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‘Striving for Motherhood’
Understanding the Socio-Cultural Context of Realizing Childbearing and HIV
Therapeutic Behaviors Among Women in Kenya.

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***TO MY PARENTS PAUL AND JULIA
FOR MAKING ME WHO I AM TODAY***

ABSTRACT

PMTCT allows people living with HIV to actualize childbearing. However, it also complicates motherhood, as the medical consequences and public health implications of non-adherence to PMTCT service recommendations disrupt socio-cultural expectations of childbearing and parenthood. This thesis aimed to study childbearing and adherence to PMTCT interventions focusing on how women living with HIV realize motherhood in Kenya. We sought to answer how women on ART experience motherhood and how motherhood aggravate adherence to PMTCT services

Methods: A quantitative cross sectional study (I) with a questionnaire survey conducted among pregnant women at their first visit to antenatal clinic to study consent to HIV testing and three qualitative studies analyzed with content analysis (II and IV) and narrative structuring (III) were included. Qualitative interviews were performed with women living with HIV who were pregnant, recently delivered and those actively planning a pregnancy to explore views and experiences when seeking a pregnancy (II), the reasoning and deciding about adherence to PMTCT (III) and how motherhood interferes with HIV treatment (IV).

Results: ‘Striving for motherhood’ was the overriding theme describing the desire of women on ART to be parents while negotiating the challenges of living with HIV (I-IV). Children improve women’s position in society and are a sign of a happy and fulfilled life (II-IV). Of 900 pregnant women surveyed at their first visit to antenatal care clinic, only 17% understood that HIV testing is optional (I). Making an informed decision to decline HIV testing was associated with knowing that testing was optional (OR=5.44, 95%CI 3.44-8.59), not having a stable relationship with the child’s father (OR=1.76, 95%CI 1.02-3.03), and not having discussed HIV testing with a partner before the ANC visit (OR=2.64 95%CI 1.79-3.86). Socio-economic affluence and residence influence behaviors such as no condom use, non-disclosure of HIV infection, use of traditional medicine simultaneously with ART, home delivery and stigma and discrimination from partners, family and community, all of which undermine adherence to PMTCT services (II-IV). Structural shortcomings in PMTCT result in the lack of antiretroviral HIV medicines, practice of mixed infant feeding and missed appointments (I, III, IV).

Conclusion: Motherhood is achieved at the cost of striving to balance socio-cultural expectations of childbearing that also conceals their HIV infection at the cost of non-adherence to PMTCT recommendations. Being infected with HIV does not remove the desire of motherhood and related socio-cultural demands. It is important to acknowledge the significance childbearing among women infected with HIV to improve adherence. Women with chronic illness such as HIV-infection who are dependent on continuous medication and health check-ups struggle to balance the desire for children with the needs related to their illness and the expectations of being a ‘good mother’.

LIST OF PUBLICATIONS

This doctoral thesis is based on the following papers that correspond to the specific aims, referred to in the text by roman numerals.

- I. Opondo Awiti Ujiji, Birgitta Rubenson, Festus Ilako, Gaetano Marrone, David Wamalwa, Gilbert Wangalwa, Anna Mia Ekström. Is 'Opt-Out HIV Testing' a Real Option among Pregnant Women in Rural Districts in Kenya? BMC Public Health 2011; 11: 151.
- II. Opondo Awiti Ujiji, Anna Mia Ekström, Festus Ilako, Dorcas Indalo, Birgitta Rubenson. "I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya – a qualitative study. BMC Women's Health 2010; 10: 13.
- III. Opondo Awiti Ujiji, Anna Mia Ekström, Festus Ilako, Dorcas Indalo, David Wamalwa, Birgitta Rubenson. Reasoning and Deciding PMTCT- Adherence during Pregnancy in HIV-infected Women in Kenya. (accepted for publication in Culture, Health and Sexuality Journal, April 20 2011).
- IV. Opondo Awiti Ujiji, Anna Mia Ekström, Festus Ilako, Dorcas Indalo, Abigael Lukhwari, David Wamalwa, Birgitta Rubenson. 'Keeping healthy in the backseat'. How motherhood interrupts HIV-treatment among recently delivered women. (accepted for publication in Africa Journal of AIDS Research, April 18 2011).

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Table of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
AZT	Zidovudine
CIA	Central intelligence Agency
HIV	Human Immunodeficiency Virus
HAART	Highly Active Antiretroviral Therapy
3TC	Lamivudine
KAIS	Kenya AIDS Indicator survey
MTCT	Mother-to-Child Transmission
NVP	Nevirapine
PCT	Provider initiated routine Counseling and Testing
PMTCT	Prevention of Mother-to-Child Transmission
SSA	Sub Sahara Africa
UNAIDS	Joint United Nations Program on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNGASS	United Nations General Assembly
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

INTRODUCTION

The increased access to antiretroviral (ARV) medication for HIV means that infected persons are able to live longer and healthier lives. On the African continent prevention of mother to child transmission (PMTCT) programs give hope for children that is an important life project and successful childbearing can become a reality. In African societies childbearing is a social affair and a culturally attuned aspiration making parenthood a concern for both the individual and family at large. Although ARV enables recipients to consider a pregnancy by minimizing the risk of both vertical and horizontal transmission, they face numerous social, ethical, and medical dilemmas as they pursue their desires for parenthood and fulfill socio-cultural expectations of childbearing. This thesis studies childbearing among women living with HIV to understand how the actualization of motherhood aggravates the HIV infection and complicates adherence to PMTCT programs.

According to the 2010 AIDS Epidemic Update report, it is estimated that there are around 33.3 million people living with HIV globally (UNAIDS, 2010). In sub-Saharan Africa (SSA), where the majority of new HIV infections occur, more women than men live with the HIV, and young women aged 15–24 years are as much as eight times more likely to be HIV infected than men in the same age group. As access to services for PMTCT of HIV has increased, the total numbers of children being born with HIV are decreasing. An estimated 370 000 [230 000 – 510 000] children were infected with HIV in 2009, a drop of 24 percent over the last five years due to rapid expansion of better models of providing PMTCT (UNAIDS, 2010). Worldwide 53 percent (40 to 79 percent) of pregnant women living with HIV in low and middle-income countries received antiretroviral therapy (ART) in 2009 versus 45 percent in 2008 and 15 percent in 2005 (UNAIDS, 2010).

PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV

Interventions for preventing mother to child transmission of HIV respond to three of the most problematic areas of global health: combating HIV and AIDS, reducing infant mortality and improving maternal health. Without any interventions 30 to 35 percent of children born to mothers living with HIV risk infection. Of these 15 to 25 percent will be infected during pregnancy, 50 to 60 percent at labor and delivery and 33 percent during breastfeeding (Bertolli, et al., 1996; Zijenah, et al., 2004). MTCT is the primary cause of all HIV infections in children under fifteen years of age (Newell, 2003). When effectively and appropriately implemented, PMTCT has the potential to prevent infection in the 95 to 98 percent of babies who would otherwise risk being born with HIV-infection (UNAIDS, 2009). PMTCT is a comprehensive strategic approach that includes the following four critical components:

1. Primary prevention of HIV infection among women of childbearing age;
2. Prevention of unintended pregnancies among women living with HIV;
3. Prevention of HIV transmission from a woman living with HIV to her infant;
4. Provision of appropriate treatment, care and support to mothers living with HIV and their children and families.

PREVENTION OF HIV TRANSMISSION FROM A WOMAN LIVING WITH HIV TO HER INFANT

Highly active antiretroviral therapy (HAART) has reduced MTCT rates to between one and two percent in high-income countries. However, this is not the case in low- and middle-income countries where HAART regimens are not yet widely available and where simplified and cost-effective prophylactic ARV regimens are offered to pregnant women and/or their newborn babies (Volmink, Siegfried, van der Merwe & Brocklehurst, 2007). Studies have shown that in breastfeeding populations the regimens of Zidovudine (AZT) or AZT/ Lamivudine (3TC) in the last trimester (at 24 weeks gestation or immediately after) together with a single dose of Nevirapine (NVP) at labor to the mother and within 72 hours of birth to the new born could reduce MTCT rates to six to 15 percent (Thior, et al., 2006; Volmink, Siegfried, van der Merwe & Brocklehurst, 2007). Observations in non-breastfeeding populations show that prophylactic ARV regimens can reduce the risk of transmission during pregnancy and childbirth to two to four percent when provided at or immediately after the 24th pregnancy week, together with intra- and post-partum prophylaxis (Lallemant, et al., 2004). There has been a 53 percent (from 15% to 68%) increase in pregnant women receiving ART in Eastern and Southern Africa from 2005 – 2009, but there is still a wide variation between countries. In 2009, the numbers receiving HIV testing and counseling varied from more than 95 percent in South Africa and Zambia to nine percent in the Democratic Republic of the Congo and six percent in Chad (UNAIDS, 2010). PMTCT core interventions in pregnant women who visit antenatal (ANC) clinics include (i) provider initiated routine HIV counseling and testing, (ii) ARV prophylaxis, (iii) infant feeding counseling and (iv) PMTCT- Plus that gives family members a possibility to access care and treatment for HIV. It has been a challenge for low- and middle-income countries to translate the proven results of clinical trials into practice with unsatisfactorily low coverage of PMTCT as a result.

Provider initiated routine HIV counseling and testing (PCT)

To increase coverage of testing and identify patients in need of ART, the World Health Organization (WHO) and the joint United Nations program on HIV/AIDS (UNAIDS) revised the guidelines for HIV testing in 2007 (WHO & UNAIDS, 2007). In the former 'opt in' HIV strategy, the initiative to be tested was with the individual, not with the health care services, and individual pre-test counseling and informed consent was required before testing. In some areas, people were even required to sign a separate informed consent form, which detailed the risks and benefits of being tested (Branson, et al., 2006). With the new 'opt-out' strategy, individuals have to actively decline the HIV test after an information session, often carried out in a group. Post-test counseling is still carried out on an individual basis for all clients.

The shift from 'opt in'/client-initiated to 'opt out'/provider-initiated HIV testing has generated a debate on how to best increase the uptake of HIV testing while protecting the individual right to voluntary consent for HIV testing (WHO & UNAIDS, 2007). Proponents of "opt out" assert that the provider-initiated consent process is crucial to achieve a high coverage of HIV testing and prevention of mother-to-child transmission (PMTCT), while it can still protect autonomy (De Cock, Mbori-Ngacha & Marum, 2002). It also enhances the 'streamlining' of HIV into 'normal care' thereby decreasing the stigma (Bayer & Fairchild, 2006; De Cock, Mbori-Ngacha & Marum, 2002).

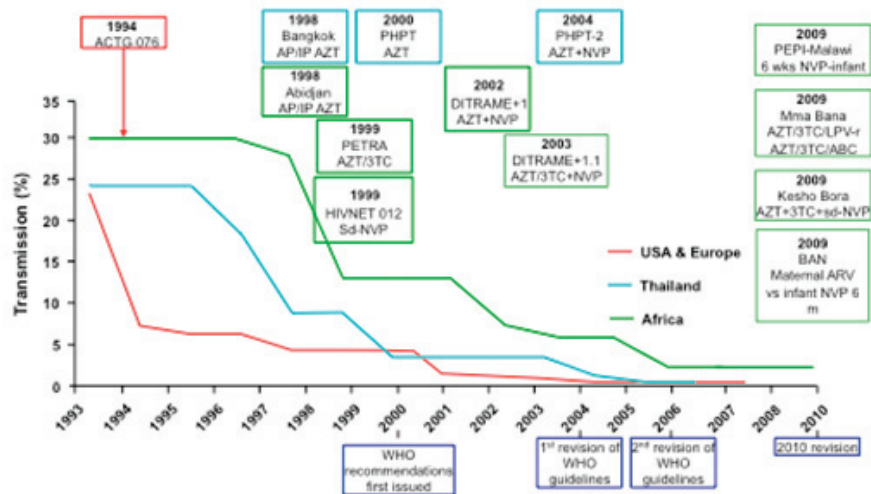
Those who question the 'streamlined' consent process express doubt about whether informed consent can be assured in the context of routinely offered HIV-testing under conditions of scarce human resources (Bennett, 2007; Csete, Schleifer & Cohen, 2004). Power differences in the provider-client relationship is also identified as a problem, since it is uncertain whether clients who normally have a lower social status will feel able to opt out against the recommendation of their providers (Maman & King, 2008). Others are concerned about the client's ability to provide voluntary consent and to what extent any choice will be presented given that providers are encouraged to motivate clients to test and could be coercive (Larsson, et al., 2010; Maman & King, 2008).

Women in particular are often also unable to make decisions independently due to gender inequality and lack of knowledge (Maman, Mbawambo, Hogan, Kilonzo & Sweat, 2001; Quin & Overbaugh, 2005). Finally, and most important from a public health perspective, there is concern that pregnant women who fail to make an informed choice about HIV testing are less likely to come back for their test results, an obvious prerequisite for identifying and enrolling HIV-infected women in the PMTCT program, thus undermining the quality and effectiveness of this important intervention (Msellati, 2009; Weiser, et al., 2006).

ARV prophylaxis

In recent years extensive progress has been realized in the development of new PMTCT ARV prophylaxis guidelines and best practices. The PMTCT guidelines offer guidance to countries on how to reduce MTCT of HIV through more effective treatment and prevention regimens. First issued in 2000, and revised in 2004, 2006 and 2010, the PMTCT antiretroviral guidelines recommend the delivery of simple, standard and effective regimens on a large scale in all settings. There has been a significant shift from the use of single dose NVP in the 2000 PMTCT policy guide to long-term HAART in the 2010 PMTCT policy guideline as shown in figure 1.

Figure 1 PMTCT Study Results and Guidelines Revisions



Source: WHO 2010 guidelines and Country level guidelines on PMTCT ARVs. www.pedaids.org/Publications/Toolkits/Phase...Toolkit.../2_PMTCT-slides_Jan_2011

Infant feeding counseling

In high-income countries most babies of women living with HIV are given formula feed from birth to minimize the risk of MTCT after delivery. In low-income countries on the contrary safe replacement feeding has not been a viable option and children who do not breastfeed are up to six times more likely to die from diarrhea, malnutrition or pneumonia.

The new PMTCT policy 2010 (WHO, 2010) recommends for mother and uninfected infants and those of unknown HIV status, ARV treatment during breastfeeding that should continue for twelve months. Mothers living with HIV are advised to exclusively breastfeed their infants for the first six months after delivery and then gradually wean, and continue breastfeeding for the first twelve months of life. Breastfeeding should stop only when a nutritionally adequate and safe diet without breast milk can be provided. For infants living with HIV, mothers are encouraged to exclusively breastfeed for the first six months of life and continue breastfeeding for two years and beyond. Women who received a three-drug regimen during pregnancy are recommended to continue until the end of the breastfeeding period. For woman who received AZT during pregnancy daily NVP is recommended for her child from birth until the end of the breastfeeding period.

The current guideline on PMTCT ARV and infant feeding counseling is based on new evidence on (a) the benefits of earlier initiation of ARV prophylaxis during pregnancy in reducing mother-to-child transmission (b) the effectiveness of ARV prophylaxis provided during breastfeeding in reducing mother-to-child-transmission (c) the effectiveness of different ART regimens for children and adults and (d) the optimal timing and criteria for ART initiation in children and adults.

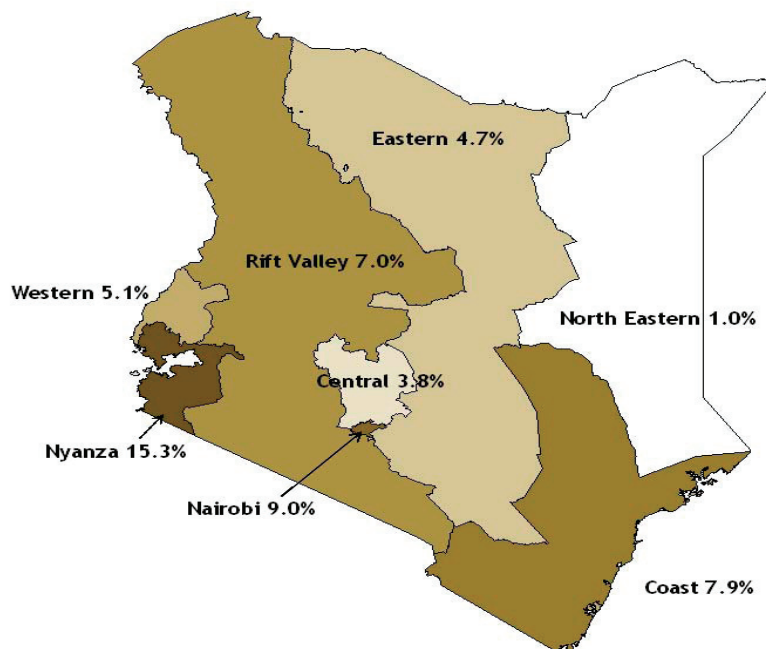
Countries are allowed to adjust and adapt a national policy depending on the capacity of the health system and the local environment of health care provision. This will

enable countries to choose a strategy that will maximize the chances for women and their babies to remain uninfected and alive.

THE HIV SITUATION FROM A KENYAN PERSPECTIVE

Kenya has a generalized HIV epidemic meaning that the virus affects all sectors of the population. Heterosexual contact is the main method of transmission followed by mother-to-child transmission (MTCT) during pregnancy, at labor and delivery and during breast-feeding. An estimated 1.5 million people are living with HIV and 80,000 died of AIDS-related complications in 2009 (UNAIDS, 2010). Additionally about 1.2 million children are orphaned. Results from the 2007 Kenya Aids Indicator Survey (KAIS) indicate that 6.3 percent of Kenyan adults age 15-64 are infected with HIV. For both women and men, HIV is occurring in all age groups (NASCOP, 2008). There are some differences in prevalence across the life span and also in distribution countrywide (figure 2). A higher proportion of women age 15-64 years (nine percent) than men (six percent) are infected with HIV. Among youth age 15-24 years, women are 4 times more likely to be infected than men (6.1 percent compared to 1.5 percent). A higher proportion of Kenyans ages 30-34 are currently living with HIV than in any other age group. The decline in prevalence among women after age 34 and among men after age 44 could represent an increase in HIV-related deaths in these age groups (NASCOP, 2008). About three quarters of Kenyans live in rural areas. The prevalence of HIV is nine percent in urban and seven percent in rural areas. Though the prevalence in rural areas is lower than in urban areas, the burden of disease is bigger in rural areas since most Kenyans live in there (NASCOP, 2008).

Figure 2 Prevalence of HIV in provinces in Kenya



Kenya covers an area of approximately 580,367 sq. km and has a population of 39 million with the majority being Christians. There are over 47 languages spoken in addition to English (official) and Swahili (national). Tourism and agriculture are the two main income earners and the gross domestic product (GDP) divides into services (62 percent), industry and commerce (16 percent) and agriculture (22 percent). The gross domestic product in 2009 was \$32.42 billion and the annual growth rate was four percent positioning Kenya 85th in the world and among middle range countries in Africa (Central Intelligence Agency (US), 2010). A majority of Kenyans work in the agriculture sector (75 percent). Additional population and economic indicators are shown in table 1.

Table 1 Selected Health Indicators in Kenya (CIA, 2010)

Health Indicator	Value
Maternal mortality ratio per 100,000 live births	488
Infant mortality rate per 1,000 live births	52
Total fertility rate	4.19
Literacy rate (age 15 and over can read and write)	85.1
Life expectancy	59.48
Population growth rate	2.46
Birth rate per 1,000 population	33.54
Under 5 mortality rate per 1,000 live births	74

PMTCT SITUATION IN THE KENYA CONTEXT

Since initiation in 2000 PMTCT efforts in Kenya have rapidly expanded. There are now more than 3,397 health facilities offering PMTCT services (UNGASS, 2010). In 2008/09 an estimated 65 percent of pregnant women were tested for HIV and 73 percent of pregnant women living with HIV received prophylaxis ARV for preventing transmission of HIV to their babies (UNGASS, 2010; WHO/UNAIDS/UNICEF, 2009). However, a lot still needs to be done for pregnant women, as MTCT of HIV is still high. For example, an estimated one in four babies born to mothers living with HIV get the virus and PMTCT services are still only available in 50 percent of health facilities (UNGASS, 2010). In 2009 there were approximately 22,259 new child infections and an estimated total of 184,052 children were infected with HIV, most of which were probably due to MTCT (UNGASS, 2010). Selected Kenya PMTCT indicators are shown on table 2.

Table 2 Kenya PMTCT indicators 2008/09

PMTCT Indicator	Value
Annual births	1,530,000
ANC attendance (at least 4 visits) %	Overall: 47 Urban: 60 Rural: 44
Estimated number of children (0-14 years) living with HIV	180,000 [98,000 -260,000]
Estimated number of pregnant women living with HIV	81,000 [41,000-120,000]
Exclusive breastfeeding for infants 6 months %	32
ANC facilities providing counseling and testing and ARV for PMTCT %	58
Timing of first ANC visit (months) %	No ANC: 7 <4: 15 4-5: 38 6-7: 37 8+: 3 Did not know: <1

Sources: (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2010; UNAIDS, 2010; WHO/UNAIDS/UNICEF, 2009, 2010)

HIV testing in Kenya

HIV testing through voluntary counseling and testing (VCT) and PCT has expanded across Kenya in recent years. In 2007 there were almost 1000 VCT sites compared to three in 2000 (UNGASS, 2008). Nationally PCT is now available in 73 percent of health facilities (UNGASS, 2010). The campaign to increase HIV testing through increased testing facilities and public advertisements has increased the number of adults aged 15-49 years who report ever being tested for HIV. In 2003 only 15 percent had taken a test compared to 37 percent in 2007 (UNGASS, 2008). In the year 2009, it is estimated that more than 4.4 million Kenyans aged 15 years and approximately 25 percent of the adult population received HIV testing and counseling. According to the 2009 Demographic and Health Survey, 73.5 percent of women and 58.6 percent of men have been tested at least once (WHO/UNAIDS/UNICEF, 2010).

An increased number of people tested does, however, not automatically mean an increased number of people who know their status. People may have been infected after an earlier negative test, or may not have come to receive their results. According to the 2007 KAIS almost two thirds of people infected with HIV who thought they knew their status mistakenly thought they were HIV negative. Women are often afraid of disclosing their HIV diagnosis to their partners because of perceived negative consequences of stigma, isolation, desertion and even violence (Kiarie, 2000; Manzi, et

al., 2005; Muhenje, Mbori-Ngacha, Akun & De Cock, 2004). Studies have observed that women fail to seek antenatal care from fear of disclosure during PCT.

In 2009 the Kenya Ministry of Health and donors initiated door-to-door HIV testing and counseling for those living in remote areas with little access to health care to reach the target to test 2 million Kenyans for HIV annually, as targeted in Kenya's National HIV and AIDS Strategic Plan 2005/06 -2009/10 (National AIDS Control Council, 2005) .

Kenya ARV for HIV PMTCT purposes and Infant Counseling Guidelines

In 2006 Kenya's President Moi announced that antiretroviral drugs would be provided for free in public hospitals and health centers (BBC News, 2006, 2nd June). In 2007 about 172,000 were on treatment and the coverage was 42 percent (UNGASS, 2010). In August 2009 the Kenyan government introduced a combination of three ARV regimens - AZT, NVP and 3TC for PMTCT, rather than the single dose NVP, which led to the development of drug resistance. Although the government intended phasing out single dose NVP from PMTCT altogether, it will take some time for the new drug regimen to be implemented as it involves additional costs and training of health workers. In 2009 recipients of ART in general HIV care had significantly increased. With the 2010 changes in the WHO ART guidelines recommending that treatment should start earlier only 48 percent of Kenyans in need of HIV treatment are receiving it (WHO/UNAIDS/UNICEF, 2009). Under the 2009 guidelines, treatment coverage would have been 65 percent.

Although there are now new PMTCT guidelines from 2010 many countries have not yet been able to implement them. Kenya uses the 2009 guidelines that state that HIV-positive mothers should exclusively breastfeed their infants for six months then rapidly wean, with replacement feeding recommended only when it is 'affordable, feasible, accessible, safe and sustainable'. As a standard protocol pregnant women in need of treatment for their own health are given HAART. The complete protocol for PMTCT is ARV prescribed in agreement with WHO recommendations, i.e., for the mother HAART or AZT for four weeks during pregnancy, a single dose NVP or AZT-3TC at labor and delivery and for the child a single dose NVP or AZT for seven days.

THE SOCIO-CULTURAL CONTEXT OF CHILDBEARING

While pregnancy and childbirth are essentially biological events, their meaning and values are constructed and judged by the society in which they take place (Liamputtong, Yimyam, Parisunyakul, Baosoung & Sansiriphun, 2005; O'Dempsey, 1988). In most societies there is common knowledge of roles and expectations during pregnancy and childbirth. Beliefs and practices take shape around the cultural traits that are passed on from one generation to the next. These practices have been entrenched into behaviors and become part of people's lifestyle (Ngomane & Maludzi, 2010).

THE VALUE OF CHILDREN

The value of children is derived from the functions and needs they fulfill for both parents and society (Hoffman & Hoffman, 1973), hence successful procreation is valued both at a personal and at socio-cultural level (Daniluk, 1997; Serour, El Ghar & Mansour, 1991). In addition, there may be religious or spiritual expectations to reproduce. The motives why men and women desire parenthood are complex and vary in importance over time and context. Parenthood motives are a prerequisite for decisions and intentions that in turn influence reproductive behavior in Africa as in the rest of the world. In Western cultures people desire children mainly for reasons related to personal and family happiness and fulfillment, and to strengthen conjugal relationships, while social reasons, religious motives and reasons pertaining to continuity are less important (van Balen, 2001). van Balen (2001) observed that infertility in Western societies carried few social consequences and that couples decided about parenthood without interference from others and reasons pertaining to the interest of the social group, social expectations, kin perpetuation and heredity were less relevant. In African societies in contrast children are vital also for the community thus making reproduction a social affair. Children confer a sense of continuity, ensure the family lineage and inherit family land and wealth (Gerrits, 1997; Runganga, Sundby & Aggleton, 2001; Yebei, 2000). Children also play an important role in the highly regarded funeral traditions, which may be affected by the fertility status of the deceased (Gerrits, 1997; Yebei, 2000).

Studies performed on the construction of masculinity in African societies have shown that starting a family is an important requirement for manhood (Barden-O'Fallon, 2005). Other studies have observed that fatherhood confers a sense of achievement, belonging and continuity. A man without a child can be equated to a boy and is commonly not treated as a man. The inability to reproduce can be perceived to undermine the male identity leading to low self-esteem and a feeling of worthlessness (Dyer, 2004, 2007). Reproductive failure could also make men be seen as 'weak' - a feeling described as 'humiliating, threatening and at times a profoundly emasculating experience' (Dyer, 2007). Infertility among women is stigmatizing and often associated with profound negative social repercussions (Gerrits, 1997). Women have their womanhood identity pegged on children and are often the first to be blamed for childlessness (Dyer, 2007; Sonko, 1994; Yebei, 2000). In selected cultures even after death the negative repercussions of childlessness and the stigma of infertility stay as dead childless women may be left to decay in the woods instead of being buried in community land as this is believed to affect the fertility of the soil (Bergström, 1992; Hollos, 2003).

HIV AND FERTILITY

The relationship between HIV and fertility can run in either direction (United Nations, 2002). HIV can affect fertility desires and outcomes, while fertility desires can affect the risk of attracting HIV. The effect of HIV on the fertility of infected persons, mainly through biological and behavioral factors, is documented in research (Beyeza-Kashesya, et al., 2010; Beyeza-Kashesya, et al., 2009; United Nations, 2002). HIV infection is associated with lower fertility through reduced likelihood of conceiving due to co-infection with other sexually transmitted infections causing pelvic inflammation or due to reduced coital frequency. HIV also lowers fertility through increased fetal loss (United Nations, 2002). Existing studies from sub-Saharan Africa show that the fertility of women living with HIV is 25-40 percent lower than for uninfected women (Allen, et al., 1993; Zaba & Gregson, 1998). Also fertility may decline as a result of HIV prevention awareness leading to delayed onset of sexual relations, increased condom use and reduced premarital sexual relations (United Nations, 2002).

Given that a majority of those living with HIV are in reproductive age and that heterosexual transmission is the most common method of transmission, childbearing is a central issue that needs critical attention among people living with HIV.

CHILDBEARING AND ARV

HIV education campaigns have made people aware of the biological and behavioral influences that increase the risk of transmitting HIV. A lowered immune system and a high viral load may lead to a quicker disease progression and eminent death among infected people. Direct contact by uninfected persons with body fluids such as blood and semen/virginal secretions of an infected person could expose them to the infection. In the early days of the HIV epidemic the modes and rates of transmission were not fully understood. HIV-infection was related to sexual deviant behavior and was perceived to be a consequence of promiscuity, which has fuelled discrimination and made disclosure of a diagnosis difficult. Despite the increase in public awareness about HIV transmission HIV is still a disease associated with sexual immorality by many in SSA. The risk of stigma is aggravated by the blame directed towards infected persons as a consequence of the perception that they are sexually deviant or promiscuous.

In most couple relationships and marriages having children is important. A dominant purpose of marriage is childbearing because children strengthen conjugal ties. Marriage without children is to many incomplete and as a result insecure. Although marital union remains a pillar of reproduction, the social transformation that is characterizing contemporary Africa is affecting also this. Individual empowerment and increased education have resulted in new ways of establishing sexual relations and subsequently marrying. Goode (1963) observed that urbanization, industrialization, and the adoption of western ideologies have moved societies away from rural extended families and closed networks towards more urban, nuclear systems, where the individual has greater autonomy in decision-making and sexual relationships. In SSA there is an ongoing and increased exposure to western media that often emphasizes romantic love (Goode, 1963). As a result ideals about couple relationships are changing to reflect the wishes of urbanizing youths (Frederiksen, 2010).

Urbanization has created opportunities for socialization that make it possible for persons of the opposite sex to meet frequently (Ghimire, Axinn, Yabiku & Thornton, 2006). It is within these socialization forums that there is an increased likelihood that youths will want to and be able to find a potential spouse on their own. In Kenya as in other countries on the continent, young people are taking an active role in identifying sexual partners (Clark, Kabiru & Mathur, 2010; Smith & Mbakwem, 2007). Nowadays romantic love is an important criterion for identifying and selecting a partner. Individual choices as opposed to arranged marriage are becoming widely accepted even though families still exert influence. Although marriage is expected in Kenyan society, young people have sexual relationships and children when not married. Infidelity among partners is causing marriage dissolution and today fewer people are seeking remarriage showing that the institution of marriage is no longer considered life binding – a change from traditional lifelong commitment among couples. Women in particular are becoming empowered and it is common for young girls to choose furthering their education and career and delaying the marriage. This increased individualism and materialism is perceived to threaten the traditional organization of marriage by giving the young persons more freedom to choose relationships while reducing greater family involvement (Smith, 2004).

The awareness about the transmission, prevention and consequences of the HIV epidemic affects marriage, sexual relationships and childbearing in intricate ways. The stigma of HIV blames the individual for moral failure due to indecent sexual behavior. This strengthens the belief that infected persons have deviated from values that ensure social control and are the cause of social breakdown and a symptom of moral failure by virtue of being infected with HIV. In Kenya, as in many places in Africa, HIV is perceived as a disease of modernity, associated with social changes attributed to urbanization, globalization, and development (Setel, 1999) that directly contribute to concerns over sexual promiscuity such as concurrent sexual partnerships and transactional sex. People explain HIV as the result of too much change, excessive western influence, and the abandonment of traditional culture (Rodlach, 2007; Setel, 1996) that promoted virginity at marriage and recognized sex in matrimony. This association is evident when older people blame young persons for not following social and cultural norms for establishing sexual relationships, but instead have sexual relationships before marriage and with multiple sexual partners.

As ARV treatment has expanded and enabled people living with HIV to hope for and actualize childbearing goals, more attention has been given to the implications of treatment on the sexual behaviors of recipients (Lurie, et al., 2008; Ragnarsson, et al., 2011; Seeley, et al., 2009). Two concerns motivate studies on sexual behavior among people on ART: i) a fear that with the availability of successful treatment, people may feel reluctant to practice protective behaviors (sexual disinhibition) and ii) a lack of reproductive assisting technologies leading to unprotected sex for conception. A considerable amount of literature has been published in low income countries on risky behavior at an individual level (Bateganya, et al., 2005; Boily, Godin, Hogben, Sherr & Bastos, 2005; Bunnell, et al., 2006; Diamond, et al., 2005; Elford, 2006; Moatti, et al., 2003; Stolte, Dukers, Geskus, Coutinho & de Wit, 2004; Vanable, Ostrow & McKirnan, 2003), on the clinical consequences of reinfection (Barroso, et al., 2003; Blackard & Mayer, 2004; Colfax, et al., 2004) and on the sexual behavior of recipients of ART from the perspective of their reproductive desires (Cooper, et al., 2007; Homsy, et al., 2009; Myer, Morroni & Rebe, 2007). A common conclusion in these studies is that the conduct of people on ART must be understood through linking sexuality to gender, reproduction, and larger social contexts (Gruskin, Firestone, Maccarthy &

Ferguson, 2008; Hirsch, 2007; Laher, et al., 2009). More research is needed to understand the association between reproduction and adherence to PMTCT.

ARV treatment makes it possible for people infected with HIV to regain normalcy both in terms of a healthy looking appearance and strength to work and in attaining higher life priorities as sexual relations, marriage and childbearing. In essence ARV treatment conceals the HIV infection and childbearing protects social reputation and averts stigma. Childbearing enables HIV infected persons to fulfill reproduction, while contesting the view that they are socially deviant and morally suspect.

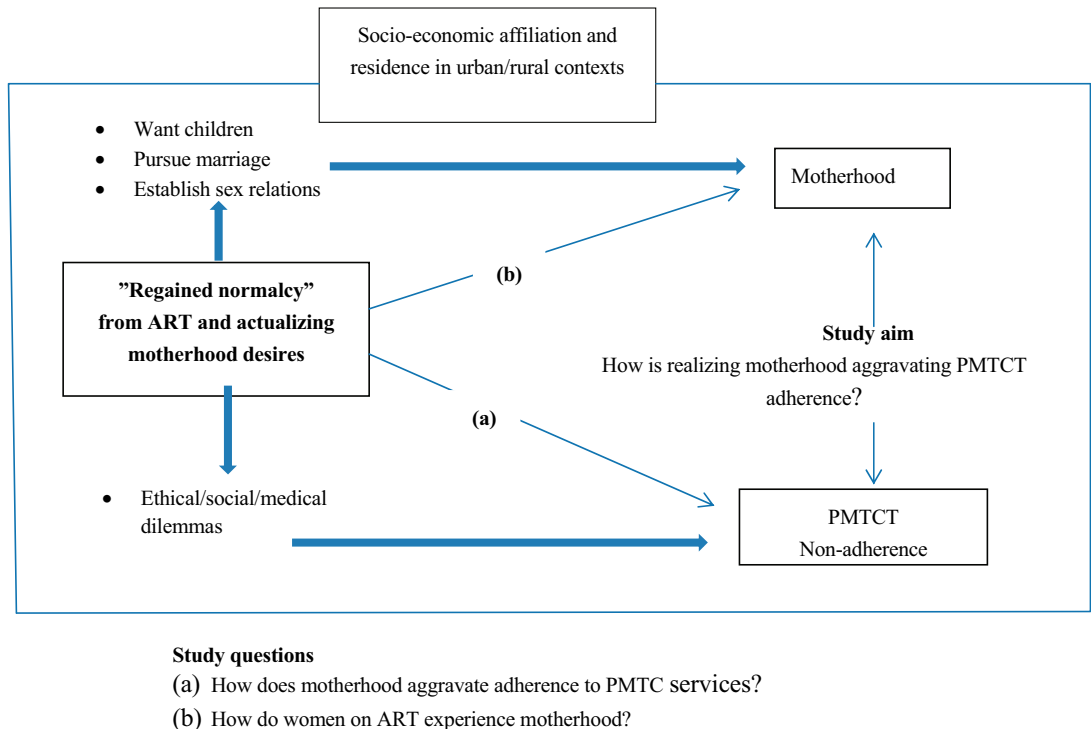
CONCEPTUAL FRAMEWORK

Women living with HIV want to have children and become mothers thus achieving personal and socio-cultural expectations for parenthood. A biological child symbolizes involvement of a male partner and an established relationship. Motherhood introduces social, ethical and medical dilemmas for women living with HIV and challenge adherence to PMTCT. The regained “normalcy” from ARV treatment comes with recommendations that limit the HIV infected women’s ability to follow expected socio-cultural procedures that normally come with pregnancy and childbirth. The conceptual idea of this thesis explores the realization of motherhood and adherence behavior of women enrolled in PMTCT in the context of the importance of childbearing and the worries about compromising good PMTCT outcomes and thereby the health of mother, infant and even partner.

To further understand the association between women’s actualization of motherhood and adherence to PMTCT, we argue that as urban and rural areas have different social structures their values, expectations and experiences vary. We therefore embody the analysis of our findings in the conceptual framework of ‘group affiliation’ introduced by the German sociologist Simmel (1955) and further expanded by Pescosolido (1992, 2000). They describe how patterns of relationship transform when social settings change, and how that influences behavior. They describe pre-industrial societies (rural areas) as formed in concentric circles, where participation in the smallest group also means participation in the larger groups. The complete overlap of ‘group affiliations’ in pre-industrial societies ensures strong ties between individuals and their social relations at different levels. The closeness entails control and enhances social security, but gives little room for personal development and the tolerance for the new and unexpected are low (Pescosolido, 1992; Pescosolido & Rubin, 2000; Simmel, 1955). In contrast, in the modern society (urban areas) the circles are only partly overlapping. The individual stands at the intersection of diverse group affiliations providing choice and freedom. He/she maintains ties with different groups: having loose and weak connections with some circles, while stronger with others. The affiliations are more flexible and short-lived and thus also provide less security. The concept of varying ‘group affiliations’ depending on level of social and productive development is useful to describe the differences in worries around HIV during the realization of motherhood and PMTCT adherence behavior in urban and rural areas in Kenya (Pescosolido, 1992; Pescosolido & Rubin, 2000; Simmel, 1955).

The fear of remaining childless and the stigma associated with being immoral is clearly expressed in the lives of women living with HIV. It is possible to hide one’s HIV status, but it is not possible to hide from the social and cultural expectations of reproduction, a point that will emerge repeatedly in this thesis. The high priority that women attach to children is explained by their overall value in Kenyan society, and also by the fact that children conceal the HIV - an illness associated with unprotected sex, which increases its transmission. These experiences vary between urban and rural Kenya and women’s experiences are different depending on the existing social networks and expectations.

Figure 3 Conceptual framework explaining how realizing motherhood is associated with PMTCT adherence among women on ART in urban and rural contexts



STUDY RATIONALE

PMTCT allows people living with HIV to hope for and actualize childbearing. However, it also complicates reproduction, as personal life priorities and social expectations conflict with the medical consequences and public health implications of unprotected sex and non-adherence to treatment guidelines. Achieving reproductive goals interferes with preventing further HIV transmission and following PMTCT recommendations. This underscores the need to explore childbearing among women living with HIV and to increase knowledge on how childbearing influences their ability to adhere to PMTCT recommendations and take adequate precautions to protect themselves, infants and even partners from further infection.

AIM

To increase knowledge on childbearing and adherence to PMTCT interventions focusing on how women living with HIV realize motherhood in urban and rural Kenya.

SPECIFIC AIMS

1. To identify factors associated with consent to antenatal HIV testing in the ‘opt out’ strategy.
2. To explore experiences of intentionally becoming pregnant among women receiving antiretroviral therapy
3. To explore how pregnant HIV-infected women on PMTCT cope with the pregnancy, ARV for HIV PMTCT purposes and plan for the delivery.
4. To explore reasons for interrupting HIV treatment in newly delivered mothers in Kenya.

METHODS

STUDY SETTING

Busia

Busia district is located in Western Kenya and borders Uganda to the west and Lake Victoria to the south. It is a rural resource-poor area with high HIV prevalence. Agriculture, fishing and commercial undertakings on small scale are the main economic activities in the district. The average household in the district generates approximately \$84 per month (Central Bureau of Statistics, 2003). Surveillance studies at antenatal clinics indicate HIV infection rates of close to 10 percent (National AIDS and STI Control Programme (NASCOP), 2008). More than 50 percent of school-age children do not complete eighth grade due to pregnancy, early marriage, child labor, death of parents and the lack of support (Central Bureau of Statistics, 2003). Busia is a collectivist society that enjoys strong social cohesion. Every individual is identified through age group, clan and village belonging. This common identity breeds connectedness and solidarity among people, who care for and are concerned about each other's well being. Family members live in individual households that are close to each other within the family homestead. The eldest person in the family usually is responsible for maintaining harmony among the extended family members. The houses are mainly mud walled and grass thatched with a few with iron sheet roofs. The houses usually belonging to sons are constructed in specified positions in the compound in relation to age.

Kibera

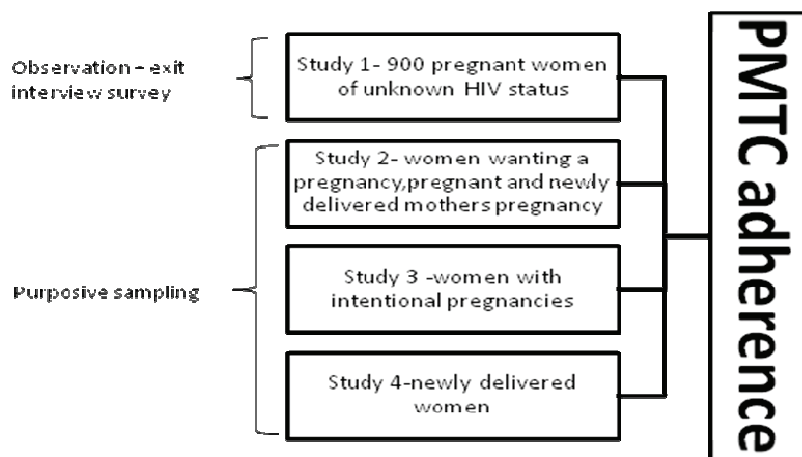
Kibera is a slum in Nairobi and one of the oldest and largest slum settlements in Africa, composed of multiple "villages". The population in Kibera ranges from 0.5 to 1 million and it is estimated that one in four Nairobi residents live there. It is an "informal settlement", a term that underscores its non-permanence and implicitly justifies the lack of infrastructure and services. Living conditions are deplorable, with toilets in short supply, safe water unavailable, and garbage collection virtually non-existent. Many residents live in one-room homes made of semi-permanent material such as mud, wooden planks or metal sheets. Many have migrated into Kibera from rural areas in other regions (Erulkar & Matheka, 2007) bringing together people of different backgrounds and diverse cultures to form a highly cosmopolitan population.

People moving to Kibera normally bring their young sons with them, while leaving their daughters behind until late adolescence, when they move on their own or with boyfriends or spouses (Erulkar & Matheka, 2007). Men engage in a wide range of jobs while the women often perform domestic work or small-scale business for survival with only a few having formal employment. It is in this setting that many adolescents make their transition to adulthood (Erulkar & Matheka, 2007). Married women often move back to take care of the rural home and extended family, while the husband and older children stay in Nairobi. Kibera thus constitutes a high-risk environment for HIV transmission with an estimated HIV prevalence above nine percent (Central Bureau of Statistics, 2003). Some of the drivers of the HIV transmission are existence of high unemployment and substance abuse that lead to involvement in transactional sex (Gulis, Mulumba, Juma & Kakosova, 2004). Kibera constitutes a highly mobile and sexually active young population interacting in loosely structured sexual relationships and social networks. Most city residents retain links with their rural extended families and leave the city periodically to help work on the family farm.

STUDY DESIGN

The aim of the study was to increase knowledge on childbearing and adherence to PMTCT focusing on how women living with HIV realize parenthood in urban and rural Kenya. The analysis is based on interviews with three groups of women: pregnant women, recently delivered and those actively planning a pregnancy (see figure 4).

Figure 4 Sub studies, research methods and participants



The study employed both quantitative (I) and qualitative (II-IV) research methods. Quantitative research was used to investigate consent to HIV testing at antenatal care among first time attendees. It focuses on what is measurable and quantifiable and aims at establishing facts and testing hypotheses (Dahlgren, Emmelin & Winkvist, 2004; Stainton, 2003 (a)). For the quantitative cross sectional study a questionnaire survey was performed. It is the most appropriate method of collecting standardized information in a large group of participants. A broad information base requires that data be structured to enable grouping of variable during data analysis thus the need of a standardized structured questionnaire. Qualitative methods were used to get a deeper understanding of how women reason and act when seeking a pregnancy, to explore how HIV-infected women explain their coping with pregnancy and how they experience motherhood and manage adherence to PMTCT as newly delivered mothers. Qualitative research is a systemic, interactive, subjective approach, used to describe life experiences and give meaning to them (Burns & Grove, 2005; Kvale S, 1996). Information is collected through the interaction and conversation between the study informant and the researcher. The findings represent those participating in the study, and can be used to develop theory (Kvale, 1996; Morse & Field, 1995). In-depth interviews (IDIs) were chosen for article II, III and IV to enable participants to share and express feelings and experiences pertaining to their own experiences of realizing parenthood (Kvale, 1996; Morse, 1994; Ritchie & Lewis, 2003). For the IDIs interview guides were prepared to ensure that all relevant areas were covered during the interview.

The research team

The research team consisted of a group based in Kenya consisting of a physician and epidemiologist, a community social worker, an anthropologist, a community health nurse and a monitoring and evaluation specialist. Another group based in Sweden consisted of me – the author – a sociologist, an infections diseases doctor and epidemiologist and a public health and child's rights nurse. For the field studies I worked in close collaboration with the Kenya team, who were more updated on the current issues and changes in the social context. Although born and raised in Kenya, I encountered new words and meanings that had been coined in the sheng' language spoken in urban areas and I was to some extent 'foreign'. Research assistants trained in questionnaire data collection method performed study I. Interviews for studies II-IV were performed by an anthropologist, a nurse and me depending on whether the language used was Sheng', Kiswahili or Luhya. My previous work experience and knowledge of the Kenyan context was advantageous and enabled me to blend in among urban and rural populations. I was perceived as a member of one of many local non-governmental organizations that provide health care and also carry out research on health issues. This built confidence in the community and they were willing to participate and support the study.

PARTICIPANTS AND SELECTION CRITERIA

For the first study (I) all pregnant women who were tested for HIV at their first visit to ANC in any of the three hospitals in Busia between August and December 2008, were eligible for enrollment. A midwife informed the women about the study and those willing to participate were recruited reaching a sample of 900 consecutive women in three months.

For the second study (II) the participants were purposively selected from the registers at an urban ART and PMTCT program. The criterion was that the women had been on HAART for not more than six months. Assuming that women's experiences and decisions about PMTCT would differ depending on where they were on their pregnancy time-line we wanted women from three groups: (i) pregnant women (ii) women who had delivered in the past 12 weeks and (iii) women who were seeking to become pregnant. Twenty-three women consented to participate.

For the third study (III) we purposively recruited pregnant women already enrolled on ART to explore the behavior and challenges in following PMTCT when fully aware of their HIV diagnosis, of the benefits of adhering to HIV treatment and of how to reduce the risk of mother to child transmission. Pregnant women on ART were identified through the PMTCT registers in an urban and rural area and contacted by a community health worker from the PMTCT program. Twenty-eight women: 12 in urban and 16 in rural area consented and were interviewed.

For the fourth study (IV) female ART recipients with infants aged less than six months were purposively selected from the registers in urban and rural PMTCT programs. Further inclusion criteria were based on residence (urban or rural), marital status (married /unmarried), and duration on ART before pregnancy (newly initiated <1 years/experience) and number of children (women with older children and first time mothers). A community health worker at each site introduced the study and its objectives to the women. Twenty-six women: 16 in urban and 10 in rural gave verbal informed consent and were interviewed. No one declined to participate.

DATA COLLECTION TECHNIQUES

Questionnaire survey

A questionnaire with a total of 35 questions was developed and translated into Kiswahili and Luhyia by the author, a nurse and a midwife. It included both closed and open-ended question and was tested for clarity and cohesion with a sample of ten pregnant women who were not to be included in the study. After making necessary adjustments the questionnaire was shared with three trained data collection assistants who piloted the questionnaire at three antenatal clinics. The questionnaire was performed with 900 women and took about 45 minutes to complete. Research assistants who were not employed at the three facilities included, administered the questionnaire as the participant left the HIV testing room. There was no reimbursement given to the informants. The questions were orally asked to the respondents who provided oral answers that were filled in by the interviewer. The language comfortable and understood by the participants was used. The questionnaire covered the areas of PMTCT awareness, MTCT knowledge, sexual relationships and HIV testing and counseling.

Qualitative interview

Qualitative interviews were used to provide a deeper understanding of specific issues. Interview guides were prepared at the level of large themes to be covered during the interview (Dahlgren, Emmelin & Winkvist, 2004). This was to enhance flexibility and to let the researcher be as open-minded as possible to meet new emerging ideas and the unexpected information from the respondents. Face-to-face interactions were used to build trust during the interview process and to enhance free interaction between the researcher and the participants (Dahlgren, Emmelin & Winkvist, 2004; Kvale, 1996; Ritchie & Lewis, 2003). Study three (III) used more open-ended questions for example, “please describe your feelings when you discovered that you were pregnant?” to allow the respondent to lead the interviewer towards issues that were of personal importance and relevance to the topic being studies. The researcher also asked further follow-up questions based on the themes generated during the conversation (Ritchie & Lewis, 2003). During the interviews techniques such as probing, clarifying questions, and reflecting and para-phrasing were used to encourage participants to express themselves freely and to enhance in-depth descriptions of the required topic. Phrases such as ‘Please tell me more’, ‘Alright!’, ‘I see’, ‘Oh!’ and anything more?’ were used to facilitate the flow of the conversation. Confirmatory (double-checking) questions were also asked in order to confirm what participants stated and to clarify meaning.

All conversations were tape recorded with permission from the respondents and the interviews were performed in English, Kiswahili/ Sheng’ or Luhyia languages. During the interviews the researcher noted down body language, body reactions, and happenings in the surrounding as the interview progressed. The researcher was attentive to when participants were uneasy, bored, tired, angry or embarrassed. To facilitate smooth flowing of the interviews, the researcher strived for good communication skills with a balance between talking and listening. The tape-recorded conversations were transcribed and translated into English by the thesis author or the research assistant depending on the language used.

Participant observations

First emphasized by Bronislaw Malinowski (1961) participant observation involves systematic observations that allow a researcher to get close to study participants. Close proximity enables the researcher to understand the point of view as well as visualize the world of the study informants (Malinowski, 1961). Study one (I) employed passive onlooker observation – meaning that the researcher develops an insider's view of what is happening without participating but purely observing. The researcher was unknown (covert) to the people being studied making it possible to get trustworthy data (Malinowski, 1961).

DATA MANAGEMENT AND ANALYSIS

Quantitative analysis

For the cross-sectional study (I), data was collected through exit interviews using the questionnaire survey described above for a period of three months by the research assistant. At the end of each day the assistants checked to ensure that all questions were correctly filled in. The author and the data entry clerk checked the data at the end of each week. Data was entered into SPSS-PASW, version 18 (SPSS, Inc., Chicago, IL), coded and cleaned.

Descriptive statistics were performed on socio-demographic characteristics and the outcome variable 'making an informed decision to decline HIV testing'. The outcome variable '*making an informed decision to decline HIV testing*' was derived from the question 'If you could choose to HIV test or not, would you decline? (Yes/No)'. Independent variables that were used to model the outcome variable included; *type of union* – 'What is your marital status? (Married/Unmarried)', *duration of current sexual relationship* – 'How long have you been in the current relationship? (Not in a relationship, ≤ 4 years and > 4)', *stable relationship with the child's father* – 'Do you live together with the child's father? (Yes/No)', *knowing HIV testing is optional* – 'Do you know that you can choose to HIV test or not? (Yes/ No)', *tested for HIV* – 'Have you tested for HIV at this visit? (Yes/No)', *discussing HIV testing with the partner before the ANC visit* – 'Have you discussed HIV testing with your partner before this ANC visit? (Yes/No) and *knowing testing is performed at ANC before the visit* – 'Did you know that HIV testing is done at ANC before coming today? (Yes/No)'.

Following the descriptive analysis bivariate and multivariate analyses were used to measure the association between the outcome variable and each categorical independent variable. Independent variables with a p-value of < 0.20 associated with the outcome at the bivariate level were entered into multiple logistic regression models and removed using a forward stepwise method (Likelihood Ratio Test with a removal level of significance of $p < 0.1$). Odds ratios (ORs) and their 95% confidence intervals (CI) were computed. A value of $p < 0.05$ was considered statistically significant and tests of significance were two-sided. The final multivariate model was tested for goodness of fit using the Hosmer-Lemeshow test.

Qualitative analysis

Content analysis

In studies two and four the data was organized and interpreted using content analysis focusing on the meanings given to messages and concepts (Graneheim & Lundman, 2004; Morse & Field, 1995). The interpretation of data involved a constant comparison of the different messages in the transcripts at the participant/individual level and between the participants to provide insight to the underlying meaning. The passages of the interviews were reviewed within the context of the entire interview to explore and identify the meaning and importance of the passage in relation to the whole (Morse & Field, 1995). Initially, the transcribed material was read a number of times to get a sense of the interviews. Meaning units were identified, condensed and coded. The codes were compared and grouped into sub-categories and categories. In the process of consistent moving between the fragmented text and the whole, the sub-categories and categories were re-organized and the theme developed (Graneheim & Lundman, 2004). The main author did the initial coding and later the research team discussed the coding process and reached consensus. The staff at the ART clinics was also involved in the analysis phase to provide their views and understanding.

Narrative structuring

In study three narrative structuring was used to organize the data (Kvale, 1996; Riessman, 1993). When people tell their stories they try to explain their choices and actions, in a manner that portrays their justification and position of the issue being studied (Mischler, 1986). Narratives aim to give a voice and position to the participants thereby justifying their actions and behavior on a given issue. The transcripts were read several times to gain a general sense of the experiences and thoughts of the participants. Initially the reading focused on content and coherence. The interviews were then compared and stories searched for, showing the responses of the women justifying their actions and decisions for managing their lives. Narratives are not exact records of what actually happened but represent how the participants choose to tell the story to the interviewer at the time of the interview (Frank, 1995; Kvale, 1996). The values and interests of the narrator will influence how the story is told depending on the audience and occasion (Riessman, 1993). Still the stories people tell about their lives, or special events in their lives, help us understand their choices and decisions in life (Mischler, 1986).

ETHICAL CONSIDERATIONS

In research involving human beings, respect for the integrity of the participants requires that participation is voluntary and based on adequate information. People enrolled should be treated ethically not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their wellbeing. The general principles of research lead to considerations of the following requirements: informed consent, risk/benefit assessment, and the selection of participants for the research. Assessments of risks and benefits have been undertaken and follow strict criteria reflected in the research design. Each of the participants was assigned a unique study identity to be used in all subsequent data analyses. The identity number will not be released outside the immediate research team. Data was used anonymously and only was accessed by the research team. This was explained to the informants and included in the ethical consent form.

Strict criteria for obtaining consent have been established for health behavior research. Informed consent was sought verbally. All study participants were assured that their anonymity would be strictly upheld. It was stressed that participation in the studies was voluntary, and participants could withdraw at any time with no effect on them, their family or care and treatment given.

Ethical clearance was obtained from Kenya at the Kenya Medical Research Institute (KEMRI) KEMRI/RES/7/3/1 and in Sweden at the Stockholm Regional Ethics Committee 2009/50-31/3.

MAIN FINDINGS

This thesis seeks to answer the central questions: (a) How does realizing motherhood among women on ART aggravate their adherence to PMTCT interventions (I-IV)? (b) How do women on ART experience motherhood (II-IV)? The findings related to these questions are summarized in the theme ‘Strive for motherhood’ including (i) Typical identities of women in a village (Busia) and a slum (Kibera) (ii) The pathway to motherhood and (iii) Challenges for adhering to PMTCT capturing the women’s efforts to balance childbearing and the struggle to follow PMTCT recommendations (see table three).

Table 3 Main findings

	Strive for motherhood	
	Urban	Rural
	‘Vulnerable and striving to survive’	‘Secure and family controlled’
Experience of motherhood	<ul style="list-style-type: none"> • Limited presence and involvement of the family • Widespread poverty and lack of income • Tactical soliciting for a suitable partner • Non-established sexual relationships • Proactive and decisive in solving daily challenges that are normally unpredicted 	<ul style="list-style-type: none"> • Constant family presence and supervision • Disclosure to spouses • Socialized to become mothers • Motherhood a function of marriage • Pregnancy and childbirth responsibilities of the mother-in-law
PMTCT non adherence	<ul style="list-style-type: none"> • Pregnancy a private affair that does not involve health providers • Physical strength and not clinical markers a prerequisite for parenthood • Lack of food leads to missed doses and mixed feeding • Uncoordinated healthcare provision from NGO’s 	<ul style="list-style-type: none"> • Health problems expected after childbirth and treated at home • Use of traditional medicine • Specific days to access ART • Lack of health staff leads to long waiting time • High coverage of HIV testing at the cost of not understanding that testing is optional

'STRIVE FOR MOTHERHOOD' (I-IV)

This is an overriding theme that describes the desire of women on ART to have biological children and be parents while at the same time negotiating the challenges of living with HIV (I-IV). Children improve women's position in society, earn them respect and are a sign of a happy and fulfilled life (II-IV). As women on ART regain normalcy they have to conform to the way of life in their respective environments and face the challenges of daily life resulting from existing social structures (III, IV). During the process of realizing motherhood the women's HIV infection may attract stigma and discrimination from partners, family and community leading to non-disclosure or selective disclosure (II-IV). Although ART has enabled the women to pursue motherhood, PMTCT policy seems rigid and not adjusted to the reality of becoming a mother when on ART, which may lead to non-adherence (I-IV). Therefore the women on ART become mothers striving to balance the adherence to PMTCT recommendations with the socio-cultural expectations of motherhood, which helps conceal their HIV infection.

The most important thing . . . I want to prove my capability as a woman [childbearing] . . . I want to be recognized in my family and community. I will not let my status stand in the way. I will not share it [my HIV diagnosis] with him [partner] if he will not support me. I can worry about the other things [love and marriage] afterwards. (Married and 44 years old Kibera resident)

Typical identities of women in a village and a slum (III)

The social contexts of urban Kibera and rural Busia constitute different social networks influencing lifestyles and interaction patterns of the women (III).

'Secure and family controlled'

The women in Busia told about living in a homestead and close together with the members of the extended family, to whom they were related through marriage. They had been brought up and socialized into knowing what their role in parenthood was and what was expected of them and they accepted it. They also were in close contact with members of the village and would meet the same people for church on Sunday and in the market or hospital during the week. Most of what happened in the village was common knowledge and all participated in each other's joys and sorrows. They belonged to social networks that were intertwined and well defined. This gave the women security and predictability in life, but also meant that it was difficult to keep secrets. Women in Busia therefore identified themselves and described their lives as 'secure and family controlled'.

'Vulnerable and striving to survive'

For the women in Kibera life was different. They told about an uncertain and hard to predict reality in the slum, but also of self-reliance and decisiveness. As different from in Busia they had chosen their social networks and developed their relationships with neighbors and others themselves. They did not have family members living close and for most women their families resided in rural areas. Thus they belonged to several, partly overlapping, partly independent, social networks serving different functions for them and offering them some sense of security. They portrayed themselves as 'vulnerable and striving to survive'.

The role and importance of children (II, III, IV)

The women told about the importance of children for the fulfillment of their lives (II-IV). They were seen as important symbols of social status in the community and strengthened the relationship with the partner. Pregnancy and childbirth were perceived as signs of good health (II, IV). Although children were important to women residing both in Kibera and Busia they played different roles because of the differences in social structures between the two settings (III, IV).

Children stabilize relationships

Children in the setting of Busia were more of an expectation as the women were brought up looking forward to be married and becoming mothers (III, IV). The women told about knowing in advance what was expected of them in life and ensuring family harmony was important for them when making decisions (III). For them childbearing was the purpose of marriage and children were perceived to stabilize marriages, make them secure and a source of pride.

I am proud to be a mother. Some women have a marriage without a child. Children have made my marriage real and this is the way it has to be. Children change marriages for a better future. I am satisfied to have a happy marriage with my husband. (Married and 27 years old Busia resident)

Children provided the cue for an established relationship and an opportunity to formalize the relationship soon. In Kibera children were perceived to strengthen the relationship particularly when the woman had other children from another previous relationship.

I have been seeing him [partner] for two years [in the past] . . . he asked me to bear him a child . . . I happily agreed . . . I already have two [children] . . . from before [previous relationship] . . . it showed me that he [partner] loves me. . . he [partner] wanted me to have a child . . . his own blood to bond us . . . he was serious about staying with me . . . and build a family. (Cohabiting and 28 years old Kibera resident)

Children were not only described as improving relationships between women and their partners, but also played a role in bringing together relatives especially during pregnancy and childbirth (II-IV).

Children as a symbol of matrimony

Among the unmarried women in Kibera biological children showed that a man was involved. This meant that the woman had attracted a man who wanted her to be a mother to his child hence possibly going to marry her. This prevented questions from family members when unmarried women visited home (II). A male presence ensured the women that they would be provided for thus children secured their livelihood and continued support from the child's father (II, III). As many women were unemployed and did not have their own money, this gave them security in an environment that was unpredictable and tough to survive in.

My husband treats me well . . . gives me money . . . to buy food and clothes. . . he [husband] pays the rent. I will get pregnant . . . he wants to name after his father, mother or any person he loves. . . he will be happy. He will always be concerned for it [child]. . . the child has replaced his relative . . . it [child] is a living reminder . . . I will take care of him and the child. (Married and 34 years old Kibera resident)

Pathway to motherhood (I-IV)

In their longing for identity and position women in Kibera and Busia had made the choice to bear a child, which would give identity as a mother and status as a woman (II-IV). To become pregnant it was important for the women to have sex without a condom. However, the HIV infection proved a hurdle in realizing these goals in several ways (I-IV).

Tactful soliciting to avoid condom use

In Kibera life was individualistic and depended on how challenges to survival were best overcome. Many women in Kibera who described having non-formal relationships with their partners (II, IV) told about the difficulty to establish and maintain relationships and to get married (II, IV). This meant that they could refuse to have sex with men they did not want to father the child (II). They explained that they 'tactfully solicited' men and lured them into a relationship to get pregnant (II). Men in Kibera perceived women as sexual objects and women knew that men did not want to use condoms after a few encounters. Seeking a pregnancy after previous sex encounters was hence preferred as condom use became irregular.

All men see in us [woman] is sex . . . I just dress smart and have a nice hairstyle for them to see me. . . he will surely look and want me. I will flirt and show interest. (Single and 24 years old Kibera resident)

Disclosure and stigma

Although this thesis focused on the women partner support was mentioned as critical for becoming a woman and adhering to PMTCT recommendations (I-IV). Women residing in Kibera in non-established relationships avoided discussing pregnancy intentions and disclosing HIV infection with their partners (II). Even though they were concerned about infecting the partners through unprotected sex, the fear of not conceiving was greater.

I know telling my partner about the HIV infection is right. I choose not to . . . I look bad for thinking of me. . . he [the partner] can get that from me but you need to understand my situation[I want a child].I cannot get it [pregnant] if he leaves or chooses to use a condom. (Widow and 33 years old Kibera resident)

Women in Kibera were decisive in negotiating daily challenges to survive and at the same time managing to achieve motherhood while living with HIV (II-IV). However, the wish to have children among women living with HIV and whose infection was common knowledge was not always understood by the Kibera community (III). Women known to have HIV said they were surprised by the stigmatizing reaction among community members and felt abandoned by their trusted social networks particularly fellow post-test club members. This led the women to move in with distant relatives elsewhere where they were able to keep the HIV infection a secret. However, the relatives expected the women to perform housework making them struggle with keeping hospital appointments (III).

In contrast to the unpredictable and often changing sexual relationships of the women in Kibera the women in Busia were married. They had disclosed the HIV infection to their husbands who supported the pregnancy (III, IV). Life could continue as usual so long as the extended family did not know about the HIV infection.

Social support during motherhood

Regardless of non-disclosure or selective disclosure among Kibera and Busia women respectively the period of pregnancy and childbearing was mentioned as being delicate and risky thus requiring extra attention and supervision (III, IV). The women described family involvement during pregnancy and a few days following childbirth and told about increased visits, support and general concern about their health. Although the relatives did not live close to the women in Kibera, they often visited and brought with them food and money to help out (II-IV). There was also some help in performing household chores. Accommodation could be provided during times of difficulty as for women whose HIV infection was a common knowledge when the pregnancy became visible and attracted stigma (III).

For women in Busia the responsibility for a pregnant woman and her unborn child belonged to the older women in the family, mostly the mother-in-law (III, IV). The women told about living with the constant presence of the husband's family and described a life as befitting a queen. These women described culturally preset behavior and beliefs during the pregnancy and childbirth and that all involved knew what was expected of them (III, IV).

However after childbirth the women in Kibera and Busia were expected to return to the usual life and meet the demands and expectations of 'good motherhood'.

Motherhood and adhering to PMTCT (I-IV)

The individualistic nature of life in Kibera meant lack of social support from family and community during parenting, but gave room for greater decision making on issues related to the health of the women. For women in Busia the constant family involvement meant increased supervision to gauge their competency as mothers and wives. In both Kibera and Busia the strife to attain the social-cultural expectations of motherhood subsequently led to problems in following PMTCT recommendations (I, III, IV).

Mother first, patient later

The direct or indirect involvement of family and community during parenting and the determination of women to attain a good image of motherhood during and after pregnancy made it difficult to follow HIV treatment (II-IV). The constant presence of the family and the non-disclosure to them made women miss HIV medication and choosing to deliver at home. (III, IV). The wish to affirm and maintain a dignified image of womanhood was mentioned as a motive for striving to perform childcare and household responsibilities well. The women both in Kibera and Busia said that following HIV treatment was vital however the demands of achieving motherhood overwhelmed them and were prioritized above their health (II-IV).

I go to the clinic early but those who are relatives or know the staff get to see the doctor first...I am tired of waiting three or five hours before seeing the doctor...I have to feed my baby, clean the house, go to buy food and cook for my partner. It is too much time to wait and the staff does not consider this. So I have to leave to go and do my duties in the house. I can come back another time and get more medicine, if I get to see the doctor.
(Single and 27 years old Kibera resident)

Health and childbirth

The women on ART wanted to become mothers and knew the importance of good health to the infants and to themselves. However, beliefs around pregnancy, childbirth and parenthood together with partner reactions and perceptions of health providers made it hard to adhere to PMTCT (I-IV). 'Good health' was explained as the ability to perform house chores and showing strength enough was seen as a prerequisite for seeking a pregnancy. Pregnancy was perceived to be an individual and private choice. The women felt that seeking a pregnancy was for them to decide and described pregnancy as a personal decision that could eventually involve a partner but not health care providers (article II). They did not discuss pregnancy intentions with health providers and thus missed preconception assessment. Preconception counseling was largely misunderstood and the women told about wanting to decide when to have a child or not.

They [clinic] want me to wait [pregnancy] yet I am ready [healthy]. I see no need for them [clinic] to know when I want it [a child] . . . it [child] is mine and I get one when I want. (Cohabiting and 33 years old Kibera resident)

The women told about a health assessment that could eventually determine if they could seek a pregnancy and perceived preconception care as seeking permission to become pregnant.

They [clinic] want to check me [woman's health] before becoming pregnant . . . I will not go for that [CD4 count] . . . I know and experience it [good health] . . . I live in this body. They [clinic] cannot tell me what I feel . . . it is the other way round [woman tells the clinic how she feels] . . . tests want to tell me what I already know. (Cohabiting and 37 years old Kibera resident)

Antenatal HIV testing identifies women infected with HIV and in need of treatment. In Busia nearly all 900 pregnant women who visited ANC were tested for HIV after the group pre-test counseling session (I). However only 20 percent of those surveyed felt they could make an informed decision to decline HIV testing. Making an informed decision to decline HIV testing was associated with knowing that testing was optional (OR=5.44, 95% CI 3.44-8.59), not having a stable relationship with the child's father (OR=1.76, 95% CI 1.02-3.03), and not having discussed HIV testing with a partner before the ANC visit (OR=2.64 95% CI 1.79-3.86).

Table 3 Factors included in the final multivariate model analyzing the association with ‘making an informed decision to decline HIV testing’ among 900 pregnant women

		Crude analysis		Adjusted analysis
Factor		p-value	OR (95% CI)	OR (95% CI)
In stable relationship with child’s father	Yes		1	
	No	0.002*	2.11 (1.31 – 3.41)	1.76 (1.02 – 3.03)
Discussed testing with partner before ANC visit	Yes		1	
	No	<0.001*	2.65 (1.89 – 3.71)	2.64 (1.79 – 3.86)
Knew HIV testing is voluntary	No		1	
	Yes	<0.001*	5.29 (3.62 – 7.72)	5.44 (3.44 – 8.59)
Age (years)	≤ 20		1	
	> 20	0.513	1.07 (0.87 – 1.32)	1.09 (0.41 – 2.92)
Occupation	Unemployed		1	
	Employed	0.895	1.03 (0.67 – 1.59)	1.05 (0.65 – 1.71)
Formal education	Never in school		1	
	≤ 8 years	0.542	1.26 (0.60 – 2.63)	1.19 (0.54 – 2.63)
	> 8 years	0.309	1.53 (0.67 – 3.49)	1.49 (0.61 – 3.63)

*p-value <0.05

An important issue that emerged from observations in the pre-test sessions showed that midwives expressed their wish for the women to take the HIV test by stressing that the women were ‘mothers’ and that testing and knowing HIV status was the best decision a mother could make for her unborn child. No information was provided stating that it was an individual and voluntary choice of the woman to decline or accept HIV testing.

The women and the extended family always expected health problems after childbirth. It was common knowledge that newly delivered mothers could experience health problems after childbirth (III, IV). Furthermore it was not seen as necessary to visit the health facility as such health problems could be handled within the home. During pregnancy and after childbirth the use of traditional medicine was common.

I have delivered and all went well. How can I convince my mother-in-law that I need to see a doctor without any severe diarrhea, pain and constant vomiting or physical signs? She says headache, stomach pains and body weakness are health changes caused by childbirth and can be managed at home. She will just give me herbs and keep me at home. (Married and 21 years old Busia resident)

PMTCT clinic not flexible to reality of parenthood

The ART clinic was perceived as rigid to the changes that accompany becoming a mother and the women described waiting time as a barrier to obtaining treatment (III, IV). Even though the women in Kibera made decisions by themselves to visit the clinic and to seek treatment, they choose to return home and earn respect from the partners and community as responsible women and mothers to their children, if the waiting became too long (III, IV).

I go to the clinic early but those who are relatives or know the staff get to see the doctor first...I am tired of waiting three or five hours before seeing the doctor...I have to feed my baby, clean the house, go to buy food and cook for my partner. It is too much time to wait and the staff does not consider this. So I have to leave to go and do my duties in the house. I can come back another time and get more medicine, if I get to see the doctor.
(Single and 27 years old Kibera resident)

The constant supervision and concern from family member of women in Busia meant that every movement and action was monitored. The women explained that staying away from home and not performing womanly duties could negatively affect the image of responsible womanhood that they work hard to achieve (III, IV).

There are only two doctors here at a time to see us (ART patients). . . . it is slow . . . if only there could be more doctors, it would take less time. The child clinic has many doctors and I never have to wait there. I come with my baby and the clinic should consider that I am now a mother and help me. I should not have to stay here long . . . my duties are not complete at home . . . what kind of mother am I? . . . sometimes I choose not to come and stay home without my medicine. (Married and 25 years old Busia resident)

DISCUSSION

This thesis aimed to understand how women living with HIV realize motherhood and the challenges of adhering to PMTCT guidelines in a slum and a village in Kenya. The researchers sought to answer questions about how women living with HIV become mothers and how motherhood affects adherence to PMTCT, which in this thesis include antenatal HIV testing (I), discussing pregnancy intentions with health providers and pre-conception assessment (II), ARV to prevent MTCT, hospital delivery and exclusive breastfeeding (III-IV).

The findings illuminate social and cultural perspectives and intimate details of childbearing for women living with HIV, which explain behaviors that could otherwise be difficult to understand. We show that children are important and that becoming a mother when on ART involves respecting socio-cultural values in the family and community while managing the HIV illness and negotiating challenges that come with being HIV infected, many of which vary with residing in urban or rural areas. Women want to remain healthy to care for their children and they also want to have HIV-uninfected infants, just like women without HIV. In pursuit of fulfilling the demands of 'good motherhood' the women's own health was not any more top priority as it was during the pregnancy. Our findings illustrate the difficulties in combining successful motherhood with adherence to PMTCT in Kenya. While PMTCT services like HIV testing, ARV for PMTCT purposes, skilled hospital delivery and exclusive breast feeding or alternative infant feeding are proven to drastically minimize HIV transmission, knowledge and understanding of the social and cultural contexts, where these services are adopted, are central for successful intervention uptake and good health outcomes.

This thesis illustrates the challenges faced by women living with HIV and how they navigate through these to achieve motherhood. It wants to be a contribution to the attempt of finding better methods of translating effective PMTCT services into real life contexts and formulating practical policies that could improve adherence and promote successful implementation of a contextualized PMTCT policy in Kenya. We discuss our findings under two broad headings (i) social and cultural underpinnings in the pursuit of motherhood and (ii) challenges the PMTCT services need to respond to.

SOCIAL AND CULTURAL UNDERPINNINGS IN THE PURSUIT OF PARENTHOOD

Although pregnancy and childbearing are biological events the wish among women to be mothers is influenced by socially and culturally attuned values of motherhood. The motivation for a pregnancy depends on socially perceived meanings given to a child and the cultural importance of bearing one's own child. For the women in our study children gave identity and recognition in the community, and thus happiness and fulfillment as women (II-IV). These findings are consistent with other studies in African societies, which show how the identity of a woman is pegged on her capacity to bear children and that children are equated to a fulfilled life as a woman (Sonko, 1994; Yebei, 2000). Furthermore having children and experiencing motherhood made the women feel socially and morally accepted in the community just as women, who were not infected with HIV. Motherhood concealed their HIV infection, which has also been described from Nigeria (Smith & Mbakwem, 2010).

Premarital sex as a link to marriage

The unmarried women in Kibera explained their having sexual activity prior to marriage with the hope of becoming pregnant and being mothers. The birth of a child could make the child's father take the relationship seriously and eventually marry the woman. Among the families of the unmarried women the child would be a sign of the presence of a serious partner and the possibility of marriage in the near future. Motherhood was perceived to move the relationship towards marriage thus towards stability and security. Zulu (2003), while studying risky sexual behavior in Kibera, observed that extreme economic deprivation associated with high unemployment and low wages lead young unmarried women into engaging in unprotected sex for economic survival. In our study we found that unmarried women who had unprotected sex hoped for children and marriage, which would lead to economic and social security. For many women in Kibera there is a long-term goal explaining unprotected premarital sex and not just instant material compensation (Zulu, Dodoo & Ezeh, 2003). It is important to study unprotected sex among young women in the context of both transactional sex and marriage aspirations in Kibera. It is assumed that unprotected sex for economic survival is inherently risky and thus rejected, whereas unprotected sex in pursuit of marriage is socially and culturally accepted (Clark, Kabiru & Mathur, 2010; Ragnarsson, et al., 2011). Sex before marriage was commonly practiced among the young women in Kibera and a pregnancy was thus not unexpected. In traditional Kenya women's involvement in premarital sexual activity was discouraged and premarital pregnancies were stigmatized, and in some instances also reduced the possibilities for marriage (Calves, 1999). All the same children born before or after marriage are highly valued (Bledsoe, 1990). The unmarried women in Kibera perceived a premarital pregnancy as likely to increase their chances for marriage and failure to marry prior to the child's birth was not viewed negatively. The women in Busia were all married and had been socialized into being mothers (IV). A child was an expectation that was to bring happiness in the marriage, which was considered incomplete without the biological child.

Disclosure, non-disclosure and stigma of HIV infection

Given that the women were on ART it could be expected that they accepted their illness and that this would result in disclosure to significant persons. Our findings show that the women carefully weighed their decision to disclose their HIV infection or not against the perceived negative consequences. Nyblade (2005) studied HIV related stigma across contexts in SSA and found that gossip was a major reason for stigma. In our study the women in Kibera whose status was not common knowledge to the community chose not to disclose and keep the man rather than disclose, see the man leave and initiate gossip that would keep other men away and thus lower the chances for a pregnancy (II).

Married women in Busia disclosed their HIV infection only to the husband because they feared the negative consequences from the family and they also wanted to protect the family from pain and gossip (III-IV). Important in social life in Busia was to protect the dignity of the family. Keeping family members close and maintaining peace was dominant and the knowledge of a HIV infection could lead to gossip in the community. Our findings in Kibera and Busia show that fear of gossip was pronounced among the women living with HIV. The fear of gossip as a barrier to disclosing HIV infection has been observed also in other settings in Africa (Derlega, Lovejoy & Winstead, 1998; Nyblade & Ogden, 2005; Twehaze, 2009).

Not disclosing was a measure used by the women as a way of retaining a wider identity through concealing the HIV infection at chosen times and spaces. The women were open about their HIV infection to partners, fellow post-test club members and health providers with whom they interacted for treatment and support. Although the post club members were supportive to the women they were also stigmatized because of the association. They stopped visiting the women so as to isolate themselves and keep away from the stigma. Relatives and community members were not disclosed to because the women feared they would discriminate them. The women told about the careful process of weighing the benefits and disadvantages of disclosure to maintain their own identity and respect and also that of the family. Balancing the benefits and disadvantages of disclosing or not disclosing HIV status has been documented in literature (Derlega, Lovejoy & Winstead, 1998; Greene, Derlega, Yep & Petronio, 2003; Miller & Rubin, 2007).

Women in Kibera whose status was common knowledge in the community were involved in teaching HIV prevention, which created a positive identity in the community. They were accepted as long as they did not act in a manner that obviously showed that they were further transmitting HIV. Disclosure and involvement for prevention led to good things being said about the women in public, which 'changed reality and self-identity' in a positive way. However, they were stigmatized when their pregnancy became obvious. It revealed that they deviated from the community's expectations of a responsible life-style and from their own teachings. Hence becoming pregnant while HIV-infected 'changed their reality and self-identity' in a negative way. In his book *'Privacy and disclosure of HIV in interpersonal relationships'* Greene et al (2003) argue that the knowledge of a HIV diagnosis is an individual's own private information that he/she could choose to share or not. In our study we demonstrate how disclosure meant inviting the community into the private space. The pregnancy became a sign of carelessness. This came as a surprise for the women and they felt that becoming pregnant when on PMTCT was their own decision that nothing the community should interfere with (Greene, Derlega, Yep & Petronio, 2003).

The closed setup of Busia and the interest in each other's well being meant that the women could not take any decisions alone. It was expected that women after childbirth would experience health problems, which were not considered serious enough to warrant a visit to the hospital. Instead traditional medicine was used to manage the health problems at home. Despite the fact that traditional medicine is the primary source of health care in SSA, little is known about the interaction between traditional medicines and ART (Mills, et al., 2006). There is no conclusive evidence that traditional medicine is harmful when taken during ART, but the standard recommendation has been that they should not be combined. Recently WHO acknowledged the widespread use of traditional medicine in communities in Africa and suggested the importance of integrating indigenous medicine with the national health care system (Homsy, King, Balaba & Kabatesi, 2004; Unge, et al., 2011). The women had not disclosed their HIV infection to the extended family and it became hard to explain the need for visiting the ART clinic and get more HIV medicine. Our findings are in line with findings of a qualitative study performed to explore barriers for ART that showed patients who did not disclose their HIV infection lacked family support and stopped ART altogether (Dahab, et al., 2008).

CHALLENGES THE PMTCT SERVICES NEED TO RESPOND TO.

The women felt that the clinic was not accommodating their reality of balancing socio-cultural expectations with following PMTCT services (I-IV).

Poor delivery of information during counseling

The women knew that good health was vital for successful parenthood and that adherence to PMTCT was important for good treatment outcomes (II, III, IV). In both Kibera and Busia physical strength was perceived as having 'good health'.

For the women in Kibera 'good health' was a personal decision to make and they did not think clinical tests should be necessary. They felt that the health providers wanted to interfere with their decision on seeking a pregnancy. The women also explained that becoming pregnant was a private desire that could eventually include their partner but where clinic staff were outsiders. Thus they avoided discussing their pregnancy intentions with health providers and also missed pre-conception assessment.

In examining the relationship between making an informed decision to decline HIV testing among pregnant women in Busia (I), the number of pregnant women who understood that HIV testing was voluntary was very low (17 percent), indicating poor information that HIV testing should be a personal choice. Poor delivery of information on HIV testing at antenatal care has been identified as a reason for women failing to learn about their test results and a reason for women dropping out of PMTCT entirely (Maman & King, 2008; Manzi, et al., 2005; Weiser, et al., 2006). Our observations of pretest information sessions showed that the midwives were assertive in their recommending a HIV test as "the best decision for a mother" and gave little room for individual decision by the mothers. The health provider should motivate all women to have the test, while underlining the importance of free choice and autonomy in decision-making. This is a dilemma for the health providers, which leaves women poorly aware about their rights in relation to testing (Maman & King, 2008; Msellati, 2009).

Poverty and uncoordinated NGO health providers

Unge et al (2008) when exploring reasons for not adhering to ART in Kibera found that the lack of food was a major reason for stopping treatment. Also in our study the women stopped taking HIV medicine for fear of side effects, when they were short of food. The disruption in the regularity of doses due to missed meals has severe implications for the risk of drug resistance development and increased risk of premature progression to AIDS in the absence of effective and accessible second line treatment (El-Khatib, et al., 2011; Hardon, et al., 2007). Our study demonstrates how the additional responsibility for a child leads to even greater difficulties with adherence to ART, when resources are scarce and have to be shared. Apart from worrying about food for herself and the children, the women also had to cater for other needs such as clothes and beddings that needed money. They would decide to skip meals to save money and chose to prioritize their children's wellbeing over their own illness to meet the demands of the motherhood, which has also been shown in a study from Tanzania (IV) (Agnarson, Ericson, Ekström & Thorson, 2007).

The women were aware that non-adherence to the ART-treatment would mean an increased risk with breastfeeding, thus it became difficult to sustain exclusive breastfeeding, when short of food. In Kibera several NGOs operating independently provide PMTCT to the same population. This gave the women the opportunity to improve their situation of poverty. Poor women could migrate between the NGO's to obtain free formula milk for their infants. They would feed the children formula but often instead sell it to buy food or other items for the household. Although this behavior may benefit the women in the short-term, it creates a dilemma for HIV service providers in Kibera to follow-up and monitor their patients, making planning and evaluation very difficult. And it negatively affects the infant feeding practices resulting in mixed feeding.

Recently it has been estimated that sub-optimal breastfeeding contributes to 13 percent of all infant deaths (Jones, et al., 2003) and ten percent of the disease burden of children less than five years (Black, et al., 2008). The relationship between adequate nutrition and the cessation of exclusive breastfeeding in HIV-infected mothers in Kibera is a challenge in PMTCT that points to the need for a more comprehensive policy on infant feeding in the context of HIV in areas of poor resources. This has unfortunately not been considered in the 2010 WHO policy on ART while breastfeeding (WHO, 2010). The new 2010 PMTCT policy strongly recommends continued ARV treatment during the period of exclusive breastfeeding, which for women in areas with food scarcity, such as Kibera, is difficult to manage. Awareness among policymakers about the gap between women's poverty and the goal of reducing transmission through exclusive adherence to ART while breastfeeding is lacking. PMTCT providers need to come up with a broader more inclusive and supportive programs for PMTCT that do not exclusively focus on the biomedical interventions but also acknowledge the social-cultural and economic realities of many women.

Institutional/health system weaknesses

In Kibera the women made their own decisions about visiting the clinic while in Busia the decision was not for the women herself to make (IV). Women in Kibera could plan systematically when to perform house duties and have time to also make the clinic appointments. In addition the ART clinic operated daily except in weekends. For them life was flexible enough to allow them be 'good mothers' and at the same time keep appointments for ART. However, when they went to the clinic the staff often let those patients that were their friends or relative see the doctor first and others had to wait. Staying away from home when one is a mother was felt unacceptable and often they choose to go back home without having replenished their medication.

In contrast the women in Busia had to negotiate a visit to the clinic with the mother-in-law, which made it hard to follow appointments. Furthermore as the women in Busia had not disclosed to the family attending HIV clinic appointments was impossible and claiming a need to go to the clinic more generally when looking healthy was out of question. The specific opening hours at the clinic also meant prior planning, which was a challenge. When the women in Busia could go to the HIV-clinic (when their visit coincided with the child's clinic appointment) the long waiting hours often made them give up and go home. They did not want to be perceived as irresponsible mothers and rather missed picking up their HIV medicines. Furthermore the women in Busia were concerned about waiting at the ART clinic that was secluded from other buildings providing general health services. The women feared that someone might see them or a family member may come for them.

The clinic infrastructure was seen as impeding quick service and privacy particularly due to the lack of staff, few opening hours and seclusion of the ART clinic. Studies on the barriers of adherence in ART have found that long waiting time at the clinic, work and family responsibilities, and being away from home are reasons contributing to non-adherence (Dahab, et al., 2008; Hardon, et al., 2007; Lubega, et al., 2010; Mills, et al., 2006). Inadequate infrastructure in the form of few staff has been identified as contributing to non-adherence to ART also in other settings in Africa (Coetzee, Kagee & Vermeulen, 2011; Kagee, et al., 2010).

METHODOLOGICAL CONSIDERATIONS

SELECTION BIAS

In study II-IV purposive sampling was employed targeting women living with HIV and receiving ART. This is a unique group compared to women who find out for the first time about their HIV infection when coming to antenatal care. Firstly, our participants had known about their HIV infection for a while and they had had ample time to think through the test results, understand the consequences and adapt to living with the virus hence enrollment into ART. Secondly, being enrolled in ART gave our participants the opportunity to receive information on HIV infection and prevention strategies. They were therefore more knowledgeable and empowered to make decisions pertaining to PMTCT than women who are not on ART. Thirdly, our participants by virtue of experiencing the benefits of ART, could have navigated the discourse of disclosure and revealed their infection to someone either in the family or in a support group. Our findings pertain to a special group of women and most probably from what could be expected in newly diagnosed women. For example the stigma experienced by women with known HIV status in Kibera would not have been experienced if the women had not disclosed (III).

All our participants were recruited from ART and PMTCT centers that provided services according to the national ART or PMTCT guidelines that have been adapted from the WHO guidelines. Therefore standard HIV services were available to patients at all the facilities involved in our studies. The ART/PMTCT services were all provided by NGO's that normally prioritize on the job training and better salaries compared to government run ART/PMTCT services. In Kenya about 85 percent of ART/PMTCT services, though government owned, are offered by NGO's. Article I was conducted among 900 antenatal care attendees at their first visit. Nearly all were tested for HIV but their HIV test results could not be traced because of a change de-linking HIV testing result registers and PMTCT registers. Studying factors associated with making an informed consent to HIV test if we had known the test results would have improved the study by giving actual information about women who were more likely to drop out of PMTCT or who would enroll in PMTCT.

INFORMATION AND RECALL BIAS

Social desirability refers to informants either over-reporting positive deeds to conform to social acceptable values or to under-report bad behavior to avoid being perceived as deviant. The risk of social desirability was present in our study because we aimed at exploring sexual behavior particularly unprotected sex and non-disclosure when infected with HIV. To minimize information bias great care was taken for the researcher not to impose her thoughts and ideas on the informant. Our informants were in the process of seeking a pregnancy, were pregnant or had recently delivered and we anticipate that recall bias was low (I-IV).

REFLEXIVITY

As a researcher I have experiences that will influence my thinking and behavior. It is important to be aware of the 'self' and attempt to separate individual perceptions and interpretations from data in the research. The researcher's background will influence the conception and formulation of the research idea, approach to methods of investigation and findings considered most appropriate. Reflexivity refers to the way knowledge is shaped by the 'self' and how the role of the 'self' is taken into consideration during the research process (Angen, 2000). Reflexivity starts by discussing positions and beliefs, how to go about the investigation, knowing why the study is being performed and what the theoretical foundations are that motivate a field study in relation to education and interest (Malterud, 2001; Stige, Malterud & Midtgarden, 2009).

My first contacts in the field were our research colleagues at AMREF, who listened and discussed my study ideas in-depth. I was fortunate enough to meet a former high school colleague and a friend who introduced me to the Kibera clinic staff and introduced me to the health services provided. I came face to face with the harsh reality of life in the slum, something I had not thought about even though I was born and had lived in Kenya. During the situation analysis phase that took almost four weeks in Kibera I accompanied project staff during community outreach programs, where I met women support groups, visited satellite clinics and had a chance to meet community health workers, who were volunteers living with HIV. Being able to walk in Kibera lessened my anxiety about the high insecurity levels and I did not mind walking alone from the clinic to the main road.

I introduced myself as a member of a research collaborating team between AMREF in Kenya and Karolinska Institute in Sweden. AMREF is involved with many foreign stakeholders providing health care and performing research, and my presence was welcomed. I am a Kenyan in touch with current political, social and economic affairs and speak English, Kiswahili and Dholuo. This made it easy to build rapport and establish trust with both staff and informants but did not imply that interviewing was smooth. At piloting it was interesting for me to hear an informant respond in sheng' to a question asked in Kiswahili. Furthermore some words were new to me. Thus a fluent speaker of sheng' was included in the interview team. In Busia the encountered behavior during piloting and actual data collection were expected. I do not understand Luhya language and a nurse who was fluent in the language performed the interviews.

GENERALIZABILITY AND TRANSFERABILITY

This is the degree to which findings of research can be applied to other contexts. Qualitative research aims for "specificity" and does not seek generalizability. Instead "individual cases might point to a larger picture and illuminate similar situations" (Halloway, 2008). Morse (1994) states researchers are able to 're-contextualize' theory into many different situations, and 'theory-based' generalizations can be achieved through this (Morse, 1994). The researcher has described the 'typical reality' in the participants' view (Halloway, 2008) in the context of Kibera that has a young, multicultural, dynamic and highly mobile population and the context of Busia that is homogeneous in ethnicity and conservative. I have gained knowledge of many concepts, theoretical ideas and happenings about women living with HIV actualizing parenthood that are typical for slums and rural areas and, which can be transferred to similar situations (II-IV), but which also tell us about more general phenomena related

to motherhood when being chronically ill. The fear of stigma due to gossip and perceived negative reactions and the reluctance to disclose are also genuine problems seen in the lives of many with chronic illness. The conflicts when balancing the needs of the child with the needs as a patient and the wish to be a 'good mother' when ill are genuine to all mothers.

Article I employed a questionnaire survey among antenatal attendees coming for a first visit and the results are generalizable to the larger population. The details about the study instruments, sampling criteria and recruitment described in the methodology section support the generalizability and validity of these results.

TRUSTWORTHINESS AND VALIDATION

Trustworthiness is related to the ability of the study to capture the reality of those being studied. It focuses on how well the aim, data and analysis of the research fit together. Trustworthiness contributes to the evaluation of qualitative research methods by assessing the knowledge claims, communication and contextualization of research findings (Dahlgren, Emmelin & Winkvist, 2004; Malterud, 2001; Patton, 2002; Stige, Malterud & Midtgarden, 2009). It is how plausible and coherent the narratives are and how well the process for reaching the conclusion is described (Riessman, 1993; Sandelowski, 1991). In this thesis women who were seeking a pregnancy, already pregnant and newly delivered were included. The information was collected through qualitative interviews (studies two, three and four). Peer review was also performed. Closely related to credibility is dependability that refers to whether the process of research is logical, traceable and clearly documented. The authors clearly documented all steps in detail (see method section). Extensive deliberations were also performed in the research team of diverse backgrounds and positions that brought both an insider and outsider perspectives (Dahlgren, Emmelin & Winkvist, 2004). Findings were compared to control for interpretative bias. Coherence refers to how well the story sticks together. Focus is not on how the data was collected and on how the discussion between the researcher and informant was performed, but on how well the researcher presents the information of the informants and how true the analysis is to what the informants said. Based on our knowledge about the context and the careful process for data-collection and analysis we think these findings represent the situation of the women well.

CONCLUSIONS

Based on the findings described in this thesis, the key conclusions are:

- Children improve women's social status and a pregnancy means good health (II).
- Good health is a prerequisite for pregnancy and is perceived as physical strength to perform motherhood chores (II).
- Pregnancy is a woman's individual and private decision that could eventually include a partner but not health providers (II).
- A majority of antenatal attendees on their first visit take a HIV test but do not know that testing is optional (I).
- Stigma, disclosure and support for PMTCT vary in relation to socio-economic affiliation and residence (II-IV)
- Chronic illness, such as a HIV infection, creates dilemmas for women who want children and need to balance the needs of the child with their own health needs and with the expectations of being a 'good mother'.

The findings of this study have implications regarding the socio-cultural practices of childbearing and adherence to PMTCT services. They reveal that motherhood is important to women living with HIV because it gives status and conceals their infection – a hurdle to overcome when seeking motherhood. Being infected with HIV cannot remove the desire for motherhood and related socio-cultural demands. Therefore, failing to acknowledge the significance of socio-cultural practices during childbearing among women with HIV will affect adherence and might reverse the gains of PMTCT. Counseling about motherhood and institutional infrastructure for ART/PMTCT provision are important but not flexible enough to the reality of motherhood. Health systems need to have a greater openness and preparedness for the special needs of mothers who are HIV-infected. They depend on contacts with different parts in the health services and there is a need to increase the ability of the staff to cater for the special situation of motherhood by integrating the services for the newborn with those for the ART-recipients. More needs to be done to create awareness for laboratory indicators as a clinical criteria for good health outcomes and PMTCT staff need to be aware that women want to control the domain of childbearing but need enough information to make healthy choices without risking transmission to the unborn child or partner.

The findings of this study pertain to the situation for women with childbearing desires in Kenya, but also point to the more general dilemmas of chronically ill women who strive for motherhood.

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REFERENCES

- Agnarson, A. M., Ericson, J., Ekström, A. M. & Thorson, A. (2007). Antiretroviral therapy: what about food? *AIDS*, 21(9), 1225-1226.
- Allen, S., Serufilira, A., Gruber, V., Kegeles, S., Van de Perre, P., Carael, M., et al. (1993). Pregnancy and contraception use among urban Rwandan women after HIV testing and counselling. *American Journal of Public Health*, 83, 705-710.
- Angen, M. J. (2000). Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10(3), 378-395.
- Barden-O'Fallon, J. (2005). Unmet fertility expectations and the perception of fertility problems in a Malawian village. *African Journal of Reproductive Health*, 9(2), 14-25.
- Barroso, P. F., Schechter, M., Gupta, P., Bressan, C., Bomfim, A. & Harrison, L. H. (2003). Adherence to antiretroviral therapy and persistence of HIV RNA in semen. *Journal of Acquired Immune Deficiency Syndrome*, 32(4), 435-440.
- Bateganya, M., Colfax, G., Shafer, L. A., Kityo, C., Mugenyi, P., Serwadda, D., et al. (2005). Antiretroviral therapy and sexual behaviour: a comparative study between antiretroviral-naïve and -experienced patients at an urban HIV/AIDS care and research center in Kampala, Uganda. *AIDS PATIENT CARE and STDs*, 19(11), 760-768.
- Bayer, R. & Fairchild, A. L. (2006). Changing the paradigm for HIV testing--the end of exceptionalism. *New England Journal of Medicine*, 355(7), 647-649.
- BBC News. (2006, 2nd June,). 'Kenya to provide free AIDS drugs'. Retrieved July 4th, 2007.
- Bennett, R. (2007). Routine antenatal HIV testing and informed consent: an unworkable marriage? *Journal of Medical Ethics*, 33(8), 446-448.
- Bergström, S. (1992). Reproductive failure as a health priority in the Third World: a review. *East Africa Medical Journal*, 69(4), 174-180.
- Bertolli, J., St Louis, M. E., Simonds, R. J., Nieburg, P., Kamenga, M., Brown, C., et al. (1996). Estimating the timing of mother-to-child transmission of human immunodeficiency virus in a breast-feeding population in Kinshasa, Zaire. *Journal of Infectious Diseases*, 174(4), 722-726.
- Beyeza-Kashesya, J., Ekstrom, A. M., Kaharuza, F., Mirembe, F., Neema, S. & Kulane, A. (2010). My partner wants a child: a cross-sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda. *BMC Public Health*, 10(247).
- Beyeza-Kashesya, J., Kaharuza, F., Mirembe, F., Neema, S., Ekstrom, A. M. & Kulane, A. (2009). The dilemma of safe sex and having children: challenges facing HIV sero-discordant couples in Uganda. *African Health Sciences*, 9(1), 2-12.
- Black, R. E., Allen, L. H., Bhutta, Z. A., Caulfield, L. E., de Onis, M., Ezzati, M., et al. (2008). Maternal and child undernutrition: global and regional exposures and health consequences. *Lancet*, 371(9608), 243-260.
- Blackard, J. T. & Mayer, K. H. (2004). HIV superinfection in the era of increased sexual risk-taking. *Sexually Transmitted Diseases*, 31(4), 201-204.
- Bledsoe, C. (1990). Transformations in sub-Saharan African marriage and fertility. *Annals of the American Academy of Political and Social Science*, 510, 115-125.
- Boily, M. C., Godin, G., Hogben, M., Sherr, L. & Bastos, F. I. (2005). The impact of the transmission dynamics of the HIV/AIDS epidemic on sexual behaviour: a new hypothesis to explain recent increases in risk-taking behaviour among HIV positive gay men. *Medical Hypotheses*, (65), 215-226.

- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., et al. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR Recomm Rep*, 55 (RR-14), 1-17; quiz CE11-14.
- Bunnell, R., Ekwaru, J.P., Solberg, P., Wamai, N., Bikaako-Kajura, W. Were, W., et al. (2006). Changes in sexual behaviour and risk of HIV transmission after antiretroviral therapy and prevention interventions in rural Uganda. *Acquired Immune Deficiency Syndrome*, (20), 85-92.
- Burns, N. & Grove, S. K. (2005). *The Practice of Nursing Research, Conduct, Critique and Utilization*, Philadelphia: WB Saunders.
- Calves, A. E. (1999). Marginalization of African single mothers in the marriage market: Evidence from Cameroon. *Population Studies*, 53(3), 291-301.
- Central Bureau of Statistics. (2003). *Kenya Demographic and Health Survey 2003*.
- Central Intelligence Agency (US). (2010). The World Factbook- Kenya. Retrieved March 10th, 2011.
- Clark, S., Kabiru, C. & Mathur, R. (2010). RELATIONSHIP TRANSITIONS AMONG YOUTH IN URBAN KENYA. *Journal of Marriage and Family*, 72(1), 73-88.
- Coetzee, B., Kagee, A. & Vermeulen, N. (2011). Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers. *AIDS Care*, 23(2), 146-151.
- Colfax, G. N., Guzman, R., Wheeler, S., Mansergh, G., Marks, G., Rader, M., et al. (2004). Beliefs about HIV reinfection (superinfection) and sexual behavior among a diverse sample of HIV-positive men who have sex with men. *Journal of Acquired Immune Deficiency Syndrome*, 36(4), 990-992.
- Cooper, D., Harries, J., Myer, L., Orner, P., Bracken, H. & Zweigenthal, V. (2007). "Life is still going on": reproductive intentions among HIV-positive women and men in South Africa. *Social Science and Medicine*, 65(2), 274-283.
- Csete, J., Schleifer, R. & Cohen, J. (2004). "Opt-out" testing for HIV in Africa: a caution. *Lancet*, 363(9407), 493-494.
- Dahab, M., Charalambous, S., Hamilton, R., Fielding, K., Kielmann, K., Churchyard, G. J., et al. (2008). "That is why I stopped the ART": patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme. *BMC Public Health*, 8(63), doi:10.1186/1471-2458-1188-1163.
- Dahlgren, L., Emmelin, M. & Winkvist, A. (2004). *Qualitative Methodology for International Public Health*. Umeå, Sweden: Print and Media, Umeå University.
- Daniluk, J. (1997). Helping patients cope with infertility. *Clinical Obstetrics and Gynecology*, 40(3), 661-672.
- De Cock, K. M., Mbori-Ngacha, D. A. & Marum, E. (2002). Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *Lancet*, 360(9326), 67-72.
- Derlega, V. J., Lovejoy, D. & Winstead, B. A. (1998). Personal account of disclosing and concealing HIV- positive test results: Weighting the benefits and risks. In Derlega, V.J. & A.P. Barbee (Ed.), *HIV and Social Interactions* (pp 147-164). Thousand Oaks, CA: SAGE.
- Diamond, C. Richardson, J.L., Milam, J., Stoyanoff, S., McCutchan, J.A., Kempar, C. et al. (2005). Use of and adherence to antiretroviral therapy is associated with decreased sexual risk behaviour in HIV clinic patients. *Journal of Acquired Immune Deficiency Syndrome*, (39), 211-218.

- Dyer, S. J. (2004). 'You are a man because you have children': experiences, reproductive health knowledge and treatment-seeking behaviour among men suffering from couple infertility in South Africa. *Human Reproduction*, 19(4), 960-967.
- Dyer, S. J. (2007). The value of children in African countries: insights from studies on infertility. *Journal of Psychosomatic Obstetrics and Gynaecology*, 28(2), 69-77.
- El-Khatib, Z., Katzenstein, D., Marrone, G., Laher, F., Mohapi, L., Petzold, M., et al. (2011). Adherence to Drug-Refill Is a Useful Early Warning Indicator of Virologic and Immunologic Failure among HIV Patients on First-Line ART in South Africa. *PLoS One*, 6(3), e17518.
- Elford J. (2006). Changing patterns of sexual behaviours in the era of highly active antiretroviral therapy. *Current Opinion on Infectious Diseases*, (19), 26-32.
- Erulkar, A. S. & Matheka, J. K. (2007). *Adolescents in the Kibera slums of Nairobi Kenya*. Nairobi: Population Council.
- Frank, A. W. (1995). *The Wounded Storyteller Body, Illness, and Ethics*. London: The University of Chicago Press, Ltd.
- Frederiksen, B. F. (2010). Popular Culture, Gender Relations and the Democratization of Everyday Life in Kenya. *Journal of Southern African Studies*, 26(2), 209-222.
- Gerrits, T. (1997). Social and cultural aspects of infertility in Mozambique. *Patient Education and Counselling*, 31(1), 39-48.
- Ghimire, D. J., Axinn, W. G., Yabiku, S. T. & Thornton, A. (2006). Social change, premarital nonfamily experience, and spouse choice in an arranged marriage society. *American Journal of Sociology*, 111, 1181-1218.
- Goode, W. J. (1963). *World revolution and family patterns*. New York: Free Press.
- Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Greene, K., Derlega, V. J., Yep, G. A. & Petronio, S. (2003). *Privacy and disclosure of HIV in interpersonal relationships, a sourcebook for researchers and practitioners*, Mahwah, NJ: Lawrence Erlbaum.
- Gruskin, S., Firestone, R., Maccarthy, S. & Ferguson, L. (2008). HIV and pregnancy intentions: do services adequately respond to women's needs? *Am J Public Health*, 98(10), 1746-1750.
- Gulis, G., Mulumba, J. A., Juma, O. & Kakosova, B. (2004). Health status of people of slums in Nairobi, Kenya, *Environmental Research*, 96(2), 219-227.
- Halloway, I. (2008). *A-Z of Qualitative Research in Healthcare*, West Sussex: Blackwell Publishing.
- Hardon, A. P., Akurut, D., Comoro, C., Ekezie, C., Irunde, H. F., Gerrits, T., et al. (2007). Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa, *AIDS Care*, 19(5), 658-665.
- Hirsch, S. J. (2007). Gender, sexuality, and antiretroviral therapy: using social science to enhance outcomes and inform secondary prevention strategies, *Acquired Immune Deficiency Syndrome*, 21(5), 21-29.
- Hoffman, L. W. & Hoffman, M. L. (1973). The value of children to parents. In Fawcett JT (Ed.), *Psychological perspectives on population*, (pp. 19-76). New York: Basic Books.
- Hollos, M. (2003). Profiles of infertility in southern Nigeria: women's voices from Amakiri. *African Journal of Reproductive Health*, 7(2), 46-56.
- Homsy, J., Bunnell, R., Moore, D., King, R., Malamba, S., Nakityo, R., et al. (2009). Reproductive intentions and outcomes among women on antiretroviral therapy in rural Uganda: a prospective cohort study. *PLoS ONE*, 4(1), e4149.

- Homsy, J., King, R., Balaba, D. & Kabatesi, D. (2004). Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *AIDS*, 18(12), 1723-1725.
- Jones, G., Steketee, R. W., Black, R. E., Bhutta, Z. A., Morris, S. S. & Bellagio Child Survival Study Group. (2003). How many child deaths can we prevent this year? *Lancet*, 362(9377), 65-71.
- Kagee, A., Remien, R. H., Berkman, A., Hoffman, S., Campos, L. & Swartz, L. (2010). Structural barriers to ART adherence in Southern Africa: Challenges and potential ways forward. *Global Public Health*, 2010 May 2026:2011-2015. [Epub ahead of print].
- Kenya National Bureau of Statistics (KNBS) and ICF Macro. (2010). *Kenya Demographic and Health Survey 2008-09*. Calverton, Maryland: KNBS and ICF Macro.
- Kiarie, J. N. (2000). HIV-1 testing in pregnancy: acceptability and correlates of return for test results. *AIDS*, 14(10), 1468-1470.
- Kvale, S. (1996). *Inter Views - an introduction to qualitative research interviewing*. London: SAGE Publications.
- Laher, F., Todd, C. S., Stibich, M. A., Phofa, R., Behane, X., Mohapi, L., et al. (2009). A qualitative assessment of decisions affecting contraceptive utilization and fertility intentions among HIV-positive women in Soweto, South Africa. *AIDS Behavior*, (13 Suppl 1:47-54. Epub 2009 Mar 24).
- Lallemant, M., Jourdain, G., Le Coeur, S., Mary, J. Y., Ngo-Giang-Huong, N. Koetsawang, S., et al. (2004). Single-dose perinatal nevirapine plus standard zidovudine to prevent mother-to-child transmission of HIV-1 in Thailand. *The New England Journal of Medicine*, 351(3), 217-228.
- Larsson, E. C., Thorson, A., Pariyo, G., Conrad, P., Arinaitwe, M., Kemigisa, M., et al. (2010). Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda. *Health Policy Plan*, 2011 Feb 2013. [Epub ahead of print].
- Liamputtong, P., Yimiam, S., Parisunyakul, S., Baosoung, C. & Sansiriphun, N. (2005). Traditional beliefs about pregnancy and child birth among women from Chiang Mai, Northern Thailand. *Midwifery*, 21(2), 139-153.
- Lubega, M., Nsabagasani, X., Tumwesigye, N. M., Wabwire-Mangen, F., Ekström, A. M., Pariyo, G., et al. (2010). Policy and practice, lost in transition: Reasons for high drop-out from pre-antiretroviral care in a resource-poor setting of eastern Uganda. *Health Policy*, 95(2-3), 153-158.
- Lurie, M., Pronyk, P., de Moor, E., Heyer, A., de Bruyn, G., Struthers, H., et al. (2008). Sexual behavior and reproductive health among HIV-infected patients in urban and rural South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 47(4), 484-493.
- Malinowski, B. (1961). *Argonauts of the Western Pacific*. New York: E.P. Dutton.
- Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *Lancet*, 358(9280), 483-488.
- Maman, S. & King, E. (2008). Changes in HIV testing policies and the implications for women. *Journal of Midwifery and Women's Health*, 53(3), 195-201.
- Maman, S., Mbwapbo, J., Hogan, N. M., Kilonzo, G. P. & Sweat, M. (2001). Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counselling and testing. *AIDS Care*, 13(5), 595-603.

- Manzi, M., Zachariah, R., Teck, R., Buhendwa, L., Kazima, J., Bakali, E., et al. (2005). High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling-up requires a different way of acting. *Tropical Medicine and International Health*, 10(12), 1242-1250.
- Maxwell, J. A. (1996). *Qualitative research design: An interactive approach*. London: SAGE Publications.
- Miller, A. N. & Rubin, D. L. (2007). Motivations and methods for self-disclosure of HIV seropositivity in Nairobi, Kenya. *AIDS Behavior*, 11(5), 687-697.
- Mills, E. J., Nachega, J. B., Bangsberg, D. R., Singh, S., Rachlis, B., Wu, P., et al. (2006). Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine*, 3(11), e438.
- Mischler, E. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Moatti, J. P., Prudhomme, J., Traore, D. C., Juillet-Amari, A., Akribi, H. A., Msellati, P., et al. (2003). Access to antiretroviral treatment and sexual behaviours of HIV-infected patients aware of their serostatus in Côte d'Ivoire. *AIDS (London, England)*, 17 (Suppl.3), S69-S77.
- Morse, J. M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 220-235). Thousand Oaks: Sage.
- Morse, J. M. & Field, P. A. (1995). *Qualitative research methods for health professionals*. London: SAGE publications.
- Msellati, P. (2009). Improving mothers' access to PMTCT programs in West Africa: a public health perspective. *Social Science and Medicine*, 69(6), 807-812.
- Muhenje, O., Mbori-Ngacha, D. A., Akun, T. & De Cock, K. M. (2004). *Barriers to uptake of PMTCT services at the Provincial General Hospital, Kisumu, Kenya*. Paper presented at the XV International AIDS Conference; July 11-16, Bangkok, Thailand.
- Myer, L., Morroni, C. & Rebe, K. (2007). Prevalence and Determinants of Fertility Intentions of HIV-Infected Women and Men Receiving Antiretroviral Therapy in South Africa. *AIDS PATIENT CARE and STDs*, 21(4), 278-285.
- NASCOP. (2008). *Kenya AIDS Indicator Survey (KAIS) 2007: Preliminary report*. Nairobi, Kenya: Ministry of Health.
- National AIDS and STI Control Programme (NASCOP). (2008). *Kenya AIDS Indicator Survey (KAIS) 2007: Preliminary report*. Nairobi, Kenya: Ministry of Health.
- National AIDS Control Council. (2005). Retrieved November 10th, 2010
- Newell, M. L. (2003). Reducing childhood mortality in poor countries. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 97, 22-24.
- Ngomane, S. & Maludzi, F. M. (2010). Indigenous beliefs and practices that influence the delayed attendance of antenatal clinics by women in the Bohlabele district in Limpopo, South Africa. *Midwifery*, 2010 Dec 2019. [Epub ahead of print].
- Nyblade, L. C. & Ogden, J. (2005). Common at its core: HIV related stigma across contexts. May 14th 2007, from www.icrw.org
- O'Dempsey, T. J. (1988). Traditional belief and practice among the Pokot people of Kenya with particular reference to mother and child health: 2. Mother and child health. *Annals of Tropical Paediatric*, 8(3), 125-134.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Newbury Park, CA: Sage Publications, Inc.

- Pescosolido, B. A. (1992). Beyond rational choice: The social dynamics of how people seek help. *American Journal of Sociology*, 97(4), 1096-1138.
- Pescosolido, B. A. & Rubin, B. (2000). The Web of Group Affiliations Revisited: Social Life, Postmodernism, and Sociology. *American Sociological Review*, 65, 52-76.
- Quin, T. C. & Overbaugh, J. (2005). HIV/AIDS in women: An expanding disease. *Science*, 308(5728), 1582-1583.
- Ragnarsson, A., Thorson, A., Dover, P., Carter, J., Ilako, F., Indalo, D., et al. (2011). Sexual risk-reduction strategies among HIV-infected men receiving ART in Kibera, Nairobi. *AIDS Care*, 23(3), 315-321.
- Riessman, C. (1993). *Narrative analysis, Qualitative research methods 30*. Newbury Park, CA: SAGE Publications.
- Ritchie, J. & Lewis, J. (2003). *Qualitative Research Practice: A Guide for Students and Researchers*. Thousand Oaks, CA: SAGE Publications, Inc.
- Rodlach, A. (2007). *Witches, westerners and HIV: AIDS and cultures of blame in Africa*. Walnut Creek, CA: Left Coast Press.
- Runganga, A. O., Sundby, J. & Aggleton, P. (2001). culture, identity and reproductive failure in Zimbabwe. *Sexualities*, 4, 315-332.
- Sandelowski, M. (1991). Telling stories: narrative approaches in qualitative research. *Image - The Journal of Nursing Scholarship*, 23(3), 161-166.
- Seeley, J., Russell, S., Khana, K., Ezati, E., King, R. & Bunnell, R. (2009). Sex after ART: sexual partnerships established by HIV-infected persons taking anti-retroviral therapy in Eastern Uganda. *Culture Health and Sexualities*, 11(7), 703-716.
- Serour, G. I., El Ghar, M. & Mansour, R. T. (1991). Infertility: a health problem in the Muslim world. *Population Sciences*, 10, 41-58.
- Setel, P. (1996). AIDS as a paradox of manhood and development in Kilimanjaro, Tanzania. *Social Science and Medicine*, 43(8), 1169-1178.
- Setel, P. (1999). *A plague of paradoxes: AIDS, culture and demography in northern Tanzania*. Chicago: University of Chicago Press.
- Simmel, G. (1955). *Conflict and the web of group affiliations*. New York: Free Press.
- Smith, D.J. (2004). Premarital sex, procreation, and HIV risk in Nigeria. *Studies in Family Planning*, 35(4), 223-235.
- Smith, D. J. & Mbakwem, B. C. (2007). Life projects and therapeutic itineraries: marriage, fertility, and antiretroviral therapy in Nigeria. *AIDS*, 21(5), 37-41.
- Smith, D. J. & Mbakwem, B. C. (2010). Antiretroviral therapy and reproductive life projects: mitigating the stigma of AIDS in Nigeria. *Social Science and Medicine*, 71(2), 345-352.
- Sonko, S. (1994). Fertility and culture in sub-Saharan Africa: a review. *International Social Science Journal*, 141, 397-411.
- Stainton, R. W. (a) (2003). *What is a child?* In: *Understanding Childhood* (Woodhead, M., Montgomery, H. (eds.)). Chichester: Wiley & Sons Ltd.
- Stige, B., Malterud, K. & Midtgarden, T. (2009). Toward an agenda for evaluation of qualitative research. *Qualitative Health Research*, 19(10), 1504-1516.
- Stolte, I. G., Dukers, N. H., Gekus, R. B., Coutinho, R. A. & de Wit, J. B. (2004). Homosexual men change to risky sex when perceiving less threat of HIV/AIDS since availability of highly active antiretroviral therapy: a longitudinal study. *AIDS (London, England)*, 18(2) 303-309.
- Thior, I., Lockman, S., Smeaton, L. M., Shapiro, R. L., Wester, C., Heymann, S. J., et al. (2006). Breastfeeding plus infant zidovudine prophylaxis for 6 months vs formula feeding plus infant zidovudine for 1 month to reduce mother-to-child

- HIV transmission in Botswana: a randomized trial: the Mashi Study. *The Journal of the American Medical Association*, 296(7) 794-805.
- Twehaze, J. (2009). *Disclosure and silence*. Paper presented at the Prolonging life, challenging religion conference.
- UNAIDS. (2009). 2009 AIDS Epidemic Update Report. Retrieved December 11th, 2009
- UNAIDS. (2010). UNAIDS Report on the global AIDS Epidemic. Retrieved December 17th, 2010
- UNGASS. (2008). Country Report-Kenya. Retrieved December 16th, 2010
- UNGASS. (2010). Country Progress report-Kenya. Retrieved December 18th, 2010
- Unge, C., Ragnarsson, A., Ekstrom, A. M., Indalo, D., Belita, A., Carter, J., et al. (2011). The influence of traditional medicine and religion on discontinuation of ART in an urban informal settlement in Nairobi, Kenya. *AIDS Care*, 2011 Mar. 2010:2011-2018. [Epub ahead of print].
- United Nations. (2002). *HIV/AIDS and fertility in sub-Saharan Africa: A Review of the research literature*: Population division, Department of Economic and Social Affairs, United Nations Secretariat. ESA/P/WP.174.
- van Balen, F. (2001). *Coping with infertility. Sexual and reproductive health*. New Delhi: New Age International Limited Publishers.
- Vanable, P.A., Ostrow, D.G. & McKirnan, D.J. (2003). Viral load and HIV treatment attitudes as correlates of sexual risk behaviour among HIV- positive gay men. *Journal of Psychom Resistance*, (54), 263-269.
- Volmink, J., Siegfried, N. L., van der Merwe, L. & Brocklehurst, P. (2007). Antiretrovirals for reducing the risk of mother-to-child transmission of HIV infection. *Cochrane database of systematic reviews*, 24(1), CD003510.
- Weiser, S. D., Heisler, M., Leiter, K., Percy-de Korte, F., Tlou, S., DeMonner, S., et al. (2006). Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Med*, 3(7), e261.
- WHO. (2010). *ANTIRETROVIRAL DRUGS FOR TREATING PREGNANT WOMEN AND PREVENTING HIV INFECTION IN INFANTS. Recommendations for a public health approach 2010 version*. Geneva: WHO.
- WHO & UNAIDS. (2007). *Guidance on provider-initiated HIV testing and counselling in health facilities*, Geneva: WHO.
- WHO/UNAIDS/UNICEF. (2009). Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report. Retrieved October 14th, 2009
- WHO/UNAIDS/UNICEF. (2010). Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector - Progress Report 2010. Retrieved October 12th, 2010
- Yebei, V. N. (2000). Unmet needs, beliefs and treatment-seeking for infertility among migrant Ghanaian women in the Netherlands. *Reproductive Health Matters*, 8(16), 134-141.
- Zaba, B. & Gregson, S. (1998). Measuring the impact of HIV on fertility in Africa. *AIDS*, 12(Suppl 1), S41-50.
- Zijenah, L. S., Moulton, L. H., Iliff, P., Nathoo, K., Munjoma, M. W., Mutasa, K., et al. (2004). Timing of mother-to-child transmission of HIV-1 and infant mortality in the first 6 months of life in Harare, Zimbabwe. *AIDS*, 18(2), 273-280.
- Zulu, E. M., Dadoo, F. N. A. & Ezech, A. C. (2003). Urbanization, poverty and sex: Roots of risky sexual behaviour in slum settlements in Nairobi, Kenya. In E. Kalipeni, S. Craddock, J. Oppong & J. Ghosh (Eds.), *HIV/AIDS in Africa: Beyond epidemiology*, (pp. 167-174). Oxford: Blackwell Publishers.

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RESEARCH ARTICLE

Open Access

Is 'Opt-Out HIV Testing' a real option among pregnant women in rural districts in Kenya?

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Abstract

Background: An 'opt-out' policy of routine HIV counseling and testing (HCT) is being implemented across sub-Saharan Africa to expand prevention of mother-to-child transmission (PMTCT). Although the underlying assumption is that pregnant women in rural Africa are able to voluntarily consent to HIV testing, little is known about the reality and whether 'opt-out' HCT leads to higher completion rates of PMTCT. Factors associated with consent to HIV testing under the 'opt-out' approach were investigated through a large cross-sectional study in Kenya.

Methods: Observations during HIV pre-test information sessions were followed by a cross-sectional survey of 900 pregnant women in three public district hospitals carrying out PMTCT in the Busia district. Women on their first antenatal care (ANC) visit during the current pregnancy were interviewed after giving blood for HIV testing but before learning their test results. Descriptive statistics and multivariate regression analysis were performed.

Results: Of the 900 women participating, 97% tested for HIV. Lack of testing kits was the only reason for women not being tested, i.e. nobody declined HIV testing. Despite the fact that 96% had more than four earlier pregnancies and 37% had been tested for HIV at ANC previously, only 17% of the women surveyed knew that testing was optional. Only 20% of those surveyed felt they could make an informed decision to decline HIV testing. Making an informed decision to decline HIV testing was associated with knowing that testing was optional (OR = 5.44, 95%CI 3.44-8.59), not having a stable relationship with the child's father (OR = 1.76, 95%CI 1.02-3.03), and not having discussed HIV testing with a partner before the ANC visit (OR = 2.64 95%CI 1.79-3.86).

Conclusion: High coverage of HIV testing appears to be achieved at the cost of pregnant women not understanding that testing is optional. Good quality HIV pre-test information is central to ensure that pregnant women understand and accept the reasons for testing and will thus come back to collect their test results, an important prerequisite for completing PMTCT for those who test HIV-positive.

Background

The World Health Organization (WHO) and the joint United Nations program on HIV/AIDS (UNAIDS) revised the guidelines for HIV testing in 2007 [1]. The current guidelines were designed to increase coverage of testing and identify patients in need of antiretroviral therapy (ART). In the former 'opt in' HIV strategy, the initiative to be tested was with the individual, not with the health care services, and individual pre-test counseling followed by informed consent was required before testing. In some areas, people were even required to

sign a separate informed consent form, which detailed the risks and benefits of being tested [2]. With the new 'opt-out' strategy, individuals have to actively opt out or decline the HIV test after a pre-test information session, often carried out in a group, while post-test counseling is still carried out on an individual basis for all clients.

The implications of provider-initiated HIV testing greatly affect women in sub-Saharan Africa (SSA) where they account for nearly 60% of those infected with HIV and where 75% of those living with HIV are between 15-24 years [3]. Women have more contact with the health services e.g. during pregnancy [4] and are thus more likely to undergo HIV screening [5], but it has been observed that consent may be compromised in

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SSA, which negatively affects women's autonomy and possibly also completion of PMTCT [6,7].

The shift from 'opt in'/client-initiated to 'opt out'/provider-initiated HIV testing has generated a debate on how to best increase the uptake of HIV testing while, at the same time, protect individual rights to voluntary consent for HIV testing [1]. Proponents of "opt out" assert that the provider-initiated consent process is crucial to achieve high coverage of HIV testing and prevention of mother-to-child transmissions (PMTCT) while it still protects autonomy [8]. It also helps the 'streamlining' of HIV into 'normal care' thereby decreasing the stigma [8,9].

Those who question the 'streamlined' consent process express doubt about whether informed consent can be ensured in the context of routinely offered HIV testing under conditions of scarce human resources [10,11]. Power differences in the provider-client relationship is also identified as a problem, since it is uncertain whether clients who normally have a lower social status will feel able to opt out of testing against the recommendation of their providers [6]. Others are concerned about the client's ability to provide voluntary consent and to what extent any choice will be presented given that providers are encouraged to motivate clients to test and could be coercive [6]. Women in particular are often also unable to make decisions independently due to gender inequality and lack of knowledge [3,12]. Finally, and most important from a public health perspective, there is concern that pregnant women who fail to make an informed choice about HIV testing are less likely to come back for their test results, an obvious prerequisite for identifying and enrolling HIV-infected women in the PMTCT program, thus undermining the quality and effectiveness of this important intervention [5,13]. A study from Botswana showed that pregnant women felt compelled to test when it was routinely offered and some instead exerted their decision-making power by not returning to collect their test results [13].

Kenya introduced routine rapid 'opt out' HIV testing at antenatal care (ANC) in 2007 [14]. Approximately 76 000 pregnant women are living with HIV in Kenya, thus ranking it sixth among the ten African countries that contribute 67% of the global burden of MTCT [15]. Up to 40% of all pregnant women enrolled in ANC programs in Busia district in western Kenya are estimated to not come back for their test results and will thus never be enrolled into PMTCT (personal communication). Pregnant women and their infants in these two rural districts are considered to be highly vulnerable to MTCT due to the high HIV prevalence (9%) and high fertility rate (7.1) compared to the national average of 7% and 5.1 respectively [14]. This study aims to identify factors associated with consent to HIV testing under the 'opt out' strategy in this area in rural Kenya.

Methods

Study area

This study was performed in Busia district located in western Kenya. This rural district has five administrative divisions with a population estimated at 415 000. The study catchment area has a population of 202 348 living in 312 villages, with 50 000 women of reproductive age and 38 000 children less than five years of age. Surveillance studies at ANC show HIV infection rates close to 10% [14]. Agriculture, fishing and small-scale commercial undertakings are the main economic activities in the district where the average household generates approximately \$84 per month. The majority ethnic group is Luhya with a few Luo speakers. There are 22 health facilities in the study area that are private, mission-run or government-owned. About 90% of these facilities offer free rapid HIV testing services except for a few dispensaries that refer patients to health centers or district hospitals for testing.

The study was carried out at three public district hospitals collaborating with non-governmental organizations (NGOs) on PMTCT and ART. In all three hospitals, PMTCT and ART have been provided free-of-charge since 2005 to all women in need in line with the WHO treatment guidelines from 2007. According to the new 'opt out' guidelines implemented in 2007, all pregnant women should participate in a HIV pre-test information group session, followed by rapid 'opt out' HIV testing and individual post-test counseling at their first ANC visit. For pregnant women who test positive for HIV, a CD4 cell count is done to determine whether ART should be initiated or if a single dose of nevirapine during labor is enough (short course combination treatment during pregnancy and breastfeeding has not yet been implemented in Busia district as of end 2010). HIV-infected women should be individually counseled regarding hospital delivery, safe infant feeding and contraceptive use.

Study design, sampling and participants

The study included twelve sit-in observations of counseling sessions for pregnant women and a large cross-sectional survey among pregnant women. The observations were performed by the first author, who is of Kenyan origin and fluent in the local languages spoken in the area, during two randomly selected weekdays and with four visits at each facility.

For the cross-sectional assessment, 900 women who were on their first visit to ANC for the current pregnancy were recruited consecutively between August and December 2008. All women in the three hospitals received the same information during the routine pre-test information sessions that followed the Kenyan guidelines on PMTCT. A midwife informed them about

the study in the ANC reception area during a session on general hygiene. Those willing to participate met the midwife, gave informed consent and were enrolled into the study. No woman among those approached declined to participate and no participant had been informed of her HIV test results before the interview. The sample included all pregnant women who were tested in the three hospitals within the timeframe.

Data collection

Notes were taken during the observations about the setting for the pre-test counseling session, the content of the session and of how the information about HIV testing was given. The interviewer-administered structured questionnaire contained both closed and open-ended questions in Kiswahili or Luhya. Data was collected on socio-demographic characteristics, relationship factors, awareness and knowledge about MTCT and PMTCT and experiences of the group counseling session and the HIV testing. The Kenya Medical Research Institute (KEMRI) and the regional ethics board of Karolinska Institute approved this study.

Data analysis

The observations were compared and evaluated against the Kenya pre-test guidelines of the 'opt out' approach after each observed session.

For the cross-sectional data analysis, data were analyzed using SPSS-PASW, version 18 (SPSS, Inc., Chicago, IL). Descriptive statistics were used to summarize all variables of interest in the study population.

The outcome variable "making an informed decision to decline HIV testing" was derived from the question 'If you could choose to HIV test or not, would you decline? (Yes/No)'. Independent variables that were used to model the outcome variable included; *type of union* - 'What is your marital status? (Married/Unmarried)', *duration of current sexual relationship* - 'How long have you been in the current relationship? (Not in a relationship, ≤ 4 years and > 4)', *stable relationship with the child's father* - 'Do you live together with the child's father? (Yes/No)', *knowing HIV testing is optional* - 'Do you know that you can choose to HIV test or not? (Yes/No)', *tested for HIV* - 'Have you tested for HIV at this visit? (Yes/No)', *discussing HIV testing with the partner before the ANC visit* - 'Have you discussed HIV testing with your partner before this ANC visit? (Yes/No) and *knowing testing is performed at ANC before the visit* - 'Did you know that HIV testing is done at ANC before coming today? (Yes/No)'

The estimated prevalence of "making an informed decision to decline HIV testing" was reported as a percentage. It is important to note that the outcome variable "making an informed decision to decline HIV

testing" implies making a decision about whether to consent to HIV testing or not after awareness i.e. the actual decision of women who knew that HIV testing is optional as well as the perceived decision among those who did not know that testing is optional, had they known that this was the case.

The association between "making an informed decision to decline HIV testing" and each categorical independent variable was first assessed using Chi-square or, when the number in the contingency tables was too small, Fisher's exact test. Independent variables with a p-value of < 0.20 associated with the outcome at the bivariate level were entered into multiple logistic regression models with the exception of age, education and occupation level that were included regardless of p-value in order to adjust for potential residual confounding linked to the main independent variables. Both backwards and forward logistic regression (Wald test) was performed and gave almost similar result. P-values < 0.05 (2-sided test) were considered significant in the final model. Odds ratios (ORs) and their 95% confidence intervals (CI) were computed. The final multivariate model was tested for goodness of fit with the Hosmer-Lemeshow test.

Results

Observations during pre-test information session at group level

The setting of the pre-test counseling session

Pre-test counseling sessions were provided to groups of 10-15 pregnant women in a separate space. There were between three and four information sessions per day at each facility. The sessions normally took 45-50 minutes and were mainly performed in the national language Kiswahili and translated simultaneously into the local dialect of Luhya. Female midwives greeted the audience and introduced themselves when starting the session. The pregnant women were told that they could ask questions during the session in case they wanted to know more, but no woman asked any question or sought clarification at any of the sessions observed. The pregnant women nodded unanimously when the midwife sought to stress the benefits of HIV testing as shown below.

Midwife: Do you mothers agree that it is important to test for HIV and protect the unborn child?

Women: (nodding) yes (in a group).

The content of the pre-test counseling session

The information included a description of HIV and AIDS, modes of HIV transmission from a pregnant woman to their child during and after pregnancy, the importance of HIV testing for a diagnosis, secondary prevention of HIV transmission to uninfected male

partners and the PMTCT program (single dose nevirapine tablets for the mother and syrup for the infant during a six week period after delivery; skilled hospital delivery; and options of exclusive breastfeeding or formula feeding).

Information provided about HIV testing

The women were given information about the importance of HIV testing and of learning about their HIV status, and also the status of their partner. Women were not required, but encouraged, to bring their partners in to be HIV tested as well. The importance of having an uninfected baby was emphasized as well as the fact that testing was important in the first trimester of pregnancy. In all the sessions the midwives' undertone was motivational and the message was that testing and knowing one's HIV status was the best decision a mother could make for her unborn child. No information was provided stating that it was an individual and voluntary choice of the woman to decline or accept HIV testing. The midwives referred to the women as 'mothers' and emphasized that it was their responsibility to take the HIV test to protect the baby and have a healthy and virus-free child. When asked by the main author about reasons for not requiring women to bring their partners for HIV testing, the midwives said that men who really loved their women normally accompanied them to ANC to test of their own free will and did not need to be asked to come.

Cross-sectional survey of 900 pregnant women

Table 1 shows socio-demographic characteristics and HIV testing information of the 900 women enrolled in the study.

The median age was 20 years (inter-quartile range 5). The majority of the women (96%) had already had more than four pregnancies including the current one, although 73% were in a relationship of less than four years. About 90% had a stable relationship with the child's father. Eighty percent were in a formal union. About 85% had eight or less years of formal education and 18% were employed. Slightly over one-third (37%), had previously been tested for HIV at ANC using the 'opt-out' approach.

Lack of testing kits was the only reason for women not to be tested i.e., no woman declined HIV testing and nearly all were tested for HIV (97%). About 73% knew that HIV testing was done at ANC before coming there and 69% had discussed the test with their partner before the visit. Following the pre-test counseling session, 90% (N = 810) claimed they had understood the information, but only 17% had grasped that HIV testing was optional, 95% were aware of MTCT and 91% had understood that preventing transmission was possible. The reasons given by the 10% (N = 90) women who

reported not understanding most of the pre-test information included: the counselor speaking too fast (N = 45), using complicated terms (N = 27) and difficult language (N = 18).

Only 20% (N = 180) of the women said they would make an informed decision to decline HIV testing. After adjusting for all potential confounding factors listed in Table 1, only three factors remained independently associated with an increased likelihood of making an informed decision to decline HIV testing in the final multivariate model: knowing that testing was optional, not having a stable relationship with the child's father and not having discussed HIV testing with a partner before the ANC visit. Knowing that testing was optional was the strongest predictor for women saying that they would make an informed decision to decline HIV testing (OR = 5.44, 95% CI 3.44-8.59). Women not in a stable relationship with the child's father were more likely to perceive that they would make an informed decision to decline HIV testing (OR = 1.76, 95% CI 1.02-3.03). Not having discussed HIV testing with a partner before the ANC visit also doubled the likelihood for women saying that they would make an informed decision to decline HIV testing (OR = 2.63, 95% CI 1.79-3.86).

Age, occupation and education level were not statistically significant factors but kept in the final model to adjust for residual confounding often associated with these fundamental variables (Table 2). The number of pregnancies both as a categorical and a continuous variable was not significantly associated with the outcome, probably because only one third had been HIV tested before (OR = 1.96, 95% CI 0.63-6.09).

Discussion

None of the 900 pregnant women included in this study declined HIV testing under the routine 'opt-out' approach. A majority (83%) had not understood that HIV testing was optional and only one in five stated that they would have been able to make an informed decision to decline HIV testing. This is a fundamental shortcoming of unclear pre-test information, which undermines the assumption of voluntary consent. Thus with the current approach, high coverage of HIV testing at ANC may be achieved at the cost of women not understanding that testing is optional and at the risk of low uptake and completion of PMTCT which is a major problem not only in this area, where between 30%-40% of all pregnant women enrolled in ANC programs are estimated to not come back for their test results (personal communication by David Wamalwa project manager for Busia Child Survival Project), but also documented in other parts of SSA [16,17].

The midwives did provide correct information regarding the importance of HIV testing in the first trimester

Table 1 Socio-demographic characteristics and HIV related data of 900 pregnant women

Characteristic		'Making an informed decision to decline HIV testing'		Total N (column %)
		N (row %)	N (row %)	
All women		Yes 180 (20%)	No 720 (80%)	900 (100%)
Age (years)	≤20	100 (20%)	388 (80%)	488 (54%)
	>20	80 (19%)	332 (81%)	412 (46%)
Number of pregnancies including current	≤4 pregnancies	4 (10%)	36 (90%)	40 (4%)
	>4 pregnancies	176 (20%)	684 (80%)	860 (96%)
In stable relationship with child's father	Yes	151 (19%)	660 (81%)	811 (90%)
	No	29 (33%)	60 (67%)	89 (10%)
Type of union	Married	133 (18%)	589 (82%)	722 (80%)
	Unmarried	47 (26%)	131 (74%)	178 (20%)
Duration of current relationship (years)	Not in a relationship	12 (36%)	21 (64%)	33 (4%)
	≤4	134 (20%)	525 (80%)	659 (73%)
	>4	34 (16%)	174 (84%)	208 (23%)
Formal education (years)	Never in school	29 (22%)	102 (78%)	131 (15%)
	≤8	142 (20%)	572 (80%)	714 (79%)
	>8	9 (16%)	46 (84%)	55 (6%)
Occupation	Employed	31 (20%)	127 (80%)	158 (18%)
	Unemployed	149 (20%)	593 (80%)	742 (82%)
HIV tested	Yes	172 (20%)	700 (80%)	872 (97%)
	No*	8 (29%)	20 (71%)	28 (3%)
Aware of MTCT after pre-test counseling	Yes	161 (19%)	685 (81%)	846 (94%)
	No	19 (35%)	35 (65%)	54 (6%)
Aware of PMTCT after pre-test counseling	Yes	160 (20%)	658 (80%)	818 (91%)
	No	20 (24%)	62 (76%)	82 (9%)
Aware that HIV testing is done at ANC before visit	Yes	106 (16%)	548 (84%)	654 (73%)
	No	74 (30%)	172 (70%)	246 (27%)
Discussed HIV testing with the partner before ANC visit	Yes	101(16%)	520 (84%)	621 (69%)
	No	49 (18%)	230 (82%)	279 (31%)
Knew that HIV testing is voluntary	Yes	71 (47%)	79 (53%)	150 (17%)
	No	109 (15%)	641 (85%)	750 (83%)
Tested for HIV at ANC previously	Yes	68 (20%)	264 (80%)	332 (37%)
	No	112 (20%)	456 (80%)	568 (63%)
Understood pre-test counseling	Yes	140 (17%)	670 (83%)	810 (90%)
	No	40 (44%)	50 (56%)	90 (10%)

*HIV testing kits were lacking.

of pregnancy, but the great majority of women (83%) never understood that it was optional. By saying that testing was 'the best decision a mother could make for her unborn child' the midwives clearly revealed their expectations and left little room for the women to act otherwise. This finding is consistent with another study performed in Kenya showing that women accept HIV testing so as to avoid being perceived as not accepting the message of the midwives [7]. Our findings showed that it was difficult for the providers to remain neutral when informing about routine HIV testing. During the observed counseling sessions the midwives referred to the women as 'mothers' thereby highlighting the

importance of the baby. The reason given during the sessions for having the test was the need to protect the child, while nothing was said about HIV testing being optional. From a public health perspective it is important that the women understand and accept the reasons for testing, since this increases enrolment in and adherence to PMTCT.

The high number of women counseled simultaneously under the opt-out approach made meaningful interaction difficult and for the midwives it was consequently easiest to provide information using a top-down approach. This approach could be justified as it reduced waiting time for the many women visiting ANC, in a

Table 2 Factors included in the final multivariate model analyzing the association with 'making an informed decision to decline HIV testing' among 900 pregnant women

Factor		Crude analysis		Adjusted analysis
		p-value	OR (95% CI)	OR (95% CI)
In stable relationship with child's father	Yes		1	
	No	0.002*	2.11 (1.31 - 3.41)	1.76 (1.02 - 3.03)
Discussed testing with partner before ANC visit	Yes		1	
	No	<0.001*	2.65 (1.89 - 3.71)	2.64 (1.79 - 3.86)
Knew HIV testing is voluntary	No		1	
	Yes	<0.001*	5.29 (3.62 - 7.72)	5.44 (3.44 - 8.59)
Age (years)	≤ 20		1	
	> 20	0.513	1.07 (0.87 - 1.32)	1.09 (0.41 - 2.92)
Occupation	Unemployed		1	
	Employed	0.895	1.03 (0.67 - 1.59)	1.05 (0.65 - 1.71)
Formal education	Never in school		1	
	≤ 8 years	0.542	1.26 (0.60 - 2.63)	1.19 (0.54 - 2.63)
	> 8 years	0.309	1.53 (0.67 - 3.49)	1.49 (0.61 - 3.63)

*p-value < 0.05.

situation where pre-test counseling is the first step before receiving other services of ANC. However, the current set-up makes most women believe that HIV testing is a prerequisite for obtaining other ANC services. To avoid this, the information needs to not only discuss the benefits of the testing, but also its implications and the importance of the post-test counseling. Our findings showed that 83% of the women perceived testing as a mandatory part of ANC services, not as a service independent of antenatal care. This finding could be attributed to unclear delivery of pre-test information and is consistent with observations that poor counseling prevents pregnant women from making informed decisions about HIV testing.

Only 20% of the women felt they would have been able to make an informed decision to decline HIV testing. This is a remarkably low proportion, given that more than a third also had been tested for HIV at ANC before. Although none among the 900 women declined the test, a majority seemed to have accepted it because they felt obliged to. An explanation for the misconception could be the power difference between the midwives and the pregnant women. Midwives are trusted and have high social status among pregnant women. In a recent qualitative study exploring reasons for adherence to PMTCT in the same setting we found that HIV-infected pregnant women trusted the midwives to keep their HIV diagnosis secret from the mother-in-law at least during pregnancy appointments (data not yet published).

Our findings showed that a great majority of the women had started childbearing at an early age and that 85% of the women had eight years or less of schooling. Possibly many women accepted to have the HIV test

because they perceived the midwife to be more knowledgeable and to know best. They seemed not to understand the importance of their own active involvement in accepting or declining the HIV testing and the consequences of having the test. This is consistent with observations that patients in SSA accept to follow recommendations from health providers without fully understanding the consequences of their action as was observed in, for example, Botswana [13]. The implications for HIV testing could be that pregnant women accept to be HIV tested but fail to return for the test results as they realize that they are unprepared for the consequences. Failure to return for results or drop out from PMTCT has been documented from SSA [16,17]. Unfortunately, we were not able to follow the women through the PMTCT process to assess the completion rate, but as mentioned above, a high proportion of pregnant women in this area are reported to never pick up their test results. The rapid test results are available within a quarter of an hour, and so failure to come for them strongly indicates that many women were not ready to face the consequences of a positive test result. They exerted their decision-making power in a more socially acceptable way by dropping out directly after testing. For improved access to and completion of PMTCT pregnant women need to understand the process of testing and voluntarily and consciously consent to HIV testing [18].

In a qualitative study in the Kibera slum in Nairobi exploring the reasons for becoming pregnant among women on ART, we found that women planned to become pregnant to strengthen their sexual relationships and possibly formalize them [19]. In this study the women who did not discuss with their partners felt

more able to decline testing, as did those in unstable relationships. These women live in a more insecure situation and lack support to handle the test results, while those in stable relationships and those who have discussed the testing know that they will have support irrespective of the test-results. Couple testing is often promoted as a means to increase male partner support. However, the state of the relationship between a woman and her partner influences the decision-making of the woman in relation to testing. Perceived negative consequences of an HIV diagnosis, such as partner abandonment, isolation and loss of financial support, may be an important reason for women to test alone, to decline picking-up their test results or to avoid HIV testing altogether. This study shows the importance of having a secure relationship and a supportive environment before the testing. A recent study in rural Uganda showed that pregnant women often feel heavily burdened by partner disclosure and couple testing recommendations in relationships where they feel disempowered and dependant on their male partner [20]. It becomes necessary to understand individual women's sexual relationships and dependencies on men in order to improve acceptance of HIV testing and also enrolment and completion of PMTCT.

The likelihood of selection bias was low since ANC attendance is high in Kenya, about 90% visit ANC at least once, and one can assume that our participants represent of a majority of pregnant women in this area. The hospitals included in this study are NGO-affiliated and one can assume that the quality of care is similar across the PMTCT programs.

Conclusion

High coverage of HIV testing appears to be achieved at the cost of pregnant women's lack of knowledge that testing is optional. Good quality HIV pre-test counseling is central for making pregnant women understand and accept the reasons for testing and encourage consent to HIV testing, an important prerequisite for the consequent completion of the PMTCT program by those who are HIV infected. While provider-initiated HIV testing is necessary to increase the number of women who access PMTCT and ART, caution must be taken to actively involve the woman during the consent process, to respect their autonomy and improve the enrollment and completion of PMTCT. Intensive community campaigns are warranted to raise awareness of the HIV testing being performed at ANC and the reasons why it is being carried out, to sensitize the community and make them better prepared to make informed decisions. Health authorities could collaborate with NGOs to disseminate information, improve education and increase communication at household level in rural areas to

supplement human and material resources shortages. More work is needed to understand how best to develop testing policies that both protect the voluntary consent process and expand testing to increase the implementation of functioning PMTCT-programs in areas with high HIV prevalence in SSA.

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Authors' contributions

OAU is the main author of the manuscript and involved in all aspects of the study. AME and BR provided scientific expertise and feedback throughout the development of the study and manuscript. FI was involved in the conceptualization of the idea, tool development and reading and editing of the manuscripts. GM provided statistical support, supervised the analysis and edited the paper. GW and DW were involved during preparations and pre-test of the survey, data collection and reading and editing of the manuscript. All co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

Competing interests

The authors declare that they have no competing interests.

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References

1. WHO & UNAIDS: Guidance on provider-initiated HIV testing and counselling in health facilities. Edited by: W. UNAIDS. Geneva; 2007.
2. Branson BM, et al: Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR Recomm Rep* 2006, **55**(RR-14):1-17, quiz CE1-4.
3. Quin TC, Overbaugh J: HIV/AIDS in women: An expanding disease. *Science* 2005, **308**(5728):1582-3.
4. Gruskin S, Ahmed S, Ferguson L: Provider-initiated HIV testing and counseling in health facilities—what does this mean for the health and human rights of pregnant women? *Dev World Bioeth* 2008, **8**(1):23-32.
5. Msellati P: Improving mothers' access to PMTCT programs in West Africa: a public health perspective. *Soc Sci Med* 2009, **69**(6):807-12.
6. Maman S, King E: Changes in HIV testing policies and the implications for women. *J Midwifery Womens Health* 2008, **53**(3):195-201.
7. Kiarie JN: HIV-1 testing in pregnancy: acceptability and correlates of return for test results. *AIDS* 2000, **14**(10):1468-70.
8. De Cock KM, Mbori-Ngacha DA, Marum E: Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *Lancet* 2002, **360**(9326):67-72.
9. Bayer R, Fairchild AL: Changing the paradigm for HIV testing—the end of exceptionalism. *N Engl J Med* 2006, **355**(7):647-9.
10. Bennett R: Routine antenatal HIV testing and informed consent: an unworkable marriage? *J Med Ethics* 2007, **33**(8):446-8.
11. Csete J, Schleifer R, Cohen J: "Opt-out" testing for HIV in Africa: a caution. *Lancet* 2004, **363**(9407):493-4.
12. Maman S, et al: Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counselling and testing. *AIDS Care* 2001, **13**(5):595-603.

13. Weiser SD, et al: Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Med* 2006, **3**(7):e261.
14. NASCOP: Kenya AIDS Indicator Survey 2007. Ministry of Health, Kenya.: Nairobi; 2008.
15. Global Fund: Switching from Monotherapy and Scaling Up Combination Treatment for PMTCT. Presentation to Regional and Technical Teams. 2010 [<http://www.theglobalfund.org/en/regionalmeetings/sa/malawi2009>], cited 2010 February 14th.
16. Manzi M, et al: High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling-up requires a different way of acting. *Trop Med Int Health* 2005, **10**(12):1242-50.
17. Perez F, et al: Acceptability of routine HIV testing ("opt-out") in antenatal services in two rural districts of Zimbabwe. *J Acquir Immune Defic Syndr* 2006, **41**(4):514-20.
18. Sarker M, et al: Determinants of HIV counselling and testing participation in a prevention of mother-to-child transmission programme in rural Burkina Faso. *Trop Med Int Health* 2007, **12**(12):1475-83.
19. Awiti Ujiji O, et al: "I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya - a qualitative study. *BMC Womens Health* 2010, **10**:13, 2010.
20. Larsson EC, et al: Mistrust in marriage-Reasons why men do not accept couple HIV testing during antenatal care - a qualitative study in eastern Uganda. *BMC Public Health* 2010, **10**:769, p. 2010.

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II

RESEARCH ARTICLE

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"I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study

Opondo Awiti Ujiji^{*1}, Anna Mia Ekström¹, Festus Ilako², Dorcas Indalo³ and Birgitta Rubenson¹

Abstract

Background: The African Medical Research Foundation antiretroviral therapy program at the community health centre in Kibera counsels women to wait with pregnancy until they reach the acceptable level of 350 cells/ml CD4 count and to discuss their pregnancy intentions with their health care providers. A 2007 internal assessment showed that women were becoming pregnant before attaining the 350 cells/ml CD4 count and without consulting health care providers. This qualitative study explored experiences of intentionally becoming pregnant among women receiving highly active antiretroviral therapy (HAART).

Methods: Nine pregnant women, six newly delivered mothers and five women wanting to get pregnant were purposefully selected for in-depth interviews. Content analysis was used to organize and interpret the women's experiences of becoming pregnant.

Results: Women's choices for pregnancy could be categorized into one overarching theme 'strive for motherhood' consisting of three sub-themes. A child is thought of as a prerequisite for a fulfilled and happy life. The women accepted that good health was required to bear a pregnancy and thought that feeling well, taking their antiretroviral treatment and eating nutritious food was enough. Consulting health care providers was perceived as interfering with the women's decisions to get pregnant. Becoming pregnant as an HIV-infected woman was, however, complicated by the dilemmas related to disclosing HIV infection and discussing pregnancy intentions with their partners.

Conclusions: Motherhood is important to women on antiretroviral treatment. But they seemed to lack understanding of the relationship between a high CD4 cell count and a low chance of transmission of HIV to offspring. Better education about the relationship of perceived good physical health, low CD4 cell count and the risk of mother to child transmission is required. Women want to control the domain of childbearing but need enough information to make healthy choices without risking transmission.

Background

An internal assessment in 2007 (unpublished results) at African Medical Research Foundation (AMREF) community health centre which provides free antiretroviral therapy (ART) in the Kibera slum in Nairobi, showed that 64 out of the 468 women on antiretroviral therapy conceived when their CD4 cell count was below 350 cells/ml, against all recommendations and without receiving any preconception counseling. Women enrolled on antiretroviral therapy at the AMREF community health center are

told that they can have children with a high chance to be born free of HIV if the correct precautions are taken, and women are urged to discuss their pregnancy intentions with health care providers to enable pre-conception assessment and plan for prevention of mother-to-child transmission of HIV (PMTCT). Women on antiretroviral therapy are counseled and advised to wait with pregnancy until HIV is suppressed and a stable CD4 count of 350 cells/ml is reached. In addition the counseling stresses consistent condom use to reduce the risk of transmitting the virus and sexually transmitted infections (STIs) to their partners and having timed unprotected sex during the most fertile days. Studies have shown that persons liv-

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ing with HIV continue having a sexual life after diagnosis [1-3]. Many want to have children and have intentional pregnancies [4,5]. The optimum levels of CD4 cell count and timed conception significantly reduce the risk of transmitting HIV to both a partner and an unborn child [6,7]. It was thus important to understand issues regarding becoming pregnant among women on antiretroviral treatment.

The value put on children varies between societies and depend on the functions and needs they fulfill for both parents and community [8-10]. In African societies children ensure the continuity of the family lineage, confer a sense of continuity and inherit family land and wealth [11-14]. The highly regarded funeral traditions may also be affected by the fertility status of the deceased. Thus children safeguard a proper burial for their parents [13,14]. For the individual, an HIV diagnosis is thus not only associated with fear of death, but also with anxiety caused by the realization that one may die without being married or having children [15]. Childlessness and infertility are very stigmatizing and often associated with profound negative social repercussions in African societies [13]. Women are usually blamed for childlessness [16] and regardless of HIV sero-status, they therefore want to realize motherhood. With the scale-up of antiretroviral therapy in Kenya, women living with HIV have the opportunity to bear children with a greatly reduced risk of mother to child transmission.

However, very little is known about why women with a low CD4 count may choose to become pregnant despite a higher risk of MTCT and pregnancy-related morbidity, and without consulting health care providers. In this article, we explored the reasons behind this behaviour, aiming to inform and adapt service provision to better meet the needs of HIV-positive women and increase the uptake and coverage of PMTCT and safe motherhood monitoring. The aim of this study was to explore experiences of intentionally becoming pregnant among women receiving highly active antiretroviral therapy (HAART).

Methods

Study area

The Kibera Community Health Centre supported by AMREF, a non-government organization (NGO) is situated in the Kibera slum in Nairobi. It is estimated that about 60 percent of Nairobi residents live in slums [17]. The Kibera slum, which has between 0.5-1 million people, attracts migrants from rural areas in search of employment and livelihood [18]. The existence of many entertainment spots providing alcohol, drugs and large networks of commercial sex workers make Kibera a high-risk environment for HIV transmission [19]. The exact figure for HIV prevalence in Kibera is unknown, but it is estimated to be higher than the national prevalence of 7%

[20]. Kibera has an inadequate coverage of health care services and inhabitants depend on informal health care providers and a few primary health care facilities run by NGOs. Men engage in a wider range of informal jobs than women who often perform domestic work or petty trade. Kibera constitutes a highly mobile and sexually active young population living closely together in deplorable conditions and interacting in loosely structured sexual relationships [21]. Although men and women may live in permanent unions, it is hard to predict sexual exclusivity and monogamy in these relationships [22].

The antiretroviral therapy program at the Kibera Community Health Centre

The Kibera health centre offers preventive, diagnostic and basic health care, including services focusing on immunization and reproductive health. An antiretroviral therapy program was started in 2003 and provides free treatment and care, including home based care and adherence support for HIV-infected individuals. The clinic also provides free voluntary counseling and testing (VCT) and HIV prevention of mother to child transmission (PMTCT) services. Initially, antiretroviral therapy enrolment was based on the world health organization (WHO) clinical staging only, but CD4 and viral load testing were later introduced. In 2006 the routine use of viral load was discontinued due to economic restraints but when needed the samples are sent to the national reference laboratory, at the Kenya National Medical Research Institute (KEMRI), located at the national referral hospital Kenyatta. The first line treatment consists of Nevirapine, Lamivudine, Stavudine or Zidovudine. As second line treatment Abacavir, Didanosine, Lopinavir or Tenofovir is used. No third line treatment is available.

Counselors and post-test clubs (PTCs) support adherence and retention in the antiretroviral therapy program. Additional support is provided through treatment literacy training for children and adults, social assessments and change of pill-regimes to fixed doses. At the time of antiretroviral therapy enrolment, social workers record personal and contact information of patients to enable for tracing in the event that they default. Tracing of defaulting patients is done by community health workers with support from PTCs. Patients are followed up every three months by a clinical officer to assess adverse drug effects, clinical staging and adherence to antiretroviral therapy, and to replenish their antiretroviral medicines. CD4 count is performed every six months with the exception of pregnant women who undergo routine testing every three months. As of January 2009 the antiretroviral therapy program had enrolled 2535 adults of whom 1326 were on antiretroviral treatment. The health centre had six clinical officers, 19 nurses, four midwives and two staff each for counseling, nutrition-advice and VCT.

Study design

This study employed qualitative methods aimed at uncovering, explaining and giving meaning to human behaviour from the perspective of those being studied. Qualitative interview methods facilitate rapport while enabling the interviewer to maintain focus on the issue at hand [23,24].

The research team consisted of a Kenyan sociologist (OAU) residing in Sweden, a Kenyan physician and epidemiologist (FI), a Swedish medical doctor and epidemiologist specialized in HIV and AIDS (AME), a Swedish public health scientist (BR) working in the field of HIV and AIDS and a Kenyan social worker (DI). No one in the team worked clinically with the patients at the antiretroviral therapy clinic. While in Kenya, OAU worked with projects on HIV/AIDS prevention and control focusing on gender and sexuality interventions. Her background in combination with her experience from field work and her public health perspective bring knowledge and contextual understanding to the study.

Sampling of informants

The informants were purposively selected from the registers at the antiretroviral therapy and PMTCT programs. The criterion was that the women had been on HAART for not more than six months and the theoretical assumption was that their experiences of becoming pregnant would differ depending on the time-line of pregnancy. Through the registers, it was possible to identify three different groups. The first two groups were located in the registers then retrospectively identified and the third group was prospectively identified. The groups were: (i) pregnant women (ii) women who had delivered in the past 12 weeks and (iii) women who were seeking to become pregnant. Ten were pregnant, eight had delivered and five were seeking a pregnancy. A community health worker sought the help of a female leader of the post-test club to identify women attempting to become pregnant and enrolled in antiretroviral therapy at the Kibera community health centre.

One community health worker contacted all the groups of women and introduced them to the study. The women willing to participate provided verbal consent and were asked to indicate the time and place of the interview. The interviews were performed at the clinic or home within three days of providing informed consent. No one declined to be interviewed. However, three women dropped out for other reasons.

Data collection

The main author performed all the interviews. A semi-structured question guide (additional file 1) was used during the interviews, which were tape recorded with the participants' permission, and conducted in Kiswahili. We

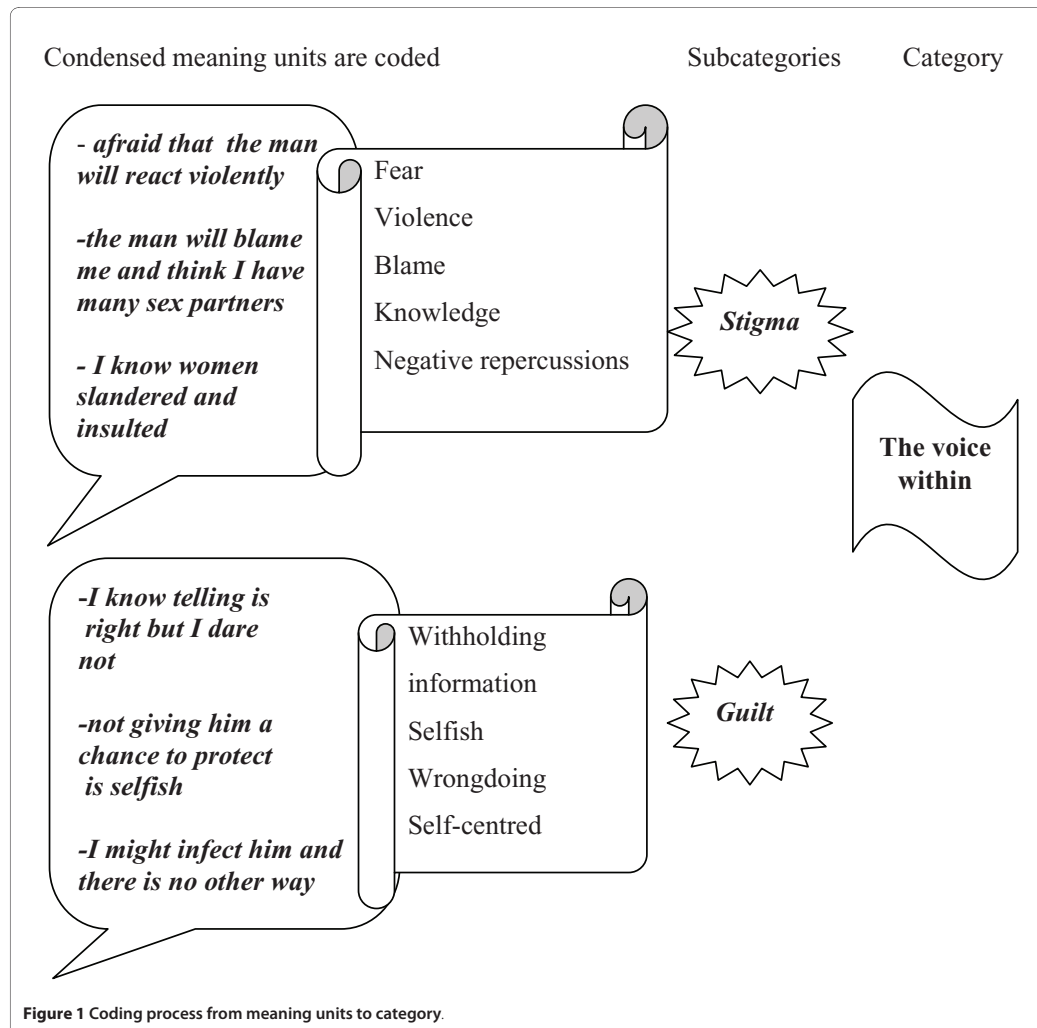
asked the women to describe freely and reflect on pregnancy in general and how they prepared for and achieved it. We used probing during the interviews to explore motivations for pregnancy, the women's role in achieving it, pregnancy discussion with the partner, HIV status disclosure, and interaction with medical providers. Positive and negative experiences and perceived problems and challenges in seeking childbearing during antiretroviral therapy were also probed. Initially one woman from each of the three groups was interviewed. A preliminary analysis was conducted by OAU and DI to provide insights and a chance to improve the flow and clarity of the questions. The women were not given any incentives or rewards. Scenarios that could arise during interviews were discussed with a nurse, social worker and counselor in advance to prepare for situations of emotional distress that could arise. The staff shared their experiences and gave OAU ideas on how to handle situations that required emotional assistance. A counselor was available for referral for women who needed support.

Data analysis

Data were analyzed qualitatively using content analysis, guided by Graneheim and Lundman (2004). Initially, the transcribed material was read a number of times to get a general sense of the material. Meaning units, which are key phrases in the text, were identified, condensed and outlined. Codes were then ascribed to each meaning unit. The codes were then compared and grouped into sub-categories. This comparison was performed consistently to identify emerging categories that were further compared, re-organized and merged into sub-themes and one overarching theme. The coding and analysis were first carried out by the OAU independently and then together with AME and BR. Sub-categories, categories and themes were arrived at by consensus between the authors to describe the women's experiences of becoming pregnant of the women. An example of the coding procedure is shown in figure 1.

Trustworthiness of the study

Trustworthiness is related to the ability of the study method to capture the reality of those being studied. In this study, OAU's prolonged engagement in understanding the functioning of the antiretroviral therapy and PMTCT programs at the AMREF Kibera health centre, her participation in field visits and data collection activities were crucial. Using face-to-face interviewing enabled the interviewer and informant to build rapport and discuss issues freely. Peer debriefing sessions and joint analysis by the research team, who represented different disciplines and experiences, were important to increase the credibility of the study results.



Ethical Considerations

Ethical approval was obtained from the Kenya Medical Research Institute (KEMRI) and Karolinska Institute. KEMRI has an ethical review committee, which vets all research proposals that involve humans. The committee is accepted by the Ministry of Health as a National Ethical Review Committee. All study participants were assured that their anonymity would be strictly upheld throughout and after the study period. It was stressed that participation in the study was voluntary, and participants could withdraw at any time with no effect on them, their family or care and treatment given. Each woman gave a verbal informed consent because of their high illiteracy levels

and reluctance to have a written record of their signatures on the informed consent form. Interviewing well-informed women living with HIV about their sexual behaviour, including unprotected sex and non disclosure of HIV infection, requires great sensitivity not to impose on the women's integrity or confuse the role of researcher with that of a counselor [23].

Results

Characteristics of the study population

In total 50 women were eligible to participate in the study. Twenty-three had been invited to participate and 20 were available for interviewing. The informants were

aged between 22 and 45 years. Sixteen had primary school education and all were Christians. Nine of the women were pregnant; six had delivered within the last eight weeks and five were seeking a pregnancy. Six women were single, six cohabiting, four married and four widowed. All women had disclosed to their mother, sister or aunt. Six women had disclosed to their partners. The women's parity ranged from two to five. None of participants had a regular income.

A theme on becoming pregnant

One theme 'strive for motherhood' consisting of three sub-themes emerged from the women's descriptions about reasons for becoming pregnant despite a low CD4 cell count. Each sub-theme illustrates a different aspect in the process of achieving a pregnancy (Figure 2). 'Activating motherhood' refers to women's explanation for pregnancy and their role in achieving a pregnancy, while the theme 'Between silence and openness' points to the dilemmas that women face in their decision to share or not to share their HIV infection and pregnancy intentions with their partners. 'Predicting the unpredictable' is an illustration of how the role of the clinic in pregnancy is not meeting the needs of the women when they wanted to become pregnant. The emergence of the theme 'strive for motherhood' is shown in figure 2.

Activating motherhood

The women wished to regain self-status and that was achievable through motherhood. Pregnancy was pursued as a proof of recovery and evidence of regained self-control.

Before I was falling sick..... I am recovered now. What is important..... is to eat properly to have energy and be strong. To carry it [pregnancy] needs strength and it [childbirth] tests.....the body. I became pregnant..... when I could cook and wash for myself.....there was no one to help me here [Kibera]. I had to be able to take care of myselfjust as I did before my illness. (Pregnant and widow 30 years old)

The women knew that children would also improve their status in their original family and make them recognized. They described a child as a proof of the presence of a man in their lives. This link was evidence of them being attractive and capable of seducing a man. Women without children often lacked acceptance.

The women underscored the importance of establishing a relationship with a man when seeking a pregnancy. They employed tactful 'soliciting' to attract men and played an active role in pursuing and keeping a man. The women knew that men perceived them as sex providers and they used sex to lure men into a relationship.

All they [men] see in us [woman] is sex..... I just dress smart and have a nice hairstyle for them [men] to see

me.....he [man] will surely look and want me.I will flirt and show interest. (Single 38 year old planning a pregnancy)

The women described how condoms were intentionally undesirable when they wanted to conceive. They explained that men did not want to use condoms after a few encounters and that improved their chances of becoming pregnant. Seeking a pregnancy after previous sex encounters was preferred as condom use subsided.

Children were vital in uplifting the women's image and were always welcomed by the women. Women in stable relationships reported that they would also get a child to make the man happy and maintain the union, and also opted for a pregnancy to meet a partner's need to name a child after family members or to consummate a new relationship.

My husband treats me well.....gives me money..... to buy food and clothes.....he [husband] pays the rent..... I will get pregnant.....he wants to name after his father, mother or any person he loves.....he will be happy...He will always be concerned for it [child].....the child has replaced his relative.....it [child] is a living reminder.....I will take care of him and the child. (Delivered and married 34 year old)

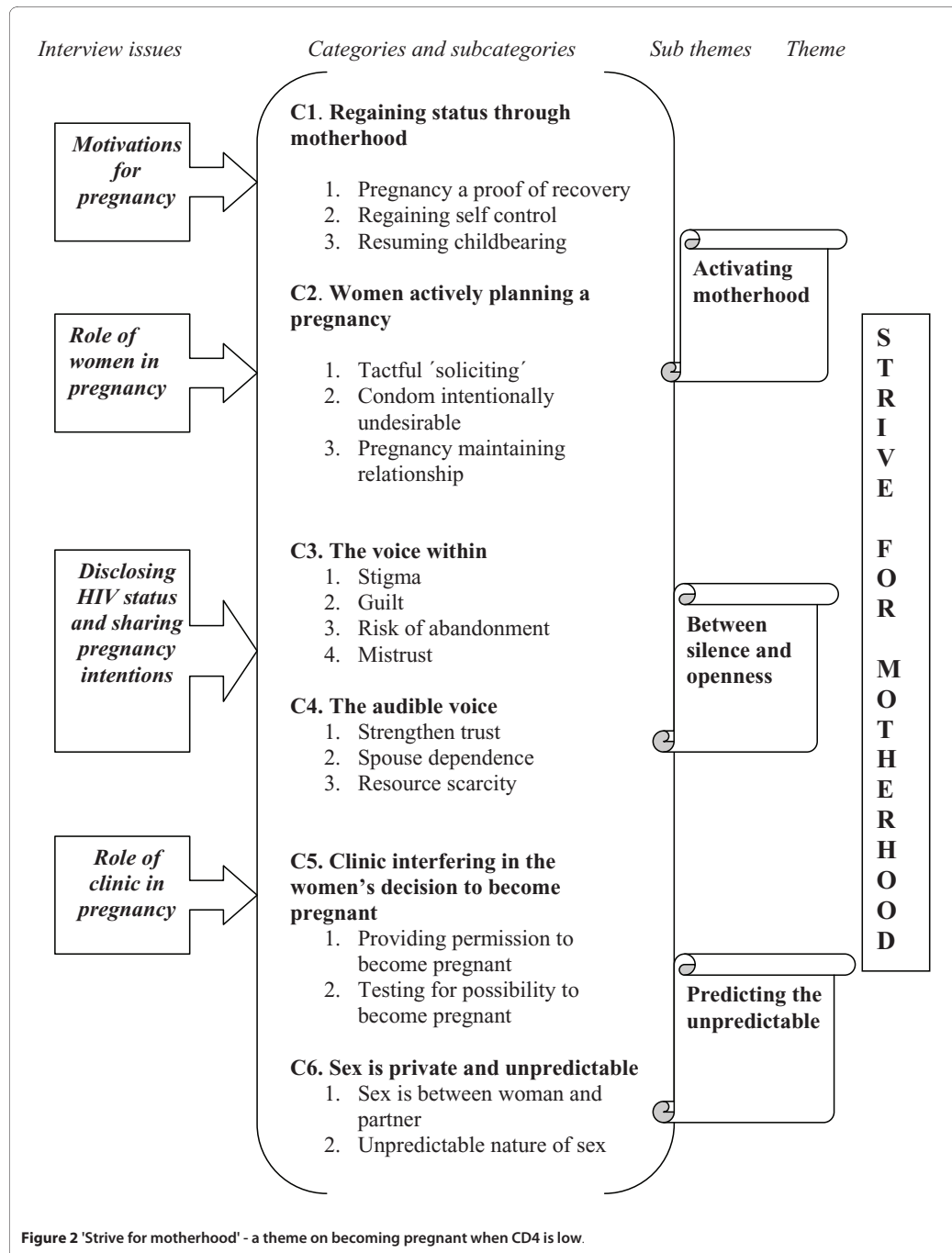
I have been seeing him [partner] for two years [in the past].....he asked me to bear him a child.....I happily agreed.....I already have two [children]..... from before [previous relationship].....it showed me that he [partner] loves me.....he [partner] wanted me to have a child.....his own blood to bond ushe was serious about staying with me..... and build a family. (Pregnant and cohabiting 28 year old)

Delaying to achieve a pregnancy could disrupt a much needed relationship.

It was not my intention for it [pregnancy].....my husband wanted another child.....it took four months [to conceive].....my husband kept asking.....if I was using them [birth control pills] but I wasn'the was very impatient.....he threatened me..... he will chase me away..... if I could not get it [pregnant]. (Pregnant and married 34 year old)

Between silence and openness

Two dilemmas were encountered in their quest for becoming pregnant: (i) fear of disclosing their HIV status, and (ii) not being able to discuss their desire for a pregnancy openly with their partners. The women expressed guilt of possibly infecting the partner, but also feared that revealing their HIV status could expose them to stigma and the risk of abandonment by the possible partner: thereby minimizing their chance of getting pregnant. Even though the women acknowledged that disclosure to a sexual partner was vital, many concluded they would



still keep this information secret to maintain the possibility of being in a relationship and becoming pregnant.

I know telling him [partner] about it [HIV infection] is right.....I choose not to.....I look bad for thinking of me he [partner] can get that [HIV] from me but you need to understand my situation [want a child].....I cannot get it [pregnant] if he leaves or chooses to use a condom. (Widow 33 years old and planning a pregnancy)

Non-disclosure also ensured that the woman could be in a relationship with another man if the current relationship did not last. Not being identified as HIV infected made it possible for them to approach men and men to be around them. This created an opportunity for women to find another man.

I will never get a man here [in Kibera].....if I am known to have HIV. No man will want me [to befriend]....not even seen together as friends. He [man] will be teased and laughed at.....I will be an embarrassment.....and no pride to a man. (Pregnant and single 26 year old)

The women feared that a discussion about pregnancy intention could be seen as trying to impose on the man.

I do not reveal that [pregnancy intentions]....he [man] will think that I want to give him responsibility [a child]..... or trap him to marry me.....he [man] may get frightened [of pregnancy].....and insist on using a condom..... or just leave me. (Delivered and cohabiting 25 year old)

When asked how they perceived disclosing and discussing pregnancy, women often described a time process. They initially wanted a child and feared not having a man to make them pregnant. After getting the child, the women were prepared to disclose and discuss a pregnancy when they wanted marriage.

The most important thing..... I want to prove my capability as a woman [childbearing]..... I want to be recognized in my family and community...I will not let my status stand in the way..... I will not share it with him [partner] if he [partner] will not support me.....I can worry about the other things [love and marriage] afterwards. (Delivered and married 44 year old)

All women felt that disclosure could strengthen partner trust as it showed their openness, encouraged partner support and improved communication. However, this happened only after the women had satisfied their desire for a child and did not fear losing the man. They felt that discussing pregnancy intentions for additional children was vital because resources were scarce and there was a need to plan for the future of an expanding family.

Predicting the unpredictable

When asked how they felt about becoming pregnant without involving the clinic, the women expressed indifference. Pregnant women and the newly delivered moth-

ers did not regret their action. They felt that the clinic had no role in planning a pregnancy. All women expressed the willingness to have a healthy pregnancy, but they perceived the role of the clinic as interfering in their decision to become pregnant. They felt that the recommendation to wait with pregnancy until the required level of CD4 cell count was reached could delay the pregnancy. They felt that the clinic was restricting them and expecting them to ask for permission to become pregnant.

They [clinic] want me to wait [pregnancy] yet I am ready [healthy]. I see no need for them [clinic] to know when I want it [a child].....it [child] is mine and I get one when I want. (Cohabiting 33 year old planning a pregnancy)

The women felt that the clinic was taking tests to make a decision on their capability to become pregnant and carry a pregnancy. For some of the women, the testing was perceived unnecessary.

They [clinic] want to check me [woman's health] before becoming pregnant.....I will not go for that [CD4 count]. I know and experience it [good health].....I live in this body. They [clinic] cannot tell me what I feel....it is the other way round [woman tells the clinic how she feels].....tests want to tell me what I already know. (Pregnant and cohabiting 37 year old)

The women acknowledged being treated well and welcomed by the counselors. They expressed satisfaction with their providing information about childbearing when living with HIV. The women hinted that this information was obtained also from PMTCT advertisements. Women who had given birth to children free of HIV provided testimonies in TV-shows or on billboards that antiretroviral therapy is effective and bearing healthy children is a possibility. This information gave the women hope and inspired them to seek a pregnancy, but it did not mention discussing pregnancy intentions with the clinic or that a pregnancy needed special tests. That treatment was free and accessibility was described as important. In addition the advertisements underlined that PMTCT programs existed just to serve HIV-infected women like them who were pregnant.

I can get it [baby].....the treatment [antiretroviral therapy] has made me feel better.....look at Lucy (pseudonym) [famous Kenyan HIV and AIDS].....she was on the television.....talking about her pregnancy..... she [Lucy] got a healthy child after taking medicine [antiretroviral therapy]. (Delivered and married 34 year old)

When asked how they felt about the advice to have timed unprotected sex, the women expressed resentment. They described sex as a private and unpredictable act. Others felt that unprotected sex did not just happen, but it was a desire difficult to dictate.

Discussion

This study highlights the various decisions faced by the women on ART in the urban slum of Kibera, from deciding for a pregnancy through to achieving it, and the determination to actively plan to control their lives in the process.

The findings show that in this urban slum setting, women became pregnant by 'activating motherhood', i.e. actively planning and strategizing to get pregnant and having children. A child gave them identity and recognition in the community, and thus happiness and fulfillment as women. Their motivation for a pregnancy seemed to depend on the perceived meaning of a child and the importance of bearing one's own child. These findings are consistent with other studies performed in African societies which show that the identity of a woman is pegged on her capacity to bear children and that children are equated to a fulfilled life as a woman [14,25]. As a result of the increased antiretroviral therapy availability women saw a possibility to restore their status through motherhood also shown in other studies [26,27]. Our study has gone a step further to also reveal the meaning of pregnancy as a sign of recovery from ill health. The capability to perform a woman's duties including resumption of child bearing was a means of obscuring the HIV-infection and assuming the same status as women without the virus.

Regained health was interpreted as feeling strong and not falling sick - a sign that HAART is working [27,28]. For the women being strong enough to take care of themselves and performing normal duties were signs of the good health permitting for seeking a pregnancy. They did not understand that physical improvements were often experienced before the recommended laboratory health markers were achieved. This perception gap between laboratory health markers and individual health indicators should be addressed during counseling, so that women understand how it relates to their childbearing goals. The women required better education on the relationship between low CD4 count and high risk of HIV transmission from mother to child. The informants in this study, just as many residents of Kibera have low education levels. Counseling could therefore be clearer and simplified to meet the needs of illiterate and semi-illiterate women. Women want to control the domain of childbearing but need enough information to frame the choices in a way that still makes them feel empowered. They want to bear healthy children but felt the preconception care was attempting to 'predict the unpredictable'. To them becoming pregnant was a private desire that could eventually include their partners but where clinic staff were outsiders. The preconception counseling was poorly matched to the contextual structures influencing how women achieved a pregnancy, i.e. how women and men

established sexual relationships. As the PMTCT advertisements did not explicitly mention counseling or the need to monitor CD4 cell counts to optimize the timing for pregnancy, such components were met with resentment and skepticism.

The women were tactical when establishing a relationship that made it possible to have sex without a condom. Their role in planning a pregnancy was based on their knowledge of men's behaviour towards sex. The reluctance to use a condom among men was exploited by the women who knew that after a few encounters the condom would be disregarded and disappear. Other studies have shown how the use of male condoms varies with partner types and that it is lowest with regular or married partners [29,30]. Although the women regarded conceiving within established relationships as preferable, they faced the dilemma 'between silence and openness', disclosing their HIV status or not, discussing pregnancy intentions or not. Family members particularly females seemed to be more preferred and trusted when disclosing a positive HIV status, which has also been shown in another in a study from Nairobi [31]. The fear that their partners could react negatively to the HIV diagnosis and leave them without a man to conceive with was a big concern. Similarly a study in Tanzania found that reactions of male partners to an HIV-diagnosis was a major concern for women [32].

Discussions with the partner about a possible pregnancy were also avoided as the women feared it might encourage condom use or that the man would leave. However women also told about men who were eager to have children and how they accepted becoming pregnant to maintain a relationship that seemed permanent. The possibility that the partner might want a child made women in stable relationships always anticipate childbearing. The decision to disclose HIV infection means weighing enormous potential consequences, both positive and negative. The women in this study expressed guilt for not giving their partners a chance to decide upon condoms. However, the need to get pregnant and attain status was more important to them than to protect a partner and remain unfulfilled and unhappy. When the desire for childbearing was at stake, the rewards of transparency were outweighed by the risk incurred. The women might choose to disclose when their need for children is satisfied.

Methodological Considerations

The fact that OAU had been seen at the health centre for a period of time before the interviews may have influenced her relations with the respondents. It was thus important to underline her role as a researcher and that what they said would not affect their access to health care at the facility. OAU's pre-knowledge about the context

and the topic were mainly an asset to the study, but it was also important to at times put it within brackets to allow for unanticipated findings.

Our study explored how women intentionally become pregnant and their reasoning around it. Issues on contraceptive use were mentioned in the interviews and will be discussed elsewhere, as they had no prominent role when pregnancy was desired. The study could have benefitted from understanding the relationship of the women with their partners when a pregnancy was not the goal, but as this was not discussed during the interviews it is not part of the study. Also the importance a pregnancy and a child ascribe to the status and acceptance of women in the Kenyan society made it so obviously part of any relationship and that is where the interviews focused. None of the women mentioned being engaged in transactional sex for survival, which may be a result of the selection of the women through the antiretroviral therapy program and the focus on pregnancy and childbearing. Further studies are needed that explore the interplay between men's relationship patterns and pregnancy needs particularly how cohabiting women manage to hide their status when on HAART.

Even if the findings in this study refer to the women participating, the desire for motherhood and the loose societal control making a pregnancy possible are factors true for many women in urbanizing Africa.

Conclusion

Motherhood is important to women on antiretroviral treatment. But they seemed to lack understanding of the relationship between a high CD4 cell count and a low chance of transmission of HIV to offspring. Better education about the relationship of perceived good physical health, low CD4 cell count and the risk of mother to child transmission is required. Women want to control the domain of childbearing but need enough information to make healthy choices without risking transmission.

Additional material

Additional file 1 Interview guide. Questions asked to study participants to obtain information on intentionally becoming pregnant.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

OAU is the main author of the manuscript and involved in all aspects of the study. BR and AME provided scientific expertise and feedback throughout the development of the study and manuscript. FI was involved in the conceptualization of the idea, tool development and reading and editing of the manuscripts. DI was involved during preparations and pre-test of the interview guide, data collection and reading and editing of the manuscript. All co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

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References

- Bunnell R, Ekwaru JP, Solberg P, Wamai N, Bikaako-Kajura W, Were W, Coutinho A, Liechty C, Madraa E, Rutherford G, et al: **Changes in sexual behaviour and risk of HIV transmission after antiretroviral therapy and prevention interventions in rural Uganda.** *AIDS* 2006, **20**:85-92.
- Olley BO, Seedat S, Gxamza F, Reuter H, Stein DJ: **Determinants of unprotected sex among HIV - positive patients in South Africa.** *AIDS Care* 2005, **17**:1-9.
- Boily MC, Godin G, Hogben M, Sherr L, Bastos FI: **The impact of the transmission dynamics of the HIV/AIDS epidemic on sexual behaviour: a new hypothesis to explain recent increases in risk-taking behaviour among HIV positive gay men.** *Med Hypotheses* 2005:215-226.
- Myer L, Morroni C, Rebe K: **Prevalence and determinants of fertility intentions of HIV-infected women and men receiving antiretroviral therapy in South Africa.** *AIDS Patient Care and STDs* 2007, **21**(4):278-285.
- Desgrees-Du-Lou A, Msellati P, Viho I, Yao A, Yapi D, Kassi P, Wellfens-Ekra C, Mandelbrot L, Dabis F, ANRS 049 Ditrane Study Group: **Incidence of pregnancies among African HIV-infected women, Abidjan, 1995-2000.** *AIDS* 2001, **15**:2327-2330.
- Barreiro P, del Romero J, Leal M, Hernando V, Asencio R, de Mendoza C, Labarga P, Núñez M, Ramos JT, González-Lahoz J, et al: **Natural pregnancies in HIV-serodiscordant couples receiving successful antiretroviral therapy.** *JAIDS* 2006, **43**(3):324-326.
- Barreiro P, Castilla JA, Labarga P, Soriano V: **Is natural conception a valid option for HIV-serodiscordant couples?** *J Human Repro* 2007, **22**(9):2353-2358.
- Daniluk J: **Helping patients cope with infertility.** *Clinic Obstet Gynecol* 1997, **40**(3):661-672.
- Serour GI, El Ghar M, Mansour RT: **Infertility: a health problem in the Muslim world.** *Popul Sci* 1991, **10**:41-58.
- Hoffman LW, Hoffman ML: **The value of children to parents.** In *Psychological perspectives on population* Edited by: Fawcett JT. New York: Basic Books; 1973:19-76.
- Tilson D, Larsen U: **Divorce in Ethiopia: the impact of early marriage and childlessness.** *J Biosoc Sci* 2000, **32**(3):355-372.
- Runganga AO, Sundby J, Aggleton P: **Culture, Identity and Reproductive Failure in Zimbabwe.** *Sexualities* 2001, **4**:315-332.
- Gerrits T: **Social and cultural aspects of infertility in Mozambique.** *Patient Educ Couns* 1997, **31**(1):39-48.
- Yebei VN: **Unmet needs, beliefs and treatment-seeking for infertility among migrant Ghanaian women in the Netherlands.** *Reprod Health Matters* 2000, **8**(16):134-141.
- Smith DJ, Mbakwem BC: **Life projects and therapeutic itineraries: marriage, fertility, and antiretroviral therapy in Nigeria.** *AIDS* 2007, **21**(5):37-41.
- Dyer SJ: **The value of children in African countries: insights from studies on infertility.** *J Psychosom Obstet Gynaecol* 2007, **28**(2):69-77.
- The Challenge of Slums** [http://www.unhabitat.org/jo/pdf/GRHS.2003.pdf]
- Erukhar AS, Matheka JK: **Adolescents in the Kibera slums of Nairobi Kenya.** Nairobi: Population Council; 2007.
- Gulis G, Mulumba JA, Juma O, Kakosova B: **Health status of people of slums in Nairobi, Kenya.** *Environ Res* 2004, **96**(2):219-227.

20. NASCOP: **Kenya AIDS Indicator Survey 2007**. Nairobi: Ministry of Health, Kenya; 2008.
21. Zulu EM, Dodoo FN, Chika-Ezee A: **Sexual risk-taking in the slums of Nairobi, Kenya, 1993-8**. *Popul Studies (Camb)* 2002, **56**(3):311-323.
22. Hattori MK, Dodoo FN: **Cohabitation, marriage, and 'sexual monogamy' in Nairobi's slums**. *Soc Sci Med* 2007, **64**(5):1067-1078.
23. Kvale S: *Inter Views - an introduction to qualitative research interviewing* London: SAGE Publications; 1996.
24. Morse JM, Field PA: *Qualitative research methods for health professionals* London: SAGE publications; 1995.
25. Sonko S: **Fertility and culture in sub-Saharan Africa: a review**. *J Intern Soc Sci* 1994, **141**:397-411.
26. Panozzo L, Battegay M, Friedl A, Vernazza PL: **Swiss Cohort Study: High risk behaviour and fertility desires among heterosexual HIV-positive patients with a serodiscordant partner—two challenging issues**. *Swiss Medical Wkly* 2003, **133**(7-8):124-127.
27. Blair JM, Hanson DL, Jones JL, Dworkin MS: **Trends in pregnancy rates among women with human immunodeficiency virus**. *Obstetrics & Gynecology* 2004, **103**(4):663-668.
28. VanDevanter N, Thacker AS, Bass G, Arnold M: **Heterosexual couples confronting the challenges of HIV infection**. *AIDS Care* 1999, **11**(2):181-193.
29. de Visser R, Smith A: **Relationship between sexual partners influences rates and correlates of condom use**. *AIDS Educ Prevent* 2001, **13**(5):413-427.
30. Ferguson A, Pere M, Morris C, Ngugi E, Moses S: **Sexual patterning and condom use among a group of HIV vulnerable men in Thika, Kenya**. *Sex Transm Infect* 2004, **80**(6):435-439.
31. Miller AN, Rubin DL: **Motivations and methods for self-disclosure of HIV seropositivity in Nairobi, Kenya**. *AIDS Behav* 2007, **11**(5):687-697.
32. Urassa P, Gosling R, Pool R, Reyburn H: **Attitudes to voluntary counselling and testing prior to the offer of Nevirapine to prevent vertical transmission of HIV in northern Tanzania**. *AIDS Care* 2005, **17**(7):842-852.

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Reasoning and Deciding PMTCT- Adherence During Pregnancy among Women Living with HIV in Kenya.

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Abstract

This study explores type identities of rural and urban slum women on antiretroviral therapies (ART) who become pregnant. Narrative structuring was chosen to develop two type narratives that illustrate how rural and urban women handle their HIV-infection and how they reason and decide about PMTCT-adherence during pregnancy and childbirth. Women in rural areas described their lives as 'secure and family controlled'. This gave the women security and predictability in life, but also meant that it was difficult to keep secrets about HIV infection. For women in the urban slum area the narratives were a tale of the uncertain and hard to predict reality in the slum, but also about self-reliance and decisiveness. They portrayed themselves as 'vulnerable and striving to survive' thus managing a tough situation without long-term solutions. We conclude that pregnancy poses different social challenges in rural and urban areas affecting how women choose to manage their adherence to PMTCT, which is also affected by HIV stigma and lack of disclosure.

Keywords – Pregnancy; HIV/AIDS; PMTCT; social identity; Kenya

Background

In most societies in Africa having children is synonymous with having a happy and fulfilling life giving a high status in society (Emneyonu et al. 2008; Cooper et al. 2007). By becoming pregnant and having children women not only meet the expectations of society but also demonstrate good health (Awiti Ujiji et al. 2010). Access to programmes for the prevention of mother-to-child transmission of HIV (PMTCT) and to antiretroviral therapy (ART) mean that the risks with childbearing and parenthood have decreased for women living with HIV (Cooper et al. 2007; Emneyonu et al. 2008). Because of stigma, however, many women choose not to participate in PMTCT (Koenig et al. 2002; Medley et al. 2004; Varga, Sherman, and Jones 2005) and many children are born with the infection (WHO 2010). Models of how stigma exerts its negative effects have emphasised the social aspects as people experience HIV stigma differently depending on their group affiliations and place of residence. How HIV-related stigma varies within and between rural and urban communities has, however seldom been explored in research in Sub-Saharan Africa (Yebei, Fortenberry, and Ayuku 2008; Turan et al. 2008; Okal et al. 2009).

In this study, we will use the concept of ‘group affiliation’ introduced by the German sociologist Simmel (1955) and further expanded by Pescosolido and Rubin (2000) to describe how patterns of relationship form and change when society changes, and how this in turn influences identity formation and decision-making. Simmel describes pre-industrial societies as formed in concentric circles, whereby participation in the smallest group also means participation in the larger groups. The complete overlap of ‘group affiliations’ in pre-industrial societies ensures strong ties between individuals and their social relations. This closeness entails a level of control and enhances social security, but gives little room for deviating personal development, and levels of tolerance for the new and unexpected are low. In contrast, in modern societies the circles are only partly overlapping. The individual stands at the intersection of diverse group affiliations, which provide choice and freedom. They maintain different ties with different groups, having loose and weak connections with some circles, while stronger with others. Their affiliations are more flexible and short-lived and thus also provide less social security. In this paper, Simmel’s concept of varying ‘group affiliation’ (Pescosolido and Rubin 2000; Simmel 1955) depending on level of social and productive development is used to analyze differences in perspective between women living in rural Busia in Kenya and the slum of Kibera, Nairobi in that same country.

This study aims at identifying the type identities of HIV-infected women on ART who become pregnant and describes and explains their behaviour and decisions in relation to type of residence or socioeconomic group affiliation.

Methods

Study design

Narrative structuring was chosen to analyze the stories of HIV infected, pregnant women as a way to explore how they talk about their lives thereby explaining their decisions and creating identity (Frank 1995; Riessman 1993). The narratives are based on the stories told by the women in unstructured dialogues between the participants and the researcher

following a thematic question guide (Townsend et al. 2010). They represent the views of those participating in the study and are used to develop themes about identity, relationships and behaviour (Kvale 1996).

Study area

Busia in Western Kenya is a rural and resource-poor district with agriculture, fishing and small scale trading as main economic activities (Central Bureau of Statistics 2003). The daily average income per household is about seven US dollars. The houses are normally made of mud with grass-thatched roofs. Society is organised around the extended families with many generations living together in the family homestead. When the young woman marries she moves into the homestead of the husband and becomes part of their system of group affiliations, where the mother-in law and the other older women make the decisions leaving little room for own initiatives by the young couple. Already as a child in a similar homestead she was socialised into her future role as a wife. The Trans-African Highway from Mombasa to Lagos passes through Busia and has contributed to a HIV-prevalence of close to 20% at antenatal clinics (Kenya National AIDS/STI Control Programme (NASCOP) 2008). The majority ethnic group is Luhya with a few Luo speakers.

Kibera is a large slum settlement in Nairobi. The population (0.5 to 1 million) consists mainly of highly mobile young men and women (Erulkar and Matheka 2007). People migrate into Nairobi from all parts of Kenya looking for an income, for education opportunities or to get away from stagnating village life. Most of them start their urban life in Kibera and move on when the opportunity occurs, but for some Kibera becomes a more permanent home. People come into Kibera alone or with relatives and develop new social networks including neighbours, church-groups, co-workers or women-groups. They consist of different people with different norms and goals and are mainly independent, but may also partly overlap. Dwellings are often small and shared with a few people. High levels of poverty characterise Kibera with more than half of the population living on less than two US dollar a day. The existence of many entertainment spots providing alcohol and drugs, and large networks of commercial sex workers make Kibera a likely environment for HIV transmission (Gulis et al. 2004).

Participants and data collection

Pregnant women already enrolled in ART were purposively recruited to explore how they describe and explain their behaviour and decision-making in relation to the challenges in following PMTCT recommendations. The selected women were fully aware of their HIV diagnosis, of the benefits of adhering to treatment and of how to reduce the risk of mother to child transmission. Pregnant women on ART (15 – 24 years) were identified through the PMTCT registers at a district hospital in Busia and a non-governmental community health centre in Kibera and contacted by a community health worker from the PMTCT programme. Those who were willing to participate in the study and share their experiences, were informed about the aims of the study and their contribution, and asked to give consent and suggest time and place for the interview. Twenty-eight women: 12 in Kibera (5 Luos, 4

Luhya and 3 Kambas) and 16 in Busia (12 Luhya and 4 Luos) were interviewed. No one declined to participate.

The research team in consultation with the health providers developed a thematic interview guide, which was translated into Kiswahili and Kiluhya. It was field-tested with similar respondents for clarity of language, comprehension and content. The interviewers discussed scenarios that could arise during the interviews with a nurse, a social worker and a counsellor from each setting in advance, to prepare themselves for situations of emotional distress. The health providers shared their experiences and gave the interviewers ideas on how to handle difficult situations.

Interviews took place in Kiswahili, Sheng (a language consisting of a mixture of English, Kiswahili and locally coined terms) or Kiluhya depending on the interviewee's preference. In Busia, a female nurse conducted the interviews in Kiluhya and the principle investigator those in Kiswahili and in Kibera an anthropologist interviewed in Sheng and the principle investigator in Kiswahili. The unstructured qualitative interviews allowed the informants to tell their stories with minimal interruption except for probing by the interviewer. This gave the informants the opportunity to talk about their experiences of becoming pregnant when living with HIV, coping with the pregnancy and planning for the delivery. In this paper the domains being explored were the reactions towards the pregnancy among social relations, the challenges experienced during pregnancy in relation to adhering to HIV treatment, following hospital appointments, disclosing the HIV infection to significant others and having skilled hospital deliveries. We also looked for how the pregnant women prepared for childbirth. With the permission of the participants the interviews, each taking about an hour, were tape-recorded. Interviewing was continued until the interviewer felt that there was no more new information to be obtained (Kvale 1996). All interviews were transcribed verbatim and translated into English by the interviewers.

Method of data analysis

All the transcripts were read several times to gain a general sense of the experiences and thoughts of the participants. The actions and behaviours of people (social actors) around the women and their relationships to the women were used as a frame of analysis when interpreting their experiences, their understanding of the situation and their ways of coping. The reading focused on content (what did the women experience and how did they behave in these experiences) and coherence (how did the women reason and depict themselves and their behaviour). The interviews were searched for stories showing how the women justified their actions and decisions. There was constant comparison of the transcripts on partner involvement and support, HIV infection disclosure, reactions from social networks to the women becoming pregnant and following PMTCT recommendations. The women's behaviours when dealing with each of the above-mentioned issues were identified.

While reading the transcripts we made condensed notes on the patterns and characteristics of each pregnant woman and then in relation to their urban and rural residence. During analysis, we alternated between being 'narrative finders' looking for the narratives contained in the interviews and 'narrative creators' moulding the stories of the women into

two understandable and coherent stories (Kvale 1996). Thus, the final narratives are a condensation of the many stories told by the women into two richer, condensed and coherent thematic stories, including the varied experiences of the women (Kvale 1996).

In the narratives the participants described their daily lives and their environment, the stigmatising reactions to their pregnancy, how they managed the stigma and how it affected their adherence to PMTCT. Narratives are not exact records of what actually happened but represent how the participants choose to tell the story to the interviewer at the time of the interview (Frank 1995; Kvale 1996). When people tell their stories they try to explain their choices and actions, to make their life understandable to the listener, and to formulate an identity they can live with (Mischler 1986). Thus the values and interests of the narrator will influence how the story is told depending on who the listener is and when it is being told. As the past is selectively reconstructed, stories and memories of troubling events may be reformulated when retold and a life-narrative is always a representation of what the narrator chooses to tell at a special time (Riessman 1993). Still the stories people tell about their lives, or special events in their lives, help us understand their choices and decisions in life (Mischler 1986).

Ethical Considerations

Ethical approval was obtained from the Kenya Medical Research Institute (KEMRI) and Karolinska Institute. All study participants were assured that their anonymity would be strictly upheld throughout and after the study period. It was stressed that participation in the study was voluntary, and participants could withdraw at any time with no effect on them, their family or the care and treatment given. Each woman gave verbal informed consent because of the high illiteracy levels and the perception that signing a consent form could mean a strong commitment.

Interviewing well-informed women about the situation of their pregnancy, when already suffering from a condition perceived to be life threatening and equated to death, requires great sensitivity not to impose on the women's integrity or confuse the role of researcher with that of a counsellor (Kvale 1996).

Findings

The findings show that women living with HIV on ART and who choose to become pregnant, experience stigma and decision making power differently depending on social affinity (closed/open relationship networks) and type of residence (urban/rural).

In creating the two type-narratives we focused on behaviour that was common among the rural and the urban slum group and characteristic for their social situation. Individual deviations pertaining to special circumstances were not included as we were looking for the typical situations. The narratives were created out of the many different interviews of the two groups to show how the pregnant women handled their HIV-infection and how they reasoned around and decided about PMTCT-adherence. All pregnancies were intentional

and ethnicity, marital status and number of children delivered after the HIV diagnosis did not appear to influence following PMTCT recommendations among the women.

The first narrative is derived from the interviews with women in Busia. All were married, three were living with men who were not the father of the unborn child and nine were in their second marriage. Seven had lost their previous partner to AIDS. The second narrative is based on the interviews with women residing in Kibera. Three were married, seven cohabiting and two living in stable relationships. The major topics include (a) stigma experiences in urban and rural areas, (b) challenges of following PMTCT recommendations in open/closed social networks and, (c) residential and socioeconomic influences for home or hospital delivery. Nekesa and Jane (pseudonyms) tell their stories.

'Secure and Family Controlled' (Busia)

Nekesa, 23 years old is married and lives with her husband and extended family in one compound. She has disclosed her HIV infection only to her husband, who is also HIV-infected and he supports her through HIV treatment and PMTCT. As Nekesa is pregnant, she enjoys the unlimited family support normally guaranteed during pregnancy. She is relieved of household chores and given care for the unborn child and herself. The pregnant challenges her wish to keep the HIV infection secret.

I wanted a pregnancy and told my husband when I became pregnant. He told my mother-in-law, who invited fellow church members to pray for my good health and the wellbeing of the baby. Everyone treats me nicely and is happy for me. They enjoy that I am fertile. My pregnancy makes my husband proud that another child is on the way. Our home is big and the children help in chores such as fetching water, collecting firewood and herding cows. My mother-in-law tells me to rest and take it easy. Elders perform traditional rituals emisiro kinyala for the child and me to appease the dead relatives and to seek their blessings. I take traditional medicines that are boiled and drunk or rubbed over my belly to keep diseases away. I know it is wrong to take traditional medicine together with antiretroviral medicine, but I cannot refuse. My family would be upset as if did not want to be part of them. I would be seen as going against the ways of our forefathers and against our culture.

I laugh with them and I care for them but I am not telling them about my HIV infection. My husband and I keep our sickness a secret, but it is just so hard to pretend. We fear we would cause much pain to the family and ourselves if we disclose. We do not want to make them worried. We do not want to make them cry. We are alive not dead. I go to antenatal care with my husband's sister or my mother-in-law. Normally they remain in the waiting bay as I meet the doctor or talk to the midwife. At home I take my medicine in my bedroom in hiding from the family. Otherwise they may ask why I take medicine everyday and be suspicious that I have the bad illness. I

will not go to the hospital for the delivery, as it will make my mother-in-law and everyone know I have it. My result is on the card. The nurse will want to know when I took medicine (ARV) last. All this time my mother-in-law will be beside me and will understand. My mother-in-law will be present also when the baby is born and is to be given medicine. I will be found out. I fear the negative things that could happen like being chased away, seen as an embarrassment, thought of as dying soon, avoided and even blamed for the disease.

I will stay with my labour pains and only tell my mother-in-law when delivery is close. Then she will call a traditional midwife. I have the baby's medicine with me but it will be hard to give the baby medicine because of the midwife and my mother-in-law. Instead I will go to the clinic a day after and the baby will get the medicine there. No one will ask questions because babies delivered at home should be taken to the clinic to see the doctor. I will be happy that the placenta is to be buried behind my house and in the child's father's land. This will link my child to his dead relatives. The hospital usually throws it in the rubbish to burn. Leaving the placenta out of the home is breaking the child's cord to his clan.

The stories of how the women dealt with the situation during pregnancy and PMTCT in their rural social contexts were very similar among the 16 women interviewed in Busia. However, women with older children seemed less worried about birth complications and successfully convincing mothers-in-law about home delivery compared to first time mothers. Planning for a home delivery was easier if wives of older and married brothers to the women's husbands had delivered at home previously.

In summary, the women in Busia described their lives as 'secure and family controlled'. They lived close together with the members of the extended family, to whom they were related through marriage. They knew what their role in the homestead was and what was expected of them and they accepted it. As long as their HIV infection remained secret, life could continue along the well-known path. However, the pregnancy meant that the elder women in the family made decisions concerning the health of the pregnant woman and the unborn child. This forced the pregnant woman to come up with solutions to balance the expectations of her role and keeping the HIV infection a secret from the extended family.

'Vulnerable and Striving to Survive' (Kibera)

Jane, 28 years old was diagnosed with HIV and is enrolled in ART. Currently she lives together with her first child and a partner, who pays rent and buys food. She has experienced stigma because of her HIV infection, but is now living positively having accepted her situation. She is also a member of the post-test club (PTC) and volunteered in educating the community on HIV prevention before her pregnancy was visible. She is knowledgeable about PMTCT and decided to become pregnant. However, the reaction of the community towards her pregnancy was surprising.

This pregnancy is good for me and it shows that my partner and I are serious about our relationship. As a woman, the more children I have the more respect I get from the community. My partner provides for my needs and cares for me now that I will have his child. I am happy to have another child. However, my neighbours are unhappy with the pregnancy. They blame me for becoming pregnant when already sick with a dangerous disease. They say I am not serious when not protecting others people's lives. I am accused of not following the rules on HIV prevention [e.g. consistent condom use] and scorned for engaging in unprotected sex. I am called a murderer because of intentionally sleeping with someone without a condom, as there is no medicine to cure HIV. I am blamed for being pregnant, as I will soon be dying and leave the baby without a mother. My baby will be suffering and also die. My partner also gets ridiculed and his joy is turned into sorrow. He is picked on and told to leave me. He is unhappy, worried and in deep thought. Fingers are pointed at him because of making me pregnant and bringing death to himself.

I feel discriminated against when receiving such negative comments. The PTC members stopped visiting me because they too were insulted for not advising me against the pregnancy. My relatives live too far away to know about the disease to hear me being called a HIV woman. I was left alone because of getting pregnant when sick and was afraid of leaving my house of fear for being insulted now that my stomach is showing. I asked myself what was wrong, why my pregnancy made people look at me differently from before. My partner is a casual labourer and has to go out every day to look for work. I was alone in the house even fearing someone could harm me. You cannot know what someone might do to you when you are considered useless and not serious. So, after discussing with my partner, I decided to leave the house and go to live with my cousin. In the house it is only my cousin, the child and I and as the woman in the house I have to do everything: washing, cleaning, fetching water and buying food to cook. I am now the woman in the house. I forget to go to see the doctor and sometimes also to take my medicines. If someone helped me with the work it would be easier.

I will go back home to my partner's house to deliver there. I know it is important to deliver at the health centre but I will not. It will take an extra day before I can go home. Women without HIV can leave almost immediately after delivery, but those like me have to stay longer. It is difficult for me, as I have to take care of my house and the other child. I will not be considered a responsible mother and wife if I let my family go hungry after my pregnancy. I will get a mkunga [traditional birth attendant] to help with the delivery at home. Normally she uses gloves and does not ask about HIV status. She will work in my house and it will be possible for me to be in control. The mkunga cooks, washes clothes and utensils, and fetches water

for four to five days. She can also feed the older child. I will be able to rest. I have medicine for the child and I that we will take after the delivery. For me it is about wanting to have a healthy child and to be a good mother and wife.

Although the lives of the women in Kibera were typically presented as vulnerable and striving to survive, there were some variations in their stories. Those women whose HIV infection was unknown to the community did not experience the same negative reactions and did not find a need to move elsewhere. However, they talked about fear of stigma if their infection was disclosed in the community. They were better able to follow the PMTCT appointments and did not miss taking HIV medicines. However, they also did not plan a hospital delivery, as it would prevent them from fulfilling their womanly role in the house.

To summarise, life for the women in Kibera was a tale of the uncertain and hard to predict reality in the slum. They had chosen and developed their social networks and developed when moving into the area, thus achieving some sense of security and belonging. With the visible pregnancy, however, these social networks failed them and the women portrayed themselves as 'vulnerable and striving to survive'.

Both rural and urban women avoided disclosing their HIV infection and experienced stigma during pregnancy. Their different social networks and relationships lead to different behaviour and reasoning in relation to PMTCT-adherence.

Interpretation and Discussion

The choice of narrative structuring as method proved to suit our data well and gave the opportunity to focus on what was typical for the women in the two areas selected for the study. Based on our knowledge of the context and the careful process for data-collection and analysis we think these stories represent the situation of the women well. The two narratives highlight how differences in social composition and way of life between the urban and rural settings lead to varying experiences when becoming pregnant and, thus also to different strategies for managing PMTCT adherence.

Daily life and social environment

In their narratives, women in Busia described their lives as 'secure and family controlled'. They lived close together with the members of the extended family, to whom they were related through marriage. They knew what their role in the homestead was and what was expected of them and they accepted it. As long as their HIV infection remained secret, life could continue along the well-known path. The social networks they belonged to encompassed everyone in the village in concentric circles (Pescosolido and Rubin 2000; Simmel 1955), and they would meet the same people for church on Sunday and in the market or hospital during the week. Most of what happened in the village was common knowledge and all participated in each other's joys and sorrows. This gave the women security and predictability in life, but also meant that it was difficult to keep secrets. Keeping their HIV-infection secret was a choice they made for acceptance and survival. They and their husbands knew that revealing it would shake the family stability, cause problems and most probably exclusion. The pregnancy was received with joy and seen as a gift to the family and the community. It was the responsibility of the whole family and the

mother-in-law took charge of the wellbeing of both mother and unborn child. This is consistent with observations that village members are controlled by group expectations and a good member is one who puts the good of the community first (Oboler 1985).

For the women in Kibera life was different. Their narratives were a tale of the uncertain and hard to predict reality in the slum, but also of self-reliance and decisiveness. They portrayed themselves as 'vulnerable and striving to survive'. Different from in Busia they had chosen their social networks and developed their relationships with neighbours and others themselves, when moving into the area. Women belonged to several, partly overlapping, partly independent, social networks serving different functions and offering them a sense of security (Pescosolido and Rubin 2000; Simmel 1955). In their longing for identity and position, women had made the conscious choice to bear a child, which would give identity as a mother and status as somebody's woman (Emneyonu et al. 2008; Cooper et al. 2007). They were aware of the risks to the baby and the responsibility they took on. When discovering how negatively their closest networks, the neighbours and the peer-group reacted to their pregnancy, they looked for support from elsewhere. For them, as for most Kenyans, they turned to relatives, a network with no intersection with their other group affiliations. Relatives do not fail, but also expect service in return. Here they could keep their HIV status secret but had to struggle to keep hospital appointments.

The challenges of disclosure and non-disclosure

In both narratives, the women explained how disclosure and non-disclosure strained existing relationships during pregnancy. It became difficult for the women in Busia to keep their HIV-status secret, when family members took responsibility for the well being of the pregnancy and the baby. They lived in a constant conflict of either adhering to the PMTCT-instructions, not using traditional medicine and delivering in the hospital or following the advice of the mother-in-law to use traditional medicine and accepting the constant supervision of family-members. For them, the decision to keep the HIV-infection secret and not to obstruct the stability of the traditional social set-up was more important than PMTCT compliance. Their strategising focused around how to stay within the social norms and avoid suspicion or disclosure of their infection.

For the women in Kibera who decided to become pregnant to gain in position and identity, the reaction of neighbours and PTC-members when the pregnancy became visible was a shock. The different social relationships they had established failed them and they were left to manage by themselves. Their pregnancy raised fear among neighbours, as it was a signal that not even people who knew better and had been taught about safer sex were to be trusted. It drew slander over both the women themselves and their partners. Life had taught these women that they had to solve the situation themselves and they chose to leave instead of accepting isolation and slander. To manage, they decided to return to the most basic network, the extended family, for support. During the pregnancy they moved in with distant relatives in other parts of Kibera, where their involvement with the PTC was not known. For them the struggle was not to keep their status secret but to manage the duties they had to do in return for board and lodging as well as keeping the PMTCT-appointments.

According to Goffman (1963) a person, known or perceived to have a stigma is aware of his differentness and is adept at managing it. For both groups of women, stigmatisation due to either disclosure or non-disclosure guided their decisions. For the Busia women, their identity and security was part of the social set-up they belonged to and they chose to conceal their status not to disturb the relationships. Adjustment and being part of a community was guiding their choices. For the Kibera women, HIV-infection was not a reason for stigmatisation and so they had chosen to be open about their infection. Their problem was that their choice to become pregnant while being HIV-infected was not accepted. Their new social networks failed them and they were left to fend for themselves. The self-surviving mobile women in Kibera found that to break up and leave was the best option at that point in time and for the short-term future.

Challenges and implication for Prevention of Mother-to-Child Transmission of HIV

There were certain similarities to being non-adherent to PMTCT in the two narratives. The women missed PMTCT appointments, delayed or missed taking HIV medicines and planned to have home deliveries because of the fear of stigma originating from disclosure of the HIV infection. All women had disclosed to their partners and they pointed out how they trusted their partners to help them follow PMTCT requirements. The importance of the trust and support of the partners has been shown in previous studies (Ezegwui et al. 2009; Antelman et al. 2001; Varga, Sherman, and Jones 2005). Partners were consulted in times of need and they proved dependable and concerned about the wellbeing of the women and the baby. This supports studies showing that the form of relational ties that exist between the individual and his/her network determines disclosure of a HIV diagnosis (Miller and Rubin 2007).

The women were determined to fulfil their roles as mothers and homemakers thus avoiding hospital delivery to maintain the social image as responsible women. In Kibera, the community was not always aware that women living with HIV could minimise the transmission of HIV to their partners and chose pregnancy thanks to ART. Information on the possibility of childbearing for women with HIV should be available at the community level to reduce stigma.

All the participants preferred the services of the TBA for delivery because this enabled them to perform their duties at home and meet the perceived expectations in their community. The TBA services were preferred because the social organisation of homebirths, the socio-physical closeness of TBA to the women, their acceptability and availability, as well as the sensitivity of their services to the cultural, economic and personal needs of the families, households and communities.

In this study, the women themselves decide what to tell and what to conceal and the narratives are based on how they chose to depict themselves and what they wanted to convey about their situation. To enhance trustworthiness, the findings were shared with the PMTCT programme staff, who recognised the stories as adequate representations of the women's situation and experiences. The main criterion for assessing trustworthiness in

qualitative research is how plausible and coherent the narratives are and how well the process for reaching the conclusion is described (Riessman 1993; Sandelowski 1991).

Significantly, however, our study focuses on the special group of women who chose to become pregnant while on ART. This is a unique sample being studied as many women in Kenya, as is in other African countries, get to know of their HIV infection during antenatal care. For newly diagnosed women, knowledge of the infection and the requirements of the ART would be both new and demanding, and they would probably not have discussed it with partner.

Conclusion

Our findings identify the difficulties of adhering to PMTCT that the HIV infected pregnant women face either due to fear of stigma in the closely-knit family network or due to negative reactions from new social networks in a slum. Despite the differences observed in these two contexts, HIV-related stigma and lack of disclosure pose important challenges to PMTCT in relation to maternal and child health.

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References

- Antelman, G., M.C. Smith Fawzi, S. Kaaya, J. Mbwambo, G.I. Msamanga, D.J. Hunter, and W.W. Fawzi 2001. Predictors of HIV-1 serostatus disclosure: a prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *AIDS* 15 (14):1865-74.
- Awiti Ujiji, O., A.M. Ekstrom, F. Ilako, D. Indalo, and B. Rubenson 2010. "I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study. *BMC Women's Health* 10 (13).
- Central Bureau of Statistics. 2003. Kenya Demographic and Health Survey 2003. edited by Ministry of Planning. Nairobi: Kenya Government Printers.
- Cooper, D., J. Harries, L. Myer, P. Orner, H. Bracken, and V. Zweigenthal 2007. "Life is still going on": reproductive intentions among HIV-positive women and men in South Africa. *Social Science and Medicine* 65 (2):274-83.
- Emneyonu, N., M. Maier, I. Andia-Biraro, A. Kaida, R. Hogg, and D.R. Bangsberg. 2008. ART, fertility desire and recent fertility history of HIV-positive Ugandan women. In *Presented at conference "Switching gears in HIV research"*. Johannesburg, South Africa.
- Erulkar, A.S., and J.K. Matheka. 2007. Adolescents in the Kibera slums of Nairobi Kenya. Nairobi: Population Council.
- Ezegwui, H.U., E.E. Nwogu-Ikojo, J.O. Enwereji, and C.C. Dim 2009. HIV serostatus disclosure patterns among pregnant women in Enugu, Nigeria. *Journal of Biosocial Sciences* 25:1-10[Epub ahead of print].
- Frank, A.W. 1995. *The Wounded Storyteller Body, Illness, and Ethics*. London: The University of Chicago Press, Ltd.
- Gulis, G., J.A. Mulumba, O. Juma, and B. Kakosova 2004. Health status of people of slums in Nairobi, Kenya. *Environmental Research*. 96 (2):219-27.
- Kenya National AIDS/STI Control Programme (NASCOP). 2008. Kenya AIDS Indicator Survey (KAIS) 2007: Preliminary report. Nairobi, Kenya: Ministry of Health.
- Koenig, L.J., D.J. Whitaker, R.A. Royce, T.E. Wilson, M.R. Callahan, M.I. Fernandez, and Perinatal Guidelines Evaluation Project Group 2002. Violence during pregnancy among women with or at risk for HIV infection. *American Journal of Public Health* 92 (3):367-70.
- Kvale, S. 1996. *Inter Views - an introduction to qualitative research interviewing*. London: SAGE Publications.
- Medley, A., C. Garcia-Moreno, S. McGill, and S. Maman 2004. 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 Organisation*. 82 (4):299-307.
- Mischler, E. 1986. *Research Interviewing: Context and Narrative*. Cambridge, MA: Harvard University Press.
- Neville Miller, A., and D.L. Rubin 2007. Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: people living with HIV/AIDS in the Sub-Sahara. *Qualitative Health Research*. 17 (5):586-98.
- Oboler, R.S. 1985. *Women, power and economic change. The Nandi of Kenya*. California: Stanford University Press.

- Okal, J., S. Luchters, S. Geibel, M.F. Chersich, D. Lango, and M. Temmerman 2009. Social context, sexual risk perceptions and stigma: HIV vulnerability among male sex workers in Mombasa, Kenya. *Culture Health and Sexuality*:2009 May 29:1. [Epub ahead of print].
- Pescosolido, B.A., and B. Rubin 2000. The Web of Group Affiliations Revisited: Social Life, Postmodernism, and Sociology. *American Sociological Review* 65:52-76.
- Riessman, C.K. 1993. *Narrative analysis*. London: SAGE Publications.
- Sandelowski, M. 1991. Telling stories: narrative approaches in qualitative research. *Image-The Journal of Nursing Scholarship* 23 (3161-6).
- Simmel, G. 1955. *Conflict and the web of group affiliations*. , Translated by K. H. Wolff and R. Bendix. New York: Free Press.
- Townsend, L., A. Ragnarsson, C. Mathews, L.G. Johnston, A.M. Ekström, A. Thorson, and M. Chopra 2010. "Taking Care of Business": Alcohol as Currency in Transactional Sexual Relationships Among Players in Cape Town, South Africa. *Qualitative Health Research* [Epub ahead of print].
- Turan, J.M., S. Miller, E.A. Bukusi, J. Sande, and C.R. Cohen 2008. HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services. *AIDS Care* 20 (8):938-45.
- Varga, C.A., G.G. Sherman, and S.A. Jones 2005. HIV-disclosure in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa. *AIDS Care* 18 (8):952-60.
- WHO. 2011. *PMTCT Strategic Vision 2010-2015* 2010 [cited Accesses February 15 2011]. Available from http://www.who.int/hiv/pub/mtct/strategic_vision.pdf, page 6.
- Yebei, V.N., J.D. Fortenberry, and D.O. Ayuku 2008. Felt stigma among people living with HIV/AIDS in rural and urban Kenya. *African Health Sciences* 8 (2):97-102.

IV

**‘Keeping Healthy in the Backseat.’
How Motherhood Interrupts HIV Treatment in Recently Delivered Women.**

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Abstract

Background. Although there is a large body of literature related to the experiences of motherhood and the aspects of change that it brings about, how experiences of motherhood affect care of women with chronic illness is less documented. This study explores how motherhood in newly delivered HIV-infected mothers in Kenya interrupts treatment.

Methods. Qualitative interviews were performed with 26 mothers on ART in rural and urban areas. The data was organized and interpreted using content analysis.

Results. The study found that adherence is influenced by contextual differences in socio-cultural expectations and family relationships. Urban life enabled women to make decisions on their own and negotiate challenges that were often unpredictable. Women in rural areas always knew what was expected of them and decisions were not for them alone to make. The women had difficulties combining adherence with attaining the socio-cultural definition of 'good mothering'. Lack of support from health providers and weak health systems contributed to inadequate stocks of HIV drugs and inaccessibility of HIV care. The theme 'Keeping healthy in the backseat' with two sub-themes 'regaining self-worth through motherhood' and 'mother first - patient later' were developed.

Conclusion. Motherhood is context specific and follows socio-cultural practises making it difficult for women in Kenya to follow ART-treatment instructions. There is a need to reassess HIV-services for mothers on ART to give them a better chance to stay on treatment and be 'good mothers'. Context specific HIV treatment policies are necessary for ensuring adherence and successful treatment outcomes.

Key words: Adherence; Antiretroviral therapy; Childbearing; Fertility; HIV prevention; Social context;

Background

The increased access to antiretroviral therapy (ART) has enabled infected people to live longer and healthier and pursue childbearing. As ART has to be taken for life, adherence is crucial for treatment success. In the past two decades human rights and equity considerations have played a key role in the formulation and implementation of HIV treatment policies. Recently there has been increased concerns about the little attention given to the local socio-cultural realities that determine treatment success in sub Sahara Africa (SSA) (Hardon, 2005). ART gives hope to resume normal life courses including sexual relationships, marriage and childbearing, and to attain socio-cultural aspirations. During reproduction women follow cultural practices and perceptions that at times complicate adherence to ART and general HIV treatment and care.

Motherhood takes place within a cultural context and is shaped by the perceptions and practices that give meaning to the social construction of motherhood in that culture. Beliefs and practices take shape around the cultural traits that are passed on from one generation to the next. These practices are deeply rooted and embedded in society and thus become part of people's lifestyles. They are innate and difficult to change as people have adhered to them throughout their entire lives (Ngomane & Maludzi, 2010). Bhopal (1998) in his studies stated that: "... the woman is judged as a good or a bad mother [within her social context](Pescosolido & Rubin, 2000)" (p. 492). The HIV and AIDS prevention campaigns have advocated many changes in the lives of women in the last decade, such as the age at which to start sexual relationship, marry and even have children. Although there is a large body of literature related to the context-specific experiences of motherhood and the aspects of change that it brings about (Liam, 1999; Liamputtong, 2002; Liamputtong & Naksook, 2003; Sethi, 1995; Weaver & Usher, 1997) how the experiences of motherhood affect care of women with chronic illness like HIV and AIDS are less studied. Obviously illness disrupts mothering ability as has been shown in nursing studies (Vallido, Wilkes, Carter & Jackson, 2010). However, how chronic illness management is associated with socio-cultural expectations of reproduction is less understood. In a recent study in Kenya on sexual behaviour with the hope of becoming pregnant we found that the ability to perform house chores was a sign of resumed strength and meant good health which was a motivation for pursuing motherhood against the advice of ART providers (Awiti Ujiji, Ekström, Ilako, Indalo & Rubenson, 2010). In another qualitative study in the same setting about adhering to PMTCT we found that women reasoned and behaved differently depending on the social structural variations in a slum compared to a rural area (unpublished data). We argued that the patterns of social relationships in urban and rural areas influenced pregnant women's identity formation and decision-making on PMTCT adherence differently depending on social environment. Referring to Simmel's (1955) work on 'group affiliations' and social relationships (Pescosolido, 1992) we demonstrated how the complete overlap of 'group affiliations' in rural areas ensured strong ties between the pregnant women and their family and community. This inclusive closeness entailed a level of control and enhanced social security, but gave little room for deviating personal development and levels of tolerance for the new and unexpected were low. This made following PMTCT difficult as decisions were not for the pregnant women alone to make but were taken over by elderly women in the extended family with responsibility for the pregnant woman and her unborn child. The study further showed that pregnant women receiving ART accepted traditional medicine and participated in cleansing ceremonies to fulfil community expectations (unpublished data). When describing social relationships in urban areas Simmel (1955) found that 'group affiliations' to a larger extent only overlap partly and that can be joined and left at wish without affecting other affiliations. The pregnant women in the slum were able to join

different groups who provided them with choice and freedom to make personal decisions. They maintained ties with different groups: having loose and weak connections with some circles, while stronger with others. The affiliations were more flexible and short-lived and thus also provided less interference. This made the pregnant women in urban areas more vulnerable to the challenges of daily survival that was normally unpredictable but also more decisive about finding solutions to overcome the immediate problems. This unfortunately at times led to not following PMTCT instructions. Our findings suggested that the behaviours and experiences of residents in rural and urban areas are bound to differ following contextual variations.

Adherence to ART is crucial for treatment success. Socio-cultural expectations in the contexts where women live determine mothering. This study explores how motherhood leads to interrupting HIV treatment among newly delivered mothers in Kenya.

Methods

Study areas

The study was designed to represent both urban and rural areas in Kenya with a slightly higher HIV prevalence than the national average. The Kibera slum is composed of multiple villages with a population of 0.5 to 1 million (Erulkar & Matheka, 2007). It is estimated that one in four Nairobi residents live here (Central Bureau of Statistics, 2003). Most residents are tenants, with the land being government owned. Dwellings are generally small and of poor quality. High levels of poverty characterize Kibera with over half of the population living in poverty. People earn their living through small-scale business or as casual labourers on building sites. Jobs for women are scarce and many perform domestic work that is often unpaid. There are no government hospitals in Kibera and health services are provided by non-governmental organizations. The many entertainment spots providing alcohol and drugs and the large networks of commercial sex workers make Kibera a high-risk environment for HIV transmission (Gulis, Mulumba, Juma & Kakosova, 2004).

Busia is a rural and resource-poor area with a high HIV prevalence in Western Kenya (Central Bureau of Statistics, 2003). The study catchment area has a population of 202,348 living in 312 villages, with 50,000 women of reproductive age and 38,000 children under five years. There are 22 health facilities that are either private, church or government owned. Agriculture, fishing and commercial undertakings on small scale are the main economic activities in the district. The average household in the district generates approximately \$84 per month (Central Bureau of Statistics, 2003).

Study design

This study has a qualitative design and aims at exploring how motherhood mitigates HIV-treatment in newly delivered mothers on ART. The data is collected in a dialogue between the participants and the researcher. The findings represent those participating in the study and can be used to develop an understanding of relationships, decision-making and behaviour.

Participants

Female ART recipients with infants aged less than six months were purposively selected from the registers in the Kibera and Busia PMTCT programs. To get a wide representation the women were selected not only by residence (urban slum Kibera or rural Busia), but also in terms of marital status (married/unmarried), duration on ART before pregnancy (newly initiated <1 years/experience) and number of children (women with older children and first time mothers). A community health worker at each site introduced the study and its objectives to the women. Those who were willing to share their experiences and agreed to

participate in the study gave verbal informed consent and were asked to suggest the time and place for the interview. Twenty-six women: 16 in Kibera and 10 in Busia were interviewed. No one declined to participate.

Of the 16 women residing in Kibera, three were single, three were married and ten were cohabiting. Ten had been on HIV treatment for less than one year before the pregnancy. The longest and shortest time on ART was six years and one year respectively. All were unemployed and relied on their partners for food, rent and general upkeep. Almost all had immediate family members living in rural areas. Five had disclosed their infection to the partner and fourteen had disclosed to a female relative. Thirteen women chose to exclusively breastfeed their infants at birth.

All the ten women in Busia were married and lived in a hut with the husband in a shared homestead with the extended family. Even though the women had decision-making power within their respective households, an elder woman in the family usually the mothers-in-law oversaw that the larger family lived in harmony. All the Busia women had disclosed to husbands. The longest and shortest time on ART was four years and one year respectively with one woman becoming pregnant during the first year on ART. All women were aware of their HIV infection before pregnancy and were exclusively breastfeeding their infants.

Data collection

The main author performed all the interviews in Kibera and a midwife trained in qualitative research did the interviews in Busia. A semi-structured question guide was used during the interviews, which were tape recorded with the participants' permission. The interviews were conducted in Kiswahili in Kibera and in Luhya in Busia. We asked the women to reflect on adherence to HIV treatment after childbirth and to tell about their experiences. Probing was used during the interviews to explore views about adherence when being a mother, including motivations for adherence and challenges in adhering. The interviews lasted between two and three hours depending on the women's willingness to talk. The interviews were interrupted by childcare demands and other tasks that the woman had to perform. When needed the interviewers stayed on to assist the mother with childcare, and sometimes cooking and cleaning. The interview guide was piloted to provide insights and a chance to improve the flow and clarity of the questions. The women were not given any incentives or rewards. A counsellor was available for referral for women who needed support but no woman was referred.

Data analysis

Data were analyzed qualitatively using content analysis, guided by Graneheim and Lundman (2004). Initially, the transcribed material was read a number of times to get a general sense of the interviews. Meaning units were identified, condensed and coded. The codes were compared and grouped into sub-categories and categories. In the process of consistent moving between the fragmented text and the whole, the sub-categories and categories were re-organized and the theme developed (Graneheim & Lundman, 2004). The first author initially performed the coding and analysis independently and then together with the research team. The categories and the theme were arrived at by consensus between the authors to describe why mothers interrupt HIV treatment during the postnatal period.

Trustworthiness

Trustworthiness is related to how well the study captures the reality of those being studied. The interviewer's prolonged engagement in the study area, her following support group

sessions and participating in data collection activities were crucial for understanding the situation and the stories of the participants. Using face-to-face interviewing enabled the interviewers and participants to build rapport and discuss issues freely. Peer debriefing sessions and joint analysis by the research team representing different disciplines and experiences, were important to increase the credibility of the study results.

Ethical Considerations

Ethical approval was obtained from the ethical review committee of the Kenya Medical Research Institute (KEMRI) and the regional ethical board at Karolinska Institutet. All study participants were assured that their anonymity would be strictly upheld throughout. It was stressed that participation in the study was voluntary, and that they could withdraw at any time without any effect on them, their family or care and treatment given. Due to the high illiteracy levels and the reluctance among the women to have a written record of their signatures only verbal consent was asked for.

Findings

The theme ‘keeping healthy in the backseat’ consisting of two sub-themes (i) ‘regaining self-worth through motherhood’ and (ii) ‘mother first – patient later’ was developed from the data. The theme ‘keeping healthy in the backseat’ illustrates how motherhood experiences when infected with HIV vary in contexts leading to different expectations, dilemmas and contextual realities that influence adherence to ART/ PMTCT hence the need for context adapted HIV treatment programs. The sub-theme ‘regaining self-worth’ points to how becoming a mother gave hope for a normal life that initially seemed challenged by the HIV-infection through the possibilities for improving social relationships and achieving cultural aspirations. The sub-theme ‘mother first - patient later’ highlights contextual difficulties in following the ART/ PMTCT-guidelines leading poor adherence.

Keeping Healthy in the Back Seat			
Regaining self-worth through motherhood		Mother first – patient later	
Finding self in motherhood	Reduced support for woman after childbirth	Not pregnant, not sick	Healthcare not supportive after childbirth

‘Regaining self-worth through motherhood’

Finding self in motherhood The women explained how the child changed their socio-cultural context making it possible not only to achieve womanhood but also to regain normal life even if infected with HIV. For women in Kibera becoming a mother made it possible to regain dignity while negotiating the challenges of being HIV infected that included loneliness, poverty and stigma. A child was perceived to make a relationship stronger and keep the man close. Single women in Kibera told about a child indicating a male presence and a possible entry into marriage, which gave them purpose in life and a feeling of being seen as useful in the community. They explained that disclosing the HIV infection had made it difficult to start relationships and they were worried that as single women they would be belittled and loose respect.

‘I feel like am contributing something with my life now that I am a mother. I can show that there is a man in my life . . . it is hard to get a man when having HIV. I am not afraid of being despised anymore because of not staying with a man . . . I worried about not having a man . . . now I am respected and treated well . . . my child links me to a man (22 years, 2 years on ART-Kibera).’

Motherhood guaranteed some security and the women told about actively planning the pregnancy to have a man provide for food that is crucial to taking HIV medicine. Women whose HIV infection was known in the community described negative reactions from the community when their pregnancy was visible. A child would convince the community that they still cared about human life despite being HIV infected and that it was not their intention to transmit HIV to partners or anybody for that matter. They explained that being a mother provided the opportunity to show they were humane, good and responsible.

For women in Busia motherhood would ensure that they fulfilled the many expectations of childbearing that they felt were threatened by being HIV infected. They told of their worries about not only having children, but also about having children infected with HIV. Motherhood was a role that they had been socialized to attain and childlessness meant failing in the wife’s duties and in conforming to cultural values. Children were thought of as a

natural result of marriage and a son was important for clan-continuity. For first time mothers the child justified marriage and showed determination to abide by the role as a wife. For mothers with more children it secured their position and the constant praises after childbirth gave the women self-worth. They were happy to overcome the HIV infection and ensure continuity of kinship by attaining motherhood.

'I have proved to myself that I can still be a real woman even when sick. Having my child reminds me that I have not allowed this disease to hold me down. Becoming a mother has saved my face and brought pride to my husband and his family. I am the same with the one without it [HIV uninfected woman] (25 years, 2 years on ART-Busia).'

Despite the different experiences in Busia and Kibera motherhood was an opportunity for recipients of ART to fit in, be real women and not to be seen as failures.

Reduced support for woman after childbirth After the delivery the women felt a constant pressure to prove that they were good mothers by performing childcare and domestic chores. However, it also meant not being allowed to be sick especially without having any visible signs of illness (a consequence of ART). The lack of social support was mentioned as hindering the treatment of HIV.

Women in Kibera did not live close to their family members, but during the pregnancy they had received some support from relatives in the form of food and even with house chores. This social support was mentioned as crucial when on ART. After childbirth, however, the women continued to live as before the pregnancy, facing loneliness, the lack of food and no money.

Instead of being alone with the responsibility the women in Busia lived with the constant presence of older women, who advised them on how to take care of the children and house duties. They felt obliged to always do things right according to the requirements and were striving to be 'good mothers' to attract pride and respect from the family. Their own health needs had to be put in the background, as everybody was concerned about the new child.

Mother first - patient later

Not pregnant, not sick The women were all on ART and needed regular contact with a health facility. They knew about the relationship between good health and adherence and between adherence and low viral load. Good nutrition was also mentioned as contributing to good health, a prerequisite for good mothering. However, being a mother you are expected not to be sick and the women felt it became difficult to seek timely health services. Women in Kibera were restricted when visiting their families in rural areas and also reported delaying to seek health care, as they were unsure about the nature of their health problems.

'I do have headaches and feel unwell . . . it could be because of too little sleep or worry about the future of my children. Motherhood is stressful and can make someone feel sick. In my condition it is hard to know if my HIV is the cause or it is because of mothering these children of mine. (26 years, 3 years on ART-Kibera).'

In Busia a successful delivery meant that the perceived health risks during the pregnancy were over. It was common knowledge to the elder women in the community that mothers had health problems after delivery that were not serious enough to warrant a visit to the health facility.

'I have delivered and all went well. How can I convince my mother-in-law that I need to see a doctor without any severe diarrhoea, pain and constant vomiting or physical signs? She says headache, stomach pains and body weakness are health changes caused by childbirth and can be managed at home. She will just give me herbs and keep me at home (21 years, 3 years on ART-Busia).'

For women who had not disclosed it could be difficult to explain for example the need to maintain clinic appointments, as they did not have any visible symptoms of the infection. It became hard to convince elder women to accept visits to the health facility, especially if the baby was not involved.

Healthcare not supportive after childbirth The staff at the clinics had been very supportive during the pregnancy, which had enabled the women to adhere to the guidelines of ART/PMTCT. Now the women had difficulties combining the care of the newborn child and the expectations of being 'good mothers and housewives' with the ART-services, especially the distribution of HIV medicines. The services were the same as during the pregnancy, but then others readily helped them with the care of older children and housework. This made the women feel that there was no consideration for their reality and possibilities to follow HIV treatment with a newborn child. Long waiting time was a main reason for non-adherence to HIV treatment. Women in Kibera also complained about nepotism among the clinic staff. The constant lack of food and income together with the tasks of motherhood were mentioned as reasons for forgetting to take medicines. Women in formal relationships had partners who could remind them about the medicines. The women knew the importance of eating well while on ART and they feared the negative side effects from taking medicine without food. Nearly all women said that they had interrupted breastfeeding and opted to feed their babies with formula milk after realizing that they did not have enough to eat. Then they had to skip meals for the child, as formula milk was too expensive.

'During the pregnancy I had decided to breastfeed my child. I did so when she was born but stopped when she was two months because of food shortage. I had little breast milk and was worried that it was not good enough for the child. I started on formula milk, which is very expensive. I only eat once a day and save the money for my baby's food (30 years, 4 years on ART-Kibera).'

Non-governmental organizations (NGOs) providing PMTCT made it possible for the women to occasionally get free formula milk for their infants.

In Busia the women worried that the long waiting-times could make them seem incapable and irresponsible as mothers and possibly distort the aspired image of being 'a good mother'. The women complained that the clinic was not flexible and willing to accommodate to their needs now that they were mothers of newborns with all the attention and expectations that meant in the family environment.

'There are only two doctors here at a time to see us (ART patients)it is slow...if only there could be more doctors, it would take less time The clinic should consider that I am now a mother I should not have to stay here long....my duties are not complete at home...what kind of mother am I?sometimes I choose not to come and stay home without my medicine (25 years, 4 years on ART-Busia).'

The women were also concerned that that the ART clinic was secluded and could lead to the disclosure of their HIV infections to the community and extended family.

Discussion

Our study illuminates how motherhood impinges on following HIV treatment focusing on (a) the influence of social context on experiences of motherhood when infected with HIV and (b) how changes that come with becoming a mother affect adhering to HIV treatment. Our findings illustrated how women living with HIV engaged in maternal practice that included love for their children and the wish to protect them from the virus, toil to be good mothers and meet expectations, and difficulties with adhering to ART/PMTCT guidelines thus risking good treatment outcomes. Kitzinger (1993) observed that becoming a mother is not only a biological process but also a social transformation involving the whole life situation of the woman and her relationships (Kitzinger, 1993). We show that motherhood among women living with HIV involved managing the illness itself as well as the social consequences when trying to protect the child from infection and preserving a positive mother identity. In addition we found that adherence behaviour was different in urban and rural areas because of the variation in socio-cultural expectations and family relationships.

The women knew that adhering to HIV treatment was a pre-requisite for staying healthy. The pregnancy attracted attention from relatives who became involved in maintaining the health of the woman both in Kibera and Busia.

In the context of Kibera survival was tough and the women faced extreme poverty. The environment was unpredictable and it was not unusual to miss meals. The women told about having immediate family members living in rural areas. They had distant relatives staying within Kibera but not close to them. For mothers on ART in Kibera life was all about surviving on their own and being vulnerable to poverty and its challenges to adhering to treatment. Even though the relatives did not live close to the women in Kibera, they showed concern, brought food and helped with house chores. After childbirth the involvement decreased again and the women had to move on with their lives just as before the pregnancy. The women had to toil to have basic needs like food, which was important for adherence. Taking ART on an empty stomach produced negative side effects and the women feared taking HIV medicine as prescribed when hungry. In Kibera the reality of poverty and high levels of unemployment make it hard to obtain essential needs for survival. Apart from worrying about food for herself and the children, the women had to also had to cater for other needs such as clothes and beddings that needed money. They decided to skip their own meals so as to save money. Although aware of the relationship between adhering to HIV medicine and eating regularly, they chose to prioritise their children's wellbeing over their own illness to prove that they could meet the demands of motherhood and were capable mothers hence 'finding self through motherhood.' Other studies have shown that the lack of food contributes to patients not adhering to HIV treatment (Unge, et al., 2008). Our study demonstrates how the responsibility for a child adds additional reason for poor adherence, when resources are scarce and have to be shared.

For the women in Kibera sustaining exclusive breastfeeding during ART without food was difficult. The women knew that their health would deteriorate because they were non-adherent to ART. Adherence is important for suppressing the HIV and keeping the viral load in the breast milk low. The women worried about transmitting the HIV to their infants and thus stopped exclusive breastfeeding. They instead alternated between breast milk and formula milk, even though they knew it was wrong and initially had decided to breastfeed their infants at birth. They were also concerned about being undernourished and that the breast milk would not be enough. According to PMTCT guidelines infants exposed to HIV should be either exclusively breastfed for six months and rapidly weaned or they should be

provided with alternative feeding exclusively. Instead of exclusively breastfeeding the women in Kibera began to alternate between formula and breast milk depending on the availability of formula, which was distributed free of charge from some PMTCT-programs (not where the study was done). This had implications for the sustainability of exclusive breastfeeding. The NGOs providing PMTCT operate independently from each other but share patients within Kibera. Women could thus obtain free formula milk from other NGOs for their infants. Poor women even sold some of the formula to get money for food and instead breastfeed their child intermittently (personal communication by Dorcas Indalo, social worker and community mobiliser at the AMREF clinic in Kibera). It is important for PMTCT programs to counsel about the benefits of sustaining infant feeding methods and prepare mothers in relation to individual concerns.

The too many demands on motherhood and the women's strive to be 'good mothers' interfered with adherence to ART.

In the context of Busia the mothers on ART had continuous involvement and presence of female family members. It also meant that the mothers on ART could not make decisions on their own. Older women were responsible for the health of both mother and child during the pregnancy and in the period after childbirth. It was common knowledge that health problems are experienced after childbirth and hospital visits were normally unnecessary. Traditional medicine was used to manage the health problems at home. Recently, WHO acknowledged the importance of integrating indigenous medicine with the national health care system (Homsy, King, Balaba & Kabatesi, 2004). Despite the fact that traditional medicine is the primary source of health care in SSA, little is known about the interaction between traditional medicines and ART (Mills, et al., 2006). The women had not disclosed the HIV infection to the elder women and it became hard to explain the need for visiting the ART clinic to pick up medicines. This is consistent with findings that non-disclosure and the lack of social support encourage dropping out of ART (Dahab, et al., 2008). We add on to show that the extent of social support from a partner during mothering is context specific. Whereas it could benefit mothers on ART who do not live close to family members such as in Kibera, among those in living in a traditional rural homestead partner support was limited. The women's husbands knew about the HIV infection. However they did not play a significant role during mothering and did not make any decisions regarding the women's visit or the child's visit to the clinic. This points to the need for HIV service providers to find better way of reaching women on ART after childbirth in rural areas.

The women looked healthy and thus there was little understanding for their need for regular follow up in the clinic. The women knew about the importance of keeping appointments and taking medicines. In Kibera the women made their own decisions about visiting the clinic. However, they often had to wait and they would chose to go home to perform duties so as to maintain their role as good mothers. For the women in Busia the decision to visit the clinic for their own sake was not for them to decide on. If they managed to visit the ART clinic at the same time as the visit to the child clinic, the long waiting hours often made them give up and go home. They did not want to be perceived as irresponsible mothers and rather missed picking up their HIV medicines. Long waiting time, work and family responsibilities, and being away from home have been shown to be barriers to adherence in ART (Dahab, et al., 2008; Hardon, et al., 2007; Mills, et al., 2006). Staying long at the hospital could also make family members follow them to the clinic to see why they were late, which could possibly reveal their HIV infection.

Conclusion

Motherhood is context specific and follows socio-cultural practises making it difficult to follow ART-treatment instructions in Kenya. There is a need to reassess HIV-services for mothers on ART to give them a better chance to stay on treatment and be 'good mothers'. Context specific HIV treatment policies are necessary for to ensure adherence and successful treatment outcomes. An option could be to combine mother and infant clinic appointments and provide HIV care for mothers at the postnatal clinic. There is also a need to reduce waiting when they come to pick up their medicines.

REFERENCES

- Awiti Ujiji, O., Ekström, A. M., Ilako, F., Indalo, D. & Rubenson, B. (2010). "I will not let my HIV status stand in the way." Decisions on motherhood among women on ART in a slum in Kenya- a qualitative study. *BMC Women's Health*, 10(13), doi:10.1186/1472-6874-1110-1113.
- Central Bureau of Statistics. (2003). *Kenya Demographic and Health Survey 2003*.
- Dahab, M. Charalambous, S. Hamilton, R. Fielding, K. Kielmann, K. Churchyard, G. J., et al. (2008). "That is why I stopped the ART": patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme. *BMC Public Health*, 8(63), doi: 10.1186/1471-2458-1188-1163.
- Erulkar, A. S. & Matheka, J. K. (2007). *Adolescents in the Kibera slums of Nairobi Kenya*. Nairobi: Population Council.
- Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Gulis, G., Mulumba, J. A., Juma, O. & Kakosova, B. (2004). Health status of people of slums in Nairobi, Kenya. *Environmental Research*. 96(2), 219-227.
- Hardon, A. (2005). Confronting the HIV/AIDS epidemic in sub-Saharan Africa: policy versus practice. Retrieved January 24th, 2011, from http://www.cghi.nl/uploaded_files/publications/Hardon_IntSocScJournal_2006.pdf
- Hardon, A. P. Akurut, D. Comoro, C. Ekezie, C. Irunde, H. F. Gerrits, T., et al. (2007). Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. *AIDS Care*, 19(5), 658-665.
- Homsy, J., King, R., Balaba, D. & Kabatesi, D. (2004). Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *AIDS*, 18(12), 1723-1725.
- Kitzinger, S. (1993). *Ourselves as mothers*. London: Bantam Books.
- Liam, I. I. L. (1999). The challenge of migrant motherhood: the childrearing practises of Chinese first-time mothers in Australia. In Liamputtong Rice P (Ed.), *Asian mothers, Western birth*. Melbourne: Ausmed Publications.
- Liamputtong, P. (2002). Childrearing practices and child health among the Hmong in Australia: implications for health services. *International Journal of Health Services*, 32(4), 817-836.
- Liamputtong, P. & Naksook, C. (2003). Perceptions and experiences of motherhood, health and the husband's role among Thai women in Australia. *Midwifery*, 19, 27-36.
- Mills, E. J. Nachega, J. B. Bangsberg, D. R. Singh, S. Rachlis, B. Wu, P., et al. (2006). Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine*, 3(11), e438.
- Ngomane, S. & Maludzi, F. M. (2010). Indigenous beliefs and practices that influence the delayed attendance of antenatal clinics by women in the Bohlabele district in Limpopo, South Africa. . *Midwifery* 2010 Dec 2019. [Epub ahead of print].
- Pescosolido, B. A. (1992). Beyond rational choice: The social dynamics of how people seek help. *AJS*, 97(4), 1096-1138.
- Pescosolido, B. A. & Rubin, B. (2000). The Web of Group Affiliations Revisited: Social Life, Postmodernism, and Sociology. *American Sociological Review*, 65, 52-76.
- Sethi, S. (1995). The dialectic in becoming a mother: experiencing a postpartum phenomenon. *Scandinavia Journal of Caring Sciences*, 9(4), 235-244.
- Unge, C., Johansson, A., Zachariah, R., Some, D., Van Engelgem, I. & Ekstrom, A. M. (2008). Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya. *AIDS Care*, 20(2), 146-149.

- Vallido, T., Wilkes, L., Carter, B. & Jackson, D. (2010). Mothering disrupted by illness: a narrative synthesis of qualitative research. *Journal of Advanced Nursing*, 66(7), 1435-1445.
- Weaver, J. & Usher, J. (1997). How motherhood changes life- a discourse analytic study with mothers of young children. *Journal of Reproductive and Infant Psychology*, 15, 51-68.