Summary of methods and issues explored for each paper in the thesis.

Paper and focus	**Number and category of study participants**	**Issues explored**
Paper I – Women's experiences of routine HIV counselling and testing	30 Pregnant women attending follow up ANC visit after they had tested for HIV - 15 HIV negative - 15 HIV positive women	- Characteristics - age, marital status, type of marital relationship, education, source of income and parity (paper I and II) - Open ended questions – prior knowledge about HIV testing, and experience with HIV counselling and testing, the meaning of test results and conduct of health workers.
Paper II – Women's experiences of disclosing HIV status to partner	Same as above	- whether women had disclosed their HIV status to their sexual partners or not -process of disclosure - benefits and fears of disclosure - partners' reaction to disclosure - Support required by women before and after disclosure
Paper I and II	6 Health workers involved in PMTCT at Mbale hospital	- Experience with RCT, women's concerns about the RCT and what needs to be done - Disclosure to partners, women's experiences, fears and support required before and after disclosure
Paper III – Lessons learnt to improve the PMTCT programme	24 Health workers involved in PMTCT at 10 health facilities	- Structured questions on: category/position, training on PMTCT, and length of time involved in PMTCT. - Open ended questions on: routine counselling and testing, and what could be done to strengthen the PMTCT programme
	4 Key informants 2 TASO officials 2 Mbale District officials	- State of PMTCT services, HIV counselling and testing, maternity, ARVs for prophylaxis and what needs to be done to improve the programme

Selection of study participants

The study participants for paper I and II were thirty pregnant women (15 HIV positive and 15 HIV negative) attending their subsequent antenatal care clinics after they had tested for HIV at Mbale Regional Referral Hospital. Study participants were enrolled consecutively after they had been attended to by health workers. They were selected purposively having been tested for HIV during their previous visit to the antenatal clinic during the current pregnancy and had to be 18 years old or more. Eligible women who agreed to participate in the study were identified through their attending health workers as gate keepers [101]. In line with qualitative research literature [104, 105], recruitment of women in the study continued until 15 women had been interviewed in each of the groups and at that time we felt no new information was emerging from later interviews compared to earlier interviews, no further interviews were conducted.

To facilitate a better understanding of women's experiences of routine HIV counselling and testing as well as disclosure to sexual partners in the study setting, six health workers involved in providing antenatal care services at Mbale Hospital were interviewed as key informants. Interviews with women were conducted first and those with health workers (key informants) later. This helped to crosscheck and follow-up some of the issues generated during interviews with the women. At the end of each day of data collection, a study team meeting was held to discuss emerging issues and identify areas for probing and further data collection. The key insights from study meetings and reading of transcripts progressively gave me an early opportunity to understand the data and prepare for detailed analysis. Besides, such early insights were shared with supervisors during debriefing meetings.

For paper III, we purposively recruited 24 health workers involved in the PMTCT programme at ten selected health care sites in Mbale and Bukedea Districts. Health workers included in the study had worked at the study health facility for at least 6 months and were working in the PMTCT clinic at the time of the study. In addition, two district officials from the Department of Health Mbale and two administrators from TASO Mbale participated in the study as key informants. To enable follow up on the suggestions made by health workers on how to strengthen the PMTCT programme, key informant interviews were conducted after those of health workers. Since Mbale hospital was the main study site, at the end of the data collection phase of the study, preliminary insights emerging from the study were shared with staff working in the antenatal clinic.

Data collection

Paper 1 and II

The main methods for data collection for paper 1 and II were: in-depth interviews with pregnant women and key informant interviews with health care workers. Semi-structured interviews [106] were conducted to elicit information on women's experiences with routine HIV counselling and testing as part of antenatal care (paper 1) and women's experience with disclosure of their HIV status to sexual partners (paper II). A pre-tested interview guide [102, 105] was used to explore study concerns (Table 4). A flexible interview guide with probes facilitated an in-depth understanding of women's experiences of the RCT as an entry point into the PMTCT programme and their disclosure experiences to their sexual partners including partners' responses and the nature of support women needed before and after disclosure. This open ended nature of the research approach helped to identify the concerns of both HIV positive and negative women. The concerns of the later are often missed in HIV research. Interviews were conducted in a language of choice for the mother which was Lumasaba, Luganda or English. The author conducted interviews in Luganda and English while research assistants fluent in English and Lumasaba conducted interviews in Lumasaba. On average each interview lasted for about 40-45 minutes.

Key informant interviews were conducted with health workers involved in the antenatal care at Mbale hospital. The main focus of the interview was on their experience with RCT, the process of HIV counselling and testing, women's concerns about the RCT, disclosure to partners and related issues.

Data collection Paper III

Data for this paper was drawn from individual interviews with 24 health workers involved in the PMTCT programme at 10 health care facilities. A semi-structured interview guide [105] was used to conduct the interviews. Broadly, the focus of interviews was: characteristics of the health worker, views with regard to routine HIV counselling and testing, performance of the PMTCT programme and what could be done to strengthen the PMTCT programme. All interviews were conducted in English, most by the author with assistance of three research assistants (female university graduates) with experience in conducting qualitative interviews who assisted with note taking. The research assistants were also involved in data collection for the study on women's experiences of routine HIV counselling and testing. The research assistants were trained on study concerns including interviewing, observation and note taking; were involved in pre-testing of study instruments at Mbale Hospital and they worked with me on rotational basis as note takers on data collection for paper III and interviews conducted in English and Luganda (papers I and II).

Additional data for paper III were collected through four key informant interviews with officials from Mbale District health department and TASO Mbale. These interviews helped to situate study findings in the broader picture of the district health system.

Observation

During the fieldwork phase of the study, I observed the PMTCT processes at TASO Mbale, TASO Bukedea outreach and Mbale Regional Referral Hospital. This helped me to gain an in-depth understanding of the PMTCT programme and the context within which the PMTCT services are provided and utilised. Together with the research assistants, I attended health education talks and group counselling sessions at the start of clinic days. I followed the observations, with interviews with staff and women to clarify issues that were captured during the observations. For instance, at Mbale hospital, we observed that pregnant women, who had bypassed lower level health facilities to attend antenatal care at the hospital, were being told to go back and attend ANC from those health facilities. Follow up interviews with health workers at Mbale hospital clarified that this procedure was meant to decongest the hospital. This practice was also confirmed by health workers at lower level health facilities.

Data analysis

Preliminary data analysis was done concurrently with data collection by having study team meetings and regular de-briefing of co-authors. The author of this thesis who conducted and supervised the data collection phase of the study conducted research meetings and provided up-dates to co-authors. During this phase, emerging issues and further data collection needs were identified. The intensive phase of data analysis was conducted by JR and HKH. Data management for papers I and II was done using NVivo [107] version 9.0 while that for paper III, was done manually.

The content thematic approach, a widely used approach in qualitative health research [101] was used for data analysis for all the three papers. Data analysis was guided by the Graneheim and Lundman 2004 framework [108] to capture latent and manifest content in the interview scripts. This process followed multiple readings of interview scripts to get a sense of the material, identify study themes and sub-themes which were then used to code the data (grouping of sections of data under the themes and sub-themes). For instance, in paper III, themes and sub-themes relating to lessons learnt by health care workers that could help to improve the PMTCT programme were identified and used to group data for interpretation. The same process was done for paper I and II. We also conducted sub-group analysis which involved comparing findings from health workers in public health care facilities with those of health workers from TASO (paper III). For papers II and III we compared findings from HIV positive women and those of their HIV negative counterparts. In addition, we carried out concurrent triangulation [101] involving comparing findings from health workers and those of officials from TASO and the Mbale District administration as key informants (paper III) and findings from pregnant women and those from health workers at Mbale Hospital (papers I and II). As much as possible, we selected quotations reflecting lessons learnt by health workers and women's experiences of HIV testing and disclosure of their HIV status which we used in presentation of study findings. The analysis process involved a number of meetings between the thesis author and other co-authors to harmonise understanding of the process and the key issues for inclusion in the papers. This process of peer briefing I believe enhanced the credibility of study findings.

Ethical considerations

Ethical clearance for the study was obtained from the Makerere University, College of Health Sciences, Research and Ethics Committee and the Uganda National Council for Science and Technology; The Mbale Regional Referral Hospital Institutional Review Committee and the TASO Uganda Institutional Review Board. Written consent to participate in the study was obtained from all study participants after explaining to them the purpose of the study, assuring them of confidentiality and anonymity. Study participants were informed that participation in the study was voluntary and they could withdraw from the study at any time and this would not affect the care they received. Ink pads for a thumb print were provided for study participants who could not read or write. Confidentiality and anonymity of study participants were ensured. For instance, individual characteristics of study participants were masked throughout the handling of data and publication process. Data was stored and only accessed by the research team.

Results

The results of the study are presented in the three papers I-III. In this section; the main results of each of the papers are summarized.

Paper I: Women's experiences of Routine HIV counselling and testing

This paper focuses on the experiences of pregnant HIV positive and negative women with regard to routine HIV counselling and testing as part of the antenatal care, a relatively new approach of providing HIV counselling and testing that started in 2006, in Uganda. The study participants were 30 pregnant women attending their subsequent antenatal visits after they had tested for HIV. The women were aged between 18 and 43 years old and most of them were married and depending on agriculture for survival. The study findings reveal that most pregnant women experienced HIV counselling and testing as an expected service that they were already aware of before attending the antenatal clinic. Many women had accessed information on routine HIV counselling and testing during their past visit to health facilities, through the media and their social networks, mainly family and friends.

Most women perceived HIV testing as part of the antenatal care as a compulsory procedure that every pregnant woman had to undergo and indeed some women understood HIV testing as a new "law" by the government geared at preventing babies from HIV infection. This compulsory perception of HIV testing among women was re-enforced by health workers who often down played the opt-out option by emphasizing the benefits of HIV testing to the mothers and their babies during health education and counselling sessions. Overall, women in this study viewed routine HIV testing as beneficial by enabling those who test HIV positive to access treatment and interventions for prevention of mother-to-child transmission of HIV, as one woman noted: *"Testing is for every pregnant woman, which is good. If I have HIV, my child should be saved from it"*.

Women found the process of moving forward to undertake the HIV test a difficult step to take, mainly because of fear associated with the possibility of testing HIV positive. This difficulty was, however, overcome owing to the routine nature of the service (all women were tested) and the strong desire by women to protect their babies from HIV infection just in case they were found HIV positive.

Women applauded the health education session which doubled as the pre-test counselling session usually conducted at the start of the ANC clinic day, for providing them with information about the process and the benefits of HIV counselling and testing during pregnancy.

In general, HIV positive women were satisfied with the immediate post-test counselling they received but had worries on how to live with HIV, especially in meeting the needs of their children, an indication of the need for follow-up counselling and support. Surprisingly, some HIV negative women felt that the post-test counselling they received was inadequate and left them with unanswered questions. Some HIV positive and negative women were in doubt of their HIV test results, a threat to the effectiveness of the PMTCT programme, and HIV prevention and care in general. Doubt of the negative test results was enhanced when women were told that they did not have HIV and syphilis especially when they experienced "skin rash", an indication commonly linked to syphilis in their communities. Doubt among HIV positive women was related to the low perceived risk and the expression that women had been faithful to their partners.

Most women who tested HIV negative interpreted their test results to mean fidelity and meant relief from worries. On the contrary, most women who tested HIV positive associated positive results with infidelity and betrayal by their sexual partners. Women's positive results also meant uncertainty about the future of their marriage and the care for the women and their children. For some HIV positive women, knowledge about the availability of ARVs and being aware of some people whose lives had improved on ARVs, was a source of inspiration, and courage to face the future beyond HIV testing with determination. The underlying source of determination for such women was to be able to care for and see their children grow.

Women who tested HIV positive, resisted referral to HIV specialist clinics and care centres for fear of being identified as HIV positive clients, a situation that would have far reaching implications on their relationships and valuation by their partners. This is a clear indication that despite increased access to ARVs, the reality of HIV related stigma is still prevalent.

Most women in this study revealed that health workers at the antenatal clinic were generally caring though being few in number was a major constraint that negatively affected the quality of post-test counselling women received. Most women who tested HIV negative felt that they were accorded limited time during post-test counselling. Health workers concurred that they would really have loved to provide more time for counselling to women who test HIV negative, but instead focused more on women who tested HIV positive due to the high client load amidst few staff. The limited counselling offered to the majority of the women who tested HIV negative indeed emerged as a missed opportunity to assist such women to remain HIV negative, one of the four pillars for the PMTCT programme.

Paper II: Disclosure of HIV test results to partners

In this paper we document experiences of pregnant HIV positive and negative women with regard to disclosure of their HIV status to their sexual partners after testing for HIV as part of the antenatal care at Mbale hospital and the support women require before and after disclosure (derived from the same data-set as for paper 1).

All the fifteen HIV negative women interviewed reported that they had disclosed their HIV status to their sexual partners. On the contrary most of the women who had tested HIV positive (11\15) had not told their sexual partners their HIV status. The main hindrance to disclosure in this study among HIV positive women related to the profound fear that disclosure would damage the social relations between women and their partners. This fear would manifest in the form of: women being abandoned, beaten, or being accused of bringing HIV infection into the family. HIV positive women’s desire to disclose their HIV status to their partners was largely hindered by the threat it posed to the survival of women and their children. Our findings revealed an intersection of gender roles, women’s dependency on men, polygamy and young age as key social identities that worked in tandem to hinder disclosure. Health workers concurred that, women who tested HIV positive found disclosure of their HIV status to partners extremely difficult. Most HIV positive women thus deferred disclosure of HIV status to their partners until after giving birth or when their partners would accept to go for HIV counselling and testing as a couple which would shift the burden of disclosure from the women to health workers. Some HIV positive women also believed that non-disclosure was beneficial for their sexual partners as it shielded them from worry and stress.

Women who tested HIV negative found disclosure easy but encountered resistance from their sexual partners to go for HIV testing assuming that they were equally HIV negative "HIV testing by proxy", and saw no need for them (men) to go for HIV testing as one of the women explained: "*I told him to go and test he laughed…he said we both do not have HIV since I had tested HIV negative"*. Some women in polygamous marriages reported that their men used negative HIV test results of their wives to confirm their assumed HIV negativity. Such women found the task of convincing their partners to go for HIV testing even more difficult. Women also indicated that some men believed HIV testing especially in the antenatal clinic was only meant for women, but not men.

Contrary, to the expectations and fears of most HIV positive women, the few women in our study who disclosed their status to their partners generally experienced positive outcomes and support. Two of the four men to whom their partners disclosed went and tested, one was already on treatment and also disclosed to his partner while one responded in denial that he and the partner could not be infected.

Most pregnant women who tested HIV positive expressed the need for support from health workers with disclosure of their HIV status to their partners and those who tested HIV negative indicated that they required support to get their partners tested given the wide spread practice of " HIV testing by proxy". HIV negative women mentioned that they often gave up on requesting their partners to go for HIV testing whenever men refused.

Paper III: Lessons from health care providers to improve PMTCT

This paper describes the lived experiences of health workers and the lessons they have learnt during the implementation of the PMTCT programme in eastern Uganda, and provides insights for programme improvement.

Although PMTCT services have been extended to lower level health facilities, narratives of health workers documented in this paper indicate that having a successful PMTCT programme requires, that the government and donors take seriously the need to address the perpetual stock-out of critical PMTCT supplies, especially HIV test kits and ARVs for mothers and babies. These hindrances were more pronounced in public health facilities compared to TASO which is a nongovernmental organization. "*For me, government needs to do everything possible to avail us with at least HIV testing kits and ARVs for mothers and their babies" (Health Worker, Mbale Hospital).*

The shortages of PMTCT supplies translated into high costs for mothers in attempts to save their babies, missed opportunities to engage men and strained relationships between health workers and their clients. "*Like now we do not have nevirapine. If we get a mother who needs it we can only refer… if they also do not have it they will refer her... this makes the process very costly for women and their families".*

Health workers also mentioned that addressing the perpetual shortages of other supplies necessary for health facility delivery like gloves, cotton wool etc. would broadly benefit the PMTCT programme by increasing health facility delivery thus making it possible to provide the package for PMTCT and adoption of safe delivery practice. *"We do not have enough gloves, cotton wool and other supplies, so we tell mothers to buy them. …we know some of the women cannot afford …(Health worker Mbale Hospital).*

A closely related challenge that should be addressed especially at lower level health facilities relates to ensuring that all health workers are constantly updated given the rapid changes in the field of HIV, more especially when international and subsequently national guidelines change. *"The issue of drugs still puzzles me. …we received Combivir last week to give pregnant mothers but I am not sure when I should give it to the mother. We have not been trained on use of these drugs" (Health worker, Health Centre C)*

HIV stigma emerged as a persisting challenge despite antiretroviral drugs becoming increasingly available in Uganda and the study setting. This calls for more integration in the delivery of HIV services. Health workers believed that the health system as part of the social context in which the PMTCT services are delivered and utilized should be strengthened for an effective programme.

The need to support mothers, especially those who test HIV positive beyond the clinic setting emerged as a priority area. Study findings revealed that whereas this support was desired it was largely missing at most health facilities due to lack of funding or end of a project that was supporting such initiatives, like post-test support groups. One opportunity that emerged in this study is the need to create linkages between health facilities and existing groups and networks of persons living with HIV as an additional source of support.

Discussion

In this section, the main findings (table 5) are discussed, followed by a discussion on the methodological issues.

Routine HIV Counselling and testing: implications for PMTCT

Although routine HIV counselling and testing in Uganda is relatively new, introduced in 2006, compared to high income settings where the practice has been operational for over two decades [44-47], women in our study generally had been informed about testing before attending antenatal care. The past interaction with the health care system as well as information from radio and social networks were instrumental in preparing women to expect HIV counselling and testing as part of the antenatal care. Thus the formal and informal sources of information emerged as critical in popularizing routine HIV counselling and testing. The implication here is that, the media and social networks could provide an opportunity to reach women with information on other important health services like promoting health facility delivery and use of drugs for PMTCT. While over 90% of the women in Uganda attend the antenatal clinic at least once, less than half of them give birth at health facilities [23, 86]. Health facility delivery, especially for HIV positive women, could improve the use of drugs for PMTCT, estimated at about 50% in 2009 [13].

Most women in our study perceived HIV testing as part of antenatal care as compulsory. This notion was reinforced by health workers who generally downplayed the opt-out option during health education and counselling sessions. Our finding on the perception that HIV testing was compulsory is in consonance with what has been documented elsewhere in African settings [57, 79, 80]. Although, it has been speculated that the perception that HIV testing is compulsory might negatively affect ANC attendance, in the study setting new ANC attendance continued to increase even when there was a policy shift from providing HIV counselling and testing as a voluntary service to being provided as a routine [32]. Moreover, the introduction of routine counselling and testing has been associated with increased testing rates within the context of PMTCT in many African settings [50, 51, 53, 109]. However, the fact that health workers downplayed the possibility of women opting out of HIV testing, demonstrates how difficult it is in practice to implement such a policy that

Table 5: Summary of main findings for each paper in the thesis

Paper	Main findings
Paper I Women's experiences of HIV testing	- HIV testing as part of ANC was no surprise for pregnant women. - Most women perceived ANC based HIV testing as a compulsory procedure. - HIV testing was perceived as beneficial especially to HIV positive women and their babies. - The strong desire by women to protect their babies was a motivation for testing - Post-test and follow-up counselling were insufficient. - Women who tested HIV positive resisted referral to HIV specialist clinics and care centres for fear of stigma. - Health workers were supportive but constrained by being few in number.
Paper II Women's disclosure experiences	- Disclosure was more difficult in HIV-positive women owing to the threat it posed to family stability. - Women encountered difficulties to convince their partners to go for HIV testing. Some men assumed they were HIV-negative based on their women's negative test results (testing by proxy). - Some HIV positive women did not disclose their status to protect their spouses from the psychological impact of a positive test. - The few HIV positive women who had disclosed experienced support from their partners.
Paper III Lessons to improve PMTCT	- Ensure constant availability of critical PMTCT supplies - Ensure regular updates and re-training of all health workers on PMTCT policies and guidelines - Ensure adequate integration and rollout of PMTCT services - Provide more support for mothers beyond the clinic.

seeks to keep a balance between the known public health gains of HIV testing and the individual's right to opt-out. Indeed, health workers in our study choose to promote the benefits of HIV testing as opposed to making opt-out explicit. This dilemma is also reflected in the Uganda national policy on HIV counselling and testing which states that 'providers should de-emphasize full counselling if it is causing a barrier to testing' [43]. The on-going media programmes, aimed at popularizing the PMTCT programme as well as the underlying value for children, further re-enforced the perceived compulsory nature of HIV testing. In line with critical theory, women's encounter and perception of HIV testing as a compulsory procedure emerged in this study as a reflection of health facility practices regulated by the contest between individual client rights and public health benefits, health worker values, national HIV policy provisions and women's interface with the media.

In general, women in our study believed that HIV testing as part of ANC was beneficial, especially, by providing an opportunity to those who test HIV positive to enrol into the PMTCT programme and accessing HIV treatment themselves. The central theme of saving babies was eminent in narratives of pregnant women in support of routine HIV testing. This was linked to the social and cultural value of children in this setting [110], but also the moral underpinning that children are innocent and thus should be protected from HIV infection. The strong desire by pregnant women to save their babies from HIV infection presents a potential that could be taken advantage of to improve the utilization of PMTCT interventions, currently, performing at undesired levels [13].The strong desire for women to save their babies from HIV infection has been a motivator for women to undergo HIV testing from the onset of the PMTCT programme, even when there was no treatment to improve the mother's health. For instance between April 2002 and January 2003 the majority (77%) of the women who attended ANC at hospitals providing PMTCT services in Uganda were given information about PMTCT and 65% chose to test for HIV mainly to save their babies [35]. In addition our study findings are consistent with those of a recent study conducted in central Uganda where men were in general supportive of their wives testing as part of antenatal care as necessary for the health of the baby [111]. Taken together, these findings are re-assuring that both men and women shared a common goal of protecting their babies from HIV infection. This could be a building block to strengthen the PMTCT programme in Uganda and other African settings where children are highly valued.

Contrary to our findings, a study conducted in 2008 in the neighbouring Iganga District revealed that women did not fully understand the benefits of HIV testing [57]. This difference in findings could be explained by differing time lines and study populations. A striking finding from our study is that the benefits of HIV testing for the majority of the women who tested HIV negative were rarely mentioned. This finding suggests a need to give attention to women who test HIV negative as well as those who test HIV positive for effective HIV prevention. In this regard, partnerships with support groups as those at the AIDS Support Organization (TASO) could be of help.

Study findings revealed a need to strengthen post-test and follow-up counselling and support. While HIV positive women were generally satisfied with the immediate counselling they received, they required follow-up counselling and support, especially to address the worries and fear related to living with HIV and meeting the needs of their families. On the other hand, some HIV negative women felt that the post-test counselling they received was inadequate mainly due to scarcity of health workers. Moreover, health workers also acknowledged that they prioritized more time for counselling the HIV positive women, compared to their HIV negative counterparts. This presents a missed opportunity to foster primary HIV prevention. While international debates in favour of VCT uphold the need for detailed pre-test counselling to facilitate choice and autonomy, results of our study show that routine HIV counselling and testing requires strengthening of post-test and follow-up counselling and support for better HIV prevention.

Moreover, some women in our study were in doubt of their HIV test results, a real threat to the PMTCT programme. Doubt of test results was related to limited time for post-test counselling but also the prevailing community ‘diagnosis’ of syphilis based on a skin rash and pale skin. Thus women were in doubt of the test results, if they thought they had syphilis, but were told that they tested negative for HIV and syphilis. This finding brings to the fore how the patient’s and doctor’s (different) explanatory models often co-exist in a clinical encounter [77] and threaten the success of medical interventions. For women who are HIV positive but in doubt of their HIV status, they are unlikely to use PMTCT services while those who are HIV negative may not adopt HIV prevention behaviours and practices.

Such areas of disagreement between patient's and health worker's explanatory models should be identified and addressed in health education and counselling sessions.

Similarly, the human resource constraints and the intermittent provision of PMTCT and maternity services at lower level health facilities as key structural barriers should be addressed. One possibility is for health care providers to develop partnerships with lay counsellors who may include members of village health teams and persons living with HIV as expert clients or support groups. Lay counsellors have been used to support HIV counselling, testing and treatment with promising outcomes in resource limited settings [112].

Meaning attached to HIV test results – notions of betrayal, worry and fidelity

Our findings revealed that women often interpreted their HIV test results in terms of relationships with their sexual partners. Most women who tested HIV negative understood their results to mean fidelity by their partners. And most women, who tested HIV positive, understood their HIV results to mean infidelity and betrayal by their sexual partners, as a source of HIV. For both HIV positive and negative women, the need for them to encourage their partners to go for HIV testing should be emphasized given the high possibility of discordance [22]. A Ugandan study among HIV-infected married people on antiretroviral therapy revealed that 43% of their spouses were HIV negative [113]. Another recent study conducted in western Uganda documented sero-discordance of 38.7% [114]. The need for women to encourage their partners to attend ANC in this setting is of necessity given that men often do not attend ANC and thus miss out being counselled and receiving support to reduce negative outcomes when their partners disclose their HIV status [111]. In line with Critical Theory, efforts by women to encourage their partners to go for HIV testing were less effective owing to the power imbalances between men and women as an example of structural forces that keep women and their children at risk of HIV infection.

Between silence and disclosure of HIV status to partner

Most HIV positive women in our study opted for non-disclosure of HIV status to their partners. Non-disclosure was motivated by the need for women to ensure that their livelihood and that of their children remain undisturbed. Indeed the daily struggles and concerns for HIV positive women to secure their own and their infant's survival amidst poverty and marginalization have been documented as common realities of women in the African setting [115]. The social identities that women occupy, such as being mothers, dependent on men, married in polygamous families, being pregnant and of young age, worked in an intersectional nature, reinforcing each other [74, 75, 116, 117] to hinder women from disclosing their HIV status to sexual partners. In consonance with other studies done in the African setting [54, 56, 59, 118], findings of our study revealed a profound fear of blame for bringing HIV into the family, being sent away from home and domestic violence as key barriers to disclosure. Most HIV positive women in our study opted to defer disclosure of their HIV status to partners until when they have given birth or when their partners would agree to go for couple HIV testing and counselling, where health workers would facilitate disclosure.

A study done in Malawi found that women postponed disclosure of their HIV positive status until when their partners showed signs of illness [119]. In case of discordance, men are likely to become infected due to the secrecy surrounding HIV. Besides, non-disclosure may hinder women's utilization of PMTCT services. The profound fear by women to disclose their HIV status to their partners makes the dominant approach of using women to convince their partners to go for HIV testing a problematic undertaking. These findings reveal that the social structural forces within the social context where women live tend to converge and hinder disclosure a limiting factor to women's access to PMTCT and HIV care interventions. These notions are well articulated by Critical Theory. It is imperative that other complementary approaches of promoting HIV testing like couple counselling and testing [120, 121] and home based HIV testing interventions, are scaled-up [122-124]. In general, home based HIV counselling and testing has been associated with substantial increase in the proportion of people who test for HIV [125], but also higher proportions of those who test as couples [126], thus reducing the barriers to disclosure.

Although disclosure is generally beneficial and thus promoted during health education and counselling sessions [24, 43], some of the HIV positive women in our study felt that non-disclosure was beneficial to their partners as it protected them from stress and worry related to knowing that one is HIV positive. Underlying this thinking was the continued perception of HIV as a fatal infection despite ARVs becoming more available in Uganda. At the end of 2011, ART coverage for eligible children and adults was 58% [19]. In this regard, women require continuous support to confront disclosure as an on-going process. Whereas routine HIV counselling and testing as part of the antenatal care has reduced barriers to testing among women, it carries with it the burden of communicating HIV positive test results especially to partners.

Whereas most HIV positive women feared to disclose their HIV status to their partners, the few who disclosed generally experienced positive outcomes, including men going for HIV testing and being supportive. Similar to our findings, a study conducted in Abidjan, Cote d'Ivoire revealed that most of the partners of HIV infected women, who were informed about women's HIV status, were understanding and provided moral support to their spouses [60].

HIV testing by proxy – an emerging challenge

Whereas HIV testing is promoted for both prevention and for being an entry point into early HIV care, most HIV negative women who disclosed their status reported that men assumed a similar HIV negative status (HIV testing by proxy) [127]. For men in polygamous relationships, they assumed they were HIV negative when two or more of their wives had tested HIV negative. This finding is worrying, since this assumption keeps women and their babies at risk of HIV infection if the man is already infected, and is a threat to HIV prevention in general and the elimination of mother-to-child transmission, a national and global target. HIV testing by proxy works against primary HIV prevention, a key pillar in the PMTCT programme [21, 24] which aims at preventing HIV infection before it happens. Moreover, the risk of mother-to-child-transmission of HIV increases if HIV is acquired during pregnancy [128]. The practice of HIV testing by proxy may be a reflection of male partners' limited understanding of the likelihood of HIV discordance, a common occurrence in Uganda [22, 113, 114]. The power imbalance between men and women in this patrilineal setting also emerged as a barrier to women's attempts to convince their partners to go for HIV testing. It is important that dissemination of information on discordance is intensified to reach more people, especially men who are largely the power holders in this setting.

Similar to our finding on testing by proxy, community Focus Group Discussions (FGDs) conducted with women and men in Malindi, Kenya also revealed that men often believed they were HIV negative when their women tested negative [55]. Therefore, more research is needed to document and quantify the practice of testing by proxy in Uganda and other settings as well as how it can be addressed.

Measures to strengthen the PMTCT programme

Our study findings revealed the need to ensure constant supply of critical supplies for the PMTCT programme, especially HIV test kits and ARVs for mothers and their babies, if elimination of mother-to-child transmission of HIV is to be realized. Our findings are in consonance with those of a study conducted in the early years of the programme in 2003 which recommended the need to address challenges related to supplies as a prerequisite for a successful programme [85]. Challenges of stock-outs of PMTCT supplies have also been documented in other studies in Ugandan [32, 129] and other African settings [130]. This study confirms that this problem has persisted for a decade and that unless adequate supplies and drugs are provided at each level of the health system, there is little chance that HIV among children and adults can be reduced. In fact the new figures show (UAIS 2011) an increase in prevalence in most districts of the country [10]. Whereas the increase in HIV prevalence can partly be explained by more people accessing ARVs and living longer, the sustained high number of annual new HIV infections also contributes to an increase in HIV prevalence. Recent estimates revealed that the annual number of new HIV infections in Uganda increased by 11% from 113,473 in 2007 to 126,299 in 2010 [19]. The high number of new HIV infections reflects a reversal in the gains the country had made in the fight against HIV. It is important that efforts aimed at increasing access to HIV treatment, go hand in hand with the strengthening of HIV prevention interventions to curb the epidemic. More research can only show if this negative trend will continue but only assertive budgetary action at the national level can improve the situation. If we are at all serious about reducing HIV, good intentions are not enough, action must follow words. As stated by the Minister of Health in the recent press release ‘These results (from the 2011 UAIS) demonstrate indisputably that HIV/ AIDS remains a significant problem for Uganda and should serve as a call to action for us all’ [10]. Our study also calls for such action to eliminate mother-to-child-transmission of HIV.

Health system constraints in the form of shortage of PMTCT supplies was a major source of frustration for both mothers and their health care providers and constituted missed opportunities to engage men in the programme. For mothers, shortages of supplies meant that they had to incur more costs, especially on transport to other health facilities, for instance, to find ARVs for their babies. In the event that such facilities also did not have the drugs or women could not afford the transport, their babies remained at risk of HIV infection. These findings show how health system inadequacies together with poverty and other social contextual factors are intertwined to limit access and utilization of the PMTCT services.

A related suggestion to improve the PMTCT programme was the need for government and other actors to provide the necessary equipment for use during delivery, clean delivery kits, locally known as *maama* kits. These include gloves, polythene sheets, razor blade, threads for tying the cord, baby sheets, soap, cotton wool etc. While *maama* kits were expected to be supplied by the National Medical Stores, like other medical supplies, these kits were often out of stock in the study setting, thus pregnant women were told by the ANC health staff to purchase them from the open market. In this setting where health services are by policy supposed to be free, health workers faced a challenge of requesting women to buy *maama* kits. This resonates well with what has been described as ‘the bring your own pattern’ typical of public health care services in Uganda [35]. This pattern denotes a situation where health service users are often told by health workers to bring or buy supplies for use at health care facilities such as exercise books for medical records, drugs, syringes and *maama* kits for the case of maternity attendees. Inability to afford such requirements emerged as a major hindrance for mothers to give birth at health facilities. For HIV positive women, giving birth outside the health facility reduces chances for utilizing PMTCT services. This finding depicts how health system constraints and poverty work in tandem to constrain women from utilizing PMTCT services. Recent estimates revealed that 25% of Ugandans live in absolute poverty (spend less than necessary to meet their caloric requirements and to afford non-food needs while 43% are food insecure non-poor. By place of residence, 27% of the rural dwellers live in absolute poverty compared to 9% of their urban counterparts. In the Eastern region, where Mbale is located, absolute poverty is estimated at 24% [95]. Similar to our finding, an earlier study conducted in eastern Uganda revealed that stock out of *maama* kits was common and hindered women from delivering at health facilities [131]. This is a major dilemma since health facility delivery is necessary to ensure that HIV positive mothers and their infants access antiretroviral prophylaxis during delivery. A study done in Malawi, documented delivery outside the health facility as a barrier to HIV positive women's access to PMTCT drugs and this was worse for their infants [132].

Our findings revealed marked differences between the AIDS Support Organization (TASO) PMTCT programme and that implemented by the public health sector health facilities. While the TASO programme did not experience stock-outs, it was still less preferred by the newly tested HIV positive women for fear of stigma. The PMTCT programme (integrated with other services) at public health facilities was preferred though faced by challenges of stock-outs. The implication here is that HIV stigma together with health facility challenges as part of the social context co-exists to limit access to HIV care and prevention services. In addition, our findings show that support groups for HIV positive women were available at TASO but were generally lacking at public health facilities. Thus, partnerships between TASO and public health facilities could ensure that the two service delivery models complement each other better. For instance members of the support groups from TASO could be involved in health education and post-test counselling at public health facilities which lack such groups and face the scarcity of staff.

Health workers in our study highlighted the need to ensure that health workers, especially those at lower level health facilities, are re-trained when the national PMTCT guidelines change. Our findings indicated that in some instances new drugs for PMTCT had been delivered at some health facilities but staff had not been oriented on use of such drugs. For programme stakeholders, at national and international levels, it is important that policy changes are always matched with resources and plans to ensure that frontline health service providers are fully trained and re-oriented when policy guidelines change or new evidence emerge. This finding also indicates the need for programme stakeholders to appreciate the intensity of adjustments needed at health facilities whenever policies change. The Uganda National PMTCT Guidelines were first issued in 2003 [38] and have been revised several times [20, 24, 37, 39] to incorporate new evidence and guidance by the World Health Organization.

Methodological reflections

Qualitative Research methodology

A qualitative methodology was adopted for the sub-studies on which this thesis is based. Qualitative research methods denote strategies for the systematic collection, organization and interpretation of textual material obtained by talking to people or through observation, to explore the meaning of social events as experienced by the people being studied [133]. Use of qualitative methods was deemed appropriate given the exploratory nature of the research issues and the need to attain an in-depth understanding of the study concerns; women's experiences of routine HIV counselling and testing **paper 1**, disclosure of HIV status to sexual partner and support needs **Paper II** and the lessons learnt by health workers that can help to improve the PMTCT programme **paper III**. Central to qualitative research, is interest in understanding the meaning people attach to their experiences [101].

Some scholars have argued that qualitative methods obtain types of information which are out of reach with other approaches [99, 100]. For instance, the qualitative nature of our study unearthed additional meanings attached to HIV test results, reasons why some women doubt test results which the conventional quantitative methods would possibly not establish.

While we attained a good understanding of the study concerns, new questions and a wish for further investigation also emerged. For instance, while the assumption of HIV negativity by men whose wives had tested HIV negative became apparent in this study as a barrier to primary prevention of HIV, in case a man was HIV positive, the qualitative methodology we employed cannot answer this emerging question: how wide-spread is the assumption of HIV testing by proxy? This example brings to the fore, the need for both qualitative and quantitative methods, as well as for researchers to work in a complimentary manner [133] to find comprehensive answers for multifaceted public health problems.

In papers I and II we used in-depth and key informant interviews which helped in triangulation of study findings. This increased the validity of our study findings. Individual interviews were appropriate, instead of focus group discussions, for facilitating discussion of sensitive issues like HIV which is still stigmatized in the study setting. In paper III we used in-depth interviews with health workers, key informant interviews with services managers, as well as observation during service provision. Again, use of multi-methods facilitated a better understanding of the experiences of health workers and the lessons they have learnt for improving the PMTCT programme in Eastern Uganda.

For the studies reported in this thesis, interviews with primary respondents were conducted first followed by those with key informants. This enabled us to cross-check study findings, but also provided an opportunity to give feedback to key stakeholders on some of the changes needed for a better PMTCT programme. For instance, the gaps in the PMTCT programme identified in our study, like shortage of HIV test kits and incomplete roll-out of health worker training, were communicated to district and health facility managers. Similarly, the need by health workers to allocate adequate time to women who test HIV negative as well as to those who test HIV positive was discussed with frontline health workers. In this regard, we made attempts to bridge the gap between research and making critical information available to end users.

In these studies, we included pregnant women (HIV negative and positive) as well as their health care providers which provided an opportunity to capture the perspectives of both service users and providers. In many instances, the views of women and health workers were in agreement, which is re-assuring that, our findings were valid.

Selection bias

In all the papers, purposive sampling was employed to select study participants, a potential for selection bias. In paper I and II, pregnant HIV positive and negative women who returned to the clinic for their subsequent antenatal care visits were interviewed. It is possible that the women who did not return to the antenatal clinic for subsequent ANC visits could have had different experiences with HIV counselling **(paper I)** or even with disclosure of their HIV status to partners **(paper II).** However, given that the findings from interviews with women were generally corroborated by those of interviews with health workers, gives us a strong sense that our study findings describe what occurred in the study setting. Besides, selecting women at the antenatal clinic served as an advantage for the study, as women were able to talk about their direct experiences of testing within the ANC, a benefit that may not have been guaranteed if women were selected at community level. Moreover, it would have been difficult to identify women who had gone through ANC based HIV counselling and testing especially, those who tested HIV positive, given the continued HIV related stigma. Purposive selection of study participants also enabled us to target HIV positive and HIV negative women. We were also able to include women of varied characteristics, for instance, study participants differed by age, parity, education, among others.

In **paper III,** most of our study participants were from public health facilities. Although such facilities are a dominant source for maternal and child health care, the experiences and lessons learnt by mothers and health workers in the private sector about the PMTCT programme are likely to be different than those documented in our study.

Possible information bias due to place of interview

We conducted all in-depth interviews **(papers I–III)** at health facilities, which could have influenced study participants' responses. However, use of qualitative interviews with probes helped to minimize this potential bias. In addition, the perspectives of women were largely in agreement with those of health care workers on most of the study concerns which is re-assuring. Moreover, our findings on barriers to disclosure and women's experiences of HIV testing were largely in concurrence with what has been documented elsewhere, an indication that the influence of social desirability (answering with what they felt were the 'right' answers) on our study findings could have been minimal. Training of research assistants, pre-testing of study tools and use of varied methods of data collection also helped reduce the potentials for information bias.

In **paper II,** our findings on disclosure could have benefited from including men in the study. This was not possible, given that in the study setting, few men attend the antenatal clinic with their wives. However, a recent publication of a study conducted in Uganda among men, indicated that most men were in support of women testing as part of the antenatal care, but also, acknowledged that disclosure of test results could be a huge challenge for women [111]. We thus believe that our study findings on women's experiences of HIV testing and disclosure are valid.

Reflexivity

Reflexivity refers to being aware of how the characteristics and experiences of a researcher could affect study results [101]. In this regard, my personal attributes as a social worker, male, married and as a father had potential to affect the way I interacted with study participants, especially with pregnant women. However, I believe my characteristics as a Ugandan social worker with extensive experience in conducting interviews with women, children and health care workers benefited the study.

Women in general, including those who had tested HIV positive, were open to discussing their concerns and experiences regarding HIV testing and disclosure of their HIV status to their sexual partners more than I had anticipated. This, in part, could be explained by how the attending health workers introduced me and my research team to the women. The nurses made it clear that we were not staff of the clinic but we were finding out how women found the HIV counselling services and their suggestions on how the services could be improved. Health workers also encouraged the women to feel free when talking with us. In addition, members of the research team and I, took time to build rapport with the women, explained the purpose of the study and stressed the importance of confidentiality. Being able to speak Luganda, one of the languages spoken in the study setting, also worked in my favour. I was able to conduct some interviews directly with women, in addition to some that I conducted in English. This made it possible to have a feeling of emerging issues even while data collection was still going on. Regular meetings with research assistants further enhanced this opportunity to capture key study insights as they unfolded during fieldwork. This way, data collection and analysis emerged as closely related and overlapping phases.

The women's confidence in members of the research team became more vivid in the comments they made at the end of the interviews, like: 'at least you care to find out how we feel' and some recommending that this study should be extended to other areas like the maternity and children's ward, so that services can be improved.

My previous research experience was a resource for me in training my research assistants and in supervising data collection. In this research, I took a lead in study design, data collection, analysis and interpretation of study findings with guidance from senior researchers. In particular, my participation in the design of the study helped me to present and defend the research proposal to various research ethical approval committees. More importantly, the understanding of the study was critical in providing continuous explanations to formal and informal gatekeepers at various levels during data collection. Pope and Mays define gatekeepers as people who can allow and facilitate access to study participants [101]. These ranged from administrators, doctors, nurses/midwives, counsellors, health educators, outreach coordinators and data managers among others. Interacting with gatekeepers asking different questions about my research was sometimes challenging. On the whole, it was a good opportunity for me to reflect on the potentials for my research undertaking.

The involvement of different researchers in this study with varied professional backgrounds including social work, public health, medical anthropology as well as paediatrics and child health, further strengthened the study. All co-authors participated in study design, data analysis and interpretation of study results. In this regard, multiple researchers offered an opportunity to compliment and contest each other's understanding of study results [134]. Three of the co-researchers have had long-term involvement in maternal and child health research in the study setting. These enriched the study with contextual knowledge. In some instances, I encountered the multiple research perspectives as a challenge. For instance, while the researchers more inclined to medicine were interested in shortened write-ups, those from medical anthropology would often ask for expounding on the write-up. In this regard, I had to balance between these varying views. Overall, I believe the multiple perspectives were beneficial for the study and enhanced my personal learning, especially when aiming for clarity in writing.

Most of the interviews with women were audio recorded and transcribed which enhanced the accuracy of the data. The fact that interviews with health workers and those of three women were not recorded could potentially have affected the accuracy of data from these interviews. However, researchers were paired in all interviews, one as a note taker and the other as an interviewer. At the end of each interview, the researchers compiled and reviewed interview notes.

Reflections on fieldwork

Attending clinic activities like health education talks which also served as pre-test counselling sessions at Mbale Regional Referral Hospital, TASO clinic and outreach sessions at Bukedea Health Centre gave me an ‘insider’ perspective of the day to day realities that pregnant women and their health care providers encounter in attempts to save children from HIV infection. The five months of fieldwork in the study setting interacting with health workers and women helped to explore study concerns in a natural setting (clinic setting) and formed a good basis for the detailed analysis and interpretation of study findings. At the start of the study, I had a feeling that health workers would treat me as an evaluator of the programme, which would potentially affect study results. To counter this possibility, I held a meeting with the health workers involved in the ANC clinic in which the purpose of the study was explained. I also used this meeting to introduce research assistants and to request for health worker’s support in the identification of study participants. Throughout the data collection phase of the study I felt that health workers were open and shared their experiences and perspectives.

During data collection, the interface of health facility constraints like the large number of clients served by few health workers, shortage of supplies, like antenatal cards and *maama* kits, which women are expected to buy, became more visible. Through this fieldwork, I understood better how the structural limitations within which health care workers operate constrained access even of basic health services, including antenatal care and maternity services. In particular, instances where women were told to collect money to photocopy ANC cards at the beginning of the health education talk, as well as the list of requirements women needed to buy in preparation for delivery, made me wonder how researchers can help to ease the ‘pain’ health workers and their clients encounter. Inability to render help in such instances of need made me feel ethically and morally challenged. Upon reflection, I realized that although I was not able to offer immediate relief to the day to day constraints that health workers and women encountered, the need to document such constraints to provide a voice for change became clearer. At the end of the data collection, I gave feedback to district health managers, in the form of debriefing meetings with the hope that action could be taken to bridge some of the gaps documented in this research.

My long stay in the study site, especially at Mbale Hospital, also had some disadvantages. On some occasions, I was mistaken as one of the health workers and sometimes students from the school of clinical officers and some nurses approached me to inquire about certain medical conditions and whether I could help them to attend to some patients. To this I kept reminding them what my profession is and what I can do or not do. Towards the end of the fieldwork, I assisted with counselling some women and also in providing health education at the ANC clinic. Whereas my involvement in service delivery at the clinic could have had an influence on the information health workers provided to me, I believe, this was not the case since this happened in the last month of the study. At this time, interviews with women had been completed.

While conducting interviews as a researcher and social worker I encountered one woman who broke down during the interview while she was explaining how she had been faithful but still was infected with HIV by her husband. She worried a lot about how she would care for her children given the HIV diagnosis. For this woman, I offered guidance, but also linked her to a counsellor at TASO for further help. While this intervention assisted this woman, this encounter made the need for providing support to women beyond HIV testing more visible.

Triangulation

Triangulation, a notion drawn from land surveying implies that an adequate account of a phenomenon can be provided when a point is described from different perspectives or angles [133]. In this study, different methods of data collection were employed. These included use of in-depth interviews, key informant interviews and observation. Use of multiple methods of data collection provided an opportunity to generate complementary data and sometimes an avenue to cross check study findings. Thus attaining a holistic view of women and health workers' experiences of the PMTCT programme and the context in which such services are delivered and utilized.

For instance, while interviews with women revealed how those who were HIV negative were dissatisfied with the post-test counselling they received, interviews with health workers and observations at the antenatal clinic made the reality of overwhelmed health workers more vivid. This pattern was acknowledged by district officials. In this regard, the multi-methods used in our study turned out to play complimentary roles and enhanced the validity of our findings.

One gap in our attempts to provide a comprehensive picture of mothers and health care provider's experiences of the PMTCT programme was the lack of perspectives from male partners which would have enriched our findings further. The perspectives of men on PMTCT are critical, given their central role as power holders and decision makers. However, some aspects of male involvement in PMTCT within the study setting have been explored [69, 135].

Member checking

Member checking or respondent validation is one of the techniques to improve the validity of study findings. This technique involves comparing the investigator's account and those of study participants to establish the level of correspondence [101]. In this study we did not return to study participants, but at the end of each interview, the key points raised in the interview were summarized and study participants were given an opportunity to comment whether their views had been captured correctly. Key insights from fieldwork were shared with district health administrators and health workers in the form of de-briefing meetings.

Transferability

Transferability relates to the external validity of study findings. The question is whether study findings could be applicable to other settings [134]. In this regard, the researcher should provide detailed information about the population; methods, study area and the results, to enable readers to decide whether the findings are relevant to other contexts.

Our findings on women's experiences of HIV testing, like the perception that HIV testing as part of ANC was compulsory [57, 79, 80], and women's fears of disclosure of HIV status to sexual partners [56, 58, 118] are in consonance with what has been documented in other African countries. The notion of HIV testing by proxy has also been documented in Malindi, Kenya [55] and the health system constraints as a barrier to the PMTCT programme have also been documented elsewhere [130, 132, 136]. Taken together, these studies suggest that our findings may have wider applicability beyond the study area. This possibility notwithstanding, findings from qualitative studies like the one reported in this thesis are generally time and context specific thus generalisability is never the goal. As Guba argued, the difficulties with generalization are compounded by the fact that the phenomena studied are intimately tied to the times and the context in which they are found [137].

Reflections on theoretical perspectives used in this thesis

Framed within the critical theory tradition, this thesis renders credence to the notion that the effectiveness of the PMTCT programme in Uganda requires an understanding of the forces within the social context where women live, contract HIV and seek to prevent their children from being infected. This theoretical perspective in our study brought to the fore the structural forces that women are confronted with at family, community and health facility levels that hinder effective HIV prevention. For instance, the gender and power relations at family level emerged as a barrier to women's disclosure of their HIV status to their partners, but also as a force that worked against HIV negative women's attempts to encourage their partners to go for HIV testing. Persistent stigma also remained a challenge keeping away women from utilizing HIV services at easily identifiable HIV specialized care centres like TASO. In line with the Critical Theory tradition, these findings reflect how social relations impede [71, 72] women's ability to prevent HIV infection for themselves but also to utilise PMTCT services.

At a broader level, shortage of PMTCT supplies, few health workers together with poverty in the community emerged as key limitations to the success of the PMTCT programme. In the study setting, women received inadequate counselling due to the limited number of health workers while shortage of PMTCT supplies constituted a missed opportunity to women's access and utilisation of PMTCT services. These findings reflect how structural constraints limit programme effectiveness a notion well articulated by Critical Theory [71]. In addition, constant changes in the national PMTCT policy guidelines informed by global guidance from WHO was another challenge that reflects the interface between the local and the global in shaping how women and their health care providers encountered the PMTCT programme in the study setting. It also became clear that while the Ugandan Ministry of Health had been effective in aligning national policy guidelines to match the emerging evidence and guidance from WHO, inadequate resources at health facility level made actualization of these policy intentions sub-optimal. The local and global interface reflected in this study is well articulated by critical theory. Proponents of Critical Theory have argued that health and well-being [71] and indeed the effectiveness of health promoting interventions are fundamentally linked to the micro and macro societal conditions and constraints. Improving programme performance, therefore, requires that such structural barriers are addressed.

One limitation of critical theory for this study was the inability to comprehensively explain our finding in paper I, where women were in doubt of their test results. Doubt of HIV test results by some women could be explained by the presence of few frontline health workers which compromised the quality of counselling that women received. This dimension fits within the critical theory framework. However, the fact that some of the women were in doubt of their HIV test results because of their beliefs and interpretation of illness reflects the co-existence of the patient's and doctor's varying explanatory models in a clinical encounter. In this regard, notions of explanatory models advanced by Kleinman [77] were deemed appropriate to serve as a complimentary model in this thesis.

Similarly, we found the gender intersectionality theory [73, 74, 117] an appropriate complimentary theory to explain the interrelated nature of women's identities especially as mothers, of young age, economically dependent on men and those in polygamous marital relationships as key barriers to women's disclosure of their HIV status to their partners. Our findings support the view by proponents of intersectionality theory that individual's social identities influence ones experience of gender [74] and that the social identities can lead to greater advantage or disadvantage [76, 117]. In our case, the varied social identities of women hindered disclosure of their HIV status to their sexual partners which is likely to limit utilisation of PMTCT services.

Implications for research

More inquiry is needed to improve understanding of the prevalence and ways to address the perception of HIV testing by proxy among men to ensure that women, who test HIV negative, remain so and protect their babies from HIV infection. Specifically, such studies should reach out beyond the health facility to capture the perspectives of men.

Interventions that promote couple counselling like use of the invitation letter, home based HIV counselling and testing should be implemented on a wider scale in real life programmes. Lessons learnt from such programmes should be documented to inform further strategies that can help to strengthen the delivery of interventions aimed at the elimination of mother-to child transmission of HIV (eMTCT).

With regard to shortage of critical PMTCT supplies, it is important that these are closely monitored and national prevalence of such gaps documented and regularly shared with stakeholders for action.

While many clinical trials are ongoing to test other drugs that can be used in the PMTCT programme, studies that address social, family, community and health system barriers are equally needed to ensure that these interventions reach the intended beneficiaries. Indeed with weak health systems, even the most effective drugs will not achieve the desired impact.

Women's experiences of disclosure of HIV status documented in this study were of short-term nature. Thus follow-up studies over a long time after HIV testing may reveal broader impacts of HIV testing and support needs before or after disclosure. Such a design would also help to follow-up some of the fears women anticipated with regard to disclosure.

Operational research is needed to explore and test mechanisms for providing support to women who test HIV positive to disclose their test results to their partners while minimizing the anticipated negative outcomes.

Implications for policy and practice

In order to improve the value of HIV counselling and testing, and to maximize opportunities for prevention of mother-to-child transmission of HIV, including primary prevention (before infection occurs), there is a need to strengthen post-test and follow-up counselling for both HIV positive and negative women. Working collaboratively with people living with HIV, especially those in existing support groups as those at The AIDS Support Organization (TASO) could provide an opportunity to increase support for health education, counselling and support for women and their partners.

The on-going revival of Village Health Teams (VHTs) in Uganda could also be another opportunity for providing the needed community support for the PMTCT programme. For this to happen, there is need for deliberate efforts to ensure that issues related to PMTCT are integrated in the training of VHTs and once trained, mechanisms should be put in place to ensure that continuous interaction between health workers and VHTs is maintained for feedback and mutual support.

In male dominated patriarchal societies prevalent in Uganda and other African settings, long term strategies to empower girls and boys with formal education are needed to increase possibilities of reducing gender imbalances based on access and control of resources. Agents of socialization like schools, families, religious institutions and peer groups should be engaged for the young people to embrace the notions of respect for each other and build negotiation skills between boys and girls for better social relations between future men and women, as vehicles for health promotive behaviours, including prevention of diseases.

Our findings on HIV testing by proxy, illness interpretation, women’s fears of disclosure and the difficulties they face in convincing their partners to go for HIV testing should be included in health education and counselling sessions, media discussions, community outreach programmes and in the development of information, education and communication materials.

Conclusions

In this setting, routine HIV counselling and testing services are known and acceptable to mothers. Our findings indicated that pregnant women who underwent routine HIV counselling and testing services felt it was difficult to do so but the routine nature of the service and the benefits of HIV testing for themselves and their babies made it possible for them to undergo the test.

Post-test counselling and follow-up support for both HIV positive and negative women was inadequate. These need to be strengthened for an effective PMTCT programme.

Within the context of routine HIV testing as part of the ANC, most women who tested HIV positive, found disclosure of their HIV status to partners extremely difficult. The intersectionality of gender, women's dependency on men, young age, polygamous marital relationships and motherhood role expectations compounded the women's fears of disclosure.

Whereas women who tested HIV negative, disclosed their HIV status to partners, most of their partners assumed that they were also HIV negative and resisted women's quest for men to go and test. The assumption of 'HIV testing by proxy' revealed in this study implies that, pregnant HIV negative women and their unborn babies remained at risk of HIV infection.

The voices of health workers in our study revealed that mothers and their health care providers have to navigate considerable health system challenges, especially shortage of the critical PMTCT supplies like HIV test kits and drugs. The inability of health systems as social institutions to effectively deliver the PMTCT package co-exist with the constraints of poverty, HIV related stigma, limited support for HIV positive women and the like as day to day realities of the social context in which women live and seek to protect their children from HIV infection. Constant changes in global and national PMTCT guidelines and the incomplete roll-out of staff orientation to new guidelines was a huge limitation for front line health workers.

References

1. WHO, UNAIDS, UNICEF: **Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access**. Geneva; 2011.
2. UNAIDS: **Report on the global AIDS epidemic 2008**. Geneva: UNAIDS; 2008.
3. UNAIDS: **The UNAIDS Report on the Global AIDS Epidemic**. Geneva: UNAIDS; 2010.
4. UNAIDS: **World AIDS Day Report**. *How to get to zero: faster, smarter, better*. Geneva; 2011.
5. World Health Organisation (WHO): **PMTCT Strategic Vision 2010-2015, Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals.** *Moving towards the elimination of Paediatric HIV*. Geneva: WHO; 2010.
6. De Cock KM, Fowler MG, Mercier E, de Vincenzi I, Saba J, Hoff E, Alnwick DJ, Rogers M, Shaffer N: **Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice**. *JAMA* 2000, **283**(9):1175-1182.
7. Okware SI: **Towards a national AIDS-control program in Uganda**. *West J Med* 1987, **147**(6):726-729.
8. Johansson KA, Miljeteig I, Kigwangalla H, Norheim OF: **HIV priorities and health distributions in a rural region in Tanzania: a qualitative study**. *Journal of medical ethics* 2011, **37**(4):221-226.
9. Muyinda H, Seeley J, Pickering H, Barton T: **Social aspects of AIDS-related stigma in rural Uganda**. *Health and Place* 1997, **3**(3):143-147.
10. Ministry of Health: **Press Release - Release of key results of the 2011 Uganda AIDS Indicator Survey**. Kampala: Ministry of Health, Republic of Uganda; June, 2012.
11. Ministry of Health (MOH) (Uganda) and ORC Macro: **Uganda HIV/AIDS Sero-behavioural Survey 2004-2005**. Calverton, Maryland,USA: Ministry of Health and ORC Macro; 2006:1-201.
12. Ministry of Health (MOH): **Uganda AIDS Indicator Survey 2011- Preliminary report**. Kampala: The Republic of Uganda, Ministry of Health; 2012.
13. UAC: **Government of Uganda-UNGASS Country progress report January 2008-December 2009.** Kampala: Uganda AIDS Commission; March 2010:1-103.
14. Roberts B, Odong VN, Browne J, Ocaka KF, Geissler W, Sondorp E: **An exploration of social determinants of health amongst internally displaced persons in northern Uganda**. *Conflict and health* 2009, **3**:10.
15. Rujumba J, Kwiringira J: **Interface of culture, insecurity and HIV and AIDS: Lessons from displaced communities in Pader District, Northern Uganda**. *Conflict and health* 2010, **4**(1):18.
16. Murphy EM, Greene ME, Mihailovic A, Olupot-Olupot P: **Was the “ABC” Approach (Abstinence, Being Faithful, Using Condoms) Responsible for Uganda's Decline in HIV?** *PLoS medicine* 2006, **3**(9):e379.
17. Parikh SA: **The political economy of marriage and HIV: the ABC approach, "safe" infidelity, and managing moral risk in Uganda**. *American journal of public health* 2007, **97**(7):1198-1208.
18. Konde-Lule JK: **The declining HIV seroprevalence in Uganda: what evidence?** *Health Transition Review* 1995, **5**:27-33.
19. UAC: **The Republic of Uganda- Global AIDS response progress report- country progress report**. Kampala: Uganda AIDS Commission; April 2012.
20. Ministry of Health (MOH): **New Guidelines on use of HAART for Prevention of Mother-to-Child Transmission of HIV (PMTCT) in Uganda**. Kampala: The Republic of Uganda, Ministry of Health; 2012.
21. WHO: **Global health sector strategy on HIV/AIDS 2011-2015**. Geneva: World Health Organisation; 2011:1-40.
22. UAC: **Uganda HIV modes of transmission and prevention response analysis** Kampala: Uganda National AIDS Commission; 2009.
23. UNICEF: **The State of the World's Children; Children in an urban world**. New York: United Nations Children's Fund; 2012:1-156.

24. Ministry of Health (MOH): **Policy Guidelines for Prevention of Mother-to-Child Transmission of HIV**. Kampala: The Republic of Uganda, Ministry of Health; 2006.
25. UBOS: **Statistical Abstract**. Kampala: Uganda Bureau of Statistics; 2012.
26. MOH: **The Second National Health Policy: Promoting People's Health to Enhance Socio-economic Development**. *Volume 2*. Kampala: Ministry of Health, Uganda; 2010:44.
27. MOH: **Annual Health Sector Performance Report 2007/08**. Kampala: Ministry of Health, Uganda; 2008.
28. MOH: **Annual Health Sector Performance Report 2009/10**. Kampala: Ministry of Health, Uganda; 2010.
29. MOH: **Health Sector Strategic & Investment Plan: Promoting People's Health to Enhance Socio-economic Development, 2010/11–2014/15**. *Volume 3*. Kampala: Ministry of Health, Uganda; 2010.
30. MOH: **Annual Health Sector Perfomance Report**. Kampala: Ministry of Health Uganda; 2011.
31. Stringer EM, Ekouevi DK, Coetzee D, Tih PM, Creek TL, Stinson K, Giganti MJ, Welty TK, Chintu N, Chi BH *et al*: **Coverage of nevirapine-based services to prevent mother-to-child HIV transmission in 4 African countries**. *JAMA*, **304**(3):293-302.
32. Byamugisha R, Tylleskar T, Kagawa MN, Onyango S, Karamagi CA, Tumwine JK: **Dramatic and sustained increase in HIV-testing rates among antenatal attendees in Eastern Uganda after a policy change from voluntary counselling and testing to routine counselling and testing for HIV: a retrospective analysis of hospital records, 2002-2009**. *BMC health services research* 2010, **10**:290.
33. World Health Organization (WHO): **Guidance on global scale-up of the prevention of mother-to-child transmission of HIV: Towards universal access for women, infants and young children and eliminating HIV and AIDS among Children**. Geneva: WHO; 2007:1-40.
34. UAC: **Government of Uganda-UNGASS Country progress report January 2006-December 2007**. Kampala: Uganda AIDS Commission, Kampala Uganda; 2008.
35. Whyte SR, Whyte MA, Meinert L, Kyaddondo B: **Treating AIDS: Dilemmas of unequal access in Uganda**. *SAHARA-J: Journal of Social Aspects of HIV/AIDS* 2004, **1**(1):14-26.
36. World Health Organisation: **Rapid Advice, Use of Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants**. Geneva: WHO; 2009.
37. Ministry of Health: **The New National Guidelines (2010) for PMTCT and Infant feeding in the Context of HIV**. Kampala: Ministry of Health, Uganda; 2010.
38. Ministry of Health (MOH): **Policy for reduction of the Mother-to-Child HIV transmission in Uganda**. Kampala: Ministry of Health, Uganda; 2003:1-26.
39. Ministry of Health (MOH): **New Guidelines on use of ARVs for Prevention of Mother-to-Child Transmission of HIV (PMTCT) in Uganda**. Kampala: The Republic of Uganda, Ministry of Health; October, 2008.
40. WHO: **Strategic approaches to the prevention of HIV infection in infants: Report of a WHO Meeting**. Morges, Switzerland; 2002.
41. WHO: **Scalling-up HIV Testing and Counselling Services: a toolkit for programme managers**. Geneva: World Health Organisation; 2005.
42. WHO, UNAIDS, UNICEF: **Towards universal access: scaling up priority HIV/AIDS interventions in the health sector. Progress report**. Geneva: World Health Organisation; 2009.
43. MOH: **Uganda National policy guidelines for HIV counselling and testing**. Kampala: Ministry of Health Uganda; 2005:1-41.
44. Lindgren S, Bohlin AB, Forsgren M, Arneborn M, Ottenblad C, Lidman K, Anzen B, von Sydow M, Bottiger M: **Screening for HIV-1 antibodies in pregnancy: results from the Swedish national programme**. *BMJ (Clinical research ed* 1993, **307**(6917):1447-1451.
45. Aavitsland P, Nilsen O, Lystad A, Bjorndal A: **Impact of antenatal HIV screening to prevent HIV infection in children in Norway 1987-99**. *J Med Screen* 2002, **9**(2):57-59.
46. Rey D, Carrieri M-P, Obadia Y, Pradier C, Moatti J-P: **Mandatory prenatal screening for the human immunodeficiency virus: the experience in south-eastern France of a national policy, 1992–1994**. *BJOG: An International Journal of Obstetrics & Gynaecology* 1998, **105**(3):269-274.

47. Rey D, Obadia Y, Carrieri M-P, Jean-Paul M: **HIV screening for pregnant women in South Eastern France: evolution 1992-1994-1996**. *European Journal of Obstetrics & Gynecology and Reproductive Biology* 1998, **76**(1):5-9.
48. Greeson D, Preble E, Jimenez MS, Blazer C: **Increasing Access to Prevention of Mother-to-Child Transmission Services.** . Arlington, Va: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.; 2011.
49. UNAIDS/WHO: **Policy statement on HIV testing**. Geneva: UNAIDS/WHO; 2004:1-3.
50. Creek TL, Ntumy R, Seipone K, Smith M, Mogodi M, Smit M, Legwaila K, Molokwane I, Tebele G, Mazhani L *et al*: **Successful Introduction of Routine Opt-Out HIV Testing in Antenatal Care in Botswana**. *JAIDS Journal of Acquired Immune Deficiency Syndromes* 2007, **45**(1):102-107
51. Mirkuzie A, Hinderaker S, Morkve O: **Promising outcomes of a national programme for the prevention of mother-to-child HIV transmission in Addis Ababa: a retrospective study**. *BMC health services research* 2010, **10**(1):267.
52. Byamugisha R, Tumwine J, Ndeezi G, Karamagi C, Tylleskär T: **Attitudes to routine HIV counselling and testing, and knowledge about prevention of mother to child transmission of HIV in eastern Uganda: a cross-sectional survey among antenatal attendees**. *Journal of the International AIDS Society* 2010, **13**(1):1-11.
53. Falnes EF, Tylleskar T, de Paoli MM, Manongi R, Engebretsen IM: **Mothers' knowledge and utilization of prevention of mother to child transmission services in northern Tanzania**. *J Int AIDS Soc* 2010, **13**:36.
54. Hardon A, Vernooij E, Bongololo-Mbera G, Cherutich P, Desclaux A, Kyaddondo D, Ky-Zerbo O, Neuman M, Wanyenze R, Obermeyer C: **Women's views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries**. *BMC public health* 2012, **12**(1):26.
55. Njeru M, Blystad A, Shayo E, Nyamongo I, Fylkesnes K: **Practicing provider-initiated HIV testing in high prevalence settings: consent concerns and missed preventive opportunities**. *BMC health services research* 2011, **11**(1):87.
56. Awiti Ujiji O, Ekström AM, Ilako F, Indalo D, Wamalwa D, Rubenson B: **Reasoning and deciding PMTCT-adherence during pregnancy among women living with HIV in Kenya**. *Culture, health & sexuality* 2011, **13**(7):829-840.
57. Larsson EC, Thorson A, Pariyo G, Conrad P, Arinaitwe M, Kemigisa M, Eriksen J, Tomson G, Ekstrom AM: **Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda**. *Health policy and planning* 2011, **27**(1):69-75.
58. Medley A, Garcia-Moreno C, McGill S, Maman S: **Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes**. *Bulletin of the World Health Organization* 2004, **82**(4):299-307.
59. King R, Katuntu D, Lifshay J, Packel L, Batamwita R, Nakayiwa S, Abang B, Babirye F, Lindkvist P, Johansson E *et al*: **Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda**. *AIDS and behavior* 2008, **12**(2):232-243.
60. Brou H, Djohan G, Becquet R, Allou G, Ekouevi DK, Viho I, Leroy V, Desgrees-du-Lou A: **When do HIV-infected women disclose their HIV status to their male partner and why? A study in a PMTCT programme, Abidjan**. *PLoS medicine* 2007, **4**(12):e342.
61. WHO: **The world health report: Health systems: improving performance**. Geneva: World Health Organisation; 2000.
62. WHO: **Improving equity in health by addressing social determinants, edited by the Commission on Social Determinants of Health Knowledge Networks, Jennifer H. Lee and Ritus Sanana**. Geneva: World Health Organisation; 2011.
63. Rasanathan K, Montesinos EV, Matheson D, Etienne C, Evans T: **Primary health care and the social determinants of health: essential and complementary approaches for reducing inequities in health**. *Journal of epidemiology and community health* 2011, **65**(8):656-660.

64. WHO: **Closing the gap in a generation: health equity through action on the social determinantsof health: final report of the Commission on Social Determinants of Health.** Geneva: World Health Organisation; 2008.

65. WHO: **The world health report**: **P*rimary health care now more than ever***. Geneva: World Health Organisation; 2008.

66. Kim JC, Watts CH: **Gaining a foothold: tackling poverty, gender inequality, and HIV in Africa**. *BMJ (Clinical research ed* 2005, **331**(7519):769-772.

67. Chinkonde JR, Sundby J, Martinson F: **The prevention of mother-to-child HIV transmission programme in Lilongwe, Malawi: why do so many women drop out**. *Reproductive health matters* 2009, **17**(33):143-151.

68. Muhamadi L, Nsabagasani X, Tumwesigye MN, Wabwire-Mangen F, Ekström A-M, Peterson S, Pariyo G: **Inadequate pre-antiretroviral care, stock-out of antiretroviral drugs and stigma: Policy challenges/bottlenecks to the new WHO recommendations for earlier initiation of antiretroviral therapy (CD<350 cells/µL) in eastern Uganda**. *Health Policy* 2010, **97**(2–3):187-194.

69. Byamugisha R, Tumwine JK, Semiyaga N, Tylleskar T: **Determinants of male involvement in the prevention of mother-to-child transmission of HIV programme in Eastern Uganda: a cross-sectional survey**. *Reproductive health* 2010, **7**:12.

70. Jones SA, Sherman GG, Varga CA: **Exploring socio-economic conditions and poor follow-up rates of HIV-exposed infants in Johannesburg, South Africa**. *AIDS care* 2005, **17**(4):466-470.

71. Singer M: **Critical Medical Anthropology**. In *Encyclopedia of Medical Anthropology: Health and Illness in the world's of Cultures*. Edited by Ember CR EM. New York: Kluwer Academic/Plenum Publishers; 2004:23-30.

72. Brown P: *Understanding and Applying Medical Anthropology*. London: Mayfield Publishing Company; 1998.

73. Crenshaw K: **Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color**. *Stanford Law Review* 1991, **43**(6):1241-1299.

74. Shields S: **Gender: An Intersectionality Perspective**. *Sex Roles* 2008, **59**(5):301-311.

75. Hankivsky O, Reid C, Cormier R, Varcoe C, Clark N, Benoit C, Brotman S: **Exploring the promises of intersectionality for advancing women's health research**. *International journal for equity in health* 2010, **9**(1):5.

76. Warner L: **A Best Practices Guide to Intersectional Approaches in Psychological Research**. *Sex Roles* 2008, **59**(5):454-463.

77. Kleinman A, Eisenberg L, Good B: **Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research**. *Ann Intern Med* 1978, **88**(2):251-258.

78. UAC: **National HIV/AIDS Strategic Plan 2007/08-2011/12, Moving towards universal access**. Kampala Uganda: Uganda AIDS Commission; 2007.

79. Angotti N, Dionne KY, Gaydosh L: **An offer you can't refuse? Provider-initiated HIV testing in antenatal clinics in rural Malawi**. *Health policy and planning* 2011, **26**(4):307-315.

80. Ujiji O, Rubenson B, Ilako F, Marrone G, Wamalwa D, Wangalwa G, Ekstrom A: **Is 'Opt-Out HIV Testing' a real option among pregnant women in rural districts in Kenya?** *BMC public health* 2011, **11**(1):151.

81. Kyomuhendo GB: **Low use of rural maternity services in Uganda: impact of women's status, traditional beliefs and limited resources**. *Reproductive health matters* 2003, **11**(21):16-26.

82. D'Ambruoso L, Abbey M, Hussein J: **Please understand when I cry out in pain: women's accounts of maternity services during labour and delivery in Ghana**. *BMC public health* 2005, **5**:140.

83. Amooti-Kaguna B, Nuwaha F: **Factors influencing choice of delivery sites in Rakai district of Uganda**. *Social science & medicine (1982)* 2000, **50**(2):203-213.

84. Clapham S, Pokharel D, Bird C, Basnett I: **Addressing the attitudes of service providers: increasing access to professional midwifery care in Nepal**. *Trop Doct* 2008, **38**(4):197-201.

85. Nuwagaba-Biribonwoha H, Mayon-White RT, Okong P, Carpenter LM: **Challenges faced by health workers in implementing the prevention of mother-to-child HIV transmission (PMTCT) programme in Uganda**. *J Public Health (Oxf)* 2007, **29**(3):269-274.

86. UBOS: **Statistical Abstract**. Kampala: Uganda Bureau of Statistics; 2011.
87. UNICEF: **The State of the World's Children: Adolescence, An Age of Opportunity**. New York: United Nations Children’s Fund; 2011.
88. UNICEF: **The State of the World's Children; Girls, Education and Development**. New York: Unicef; 2004:1-156.
89. UNICEF: **The State of the World's Children: Child Survival**. New York: Unicef; 2008:1-164.
90. UBOS: **Uganda Demographic and Health Survey,** . Kampala: UBOS, Kampala Uganda.; 2006.
91. Uganda Bureau of Statistics: **Uganda Demographic and Health Survey 2011-Preliminary Report**. Kampala: UBOS; 2012.
92. UNFPA: **The State of the World Population 2011**. New York: United Nations Population Fund; 2011.
93. UBOS: **Statistical Abstract**. Kampala: Uganda Bureau of Statistics,; 2010.
94. UBOS: **2002 Uganda Population and Housing Census**. ***Analytical Report, Population Size and Distribution*****.** Kampala: Uganda Bureau of Statistics; October 2006.
95. UBOS: **Uganda National Household Survey 2009/10**. Kampala: Uganda Bureau of Statistics; 2010.
96. **Background of TASO Uganda** [http://www.tasouganda.org]
97. **Mbale-The AIDS Support Organisation** [http://www.tasouganda.org]
98. Curry LA, Nembhard IM, Bradley EH: **Qualitative and Mixed Methods Provide Unique Contributions to Outcomes Research**. *Circulation* 2009, **119**(10):1442 - 1452.
99. Pope C, Mays N: **Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research**. *BMJ (Clinical research ed* 1995, **311**(6996):42 - 45.
100. Geen J, Thorogood N: *Qualitative Methods for Health Research*. 2 edition. London: Sage; 2009.
101. Pope C, Mays N (Eds.): *Qualitative research in health care*. 3rd edition. Malden, Massachusetts: Blackwell Publishing Ltd; 2006.
102. Kvale S: *Interviews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage; 1996.
103. Popay J, Williams G: **Methodology in health services research**. *BMJ (Clinical research ed)* 1993, **306**(6884):1069.
104. Hardon AP, Boonmongkon P, Streefland P, Tan M.L, et al,. **Applied Health Research Manual-Anthropology of Health and Health Care.** Amsterdam, Netherlands: The Netherlands Royal Tropical Institute, University of Amsterdam, Medical Anthropology Unit; 1995:1-213.
105. Hudelson P, M. **Qualitative Research for Health Programmes**. Geneva: Division of Mental Health, World Health Organization; 1994.
106. Britten N: **Qualitative Interviews**. In *Qualitative research in health care*. 3rd edition. Edited by Pope C, Mays N. Malden, Massachusetts: Blackwell Publishing; 2006:12-20.
107. QSR, International: **NVivo9, Software package**. Manningham, Victoria: QSR International; 2010.
108. Graneheim UH, Lundman B: **Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness**. *Nurse education today* 2004, **24**(2):105 - 112.
109. Chandisarewa W, Stranix-Chibanda L, Chirapa E, Miller A, Simoyi M, Mahomva A, Maldonado Y, Shetty AK: **Routine offer of antenatal HIV testing ("opt-out" approach) to prevent mother-to-child transmission of HIV in urban Zimbabwe**. *Bulletin of the World Health Organization* 2007, **85**(11):843-850.
110. Beyeza-Kashesya J, Kaharuza F, Mirembe F, Neema S, Ekstrom A, Kulane A: **The dilemma of safe sex and having children: challenges facing HIV sero-discordant couples in Uganda**. *African health sciences* 2009, **9**(1):2 - 12.
111. Medley AM, Mugerwa GW, Kennedy C, Sweat M: **Ugandan Men's Attitudes Toward Their Partner's Participation in Antenatal HIV Testing**. *Health care for women international* 2012, **33**(4):359-374.
112. Cohen R, Lynch S, Bygrave H, Eggers E, Vlahakis N, Hilderbrand K, Knight L, Pillay P, Saranchuk P, Goemaere E *et al*: **Antiretroviral treatment outcomes from a nurse-driven, community-supported HIV/AIDS treatment programme in rural Lesotho: observational cohort assessment at two years**. *Journal of the International AIDS Society* 2009, **12**(1):23.

113. Were WA, Mermin JH, Wamai N, Awor AC, Bechange S, Moss S, Solberg P, Downing RG, Coutinho A, Bunnell RE: **Undiagnosed HIV infection and couple HIV discordance among household members of HIV-infected people receiving antiretroviral therapy in Uganda**. *Journal of acquired immune deficiency syndromes* 2006, **43**(1):91-95.
114. Osinde MO, Kaye DK, Kakaire O: **Sexual behaviour and HIV sero-discordance among HIV patients receiving HAART in rural Uganda**. *Journal of Obstetrics & Gynaecology* 2011, **31**(5):436-440.
115. Blystad A, Moland KM: **Technologies of hope? Motherhood, HIV and infant feeding in eastern Africa**. *Anthropology & Medicine* 2009, **16**(2):105-118.
116. Gita S, Ostlin. P (Eds.): *Gender equity in health: the shifting frontiers of evidence and action*. *Volume 1*. 1st edition. New York: Routledge; 2010.
117. Hankivsky O, Christoffersen A: **Intersectionality and the determinants of health: a Canadian perspective**. *Critical Public Health* 2008, **18**(3):271-283.
118. Bond VA: **“It is not an easy decision on HIV, especially in Zambia”: opting for silence, limited disclosure and implicit understanding to retain a wider identity**. *AIDS care* 2010, **22**(sup1):6-13.
119. Parrott FR, Mwafulirwa C, Ngwira B, Nkhwazi S, Floyd S, Houben RMGJ, Glynn JR, Crampin AC, French N: **Combining Qualitative and Quantitative Evidence to Determine Factors Leading to Late Presentation for Antiretroviral Therapy in Malawi**. *PLoS ONE* 2011, **6**(11):e27917.
120. Farquhar C, Kiarie JN, Richardson BA, Kabura MN, John FN, Nduati RW, Mbori-Ngacha DA, John-Stewart GC: **Antenatal couple counseling increases uptake of interventions to prevent HIV-1 transmission**. *Journal of acquired immune deficiency syndromes* 2004, **37**(5):1620-1626.
121. Grabbe KL, Bunnell R: **Reframing HIV Prevention in Sub-Saharan Africa Using Couple-Centered Approaches**. *JAMA: The Journal of the American Medical Association* 2010, **304**(3):346-347.
122. Wolff B, Nyanzi B, Katongole G, Ssesanga D, Ruberantwari A, Whitworth J: **Evaluation of a home-based voluntary counselling and testing intervention in rural Uganda**. *Health policy and planning* 2005, **20**(2):109 - 116.
123. Mutale W, Michelo C, Jurgensen M, Fylkesnes K: **Home-based voluntary HIV counselling and testing found highly acceptable and to reduce inequalities**. *BMC public health* 2010, **10**(1):347.
124. Were W, Mermin J, Bunnell R, Ekwaru JP, Kaharuza F: **Home-based model for HIV voluntary counselling and testing**. *The Lancet* 2003, **361**(9368):1569-1569.
125. Nuwaha F, Kasasa S, Wana G, Muganzi E, Tumwesigye E: **Effect of home-based HIV counselling and testing on stigma and risky sexual behaviours: serial cross-sectional studies in Uganda**. *Journal of the International AIDS Society* 2012, **15**(2).
126. Menzies N, Abang B, Wanyenze R, Nuwaha F, Mugisha B, Coutinho A, Bunnell R, Mermin J, Blandford JM: **The costs and effectiveness of four HIV counseling and testing strategies in Uganda**. *AIDS (London, England)* 2009, **23**(3):395-401.
127. Morrill AC, Noland C: **Interpersonal issues surrounding HIV counseling and testing, and the phenomenon of "testing by proxy"**. *Journal of Health Communication* 2006, **11**(2):183-198.
128. Moodley D, Esterhuizen T, Reddy L, Moodley P, Singh B, Ngaleka L, Govender D: **Incident HIV infection in pregnant and lactating women and its effect on mother-to-child transmission in South Africa**. *The Journal of infectious diseases* 2011, **203**(9):1231-1234.
129. Medley AM, Kennedy CE: **Provider Challenges in Implementing Antenatal Provider-Initiated HIV Testing and Counseling Programs in Uganda**. *AIDS Education and Prevention* 2010, **22**(2):87-99.
130. Nkonki LL, Doherty TM, Hill Z, Chopra M, Schaay N, Kendall C: **Missed opportunities for participation in prevention of mother to child transmission programmes: simplicity of nevirapine does not necessarily lead to optimal uptake, a qualitative study**. *AIDS research and therapy* 2007, **4**:27.
131. Waiswa P, Kemigisa M, Kiguli J, Naikoba S, Pariyo GW, Peterson S: **Acceptability of evidence-based neonatal care practices in rural Uganda - implications for programming**. *BMC pregnancy and childbirth* 2008, **8**:21.
132. Kasenga F, Hurtig AK, Emmelin M: **Home deliveries: implications for adherence to nevirapine in a PMTCT programme in rural Malawi**. *AIDS care* 2007, **19**(5):646-652.

133. Malterud K: **The art and science of clinical knowledge: evidence beyond measures and numbers**. *The Lancet* 2001, **358**(9279):397-400.

134. Malterud K: **Qualitative research: standards, challenges, and guidelines**. *The Lancet* 2001, **358**(9280):483-488.

135. Byamugisha R, Astrom A, Ndeezi G, Karamagi C, Tylleskar T, Tumwine J: **Male partner antenatal attendance and HIV testing in eastern Uganda: a randomized facility-based intervention trial**. *Journal of the International AIDS Society* 2011, **14**(1):43.

136. Kasenga F, Hurtig AK, Emmelin M: **HIV-positive women's experiences of a PMTCT programme in rural Malawi**. *Midwifery* 2008.

137. Guba E: **Criteria for assessing the trustworthiness of naturalistic inquiries**. *Educational Technology Research and Development* 1981, **29**(2):75-91.

Papers

I-III