“The Virus Stops with Me”:
Couples Living Positively with HIV in Rural, Eastern Uganda

Rachel Lisa King

Stockholm 2012
Front cover painting by Ssali Yusuf; ‘Love Under a Tree’. Afriart Gallery
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Back cover painting by Thomas Nixon and inspired by Joe Average; ‘The Many Faces of AIDS’

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ABSTRACT

Background: Historically people living with HIV (PLHIV) were left out of the center of the HIV prevention agenda in Africa, yet more recently greater attention has been placed on interventions that forefront PLHIV.

Aim: The overall aim of this thesis was to increase knowledge on the ways couples living with HIV prevent further transmission of HIV and live with health and dignity.

Methods: We identified four main research themes: HIV serostatus disclosure (I), altruism (II), reproductive behavior in the context of antiretroviral therapy (ART) (III), and HIV serodiscordance (IV). We designed, conducted and have reported the results around each of the themes. We used a combination of quantitative and qualitative methods for Articles I & II and purely qualitative methods for Articles III and IV. Participants were selected from two parent studies, both in Eastern Uganda. The first was a cross-sectional study of men and women living with HIV in Jinja District (Articles I & II) and the second was a longitudinal cohort of over 1,000 adults on ART in Tororo and Busia Districts (Articles III & IV). Article I assessed health and social predictors of HIV serostatus disclosure to sexual partners among 1092 adults and purposely selected 45 men and women for in-depth interviews on processes and outcomes of disclosure. Article II explored, among the same participants, concerns about HIV transmission, feelings of responsibility for HIV prevention and associated prevention behavior. Article III explored reproductive decision-making among 29 women and 10 of their partners. Article IV explored understanding of serodiscordance, couple communication and risk reduction, among 40 HIV serodiscordant couples, before and after a risk reduction intervention.

Findings: Disclosure of HIV serostatus among sexual partners was associated with being married, increased condom use and knowledge of partner’s serostatus. Disclosure resulted in far more positive than negative outcomes and was associated with risk reduction behavior. The reasons adults living with HIV provided for their sense of prevention responsibility revolved around ethical and practical themes such as “leaving children orphaned”. Among couples where the women were living with HIV, on ART and were pregnant or had recently delivered a baby, most stated their pregnancy was unintentional and often occurred because they believed they were infertile. In the same study, women who did not get pregnant, mentioned reasons for their choice: poor health, financial strain, the counseling received, not wanting an HIV-infected infant and having already reached their desired family size. Among discordant couples, their current risk behavior was influenced by their understanding about discordance and couple relations /communication and mediated by gender norms around sexual and reproductive health, their past behavior, physical health and the intervention.

Conclusions: A couple’s ability to communicate with each other has a powerful influence on their capacity to adopt risk reduction behavior. To be relevant and effective, interventions to reduce HIV transmission should be mindful of the cultural and structural influences on behavior and consider culturally relevant communication skill building as an integral element of prevention interventions, both with individuals and/or couples.

Keywords: HIV, Uganda, discordant couples, disclosure, reproductive decision making, people living with HIV, ‘positive health, dignity, and prevention’
LIST OF PUBLICATIONS

I. Rachel King, David Katuntu, Julie Lifshay, Laura Packel, Richard Batamwita, Sylvia Nakayiwa, Betty Agang, Frances Babirye, Pille Lindkvist, Eva Johansson, Jonathan Mermin, Rebecca Bunnell
"Processes and Outcomes of HIV Serostatus Disclosure to sexual Partners among People Living with HIV in Uganda"

II. Rachel King, Julie Lifshay, Sylvia Nakayiwa, David Katuntu, Pille Lindkvist, Rebecca Bunnell
"The virus stops with me": HIV-infected Ugandans’ motivations to prevent HIV transmission

III. Rachel King, Kenneth Khana, Sylvia Nakayiwa, David Katuntu, Jaco Homsy, Pille Lindkvist, Eva Johansson, Rebecca Bunnell
"Pregnancy Comes Accidentally - like it did with me": Reproductive Decisions among Women on ART and their Partners in Rural Uganda

IV. Rachel King, Nafuna Wamai, Kenneth Khana, Eva Johansson, Pille Lindkvist, Rebecca Bunnell
“Maybe his blood is still strong”: A qualitative study among HIV sero-discordant couples on ART in rural Uganda (2012) (submitted)

These articles will be referred to in the text by their Roman numerals (I-IV)
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<th>Abbreviation</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ANC</td>
<td>Antenatal Care</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
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<td>ARV</td>
<td>Antiretroviral</td>
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<td>CD4</td>
<td>Cluster of Differentiation 4 (white blood cells)</td>
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<td>CI</td>
<td>Confidence Interval</td>
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<td>DARI</td>
<td>Discordant Action Research Intervention</td>
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<td>FP</td>
<td>Family Planning</td>
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<td>HBAC</td>
<td>Home-based AIDS Care</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>OR</td>
<td>Odds Ratio</td>
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<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<td>PHDP</td>
<td>Positive Health, Dignity, and Prevention</td>
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<tr>
<td>PLHIV</td>
<td>People (or Person) Living with HIV</td>
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<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission of HIV</td>
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<td>PP</td>
<td>Positive Prevention</td>
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<td>PWP</td>
<td>Prevention with Positives</td>
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<td>TASO</td>
<td>The AIDS Support Organization</td>
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<td>TL</td>
<td>Tubal Ligation</td>
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<td>UNAIDS</td>
<td>United Nations Program on AIDS</td>
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<td>WHO</td>
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PREFACE

The community AIDS education group ranged in age from 10 to 35 years; a 10 year old was on stage - a little girl who had been orphaned for 2 years. The group used dance, drama and song as their most powerful means of communicating AIDS prevention and care messages in their community in central Uganda. This little Ugandan girl became one of the shining stars of the HIV prevention group as she could sing, dance and tell her story so poignantly she consistently moved audiences to tears. I witnessed many of their education events, but one in particular will stay with me forever as I accompanied one of our funders from Geneva who was equally moved. The audience was over 100 people and the venue a community center made of mud walls with rusty iron sheeting roof. The occasion began about an hour late as a heavy rain prevented anyone from congregating under a shelter that didn’t really keep rain out. When Nasuna, this 10 year old frail little girl, stood in front of the older women singing, smiling brilliantly, I realized she held the group together with her character and strength. She grinned as she raised her shirt showing crowds the painful shingles rash across her belly. Her courage brought a flood of tears to all of us who witnessed her ability to bring us all in. As we cried, she danced on, and continued singing and smiling. Her powerful little voice glowed. She held captive group after group, teaching youth and teaching adults about living with AIDS. Her beauty and young wisdom radiated in her songs as from an old soul. This tender being, born with HIV, spent her entire short life trying to teach the rest of us something. I wish she was not gone.

Nasuna inspired me when I met her in 1994 and her memory continues to inspire my work. I am grateful to have known her; and am indebted to her. I have lived in Uganda most of my adult life. My roles have changed over time. During most of the time I have worked on this thesis I was with the Centers for Disease Control and Prevention (CDC)-Uganda with multiple projects that formed the material for this work.

Living with HIV, this thesis portrays a few stories of many lives; a quilt of the living and let me hope that this story will add to the larger quilt of knowledge we have gained over these past few decades as one more patch that assembles the quilt of solidarity for our global response.

Figure 1: AIDS Memorial Quilt Washington DC 2012

1 The AIDS memorial quilt weighs currently more than 54 tons and is the largest piece of community art in the world. It was started in 1987 and represents more than 94,000 people; estimating about 20% of the lives lost to AIDS in the US.
BACKGROUND

“Secondary HIV prevention”, or “positive prevention,” is concerned with reducing HIV transmission risk behavior and optimizing the health and quality of life of people living with HIV/AIDS (PLWHIV).

BURDEN OF DISEASE, HIV AND THE GLOBAL RESPONSE

Recent scientific breakthroughs in HIV prevention have been echoed by declarations about “the beginning of the end of AIDS?”[2]; the “elimination of mother-to-child HIV transmission”(UNAIDS) [3] and an “AIDS-free generation”[4]. However, thirty years into this epidemic, UNAIDS estimated that there were 34 million [31.4 million–35.3 million] people living with HIV and 2.7 million [2.4–2.9] newly infected with HIV at the end of 2010 [5]. These numbers paint a many-sided picture of this epidemic and the toll this disease inflicts on people worldwide. For example in 2010, Sub-Saharan Africa, where 12% of the global population resides, was home to 68 % of HIV cases worldwide and 1.9 million (70%) new infections [1]. Women in sub-Saharan Africa remain disproportionately affected [1,6,7]. In 2010, UNAIDS estimated that globally, 50% [48–53%] of the adults (15 years old and older) living with HIV were women, and in sub-Saharan Africa, women comprised 59% [56–63%] of the adults living with HIV[1]. These figures have barely changed in over 15 years. With the dynamic demographics, increasingly data shows that rising proportions of the people newly infected with HIV are in HIV-discordant couples [8,9]. In a context such as Uganda where many members of long-term cohabiting relationships are unaware of their HIV-status, and even greater numbers do not know their partner’s HIV status, many new infections now occur within cohabiting couples [10].

The good news is that the 2011 WHO report estimates that the number of people newly infected globally and in sub-Saharan Africa is decreasing [1]. Compared with 2001, about 16% fewer people acquired HIV in 2010. However, as HIV-infected people on antiretroviral therapy and in care usually live longer, the total number of people living with HIV in sub-Saharan Africa is increasing; it reached 22.9 million [21.6–24.1] in 2010 [1]. Thus, despite the unprecedented increase in numbers of individuals accessing HIV treatment (see Figure 2), UNAIDS noted in 2010 that for every person put on treatment in low- and middle-income countries, two more became newly HIV-infected and fewer than one in five people needing services have access to basic prevention [11,12]. Over 6 million adults and children in low-income countries have initiated treatment but this only represents half the population that is in need of Anti Retroviral Therapy (ART) [2].

Figure 2: Number of People Accessing ART and People dying of AIDS-related causes in low and middle income countries between 2000-2012 [1]
This is an HIV prevention story. HIV prevention strategies are varied, numerous successes have been reported over the last 25 years [13] and today’s HIV prevention stories are inextricably linked to success of ART. HIV can be prevented, but as the director of UNAIDS stated, “If HIV can be prevented, why did 2.6 million people become infected in 2009?”. Today, in 2012, HIV prevention success depends on the committed solidarity and enthusiasm evident in the early response, the accumulated knowledge and scientific breakthroughs of the last couple of years combined with a creative transparency that can transcend barriers of misunderstanding and competing differences.

The particular spotlight of this thesis is on how HIV-infected individuals themselves live the prevention experience. The rationale is explained in greater detail below, but briefly, I set out to explore motivations and communication issues among people living with HIV to better inform HIV prevention and care programs. At the heart of this thesis is the belief that individuals living with HIV can provide valuable expertise into the HIV prevention and care agenda. I address four aspects of HIV prevention among HIV positive adults in Eastern Uganda. The first is processes and outcomes of HIV serostatus disclosure; the second is motivations for prevention among HIV-infected men and women, the third is reproductive decision-making among HIV-infected couples on ART, and the fourth is beliefs about and coping with HIV serostatus discordance. I address these four topics within the framework of “positive prevention” or “prevention with positives” or “positive health, dignity and prevention” (see below), using qualitative methods for all studies and a mixed methods approach for two of the four studies.

POSITIVE HEALTH, DIGNITY AND PREVENTION

HIV transmission is a social, biological, often emotional phenomenon that merits an equally complex prevention strategy. A prevention plan designed to involve HIV-infected individuals was developed in the early 1990s. It contrasted to earlier prevention approaches and activities that focused on known HIV-negative individuals and populations while treatment programs focused on people known or suspected to be already infected with HIV. The rationale of this new approach was that it is more efficient to concentrate attention and resources on the fewer HIV-infected individuals than the many more HIV-uninfected people even though the latter are the eventual beneficiaries of effective prevention. We know that every new infection requires contact between an infected and an uninfected person. With current research in sub-Saharan Africa highlighting the significance of new infections among HIV-serodiscordant couples, it has become clear that prevention efforts aimed at individuals who know that they are infected may have a greater chance of effectiveness [1,14].

Auerbach² clearly outlined principles to be considered in implementing positive prevention programs [15]. These principles include:

* “Relationality”; prevention should be approached as a relational experience. Historically, transmission prevention was focused on the individual, yet it always involves at least two people in a relationship, whether they are a mother and her child, sexual partners or drug users sharing needles.

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²Dr Judith Auerbach currently is the Vice President of Research & Evaluation at San Francisco AIDS Foundation, and has had a distinguished career in HIV research as the HIV Prevention Science Coordinator and the Behavioral and Social Science Coordinator in the Office of AIDS Research at the National Institutes of Health (NIH) in addition to numerous other influential positions.
* Due to this relational aspect, both the transmission side and the acquisition side must be well thought through.

* Lastly, prevention must be viewed in social, cultural and structural contexts. Auerbach also highlighted that no one method will be 100% effective, that HIV prevention and treatment should not be viewed separately but as a combined effort and that science should drive the development of interventions, not politics or ideology [15]. Despite the fact that Auerbach wrote these principles in 2004, they remain more than ever relevant to the epidemic we experience in 2012.

Recognizing the urgency and relevance of the topic, Kalichman3 wrote a book on Positive Prevention that brings together the body of literature on risk behavior and interventions aimed at people living with HIV and included a meta-analysis of 23 studies examining behavior change proximal to receiving an HIV-positive diagnosis [16]. One important finding he reported was that “an HIV diagnosis, whether provided to an individual patient or to a couple, significantly reduces the occurrence of unprotected intercourse and reduces the number of sexual partners of individual HIV-positive patients” [16]. Interestingly, Kalichman noted that a relatively stable small proportion of people continue to engage in HIV risk behavior after the first year post-diagnosis and men and women respond differently to HIV diagnosis: the reduction in risk behavior is higher among women than men [16].

More recently, the Global Network of People Living with HIV has described an evolution from what was “Prevention with Positives” to what became “Positive Prevention” or “secondary prevention” and to what currently is termed “Positive Health, Dignity and Prevention” (PHDP). PHDP stresses the importance of addressing prevention and treatment concurrently and holistically[17]. It also highlights the critical roles of leadership for people living with HIV in responding to policy and legal issues within the socio-cultural and legal environments where they reside [17]. Framed within a human rights perspective, PHDP is founded on a broad basis that includes improving and maintaining the dignity of the individual living with HIV, promoting and enhancing that individual’s physical, mental, emotional and sexual health, which, consequently, enables an environment that will reduce the likelihood of new HIV infections [17].

**DISCLOSURE OF HIV SEROSTATUS**

HIV serostatus disclosure to sexual partners is key to HIV prevention and treatment strategies [18,19]. Disclosure to sexual partner(s) and others by infected individuals has been found to benefit the individual disclosing by improving physical health including increased adherence to HAART and retention in care, alleviating anxiety, loneliness and depression as well as allowing easier access to care, treatment and social support [20,21,22,23]. In addition, disclosing HIV positive status to a sexual partner can initiate preventive behavior [19,24]. The assumption is that disclosure will increase the safety of subsequent sexual activity [18,25]. Additionally, one study showed a dose response relationship between the number of times persons living with HIV were counseled and the frequency of disclosure by these persons [26].

3Dr Seth Kalichman is currently the director of the Southeast HIV and AIDS Research and Evaluation (SHARE) Project, a research program within the AIDS Survival Project in Georgia, USA. He is also the current editor of the bimonthly journal AIDS and Behavior.
Disclosure of HIV serostatus has been studied both in a relational context i.e. who does one feel comfortable disclosing to and not disclosing to, as well as in relation to one’s identity i.e. making HIV status central to one’s personal identity, or not [19,27]. Mayfield Arnold describes a model that posits that disclosure behavior is contingent upon the relationship between individual self identities, community stigma towards HIV, and role relationships within the community [19].

Within the large body of HIV disclosure literature to date, most studies and models have looked at the rates of disclosure and the factors associated with the likelihood of disclosure, while fewer studies have looked at the processes and outcomes of disclosure. Chaudoir and colleagues proposed using the Disclosure Processes Model to address the critical questions of when and why disclosure might actually be beneficial to not only the individual, but to the dyad and the wider community as well [18]. The model hypothesizes that disclosure is a process involving decision-making and outcomes and that there are mediating processes. Underlying disclosure behavior are antecedent goals of either avoidance (avoiding negative outcomes) or approach (pursuing positive outcomes). Disclosure can affect outcomes at the individual, dyadic, and social and contextual levels [18]. Few authors have studied the methods of disclosure. Miller and Rubin found in their study of over 300 HIV-infected adults in Kenya that the method of disclosure most frequently practiced was direct, while mediated disclosure was common in partner/spouse relationships where about one-third of individuals preferred to disclose through a third party [28]. In addition, Mayfield Arnold and colleagues noted that a disclosure process may involve gauging their target audience for the disclosure for potential stigma perceptions before full disclosure [19].

It has been often cited that, “about one third of HIV-infected individuals continue to have unprotected sex, sometimes without informing their sexual partners” [29]. Rates of disclosure to sexual partner around the world have ranged between a low of 19% after 6 months of testing in a study among 154 newly diagnosed HIV-positive adults in Tanzania [30] to over 90% among 345 HIV-infected adults in Ethiopia [31].

Globally, reasons for non-disclosure have generally centered around fear of, or real stigma, discrimination/rejection and separation from partner [19,32,33,34]. The risks involved following serostatus disclosure include social ostracism, physical harm, discrimination and fear of accusations of infidelity, and abandonment [18,35,36]. In Uganda, one study showed reasons for non-disclosure included blame for infection and fear of separation [37]. Among women in developing countries, between 3.5% and 14.6% reported experiencing a violent reaction from a partner following disclosure [38].

**PREVENTION WITHIN COUPLES; PREVENTION ALTRUISM**

Altruism in the context of this study is related to how an HIV-infected individual perceives and acts in a way to prevent further transmission of HIV infection. It can be defined as the relationship between sexual risk taking and the motivations and practices of caring about one’s sexual partners to prevent HIV transmission. There is a dearth of literature on altruism and HIV prevention globally, but even more so in Africa. HIV prevention altruism has been investigated among men who have sex with men in a few qualitative and quantitative studies. These studies found that sexual risk behavior was related to altruistic intentions although other factors, both contextual and psychological play important roles as well [39,40]. One qualitative study with gay men used the perspective of “sexual citizenship” addressing the dual discourse of
transgression and altruism; thus comparing the individualism of a “transgressing behavior” versus an altruistic sense of community responsibility aiming to highlight how gay men living with HIV engage with the sexual responsibilities attached to HIV serostatus[41]. Although not specifically looked for, prevention altruism (also called “informed altruism”) was found in a survey of injection drug users in New York City, where drug users entering a detoxification center and who knew they were infected with HIV reduced their transmission behavior more than those who did not know their serostatus. In a recent study assessing the prevention effect of couple HIV testing in Malawi in two consecutive surveys of over 3,200 adult men and women, participants who learned both, their own and their partner’s HIV test results were found to be more likely to report risk reduction behavior [42]. A 1999 review of 66 studies globally among HIV-infected men and women noted that: “the evidence for preventive altruism is so widespread and so compelling that the following assertion can safely be made: that people who know themselves to be HIV-infected nearly always do as much, and usually do considerably more, to avoid passing on the virus than people who are (or believe themselves to be) uninfected do to avoid catching it” [43].

REPRODUCTIVE DECISION-MAKING

More than 80% of all individuals diagnosed with HIV are in their reproductive age [44,45]. These individuals continue to desire children just as individuals without HIV [46]. Yet their reproductive decisions have added complexities related to their HIV status as these decisions impact on potential transmission of HIV to a sexual partner and to the unborn child, as well as on their own health. With the advent of ART, new layers of complexity arise and a combination of factors may be related to the currently observed increase in pregnancy rates among women on ART [46,47,48,49].

One reason for increase in pregnancy with ART is the improved immunologic function and the general return to health which includes a revived sexual desire. However, globally many pregnancies are unplanned or unintended. Worldwide in 2008, it was estimated that about 86 million (41%) of all pregnancies were unintended, 59% of which occurred in southern Africa [50,51]. Schwartz and colleagues recently found that in South Africa, 62% of 170 pregnancies were unintended and 47% were not carried to term [49]. In sub-Saharan Africa, it is estimated that between 10 and 50% of all pregnancies among both HIV-infected and HIV-uninfected women are unintended [52,53]. In Uganda, the rate of unintended pregnancy rose from 29% in 1995 to 46% in 2006 [54]. There is no specific indicator for unintended pregnancy in the 2011 DHS, but there was a slight decrease in total fertility (6.7 to 6.2) and increase in contraceptive methods from 8% in 1995 to 26% in 2006 [55].

Findings as to whether the desire for children is associated with subsequent pregnancy among women on ART vary. In some studies the women’s, the men’s or the couples’ desire was associated with future pregnancy [48,53,56] while in others it was not [57,58]. Interestingly, the factors associated with desire for pregnancy and the factors associated with pregnancy itself, differ. Nattabi and colleagues conducted a global review of 27 studies that measured the factors related to desire for children among HIV-infected adults[47]. They found that younger age, being under familial and socio-cultural pressure, having fewer children and having lost children were factors associated with having (more) children. A few studies in the review highlighted the importance of cultural and relational factors influencing the desire for a child [59]. Wagner
and colleagues assessed the correlates of intention to conceive in two clinics in Uganda and found similar factors as the Nattabi review among 44% of 233 HIV-infected clients who mentioned a desire to have another child in the near future [60].

Globally, studies that assessed factors related to actual pregnancy found that younger age, relationship status, health status, and previous experience with pregnancy were associated with pregnancy and pregnancy outcomes [56,58,60,61,62]. Among African-American participants, Craft and colleagues reported that most women chose not to become pregnant after being diagnosed HIV positive [56]. In a multi-country cohort study among 4,531 women before and after ART initiation, ART use was associated with an 80% increase in pregnancy incidence [63]. Proposed reasons for this dramatic increase include improvement in physical and mental health status which could lead to increased sexual activity and desire for children. In addition, rapid improvement in immunological functioning could lead to unintended pregnancies [63].

**HIV SERO-DISCORDANCE AND RISK REDUCTION**

HIV serodiscordance rates are either measured using as a denominator of all couples where both members have been tested, or couples where one member has tested sero-positive. The latter is usually termed “infected couples”. In sub-Saharan Africa, in studies where both members of the couple have been tested, rates of serodiscordance range between 1-31% [64,65,66,67,68,69]. In a study of five African countries using Demographic Health Survey (DHS) and AIDS Indicator Survey (AIS) data, de Walque found that among 9,297 infected couples, more than two thirds were in serodiscordant relationships [70]. In a systematic review of 27 cohort studies in 14 African countries, women were the index partner in about 47% of the couples studied [66].

In sub-Saharan Africa, more new HIV infections occur in stable discordant couples than in any other group [68,71,72,73]. Coburn and colleagues designed a mathematical model to assess HIV transmission rates in discordant couples in 14 African countries and found that transmission can be as low as 1.9 per 100 person-years to as high as 19.0 per 100 person-years with the difference depending on the proportion of the population in stable relationships [65]. Studies that assessed risk for transmission among discordant couples found that in Uganda, factors such as lack of male circumcision, cohabitation, and CD4 counts were associated with being seroconcordant HIV positive rather than serodiscordant [74]. In Kenya, additional factors included HSV2 infection in both partners [75]. The risk for women principally comes from the sexual behavior of their sexual partner.

There have been both behavioral and biomedical research studies and programs focused on couples for HIV prevention.

A systematic review conducted by Burton and colleagues found that couples-focused behavioral interventions reduced unprotected sexual intercourse and increased condom use compared with control groups [76]. Most of the couples-focused behavioral interventions in Africa are based on couple counseling and testing and have shown positive results including increased condom use from 4% to 57% in one year in Kigali Rwanda [73] and reported reduction of unprotected sex in Kenya, Tanzania and Trinidad [77]. Particular features of some of the successful interventions included a particular focus on gender dynamics and
strengthening couple communication [78], counselor-facilitated disclosure [79] and increased number of follow-up visits after initial HIV diagnosis and counseling [80]. There have been a few discordant couples focused interventions using group-based methods [81,82]; one implemented in Uganda, Thailand and India conducted four group-based sessions, with content including communication, problem solving, and negotiation skills [81].

Recent biomedical prevention studies have focused on reducing HIV susceptibility and infectivity in sero-discordant couples which means treating either the HIV-infected partner to reduce viral load or the HIV-uninfected one to prevent acquisition. Studies that treated the HIV positive partner with daily acyclovir did not reduce risk of HIV transmission [83]. However, treating the infected partner with ART to prevent transmission to the uninfected partner found a prevention effect of 96% [84,85,86]. Additional studies have assessed the prevention efficacy of the use of single or combination anti-retroviral drug regimens by the HIV-negative partner and have shown up to 92% transmission reduction among men who have sex with men [87].

BRINGING TOPICS TOGETHER

There have been a limited number of studies that assessed disclosure and reproductive decisions together. In one study, knowledge of HIV status had a significantly greater effect on contraceptive use among those who disclosed their status to their partner compared with those who did not disclose [53]. Another study looked at communication with health care providers regarding reproductive decision-making in Uganda and found that one-third (35%) of couples with fertility intentions expressed having difficulty discussing these intentions with their providers [60]. A third study found that couple communication was a theme related to desire for fewer children among youth focus group discussion members in Uganda [88]. Beyeza and colleagues studied reproduction-decision making among discordant couples in four clinic settings in Kampala and found that participants who desire children and those with multiple sexual partners were less likely to use condoms. They reported their main reasons for wanting a child included: guaranteeing that the lineage is maintained, ensuring stability in relationships and insistence from relatives [46]. A similar qualitative study among 30 HIV-positive women and 20 HIV-positive men, all with a sero-negative (or unknown status) partner in South Africa found that pregnancy planning occurred on a continuum between completely intended to completely unintended [89].

This thesis would like to take an additional step and try to bring together the voices of people living with HIV, what motivates prevention, does couple communication influence the picture, what impacts reproductive decision making and how do couples understand living together with HIV in concordant and discordant relationships. Those are the questions that have provoked my particular interest in the work in my many years in Uganda and eventually into this thesis.

UGANDA: THE CONTEXTUAL FABRIC

Uganda is a landlocked country in Eastern Africa covering 241,000 sq km. with a population of about 34.5 million and the third highest population growth rates (3.1%) in the world after Niger and Malawi [90]. Currently Uganda’s population is about 85% rural and is spread into 112 administrative districts (see Figure 1). In the 2011/2012 DHS, it was reported that the majority of Ugandans had some primary education with slightly more males (82 %) than females (80 %) having completed some or all primary school. Thirteen percent of men and 23 % of women had never attended school and about 5% of men and 3% of women had finished secondary school.
In the 2007 DHS, 20% of households in urban areas and 1% of rural households had access to piped water and overall 9% of households in Uganda had electricity (42% urban & 3% rural) [54]. The 2011/2012 report did not describe household water and electricity.

The infant mortality rate in 2011 was 54 per 1000 births; while the total fertility rate was 6.2 children per woman; down from 6.7 in the 2006 DHS [55]. The fertility rate has remained more or less stable since 1995 but shows significant variation by region, education and rural vs urban areas. In urban areas women have many fewer children (4.4 children per woman) than in rural Uganda (7.1 children per woman) [54]. In the 2011 survey the urban/rural difference remains significant as rural women give birth to nearly three more children during their reproductive years than urban women (3.8 and 6.8, respectively) [55]. By region, fertility differs from 3.7 children per woman in Kampala to 7.7 children in the Eastern region [54]. In addition, wealth categories vary considerably, where women in the poorest households have twice as many children as women in the wealthiest households (8.0 children versus 4.3 children, respectively).

In contrast to the unchanged fertility rate, family planning use (defined as modern contraceptive use) among married women in Uganda was found to have increased considerably in the past 17 years from 15% in 1995 to 24% in 2006 to 26% in the last survey [54,55]. The increase is especially noted for modern methods which more than doubled in the 11 years. The change is mostly due to the increase in the use of injectable Medroxyprogesterone acetate (MPA or Depoprovera) from 3% in 1995 to 11% in 2006 and up to 14% in 2011 [55]. The survey also found that almost all pregnant women (95%) received antenatal care at least once before delivery and 57% of them were attended by a skilled health personnel during their last delivery [55].

**Figure 3: Uganda map showing study sites; Jinja and Tororo & Busia Districts**

**HIV and Uganda**

The HIV epidemic in Uganda reached a peak in 1992 when HIV prevalence in antenatal sites reached over 30%. In 2005, Uganda became one of the first countries to report a declining HIV prevalence of 6.4% through the national AIDS Indicator survey. In the same year, a national sero-behavioral survey showed that there were about 1 million people living with HIV (PLHA), 58% of whom were women and 42% were men. Approximately, 160,000 PLHA were in urgent need of ART. At that time, less than 20% of sexually active Ugandans had been tested for HIV and about 135,000 new infections were occurring in a year [91].
Table 1: Selected Demographic, Health, and Social Indicators for Uganda in 2005/2006 and 2011

<table>
<thead>
<tr>
<th></th>
<th>2005/2006</th>
<th>2011</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>32 million</td>
<td>34.5 million</td>
<td>[90]</td>
</tr>
<tr>
<td>Population growth rate</td>
<td>3.3%</td>
<td>3.6%</td>
<td>[92]</td>
</tr>
<tr>
<td>Completed Secondary school</td>
<td></td>
<td></td>
<td>[54,55]</td>
</tr>
<tr>
<td>Men</td>
<td>5%</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>3%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Infant mortality rate</td>
<td>76 per 1000 births</td>
<td>54 per 1000 births</td>
<td>[55]</td>
</tr>
<tr>
<td>Fertility Rate</td>
<td>6.7 children/woman</td>
<td>6.2 children/woman</td>
<td>[54,55]</td>
</tr>
<tr>
<td>Use of Family Planning</td>
<td>24%</td>
<td>26%</td>
<td>[54,55]</td>
</tr>
<tr>
<td>HIV prevalence</td>
<td>6.4%</td>
<td>7.3%</td>
<td>[91,93]</td>
</tr>
<tr>
<td>*Prevalence of HIV sero-discordance</td>
<td>5%</td>
<td>6%</td>
<td>[91,93]</td>
</tr>
</tbody>
</table>

*These are couples where one member (either the man or the woman) is HIV-positive and the other is HIV-negative and the denominator is all cohabiting couples.

Discussion of HIV between sexual partners and knowledge of partner HIV serostatus was low. Eighty-three percent of national sero-surveillance respondents had never discussed HIV with any sexual partner while higher education and wealth were associated with greater discussion of HIV and knowledge of partner status [91]. HIV services were delivered through both public and private facilities, but ART was more widely available in NGO-supported health facilities.

Numerous studies have found an association between the decline in HIV prevalence and decrease in risk behavior, not only in Uganda, but other countries as well. Cohort studies carried out in Southwestern Uganda, found that HIV prevalence declined between 1990/1991 to 2004/2005 and began to rise after that; HIV incidence followed a similar pattern showing a preliminary rise in 2006 [94]. Behavioral studies and sentinel surveillance data also reflect the changes in HIV prevalence, both during the period of decline as well as during the increase in recent years [94,95,96].

In 2011, the Ugandan Ministry of Health carried out a repeat AIDS Indicator Survey and found that overall HIV prevalence had increased to 7.3% nationally from 6.4% in the 2005. Women remain at higher risk than men with an overall higher HIV prevalence of 8.3% compared with 6.1% for men [93]. Regarding general knowledge about HIV and AIDS, the proportion of women aged 15-49 who knew that HIV can be transmitted through breastfeeding and that transmission to an unborn or breastfeeding child can be reduced by a mother taking drugs during pregnancy and lactation increased from 36% in 2004-05 to 52% in 2006 and to 65% in 2011. The proportion of men aged 15-49 who knew the same also increased from 35% to 43% and to 56% in the same period and the number of men and women having ever been tested for HIV rose to 45% and 66% respectively. Among couples where both members have been tested, in 2011 6% were sero-disscordant (3% female positive) [97].

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*The full 2011 AIS report is not out yet; we had access to the 2011 HIV Indicator Factsheet which has basic information but not all the details that should be available in the full report.
AIMS

Overall Aim
The overall aim of this thesis was to increase knowledge on the ways couples living with HIV prevent further transmission and live with health and dignity in Uganda.

Specific Aims
- To assess health and social predictors of disclosure and to describe experiences and outcomes related to disclosure among HIV-infected men and women in Eastern Uganda
- To explore and describe the motivations, beliefs, and attitudes of HIV-infected Ugandans about reducing their risk of HIV transmission and the relationships between motivations and specific behaviors
- To describe how HIV and ART influence desires and decisions to have children
- To explore and describe the relationships between individual and couple beliefs around HIV serodiscordance, couple relationships and risk behavior over time among HIV-serodiscordant couples

CONCEPTUAL FRAMEWORK

Positive prevention (PP) is premised on a pragmatic public health approach. Targeting interventions on the few HIV-infected individuals rather than the many HIV-uninfected individuals is a more efficient use of limited public health resources and addresses the physical, mental and emotional needs of people living with HIV as well as addressing the important prevention agenda for the wider community.

Caitlin Kennedy and colleagues published, in 2010, a positive prevention conceptual framework shown below [14]. The main goals of this framework are to keep PLHA physically and mentally healthy, to prevent HIV transmission to other people, and to increase the participation of PLHA in achieving these goals. Each goal is supported by a comprehensive set of biomedical, educational, and socio-behavioral interventions aimed at preventing illness and infection, improving coping, and reducing risk behavior and unintended pregnancies, all with the active participation of PLHA. The PP concept was used to guide the research aims in our PWP study in Jinja. This framework was also useful in bringing together our four sub-studies. Our empirical findings may enrich the use of this framework in the future.
Figure 4: Positive Prevention Conceptual Framework proposed by C. Kennedy et al [14]

- **GOALS**
  - Keep people living with HIV physically healthy
  - Keep people living with HIV mentally healthy
  - Prevent HIV transmission to other people
  - Increase the agency of people living with HIV

- **INTERVENTIONS**
  - Provision of ART
  - Prevention of opportunistic infections
  - Adherence counselling and support
  - STI diagnosis/treatment
  - Distribution of condoms
  - Clean water programmes
  - Nutritional education and support
  - Support groups
  - Substance abuse treatment programmes
  - Gender substitution therapy
  - Mental management of depression
  - Psychosocial counselling and support programmes
  - Prevention counselling (e.g., HIV disclosure, sexual risk reduction, alcohol reduction)
  - Partnership/peer counselling
  - Health promotion education/counselling
  - Programmes for prevention of mother-to-child transmission
  - Needle-syringe exchange programmes
  - Condom distribution
  - Mass media programmes
  - Training of people living with HIV in advocacy methods
  - Encouragement and support for formation of advocacy groups by people living with HIV
  - Participation of people living with HIV on country-level technical working groups and other policy development groups

- **OUTCOMES**
  - Prevent illness and infection
  - Improve coping, prevent depression, and reduce risk behaviour
  - Reduce risk behaviour/unintended pregnancies
  - Increase visibility/participation of people living with HIV
  - Reduced morbidity and mortality related to HIV/AIDS
  - Reduced HIV incidence
  - Reduced stigma

* AIDS, acquired immunodeficiency syndrome; ART, antiretroviral therapy; HIV, human immunodeficiency virus; STI, sexually transmitted infection.
* “Positive prevention” denotes preventive interventions that target HIV+ individuals.
METHODS

OVERVIEW OF STUDY DESIGN

We have combined quantitative and qualitative methods to tell more complete stories. We used quantitative methods to describe the first two studies’ populations and answer the research questions looking at factors associated with some of the outcomes of interest. We used qualitative methods to address questions related to describing and exploring in-depth processes, experiences, beliefs, behaviors and motivations.

All four sub-studies were nested within parent studies (described below); Studies I and II were conducted within the cross-sectional Prevention with Positives (PWP) study (shaded in table below) in Jinja District while studies III and IV took place within the HBAC longitudinal cohort study in Tororo/Busia Districts.

Table 2: Overview of study design

<table>
<thead>
<tr>
<th>Article Specific Aim</th>
<th>Design, method (N)</th>
<th>Population group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To describe health and social factors associated with HIV serostatus disclosure to sexual partners</td>
<td>Quantitative, cross-sectional / N=1,092</td>
<td>“Prevention with Positives (PWP)” Study</td>
</tr>
<tr>
<td></td>
<td>To explore the processes, experiences and outcomes related to HIV serostatus disclosure</td>
<td>Qualitative interviews / N=45</td>
<td>Women and men living with HIV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Qualitative interviews / N=47</td>
<td>Rural, Eastern Uganda (Jinja)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quantitative, cross-sectional / N=1,092</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>To explore the perceived sense of responsibility and behavior towards prevention among HIV-infected men and women.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>To describe how ART influences desires and decisions to have children among HIV-infected women on ART &amp; their partners</td>
<td>Qualitative interviews Women (N=29) Partners (N=16)</td>
<td>“Home-based AIDS Care (HBAC)” Study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HIV infected women on ART &amp; their partners</td>
<td>Rural, Eastern Uganda (Tororo, Busia)</td>
</tr>
<tr>
<td>IV</td>
<td>To explore and describe the relationships between individual beliefs on discordance, couple relationships and risk behavior among HIV-serodiscordant couples</td>
<td>Qualitative interviews before/after intervention Couples (N=40)</td>
<td>HIV serodiscordant couples with index on ART</td>
</tr>
</tbody>
</table>

In Studies I and II, we aimed at describing two outcomes; HIV serostatus disclosure and motivations for prevention among men and women living with HIV in Eastern Uganda. We
used quantitative methods to describe the population and the factors associated with HIV serostatus disclosure in Article I. In Article II, we used quantitative methods to analyze an “altruism scale” and to relate condom use or disclosure to sexual partner with feelings about HIV-transmission. The rationale for using a mixed methods design for Articles I & II was to triangulate specific outcomes that could have a potential for social desirability bias. In all four articles we used qualitative methods to explore issues that we had limited prior knowledge about and where the questions demanded an in-depth inquiry. The aim was not only to explore but also to understand and explain complex behaviors in a dynamic context to better inform health interventions. In Article IV, the intervention design was longitudinal and explored if HIV-serodiscordant couples felt that potential key areas were related to risk reduction.

PARENT STUDY SETTINGS

The two parent studies described in this thesis were conducted in rural Eastern Uganda in Jinja district (PWP study, Articles I & II) and Tororo, Busia districts (HBAC study, Articles III & IV); see Figure 1 in background above.

Eastern Uganda is principally rural and among the poorest areas of Uganda. Jinja District is 87 km northeast of the capital, Kampala, and has a population of 414,000 people. Tororo district has a population of about 650,000 and is ethnically very diverse, thus all survey instruments had to be translated into seven different languages: Jopadhola, Ateso, Samia, Kiswahili, Luganda, Lunyole, and Lomasaba (also known as Lugisu).

Marriage and having children are highly valued, strong cultural institutions in both study settings (discussed in greater detail in the discussion). The latest 2011 Uganda Demographic and Health Survey (DHS) found that 63% of Ugandan women and 56% of Ugandan men were either married or cohabitating. The 2011 DHS also found that overall, 14% of women desire another child, and this was relative to how many children they had. About four out of five (79%) women with no living child desired a child soon [55].

PARTICIPANTS, DATA COLLECTION AND ANALYSIS

Both the quantitative and qualitative data collection took place in multiple languages (as mentioned above). In Studies I and II which took place in Jinja, the interviews were conducted primarily in Luganda and Lusoga. In Studies III and IV that took place in Tororo and Busia, interviews were in one of the seven indigenous languages mentioned above. Interviewers were fluent in the local languages. All transcripts were translated and transcribed into English. Studies I and II had both quantitative and qualitative sections and Studies III and IV were purely qualitative.

Quantitative Methods

Disclosure Study (Article I) and Altruism Study (Article II)

Clients for both studies were recruited at The AIDS Support Organisation (TASO) center in Jinja town and at two additional TASO outreach sites in Jinja district. TASO is a non-governmental organization that has provided care and support services for HIV-infected people in Uganda since 1987 through a national network of care clinics and counseling centers. Participants were recruited during routine TASO clinic visits. After a group education session
introducing study I to clients, interested clients were evaluated regarding eligibility criteria which included being ≥18 years of age and healthy enough to participate in an interview and have a blood test. Potential participants were selected randomly. Random selection was conducted by field officers who prepared lottery papers for the corresponding number of clients who had registered that day. All potential participants meeting the eligibility criteria provided written informed consent for participation and had HIV infection confirmed through sequential serologic testing using Abbott Determine HIV-1/2 (Abbott Diagnostics, Illinois, USA) as the initial screening test and Hemastrip HIV-1/2 (Chembio Diagnostics Systems, New York, USA) as the confirmatory test, according to national guidelines. The sample size was calculated based on the main outcome (reporting condom use at last sex), a power of .80, and an alpha of .05 to detect a difference of 20% in the proportion of disclosed vs not disclosed clients reporting condom use at last sex. A total of 480 clients per gender (960 in total) was needed to detect this difference, assuming a minimum response rate of 85% and an estimated proportion of 30% male clients.

We measured “risky sex” defined as inconsistent or no condom use with a partner of HIV-negative or unknown HIV status while “safe sex” was defined as always using a condom or having sex with a concordant HIV-positive partner. “Discuss sexual issues with partners” was defined as client reporting having discussed their sexual life with their partner. “Knowledge of partner status” was defined as clients’ response to the question: “what is your partner’s HIV serostatus?” Years spent as a TASO client was calculated by subtracting the interview date from the clients’ TASO registration date.

Figure 5: Flow chart showing the four Sub-Studies

Study II was primarily qualitative, but a quantitative section described and assessed the behavioral variables condom use and HIV serostatus disclosure in relation to the responses to the questions: “how bad would you feel if you transmitted HIV to your sexual partner?” and “how bad would you feel if you transmitted HIV to your unborn child?”, both unadjusted and adjusted for HIV-status of sexual partner among the same participants as in sub-study I. In addition for article II, an “altruism score” was computed from a 14-item scale where participants were asked to think about people in general and were assessed on a Likert scale to a series of questions addressing feelings about beliefs in, and care for self and for others.5

5Only participants with responses to all items on the scale were included in the calculation of the score. Responses to items that were in a negative direction were reverse-coded by subtracting the value of the response from 8. This applies to the items “I am not too concerned about what happens to other people”; “It is most important to look out for yourself and your loved ones, even if doing so comes at the expense of others” and “It is a fact of life that people are always out for themselves”.

25
Quantitative Data Analysis

Disclosure Study (Article I)
In order to assess rates of disclosure and health and social predictors of disclosure, a quantitative questionnaire focusing on sexual risk behavior, voluntary counseling and testing (VCT) and prevention of mother-to-child HIV transmission (PMTCT) was administered to 1,092 participants (488 men and 604 women). Data were double-entered using Epi-Info (version 2000, Atlanta, Georgia, USA) and analyzed in SAS version 9.1 (SAS Institute, Cary, North Carolina, USA). HIV sero-status disclosure patterns (whom disclosed to, time between HIV test and disclosure, difficulty disclosing, and reason for disclosing) were assessed separately for men and women. We developed a multivariate logistic regression model to assess associations between HIV disclosure by participants to their most recent sexual partner and socio-demographics, sexual behavior, condom use, health characteristics, knowledge of partner’s HIV status and years enrolled at TASO. For this analysis, we excluded 308 individuals who reported last having sex on a date prior to receiving their HIV test result.

Altruism Study (Article II)
The means, standard deviations, and ranges for the “altruism score” were presented. The altruism score was derived by summing up the values.

Qualitative Methods
Sampling:
For all our studies we used a theoretical sampling approach. Theoretical sampling can be defined as “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory” [98].

For Studies I & II, a subset of 23 men and 24 women were selected out of all 1,092 participants based on gender and disclosure (equally distributed between disclosed and not disclosed).

ART and Pregnancy Study (Article III)
Participants were selected for the qualitative sub-study from participants enrolled in the Home-Based AIDS Care (HBAC) project in rural Eastern Uganda between September 2006 and June 2007. HBAC delivered free HIV and TB care and support services to the homes of approximately 1,000 participants in the project catchment area that covered a 100 km radius around Tororo town in Eastern Uganda. Subsistence agriculture was the main livelihood of the people in the area; nearly half of them lived below the poverty line and the majority had not received education beyond primary school level [99]. HBAC participants were recruited from the TASO Tororo branch. TASO clients >18 years-old and with a CD4 cell count <250 cells/µL or in WHO disease stage three or four were offered first-line ART according to national guidelines. HBAC study participants were enrolled at the HBAC study clinic between May 2003 and June 2006, and received ART and tuberculosis drugs at their homes on a weekly basis. No future routine clinic visits were scheduled but participants could come or be referred to the clinic or hospital for treatment of symptoms. Research counselors visited participants quarterly to collect behavioral data and to provide ongoing support on ART adherence and sexual risk behavior. They also provided home-based individual or couple HIV counseling and testing to all household members of HBAC participants. Confidentiality was emphasized in all
counseling sessions. Study participants were counseled at enrolment about the potential effects of ART on restoring health, fertility and sexual activity, and were referred to the hospital family planning (FP) clinic adjacent to the study clinic if interested in using modern FP methods other than condoms.

In-depth interviews were conducted among 29 HBAC women on ART and 16 of their partners to explore personal beliefs and experiences among both couple members. Participants were purposefully selected to provide a range of views. The theoretical sampling approach was based on two basic criteria: ART and pregnancy status in the last 12 months. In all, they included: 21 women on ART who had become pregnant and/or had delivered or aborted in the last 12 months (after starting ART) and 11 of their partners; and 8 women who had not become pregnant since starting ART and 5 of their partners. Counselors attempted to interview all partners of women selected for the study, but not all partners were able to participate. The 16 men who agreed to be interviewed were in an ongoing and/or stable relationship with their partners. Data responses for key themes reached saturation with the 45 selected respondents.

HIV sero-discordant couples on ART Study (Article IV)

Participant couples in the Discordant Couples Action Research Intervention (DARI) were identified through home-based HIV counseling and testing as part of the package offered to ART clients in the HBAC study. Through this process, 72 discordant couples were identified and all participated in the DARI intervention. Forty of these 72 couples were selected for in-depth interviews using a theoretical sampling strategy using three pre-conditions and three criteria to include a variety of experiences: (1) Couple agreement to participate (all), (2) Absence of depression, (3) Couple ability to articulate ideas clearly (all—for rich description), (4) Gender of HIV-positive partner (equally distributed HIV-positive males and females), (5) Couple risk-reduction plan (range of risk practices), (6) Couple desire for children (range of desire).

Qualitative Data Analysis

For Studies I, II and III, we used a thematic coding approach portrayed by Boyatzis [100]. Boyatzis describes guidelines that include three distinct stages: sampling and design, theme development, theme validation and code use. This methodology was used for thematic coding as the primary analytic strategy with an emphasis on descriptive thematic coding. After reading two transcripts, the analysis team members collaboratively developed a codebook of themes based on the interview topics as well as those themes emerging from the data. Two more transcripts were then reviewed to include additional topic areas and themes. This process was repeated until a sample of 12 transcripts had been reviewed (which equaled 12 versions of the codebook). At that point the codebook reached a stage where no new themes or topic areas emerged. To ensure inter-rater consistency, the analysis team compared their individual coding of the same transcripts and a coding concordance was calculated. All transcripts were then coded using the final version of the codebook and merged using NVivo software (Version 2.0, QSR International Pty. Ltd, Victoria, Australia) before themes were summarized across respondents. The merged project was transferred to NVivo Version 7 for analysis. Analysis focused on identifying dominant explanations for motivations for preventive behaviors and

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6 HBAC did begin providing FP methods during the period of this study (2005)
comparisons across clients. Regular interactive discussions were held with the analysis team and stakeholders to validate data interpretations and resolve any interpretation discrepancies.

Boyatzis describes how to avoid major obstacles using familiarity with the phenomenon being studied and the source material as a key; being mindful of the delicate balance between insufficient and excessive familiarity. He advises that during coding in particular, it helps to develop explicit rather than vague codes. In that way, multiple coders can be more consistent in their judgment of the material, which was particularly relevant in our case where we were using a diversity of coders with fairly different backgrounds. In addition, sticking close to the raw information in development of themes and codes keeps the coding true to the data [100].

The coding team comprised of one PhD student and myself for Studies I and II as well as three Ugandan senior social scientists and an additional doctor and social scientist for Studies III and IV. For the analysis, we benefited from expert advice and input from Swedish colleagues at the Karolinska Institute.

The analysis strategy for Study IV differed from the first three as the amount and complexity of the data were significantly greater. The fact that we wanted to analyze the couple members’ responses in relation to each other and to connect them over three time points suggested a strategy called “Framework Analysis”. The key stages of Framework Analysis include: 1) Familiarization, 2) Identifying a thematic framework, 3) Indexing, 4) Charting, and 5) Mapping and Interpretation [101]. Both the interviews and group discussions were analyzed using a framework approach combined with a dyadic perspective to accommodate couple dynamics. Analysis was based on the perspective that cultural expectations, lived socio-economic realities and gender norms woven together with each individual and dyadic relationship would influence how participants viewed and lived their experiences during this study. These methodologies allow for use of pre-defined topics but additionally have the flexibility to explore new themes [102,103,104]. The first three analytical stages included: familiarization (reading multiple times), identification of a thematic framework (codebook), and indexing (using Nvivo), which are common to many qualitative analysis strategies [102]. The fourth step, “charting”, involved arranging summaries of the data into a database according to theme, sub-theme, category, while the fifth phase, “mapping”, allowed us to search for interpretations in the data.

THEORETICAL FOUNDATIONS

Our PWP study in Jinja draws on theoretical constructs of a message framing approach. We analyzed the potential effects of gain frame and loss frame messaging in counseling HIV infected adults[105]. Information that considers risk and differing motivations to reduce risk can be communicated in ways that highlight either the benefits or positive consequences of protective behavior (gain-frame) or the risks and negative results of risky behavior (loss-frame). These two strategies may have a very different impact on the individuals receiving the counseling depending upon the health care issue being addressed, how the individual perceives the information, and the way in which the information is delivered. In other studies, assessing varied health conditions, loss-framed messages have shown better results than gain-framed messages in promoting detection behaviors and gain-frame have been more effective in promoting prevention behaviors [105,106,107].
Studies III and IV draw on constructs from The Theory of Gender and Power, that considers the wider social and environmental issues surrounding women, such as distribution of power and authority, and gender-specific norms within heterosexual relationships as mediating factors [108]. Wingood and DiClemente adapted the original Gender and Power theory specifically to address several conditions which impact women’s risk for HIV infection, including societal and cultural influences, socioeconomic risk factors, divisions of power and labor, and manifestations of power in relationships (including reproductive health decision-making). Other considerations include the social, gender and economic inequities placing women at greater vulnerability [108]. Our studies were also informed by the Social Ecological Model that considers behavior as being determined by five interdependent factors: a) Interpersonal processes and primary groups - formal and informal social network and social support systems; b) Intrapersonal factors – attributes of the individual such as knowledge, attitudes, behavior, self-concept, skills; c) Institutional– social institutions with organizational characteristics and formal and informal rules and regulations; d) Community– relationships among organizations, institutions and informal networks; and e) Public policies – local, state and national laws and policies [109]. The theory recognizes the importance of the interaction between the individual and the environment, and considers multi-level influences including the contextual factors and actors on behavior choices [110]. It has been utilized in other couples-based interventions for HIV risk reduction such as Project Connect [111]. In the initial stages of developing the intervention in sub-study IV, constructs from the Health Belief Model such as perceived self-efficacy and perceived susceptibility were incorporated [112]. These constructs were not used in analysis.

The thesis as a whole benefitted from the conceptual framework of Kennedy et al [14] and a specific framework was developed out of the data for each individual article as part of the analysis process.

**ETHICAL CONSIDERATIONS**

All participants in each of the studies provided written informed consent. The studies received scientific and ethical approval from the Science and Ethics Committee of the Uganda Virus Research Institute in Entebbe, Uganda, and from the CDC IRB in Atlanta, Georgia, USA (protocol numbers 3997 and 3666). In addition for studies I and II, ethical clearance was obtained from the University of California, Berkeley, USA.

No names or identifiers were recorded to ensure confidentiality of the participants. Participants were interviewed at a study site for studies I and II and at home for studies III and IV. Study IV included group sessions conducted in a convenient location identified by participants. A separate study was conducted on potential social harms in conducting home visits in connection with ART delivery among our study participants. It was found that participation in a home-based ART program was associated with many positive social outcomes [113]. For example, study participants were more likely to report community and family support as well as relationship strengthening at follow-up than at baseline and 84% of the participants attributed the support to program participation[113]. Negative experiences were also investigated; there was no significantly different change reported in the incidence of these experiences [113].
KEY FINDINGS

The findings are summarized from the four articles but also include additional data that may not have been included in the published articles. Findings are organized by main themes.

All participants for these studies were either living with HIV or in a HIV-discordant couple. All participants were either a TASO client or a former TASO client in Jinja, Tororo, or Busia, Eastern Uganda.

DISCLOSURE OF HIV SEROSTATUS (ARTICLE I)

Among the 1092 participants in the Prevention with Positives (PWP) study, the median age was 37 for women and 40 for men. Most participants were widowed, separated or divorced (55%), had completed at least primary school (51%), and had a salaried job (29%), a small business (25%), or worked in subsistence farming (27%). Of all respondents, 42% reported being sexually active and of those, 69% had disclosed their HIV-positive status to their most recent sexual partner. Eighty percent of respondents had discussed sexual issues with their current partners and 39% had two or more relatives who had died of AIDS.

In Article I, we looked at the factors associated with disclosing one’s HIV status, and multivariate logistic regression showed that the odds of disclosure among clients who were married or co-habitating were 11 times higher (95% CI 1.98–60.39) while those who were widowed, separated or divorced were three times higher (95% CI 0.50–15.18) than those who were single. Length of time as a TASO client was independently associated with disclosure (more than 2 years: adjusted OR 2.49, 95% CI 1.45–4.27). The odds of disclosure were two times higher among clients who “sometimes” or “always” used condoms compared to those who “never” used them.

In Uganda as elsewhere, disclosure to sexual partner has been promoted as a prevention strategy focused on partner notification to enable sexual partners to access testing and care services and the HIV positive person to access treatment as well as to confront stigma and discrimination. This model is founded on a concept of direct face-to-face communication in which HIV-infected individuals discuss their results directly with their sexual partner. We found that among our study participants, communication in general and disclosure in particular can be a complex process and can come in diverse forms such as stories, parables, or other indirect routes. In our study, the disclosure techniques included; direct (55%), indirect (27%), and assisted (18%) methods. As one woman narrated:

My husband had been bed ridden for sometime before he decided to go for an HIV test. He did not tell me where he was going [. . .]. When he came back, he had condoms with him and he put them where I could see them” (33 year-old woman).

One of the domains explored in the qualitative study was motivations for disclosure to sexual partner. An emerging theme was love or care for one’s partner as explained by this woman,

“You know people say, “people who are in love can do anything for love”. If I love you dearly, I tell you my HIV status [. . .]. I told him (sexual partner) our sexual relationship, had to end because I didn’t want to infect him with my HIV” (49 year-old woman).
Generally interview participants who had disclosed their serostatus, experienced more positive than negative outcomes following their disclosure (24 positive; 4 negative) while five reported no change in their relationship after disclosing (Figure 6). Twelve respondents who did not disclose reported fears of abandonment, abuse, and blame that might be associated with disclosure. Concern about which member of the couple was first infected ran throughout the interviews as a significant barrier to disclosure for both men and women. Many believed that the partner who tests first and discloses will be seen as the one who was infected first. Fear of blame from the extended family was just as serious as from the partner him or herself. Blame was often associated with infidelity and accusations that lead to stigma and discrimination.

Of participants in the quantitative survey who disclosed, 87% stated it was not difficult. Many (16) individuals reported that the outcome of disclosing their HIV results to their partner included varied risk reduction measures. This was true of both men and women and of both those who disclosed directly or indirectly. Men and women who had disclosed said that one of the main reasons they had done so was to avoid transmission to their partner. They felt that disclosure would facilitate consistent condom use, abstinence, or other safer sex options within the couple. Respondents explained that in order to initiate safer sex options, it was important to first disclose their HIV status. They also reported that suggesting condom use without first disclosing can initiate mistrust, quarrels and misunderstandings in the home.

In Article II we examined reasons and motivations HIV infected adults would have for wishing to prevent further transmission of the virus.
MOTIVATIONS FOR HIV PREVENTION (ARTICLE II)

Overall, 99% of the 1,092 participants said that they would feel bad or very bad if they transmitted HIV to their partner. Ninety nine percent of all participants also stated that they would feel bad or very bad if they or their partner transmitted HIV to their unborn infant.

As shown in Table 3 below, motivations for preventing HIV transmission were either altruistic: including protection of sexual partners (protection of physical and psychological pain, suffering and death), preventing spread of infection, caring for children and the community, or ethical and religious, or were about caring for self.

Table 3: Personal motivations of women and men living with HIV for preventing sexual transmission in Jinja, Uganda

<table>
<thead>
<tr>
<th>“Why don’t you want to transmit HIV to your partner”</th>
<th>Quotes</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>To care for children</td>
<td>Her child will suffer because she (child) may lose her mother. By infecting her, I will be infecting her husband with HIV. The child will be an orphan and may suffer without school fees.</td>
<td>36 year-old man</td>
</tr>
<tr>
<td>To protect sexual partners</td>
<td>I want her to live, you never know she may be chanced and the cure is discovered when she is still alive.</td>
<td>29 year-old man</td>
</tr>
<tr>
<td>To prevent general spread of infection</td>
<td>There the whole world becomes infected because when you infect him/her, he/she can’t know that he/she has HIV and he/she is infecting the other person and so the whole world is going to be infected.</td>
<td>18 year-old woman</td>
</tr>
<tr>
<td>Ethical &amp; Religious reasons</td>
<td>You regret why did I do it; which Satan is this that influenced me to do it? And yet you have done it. I am not interested in infecting others. Immediately I got to know my HIV status, I didn’t misbehave [have sex]. I feel very bad [if I infected partner] and I don’t want it. I am a Christian. It is one of the ten commandments. You will be wasting the little energy by killing others it is a bad disease. It has bad effects. It kills. I have some “small” faith; so I will have sinned before God. The bible says, “Don’t kill”.</td>
<td>49 year-old woman, 36 year-old man</td>
</tr>
<tr>
<td>To care for self</td>
<td>My partner has already tested positive for HIV. But I want us to use condoms to avoid re-infection so that we can live longer and look after our children.</td>
<td>33 year-old woman</td>
</tr>
</tbody>
</table>

What we have done for ourselves alone dies with us; what we have done for others and the world remains and is immortal. ~Albert Pike

In the HBAC Study (Articles III and IV), themes related to prevention behavior included, having disclosed HIV status to partner, fear of transmitting a resistant virus, caring for self and keeping partner safe as well as belief in serodiscordant status (unpublished data).
PWP Jinja participants reported that their sense of responsibility was associated with preventive behaviors (Table 4). Risk-reduction and detection behaviors frequently mentioned by respondents included condom use, abstinence, decrease in the numbers of partners or frequency of sex, accessing treatment, as well as partner HIV testing, AIDS education and disclosure of results (as shown below).

Table 4: Preventive actions taken by PLHIV motivated by altruism, Jinja, Uganda

<table>
<thead>
<tr>
<th>Actions Taken</th>
<th>Quotes</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk reduction/condom use</td>
<td>It would hurt me so much because I don’t want to have a sin that I killed somebody. I don’t want to kill her, that’s why I have always insisted on condom use.</td>
<td>36 year-old man</td>
</tr>
<tr>
<td>Initiate Partner testing</td>
<td>I insist that my partner goes for a test so that she can begin getting treatment. I really feel so bad. I do not want to kill another person. You never know that same woman may have sex with another person like my friend or even my brother and he also gets infected.</td>
<td>37 year-old man</td>
</tr>
<tr>
<td>Educating others on HIV and AIDS</td>
<td>The HIV-infected person must always pass on HIV prevention messages to people like in a gathering or if it is a community meeting. Always tell people how the virus affects one’s life and various ways of preventing transmission. Encourage people to go for HIV-testing [...] if they are positive, this will give them a chance to try and not spread it.</td>
<td>45 year-old woman</td>
</tr>
<tr>
<td></td>
<td>To show the others this disease we have is a terrible one and it treats us badly and if you get it - know that you will be like me.</td>
<td>38 year-old man</td>
</tr>
<tr>
<td>Disclosure (private and public)</td>
<td>[...] disclosing HIV status to partner and those close [...] I think that is the most important, if they are not made aware, then you have the intention of infecting other people, which is not good.</td>
<td>58 year-old man</td>
</tr>
</tbody>
</table>

REPRODUCTIVE DECISIONS AND OUTCOMES (ARTICLE III)

Pillar three in the Medley conceptual framework (Figure 4) for positive prevention is based on preventing further infection. Our third study investigates factors specifically related to reproductive decision-making among HIV-infected women on ART and their partners who may or may not be HIV infected and how this relates to family planning and prevention of vertical HIV transmission and prevention.

Selected from the HBAC trial in Eastern Uganda, we interviewed 29 women living with HIV and on ART and 16 of their sexual partners. Sixty nine percent (20/29) of the women and 75% (12/16) of the men were married or co-habiting. Their mean ages were 37 and 32 years respectively. Eight women were pregnant at the time of the interview, seven had delivered within the past year, six had aborted and eight had not become pregnant since starting ART. Of the 16 men, three were partners of pregnant women, five of women who had not become
pregnant since on ART, two were partners of women who had aborted and six of women who had delivered an infant in the last year.

Women and their partners were in categories of either: pregnant, aborted or delivered within the last 12 months. Most of the individuals (women and partners) from the three categories clearly expressed that their pregnancy was unintended. Many mentioned that the current pregnancy was an accident and a surprise because they believed that they were infertile following long periods of amenorrhea or the absence of pregnancy despite having unprotected sex. However, individuals also mentioned multiple motivations for pregnancy, with the main reasons often intertwined in a number of interactions between human relations, health, social, economic and cultural factors. Two broad categories emerged from this tangled web of motivations: emotional/personal and practical/structural reasons (Figure 7 below).

### Figure 7: Themes and sub-Themes Associated with Becoming Pregnant among women and men in HBAC qualitative Pregnancy Study: Eastern Uganda, 2006-2007

<table>
<thead>
<tr>
<th>Emotional &amp; Personal Reasons</th>
<th>Practical &amp; Structural Reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Partner’s desire</td>
<td>* Lack/ inconsistent FP</td>
</tr>
<tr>
<td>* Desire heir/boy child</td>
<td>* Believed self/spouse infertile</td>
</tr>
<tr>
<td>* Replacing dead child</td>
<td>* Improved financial situation</td>
</tr>
<tr>
<td>* New partner (women only)</td>
<td>* Alcohol use during sex</td>
</tr>
<tr>
<td>* Love for partner</td>
<td></td>
</tr>
<tr>
<td>* Wanted HIV-negative child</td>
<td></td>
</tr>
<tr>
<td>* Improved health</td>
<td></td>
</tr>
</tbody>
</table>

Partner desire for pregnancy was given as a reason for the pregnancy by both men and women but was expressed differently by men and women. The woman in the following quote expressed surprise as reproductive decisions were sometimes not taken actively.

> Nothing led me to have this baby. In the first place I didn’t want to have a child because I knew my health conditions but like I said, this took me by surprise and I felt bad for some time but I left everything to God. Personally I can’t explain how it happened but I found myself in that situation and I had nothing to do but keep the pregnancy and deliver the child (woman with 2 children; 2 deceased; delivered).

Culturally, in Uganda, it is very important to have a child and preferably at least one male child. Uganda is a patrilineal society and couples must have male children in order to inherit land. Girl children are valued as they bring bride price into the family, but male infants are more highly esteemed as they are allowed to succeed the father.
It is believed that when one dies without a child, then that life is gone wasted. And even biblically when you die without a child it means that your generation stops/ends there (man with one living girl child; 4 deceased; wife delivered).

I really wanted her to get pregnant because I felt I wanted to try and have a child who would be negative [. . .]. Actually emotionally I felt the pressure within myself that I should have a child so that when I die, he could take over my estates (man with 2 children; 1 on ART, 12 month old girl).

In group discussions regarding reproductive decisions, one man mentioned the importance of religious beliefs in childbearing decisions.

In the Bible, it is said that people should produce and fill the world. So if a woman has, I don’t know how many eggs, she should complete them to the last. Because you can produce say two children and they are both thieves. They should be many, say like ten, so that if some become thieves, then you may have some that are ok (HIV-positive man, group discussion).

For women specifically, a new relationship with a man would often mean cementing this relationship with another child. One woman explained that her new partner began helping her financially and she then became pregnant.

This man promised to help me and my children. But as it is, men cannot simply give you all the help when [. . .] you do not have his own kid (woman with 5 children; pregnant).

Financial hardship and lack of family planning were two of the structural reasons described by women for becoming pregnant when they had not planned it.

I tried to suggest to my [new] sexual partner to use condoms [. . .] he refused and I accepted to have unprotected sex because he was very supportive financially. He would bring domestic necessities and there was no way I could disobey him (widowed woman with 3 living children, none deceased; delivered).

For some individuals, initiating ART meant starting a new life including renewing a sexual relations. Men and women gave positive and negative responses regarding the influence of ART on their reproductive-decision making. Most of them noted that improved physical and emotional health due to ART had resulted in increased desire for sex and thus pregnancy in some cases; a few mentioned as well that becoming stronger and healthier allowed them to look after children much better and to plan for the future.

The drugs make us regain our normal strength that we tend to forget about the fact that we are infected. As for me, I do not even remember that I am infected. Life is so normal I go on my daily work like I used to do (woman with 3 living children, 2 deceased, aborted).

Perceived reasons for women not getting pregnant included: ill health (included HIV infection and ART), having enough children, financial constraints, fear of mother-to-child HIV transmission or transmission to partner, death of a child, and health education. The most
frequently mentioned reason for not getting pregnant among our participants, both men and women was ill health both physical and emotional.

I really worried a lot because I kept thinking about the miscarriage I had before and the pain that I went through. I wondered how I would be this time around. Life became so miserable [. . .] I felt like committing an abortion or even dying for that matter. I kept thinking that even if the child would live, it would live a desperate life because it would also suffer like I have suffered (woman with 1 living child; 3 deceased; aborted).

Another frequently mentioned reason to try and avoid pregnancy was the pain of having lost previous children to HIV or another illness. Most women reported FP experiences with condoms and hormonal injections only. Men had limited FP information apart from condoms.

Who decides about getting pregnant; the man, the woman or other factors?

About half of the men and women said that the man decides about getting pregnant. Women gave socio-cultural explanations related to male dominance in decision-making irrespective of women’s desires. Some mentioned force and financial constraints, while others stated that it was the husband’s decision. Generally men had similar explanations, for example saying, “The decision must come from the man. I have the authority over her” (man with 3 children). More women than men mentioned that in the end it was a woman’s decision because as one woman noted, family planning can also be used secretly. “The decision is mine. I just stop taking the injections (FP) and conceive” (woman with 5 living children, not pregnant).

Some mentioned that both decide either through discussion and agreement, or through disagreement as the following woman explained:

This recent baby we are having, it was the father (deciding). A man has the powers and if I don’t want to give birth again, I just say no. Only that at times when you refuse and he wants, it brings quarrels. So I think it will be both of us to be responsible (woman with 3 living children, 3 deceased, aborted).

Apart from the issues of desires and motivations surrounding pregnancy, we also explored family planning practices and asked participants about their experiences regarding family planning use. Many participants, both men and women, mentioned that they, or their partner, wanted to get a tubal ligation because of its permanence.

The best is TL (tubal ligation) because there is no way you can get back to a situation as bad as mine. I am looking forward to delivering and having the TL done. I do not have time to listen to any other method (woman with 3 living children, 2 deceased, pregnant).

**HIV SERODISCORDANT COUPLES (ARTICLE IV)**

Selected from the same trial as for Article III, 72 couples were identified as discordant, of those, 40 were selected to participate in individual interviews. The mean age of the couple members who participated in the interviews was 41 years; 36 years for women and 46 for men. Almost all couples were married for an average duration of about 15 years. Eight women and three men had no formal education while just over half the women and just under half the men had some
level of primary school education. Women stated that their income came primarily from trade and men from agriculture. More men (64%) than women (14%) stated that they were consistently using condoms at baseline interview.

This article reports on an action research study called “Discordant Couples Action Research Intervention” (DARI). We interviewed discordant couple members separately before and after the DARI intervention which consisted in bringing them together as couples for four group sessions over time to discuss key issues relevant to living with discordance and risk reduction.

The story that emerged is portrayed in Figure 8. At the three DARI data collection points - baseline and repeat interviews as well as intervention group discussions - data showed that individual beliefs’ about discordance influenced couple relations which in turn influenced current behavior and these three domains are strongly influenced by the mediating contextual and structural factors.

Individual beliefs included, whether or not discordance actually exists; attributes of blood which makes it “strong” enough to resist either the HIV virus or the HIV testing machines; whether or not ARVs have an influence on HIV serostatus; individual desire and beliefs around child-bearing; the belief in the efficacy of the HIV testing machines; God’s plans regarding discordance; and individual beliefs on the efficacy of condom use. Regarding individual beliefs, we focused primarily on beliefs around discordance and what influenced those beliefs and understanding. Couples fell into three main groups according to their beliefs about serodiscordance at all time points (Figure 8).

The first group was defined as couples who were not sure of their HIV serodiscordant status, the second group included couples who did not believe in HIV serodiscordance, and the third group as couples who did believe their serodiscordant status.

Many couples, including both the positive and the negative members, and both males and females, believed in the notion that some aspect of the negative partner’s blood protected them from testing positive. This notion could be expressed as either a complete protection, or an attribute enabling the testing instruments to miss detecting the virus for varied amounts of time. In some cases, this notion was reinforced by past behavior that may have involved years of unprotected sex, possible poor health and the complete disbelief in discordance by the larger community. Many HIV-negative couple members tested multiple times (up to 12 times) as a result of these beliefs.

“I think my blood is still heavy (strong) it [the virus] can’t show up very fast. Possibly in future it will show up. I can’t say it is not there. One time it will show up; [...] My blood is strong” (HIV-negative woman, baseline interview).

“I am living with a person who has it. I confirm within myself that I have the AIDS virus except that it hasn’t come out yet. [...] My health is not ok. I have it except that its quiet somewhere in the body (HIV-negative man, repeat interview)

Couple relations were linked to beliefs and behavior about discordance as shown in the following figure.
During and following the intervention, as shown in the figure above, analysis revealed pre-identified concepts and emergent themes that were relevant to this conceptual model. Four major categories of factors affecting couple relations, beliefs and current risk behaviors emerged: DARI intervention factors, structural/contextual factors, physical health factors, and past risk behavior.

In addition, two main themes surfaced out of the DARI group discussions. One was the importance of communicating with partners, not only about protected sex, but about relating with each other in general. The second was about the importance of having a boy child (similar to study III).

*You try again to get another one (child). God may even kill that one and you remain with zero. You have to keep trying because the aim is to get a boy. It is better to try to at least get two or three boys.* (HIV pos male, group discussion 3)

The contextual and behavioral factors highlighted by couples as influential to behavior were gender norms around sexual decision-making and multiple sexual partnerships. Some couples mentioned multiple partners that either caused conflict between the couple or took pressure off of the discordant relationship. One HIV-positive man who had two partners, one HIV-positive and one HIV-negative, mentioned that his legal wife complained when he spent time with the second wife, but he explained (to interviewer) that culturally, a woman should not complain.
Past sexual behavior was a theme emerging multiple times both in terms of unprotected sex but also in relation to alcohol use. One third of the men in this sample reported drinking. Below, this woman talks about her past behavior with her partner.

At first I was having sex with him without condoms. We were not using condoms. In the beginning he lied to me and hid the facts from me about his HIV positive status. Later on I saw that he was very ill (said with much emphasis). I asked him, “my friend, what is it really? Aaah, then he told me, “I was afraid to tell you, because I thought you would leave me. But I am HIV positive”. I also came to think that since we had unprotected sex with him, a time will come and the infection he gave me that time will show, otherwise I don’t know. But in my heart, I am strong (HIV-negative woman, repeat interview).

Finally, the repeat interviews of both men and women, positive members and negative members attributed safer behavior to their counseling through the DARI intervention, their improved communication as a couple, and their increased understanding of discordance. Clearly, human sexual behavior, in its dyadic and dynamic nature depends on the multiplicity of intertwined factors that enable a couple to decide together and implement changes.

We are now getting to understand one another. Because if she refuses [sex] I also leave it so now “we’re together” (respondent’s own English). Supporting each other is not hard based on the discordance education session we had and what we were educated about ARVs (HIV-negative man, repeat interview).
DISCUSSION OF FINDINGS

Our studies looked at specific behaviors within the framework of positive prevention. The first study investigated the communication of HIV positive test results, both the processes and the outcomes of this communication. The second study was focused on the motivations of behavior change, personal, dyadic and community-wide to better inform intervention approaches. The third study explored specific issues around vertical HIV transmission and desires for pregnancy and contraception use among women and men on ART. This qualitative study was a complement to our previously published quantitative study (which was not part of this thesis) where we found that 93% of the incident pregnancies were termed “unintended”. The fourth study assessed individual and couple beliefs around discordance, couple relationships and risk behavior over time among HIV-serodiscordant couples enrolled in a longitudinal cohort study. We found that HIV serostatus disclosure to sexual partner can be a complex process and that the positive disclosure outcomes far outweighed negative in our study (Article I). We also found that HIV-infected adults have strong, multiple and diverse motivations to prevent further HIV transmission. Their reasons include altruistic and self care motives and can be linked to direct couple and individual behavior (Article II). Thirdly, reproductive decision-making in the context of HIV and ART encompasses a complicated web of influences where the actors navigate with and without active decision-making (Article III). Lastly, we found that understanding of HIV serodiscordance influenced couple relations and communication which in turn acted on risk behavior mediated by factors such as past behavior, as well as structural and cultural factors among HIV serodiscordant couples (Article IV).

Figure 9: Billboard in Kampala advertising HIV test and

Positive prevention; Disclosure and Altruism

Using mathematical modeling, Pinkerton and Galletly estimated that serostatus disclosure to sexual partners has the potential to decrease HIV transmission by 17.9% to 40.6% when compared to not disclosing [114]. Disclosure has to be individually motivated- and dyadically enabled, and is a first step to both emotional relief and altruistic behavior change. Yet for some people it has been shown to be a scary decision as it opens up the potential for blame, misinterpretation and misunderstanding.

Our findings add to the rapidly expanding body of disclosure knowledge by exploring, in greater depth, the processes and outcomes of disclosure for both men and women. It was noted in a recent review of the disclosure literature that of 210 disclosure studies reviewed, 69% focused on factors antecedent to the disclosure, 56% assessed disclosure outcomes, and 7% examined the disclosure process [18]. We were among the first to report on indirect methods of disclosure, which can be extremely useful in culturally-relevant counseling messages on the
topic. Our results show that, though far from a straightforward direct process, most of our study participants who devised creative methods of disclosing their HIV status, found greater support to manage their HIV infection and to sustain their chosen prevention behavior. Others have noted how individuals diagnosed with HIV have a need for emotional support on the one hand and have concerns about stigma on the other hand, which contribute to the complexity of the disclosure process [21]. Our study showed similar results; but we found that the positive disclosure outcomes far outweighed the negative overall.

To compare to another site in Uganda, among the HBAC clinical trial population in Tororo where studies for Articles III and IV were housed, 97% of the 971 participants who were enrolled and subsequently initiated onto ART, had disclosed their HIV serostatus to at least one person at the time of ART initiation. The majority (82%) disclosed on the day of their first HIV-positive test. More than half of the women (52%) reported their first disclosure to a relative; 43% men reported disclosing their serostatus to their spouse(s). Before ART, the most common reason given for disclosing HIV status was for emotional support (41%) and the majority (95%) of participants reported receipt of emotional support following disclosure (HBAC study, Tororo, unpublished information). Following ART initiation, the most frequently mentioned reason for disclosing was to enable other community members to access treatment (Nakayiwa, unpublished data). These results echo our Jinja data, and bring together aspects of prevention altruism, positive outcomes and the affirmation that disclosure, though at times risky, can continue to be encouraged in prevention counseling. In the event of a history of domestic violence, disclosure counseling should proceed with caution.

There is a paucity of research on HIV altruistic behavior, especially in resource-constrained settings. Our findings highlight a sense of responsibility among HIV infected men and women that extends well beyond self-care, to care for family and community. Until now, prevention altruism has only been explicitly described among men who have sex with men in resource-rich environments [39,40,41] and injection drug users in New York City [115]. The implications of building on this research are interesting in our context; care for the family, clan and community is a culturally-relevant approach that could potentially invigorate the prevention agenda significantly if implemented mindfully. If risk-reduction counseling could highlight the benefits of altruistic prevention behavior especially towards benefitting the family, clan and wider community rather than the individual alone, they could prove to be an important additional strategy in the package of combination prevention. As others, our findings suggest that positive prevention approaches must also emphasize agency among people living with HIV [14]. Empowering individuals and couples, not only for self-care, but about how they can embrace and implement the prevention agenda in their homes and communities can be a powerful health maintenance tool [116].

**Positive prevention; reproduction decisions and discordance**

Reproductive decision-making is multifaceted and complicated with or without HIV infection. As research and experience have shown, individual as well as relationship, structural and cultural influences all impact on these critical decisions. In addition, influences, situations and motivations change over time. When we bring HIV into the picture and then ART, we add additional layers of complexity.
We, as others, have described that most of the incident pregnancies among women on ART reported in studies in sub-Saharan Africa, were unintended. Our previous quantitative study found that less than 7% of HBAC women over 2.3 years of follow-up stated they desired a pregnancy, yet 17% became pregnant over the follow-up period [58]. Similar studies report rates of unintended pregnancies between 50-93% [49,54,58,118,119,120]. Over the years, there have been multiple reasons that women (in HIV studies) become pregnant when they don’t intend to. Some of these reasons are not new and include little or no access to family planning (including cost), fear of side effects [89,118], younger age and fewer children [119], health facility or provider-related issues [120], male-partner related reasons and misunderstanding of discordance [89], as well as poverty and unemployment [88]. As the base of knowledge and experience grows regarding pregnancy among populations on ART, we may find that HIV-infected men and women are more likely to express desire than they were earlier on in the ART roll out period. Our study also highlighted the lack of active decision-making with respect to reproductive health decisions (Article III) and this may be perceived as a “safe” default position where the community norm is to have children. Additional studies have assessed the relationship between HIV diagnosis and pregnancy desires and decisions as well as accessing ART and how being on treatment has impacted both desires and pregnancy incidence [121,122]. What our study highlights are the nuanced influence of ART on the couple’s situation from a qualitative perspective and how, not one, but both partners have reacted and responded to reproductive decision-making in the context of ART. Both our study and Marlow’s qualitative study in South Africa found that client-provider interactions and structural issues, such as whether family planning methods are available, have had a powerful impact on uptake of modern family planning methods in general and specifically of longer acting methods [120]. Clinicians and counselors that couples of reproductive age consult at the time of pregnancy need to be aware that many of these couples struggle with personal and socio-cultural issues of reproductive decision-making and that openly discussing with clear information is crucial to elucidate the factors at play in making these decisions. For women and couples who do not desire more children, more user-friendly, innovative services that can conveniently integrate family planning with HIV, are urgently needed and are specifically needed on a regular basis, not only at initiation, but on an ongoing basis [45,48,49,53,58,123]. Counsellors and clinicians should also be aware of the importance of younger age in relation to reproductive decision-making and risk of transmission.

It is crucial to revitalize the prevention agenda to include interventions which focus on discordance [124,125]. Our findings, similar to others, suggest that ingrained cultural beliefs about health and disease transmission have a powerful effect on behavior (Article IV) [126]. The bulk of the literature on discordant couples is focused on rates of discordance and factors related to transmission. Understanding the background to discordance is important, but even more critical at this point is to assess behavioral patterns among discordant couples. Ware and colleagues found that among 60 discordant couples enrolled in a study assessing adherence to (PrEP), relationship dynamics have an important impact on adherence among discordant couples [127]. Discordant, like other non-discordant couples, wish to stay together and this desire motivated them to adhere to their medication regimen [127]. What our study adds to the

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7 There are discussions regarding the definitions of “unintended pregnancy”. Trussell and colleagues found that the definitions and therefore the measurement remain elusive. 117. Trussell J, Vaughan B, Stanford J (1999) Are all contraceptive failures unintended pregnancies? Evidence from the 1995 National Survey of Family Growth. Fam Plann Perspect 31: 246-247, 260.
discussion is the importance of how couples understand and perceive their discordance in relation to each other, their context and their capacity to change behavior over time.

**Focus on the individual versus the dyad**
Numerous studies since the early 1990s, and new couple counseling guidelines from WHO, have advocated for a strengthened approach to dyadic rather than individual approaches to HIV prevention research and programming [124]. The rationale has been the need to address the obvious reality that most decisions regarding whether or not one can behave in a safe manner is made by a couple rather than an individual [73,77,128,129,130,131]. Most research and programming for HIV in Africa to date has been individual-centered. Yet, three quarters of adults in sub-Saharan Africa report being in couples and couple-based strategies for HIV prevention in Africa have multiple advantages over individual-focused strategies [124]. For example, couples HIV testing and counseling provides opportunities to address gender imbalanced power dynamics, including mitigating the process of disclosure and including communication on relevant prevention topics specific to the couple such as reproductive health, family planning, partner reduction and condom use with outside partners as well as male circumcision, and adherence to treatment as part of the counseling messages [13,124,129]. The shared responsibility of HIV prevention and care can be addressed to both couple members in a couple counseling session [130]. The recently completed Partners in Prevention study reported that up to 29% of new HIV infections within serodiscordant couples may have come from external partners [83]. Kebaabetswe and colleagues explored couples HIV testing and counseling vs individual approaches in Botswana and found consistently that stakeholders in both key informant interviews and focus group discussions preferred couple to individual approaches though caution was suggested in the implementation to avoid blame, misunderstanding and mistrust [132]. Darbes and colleagues reported that improving sexual communication between partners through couples-based HIV counseling and testing rates can potentially improve uptake of counseling and testing services. Their study focused on enhancing communication can either by training on communication skills, by strengthening the relationship factors or through combining both strategies [131].

**Combination approaches**
Just as combination anti-retroviral drugs are recommended for treating HIV infection, so are combination approaches suggested for more effective prevention. Combination prevention can be a harmony of approaches relevant for the couples such as promotion of couples' counseling, testing and disclosure; condom promotion as well as alcohol risk-reduction, while biomedical interventions include provision of antiretroviral treatment to the HIV-infected and HIV-uninfected partner, medical male circumcision and treatment of sexually transmitted infections [124,133,134]. In order for these combination approaches to yield a global impact, they need to be effectively coordinated, implemented to scale, linked to each other, evidence-informed, human-rights based and community-owned and led [17].

**Positive prevention and the social cultural and structural context**
Changing behavior remains at the cornerstone of all HIV prevention and care and all preventive behaviors are embedded within a relational, social, cultural fabric. The patriarchal society forms the foundation for gender relations in Uganda as in many sub-Saharan African countries [135]. Marriage is a powerful institution in these contexts and can be seen as not only a relationship between the two newlyweds, but also between two kin groups [136]. Other studies
have noted the prevailing influence of patriarchy on prevention and reproductive behavior [88,132]. This plays out in different ways as perceptions and socialization around sexual behavior begins in young people [88] through multiple routes including peers, parents, traditional aunts (called ssengas in Uganda), and school and media [137]. Many residents in Eastern Uganda accept multiple sexual partnerships with men as long as they fit within accepted parameters [136]. There are different ways that cultural gender norms are expressed in relation to HIV prevention. As we found in some couples in our studies, some women advise other women to remain submissive in order to keep the peace at home [138]. This would reflect the modern view of marriage as monogamous. Men have mentioned in our study (and others), that women have no right to refuse sex within marriage. As Parikh mentions in her ethnographic study in Eastern Uganda, “practices, conceptions and meanings of men’s concurrent partnering and wives’ reactions have shifted over time and emerge within historically specific moments” [136]. How men and women perceive their gender identity in relation to their partner (or partners), the family and clan is central to how they will behave in relation to risk practices, reproductive practices as well as protective practices.

Another very strong influence on behavior in Uganda as in many other sub-Saharan African countries over time is religion. The pervasive Christian views dominated discourse on AIDS and sexual behavior especially early in the epidemic. With the Catholic and Muslim voices added to a conservative rural population and the donor ideologies, a quilt of AIDS controlling influences on policies has formed that end up effecting individual and couple sexual behavior [139]. “Being Faithful” was and still is part of Uganda’s well-know “ABC” (Abstinence, Being Faithful and Using Condoms) strategy for AIDS prevention and is key to the Christian marriage vows as well. Ethical, religious and moral values were noted in our Article II as strong motivators to prevent further transmission of HIV.

Using alcohol was mentioned in our studies as a challenge to safe sexual behavior (Articles III, IV) and has been mentioned by many others in relation to sexual violence experienced by women [138,140] as well as poor adherence to ART [141]. In Zimbabwe, a recent qualitative study described forced sex during pregnancy as associated with alcohol consumption and men not accepting or understanding the pregnancy and emotional changes in connection with it [138]. In Uganda, the per capita consumption of alcohol was the highest in the world in 2004, but has come down to second highest in Africa by 2011 [142]. In our couple studies, alcohol use was mentioned in relation to the respondents own use as well as their partners’ use; which obviously makes this behavior even more difficult to control with respect to its impact on sexual behavior.

Prevention strategies need to be tailored to current local trends and patterns of HIV transmission, with behaviorally - customized programs that aim to reduce risk behavior and expand HIV testing and counseling for couples, including for preventing mother-to-child HIV transmission.

**METHODOLOGICAL CONSIDERATIONS**

I will discuss the strengths and limitations of the study designs for each of the sub-studies in this thesis. For the first two articles, based on one parent study, we used both quantitative and qualitative methods to answer the research questions. As Boyatzis mentions, the combination of both methods allows us to join the richness and exclusiveness of qualitative information and
the precision and discipline of quantitative methods [100]. This has allowed for a meta-
theoretical approach.

Quantitative Studies (Articles I & II)

The quantitative aspects of this body of work were more limited in scope than the qualitative. My studies were conceived as adding value to other studies conducted within the PWP parent study. In Studies I & II we used both quantitative and qualitative methods. The main potential errors to consider with respect to these two studies are selection bias and social desirability.

Selection bias

Selection bias is important to consider as it cannot be adjusted for in the analysis. This bias is related to how individuals are selected to participate in the studies. For Studies I & II, potential participants were selected randomly from the TASO clinic. Random selection was conducted by field officers who prepared lottery papers for the corresponding number of clients who had registered that day. Thus our participants are generalizable to the TASO population in and around Jinja (and Tororo/Busia for Articles III & IV). We cannot generalize to all HIV-infected individuals in Uganda who do not access treatment, but TASO is currently present in 75% of the 110 districts of Uganda and many of the other ART providers have been trained by TASO training staff. TASO is currently marking 25 years of AIDS prevention and care service in Uganda and has formal branches in 11 districts. Cumulatively 281,900 clients have accessed TASO's care since inception in 1987 and over 63,000 people have received anti-retroviral therapy from TASO. To get an idea of who these clients are; the mean age of TASO clients is 35 years and about 37% are married or cohabitating. The TASO culture appears to be more prevalent, more pervasive than its clientele and its tangible technical reach. TASO has a strong philosophy based on “positive living” which includes compassionate prevention, care, treatment and protection of rights. The founder of TASO described to me that at a recent funeral of someone who died of AIDS, the deceased was described as someone who lived as a TASO client, meaning that, he had lived openly, positively, though he had never entered a TASO center. To compare with three other AIDS service organizations, one mentioned a rate of 18% serostatus disclosure to their sexual partners. In a second one, 54% reported having sexual partners and among them, 50% reported having disclosed to their sexual partner. The rate of disclosure to sexual partners at Reach Out Mbuya was 73% (Alamo, executive director, personal communication). In the PWP, Jinja study (TASO, Jinja) the disclosure rate was 69% to sexual partner. In addition, I spoke to clients. One PLHA who is not a TASO member, clarified that he is counseled on adherence and prevention at every clinic follow-up visit at his non-TASO site. This friend/client had disclosed his HIV serostatus to many people, his employer included. Currently, TASO is undergoing a transition where outreach sites are in the process of being handed over to the government health facilities. While the endeavor is to scale up support of PLHA, the challenge will be to sustain the TASO strength in patient support [143].

Social desirability bias

Social desirability could have influenced respondents to answer in a manner expected of them by the interviewers. Addressing potential social desirability bias is critical. We took measures to limit this bias by developing rapport with our participants, training interviewers to be mindful of this bias and triangulating information (discussed below). We developed a multivariate
logistic regression model to assess associations between HIV disclosure by participants to their most recent sexual partner and socio-demographics, sexual behavior, condom use, health characteristics, knowledge of partner’s HIV status and years enrolled at TASO. We checked for interactions between variables that might be related. For the analysis, we excluded over 300 individuals who reported last having sex on a date prior to receiving their HIV test result.

**Qualitative Studies (Articles I & IV)**

Qualitative inquiry has a long history often distinguishing and defining itself in contrast to quantitative methods. Its origins are usually described in fields of anthropology and sociology [144]. Qualitative researchers use multiple approaches to design, collect and analyze data [145].

Different methods differently “produce, reveal, and enable the display of different kinds of identities” [144]. We used different methods to highlight different perspectives, not necessarily to produce a coherence, or convergence, but as Denzin and Lincoln put it, to listen to, “a quilt of stories and a cacophony of voices speaking to each other” [144]. For the four qualitative sub-studies, we discussed the strengths and weaknesses of different qualitative approaches. For studies I-III, we decided that thematic analysis, from the Boyatzis perspective, fit the analysis needs of our projects. Boyatzis’ thematic analysis has the benefit of providing a “methodological translation and conceptual bridge” between approaches to allow for understanding and acceptance by a wide variety of different disciplinary backgrounds [100]. It encompasses both a positivist’s view of importance of reliability and consistency as well as the interpretive social scientist’s view of the social construction of meaning to be articulated. Thus our choice for thematic analysis provides for our view that we would like to communicate to a broad audience while considering a variety of theoretical foundations.

**Reflexivity**

Reflexivity brings to the discussion the place of the researcher in the interpretation of the findings. Using qualitative inquiry necessarily brings together the researcher, her participants and how knowledge is shaped and presented. It is the conscious effort to acknowledge the researcher’s own engagement in the study [146]. Who we are, where we were raised, in what field we were trained, our gender and age during the time data were collected and analyzed are all intertwined in the final outcome. Thinking about reflexivity over the course of this research process forces us to think critically about our place within the journey of not only the doctoral research, but of our relation to the participants - how we have touched their lives and how they have touched ours.

As a woman, trained in public health and behavioral science, my views are generally tinted with a public health lens and seen through the eyes of my different social roles. As a mother, I felt deep compassion for the many participants who have lost children to HIV, and as a woman and a health professional, much of the data and related interpretations that have jumped out at me at different points in the analysis process are most certainly a result of the different facets of who I am. I have found that during the years of this research process I have at numerous times had to check back with the research team to confirm my views. I see myself, as both an insider and outsider, having lived in Uganda my entire adult/working life, but having grown up in North America. I continue to ask questions as an outsider, and answer them as an insider to others who are “more outsider” than me! I hope to continue the learning process of what it means to live with HIV in Uganda for as long as I am here. The context changes over time as do my
views and perceptions in relation to it. During the time of this thesis I worked at CDC-Uganda, which was a tremendous opportunity for me as I was exposed to multiple projects and was able to take part in the entire process from idea generation, to proposal writing, ethical approvals, study design and implementation, and analysis and write up. My role in this work has been in collaboration with colleagues at CDC-Uganda and IHCAR, Karolinska; from whom I have benefited tremendously. I have driven the process in different ways at different points for each of the studies. The more challenging aspect of working in such big organizations was that there were delays in approval processes; and that I had little control over some decisions.

In all of the studies for this thesis, the interviewers recorded the interviews and spoke the language of the participants. The interviewers translated their own interviews into English. We held many discussions about the meanings of different terms during the analysis process. The social scientists with whom I worked were highly skilled in interviewing, coding, and in the further analysis and interpretation of our results. There has been discussion about whether or not the interviewers should transcribe their own interviews and whether or not this gives room to the possibility of “correcting” potentially “wrong” answers instead of transcribing verbatim. We felt that the benefits of having the interviewers transcribe their own interviews outweighed the risks in these studies. It does take much time, but interviewers were able to understand exactly what was said in cases where the quality of recording may not have been perfect, and to actually transcribe the “chuckle” or other not completely verbal language used as they were present. The social scientists who conducted the interviews were both males and females and within the age range of the participants for all studies. This allowed for limited hierarchy of participant/researcher bias.

**Rigour**

Validity and reliability are critical aspects in all research. Ensuring that qualitative data analysis is rigorous is especially important given a frequent criticism that qualitative results are subjective. One way to increase qualitative robustness is ensuring method reliability, triangulation and respondent validation. For qualitative research it is linked to integrity [146].

**Reliability**

To ensure quality of qualitative analysis the researcher must ensure reliability of the methods used by demonstrating reproducibility and consistency. This can be done by:

- clearly describing of the approach to and procedures for data analysis
- providing a rationale about why procedures and approaches are appropriate and relevant within the context of the studies
- documenting the process of generating themes, concepts or theories from the data
- referring to additional evidence, including previous qualitative and quantitative studies, to test the conclusions from our analyses as appropriate.

In each of our studies, we discussed our findings in relation to the previous results of studies within the same environment. Our rationale for choosing thematic analysis in studies I-III was discussed above. The process of thematic analysis involves three stages: stage I is the sampling and design, stage II, developing themes and the code, and stage III is validation and use of the code [100]. The methods of code development included theory-driven, prior data driven and inductive. In each of our studies, we used a measure of inter-rater reliability to
ensure we were consistently coding throughout the process as well as regular, structured team meetings to discuss discrepancy of meanings and interpretations.

**Validity**

When assessing validity in qualitative research, the emphasis is on the validity of the interpretation. In our qualitative work, we were not aiming for validity as it is commonly understood, but rather for understanding. We were not trying to find the right or only correct answer, but one of the possible truths. There may be multiple overlapping truths operating at different levels, by different individuals in a fluid nature subject to constantly changing influences. We judge validity here by the extent to which the findings seem to appropriately and accurately represent the data collected. The approach we used included:

* Systematic use of the original data through quotations from different participants (males and females as well as HIV negative and positive where relevant)
* The fit between study design and analysis of findings [147]
* Consistency of findings; specifically we checked for inter-coder reliability
* Representation of relevant views by checking for “negative” or deviant cases to examine interpretations
* Throughout the analysis process, regular interactive discussions were held with the analysis team, who were from diverse backgrounds (physician, social scientists, counselors) to validate data interpretations and resolve any discrepancies. In all four studies, interviewers were asked to comment on the interpretation of preliminary findings. In addition, for Articles III & IV the research counsellors knew the area and the participants well, and could thus check for consistency easily.

**Triangulation**

The term triangulation most often means obtaining different insights into the same situation using different methods. One common form of triangulation in qualitative research is in use of varied methods to explore an issue which will increase the chances of depth and accuracy as well as demonstrating rigor. One way to do this is to combine interviews with observation or in our case to analyze and describe both the qualitative and quantitative results in one manuscript. Use of multiple time points can also increase rigor. This allows for the consideration of the process of events. In our last study, we used both individual interviews as well as discussion groups to a) present beforehand what content and approach were planned; b) observe as demonstrations took place; c) discuss afterwards feelings and attitudes about issues discussed and as well as explanations for particular responses or actions. In addition, in study IV, we triangulated persons by interviewing the two members of the couple and consulting with their counsellors if any questions arose. Checking different accounts can lead to closer interrogation of data. In studies I & II we triangulated by using both qualitative and quantitative methods.

**Conceptual Framework**

As customary in the scientific tradition, I would like to build upon the accumulated knowledge in my field. The framework proposed by Kennedy and colleagues [14] has been extremely useful in a programmatic paradigm; in conceptualizing what the goals of positive prevention are, how can implementers design programs to realize the intended outcomes and what would
one expect as an impact. The expanded framework below draws from the empirical data in Articles I-IV and suggests that the programmatic concept lie within a context. This context includes environmental influences - socio-cultural (including gender norms) and structural influences - and two levels of mediators such as couple communication that can lead to relational risk reduction, dignity and strengthened relationships. These mediate between the outcomes suggested in the Kennedy framework as shown in the figure below.

The constructs have been drawn from different theories as mentioned in the background and were beneficial in different ways. In the prevention with positives study, we used constructs such as “self efficacy”, “perceived barriers” and “perceived norms” in designing the data collection tools; well aware of the limitations of individual cognitive level constructs. We have tried to use these individual-level constructs within the framework of a larger understanding of peoples’ lives in context. The loss frame/gain frame approach was used with the idea to ask participants openly their motivations and experiences with disclosure (Article I) and more broadly with motivations for prevention (Article II) and assess whether what comes out of the data rings true with a gain frame/loss frame messaging approach. The theories of gender and power and the social ecological model were used in Articles III and IV at the analysis stage when trying to make sense of the data and assess how different influences and different levels of influence have affected individual and couple behavior. Particular constructs that informed the analysis included gender norms, societal/cultural expectations and economic risk.

When we planned and then implemented these studies the roll-out of ART was just starting in Africa. Our first participants didn’t have access to these drugs. As we report these studies, the agenda for ART roll out has an immeasurably different trajectory. However, the results, though dated, are almost more timely today than they would have been in the early 2000s when parent studies were designed, as today the spotlight is on prevention and more specifically, on a combination approach which includes a “test and treat” strategy as part of the prevention package (see Figure below). For individuals asked to take a daily treatment for life, with or without symptoms, counselors need to have powerful messages to ensure adherence to these new drug regimens. Our results from Article II suggest that emphasizing a culturally relevant approach that ensures partner health to protect the child like ensuring the “clan” health, would help to invigorate counseling messages. In addition, few high impact interventions have a chance of success without considering the individual’s ability to communicate with his or her partner, without considering how our interventions are embedded into the socio-cultural and political environment.

The most interesting findings of these studies highlight the importance of relationality and context in a vastly dynamic environment. The common thread through all our studies is the importance of a couple-based communication for prevention and relationship well-being. No intervention, whether biologically founded or behaviorally-based, has a chance at success unless the individuals in question can understand and communicate the relevance and importance of changing their behavior to adhere to whatever practice, whether a drug regimen, using condoms or a combination prevention approach. The keys to making prevention work on today’s HIV canvas are to highlight those at highest risk, discordant couples for example, roll out the interventions we already know are effective and coordinate and link the numerous interventions to each other so that valuable information and resources are put to the most-effective use.
Figure 10: Expanded conceptual framework
CONCLUSIONS

* This population of Ugandans living with HIV experienced benefits from sharing their HIV serostatus that outweighed negative experiences. Disclosure rate was high and facilitated HIV-infected individuals to increase the social support to improve their medical management as well as to initiate risk-reduction behavior. (I)
* Men and women living with HIV reported a strong sense of responsibility to prevent infection to their sexual partners and unborn children. This altruism was linked to their beliefs that conscious transmission of HIV infection was akin to murder. Participants directly linked their altruistic beliefs to self-reported safer sexual behavior. (II)
* Categories of self-protection and protection of others may not be mutually exclusive, rather individuals can have a myriad of psychological, environmental and relational factors at play where their sexual behavior is the final outcome. (II)
* Fertility desires among HIV infected couples change over time especially in relation to health status and ART. Counseling for reproductive decision making needs to consider the quickly changing health and emotional status of clients initiating ART. (III)
* Group interventions can be useful for discordant couple interactions as the concept of discordance is complicated and bringing discordant couples together helps encourage feelings of solidarity, which can facilitate discussion on risk reduction and care seeking. (IV)

RECOMMENDATIONS FOR PROGRAMMING AND RESEARCH

* Post-test counseling of HIV-positive individuals should include clear messages on varied, client centered, disclosure techniques and strategies to minimize negative consequences and maximize the positive benefits of HIV serostatus disclosure. (I)
* When counseling men and women who test HIV positive, highlighting the personal motivators as well as the negative consequences of not enacting specific risk reduction behaviors may re-inspire HIV counselors and clients in sub-Saharan Africa. (II)
* Greater attention needs to be placed on individuals who succeed in their sexual protection of both self and others in order to identify factors enabling them to sustain the changes they desire. (II)
* Evaluating the impact of theoretically informed interventions with a focus on altruistic motivations for HIV transmission risk reduction may be important for guiding the expansion of positive prevention in Africa. (II)
Our findings highlight the need for a more comprehensive approach to ART counseling that integrates maternal and child health, family planning, and HIV care services in order to address the realities and clients’ changing fertility desires. (III)

Family Planning (FP) counseling would be more effective if conducted on separate, later occasions from ART initiation counseling when couples can focus on their reproductive desires in relation to newfound health. This approach will require specific elements including 1) effective integration of reproductive health especially FP and HIV care services for men and women, 2) offering and encouraging dual contraceptive methods for HIV discordant couples, and 3) ensuring uninterrupted access to longer-acting FP methods. (III)

Interventions aiming at the behavior of discordant couples should include promotion of combination prevention packages that encompass structural, biomedical and behavioral interventions that highlight ongoing counseling on the meaning of discordance. (IV)

It is critical that all the components of effective prevention and care are included and optimized and to be mindful of the fluid understanding and multiple factors that influence the effectiveness of these interventions. (IV)
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* * *
REFERENCES


54. UBOS MI (2007) Uganda Demographic and Health Survey 2006. Kampala, Uganda and Calverton, Maryland, USA: UBOS.


90. UNFPA (2011) People and Possibilities in a world of seven billion. New York: UNFPA.


