

**Great Expectations:
Women's Experiences of Pregnancy when HIV-
positive and on Antiretroviral Therapy in Uganda**

by

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Abstract

In Uganda, the social expectation that women should bear children competes with HIV clinic expectation that HIV-positive women should bear few or none. This contradiction undergirds this thesis, which examines how access to ART, social expectations and clinical expectations all combine to influence how HIV-positive women approach pregnancy in southwestern Uganda. From August to December 2011, ethnographic fieldwork was conducted in Mbarara, Uganda. Semi-structured interviews were conducted with 25 pregnant HIV-positive women accessing ART. The main themes that emerged were that: 1) HIV-positive women reported new optimism about pregnancy since being on ART, 2) adherence to ART and family support helped women manage social expectations placed upon them, and 3) clinic counselling about pregnancy beyond adherence to ART was not common. Thus, ART is an important link between managing social and clinical expectations for HIV-positive women since it improves women's health and decreases risks of childbearing.

Keywords: HIV/AIDS; pregnancy; reproductive health; women; qualitative research; Uganda

To my parents for always believing in me and my friends for laughing with me.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ARV	Antiretroviral
FP	Family Planning
HAART	Highly Active Antiretroviral Treatment
HIV	Human Immunodeficiency Virus
ISS	Immune Suppression Syndrome [clinic]
JCRC	Joint Clinical Research Centre
MJAP	Makerere University Joint AIDS Program
MTCT	Mother to Child Transmission
MUST	Mbarara University of Science and Technology
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission
RH	Reproductive Health
SFU	Simon Fraser University
TASO	The AIDS Support Organization
TFR	Total Fertility Rate
UNCST	Ugandan National Council for Science & Technology
USAID	United States Agency for International Development
WHO	World Health Organization

Glossary

ART	Antiretroviral therapy is a combination of at least three antiretroviral drugs that together suppress the HIV viral load, reduce the chance of vertical transmission of HIV, and slow down the progression of HIV/AIDS.
Exposed Infants	Infants who are born with pre-natal exposure to the HIV-virus. It is possible for exposed infants not become infected with proper treatment.
Positive Living	Support for living and staying healthy while HIV-positive. This support is from counsellors, clinicians, family members, and friends.
Sero-discordant couple	A relationship where in which one partner is HIV-positive and the other is HIV-negative.
TASO	The AIDS Support Organization is the Ugandan national HIV organization which was founded in 1987. The founding of TASO was based on unifying those infected and affected with HIV/AIDS. This was a community based approach to speaking out about the disease at a time when stigma and discrimination was high. TASO has been coined as a major player in Uganda's 'AIDS success'.

Executive Summary

Research Question: How does adherence to antiretroviral therapy (ART) shape HIV-positive women's reproductive expectations?

Most Significant Study Findings

1. ART gave women new optimism that they could remain healthy enough to care for their children.

n=21	Reported feeling "scared" and "stuck" after first learning HIV +	Reported "renewed hope" with ART
	85.7%	71.4%

2. Women's ideal family size decreased after learning about HIV+ status, but stayed the same after initiation of ART.

n=22	Ideal family size before learning HIV+	Ideal family size after learning HIV+	Ideal family size after starting ART
(mean)	4.0	2.6	2.6

3. Most women had disclosed HIV status to partner and family, but not to community. They reported that the support from partner and family increased their adherence to ART.

n=25	Disclosed HIV status to partner	Disclosed HIV status to family	Disclosed HIV status to community
Yes	22	18	2
No	3	7	23

4. ART, along with the support of their partners and family, enabled women to better care for their own health and better plan for their future children's health. Additionally, ART enabled women to more actively negotiate their HIV+ status relative to social roles and expectations.

5. Clinic counselling about pregnancy when HIV-positive was not common. Women who received counselling reported that the focus was on adherence to ART for mother and child, and to give birth to few or no children.

n=23	Received clinic counseling about pregnancy when HIV+	Did not receive clinic counseling about pregnancy when HIV+
	34.8%	65.2%

Uganda Context

Ugandan HIV-prevalence is 6.4%. Prevalence among women of reproductive age is almost double the national rate (12%). Uganda has seen a slight decline in the total fertility rate per woman over the past two decades, but women have an average of 6-7 children (Index Mundi 2012). HIV+ women often still desire children and are expected have children. Adult HIV prevalence in Mbarara was 13.7% in 2007 (Government of Ugandan 2010).

Research Setting and Methods

This study was conducted in Mbarara, a semi-urban town in southwest Uganda. Study participants were recruited from the Immune Suppression Syndrome (ISS) clinic within the Mbarara Regional Referral Hospital (MRRH). The ISS clinic is the hospital's HIV/AIDS clinic, and the region's primary source for HIV care services, including ART free-of-charge. Since 1998, ISS has served more than 18,000 patients.

From August to December 2011, ethnographic fieldwork was conducted and included participant observation and patient interviews while living Mbarara. Semi-structured in-depth interviews were conducted with 25 pregnant HIV-positive women who were ISS patients and on ART.

Summary

The availability of ART, the clinical expectations of adherence, and the social support of close relatives influences HIV+ women experiences and expectations of pregnancy in southwestern Uganda.

Prologue

It is almost 9 a.m., and I make my way to the HIV clinic. The garbage bins are overflowing with small cardboard boxes that women throw away, in order to discretely fit their HIV medication inside their purses. They don't want people to know they are HIV-positive. Judith¹, the head nurse of the adult section of the clinic, sees me and greets me with a smile. "Jasmine, nogambaki (How are you)?" She takes my hand and we begin to walk toward the clinic together. Judith mentions that there is a woman that I should talk to, and that she will introduce us.

We arrive at the clinic. The waiting room is packed with people. All morning long, it is always full with men, women, and children, just waiting. Eventually, their names are called and they begin their clinic visit sequence: waiting room, triage room, nurse check-up, doctor visit, counsellor, then pharmacy.



Figure 1.1. Immune Suppression Syndrome Clinic, Main Waiting Room

Photos by author

Routine check-ups for people living with HIV are not easy. 'Clinic days' can be long, and waiting amidst other individuals is a reminder of how maintaining your health requires an acceptance that you have turned your life over to HIV. Adherence to treatment means not only medication, but also the inclusion of 'clinic days' every few months for the rest of your life.

¹ All names are pseudonyms.

While most patients are very knowledgeable when it comes to HIV and the importance of medication, taking a day off work is not easy. Many women complain of the transportation costs to get to the clinic and the cost of losing a day of work. However, they are nevertheless grateful to receive free care treatment and care.

Around 11 am, Judith finds Enid, my research assistant, and me. A young woman wearing a light blue dress that shows the contours of her pregnant belly is walking behind her. Enid and I greet the young woman and explain the purpose of this research project. She agrees to be interviewed.



Figure 1.2. Immune Suppression Syndrome Clinic, Our Interview Room

Photos by author

The interview begins. The young woman explains that she moved to Mbarara, a semi-urban town, from her village when she was a teenager to find a job. A few years later, she married her current husband, which ensured her own financial security. She never asked him about his HIV status. Despite her pregnancy being unplanned, she is committed to making it to the clinic for her review dates in order to ensure that her child has the best chance of not contracting HIV. 'Clinic days' are now an important part of her life. The care she receives also helps with the social expectations she feels, relative to her HIV status and pregnancy.

1. Introduction

In Uganda, the social expectation that women should bear children competes with the HIV clinic expectation that HIV-positive women should avoid getting pregnant. This contradiction undergirds this thesis, which explores how HIV-positive women in Southwest Uganda who are on antiretroviral therapy (ART) negotiate their pregnancy planning. Despite differences between social and clinical expectations, access to ART at HIV clinics enables women to better negotiate their social roles. This shapes ART into an important link between social life and clinical care, and places both social and clinical expectations of women as important domains of analysis.

Most of the women interviewed for this study had disclosed their HIV status to their partner and family members, but not to their larger community. The added support from their partner and family increases women's adherence to ART and their approach to living with HIV. Adherence to ART helps women to maintain their social roles as reproducers, give birth to HIV-negative babies and reduce the stigma of being HIV-positive. In this way, ART enables women to better care for their own health, maintain their livelihood, and better plan for their future children's health.

Within the clinic setting, pregnancy counselling for HIV-positive women is not common. Women who did receive counselling reported that it focused on adherence to ART for mother and child, and on giving birth to few or no children. The emphasis on not getting pregnant in order to maintain health shapes women's ideal family size. Women interviewed reported that, while their ideal family size decreased after learning that they were HIV-positive, it did not increase again after they began ART. Despite their new optimism about becoming pregnant when HIV-positive and on ART, they did not revert back to their pre-HIV ideal family size. This thesis examines how access to ART, social expectations and clinical expectations all combine to influence how women approach pregnancy when they are HIV-positive.

1.1. HIV, ART and Reproductive Health Research in Uganda

Global public health protocols for HIV-positive women primarily focus on access to treatment and individual prevention methods (“safe sex”), rather than the social environment within which sex and pregnancies are negotiated. As the general health of people living with HIV improves, ART provided by global public health programs is also shaping the way that pregnancy is approached within the social environment. This is especially apparent as knowledge about HIV and HIV treatment increases within communities.

Many women want to abide by the counselling that they receive at the clinic. However, after their ‘clinic days’, HIV-positive women return to their families and communities, where social expectations and pressures about pregnancy can supersede clinic guidelines. Women are part of families and communities, and their roles are largely structured. The majority of women’s time is spent in social environments rather than the clinic. Family members have expectations about women’s reproductive roles, including giving birth to many children and maintaining the household. Attending scheduled ‘clinic days’ and having access to ART enables HIV-positive women to maintain their health and continue with their productive and reproductive social roles.

Over a decade ago, access to free-of-charge ART increased due to international interventions, mainly by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund for AIDS, Tuberculosis and Malaria (Tuller et al 2009). Gill et al (2005) were among the first to raise concerns that adherence to ART would be a challenge for HIV-positive persons living in Africa. Initial expectations were that adherence rates over time would be low, given the need for strict adherence to treatment guidelines. However, adherence rates in low-resource settings are reported to be equivalent to or higher than those in resource-rich countries (Mills et al 2006). Research now also looks at barriers to successful ART adherence. Such barriers have been found to be related to socio-economic constraints (Tuller et al 2009; Hardon et al 2007; Orrell et al 2003).

Research norms have been quantitative in their focus, dominated by epidemiologic, demographic, and clinical studies. The focus of ART studies has shifted

away from clinical outcomes, like viral load suppression, drug resistance, and AIDS progression (Bangsberg et al 2000, 2001). In recent years, research is starting to increasingly focus on how access to HIV care and treatment influences personal and clinical concerns about reproductive health care and the pregnancy of HIV-positive women. This new subsection of HIV research is based on the connection between sex, pregnancy, and transmission of HIV. Previous research in Uganda has taken a clinical focus on individual-level predictors of the reproductive desires of HIV-positive women who use ART, such as viral load, parity, contraceptive use, sexual activity and age (Andia et al 2009, Homsy et al 2009, Kaida et al 2008, Kaikare et al 2010, Kipp et al 2012).

Antiretroviral treatment (ART) improves and lengthens the lives of people living with HIV. Since 2004, access to ART in Uganda has been increasing and more women are getting regular ART treatment. The analysis of social, clinical, and global health programs that come together to shape individual pregnancy planning in Uganda is not well documented. There has been little research about how women negotiate their roles as both clinic patients and social citizens. On top of this, none of these studies have combined their research with an ethnographic focus to look at the lived experiences of HIV-positive women, and how multiple influences are weighed and negotiated within the context of pregnancy choices and everyday life.

An emphasis on a social perspective of pregnancy planning for HIV-positive women rather than just an individualistic clinical understanding is relatively new. Kaida et al (2006) designed a framework early on that argues that research on pregnancy planning of HIV-positive women using ART must use a multi-disciplinary approach. Their quantitative framework emphasizes research into the biologic, social and economic factors that impact fertility due to expanding access to ART.

There is a gap in research about how HIV-positive women negotiate social expectations alongside clinical pregnancy counselling, and how ART mediates this divide. Two qualitative studies on pregnancy planning among HIV-positive women using ART in Kampala, the capital of Uganda, have been published (King, Khana et al 2011, Kisakye et al 2011). Both studies focused on access to care, social expectations of pregnancy, and how pregnancy planning of women can be shaped. These studies

showed that the most common reasons for pregnancy among HIV-positive women are: the influence of their partner and family members, the availability of ART, that pregnancy helps women avoid the stigma of both HIV and HIV-induced barrenness, and the health of self and family (King et al 2010, Kisakye et al 2010).

HIV and pregnancy studies conducted at the Immune Suppression Syndrome (ISS) Clinic, the same location of research as this thesis, have quantitatively documented the influence of ART on fertility desires, contraceptive use, and sexual behaviour (Andia et al 2009; Kaida et al 2008; Maier et al 2009; Muyindike et al 2012). Related to the influence of ART on pregnancy planning, one quantitative study at the ISS clinic by Maier et al (2009) found that ART has a positive impact on renewing fertility desires of women, relative to when they first learnt they were HIV-positive. In contrast, two subsequent quantitative studies in Western Uganda found that ART does not influence the fertility desires of HIV-positive women (Kaikare et al 2010, Kipp et al 2011).

Given these conflicting research findings about the influence of ART on reproductive desires, my research focuses on qualitative research like the King et al (2011) and Kisakye et al (2010) studies in Kampala. A qualitative style of research like what was employed by King et al (2011) and Kisakye et al (2010) complement quantitative methods used by most previous studies at the ISS clinic. Qualitative methods focus on an in-depth understanding of factors that influence pregnancy among a small group of HIV-positive women. This provides more personal accounts than the quantitative studies that employed epidemiologic methods across a large cohort of HIV-positive women.

We are in an era where HIV and treatment is becoming increasingly normalized into everyday life in settings where HIV/AIDS is endemic, like in Uganda. By working to understand the associations and overlap between global and community levels, this thesis brings to light the needed discussion about programs and policies that shape pregnancy planning for HIV-positive women. Grounding these different forces in an ethnographic foundation of the lived experiences of HIV-positive women rebuts a static view of pregnancy. It enables a more dynamic, holistic understanding by building research from everyday life experiences, social and cultural norms, as well as shifting political and economic forces (Greenhalgh 1990, Inhorn 2007). Ethnography is a tool that

can bring focus to the interplay between policy-spaces and personal experiences, and generate visibility into lived experiences, funding programs and policies (Biehl 2007). Through this process, we can observe how individuals situate themselves within shifting power structures, as well as how these power structures shape individual “rights” and “freedoms.”

The major findings of this thesis project draw on interviews with HIV-positive women on ART, and include how communities and clinics shape individual experiences of pregnancy in Southwestern Uganda. This thesis also shows how ART mediates the link between the clinic and social domains, given that access to ART at the clinic allows women to return to being a productive member of society. This moves pregnancy planning away from an exclusively individual perspective by incorporating social and clinical domains. Discourses at the local, national, and global levels also impact pregnancy planning for HIV-positive women using ART, as detailed later in Chapters 3 and 4. Returning back to the experiences of the women at the centre of this project, each chapter of this thesis uses narratives to show how clinical and social domains do not work in isolation from each other. Rather, access to ART shapes such negotiations and provides a balance between these domains. Understanding the factors that influence pregnancy of HIV-positive women places focus on the environment in which everyday decisions are negotiated by women.

1.2. Background to HIV Endemic in Uganda

Sub-Saharan Africa continues to be the most disproportionately HIV/AIDS-affected region of the world. HIV/AIDS is one of the leading causes of death in the region, where an estimated 22.5 million adults and children are living with the disease (UNAIDS 2008). Moreover, women in Sub-Saharan Africa are disproportionately affected by the pandemic. In 2007 it was estimated that 61% of those infected were female (UNAIDS 2010). The national HIV-prevalence in Uganda is 6.4%, where women of reproductive age bear a prevalence rate of 12%. It is estimated that the HIV prevalence rate in the Mbarara region, where this study was conducted, is 13.7% (Government of Uganda 2010).

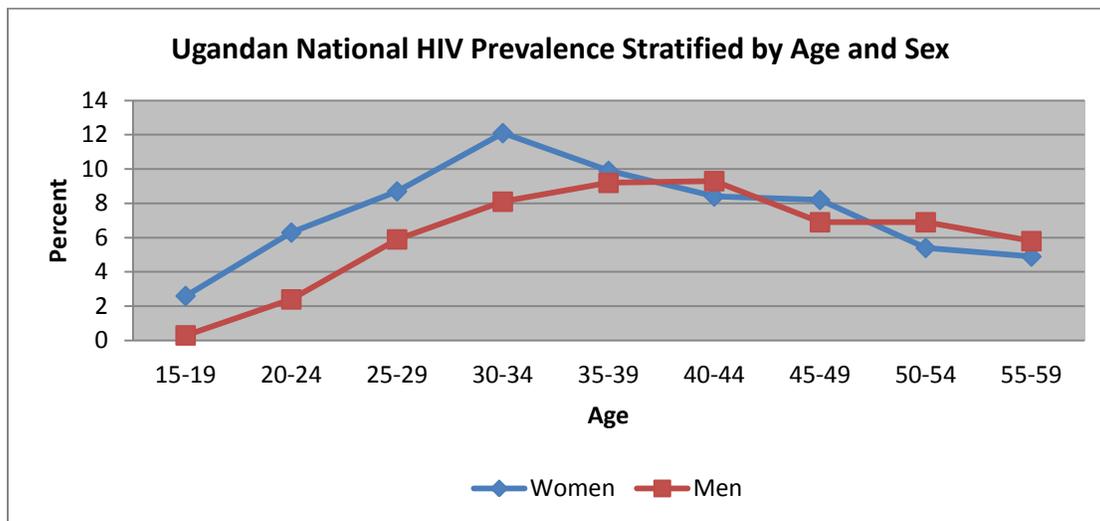


Figure 1.1. Ugandan National HIV Prevalence Stratified by Age and Sex

Note: Retrieved from Government of Uganda, UNGASS country progress report

As the AIDS era moves beyond its thirty-year landmark, HIV/AIDS has become increasingly normalized in locations where it is endemic, such as Uganda. While stigma remains, increased access to treatment and improved treatment methods over the past decade correlate to a growing knowledge that stretches from the clinic to village about “Positive Living,” support for living and staying healthy while being HIV-positive. Much of the success of “Positive Living” in recent years is due to increasing access to antiretroviral treatment (ART).

There is growing access to free ART in Uganda as part of expanding HIV care and prevention. It is estimated that, since 2004, 53.5% of men and women who are medically eligible are receiving ART (Government Uganda 2010). With proper adherence, ART reduces viral load, improves the health of individuals living with HIV, reduces the role of transmission and gives HIV-positive women the opportunity to give birth to HIV-negative babies. For many living with HIV, ART is an opportunity to return to a more pre-HIV life.

There is large political support for HIV/AIDS programs in Uganda. This is linked to Uganda’s success at reducing the national HIV prevalence rate from 18% in 1992 to 6.1% in 2002. At the same time, lack of national leadership on reproductive rights has contributed to high fertility rates in Uganda (see figure 1.2) (Maier et al 2009; WHO

2010; Richey 2005). As Cooper et al (2009) state, there is a need for program interventions that integrate HIV care with reproductive health care. It is estimated that 17.9% of women of reproductive age report contraceptive use in Uganda (WHO 2006). Given that sexual transmission contributes to 76% of new HIV-infections, only 9.1% of women and 16.1% of men between the age of 15-49 who have more than one sexual partner report condom use (Government of Uganda 2010). As the graph below shows, despite the decline in the total fertility rate per woman over the years, women still give birth to many children.

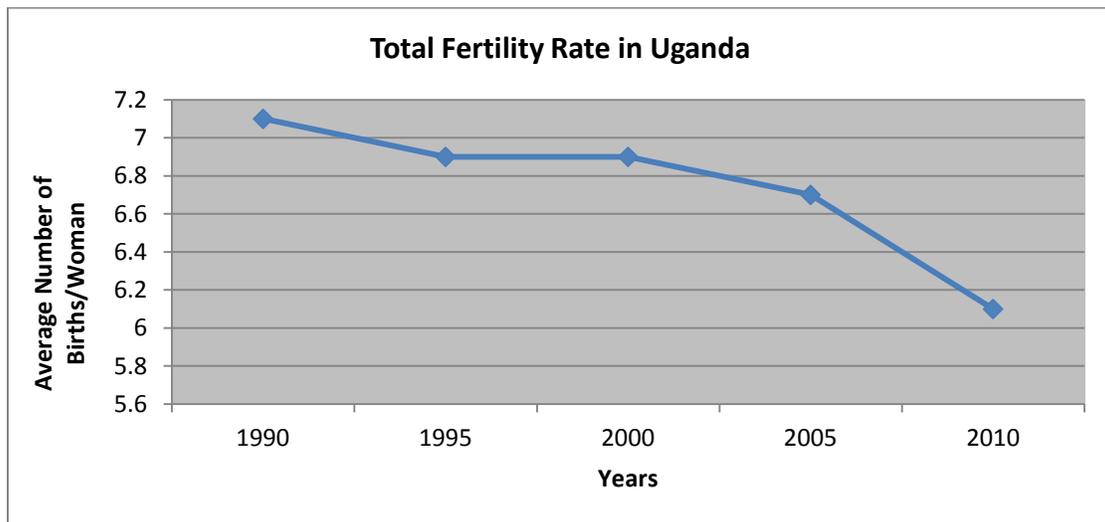


Figure 1.2. Total Fertility Rates in Uganda over Time

Note: Retrieved from WHO Uganda Country Profile

These statistics demonstrate the need for timely research into pregnancy and the reproductive health of HIV-positive women who use ART. Qualitative research into pregnancies related to these statistics investigates the behavioural characteristics behind these numbers and the factors that govern such behaviours. This thesis aims to interpret these statistics, to better understand the socio-cultural and politico-economic influences behind them. It also aims to illuminate how decisions, such as when to use or not use contraceptives, are weighed in everyday life.

1.3. Reproductive Health Expectations

The World Health Organization (WHO) defines reproductive health as:

The capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this are the rights of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. (WHO 2011)

At the core of this definition lie the rights and freedoms on which global expectations about reproductive health are based. These expectations, which are created beyond the territorial borders of nation states, set up reproduction as a choice. However, 'choice' is constructed differently in different geo-political and social spaces. Choice is often constrained by the specific social norms, environments and circumstances in which individuals find themselves. In Uganda for example, women are expected to become pregnant after marriage and bear children. The choices surrounding pregnancy are not entirely theirs. Rather, they are influenced by social expectations from their partners, families and community members. Free of the larger contextual factors that shape the lives of individuals in different parts of the world, the global definition of reproduction as a right and a choice creates global expectations of what reproduction and reproductive health programs should look like.

Medical anthropologists over the last decade have concerned themselves with clinic expectations of patients, how these relate to the individual patient experience at the clinic and, more specifically, how they relate to choice in patients' everyday lives. Ethnographic research builds on everyday lifestyle choices that do not always conform exactly to universal expectations. For ethnographies about reproductive health decisions, "questions of culture, politics, and biology are impossible to disentangle within the topic of reproduction, as they often involve transnational processes that link local and global interests" (Ginsburg and Rapp 1995:2). Much literature has been written about the variety of cultural factors that influence women's reproductive decision-making processes (Inhorn 2007).

Access to HIV medication can create a new way for people living with HIV to negotiate their social status within the community setting. HIV medication can reduce stigmatization of HIV-related illness. This medication is made possible by global HIV treatment research. New treatment methods are then translated to the community by global and national funded programs through the clinic setting. Petryna's (2003) ethnography traces changes in the social life and clinic care of sufferers, when Ukraine shifted from a Soviet to a post-Soviet state. The pressure of clinical and government structures outside of community relationships and their role in influencing lifestyles and decision-making is central. The complex negotiations and decisions of individuals seeking health care following the Chernobyl nuclear disaster is defined as "biological citizenship" (Petryna 2003). Without always realizing it, individual patients in Uganda, like those in Chernobyl, are continuously adapting and accommodating to international and national politico-economic and scientific changes in order to ensure their survival. Disease is defined differently in the contexts of political shifts, clinical practice and family ties. These all provide methods for individuals to negotiate everyday choices in their daily lives.

Through the "pharmaceuticalization of public health" (Biehl 2007:12), international HIV treatment methods are translated to the community setting through the clinic. This "pharmaceuticalization" has shaped the focus of public health towards access to medicine. Alliances between international organizations, nation states and pharmaceutical industries have created an HIV clinical package that serves as a country's public health strategy. ART and other HIV treatment methods have helped improve and save the lives of millions living with HIV. However, with a pharmaceutical shift towards access to medicine, people living with HIV are viewed as individual clinic patients, rather than also part of a social collective (Biehl 2007; Nguyen 2009). Similarly, in Uganda, an international response towards implementing mass ART programs at clinics has improved countless lives. In an era of shifting global response to the HIV/AIDS epidemic, the understanding of treatment adherence and general choices of HIV-positive individuals is divided, rather than situated within a collective view of everyday life of HIV-positive individuals. To insist that 'choice' is independent from larger social factors could compromise improvements for future global HIV strategies (Biehl 2007, Nguyen 2010).

HIV-status and HIV treatment is becoming increasingly normalized in settings where HIV/AIDS is endemic, such as Uganda. Pressures to conform to modern practices are weighed against socio-economic constraints for survival. The clinic is where global public health strategies and community perspectives can collide (Maternowska2006, Nguyen 2010, Richey 2008). Clinic expectations often come from global and national mandates, and develop in isolation from social mandates. However, a clear divide between global and social domains can also be problematic. Defining “safe sex” as the domain of global public health strategies and clinic expectations, and the want to have many children as the social expectation within communities does not depict reality. There is also an overlap between both sides. Individuals are continually weighing social expectations and clinic recommendations in order to make the best ‘choice’ that accommodates their everyday lives. Despite social expectations, global health programs still influence women’s views about pregnancy. Some HIV-positive women want to follow clinic guidelines and avoid pregnancy in order to try to be “modern women.” Grace, 32 years old and pregnant for the seventh time, explained that “if a woman does not want to give birth or does not want to breast feed, she wants to be like a modern woman.”The translation of the global expectation of “modern” into the community setting can put women in a bind, since the socio-cultural expectations to bear children still remains. Van Hollen (2003) depicts how some women are caught between social traditions about reproduction and clinical regulations. In Tamil Nadu, van Hollen (2003) found that, despite clinic violations of forcing intrauterine devices into the bodies of Indian women, global public health programs through the clinic also gave women the opportunity, if they wanted, to redefine themselves as "modern".

In rural Tanzania, global initiatives at the clinic can lack a social understanding of family planning methods. This is similar to how pregnancy is viewed as socially important by Ugandan women who are HIV-positive and on ART. The divide between understanding the use of family planning within the community setting and the contrasting global expectations shows how negotiations at different levels of family planning can reflect differing views on what best practice should be (Richey 2008). Contrary to clinic counselling, at the community level, family planning can be used to enhance the chances of having children. The difference between clinic guidelines and social realities emphasizes the divide between everyday life expectations and global

population discourse expectations about what is believed to be *best* for women (Richey 2008). Similar to the Ugandan setting, linking social, clinical and global discourse reveals the divide between 'choices' and expectations of best practice at different levels.

Focusing on social expectations, Scheper-Hughes' (1992) explains "everyday violence" (1992:116) as the collective misery and community acceptance related to social and economic constraints. This puts conventional global expectations of motherhood into perspective.

In a world of great uncertainty about life and death it makes no sense at all to put one person – not a parent, not a husband or lover, and certainly not a sickly toddler or fragile infant – at the center of anything. (Scheper-Hughes 1992:403)

Conflicting perspectives between community collectivism and global individualism creates "passive acceptors" (Richey 2005:100) who conform to community constraints and global pressures. Leaving little room for interdependence or the need to rely on others, global expectations about pregnancy require that women treat their 'choices' as self-defining acts. However, in Uganda, individuals do not thrive simply on the ability to make choices. Moral relativism shows that clinic guidelines based on global expectations can differ from social expectations. When combined, these shape the expectations and choices that HIV-positive women must deal with. HIV and reproductive health care in Uganda are divided. In the HIV clinic, HIV-positive women are counselled to have few children, given the status of their health. This divide between HIV and reproductive health care is grounded in the history of health care in Uganda.

The historical overview that Maternowska (2006) uses to focus on the politics and social life and family planning clinics in Cite Soleil, Haiti shows how money and power influence global programs and expectations. Like the HIV clinic setting in Uganda, well-intentioned family planning programs and policies in Haiti are designed separately from the realities of those for whom the programs are intended. Maternowska (2006) moves beyond victim blaming of individual women as the reason for failed family planning programs. She highlights the need for an in-depth analysis of the larger political and historical factors that come into play and how they shape the lives of Haitian women living in Cite Soleil. The need for a politico-economic understanding of this divide

between the expectations of women as clinic patients, juxtaposed with their social realities, is important to both Haitian and Ugandan settings.

1.4. Politics and Health in Uganda

Examining the link between politics and health in Uganda sets the stage for further analysis of the social and clinic environments in which HIV-positive women on ART can negotiate pregnancy. The influence that global donors exert on shaping the health sector in Uganda, particularly HIV/AIDS and reproductive health, is important for this thesis.

Prior to over a decade of civil war that started in 1976, Uganda's health care system was relatively strong and had "an excellent national referral and teaching hospital, and a hierarchy of government health units and district hospitals, as well as many mission-run facilities" (Whyte & Birungi in Richey 2005:111). After Uganda's civil war ended in 1986, the nation was ripe for international assistance. Uganda soon became one of the world's 'aid darlings,' as President Yoweri Museveni began to accept loans from the World Bank under the Structural Adjustment Program (SAP). The World Bank saw Uganda as a good investment for success, since the nation's economic infrastructure had collapsed from years of war (Parkhurst 2001). However, in 1988, war devastated economic restructuring. Structural adjustment social sector cuts caused the health system structure to fall apart. A 2003 issue of the Human Rights Watch in Uganda reported that, since the late 1980s, the international aid community and NGOs have taken on the role of repairing the health system in Uganda (Karanja 2003).

The link between national economic development, political shifts and health care becomes apparent through the analysis of HIV/AIDS program successes and a lack of focus on reproductive health. In the 1980s and 1990s, neighbouring Kenya and Tanzania led internationally funded family planning programs. This helped fertility rates to decline as discussions about reproductive health became a focus in improving life outcomes and, subsequently, the economy. Uganda, on the other hand, did not experience an international or national focus on reproductive health during this period, due to internal instability under Milton Obote (1963-1971, 1980-1986) and Idi Amin

(1971-1979). After the civil war, the country was not only open to international assistance but it also came onto the international scene as new investment and focus on the HIV/AIDS pandemic began. With reported high rates of HIV, Uganda became an opportunity for a flood of foreign donors and public health specialists to build the nation up to be the first AIDS success story (Kuhanen 2006, Parkhurst 2001, Richey 2005). Global public health focused on the new HIV epidemic, not the integration of reproductive health care.

1.4.1. HIV Focus in Uganda

As one of the first countries to openly recognize that HIV/AIDS was becoming a problem that hindered lifestyles and future economic growth, Uganda is now recognized as an HIV/AIDS 'success story.' In the early 1990s, Uganda was defined as one of the countries with the highest prevalence of HIV/AIDS. By 2000, those statistics had seemed to reverse (Parkhurst 2001). What distinguished this success was President Museveni's proactive leadership and openness in the fight against HIV, at a time when the nation was open to change and ready for this leadership. Combining leadership strategies with community-focused interventions was a new style of approach to HIV/AIDS programs. Education campaigns that spoke about sex and targeted everyone as at-risk made HIV/AIDS a national problem.

Uganda's TASO (The AIDS Support Organization) was born under this intervention strategy and helped with prevention efforts. Its community-based approach now serves as a model for other low-income countries that are facing high rates of HIV/AIDS (Nguyen 2010). Uganda's early HIV success can be attributed to a state-centric, sovereign response. Today, Uganda's HIV response is rooted in international discourse and Uganda's political status as a developing nation. The focus is now on global HIV-structured programs and funding conditionalities (Parkhurst 2001, Desclaux 2004).

Despite being an 'AIDS success' under the national approach of the 1990s, in the early 2000s Uganda began to redirect its prevention strategy by promoting the 'AB' of ABC (Abstinence, Be faithful, Condoms). Money funded by the U.S. President's Emergency Plan For AIDS Relief (PEPFAR) under President Bush dedicated one third

of the 15 billion dollars towards prevention programs structured under an “abstinence only” framework. This has done little good for the growing percentage of women infected and affected by HIV, since a large percentage of women become infected by their primary partner. As the "abstinence only" strategy worked its way into local health care, education programs and national political incentives, a shift from viewing Uganda as an AIDS 'success story' to priorities more in line with funding started to unfold(Cohen 2005).

The transition to a global funding focus means that HIV programs are no longer homegrown. They now reflect global HIV/AIDS funding strategies about ‘best practice.’ The decentralization of public health programs has created gaps between implementing a socio-cultural understanding of what is needed to address HIV/AIDS in Uganda into prevention efforts. Global ‘blueprints’ are often considered the most effective way to approach HIV (Easterly 2005).

1.4.2. *Reproductive Health Focus in Uganda*

In Uganda, reproductive health has not seen the same national leadership and focus that HIV/AIDS has. Despite its link to HIV, reproductive health has not received the same amount of national or global investment. President Museveni has not spoken out about the importance of reproductive health. Given this lack of national reproductive health “social cohesion” (Richey 2005:101), global reproductive health strategies are not nationally structured and run instead as global independent programs. Lack of national leadership, along with the heavy influence of global public health expectations of what funding should look like on the ground, creates a lack of social understanding of how reproductive health care should be approached. In 1995, Uganda endorsed a national population policy that expanded to incorporate the post-Cairo right to reproductive and sexual health. However, “Uganda’s reproductive health policies [still] failed to reduce fertility levels, and they have been even less successful in improving many of the other aspects of reproductive well-being” (Richey 2005:103).

The lack of integration between reproductive health and HIV was further impacted by the U.S. Bush administration PEPFAR promotion of “abstinence only” within HIV/AIDS programs. The divide imposed by PEPFAR funding silenced any national talk about the overlap between HIV and reproductive health care. “Abstinence only”

programs ceased being a requirement after President Obama took office in 2008 but the aftershocks are still present. Many HIV specialists and advocates for women's reproductive health rights worry that early anti-condom statements in Uganda and a continuous lack of focus on sexual health by President Museveni may cause growing shifts in sexual behaviour and reverse the decreasing trend of HIV in Uganda (Cohen 2005, Richey 2005, Kuhanen 2006). Compared to what has been seen with HIV/AIDS, reproductive health rights as an invested national focus continue to be a separate and unspoken issue. National leadership and openness to the subject has low priority. HIV-positive women often want to have children and there is a reproductive health link with HIV in relation to sexual and vertical transmission. Despite this, there is little national or global focus on local reproductive health strategies, which impacts the style of care that is available (Richey 2005).

1.5. Methods

This is an ethnographic project. Over the course of five months of fieldwork, I used participant observation, interviews, conversations and newspaper articles to collect data. The semi-structured in-depth interviews were conducted with 25 pregnant HIV-positive women who were on ART. Using an inductive approach, the interview guide included questions aimed at identifying social- and structural-level factors that shaped pregnancy planning and experiences of HIV-positive women. Participants were encouraged to address topics of interest in their own way, in their own words, and were allowed to skip questions.

In addition to the qualitative interviews, my experience volunteering in the paediatric room of the ISS clinic and working with newborn infants exposed to HIV alongside their mothers helped to provide insight into the everyday lives of both patients and the clinic staff. Informal interviews and information obtained through observations at the clinic while volunteering were included in fieldnotes over the five month period of fieldwork. Fieldnotes were written every evening to reflect on the day's events. Fieldnotes were written more frequently after an encounter or event that I found relevant to my thesis research. Although I did not speak the local Runyankole language fluently, learning a basic vocabulary helped me to gain the respect and trust of interview

participants, mothers who came to the clinic, and clinic staff. With time, this respect opened opportunities for conversations and informal interviews about this project.

1.5.1. Fieldwork Setting: Mbarara Town and the ISS Clinic

Mbarara Town is a semi-urban town and commercial centre in the southwest district of Mbarara, with a population of approximately 85,000 people. The town is also a transportation hub that connects the Ugandan capital of Kampala with other major cities to the west, like Masaka and Kabale. At an estimated altitude of 1400 m, the region is known as the milk producing and matoke (similar to plantain) growing region of Uganda. Living necessities are all available along High Street, the main road.



High Street, Mbarara Town



Secondary streets in Mbarara Town



Surrounding Streets, Mbarara Town

Figure 1.3. Streets of Mbarara Town

Photos by author

Mbarara's HIV clinic, known as the ISS (Immune Suppression Syndrome) Clinic lies about one kilometre outside of the town centre, along Kabale road. The ISS clinic was the primary research location for this study, where most fieldwork and all interviews were conducted. The clinic is situated within the compound of the Mbarara Regional Referral Hospital, the largest hospital in the region. Patients are from Mbarara town, as well as surrounding villages and towns in both the southern and western parts of the country. Adult HIV prevalence in Mbarara was 13.7% in 2007 (UNAIDS 2010). The ISS clinic is the hospital's adult and children HIV/AIDS clinic. It is the region's primary source for comprehensive, free-of-charge HIV care services, including ART. As of December 2009, 7,500 patients were registered at the clinic, 4,500 of which were women, and 5,300 patients that were receiving ART. The clinic has served more than 18,000 patients since it opened in 1998 (Muyindike et al 2012).



Figure 1.4. Immune Suppression Syndrome Clinic

Photo by author

1.5.2. Study Population and Recruitment

Women were eligible to participate in this study if they were: 1) HIV-positive, 2) currently receiving ART from the ISS clinic, 3) pregnant in their second(13-28 weeks) or third(29-40 weeks) trimester, based on self-report, and 4) willing and able to give informed consent for study participation. Women attending the ISS clinic for regular ART follow-up care were approached by a clinic nurse to determine their eligibility and willingness to participate in the study. Compensation for participating was given in the form of a monetary refund for transportation to the clinic. Participants were recruited between October and December 2011.

All participants provided informed consent in their preferred language; English or Runyankole (see appendix A and B). All procedures were approved by the Faculty of Medicine Research and Ethics Review Committee (FREC) and the Institutional Ethics Review Board of Mbarara University of Science and Technology (MUST), Uganda National Council of Science and Technology (UNCST), and the Simon Fraser University (SFU) Research Ethics Board.

1.5.3. Data Collection

After signing an informed consent form (appendix A), participants were asked to complete a brief interviewer-administered intake questionnaire (appendix D) to collect the following participant data: age, education level, marital status, number of children, date of HIV diagnosis, duration of ART use, HIV-status of the current pregnancy's father and, if HIV-positive, partner's ART use. After completion of the intake questionnaire, interviews were administered, lasting on average one hour. Interviews were structured from an interview guide (see appendix E).

The interview guide was developed in three stages and involved different levels of expertise. During the first stage, the interview guide was designed with input from the three Canadian Professors on my supervisory committee at Simon Fraser University. After arriving in Mbarara in July 2011, I received comments from two Ugandan qualitative researchers. Their feedback helped me to improve the wording of the interview guide, making it more appropriate to use within the Ugandan setting. From July through September 2011, prior to officially beginning recruitment of participants, the interview guide continued to be improved for fieldwork by conducting practice interviews with the help of my research assistant.

The interviews were conducted in a secure, private room adjacent to the ISS clinic. All interviews were audio-recorded and notes were taken during the interview process. Both primary researcher and research assistant were present during all interviews. The research assistant was fluent in English and Runyankole, the predominant local language, and helped to administer and conduct interviews. Since all participants spoke Runyankole, interview questions and answers were translated between the participant and primary researcher by the research assistant. While there were initial concerns about participants feeling comfortable with this three-way procedure, the pilot interviews supported Mitchell's (2002) observation that participants often prefer to talk to someone outside of their local clinical or communal context. In terms of data collection, this tri-interview method also helped to elaborate socio-cultural norms. Participants gave in-depth explanations of customs that would have otherwise been assumed to be understood. This method also provided the opportunity to observe the physical and emotional responses and reactions of participants during the interview,

helped in evaluating the relative importance and focus that women placed on some discussion areas over others. Directly after each interview, the primary researcher and research assistant discussed and reviewed the results, in order to gather a comprehensive understanding of the main themes and reactions.

1.5.4. Demographic Characteristics of Participants

Below is a summary of the demographic characteristics of the women interviewed. These characteristics were generated from the pre-interview intake questionnaire (see appendix B).

Table 1.1. Participant Demographic Characteristics

	N= 25 (%)
Median age (IQR)	29 (27-32)
Education level	
No schooling	3 (12%)
Primary	14 (56%)
Secondary	4 (16%)
Post-secondary certificate/diploma	4 (16%)
Marital Status:	
Currently married or co-habiting	21 (84)
Not currently married	4 (16)
HIV and ART history	
Diagnosed with HIV during current pregnancy	5 (20%)
Diagnosed with HIV prior to current pregnancy	20 (80%)
Receipt of ART prior to current pregnancy	
Yes	10 (40%)
No	10(40%)
N/A (diagnosed during pregnancy)	5 (20%)
Median months on ART (IQR)	6 (3-24%)
Reproductive history	
Mean gestation of current pregnancy (months) (SD)	7.1 (1.3%)
Number of previous live births:	

	N= 25 (%)
0	5 (20%)
1-2	9 (36%)
>3	11 (44%)
Median number of live births (IQR)	2 (1-4)
Number of living children	
0	6 (24%)
1-2	11 (44%)
>3	8 (32%)
Experienced the death of a child	
Yes	7 (28%)
No	18 (72%)

Table 1.2. Partner of Participant's HIV Characteristics

	N=25(%)
Partner's HIV status*	
HIV-positive	16 (64%)
HIV-negative	4 (16%)
Don't know	5 (20%)
Does your partner know your status now?	
Yes	22 (88%)
No	3 (12%)
Did your partner know your status prior to this conception?	
Yes	20 (80%)
No	5 (20%)
For women with known HIV-positive partners (N=16), is your partner receiving HIV-related medical care?	
Yes	12 (75%)
No	4 (25%)

* The referent partner is the biological father of her current pregnancy

1.5.5. Data Analysis

Audio-recordings of the interviews were translated and transcribed by the research assistant. Transcripts were reviewed and coded by the principal researcher. Over the course of the data collection stage, the researcher and research assistant discussed emerging concepts. Thematic analysis and content analysis were used to confirm the initial interpretations that were formed during data collection and transcript reviews (Berg 2001; Taylor & Bogdan 1998; Ulin, Robinson & Tolley 2005).

1.5.6. Narrative Description

In this thesis, I employ narrative description as a tool to describe how HIV-positive women are using ART to perceive pregnancy, along with other factors that influence their experiences (Geertz 1972). Observational data was collected as field notes while I was in Uganda. These notes reflected my observations, everyday experiences of living in Mbarara, and working at the clinic. Ethnographic description aims to capture and combine my research perspective in the field setting with empirical observations and interview data. I use narratives to describe not only individual and collective behaviour of the women I interviewed, but also the context in which behaviours unfold. Structuring this thesis around narrative descriptions enables me to draw explanatory conclusions about experiences in Mbarara that are based on the data collected and the context in which they occurred.

1.6. Outline of Thesis

There is a gap in research about how HIV-positive women negotiate social and clinical expectations about pregnancy, and how ART can mediate this divide. This thesis draw on ethnographic methods to understand factors that can shape how HIV-positive women on ART view pregnancy. This moves pregnancy planning into social and clinical domains, and away from exclusively individual domains.

Chapter 2 of this thesis describes the social setting, where a gender analysis shows how HIV-positive women's views on pregnancy are similar to social expectations of women. The focus of this chapter is on women's perspectives about HIV, pregnancy,

ART, and their roles in society. Typical social expectations of Ugandan women to bear children are highlighted. The narrative and interview findings place pregnancy and women's roles in society outside the realm of the individual, and within the social and economic currents that define the everyday lives of the women who were interviewed.

Chapter 3 examines clinic guidelines on pregnancy for HIV-positive women. The majority of women's time is spent in their social environment. However, clinic counselling and expectations for treatment regimes and pregnancy are still important factors for HIV-positive women. The findings in this chapter illustrate the 'clinic day' routines of HIV-positive women and how reproductive health services are provided within the current HIV clinic program.

Finally, Chapter 4 summarizes the social and clinical expectations about pregnancy relative to HIV-positive women's everyday lives. This chapter highlights how HIV-positive women's views about pregnancy are shaped by expectations within social and clinical environments. By exploring these expectations of pregnancy for HIV-positive women on ART, this thesis offers an ethnographic perspective that contributes to a new way of talking about HIV and pregnancy. It challenges the typical HIV research analysis, stepping beyond public health boundaries in order to generate a more complete understanding of the multiple environments that influence how HIV-positive women approach pregnancy.

2. Social Expectations

If you do not have a child, it does not secure your position in the family and your assets will be taken by someone else. The people in the community will be inquisitive as to why you aren't giving birth since you are supposed to be giving birth.

(Participant, 27 years old, 7 births, 3 children alive)

2.1. Introduction

HIV-positive women often want to have children, and describe this want as part of their roles as reproductive members of society. Access to ART at clinics gives HIV-positive women the confidence to successfully negotiate social expectations placed upon them, both within their immediate families and within their communities. This chapter analyzes how HIV-positive women's views about pregnancy are a reflection of social expectations to bear children, and how women use ART to negotiate their reproductive roles.

Social expectations to bear children compete with clinic guidelines to avoid pregnancy. After their clinic days, HIV-positive women return to their families and communities, where social expectations to bear children can supersede clinic guidelines to avoid pregnancy. Adherence to ART makes it possible for HIV-positive women to follow clinic guidelines and to better meet social expectations.

Most women had disclosed their status to their partner and some family members. ART makes disclosure of status easier, since women are healthier than pre-ART, can give birth to an HIV-negative child, and are able to continue with their reproductive roles. Given the decreased HIV-related symptoms and positive effects of ART on women's everyday lives, disclosure at the community level was not common. Improved health with ART thus provided HIV-positive women with the choice to not disclose their status, in order to avoid gossip and continue with their social roles and everyday lives.

2.2. Prudence's Story

A week after Enid and I interviewed Prudence at the ISS clinic, we were invited to visit her home. Prudence was 34 years old and pregnant for the third time. Her two children were born before she learnt her HIV-status in 2007. Both are HIV-negative. Prudence switched to ART at the start of her third pregnancy, in early 2011.

Prudence learnt about her HIV status when her husband began to get very ill in 2007. She suspected that he may be HIV positive, but he refused to test. Prudence decided to test and was found to be HIV positive. She started on medication right away, since she had grown up with family and friends who had HIV/AIDS without access to care or medication. She knew her own health and the consequential health of her children was dependent on taking ART.

The initial formal interview took place when Prudence was nine months pregnant. She gave birth to a healthy boy three days after we visited her in her home a week after the interview. The following week, Enid and I returned to meet her new baby. As she sat with her newborn tightly in her arms, she glowed with happiness. She told us that she would return to the clinic soon to get medication for her new son, so that he would remain HIV-negative.



Figure 2.1. Prudence's new addition to her family, a three-day-old baby boy.

Photo by author

2.2.1. The Interview

Growing up, Prudence experienced the effects that HIV can have on a family. Two decades ago, there was no access to free HIV medication nor was there widespread access to care. Her mother and three of her sisters died of HIV when she was young.

Due to family financial constraints, Prudence stopped school after Senior 2 (second year of high school), which is higher than the average level of schooling in the region. Since she could no longer go to school, she decided to get married.

My childhood was not the best, that's why I never completed school so I went to be married.

At age 23, she agreed to marry a man seven years older than her. She later learnt he had two previous wives who had passed away from HIV/AIDS. Shortly after she married, her husband started bringing home children that he had out of wedlock for her to take care of. On top of taking care of her own two children and being pregnant with her third, she unofficially adopted four of her husband's other children

There were two that were taken from their mother since she cannot now support them [financially] but the rest, their mothers are very sick [with HIV/AIDS] and cannot help. Even if the mothers wanted to, they could not manage, they are infected, sick, and do not have any money.

She never expected to care for the many children that resulted from her husband's infidelity and HIV/AIDS. HIV-positive and on ART herself, Prudence decided to open a small convenience shop down the road from her home in order to help pay for food and the children's schooling. When I visited her, the shop was boarded up. Her husband refused to let her keep it, since he wanted her to be a housewife. There were obvious gender roles within their relationship.

Like many women interviewed, Prudence chose to disclose her HIV-status to her family. They provided support, took an active interest in her health and helped remind her of clinic days and the importance of adhering to ART.

They got scared [when I told my family I was positive]. They cannot spend a month without coming to see me. [Laughs.]

Despite providing support, her family still holds expectations that women should have children, and that it is the woman's role in society to reproduce and maintain the household. Given their support for Positive Living and the social expectations placed on women, Prudence is caught between not wanting more children, in order to better care for her own health and that of her children, and expectations that, as a woman, she should continue to have children.

While most women that I interviewed did not disclose their HIV status to community members, Prudence was open about her status to others in her village. After the interview, Enid told me that the prevalence of HIV is particularly high in her community, since it is a trading hub. Yet most have not tested, because HIV-status can still be stigmatizing, and community gossip around HIV-status can have consequences. Prudence's openness within her community about her HIV-status is not common. However, she provides an example to others how life with HIV can continue by adhering to ART.

Other women interviewed explained why they might hide their status and not follow clinic guidelines on pregnancy, for fear of being chastised by their families and communities. Prudence's comment during the interview built on this:

People in the village would not take [learning that they are HIV-positive] well. I hear women who have been chased away from home because they don't give birth [...] most are giving birth while positive [without medication], it is normal.

This comment focuses on the social roles of women and their relationship with partner, family, and community. Adhering to ART during pregnancy and after her son's birth is now an important part of Prudence's life as an HIV-positive woman and mother. The importance that she places on adherence to treatment methods derives from the knowledge that she has gained about HIV and treatment methods from the clinic, and the experience during her youth of witnessing family members die of HIV when access to medication was not available. She knows that her health and survival, and the consequential health and survival of her children, rely on access to ART at the ISS clinic.

As the second generation to live through the HIV pandemic, Prudence and her family have a greater understanding of the causes, care, and management of HIV. They are the first generation to benefit from access to HIV clinics offering ART.

2.3. Gendered Expectations

Social expectations and everyday tasks are largely divided by gender. Analysis of interview data showed that women's expected roles in the community were mainly reproductive. Nearly all women interviewed had jobs in the informal economy, such as working as subsistence farmers or in local food and clothing markets. Yet childbearing, maintaining the household, and taking care of children are still their primary tasks. As we see in Prudence's story, men are considered the productive members of a community and the primary breadwinners for their families. Women take on reproductive roles, such as being caregivers and housekeepers.

Prudence's story shows how an understanding of the productive-reproductive relationship between men and women is important when examining pregnancy expectations. The social expectations for men to provide financial security also shapes the social expectations for women to take on reproductive roles. Like Prudence, women often choose to get married for financial security. The price of that security is the expectation that women will care for large families.

2.3.1. *Definitions for Marriage and Cohabitation*

Before going further into gender roles and social expectations, I will first discuss the term *partner* as I understood it, within the context of the interviews and over the course of my fieldwork. During interviews, 21 (84%) women reported that they were currently married, and 4 (16%) women reported that they were single. For the purposes of this thesis, marriage was defined as when partners co-habit and have children together. Both informal (co-habiting) and formal (registered through the church, government or traditional methods) unions were categorized as marriage.

Moreover, what is accepted within the marriage bond differed between men and women. During interviews, women commonly reported that their husbands had one or

two other wives or were also sexually active with other women. In contrast, the 21 married women who were interviewed reported being faithful to their one partner. This socially accepted gender divide between female monogamy, and male polygamy or polyamory is relevant when considering social expectations of women. Understanding what is accepted within a marriage is important when analyzing how gender shapes the social expectations of women and how these influence HIV-positive women's views about pregnancy.

2.3.2. Gender Roles when HIV-positive

When women are HIV-positive, their gender roles are more visible, since the fragility of their health makes it hard to fulfill their reproductive roles. Bringing a child to term can be a health risk for HIV-positive women. However, women have expressed a "wantedness" (Richey 2008:194) to fit into societal norms in Uganda (Maier et al 2009, Cooper et al 2007). A study by Cooper et al (2007) has shown that there is a large proportion of HIV-positive women who continue to want children, despite the health risks associated with their HIV status.

While HIV-positive women's personal concerns were about their own health and the health of their children, social expectations to bear children were no different than women who were HIV-negative. Women who had given birth to few or no children expressed greater pressure from their social network.

When I got married I spent two years without a child [...] but my husband would ask 'what's going on?' 'Do you think you can be accepted in a family for three years without children?' It's not possible. [If I did not start giving birth] there would be quarrels or separation. In my family, they would not be happy and say what I did was not right. (*Participant, 40 years old, 5th pregnancy*)

During interviews, there were often comments about pressure to bear children once married. Comments like the one above highlight the gendered roles of women within the community setting. The next section shows that ART gave HIV-positive women new optimism that they could negotiate social expectations based on gender roles.

2.4. New Optimism: Gender Roles and ART

This section about ‘new optimism’ explores women’s personal views about what it means to be HIV-positive, or HIV-positive and pregnant, when on ART. Individual desires are often a reflection of larger collective views, or rather a capitulation of pressures from social members . However, for women who are HIV-positive, pregnancy planning means negotiating the importance of social expectations alongside their health. With access to treatment at the clinic, “ARVs (antiretrovirals) open up a space that did not exist before” (Biehl 2007:360). ART provides HIV-positive women with the chance to live long enough to raise children and follow social expectations of raising a family (Biehl & Eskerod 2009; Kaida et al 2006). Access to ART helps women living with HIV negotiate social expectations from their family and community (Cooper et al 2007; Kaida et al 2006). As Prudence’s story shows, access to treatment enables her to minimize worry about HIV progression and transmission, while maintaining her gender role.

2.4.1. *New Optimism: HIV, ART and Pregnancy*

Upon first learning their HIV-positive status, 85.7% of women reported feeling scared after first learning their HIV-status. This fear was related to worry about personal health and their ability to fulfill social expectations. Yet as table 3 shows, 71.4% of women reported that, upon initiating ART, their fear was alleviated. ART gave women new optimism that they could maintain their health and care for their children.

Table 2.1. *New Optimism with ART*

n=21	Reported feeling "scared" and "stuck" after first learning HIV +	Reported "renewed hope" with ART
	85.7%	71.4%

Despite fear about being HIV-positive, ART shifted women’s views on living with HIV to being filled with optimism that they could stay healthy and continue living their lives normally. One woman explained how ART gave her new optimism:

When I first learnt my status I felt stuck. [...] I went to the hospital and was given medication [Septrin]. I was started on ART in September [at 6 months pregnant]. It gave me hope of giving birth to

a negative baby [this time] [if] I adhere to medication. (*Participant, 29 years old, 6th pregnancy [3 alive]*)

New hope about being HIV-positive and pregnant was related to the survival and health of herself and her children.

All women interviewed were currently taking ART. Out of the 20 women who were diagnosed with HIV prior to their current pregnancy, 10 were on ART beforehand. Just 10 women knew their HIV status before their current pregnancy and started on ART when they found out they were pregnant. ART is the only medication to prevent mother to child transmission. Current guidelines recommend that HIV-positive women and men begin on ART when their CD4 count is low, below 250 cells/mm³. Yet, once HIV-positive women become pregnant, they are prescribed ART for life. This ensures that they are receiving the best treatment in order to maintain health of self and children (Uganda Ministry of Health 2009).

2.4.2. New Optimism: HIV, ART and Changes in Ideal Family Size

While ART gave HIV-positive women new optimism about living with HIV, it did not shift women’s views about their ideal family size after learning they were HIV-positive. Having access to clinic counselling increased women’s knowledge about what it means to live with HIV and stay healthy. Table 4 summarizes ideal family size of women before learning they were HIV-positive, after learning their HIV-status, and after starting ART. After women started on ART, there was no increase in the number of desired children relative to first learning HIV status. This was linked to the knowledge that ART does not cure HIV, but rather allows women to maintain their health.

Table 2.2. Changes in Ideal Family Size with HIV and ART

n=22	Ideal family size before learning HIV+	Ideal family size after learning HIV+	Ideal family size after starting ART
(mean)	4.0	2.6	2.6

Women often explained the decrease in ideal family size after learning their HIV status as related to concerns about mother-to-child-transmission (MTCT) and their own health and survival.

I [was okay with] giving birth before finding out about my [HIV] status but later when I became positive that ceased because I thought I would give birth to an infected child. (*Participant, 33 years old, 4th pregnancy*)

Once on ART, HIV-positive women had the chance to maintain their health well enough to care for the children they have and be healthy during pregnancy. The below quote is from a 30-year-old woman who learnt she was HIV-positive after she found out in 2004 that her first child, at age 3, was HIV-positive. Both she and her child initiated ART in 2006. She expressed the following:

What has changed [now that I am on ART] is I am hopeful that I can give birth to an HIV-negative child [with this pregnancy] but I am not adding more children. (*Participant, 30 years old, 2nd pregnancy*)

ART did not change women's ideal family size relative to learning of their HIV-status. Rather, women found new optimism that they could carry the pregnancy to term, deliver a sero-negative baby, and maintain their health to care for their children. Women were able to continue being reproductive members of society with less fear about their own health and the HIV status of their newborn when on ART. In the section that follows, analysis of the interview data moves beyond individual women's views about HIV, ART and pregnancy. I analyze how women spoke about the influence of their partner, family members and the larger community on their pregnancy views.

2.5. Positive Living: Social Support and Pregnancy Expectations

Women interviewed reported a high level of HIV status disclosure to their partners and family members. Disclosure of HIV-status gave women's families a chance to provide advice and support about HIV and pregnancy. For many, like Prudence, being the second or third generation of family members to live during the HIV/AIDS endemic means that their families have experienced living with HIV both with and without treatment. The widespread knowledge of HIV within the community setting can make HIV stigmatizing, since everyone within the community knows about HIV and its health consequences. Yet many women explained that some family members were supportive

and gave them advice to maintain health while HIV-positive or HIV-positive and pregnant.

The level of support for Positive Living experienced by the women interviewed varied from just their partner, one sibling, or many family members, to also including friends. Below are the disclosure rates at the partner, family and community levels. Table 5 shows the high frequency of disclosure to partner and family. Disclosing to the larger community was not common, since it posed risks of stigma and gossip about being HIV-positive and barrenness.

Table 2.3. Disclosure of HIV Status to Partner, Family and Community

n=25	Disclosed HIV status to partner	Disclosed HIV status to family	Disclosed HIV status to community
Yes	22	18	2
No	3	7	23

During interviews, women reported that disclosing their HIV status to family gave them support for living with HIV. This helped reduce personal fears associated with being HIV-positive and pregnant. It was reported that Positive Living support was focused on adhering to medication to stay healthy during pregnancy and post-partum. Women explained that once they told their partner and select family members that they were pregnant, they received reminders about their clinic review dates, financial support for existing children, transport money to the clinic, and advice about breastfeeding and maternal health. This support gave women an opportunity to discuss being HIV-positive and pregnant, if they felt that they wanted to.

2.5.1. Positive Living: Partner Support and Pregnancy Expectations

Although interviews were only conducted with women, a large portion of the interviews centred on stories about their partner, his pregnancy expectations, and his HIV-status. Most women (88%) disclosed their status to their partner soon after they learnt they were HIV-positive. Most (80%) knew their male partner's HIV-status prior to the interview (64% of partners were HIV-positive and 16% were HIV-negative). However,

most partners did not disclose their own HIV status or choose to test prior to the women finding out their own positive status. The low rate of men testing their HIV status or disclosing their HIV status to their female partners, prior to the women learning about their own HIV-status, was understood to be part of securing a child bearer. This was similar to findings by Kisakye et al (2010) and Medley et al (2011).

Over half of the women interviewed said that they had discussed their desired number of children with their partner. For the women who had already given birth to at least a few children, their partners agreed with their wanting to stop after their current pregnancy. Mutual agreement to stop after a woman's current pregnancy was linked to the need to financially support the children that they already have and to put them through school. Some men also had children from co-wives, extramarital affairs, or previous relationships. A few women explained during interviews that this was another reason that their partners were in concordance about not wanting more children after they give birth this time.

Some women reported that their partners wanted to have more children than they did. A twenty-eight-year-old woman, with two children and pregnant for the fifth time, reported giving into her husband's want to have another child, in order to avoid conflict.

My husband insisted and complained but according to my planning I wanted to stop on the two I had. We had family conflicts to a point of failing to stay together so I decided to comply. *(Participant, 28 years old, 5th pregnancy – 2 alive)*

As we saw with Prudence, being in a relationship is important for both men and women. Pregnancy is an important part of a woman's familial role, and a way to maintain her relationship and the financial security of her and her children. The decision to have children is linked to her partner's expectations and views about pregnancy.

2.5.2. Positive Living: Family Support and Pregnancy Expectations

Even with family support and knowledge about maintaining health while HIV-positive, there was still family expectations for women to give birth to at least a few

children. This was most apparent when talking to women who had not yet given birth to a child.

The work of the woman is to give birth so if you have not given birth you have not done anything for him [or the family]. (*Participant, 33 years old, 3rd pregnancy*)

The most common reason for HIV-positive women on ART disclosing their HIV status to their family was a new optimism that they could give birth to an HIV-negative child. While many women interviewed were proud of the social support they were receiving (Ware et al 2009), family members and friends still expected women to fulfill their reproductive roles (Kisakye et al 2010). Family expectation to give birth to at least a few children was most apparent if women had not yet given birth or had only one or two children (Cooper et al 2009).

2.5.3. Positive Living within the Community Setting

Despite improvements in lifestyle with ART, social stigma related to being HIV-positive and HIV-positive and pregnant is still present. Only two women interviewed stated that they had disclosed their status to their village community. When other women were asked during interviews why they had chosen to not disclose their status, they described disclosure as something that was not required when on ART.

Women reported that ART allowed them to proceed with their pregnancy and avoid stigma by not telling anyone in their community that they were HIV-positive, if they did not want to. One woman stated that:

If I know my time for medication, I just take it and I don't have to tell them [the community]. (*Participant, 28 years old, 3rd pregnancy*)

This quote, along with the one below, shows that ART is sometimes used by women as a tool to help fulfill personal and societal expectations of childbearing, without exposing themselves to the stigma of being HIV-positive and pregnant. One woman explained why she only disclosed her status to her partner:

I felt if I can remember to take my drugs and come on the appointment date there was no need of telling them [family and

community]. Even, when you tell them [your status], instead they start laughing at you [and may not believe you since] ... I normally see them saying that one is already dead [when] they are HIV-positive. *(Participant, 33 years old, 3rd pregnancy)*

Women explained during interviews how they were aware that being HIV-positive and pregnant puts their health at risk. At the same time, HIV-positive women's perception of risks associated with not following social expectations to bear children were greater than health risks of pregnancy when HIV-positive. These perceived risks are related to women's views of their expected gender roles within a marriage.

Well, some pressures may be there to have children. For example if you are married and no children, your husband will be told you are barren then he gets another woman *(Participant, 27 years old, 1st pregnancy)*.

As a result, HIV-positive women often gave in to social pressures to have children, due to gossip about being barren, fear of being chased away from their home, and rumours about their HIV status. As the below quote explains, adherence to ART has shifted this.

[Before starting ART] I was so weak and had to be supported but now [I] am okay. People had been saying I was positive but after [I started on ART] I became healthier and even the gossip stopped. I was so energetic. *(Participant, 30 years old, 4th pregnancy, began ART in 2008 and has not disclosed to anyone in her community)*

Thus, HIV-positive women on ART have the strength to disclose their status to their partners, family members, and friends, if they choose to. It also gives them the opportunity to mediate larger social expectations and gender roles, while being HIV-positive.

2.6. Summary

Women's individual views about pregnancy are shaped by their perception of their roles within society. Gender roles to bear children have disciplined women into trying to balance their health alongside the social expectation to bear children. Women's views about pregnancy have positively changed with ART, since there is less worry

about disease progression, transmission to their children, and the social stigma of being HIV-positive. Despite new optimism with ART, all women are aware that treatment does not remove the HIV virus. Women like Prudence adhere to medication, but still worry about their health status and the health of their children. This shapes women's ideal family size. Their ideal family size decreased when they learnt that they were HIV-positive, but did not increase back to pre-HIV levels after they were on ART.

Most HIV-positive women on ART disclosed to their partners and family members despite stigma around being HIV-positive remains within the larger community setting. For the majority of women, family members were supportive and provided women with advice about Positive Living and pregnancy. In turn, social support also improved the optimism of women about being HIV-positive and becoming pregnant.

Even with social support received by most women interviewed, HIV-positive women's perceived views of their gender roles creates an added pressure which they must deal with alongside pressure to follow clinic expectations in order to maintain their health. The clinic is where women receive ART and advice about HIV care. Counselling around HIV care and adherence positively benefits HIV-positive women. The next chapter examines clinical expectations, by analyzing the role that women have as clinic patients and the reproductive health care provided at the ISS clinic.

3. Clinic Expectations

When I talk with [a health care provider], we talk about medication and condoms. They never talk about [pregnancy planning] and I never ask about it. *(Participant, 31 years old, 2 children)*

3.1. Introduction

HIV-positive women do not receive much clinic counselling about pregnancy. Women who did receive counselling reported that advice focused on avoiding pregnancy when HIV-positive and adhering to ART to reduce viral load. Women's individual views about pregnancy were impacted by clinic counselling to bear few or no children in order to maintain health; women reported a decrease in the number of children wanted, compared to pre-HIV desires.

During routine clinic days, HIV-positive women receive free HIV care and medication, including ART. The services provided at the clinic help HIV-positive women negotiate social expectations placed upon them. Women adhere to clinic guidelines in order to continue with social roles within their marriage, family, and the larger community. In this way, clinic guidelines help HIV-positive women fulfill social expectations, while also maintaining their health and reducing the risks of childbearing. The counselling that women receive at the clinic to bear few or no children is opposite to social expectations of women to bear children. However, HIV-positive women build on these polar views to shape how they negotiate pregnancy when HIV-positive.

Despite the benefits of routine clinic days, HIV-positive women lack proper reproductive health counselling to help them further balance both social and clinical expectations about pregnancy. Discussions with health care providers about pregnancy are rare, due to clinical constraints. ISS clinic staff are aware of the social roles of women and the need for reproductive health counselling at the clinic. External funding

limitations and an over-capacity clinic makes it difficult for reproductive health counselling to be integrated into the clinic days of patients.

3.2. Clinic Counselling and Pregnancy

Most women explained that they rarely spoke with health care providers about their pregnancy desires, both prior to their pregnancy and after becoming pregnant. All interviews had a question similar to “what has been your experience discussing pregnancy or pregnancy planning with a health care provider at the clinic?” As Table 4 shows, only 8 out of 23 women (34.8%) spoke to a health care provider at the ISS clinic about pregnancy.

Table 3.1. Rates Clinic Counselling about Pregnancy

n=23	Received clinic counseling about pregnancy when HIV+	Did not receive clinic counseling about pregnancy when HIV+
	34.8%	65.2%

The low number of women who received counselling about pregnancy may be associated with the negative view of pregnancy at the clinic, and women’s unease in talking to counsellors about pregnancy. For the eight women who reported receiving counselling at the clinic, they explained that the focus was on adherence to medication and bearing few or no children for the health of self and the family:

They tell us we should not give birth when we are infected, how to care for ourselves, positive living, and adherence to medication. *(Participant, 30 years old, 2nd pregnancy)*

I have not talked about pregnancy planning [at the clinic] but we are always told about family planning and not to give birth to many because you may fail to support them. *(Participant, 29 years old, 2nd pregnancy)*

Building on this, 3 out of the 4 HIV-positive women interviewed were in sero-discordant relationships, meaning that their partner was HIV-negative. These 3 women in sero-discordant relationships reported discussing pregnancy at the ISS clinic. Thus, 3 out of 8 (37.5%) women who received counselling about pregnancy were in sero-

discordant relationships. For these women, clinicians focused on discussions about low viral load and conception timing. Timing conception to coincide with low viral load helps to reduce the risk of transmission to an HIV-negative partner. The additional pregnancy counselling for women in sero-discordant relationships focused on avoiding HIV transmission to their partner, and not a discussion about their pregnancy desires. Despite the counselling on timing conception to low viral load that women in sero-discordant relationships received, none reported actually timing their pregnancy with a visit to the clinic to test their viral load. Thus, beyond adhering to ART, avoiding getting pregnant, and timing conception, women with either HIV-positive or HIV-negative partners did not receive pregnancy counselling at the clinic.

3.2.1. Counselling and Changes in Ideal Family Size

Women's views about their ideal family size were influenced by clinic expectations for HIV-positive women to bear few or no children. As discussed in Chapter 2 (page 29), there was a decrease in ideal family size from 4.0 children prior to women learning HIV-status to 2.6 children after learning they were HIV-positive. There was no change in ideal family size after beginning ART. Women still wanted an average of 2.6 children, despite improved health and lower risk of transmission. As the below quote explains, clinic expectations to bear few children does play a role in women's views about pregnancy, regardless of their improved health with ART:

They tell us that giving birth now and again reduces your life span so I decided to reduce the number of children I want. That only made me stop on the two. (*Participant, 31 years old, 2nd pregnancy*)

While few women reported discussions about pregnancy planning with a health care provider, counselling about adherence to ART and maintaining health still gave HIV-positive women a new perspective about what it means to be HIV-positive and pregnant. Similar findings about the style of counselling at HIV clinics was also seen by King et al (2011) in Kampala, Uganda, and Ware et al (2009) in various sites across Uganda, Tanzania and Nigeria.

3.3. Women's Adherence to Clinic Expectations

In order for patients to follow treatment regimes throughout their lives, they must adhere routine clinic days. As seen in the opening narrative of Chapter 1, these clinic days include extended wait times for care and treatment. Over the course of a clinic day, HIV-positive women receive advice about pregnancy from various sources: counsellors, clinicians, nurses, and other patients.

In this section I use the word adherence outside its typical pharmaceutical definition; to follow a medication regimen. With the importance of adherence to ART for personal health status in mind, I refer to HIV-positive women's adherence to two distinct clinic social settings as the reasons why they accept adherence to ART into their lives. Both peer counselling and clinic counselling shape HIV-positive women's views about clinic guidelines. On the one hand, exposure to peers at the clinic can positively shape women's views about their status and pregnancy. On the other, counsellors pressure HIV-positive women to adhere to ART by leveraging women's social roles and the importance of staying healthy to maintain them. Combined, these two binary clinic social environments shape how HIV-positive women adhere to clinic expectations, and in turn, adherence to ART.

3.3.1. *Adherence to Peer Counselling*

In the waiting room, newly diagnosed HIV-positive women or newly pregnant HIV-positive women meet other HIV-positive women who are healthy and have given birth to children. New female patients cultivate optimism about being HIV-positive with exposure to other HIV-positive women living with healthy children. These encounters give new HIV-positive and pregnant women more reason to follow clinic guidelines about adhering to medication. Some women also begin to recognize each other during their clinic days and converse while waiting. This support within the clinic walls between women who are strangers outside of this space is best exemplified when a new mother joins the queue and waits to meet with counsellors and clinicians:

I was so scared when I was told I was positive in the beginning but when I came here [to the ISS Clinic] and talked to some of the women, they shared with me that they were positive and gave birth to

children who are now four years and negative and other years so I got hope. (*Participant, 29 years old, 2nd pregnancy*)

Peer support and counselling at the clinic helped some women interviewed accept clinic days into their lives. HIV-positive women still face stigmatization outside the clinic from their larger community for being HIV-positive and expectations to have children. However, women in the crowded waiting room know that they are all at the clinic for the same reasons and can provide support to one another. While not all women talk to each other in the waiting rooms, there is still unspoken support about going through the same process together. Other women's presence alone can provide a form of social support within the clinic setting.

3.3.2. Adherence to Counselling: Pressuring Patients

Clinic staff are aware of social expectations of women and the gender divide between reproductive and productive roles within society. During clinic counselling sessions, counsellors emphasize the need to bear few or no children to maintain health in order to continue with social roles. This conversation is used as a way to pressure women into adhering to ART and general clinic guidelines. One HIV-positive woman reported that she was counselled a) about bearing few or no children since she needs to support them, and b) that her partner could leave her since she is HIV-positive, making it important to adhere and stay healthy:

When I spoke with the counsellor, she said he may [get] fed up of using condoms and leave you. You have to be very careful with the number of children you have so that in case [your husband leaves you because you are HIV-positive], you have to be able to support your children alone. (*Participant, 21 years old, 1st pregnancy*)

Clinic staff know the importance of maintaining health for self and family, especially for married women. Most married women want to continue with their caretaking roles and maintain a good rapport with clinic staff during their visits. Counsellors use this knowledge to pressure HIV-positive women into following clinical guidelines.

For example, counsellors sometimes build on the gender roles of men and women within a marriage. Whether husbands are faithful or not, a woman's role in the relationship is that of caretaker, and she must maintain her health in order to do so:

We talk about using condoms since one does not know if our partner is unfaithful [...]. They tell us the more one gives birth the more one becomes weak because of the whole pregnancy process. You must [...] be able to care for your family. (*Participant, 32 years old, 6th pregnancy*)

HIV-positive women are thus faced with the challenge of sustaining their health through monthly clinic visits, caring for their families, and finding the financial means to manage both. Pressure during counselling sessions to follow clinic guidelines is framed as a way for women to better manage their everyday lives and social expectations.

Adherence to ART requires planning for clinic follow-up days and getting transport money to attend scheduled clinic days. If women do not manage to make it to the clinic for their review day, not only do they risk not getting their prescription filled, but they also risk blame from counsellors the next time they go for their visit. Finally, for women who become pregnant more often than counselled, there is added blame on them during their counselling session about how they are not abiding by clinic guidelines.

3.4. Clinic Constraints

The everyday operations at the clinic and the services provided to HIV-positive women are shaped by available resources. There are expectations by external sources about how the clinic should be run. Looking at the clinic operations level builds on the patient-health care worker relationship and the clinic expectations of HIV-positive women.

3.4.1. Constraints: Clinic Capacity

The number of adult patients attending the clinic each day is about two hundred. With three to four clinicians working, there is little time available for the clinicians to add discussions about pregnancy planning.

During the weekly clinic meeting, one of the data management staff members provides a report of the patients who received care last week. On this day, the data team highlights how there were 48 newly admitted HIV-positive pregnant women last week. This works out to not only approximately 192 new HIV-positive women per month, but also 192 future registered infants at the clinic. Clinicians and nurses speak up after this update. Many state how they are overwhelmed with the number of patients and the work they have. Given the high number of newly registered HIV-positive pregnant women, many staff comment about how there is a need to integrate reproductive health services into the clinic setting.

Even if reproductive health services could be integrated into ISS patient care, clinic staff are working in an over-capacity clinic. The number of patients each day is high, and there is little room for nurses, clinicians or counsellors to take on a greater workload.

While there are no clinic services that focus specifically on pregnancy for HIV-positive patients, there is one nurse at the clinic who is assigned as the resource for family planning services. Her desk is at a medication dispensary window. Her contact with patients is through a window with metal bars in a busy, open space. There is a lack of private space to learn about family planning methods. Thus, HIV-positive women are often referred to the antenatal clinic (ANC) within the hospital compound for counselling about family planning methods. There is one nurse at ANC who offers short sessions on family planning methods every day or second day. Five to ten women are counselled at a time. There is little room for questions or discussion, especially around HIV status, but it is a more intimate setting than at the ISS clinic.

The process of going to another section of the hospital for family planning services in order to get some form of reproductive health care within one clinic day creates long wait times for the HIV-positive women. Many HIV-positive women do not go to the ANC since they have already spent most of their day waiting at the ISS clinic. Thus, the departmental divided between HIV treatment and minimal family planning care makes it difficult for women to seek comprehensive and complete care during one clinic visit.

3.4.2. Constraints: Expectations of Practitioners

Practitioners are expected to offer comprehensive care to their patients. As described in the above section, ISS clinic staff are aware of the lack of reproductive health services at the clinic. During clinic staff meetings, there are often discussions about how it would be beneficial to have reproductive health services for patients seeking care. However, it is difficult to implement additional care, given the few practitioners on staff available for the high number of patient appointments every day. Given the high volume of patients that practitioners see each day, a prioritization of services is made. This prioritization places prescriptions for ART and other medication first, leaving little time for much more than condom distribution at the end of a patient's short appointment. As explained in the above section, further family planning services are offered by one nurse in the general area of the clinic. While the nurse's desk is not an optimal setting for patients seeking family planning advice, it is the only source of reproductive health care available at the clinic. Thus, within this clinic environment, the expectations of practitioners are focused on prescribing appropriate medication to patients, based on Ugandan HIV care and treatment guidelines (Uganda Ministry of Health 2009).

The last part of the Ugandan HIV care and treatment guidelines is a one-page summary of comprehensive care for HIV patients. The main purpose of this is to emphasize the "family-based care concept" (2009:59). This concept focuses on targeting entire families, rather than just the HIV-positive individual receiving care and treatment. This approach addresses the importance of disclosure of HIV status, prevention methods, and availability of reproductive health care services. Thus, the care provided at the clinic reflects the low prioritization of the comprehensive care described in the HIV care and treatment guidelines. Family based care is the smallest and final section of the Ugandan HIV care and treatment guidelines, and prioritized similarly within the clinic setting.

Practitioners are caught between wanting to increase patient care and an inability to do so with the services available. They know that ART and other treatment regimens are important. They are also aware of the increased number of pregnant HIV-positive women being admitted to the clinic and the need for "family based care." However,

practitioners are constrained by the lack of clinic capacity to pursue this style of comprehensive care.

3.5. Summary

HIV-positive women adhere to ART in order to balance their health alongside a healthy pregnancy and the social expectations placed upon them. Thus, the women interviewed chose to schedule clinic visits into their everyday life routine, since that is the only source of HIV care and treatment. Although few women reported discussing pregnancy desires with a clinic care provider, counselling pressure to bear few or no children and adhere to medication still impacted their views about getting pregnant. As mentioned in section 2.4, individual pregnancy desires can be a capitulation to pressures from many different sources and not necessarily one's own choice. In this way, viewing individual pregnancy desires as a reflection of larger social and clinical influences may also be why these women rarely speak with a health care provider about their views about pregnancy. Further distinction between women's personal pregnancy desires and the pressure of external influences is beyond the scope of this thesis. Regardless of the origin of women's views about pregnancy, some women interviewed explained that they felt more optimistic about pregnancy after meeting other HIV-positive women and their healthy children during their clinic days. This exposure helped shape HIV-positive women's new optimism that adherence to ART and their clinic days would give them the opportunity to remain healthy and give birth to healthy babies.

With the high number of patients seeking care every day, there is a limit to the amount of time a practitioner can spend with a patient. The priority for practitioners is to ensure that patients have the medication they need in order to remain healthy. A practitioner's care is limited to the capacity of the clinic, making reproductive health care beyond their care ability. This makes practitioners focus on treatment regimens and medication for patients to remain healthy, rather than the comprehensive care they would like to be able provide. The next chapter summarizes how HIV-positive women combine the different social and clinical expectations about pregnancy to shape their own views and expectations about pregnancy.

4. Discussion

4.1. Summary

HIV-positive women shape their views about pregnancy from both social and clinical expectations. Women's views around bearing few or many children have changed with free access to ART at the clinic. HIV-positive women often felt "stuck" prior to access to ART. Their HIV positive status conflicted with pressures and expectations to have children and a family. Stigma from peers and the community around being HIV-positive in the pre-ART era of the HIV endemic was common (Cooper et al 2007). Today, ART helps women to not only continue with their everyday roles within their social community but also to maintain their HIV-related health, care and family dynamics. Thus, the difference between personal health and parenthood seen in previous generations living with HIV is not as apparent today.

In the social setting, there is widespread knowledge about HIV prevention, HIV transmission, and the benefits of ART. Positive living support from family members helps many women balance their health status with the social expectation to be reproductive members of society. Having children after disclosing one's status is no longer socially unacceptable. This contrasts with an earlier study conducted prior to the availability of ART (Myer, Morroni, Cooper 2006). Today, for women who report feeling "stuck" between being HIV-positive and trying to keep up with their gender roles, ART provides the option to hide their status and follow personal, partner, and societal childbearing expectations.

Counselling about pregnancy was not common at the ISS clinic. Yet, free access to ART and general HIV counselling has enforced the importance of adherence for the health of self and future children. Being a clinic patient enables women to receive free care and get advice from peers and counsellors about living with HIV. Clinic patient status also gives them new hope that they can give birth to HIV-negative babies.

Even with free access to care and ART, the clinic environment is not the optimal location for counselling and care about reproductive health. There is a high number of newly registered HIV-positive pregnant women each week at the ISS clinic. However, there is also a lack of clinic space and funding intention to integrate needed reproductive health services. Clinic practitioners are already working at over-capacity relative to the number of patients they have. They do not have the ability to increase clinic services and include more comprehensive reproductive health care. Thus, HIV-positive women are left to shape their pregnancy views from clinic counselling and the social expectations of their partners, family members, and the larger community.

4.2. Shifts in Lifestyles, Care and Research

Life with HIV/AIDS has changed over the three succeeding generations who have lived with the HIV/AIDS endemic in Uganda. With increasing access to free HIV care, treatment and knowledge about HIV is becoming increasingly normalized into everyday life. In 2005, Myer et al called for future research into how the availability of ART might affect the pregnancy and fertility intentions of HIV-positive women. By analyzing both social and clinical expectations, this thesis builds on their suggestion and contributes to a new way of talking about HIV and pregnancy. It challenges typical HIV research analysis to step beyond its public health boundaries in order to generate a more complete understanding of different environments that can influence how HIV-positive women shape their views about pregnancy.

As with Prudence's story in chapter 2, we are now in the second and third generation of family members who have lived during the HIV/AIDS endemic. Communities and family members are knowledgeable in HIV prevention and treatment, making Positive Living easier than it has been in the past. This not only improves optimism for HIV-positive women to live a healthy life and bear HIV-negative children; it also makes for a more welcoming environment for women to disclose their HIV status in the first place. While stigma is still present within the larger community, social support from family and peers at the clinic about being HIV-positive was commonly reported during interviews.

This thesis uses ethnography as a tool to bring focus to the interplay between international funding, the clinic environment and personal experience. It also generates visibility between lived experiences and funding programs (Biehl 2007). This thesis grounds different levels of health care forces in an ethnographic foundation of HIV-positive women's experiences. This style of research moves away from a static view of pregnancy as a woman's domain. It enables a more dynamic, holistic understanding by building analysis from everyday life experiences, social and cultural norms, as well as shifting international and national priorities (Greenhalgh 1990, Inhorn 1996). Through this process, it is possible to observe how individuals situate themselves, negotiate and adapt to different power structures.

4.3. The Struggle to Combine Reproductive Health and HIV Care

As the HIV/AIDS pandemic evolves, many researchers have acknowledged that improvements in reproductive health will be the next step towards addressing the HIV pandemic effectively (Cohen 2005, Cooper et al 2007, Maier et al 2009, Richey 2005). With increasing access to ART and the positive health benefits of treatment for HIV-positive women, research in the field of reproductive health and HIV calls for the integration of reproductive health services in HIV clinics (Andia et al 2009, Cooper et al 2005, Hladik et al 2009, Kisakye et al 2010, King et al 2011, Homsy et al 2009, Myer et al 2007, Mutiso et al 2008). Yet, as the health system stands in Uganda, this approach is not easy to implement. Funded by international development projects, the Ugandan national health system promotes a patient care perspective focused on adherence to treatment, viral load and treatment as prevention.

This creates a system of struggle at the ISS clinic. With the clinic running at over capacity, practitioners are busy and in no position to reflect on how they can reinforce change so that patients have access to more comprehensive care. During weekly meetings, clinic staff often discuss ideal care, which includes reproductive health services. However, clinic staff are also caught within the funding system. Their employers are funding how the clinic currently runs. Given the few working hours that they are not attending to patients, there is little point in requesting to have more services

available. At the end of the day, clinic staff must also ensure their own health and survival by staying employed. Thus, beyond clinic meetings, there is little mention about how to help HIV-positive women balance between social and clinical expectations.

As increasing access to ART is shifting HIV/AIDS towards being a chronic disease, the link between reproductive health and HIV should be addressed. Reproductive health services are imperfectly taken up within the ISS clinic setting. There is access to family planning at the ISS clinic and the antenatal clinic within the hospital grounds. However, the availability of minimal family planning services at the clinic creates systemic oversight by international funders about the reproductive health needs of HIV-positive women. Using access to contraception rather than reproductive choice to balance HIV-status and social status could jeopardise future improvements in the health care provided to HIV-positive women. As described in chapter 1, the WHO defines reproductive health as having the power for women and men to make informed decisions about access to family planning services of their choice. The WHO definition also adds the need for appropriate health services that provide couples with the best chance of having healthy infants (2008, see page 8). While the ISS clinic offers prevention of mother to child transmission (PMTCT) services and some family planning options, these are not equivalent to the care and services that could be offered to HIV-positive women.

4.3.1. *The Struggle with Funding*

External funding of HIV clinics indirectly shapes the experience of HIV-positive women at the clinic and the counselling they receive. There are four major external funding bodies for the ISS clinic. The smallest of the four is the Family Treatment Fund. This is a private organization in the United States which funds medication supplies to make sure that there are no inventory shortages. This helps ensure that patients receive the care they need. Next, the Joint Clinical Research Centre (JCRC) is sponsored by the United States Agency for International Development (USAID) and primarily funds the data management sector, some of the nurses at the clinic, and part of the infrastructure costs. The Makerere University Joint AIDS Program (MJAP), funded by the United States' President's Emergency Plan for AIDS Relief (PEPFAR), pays for part of the infrastructure costs and the salary of many clinicians, nurses and counsellors. Lastly, the

Ugandan Ministry of Health funds the clinic by paying for the supply of HIV medication and the salaries of higher-ranked clinicians and staff members. Given the overlap and different foci of funding from these four bodies, there is a clinic staff meeting every week. These meetings are needed to cohesively link staff and make sure that the clinic is running smoothly.

Every Wednesday the ISS Clinic is closed to patients. The morning is dedicated to a staff meeting. Half way through one particular general meeting, the focus of conversation moves to toilet paper, or rather the lack thereof in the staff bathroom at the clinic. The conversation continues with a staff member associated with JCRC and MJAP stating how much toilet paper their employer donates. Others build on this by saying that it is not enough, and that they need more. Dialogue continues in circles as more staff members start getting into details about logistics of who should control the toilet paper and how much each person is allowed.

The toilet paper debate is a metaphor for the larger dilemmas of funding. The debate about whose role it is to provide toilet paper exemplifies the bureaucratic challenges in managing diverse donor funding and internal responsibilities. These weekly meetings often devolved into unfocused discussions with little or no resolution about banal issues such as whose project funds will pay for toilet paper.

Each funding body has its own conditionalities and expectations about how its money can be used. The integration of HIV and reproductive health is difficult because basic needs are often not taken up as operating under any one funders budget. Suggesting which funders should take on which responsibilities, from reproductive health care to toilet paper, is a weekly debate every Wednesday morning during clinic staff meetings. The unidirectional flow of funding from external sources with strict implementation priorities provides little flexibility at the clinic level for the discretionary distribution of resources where they are needed.

4.4. Conclusion

Being a clinic patient on ART opens up a new world of social negotiation and decision-making for HIV-positive women. However, this happens when women attend

their clinic days to receive care and medication. HIV-positive women are dependent on the clinic system, and the clinic system is dependent on global funding. Thus, attending clinic review days to improve their social livelihood reinforces global influences further into their everyday lives. For example, HIV-positive women now have the opportunity to give birth to HIV-negative children if they adhere to ART provided by global funders. This system also allows HIV-positive women to continue with their everyday lives and avoid the stigmatization of being HIV-positive.

The benefits of the system are only possible if women can attend their clinic review dates. This entails getting access to transport money, receiving adherence counselling, and finding time to attend their appointments to renew their prescriptions. Thus, the new optimism that comes along with being a lifelong patient “is both [a] struggle and hope” (Biehl 2007:23) since the routinization of clinic days depends on social circumstances and personal funds.

External funding to the ISS clinic makes it difficult to integrate additional clinic services. All four funding bodies focus on addressing adherence to ART in different ways. Given the high number of newly infected pregnant women registering at the clinic, ISS clinic staff are aware of the need for additional reproductive health. Yet, funding expectations and managing an over-capacity clinic make it difficult for reproductive health counselling to be integrated into the clinic days of patients.

Aligning reproductive health and HIV priorities remains elusive. The HIV-positive women interviewed were open to conversations about HIV, ART and pregnancy. However, as current clinic programs stand, women are left to weigh their views about pregnancy alongside their patient roles and social roles. HIV-positive women’s views about pregnancy will continue to be shaped by trying to balance social realities and internationally funded mandates. This forces HIV-positive women to continue to negotiate social and clinical expectations in a way that best benefits their personal livelihood, rather than their own reproductive choices.

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Appendices

Appendix A.

Informed Consent to Participate in Research Form

NOTE: The consent form used during fieldwork below was approved by the research ethics boards of SFU, MUST and UNCST. This consent form was also translated into Runyankole. Interview participants signed either the English or Runyankole version, depending on which language they were more comfortable in.

Consent forms used during fieldwork were photocopies of the MUST research ethics board approved, date-stamped versions. Interview participants signed photocopy versions of the stamp approved consent forms. All signed consent forms are in a folder, along with the originals, locked in a cabinet in Mbarara, Uganda. Following research ethics protocol, signed consent forms will be kept for 5 years after completion of the study (December 2016).

Purpose and Background

You are being asked to take part in a research study along with 25 other pregnant women in their 2nd or 3rd trimester who are HIV-positive and using HAART. The study examines factors that influence reproductive desires and decision-making of HIV-positive women using HAART.

This study is linked to Simon Fraser University in Burnaby, British Columbia, Canada and the UARTO investigative research team in Mbarara, Uganda. If you decide to participate, your answers and comments will be confidential by the study team.

Procedures

If you agree to be in this study, the following will occur: We will interview you in a private place to learn about what influences your fertility intentions and how access to HAART has changed those intentions. The interview will take a total time of approximately 60 minutes, and will involve questions about reproductive decision-making, including questions about ideal family size, role of partner, social pressures, as well as some background questions about your personal history and reproductive health. With your permission, we will audio record the interview for later transcription. You can refuse to answer any question and you can completely end the interview at any time. There is no penalty for deciding that you do not want to be interviewed. Your participation in the study will have no impact at all on your ability to obtain health or other services that you may need.

Benefits

This study may not benefit you directly. However, the results may help other HIV-positive women who are on HAART by helping improve the services available to women and mothers who need assistance.

Risks/Discomforts

The main risk is that some of the questions may make you feel uncomfortable or upset because they ask about your health, fertility and family decision-making or are of personal nature. If any

question upsets you, you do not have to answer it. You may refuse to have the interview audio-recorded or may stop the recording at any time.

Statement of Confidentiality

If you decide to participate, your research records will be handled as confidentially as possible. Your answers will be recorded without your name attached to them. All study staff have been trained in how to keep answers confidential and have signed a pledge to do so. All our research files will have a special identifying number rather than any names on them. We will keep nothing with your name on it so there is no way to link you to any of the research files. All electronic files will be stored in a password protected database and paper copies of your answers will be stored in a locked and secured filing cabinet at the ISS clinic in Mbarara, Uganda and upon return to Canada; at Simon Fraser University in Burnaby, British Columbia. When results of this study are reported, no names will be used. All answers you give us will be grouped and summarized along with those of other participants without any personal identifying information.

Costs

There will be no costs to you as a result of taking part in this study.

Payment

If you decide to participate, there will be no compensation given upon completion of the interview.

Questions/Contact Information

With your signature below, you agree that you have talked to a study representative about this study and have had your questions answered. If you have any questions during the study, or at any future time, or if you want to read the final report, you can call (collect) to the Principal Investigator: Jasmine Kastner, MSc Student in Global Health in the Faculty of Health Sciences, SFU, 8888 University Drive, Burnaby, BC, V7W 1G6. [jkastner@sfu.ca; 01-778-835-2874] If you have concerns, complaints about this study or if your treatment as a participants you can contact the Institutional Ethical Review Committee at Mbarara University by phone at 0485421387.

Statement of Voluntary Participation

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You have read the above consent form and understand the purpose of the study and what is required of you in participation. You can decide to participate or not and you can end the interview or withdraw from the study at any time. You further understand that the study is not connected in any way with any health or social service agency. You voluntarily agree to participate in this study.

If you agree to participate you should sign below. You will be given a copy of this form to keep.

Signature of Participant

Date

Signature of Witness

Date

Appendix B.

Intake Questionnaire

NOTE: This intake questionnaire was verbally administered at the beginning of the interview process (after the consent form and before the semi-structured interview).

After a participant agreed to be interviewed, my research assistant and I would show the participant to our interview room, which was adjacent to the ISS clinic. Once we were comfortably seated together, my research assistant would introduce the study again and go through the consent form, in Runyankole. After the consent form was signed, we would begin the tri-interview process (explained in section 1.5.3.) and after asking the participant if it was okay to turn on the recorder and begin the interview. After turning on the recorder, I would begin with this intake questionnaire. Following the 12 intake questions, we would continue with the semi-structured interview (see appendix D for interview guide).

1. What is your date of birth?
2. What is the highest level of school completed?
3. What is your marital status? (single, married, co-habiting, staying together, widow)
4. How many children do you have?
 - a. All alive?
 - b. Number of girls:
 - c. Number of boys:
 - d. Age of oldest:
5. When were you first diagnosed with HIV/AIDS?
6. When did you start HAART?
7. Do you know the father of your current child's HIV-status?
8. Did you know his status prior to finding out you were pregnant?
9. Is he currently using HAART?
10. Does your partner know your HIV status?
11. Did he know your status before conception?
12. How many weeks pregnant are you? OR What is your due date?

Appendix C.

Interview Guide

Stems	Probes
1. Tell me about yourself.	...about your partner ...about your family, children, siblings ...about your living situation
2. When you were younger, how did you imagine your ideal family life?	Did it change when you found out you were HIV-positive? Did it change when you started using HAART? [Explore living situation, partner relationship, children, family.]
3. Can you tell me about what was going on in your life when you found out you were pregnant this time?	Was this a consequence or focus of becoming pregnant?
4. What do you think of the timing of this pregnancy?	Can you tell me whether or not, for you, this pregnancy was intended?
5. Today, what is the ideal family size for you?	Have you discussed these intentions with your partner? Can you tell me about your partner, does he have the same intentions about family life? How do you feel about this?
6. Would you tell me about how you learned that you were HIV-positive?	How did you feel when you first learnt you were HIV-positive? How did your husband react when he found out you were HIV-positive?
7. Please describe your experience on HAART?	Have you seen improvements in your health since being on HAART?

Stems	Probes
	<p>Has HAART changed your views about being HIV-positive? ...about having children?</p> <p>Has HAART changed your decision about family life? Tell me about it.</p>
<p>8. What has your experience been discussing fertility intentions with your health care providers?</p>	<p>What do you normally discuss with your health care provider?</p> <p>Do you ever talk about pregnancy intentions?</p>
<p>9. Do you feel any pressures (positive or negative) to become pregnant by your family?</p>	<p>...by your community?</p> <p>How did your family (...and community) respond to your current pregnancy?</p> <p>How would your family (...and community) respond if you did not have children?</p>
<p>10. So before finishing, are you happy with your current pregnancy?</p>	
<p>11. Is there anything else you would like to add about your experience being an HIV-positive woman on HAART in relation to pregnancy and future pregnancy desires?</p>	