

SOCIAL AND STRUCTURAL FACTORS AFFECTING WOMEN'S PARTICIPATION IN
PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) PROGRAMS IN
MALAWI

By

Kristan Elwell

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ABSTRACT

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In 2012, 17.7 million women were living with HIV. Ninety percent of these women lived in Sub-Saharan Africa. Malawi is especially impacted, with some of the highest rates of HIV infection in pregnant women in the world. In 2010, 63,500 pregnant women in Malawi required antiretroviral (ARV) prophylaxis. Of these women, only 53% received ARVs through PMTCT programs. In 2011, in an effort to expand access to treatment services within PMTCT programs, the Malawian Ministry of Health implemented Plan B+, a policy designed to expand access to treatment services within PMTCT programs. Plan B+ now offers lifelong treatment to all pregnant women and new mothers who test positive for the HIV virus, regardless of CD4 count. Despite a substantial national scale-up of PMTCT services, retaining women within PMTCT programs remains a challenge to successful implementation of these interventions. Recent literature suggests that approximately 27-55% of women enrolled in PMTCT programs fail to remain in them.

This dissertation examines the social, cultural, and economic forces affecting women's participation in Prevention of Mother to Child Transmission (PMTCT) programs in Southern Malawi. I employ qualitative methods including semi-structured interviews, focus group discussions and clinical observations with PMTCT patients, health care providers and community members to better understand why some women do not remain in these programs. The research questions examine: 1) The experiences and health-seeking strategies employed by

pregnant and postpartum women, 2) How broader social and gender relations affect women's participation in PMTCT programs, and conversely, 3) How participation in PMTCT programs affects women's social and gender relations. I argue that gender and power inequities shape women's social relations in marriage, the community, and the clinic, challenging women's social identities and constraining their health-seeking practices; thus demonstrating how gender inequities become embodied in the health outcomes of HIV-positive women.

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I would like to give special thanks and dedicate this dissertation to my parents, John and Sarah Elwell, who made all of this possible. I appreciate their endless encouragement, patience, and ongoing support.

And

to the memory of “Chitsulo,” a young woman whose tenacity and fearlessness as she managed her illness taught me so much about the endurance of the human spirit.

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Chapter 1:

Introduction

Living with HIV/AIDS in Malawi: Chitsulo

When I first met Chitsulo, she was sitting in one of four thatched-roof huts clustered in a semi-circle on a small stretch of land. Chitsulo had a deep and raspy voice, and spoke with a steady cadence, tenacity, and maturity. Her voice belied her age, making her appear older than twenty-two years. Her thin figure, however, revealed her youth and her recent medical challenges. Chitsulo's gentle but forceful defiance against her illness would soon capture my respect. She spoke frankly about her life, her family, her marriage, and her experience with HIV/AIDs. Despite a year filled with several social and medical challenges, she appeared to be doing well. I thought she might be a good candidate for a life history.

For the past couple of days, my research assistant and I had been poring over boxes of worn yellow medical cards to find those marked with "defaulter" in black ink across the back. I had just begun the more difficult and most sensitive stage of my study, locating and then interviewing those women unable to remain on antiretroviral (ART) treatment as participants within PMTCT programs.

I asked Chitsulo if I could return again to interview her about her life, and she agreed. Following virilocal residence patterns of her husband's patrilineal kinship system, Chitsulo had moved to her husband's natal village after she was married. Soon after her arrival, her neighbors saw her removing ARVs from a hole she had dug in the ground next to her hut, and later told her husband that she was taking ARVs. When her husband learned of her HIV status, he beat her and forbade her to take the ARVs, angered that she had not told him of her positive status and that

she had been found to be HIV-positive, which brought shame to their new marriage. She fled to her natal home and her husband soon followed. He begged her to return to him, at which point she consulted with her family. When I asked if she considered divorce, she explained that her husband's *ankhoswe* (uncle) came to the village to discuss the situation with her uncle and parents. Her uncle suggested if she stayed alone and "just did (her) business, the end thing is that (she) would be having affairs with men." Furthermore, she "can't be staying in (her) parents' home when (her) younger sisters were in marriages." After hearing this advice, she decided to forgive her husband because she did not want to be viewed by the community as a "prostitute."

During the first of three visits, I asked Chitsulo about her extended family living at the compound and their responses to her illness. "I love my mother so much," she told me, claiming that her mother did not ignore her as her other family members had. Her mother fed her and bathed her. However, when her mother was away, her siblings would let her "spend three days without a bath" and would "eat their *nsima* (maize porridge) without sharing with her." Her father ignored her, returning from work without speaking to her, "leaving (her) groaning." Her brother, in contrast, travelled to the clinic to collect her ARVs and carefully watched over her, "giving her everything she needed," including transport to the hospital. When he didn't have transport money to provide she would "walk on foot." Each time I visited the household, as the eldest male, he would greet us and remain until Chitsulo excused him. As the eldest brother, he followed kinship norms that assigned him responsibility over his sister's well-being.

During the course of our interviews, Chitsulo shared with me her challenges with her marriage. At twenty-two years old, she proudly asserted her marital status, even though she was determined to "send (her husband) packing," when he returned from jail. She loved her husband and wanted a husband because her brothers and sisters had all reached this cultural and

developmental juncture well before her. She simply wanted to get on with her life. She was sharp, outspoken, and defiant in her zest for life. I was struck by one comment that Chitsulo made about her marriage that would later hold a new meaning as I tried to understand women's experiences with HIV/AIDS management. During one of our conversations, Chitsulo told me, "For now I have discovered that it is a problem. You may hide... but for yourself the condition will worsen. Hiding it (HIV) from your man is not good. It is better you tell them and if they don't want you, that's okay." Soon after this interview, Chitsulo's health began to fail.

Because of the six months that she had not taken the ARVs, she was switched to the second line medication.¹ Emmanuel had visited Chitsulo on one of his outreach visits as a health services assistant. Her village was part of his catchment area, and I had asked him to stop in to see how she was doing. He told me she had lost a significant amount of weight and was very weak.

I returned to the clinic the next day. Emmanuel asked the community health nurse when she was next doing her rounds. She "did not have transport," she responded. Transportation for the Health Services Assistants and nurses who conducted health outreach in the surrounding villages had been an ongoing challenge because of limited resources within the public health system. Yet I knew that a bicycle had been recently supplied by the District Health Office to conduct outreach in the surrounding villages. It took twenty minutes to drive to her home, and probably would have taken forty minutes to bicycle there. When I offered to provide the transport, the nurse agreed, but added that "there were few staff" at the clinic, so she would go when she was not on duty. Limited health care staff at clinics within the public health system

¹ All patients who remain off the medication for an extended time are transferred to the second line medication to prevent drug resistance.

was an additional ongoing challenge. Two days later I drove the nurse to Chitsulo's home. She conducted an assessment and determined that Chitsulo had edema and moderate malnutrition. The nurse immediately placed her in the nutrition program at the clinic, which meant she would receive Plumpy Nut—a ready-to-eat, peanut butter-based therapeutic food that was given to patients suffering from malnutrition. “She must come in to the clinic,” suggested the nurse, so that she could be properly checked. “If we are not careful, we could lose this one.”

One week later, I asked Emmanuel how Chitsulo was doing and if he had noticed any improvement. She had not been to the clinic since the visit with the community health nurse. That Sunday when I was out of town, I noticed a text from Emmanuel stating that Chitsulo “was not well.” Emmanuel again suggested to the brother that he bring her to the clinic. When I asked Emmanuel why he thought they were not going to the clinic, he thought perhaps they did not have the money for transport. Chitsulo had mentioned there were “some problems with transportation.” Her father had a “good job” as a laborer at the nearby water company, but this money didn't reach her mother and brother's pockets because as head of the household, the father decided how money was to be spent. As Chitsulo's primary caregiver and ART guardian, her mother had little access to this money because local gender norms conferred control over household resources to husbands. As a result, Chitsulo's brother often had to leave the family farm in search of *ganyu* (day labor) to supplement the meager household income.

The next day Emmanuel and I drove to Chitsulo's family compound to take her to the clinic if her family had not done so. When we arrived, the compound was empty except for Chitsulo's younger sister and her infant Anthony, who hung from her shoulder. The mother and father had taken Chitsulo to the clinic. Her father borrowed a car from his employer at the local water company. It was the first time he had become engaged in her care. When her parents

arrived at the clinic, the clinic staff advised her to receive care at the district hospital because of her frail condition. Health clinics are staffed by clinicians, nurses, and HSAs (Health Surveillance Assistants), but not medical doctors. Further, all acute medical conditions are referred to the district hospital, the only referral center in the region. Despite the often limited resources available at the rural clinic, a brand-new white SUV had recently been supplied to the clinic to serve as the clinic ambulance. On that Monday, however, it was being used by another health clinic. For two days, Emmanuel and I waited to hear about her status. On Wednesday, I received a phone call from her brother that she had died.

When I arrived at the clinic the following week, I was greeted by the nurse I had driven to Chitsulo's home. "How is Chitsulo doing?" she asked enthusiastically, raising her voice above the noisy din of the weekly ART clinic. "She's no longer here." I answered. Her eyes widened and her expression morphed from enthusiasm to fear. I walked away and returned to a long line of patients waiting to be handed their medical chart. It didn't make sense that Chitsulo died. As my informants had been reporting over the last eleven months, "With the ARVs, people no longer are dying."

But the many bottlenecks in her "treatment cascade" (Weigel et al. 2012) were rooted in social relations that sometimes worked for her, in the social support from her mother and brother—but more often worked against her, when shaped by gender roles and inequalities, and the social stigma associated with HIV/AIDS. When situated in a context of limited resources, both within the public health system that ultimately failed her, and a household economy structured by gender norms—which had little to offer her except on the day before her death—her determination was not enough.

My study focuses on the experiences of HIV-positive women who are either pregnant or new mothers. I wanted to find out why women would be unable to remain on ARV treatment—both for themselves and their newborn child—now that ARVs are free of cost in Malawi. However, I included in my study sample other members of the community with AIDS, like Chitsulo, who could illustrate the lived experience of women who participate in PMTCT. I wondered what about Chitsulo’s experience might shed light on women’s daily lives in this community.

I learned through the course of our conversations that Chitsulo’s experience living with HIV/AIDS pointed to a similar pattern in the lives of the PMTCT patients I had met and interviewed. She had intense and unwavering support from her mother and older brother who fed her, washed her, collected her medications, and advocated for her many social and medical needs. But the trajectory of her health-seeking was ultimately shaped by gender inequalities in her marriage and a lack of HIV disclosure to her husband that reinforced them, stigma from her extended family, and political economic forces that created fractures in her household economy and within the local public health system. These social and economic forces intersected in a cascade of events—many of which had little to do with the bottle of ARVs that sat on the table next to her.

My initial interest in studying patient access to HIV/AIDS services began while conducting exploratory research to determine my dissertation topic. I spoke with several health care providers working directly with AIDS patients within the Malawian public health system. I soon learned that one of the main challenges in managing AIDS was the biomedical concept of patient “defaulting” or “non-adherence.” The problem was even more pronounced in women attending the Prevention of Mother to Child Transmission (PMTCT) clinics where rates of non-

adherence were twice that of the general adult population of HIV/AIDS patients. I had a limited understanding of women's lives from my short time in Malawi, and wanted to better understand the broader social context in which HIV-positive pregnant women and new mothers managed HIV/AIDS for themselves and their exposed child at a critical juncture in the HIV/AIDS epidemic when antiretroviral treatment was newly accessible to the poor.

Research Questions

This public health question of why some patients are able to adhere to treatment and others are not led me to broader anthropological questions: 1) What can pregnant women's HIV/AIDS management tell us about the daily lives of Malawian women? 2) Specifically, how do broader social and gender relations affect women's participation in the program? and 3) Conversely, how does participation in the program affect women's social and gender relations?

These research questions extend the literature that suggests that "social support" (Bwirire et al. 2008; Castro and Farmer 2005; Kasenga et al. 2010; Kuonza et al. 2010; Laher et al. 2012; Mephram et al. 2011; Nyblade et al. 2003; Stinson et al. 2012; Theilgaard et al. 2011; Torpey et al. 2010; Ujiji et al. 2011; Van Hollen 2013; Van der Straten et al. 2014) may interfere with women's ability to remain within PMTCT programs. The notion that social support may interfere with women's participation led me to these broader anthropological questions, which examine more closely the gendered social structures shaping women's lives outside of the clinic, at the family and community levels.

Purpose of the Study

My research centers on how gender and power relations shape Malawian women's access

to AIDS treatment in PMTCT programs. I analyze the barriers and supports women face within these programs and how these relate to the gender and social inequities within women's social relations in marriage and the community. I then analyze the implications of these social and structural factors for the health-seeking practice of HIV-positive pregnant women and new mothers within PMTCT programs.

Conceptual Framework

This research is informed by critical medical anthropology theory, and the theory of gender and power (Connell 1987). I analyze the three main “barriers” to PMTCT participation as revealed by my study—lack of HIV disclosure to husbands, fear of community-based stigma, and negative interactions with health care workers—using the concepts of structural vulnerability (Quesada, Hart and Bourgois 2011) and the theory of gender and power. Specifically, I examine how gender and power interact within the social relations of poor peri-urban PMTCT patients and through the lens of HIV/AIDS, producing HIV-related stigma and reproducing gender inequalities.

I then explore how the intersection of gender and power produce the health-seeking decisions and practices of HIV-positive pregnant women and new mothers who participate in PMTCT programs, and how these social inequalities become embodied in their treatment experiences, creating new challenges to women's access to treatment (Connell 1987). I include in this analysis the concept of identity multiplicity to explain how the social identities of HIV-positive pregnant women are located at the intersection of gender and power relations, challenging their ability to seek HIV/AIDS treatment within PMTCT programs (Sokefeld 1999).

Finally, I examine the social contexts that call upon and challenge women's identities as mothers, wives, and patients.

Identity Multiplicity as an Analytic Concept

There is a growing body of literature on the social process by which individuals understand and act upon multiple identities (Sokefeld 1999; Stirratt et al. 2008). According to Sokefeld (1999), managing conflicting identities is an important aspect of the construction of the self. Sokefeld claims that this ability to manage multiple identities is a form of agency in which individuals employ strategies that allow them to choose how to act when faced with multiple alternatives. Drawing upon social psychological perspectives, Sokefeld contends that particular identities gain "prominence" when an individual must fulfill a particular social role.

The notion of identity multiplicity has also been employed by feminist scholars applying the concept to illustrate the multiple forms of oppression linked to gender, ethnicity, class, race, sexuality, etc. The central tenets of intersectionality are: "(a) no social group is homogenous, (b) people must be located in terms of social structures that capture the power relations implied by those structures, and (c) there are unique, non-additive effects of identifying with more than one social group" (Stewart and McDermott 2004, 531-532). Intersectionality theory posits that each identity (gender, race, sex, etc.) are given equal value in shaping experiences of oppression and shaping social identity. The concept of intersectionality suggests that social actors identifying with particular identities produce unique perspectives and consequences.

Stirratt et al. (2008) argue that to better accommodate identity multiplicity, researchers must adopt methods that conceptualize individuals at intersections of multiple identities.

Following this perspective, I use the concept to situate PMTCT patients' health-seeking at the

intersection of their identities as wife, mother, and patient. I argue further that the identity multiplicity faced by these women creates a double bind in which enacting each identity may challenge a woman's ability to fulfill her other competing identities.

In the 1970's, anthropologist Gregory Bateson (1972) applied the concept to the psychological stressors that contribute to the onset of schizophrenia in children. Bateson argued that competing demands from parents created behavioral dilemmas for children who were "damned if they do, and damned if they don't."

Others have drawn upon the concept to explain the double bind of biomedical training when medical students are trained to develop rapport with patients yet also trained to be objective clinicians. To my knowledge, researchers have not applied the idea of conflicting identities to the problem of barriers to medical care. In the following chapters, I discuss how access to HIV/AIDS treatment within PMTCT programs requires women to negotiate multiple conflicting identities that places them in a double bind, creating barriers to medical care in these programs.

Organization of the Dissertation

The PMTCT clinic is a site in which limited resources constrain the services received by patients. As in other resource-depleted settings, patients often wait in queue for extended periods to be seen by a health care provider. For many women, attending the clinic is a form of forced disclosure in which the community first learns of their HIV/AIDS status. For patients who arrive late or have missed appointments, they may be subjected to the negative attitudes of some health care providers facing worker burnout as they manage larger patient loads with a shrinking health care staff. These experiences at the clinic clearly create barriers for women who wish to return to

the clinic to receive the ARVs and reproductive health care provided in PMTCT programs. However, addressing these structural and programmatic constraints, largely shaped by political economy, is not enough to support women's continued participation in these HIV/AIDS treatment programs.

To better understand why women have inconsistent participation in PMTCT programs, it is necessary to look outside the clinical context of the PMTCT clinic to the private sphere of women's social relations in marriage and the community, and the gender and power relations women must negotiate as HIV-positive mothers and wives.

To understand the challenges women may face in negotiating an HIV identity in marriage, community, and clinic, I examine local understandings of HIV/AIDS. In this study community, representations of HIV/AIDS are linked to sexual practices that may challenge local notions of morality. Yet gender roles for women as mothers, wives, daughters in law, and community members suggest women fulfill the social role to reproduce, a social identity challenged by a woman's positive HIV/AIDS status. Women's PMTCT health-seeking is located at the intersection of women's reproductive and HIV-positive identities as mothers and wives. Consequently, if a woman seeks care for herself and her child within PMTCT programs, she brings shame to and challenges the stability of her marriage. A gendering of stigma leads women to be blamed for being HIV-positive and brings attention to conflict in women's marriages. Health-seeking at PMTCT programs, therefore, may place women's identities as mothers and wives in conflict with each other, situating HIV-positive mothers outside the social categories of good mothers, faithful wives, and compliant patients.

The positionality and socioeconomic status of the PMTCT patients in this study place them at risk of losing critical economic support to care for their HIV-exposed child, who is their

ultimate priority. To respond to these gender and power inequities, PMTCT patients employ strategies that lead to secrecy and inconsistent adherence as they negotiate multiple power struggles. Each of these encounters, with husbands, health workers, and community members, is nuanced by kinship and political economic structures, demonstrating the shifting nature of power in women's social relations as HIV-positive mothers and wives.

Chapter 2: Literature Review

In this chapter, I review the following literature relevant to my study: the development of biomedicine in Southern Africa; the impact of the HIV/AIDS epidemic on the national economy, health sector and households; the public health response to the epidemic—the NGOs response and PMTCT scale-up; and the impact of HIV/AIDs on women's lives with a specific focus on social stigma, motherhood, and gender relations. The first three sections provide a broad political economic, sociocultural and historical context in which to explore the gender and power relations that emerge in the social relations and health-seeking of HIV-positive pregnant women and new mothers. The fourth section examines more closely the intersection of women's gendered identities and social relations in marriage, the community and clinic.

I share a brief history of the impact of the HIV/AIDs epidemic on gender and community relations in the Malawian health sector to draw attention to the political economic factors affecting women's experiences in these programs. I discuss the historical development of women's reproductive health care in Southern Africa to illustrate the historical roots of a gendered access to AIDS treatment, drawing a link between women's experiences with colonial biomedical treatment of STDs and contemporary experiences with stigmatization and HIV/AIDS.

Chapter 3: Research Methods

In this chapter, I describe my research site and the methods employed in the study. I conducted focus group discussions, in-depth interviews, clinical observations, and a quantitative survival analysis of patient retention within the first cohort of Plan B+ patients. Study participants included patients seeking medical care within Prevention of Mother to Child Transmission (PMTCT) programs and the health care providers who care for them. Study participants also include community members living in Blantyre and surrounding communities. Focus groups and in-depth interviews were conducted with these community members—teachers, church leaders, domestic workers, village chiefs, and traditional birth attendants—to explore the impact of gender, kinship, and class relations on HIV-positive women’s health-seeking decisions and practices choices.

Chapter 4: Local Understandings of Reproduction and the Construction of Motherhood

In this chapter, I examine the local understandings of reproduction and motherhood in Malawian society by exploring the multiple actors with social, cultural, and political interest in women’s reproductive health. I include this broad discussion of reproduction in Malawian society to illuminate the social, cultural, and economic significance of reproduction to the social identities of women who participate in PMTCT programs. To better understand how reproduction is understood in the study communities, I examine how infertility affects women social relations in the family and community—drawing parallels with women’s experiences of HIV/AIDS-related stigma.

Chapter 5: Gender Roles and Relations in Malawi

Chapter 5 examines gender roles and relations in Malawian women's lives. The chapter explores how the barriers and supports to women's HIV/AIDS management reflect the barriers and supports in Malawian women's lives. To better understand gender relations and inequities, I explore normative constructions of gender in Malawi and how these constructions are played out in women's social relations within marriage and within the community. Finally, I discuss how women's efforts to enact the maternal identities critical to their social and clinical needs (Chapter 4) are challenged when they participate in PMTCT programs, which may expose infidelities in marriage when an HIV status is disclosed, thereby constraining women's ability to enact wifhood.

Chapter 6: Local Understandings of HIV/AIDs and Community-Based Stigma

In this chapter, I analyze community constructions of HIV/AIDS, exploring the relationship between gender inequalities and local understandings of HIV/AIDS as they intersect with women's identities as mothers and wives in the community. I then discuss women's experiences with HIV/AIDs stigma and their responses to stigmatizing attitudes and practices encountered in the household, kinship group, and larger community. In my discussion of women's experiences with HIV/AIDS-related stigma, I explore how HIV/AIDs stigma challenges women's enactment of motherhood and wifhood.

Chapter 7: Dissertation Conclusions

In this chapter, I bring together my arguments in the previous chapters and make suggestions for future research.

Chapter 2:

Literature Review

In this chapter, I begin with an exploration of the current literature related to women's health-seeking practice within PMTCT programs, followed by the theoretical framework that informs this literature. I then discuss the literature related to the impact of HIV/AIDS on women's lives, the larger community, national economy, and national health sector to provide a broader political, economic, and sociocultural context in which to explore the gender and power relations in PMTCT patients' lives, and how these social forces may affect women's social identities and HIV-related health-seeking within PMTCT programs.

PMTCT Programs and Patient Adherence

In 2012, 17.7 million women were living with HIV (World Health Organization 2014). Ninety percent of these women lived in sub-Saharan Africa. Malawi, a small country within the region, is especially impacted, with some of the highest rates of HIV infection in pregnant women in the world. In 2010, 63,500 pregnant women in Malawi required antiretroviral (ARV) prophylaxis (UNICEF 2011). Of these women, only 53% received ARVs through PMTCT programs (UNICEF 2011). In 2011, in an effort to expand access to treatment services within PMTCT programs, the Ministry of Health in Malawi implemented Plan B+, a policy designed to expand access to treatment services within PMTCT programs. Plan B+ now offers lifelong treatment to all pregnant women and new mothers who test positive for the HIV virus, regardless of CD4 count.

Despite this substantial national scale-up of PMTCT services, retaining women within PMTCT programs remains a challenge to successful implementation of these interventions. Recent literature suggests that approximately 27% of women enrolled in PMTCT programs will fail to remain in them (Nachega et al. 2012). The failure to remain on treatment, or “non-adherence,” poses considerable health risks for mothers and their exposed infants, including development of opportunistic infections and resistance to medications. It is estimated that 75% adherence is necessary for ARV treatment to be effective (Nachega et al. 2012).

While PMTCT adherence rates are now well-documented, reasons women may be unable to continue in the program are less well understood (Van der Straten et al. 2014). Researchers have begun to examine potential factors that may support or constrain a woman’s participation in PMTCT programs. Below I review the social science literature on women and AIDs to situate HIV-positive women’s health-seeking and social relations within their broader sociocultural and political economic context.

A meta-analysis of the literature related to women’s participation in HIV/AIDS treatment programs reveals that health system constraints, medication side effects, transportation, health care provider attitudes, stigma, and lack of social support may be important (Gourlay et al. 2013). Several studies point to the role of health system constraints (Balcha et al. 2011; Nkonki et al. 2007; Laher et al. 2012; Sprague et al. 2011; Whyte et al. 2004) or clinical hindrances such as side effects (Stinson et al. 2010) in creating barriers to participation. Other studies cited transportation as the most important factor (O’Gorman et al. 2010), or lack of education (Kuonza et al. 2010).

Studies more closely aligned with this study’s findings found that social stigma (Bwirire et al. 2008; Castro and Farmer 2005; Chinkonde et al. 2009; Kasenga et al. 2010; Laher 2012;

Mepham et al. 2011; Nyblade et al. 2003; Stinson 2012; Theilgaard et al. 2011; Torpey et al. 2010; Ujiji et al. 2011; Van Hollen 2013; Van der Straten et al. 2014), negative interactions with health care providers (Nyirenda 2010; Painter et al. 2004) and fear of HIV/AIDS disclosure (Chinkonde et al. 2009; Van Hollen 2013) may play a role in women's participation. Limited social support in women's daily lives and within PMTCT may stem from local gender roles and gender inequalities, which may prohibit women from disclosing an HIV/AIDS status to their family and community. In Malawi, an AIDS diagnosis for a woman may not only connote promiscuity but may also threaten marital relationships in a society in which women's value is rooted in marriageability and fertility.

The potential role of stigma has been noted by several researchers who suggest stigma from the greater community may shape women's care-seeking (Bwiriire 2008; Castro and Farmer 2005; Chinkonde 2009; Kasenga 2010; Laher 2012; Mepham et al. 2011; Nyblade et al. 2003; Stinson 2012; Theilgaard et al. 2011; Torpey 2010; Ujiji 2011; Van Hollen 2013; Van der Straten 2014). Farmer (Castro and Farmer 2005) claims that stigmatization is a tool by which individuals leverage power differentials within the social hierarchy, reinforcing the marginalized positions of the poor, women, and others most vulnerable. He calls upon scholars to reveal the lived experience of patients with AIDS and to explore community perceptions of AIDS to counter the detrimental effects of stigma. Government policymakers and donors have begun to respond to such calls with the production of "sensitization campaigns," which provide more knowledge of AIDS to communities with the goal of altering stigmatizing attitudes toward AIDS.

Recent literature suggests a gendered experience of HIV/AIDS stigma, claiming that women experience greater HIV-related stigma than men (Nyblade et al. 2003; Van Hollen 2013).

The studies point to the fact that an HIV/AIDS diagnosis disrupts family and kinship relations, which may manifest in stigmatizing attitudes and practices toward women. Bond (Nyblade et al. 2003) found that women were more likely to be stigmatized for being HIV-positive because they failed to fulfill their roles as caregivers to members of the extended family because of their illness from HIV. A similar pattern was found in Van Hollen's study of HIV-positive mothers in India. Van Hollen (2013) found that women were stigmatized by mothers-in-law who blamed them for bringing HIV/AIDS into the marriage, thus threatening the moral integrity and continuity of the lineage.

Some studies have identified signifiers of an AIDS status that women must hide from members of the community. For example, in many parts of Central and Southern Africa, a woman who doesn't breastfeed a child until the child is two years old signals to the community that she may be HIV-positive, and may be subjected to criticism from community members if her breastfeeding practice conflicts with local norms (Thorsen et al. 2008). In this study, women experience stigma in their social relations with husbands, community members and health care providers.

Yet few studies deconstruct "fear of disclosure" to identify its root causes, particularly the potential role of gender relations and inequalities. Further, few studies examine the impact of a fear of disclosure on women's access to treatment in PMTCT programs. Studies exploring the role of gender relations and inequalities in HIV-positive women's lives primarily focus on the domain of prevention (Baylies 2000; Booth 2004; Tallis 2000). These studies largely focus on the role that gender relations and inequities play in heterosexual transmission. Studies focusing on Central and Southern Africa, for example, suggest that gender inequalities place women at risk for contracting HIV/AIDS (Bwirire et al. 2008; Hunter 2007; Iliffe 2006; Jewkes and

Morrell 2012; Schatz 2005; Susser 2009). These studies have shown that negotiating safe sex may lead to domestic violence (Jewkes and Morrell 2012), threaten local ideas of masculinity (Iliffe 2006), conflict with a couple's reproductive desires, and lead to divorce (Schatz 2005). The studies support the notion that gender inequities place women at higher risk of contracting HIV because women fear negotiating with husbands who may be unwilling to practice safe sex. For example, Chinkonde (2009) finds that women fear disclosing their HIV status because disclosure requires they negotiate condom use, creating tension in the marriage. Schatz (2005) found that women who failed to negotiate safe sex simply opted for divorce rather than remain within relationships that placed them at risk for contracting HIV.

Booth (2004) highlights how development agendas assume gender equality, leaving health care workers to reinterpret and reformulate health policy to fit with local realities. Booth found that nurses in AIDS prevention programs in Kenya decided to not distribute condoms to women because they didn't believe that husbands would comply with safe sex practices. Clinic staff members' ideas and ideologies rooted in biomedical training and/or positions of privilege may compel them to restructure medical protocols based on their own cultural assumptions (Booth 2004; Tsing 2005).

While several studies examine the role of gender and risk of HIV/AIDS transmission, few focus on the role of gender and women's access to treatment once they have initiated treatment. Moreover, few studies specifically identify gender relations as a potential reason for women's fear of disclosure (Bwirire et al. 2008; Chinkonde et al. 2009; Van Hollen 2013). Van Hollen (2013) finds that the structure of PMTCT programs, and women's reproductive health services in general, reinforce gender inequalities. While studying the factors that influence women's health-seeking within PMTCT programs in India, Van Hollen notes that women's biological and social

status as pregnant women and future mothers target them for reproductive health services—prenatal or antenatal services which offer HIV testing to all pregnant women attending these services. As a result, many women receive an HIV/AIDS diagnosis prior to their husband simply because they attended the antenatal clinic and agree to be tested. Husbands, on the other hand, are less likely to be tested, either because they refuse, or have fewer opportunities to be tested because of the gendered structure of women’s reproductive health services. In Chapter 6, I discuss how this aspect of PMTCT services contributes to a gendering of stigma for women which reinforces existing gender and power inequities in women’s social relations in the community.

One study of women’s reproductive health-seeking in Mozambique suggests that women’s adherence to ART treatment speaks to issues of social distrust and competition for scarce resources, a pattern that mimics women’s delayed treatment-seeking within prenatal services at the clinic (Chapman 2012). Chapman argues that women “hide” from reproductive health services because of economic marginalization and competition for husbands whose economic power may buffer the effects of limited resources in central Mozambique (Chapman 2012, 238).

Other studies conducted in rural Southern Malawi (Bwirire et al. 2008); and urban Central Malawi (Chinkonde et al. 2009) suggest a lack of support from husbands stemming from unequal gender relations may interfere with women’s participation in PMTCT programs in Central Malawi. This dissertation seeks to extend this narrative by deconstructing “fear of disclosure” to identify its root causes, particularly the potential role of gender relations and inequalities in shaping a woman’s fear of disclosure on women’s access to treatment in PMTCT programs.

Theoretical Framework

To better understand how gender roles and relations contribute to gender inequities, I deconstruct the broad concept of gender inequalities, drawing upon the work of scholars whose research examines gender and kinship relations within Southern Africa (Conroy 2013; Crehan 1997; Jewkes and Morrell 2012; Mohanty 2003; Poewe 1980; 1981). I analyze gender inequalities in terms of economic and political relations—such as control over production, reproduction, political power, (Crehan 1997; Poewe 1980; 1981) and relationship power (Conroy 2013; Jewkes and Morrell 2012).

In Chapter 5, I argue that gender inequalities for women participating in PMTCT are most pronounced in women's relationship power, where the power structures of decision-making, economic dependence, and social norms related to women's sexuality intersect, making HIV disclosure and PMTCT treatment-seeking challenging. I discuss Connell's theory of gender and power (Connell 1987) to explain how women's limited economic and decision making power place women living with HIV at risk of divorce when they disclose a positive status to husbands and the community.

According to the theory of gender and power, the social structure "labor" (Connell 1987) focuses on how gender relations shape and are shaped by economic dependence. This dimension of relationship power demonstrates how gender inequities are produced by unequal access to education and employment, resulting in limited economic power within the household. I discuss women's economic dependence within marital relations, recognizing how kinship and class shape gender inequalities within marriage.

The social structure "decision-making dominance" focuses on women's decision-making power within the household (Crehan 1997; Poewe 1981). Decision-making dominance is

particularly useful in examining where power inequities intersect with women's sexual relations—such as the negotiation of condom use and HIV disclosure to a spouse. This social structure helps explain why many poor women do not disclose their HIV status, perceiving few options for social and material security outside the marital relationship.

The final social structure shaping the balance of power within women's relationships are “social norms” (Connell 1987). Social norms related to sexuality help explain the inequities within many women's relationship power. This social structure explains where power inequities intersect with the meaning of HIV/AIDS in women's social role as wife and mother. Together, each of these social contexts demonstrate how PMTCT health-seeking is located at the intersection of these power relations: economic status, little decision-making authority, and representations of HIV/AIDS which challenge women's identities as mothers and wives.

This study employs the concept of “structural vulnerability” to explain the intersecting insults shaping women's health-seeking and within PMTCT programs. Rooted in political economic theory, and drawing upon notions of symbolic violence (Bourdieu and Passeron 2000) and normativity (Foucault 1978), structural vulnerability refers to indirect forms of violence “produced by one's social location within a social hierarchy and network of power relationships” (Quesada et. al. 2011, 1). Similar to the concept of structural violence, the notion employs a depoliticized tone while demanding social and political responses to unequal health outcomes. Structural vulnerability extends the concept of structural violence by capturing the multiple inequalities that lead to poor health outcomes. A key distinction between the two concepts is the emphasis upon social process in which positionality and power relations contribute to social suffering. While structural violence denotes a static social structure, structural vulnerability denotes a social process produced by the “effects of structural violence” (Quesada et al. 2011, 1).

To situate women's experiences with HIV/AIDS treatment programs in its broader political, economic, and sociocultural context, I discuss the impact of broader economic reforms and repercussions of the HIV/AIDS epidemic on resource constraints within the public health system.

Impact of the HIV/AIDS Epidemic

Impact on the National Health Sector

The impact of the AIDS epidemic on health sectors within the Global South demonstrates the concept of biopower² (Foucault 1978), or the biosocial process by which the "power of biology" invites intervention into the African continent and results in the creation of new social forms (Ferguson 1994; Lock and Nguyen 2010). The global response to the HIV/AIDS epidemic has fueled an emergence and application of biotechnologies to advance efforts in the prevention and treatment of AIDS (Biehl 2005). In many southern African countries, continued high rates of AIDS combined with the social and economic fallout from structural adjustment policies (SAPs) and other political economic changes attracted an influx of nongovernmental organizations (NGOs) and faith-based organizations to the region, providing health services while creating new opportunities for intervention in the lives of patients with AIDS.

Trade liberalization and privatization have increased poverty, migration, low wages, and decrease in access to social services (Mohanty 2003). SAPs had a detrimental effect on state-sponsored health services, as downsized government programming conflicted with health policies positioned to "scale-up" health infrastructure. As a result, decentralization of health services and privatization largely restricted health care access for the poor (Pfeiffer and Chapman 2010).

² Biopower, defined as the regulations of life at the population and individual levels, illustrates the productive nature of disciplinary power. Examples of biopower include the regulation of fertility, sexuality, modern technologies.

I discuss how shifts in the national economy and a decline in spending for state-sponsored health services created opportunities for a transnational response to the AIDS epidemic in Malawi, including the expansion of AIDS-related services. The process illustrates the role of political-economy in the national scale-up of prevention and treatment-based services. The process further illustrates the power differential between economic powers in the Global North—WTO, IMF, the Global Fund, faith-based organizations, and transnational corporations at the center of antiretroviral distribution as the power of self-governance among poorer nations declines and that of transnational institutions is on the rise (Pfeiffer and Chapman 2010). These global political and economic processes associated with neoliberalism and capitalistic expansion exacerbate economic, racial, and gender inequalities in many southern African nations (Mohanty 2003).

The mass distribution of AIDS prevention and treatment services such as PMTCT programs illustrates the decline in state power and authority in many African nations. As many African states attempted to repay debts from SAPs, support for AIDS-related services such as the production and distribution of ARV medications ushered in an influx of donor-funded NGOs that assumed new forms of governance as they fulfilled policy obligations.

In recent years, public health researchers have called for a greater emphasis on health systems strengthening by international donors. These researchers claim that donor aid tends to favor vertical, non-sustainable programs supported by international NGOs. Meanwhile, little aid is funneled to ministries of health so that existing programs can be reinforced with additional staff and supplies. Researchers charge that the work of international NGOs leads to “fragmented services,” an “internal brain drain” from the public sector, and “showcase projects” that are unsustainable (Pfeiffer et al. 2008, 2137). Such projects cater to the goals of international donors

rather than the goals of local ministries of health. Consequently, these international projects create parallel programs that are ultimately not linked to existing local health services (Pfeiffer et al. 2008).

NGOs and faith-based organizations operate as forms of “biopower,” responding to the health service gap with an extensive array of services dedicated to promote the health and well-being of thousands of men, women and children living with AIDS (Farmer 1992; Millen et al. 2000). In recent years, AIDS health policy has shifted from prevention-based approaches to therapeutic approaches with the mass distribution of AIDS medication. This shift in policy has created new global power relations—opportunities for pharmaceutical companies now located at the intersection of downsized state-funded health services and transnational and national treatment-oriented health policies. As a result, the pharmaceutical industry and NGOs have played a larger role in governance, shaping national health policy as state governments attempt to minimize the impact of AIDS on individual patients and the larger body politic. In Chapter 4, I discuss how resource limitations resulting from these policies shape women’s experiences at the clinic as they participate in PMTCT programs.

Just as NGOs have responded to service gaps with the provision of health and other services, pharmaceutical companies have gained entry to African markets through partnerships with transnational NGOs (Bornstein 2003). Pharmaceuticals such as ARVs provide a lens through which to observe the social processes by which structural inequalities are reproduced; who gets access to pharmaceuticals, and who doesn't, often reflects social hierarchies within the larger society. The construction, distribution, and implementation of AIDS intervention strategies has been framed as a "biopolitical assemblage" of "discourses, bodies, drugs, and technologies (Nguyen 2004). Authors claim the circulation of pharmaceuticals provides insight into the intersection of science, the state, and private industry, linking the

value of commodities with the authoritative knowledge of medical experts (Nguyen 2004). As state governments, donors and NGOs realign health policy strategy toward treatment-based methodologies, pharmaceutical companies have gained entry into a new market by increasing demands for antiretroviral medication. While authors remark on the potential contribution of lower-cost treatment, they also suggest the detrimental effects of transnational corporations (TNC) in shifting health policy away from the promotion of community health to more privatized individualized health strategies which rely heavily upon biotechnologies (Millen 2000, 220).

Scholars suggest the effects of the "biotechnical response" to the AIDS epidemic distract from the underlying structural inequalities that have fueled AIDs. Drawing upon Das' notion of the "critical event," biotechnical responses erase the suffering of individual bodies, and place the responsibility for health on the individual body or in "the power of biomedicine" such as pharmaceutical fixes while larger political economic forces remain unchanged.

Impact of HIV/AIDS on Households

As discussed earlier in the chapter, many of the economic reforms designed to promote economic growth have disproportionately affected the poor, particularly poor women and children. In Southern Africa, men and women have increasingly engaged in informal economies, devising creative strategies to compensate for failed economies from economic reforms such as structural adjustment policies (SAPs) (Tranberg Hansen 2000; Kalipeni 2009; Schatz 2005, Hunter 2007). Scholars have increasingly drawn attention to the failure of the state to create viable jobs, which has contributed to migration and the formation of new sexual networks. In countries such as Malawi, men migrate to secure work, yet women's choices for employment are limited

by these broader economic reforms and a gendered access to education which limits women's options (Mohanty 2003).

HIV/AIDs primarily has affected the health of adults in their productive years, leading to dramatic economic and social changes in the structure of households. Family members who are too ill to work contribute less to the household economy through lost wages and are often no longer able to contribute to household food production. Furthermore, these individuals may need other family members to withdraw from the workforce to provide ongoing care and support.

The loss of adults in their productive years changes the overall structure of social relations within families. For example, adult children who once provided for elderly parents and are no longer able to provide for them due to HIV/AIDS-related illness may need their elderly parents to assume caregiving responsibilities for their children, once they have passed away or are unable to care for their children independently (Drimie 2002).

In addition to its impact on traditional support systems, the HIV/AIDS epidemic has had a significant impact on food security at the household and national level. Households who lose the productive labor of family members too ill to contribute to agricultural production may shift the type of crop cultivated from cash crops such as maize and tobacco to food crops such as cassava because these food crops require less intensive manual labor (Dorward and Mwale 2011).

The economic impact of HIV/AIDS not only affects the economic well-being of HIV/AIDS households. The decline in household income negatively affects the broader macroeconomy as households consume fewer goods with reduced incomes (Bryceson and Fonseca 2006.) Consequently, reductions in household income are most severe in poor households. Research suggests that the extent to which HIV/AIDS impacts wages depends on

whether the work of the deceased family member is skilled or unskilled. When wages for unskilled labor decline, inequalities within rural communities are exacerbated (Dorward and Mwale 2011).

Early in the HIV/AIDS epidemic, a series of political economic factors intersected, leading to acute food insecurity. Low agricultural productivity, high rural population density, land shortage, and the removal of fertilizer subsidies, collectively threatened subsistence food production in many communities and intensified *ganyu* labor so that families could meet their food needs.

The HIV/AIDS epidemic played a significant role in the increase in labor migration as large numbers of individuals sought *ganyu* labor. This migration was primarily assumed by male members of the family, leaving many households as female-headed for extended periods of time. Researchers suggest this urban migration was fueled by a “declining rural peasant sector” and rise in the informal sector. In recent years, the donor climate has shifted from traditional donors from the Global North to those from the Global South. For example, India, China, Brazil, and South Africa have recently become engaged in the development of agricultural, health and other sectors of many African countries (Kragelund 2010).

Poverty and Global Inequalities—Intersections with AIDS

The ideologies and practices constituting the AIDS epidemic provide a lens through which to view the social inequalities that place certain bodies, women’s in particular, at “risk” for developing AIDS. Political economic inequalities and relations of power characterize the circumstances that have fueled the AIDS epidemic in southern Africa. These same inequalities

fuel unequal gender and power relations which continue to structure women's experiences with HIV/AIDS long after they have initiated treatment.

A number of scholars argue that the structural inequalities that led to the growth of the HIV/AIDS epidemic are "structural vulnerabilities" that require critical changes in the political economic processes that reproduce poverty (Quesada, Hart and Bourgois 2011). For example, structural inequalities linked to poverty, gender, and racism often determine who is at risk for AIDS and who gets access to treatment for AIDS (Desai and Johnson 2005; Farmer 2005; Nguyen 2004; Petros et al. 2006; Schatz 2005; Tallis 2000). Hunter (2007) argues that structural inequalities play an important role in the growth of the HIV/AIDS epidemic, and calls upon scholars to deemphasize the often-belabored connection between AIDS and sexuality (Castro and Farmer 2005; Whyte et al. 2004) in public health and anthropological discourse, which obscures the role of poverty and unemployment in the AIDS epidemic.

Many women have responded to the effects of structural violence by creating informal economies to supplement limited incomes. In urban South Africa women generate income through selling food, selling secondhand clothing, brewing beer, and providing sex work (Hunter 2007). As women attempt to compensate for limited incomes, some women are placed at increased risk for contracting AIDS and experiencing sexual abuse when earning additional income through sexual networks. Underemployment triggers a trajectory of poverty and domestic violence, causing women to lose their marriages and economic stability.

AIDS places women at increased risk of exploitation by employers who deploy power relations to take advantage of young women seeking to secure livelihoods. Kalipeni (2009) explores how women navigate the structural factors that contribute to AIDS, claiming that globalization has fueled inequalities that put women at greater risk of contracting the disease. For example, in Malawi, AIDS

deaths have transformed the structure of families as orphaned children relocate with members of the kinship network or fend for themselves through alternative strategies. Young girls who seek employment through domestic labor are placed at risk of sex abuse as economic dependence binds them to unsafe work, while others exert agency and construct new identities in sexual networks that draw upon the economic prowess of sugar daddies (Cole and Thomas 2009). Kalipeni (2009) found that women who lost family members to AIDS and sought work as domestic workers were more vulnerable to exploitation by their female and male employers, experiencing verbal and sexual abuse from female and male employers, respectively.

Some women who have lost productive members of the family may seek additional income through transactional sex, or the exchange of sexual relations for cash income. While women may supplement household income with transactional sex, men and women may seek additional income through *ganyu*, or the exchange of day labor for cash income.

Gender roles and relations often confer caregiving responsibilities to women and girls. Women play an important role in agriculture and food security, however, they are often pulled from these forms of productive labor to provide caregiving for relatives with HIV/AIDS (Drimie 2002). Similarly, girls are more likely to be withdrawn from school to assist with childcare for younger siblings and other domestic responsibilities. Such losses in education potential have long-term consequences on the earning potential of AIDS orphans. These changes in caregiving responsibilities have weakened traditional support systems (Drimie 2002).

Impact of HIV/AIDS on Women's Lives: HIV/AIDs and Motherhood

Motherhood is central to the identity of women living in Southern Africa (Walker 1995). A number of studies examining women's experiences as mothers living with HIV/AIDS have focused on HIV-positive women's fertility desires. These studies explore whether a positive

status leads women to minimize the number of pregnancies they choose to have. Employing the metaphor of the infecting body, Long reports that HIV-positive South African mothers fear HIV transmission to the unborn fetus. These women also fear being unable to care for their HIV-positive infant because of their illness (Long 2009; Van Hollen 2013). In contrast, Yeatman and Trinitapoli (2013) find that fear of mother-to-child transmission does not influence Malawian women's fertility desires. The study found that mothers with HIV/AIDs choose to continue childbearing due to its importance to women's social identities, and to the stability of marriage. Importantly, this 2013 study was conducted after the PMTCT expansion, specifically after *Option B+* implementation, which initiates mothers on ARVs immediately after diagnosis, and anticipates significantly reduced MTCT and fewer HIV-positive infants (Fasawe et al. 2013).

Other studies explore how an HIV status alters women's identities as mothers. For example, some studies examine whether HIV-positive women are blamed for being poor mothers (Liamputtong 2013; Long 2009). These studies examine how placing a child at risk for mother-to-child transmission may be understood by members of the community as a failure to fulfill the caretaking role linked to motherhood. In Chapter 4, I discuss Malawian women's perspectives on childbirth and HIV and the challenges of being both pregnant and HIV-positive during Option B+ where fewer infants are contracting HIV/AIDS through mother to child transmission. The role of gender inequalities in women's PMTCT health-seeking and their intersection with HIV/AIDS stigma has been largely unexplored. Below I explore the existing literature related to gender and HIV/AIDS to illustrate this gap in the literature.

Development of Biomedical Health Care in Colonial Africa

Women's reproductive health services have been influenced by two major historical

processes: the development of biomedical health care in Southern Africa and the social construction of population growth in the imperial and colonial eras.

The development of biomedical health care in Southern Africa was based on a set of ideologies and practices that crystallized around the domain of population health as a marker of the health of imperial nations and their colonial states. The early 1900's was characterized by a period in which the body, women's sexuality in particular, became of central concern to the colonial state and mission doctors. A global concern with fertility emerged in Europe as infectious disease epidemics caused a decline in the European population. At the same time, expansions in scientific knowledge and the emergence of the field of statistics facilitated state monitoring and assessment of population health. As a symbol of the health of populations, fertility has historically been a key interest to nation states whose interests center on productivity and growth. During the imperial era, birth rates marked the economic potency of nation states, allowing states to statistically track the success of nation building. While concerns with underpopulation plagued the European metropole, low levels of fertility within many African colonies prompted concerns that African colonies would be unable to sustain a potent labor force to support a growing economy. As a result, European states exerted increasing control over African colonies in an effort to reflect idealized representations of a productive nation state (Vaughan 1991). To address the concern of underpopulation, state and biomedical actors turned their attention to the female body as the sites of reproduction and production.

Development of Western Biomedical System

Globally, the growth of biomedicine is marked by four phases: imperial [-1920], colonial [1920-1960], nationalist [1960-1980], and non-governmental [1980-present] (Lock and Nguyen

2010, 148). Biomedicine gained prominence when clinical success with infectious disease control bolstered the credibility of western biomedicine in Europe. Vaccination campaigns, the development of antibiotics, and the development of hygienic practices mitigated against illness and mortality from infectious disease epidemics within European nations and their colonial conquests.

After World War I, the ideology and practices associated with population growth became of increasing global concern as nation states feared the decline of European populations. At this time, birth rates became a proxy for the health of nations and the pronatalist policies designed to increase birth rates evoked a medicalization of childbirth, with “potential mothers” as the target for health intervention (Lock and Nguyen 2010, 158).

In Central, Western, and East African colonies, concerns with infertility fueled fears of an “infertility belt” within the Belgian Congo. Scientific technologies that promoted safe childbirth were intertwined with European notions of bringing “civilization” to “backward” native populations. Such civilizing discourse characterized the transnational focus on fertility within African colonies (Tsing 2005). This discourse further served the political and economic needs of nation states seeking a viable African labor pool to further their economic interests.

State interest in birth rates fueled colonial and mission health policy and the transnational growth of the maternal and child health movement (Vaughan 1991; Stoler 1995). In the former colonies, rules and proscriptions related to maternal and child health and childrearing became central to colonial health policies, leading to the formation of the maternal and child health movement. Family life, with an emphasis on mothering practices, was carefully monitored as the state sought to shape its future citizens within the European metropole, and a viable labor force in its African colonies.

According to mission and colonial administrative authorities, mothers were constructed as the source of morality within the family. Aligned with the missionizing goals of constructing the “ideal”

African family, mission doctors reinforced constructions of mothers whose moralities evoked "proper" and "hygienic" practices. Such constructions were commodified in products promoting personal hygiene, such as soaps and lotions aligning consumers with modernist identities (Burke 1996).

Conceptions of the ideal family, however, were rooted in Western European notions of the nuclear family, which paid little attention to the role of kinship and extended family within African society. The institutions and practices that constituted mission reform of maternal and child health instilled values and practices associated with motherhood that failed to incorporate larger networks of social relations critical to enacting motherhood in Africa (Vaughan 1991). These proscriptions for future mothers instead espoused micro-level changes at the household level in the values and practices of women. As a result, women were assigned responsibility for conforming to normative ideals rooted in Western models of individualism. These same ideals exist today as women's compliance within PMTCT programs is based upon notions of individualism which assume women's health-seeking as mothers and wives is conducted independent of their social relations with spouses, kinship group, and community.

In the 1930s, African child rearing and feeding were monitored and managed to cultivate new subjectivities grounded in moral principles central to the ideology of Christianity. Mission doctors monitored and transformed child rearing and marital practices through discourse that incited social anxieties about the "difficult child" and "laxity in marriage." Infant feeding became central to this project as mothers were trained how to properly feed their infants to cultivate "proper character" in their children (Vaughan 1991, 67). Stoler (1995) argues that ideologies related to childhood socialization reinforce racial boundaries and structure the development of future citizens by linking everyday practices such as bathing, feeding, and breastfeeding to anxieties over personhood, race, and national identity. Coining the concept of "intimate colonialism," Stoler (2002) demonstrates how the European state deployed a moral discourse to "encourage new forms of domesticity." In Chapter 6, I discuss how a moral discourse

related to sexuality and fidelity is central to concepts of wifehood, contributing to stigma toward women living with HIV/AIDS. I show how these historical processes—the production of an African women’s sexuality and its intersection with the history of STDs—contrast with historical and contemporary understandings of motherhood and wifehood. I find that the tension between these identities produce unequal power relations and community-based stigma toward mothers living with HIV/AIDS.

By the 1960’s, the “pronatalism” that characterized the imperial and colonial eras was replaced with concerns over limiting births to produce “modern” nuclear families” (Lock and Nguyen 2010, 160). Population control and family planning became central to government economic policy, resulting in the family planning movement which linked a nation's prosperity and stability with the reproductive capabilities of its families (Lock and Nguyen 2010, 121).

Production of Sexuality in the Colonial Metropole

In the British metropole, the threat of underpopulation fueled a "pronatalist discourse" dedicated to population expansion. Pronatalist ideologies reflected racist sentiment as concerns over "dying" races intensified. Campaigns to promote white prestige led to the mobilization of the Eugenics movement, a scientific project grounded in racist ideology which sought to preserve the purity of the European "stock" in the context of the profound economic and social change accompanying industrialization (Stoler 2002, 120).

As symbols of reproduction and production, women and children were depicted as bodies particularly vulnerable to "degradation." Discourse on the "degradation" of bodies and populations led to new constructions of the sexuality of working class women, linking sexuality with racial

degeneration as the British colonial elite sought to cultivate a population that met the needs of the political and economic interests of the imperial state.

In the former African colonies, such concerns with sexuality were equally embedded within racist discourse on relations between black men and white women. European officials and citizens threatened black men against engaging in sexual relations with European women. Assumptions about the sexuality of black men were rooted in racist fears culminating in the "Black Peril," a systematic attempt to deploy racial categories to establish social boundaries between white men and black women. The Black Peril parallels the anxieties manifested in the European "Moral Panic" permitting racist and moral overtones to pervade the discourse on African sexuality. In Colonial Africa, the Zimbabwean state institutionalized similar racial divisions with the enactment of the "Immorality and Indecency Suppression Ordinance of 1916."

Institutionalized forms of racism continued to emerge as African men were charged with rape when their proximity to European women threatened racial boundaries. Invoking the concept of the social body, Setel (Setel et al. 1999) claims such attacks on the individual bodies of white women signified an attack on the larger white community.

Representations of African sexuality further operated as a strategy for maintaining political and social control of the colonial empire. Following Stoler's work on racist sentiment in the ideology and practices of the former Dutch colonies, allegations of sexual indiscretion facilitated control over the behaviors and practices of certain populations, demonstrating the processes by which sexuality operates both as a metaphor for domination as well as a marker of race and class (Stoler 2002, 45).

Health-seeking for the treatment of sexually transmitted diseases was a humiliating and shameful process in which both men and women were ridiculed by colonial authorities for "naively" stepping forward to seek health services. A discourse related to African men and women with STDs as "lacking in shame" was reproduced in the attitudes and practices of

colonial health officials who attributed this health-seeking compliance as a “perverse African sexuality.” Colonial and missionary clinicians’ emphasis on cultivating shame in patients was deemed necessary for “a new moral code to succeed” within the British colony (Vaughan 1991, 148).

In Chapter 6, I demonstrate that many of these attitudes persist today in the gendering of stigma experienced by PMTCT patients as mothers and wives living with HIV/AIDS. I discuss how local understandings of HIV/AIDS tied to morality and women’s sexuality are historically rooted in the history of STDs in colonial Malawi (Vaughan 1991). I argue that *manyazi* (shame) has been reproduced discursively and is well alive today in the treatment seeking of these women living with HIV/AIDs.

Conclusion

In this chapter, I discuss several key domains in the literature on women and HIV/AIDS that explain the barriers and supports, grounded in gender and power relations, that shape Malawian women’s social relations in marriage and the community and women’s health-seeking within PMTCT programs.

I provide a review of the current literature related to studies of patient participation in PMTCT programs. I share a brief history of the impact of the HIV/AIDs epidemic on the Malawian health sector to draw attention to the political economic factors affecting women’s experiences in these programs. I then discuss the impact of HIV/AIDS on women’s lives, exploring the relationship between gender and HIV/AIDS transmission, and the socioeconomic effects of HIV/AIDS on women’s lives.

I discuss the historical development of women's reproductive health care in Southern Africa to illustrate the historical roots of a gendered access to AIDS treatment, drawing a link between women's experiences with colonial biomedical treatment of STDs and contemporary experiences with stigmatization and HIV/AIDS. I then include literature on motherhood and gender relations to foreground my discussion on the power inequities PMTCT patients encounter in marriage, the community, and clinic.

In the following chapter, I discuss the methodology used to explore the main research questions linked to this literature.

Chapter 3:

Research Methods

This research study was conducted at Queen Elizabeth Central Hospital, surrounding health centers and several community locations within the Blantyre district of Southern Malawi. The study included both qualitative and quantitative methodology. The qualitative methods employed during the study include semi-structured interviews, focus group discussions, and clinical observations. A quantitative program survival analysis was conducted at the end of the study period at one of the study sites, Queen Elizabeth Central Hospital. This analysis is included in the Appendices section of the dissertation. The study participants included patients attending PMTCT programs, health care providers providing care in these programs, and community members from the surrounding Blantyre district.

This chapter begins with a discussion of the research questions that guided this study and summarizes the methods used to attempt to answer those questions. This discussion is followed by a description of the study sites divided by region, and provides a more detailed discussion of the research methods in each of the main three geographic areas studied here: Blantyre, Ndirande and Mpemba. Blantyre is a densely populated city in the Southern region. Ndirande is an urban township outside of Blantyre, and Mpemba is a peri-urban township in the Blantyre district. Data was collected at health facilities and community settings. I discuss additional research methods used in the study in the final section of this chapter.

Part I: Study Objectives and Research Questions

While conducting exploratory research to determine my dissertation topic, I spoke with

health care providers working directly with AIDS patients in the Malawian government-run health system. I learned that one of the challenges with the clinical management of AIDS was patient “adherence.” The problem was even more pronounced in women attending the PMTCT clinics, where rates of non-adherence were twice that of the general adult HIV/AIDS population. I wanted to explore what was happening in women’s lives that would make them unable to consistently access medication for themselves and their HIV-exposed children, when ARV treatment was now available at no cost after years of being accessible only to those who could afford it. The overall goal of the study was to identify factors that affect women’s ability to participate in PMTCT programs in Malawi.

The literature on gender, HIV/AIDS, women’s reproductive health care, and political economy discussed in Chapter 2 informed the overarching research question: Why do only some women in PMTCT programs complete treatment? More specific questions included the following: What strategies for AIDS treatment and management do pregnant and postpartum women employ? How do broader social and gender relations affect women’s participation in the program? And conversely, how does participation in the program affect women’s social and gender relations?

Part II: Data Collection

Study Setting

Between March 7 and December 5, 2012, ethnographic interviews, focus group discussions, and clinical observations were conducted at the health facilities and community settings described above: Blantyre, Ndirande, and Mpemba. I spent the first five months at QECH (Queen Elizabeth Central Hospital), followed by six months at two health centers. Patient

interviews and focus group discussions were conducted in Chichewa by two research assistants: a nurse midwife from QECH, and a Health Services Assistant (HSA) from one of the participating rural clinics. The nurse midwife conducted all interviews with current PMTCT patients at QECH and Ndirande, and the HSA independently conducted interviews with all patient “defaulters” at the Mpemba Health Centre. I conducted all health care provider interviews and attended all patient interviews except those interviews conducted with patient “defaulters.” The study was approved by the institutional review boards at Michigan State University and the College of Medicine at the University of Malawi. Interviews lasted between forty minutes and one hour, and all interviews were audio-taped.

Two health centers in addition to QECH, Ndirande Health Centre and Mpemba Health Centre were included in the sample to capture a sample of PMTCT patients who are referred back to health centers after the standard six month follow-up appointment and to ensure representation from both peri-urban and urban communities. I selected these particular health centers for several reasons. First, each had a consistent patient load to guarantee I would be able to recruit patients for interviews. I collected statistics on the number of patients attending PMTCT clinics from the District Health Office in Blantyre to identify clinics with the highest patient load, and health centers that received few PMTCT patients were not considered. Furthermore, one of the clinics, Mpemba Health Centre, was willing to allow me to volunteer to assist with administrative tasks during the weekly adult antiretroviral ART/PMTCT clinics. Finally, I wanted to include in the sample satellite health centers, as many patients receiving HIV/AIDS services travel back and forth between Blantyre and the surrounding communities.

Blantyre

Blantyre is the second largest city in Malawi, and is located in Southern Malawi. With a population over 700,000, Blantyre is the commercial capital in Southern Malawi. Blantyre is located in the Shire highlands at an elevation of 3,000 meters, and is surrounded by several mountain ranges: Michiru, Soche, Chiradzulu, and Ndirande. The largest hospital in Malawi—Queen Elizabeth Central Hospital (QECH)—is located in Blantyre, serving a patient population of 1,300 patients at a time, and over 100,000 children a year.

Several factors aligned to make QECH and the surrounding health centers an ideal location for the study. The city of Blantyre has some of the highest rates of HIV/AIDS in Malawi, with an average rate of 20.5% (Ministry of Health 2008). Since Blantyre functions as the commercial capital, QECH attracts a diverse patient population representing a cross-section of urban, semi-urban, and rural patients. QECH is a major publicly-funded tertiary-level teaching hospital and is a primary referral facility specializing in neurosurgery, orthopedics, radiology and other subspecialties (Muula 2003). The PMTCT program at QECH is based out of the prenatal clinic within the Department of Obstetrics and Gynecology (OB/GYN). The department includes on average eleven physicians including six pediatricians, three-to-five physician interns, three midwives, and three-to-five nurses. The Chatinkha Maternity Unit housed within OB/GYN offers prenatal care to approximately 1,300 women per year (Changole et al. 2010).

Mpemba

The majority of this five-month research period was spent at Mpemba Health Health Centre for reasons described later in this chapter. Mpemba Health Centre is a peri-urban health

center approximately ten kilometers from Blantyre. This clinic served all patients with HIV/AIDs, both men and women, in a combined ART/PMTCT clinic.

Ndirande

Ndirande Health Centre is an urban health center located in a high density township approximately two kilometers from central Blantyre.

Summary of Methods Used

Clinical Observations

In order to fully understand the nature of the PMTCT program and patient experiences in the program, I conducted clinical observations at each participating clinic. I observed the interaction between PMTCT staff and the women who attend the programs, permitting comparison between patient self-reports and their observed behaviors. While conducting participant observation, I noted the general atmosphere of the clinic, exploring attitudes women encountered, the impact of limited staffing on women's experiences, and whether health information, provider attitudes, or long queues discouraged women's participation. I attended health education sessions for PMTCT patients to observe patient-provider interactions, and to listen to the questions asked by women to better understand which health information elicited clarification. Finally, I observed whether women attended the clinic with a self-appointed guardian as suggested by PMTCT protocol, and whom the patient chose to be their guardian. PMTCT programs require patients to attend with a "guardian" who can assist them with medication management and encourage their adherence. Most clinics dismiss this guideline as

not relevant, and I did not observe health care providers denying treatment to women who failed to attend with a guardian.

Clinical observations were conducted at the district hospital during the weekly prenatal and postnatal clinics from which patients were recruited. The prenatal clinic was typically bustling with mothers and infants waiting for the health education sessions. Once registered, women waited in line for themselves and their infants to be weighed. Prenatal and postnatal clinics began with health education songs by Mothers to Mothers, a peer-led support group for women living with HIV/AIDS (WLWA). PMTCT nurses would conduct health education sessions as women gathered around a small courtyard. After the group health education (IEC) session, health care providers and clinicians conducted clinical exams with mothers and their infants in one of the surrounding private rooms. Women registered in PMTCT would then be called into a private room dedicated to the distribution of ARVs. Three small clinical exam rooms surrounded a large room lined with wooden benches which served as the patient waiting area, prenatal clinic and postnatal clinic.

Clinical observations were also conducted at participating health centers. At Mpemba Health Centre, I provided administrative support during weekly PMTCT clinics to observe the interactions between health care providers and patients. After volunteering for a period of months, I came to know the clinic staff well, particularly nurse midwives and health services assistants, and health center staff treated me as part of the staff. I weighed adults and babies to calculate BMI, filed medical records, counted pills, and distributed Plumpy Nut, the nutritional supplement for AIDS patients with acute malnutrition.

Focus Group Discussions—Patients

In addition to semi-structured interviews, four focus group discussions were conducted with patients. The goal of the patient focus groups was to examine the relevance of specific research questions for PMTCT patients, to focus clinical observations and patient interviews, and to allow women to discuss potential facilitators and barriers to completing PMTCT treatment. Patient focus groups reached saturation at the fourth group discussion. Focus groups consisted of seven-to-ten current PMTCT mothers initiated on the 5A regimen.

Early in the study period, it became clear that women were more forthcoming in expressing their opinions in the presence of other PMTCT participants. The social context of focus group discussions allowed for discussion of interview questions in greater depth without the pressure of a one-on-one, semi-structured interview. To capture this greater depth in participant responses, a larger number of focus group discussions were conducted than had been originally planned. Patient focus group discussions were conducted by the nurse research assistant in Chichewa, and I was present during all the focus group discussions. It is likely that given the sensitivity of the research topic, the anonymity granted within a group context allowed women to “feel free” to discuss their PMTCT experiences. During these discussions, women more candidly expressed both positive and negative aspects of their PMTCT program experiences. Further, during the focus group discussion women appeared to develop a sense of community. Several women cultivated new alliances with other focus group discussion (FGD) participants sharing their identity as HIV-positive pregnant women or new mothers.

Focus Group Discussions—Community Members

To gain a more in-depth understanding of the broader context of the lives of Malawian

women outside of the PMTCT clinic, semi-structured interviews and focus groups were conducted with community members within Blantyre and the surrounding community setting. Community members included teachers, church leaders, domestic workers, village chiefs, and traditional birth attendants (TBAs). Community interviews and focus groups provided the opportunity to gain more information on the perspectives of women in the community in order to understand their everyday lives and responsibilities related to pregnancy, motherhood, and spousal and family relations. Attention was paid to common responsibilities of motherhood, attitudes toward breastfeeding, and women's networks of social support during pregnancy within the community. The goal of these interviews was to capture the day-to-day experiences of women who may typically attend a PMTCT program. Interview questions explored the structure of women's daily lives as they are affected by gender and other familial relationships and the role of motherhood.

A total of six focus group discussions were conducted with teachers, church leaders, and male and female domestic workers. One of the teacher focus groups consisted of all women while the other focus group included both men and women. In order to find enough teachers to comprise a focus group at the second school, both men and women were included. The aim of these focus groups was to explore women's everyday lives and responsibilities. For example, the values, ideals, and practices imparted to women in PMTCT program guidelines may or may not reflect the ideals and practices espoused by a woman's family and kinship group.

Focus group discussions were held with primary and secondary school teachers, both male and female, in the study communities. Teachers were selected because as leaders in their communities they would be able to provide in-depth information about gender and kinship relations, local understandings of HIV/AIDs, and the responsibilities and experiences of men and

women within the household, kinship group and community. Questions explored the roles of husbands, wives, mothers and fathers within the community, and also examined the meanings of marriage, divorce, pregnancy, and fertility in order to understand community constructions of womanhood in Malawi and how these constructions may relate to women's experiences with PMTCT programs.

I first sought permission from the headmaster of the school to interview six to eight teachers. Teachers were selected based upon their willingness to be interviewed and their availability, and the permission to conduct focus groups was given by the headmaster on days when the school was fully staffed. Establishing rapport with the teachers was relatively easy. Many of the teachers seemed to appreciate my interest in their perspectives on gender and family relations in their communities. Moreover, in contrast to interviews and focus groups with women with AIDS, there appeared to be a significantly smaller power differential between myself and the teachers. I chose to interview teachers because as key socializing agents in their communities, teachers articulate key values and ideals of their community, convey them to students, and thus reproduce those ideals for the larger community.

Patient Interviews

A total of 71 patients were included in the patient sample. All patients were purposively sampled and were selected from the first cohort of PMTCT patients registered on Malawi's Plan B+. Patient interviews explored patients' concepts and goals regarding HIV/AIDs, their experiences in the program, the strategies they employ, the challenges they may face, and how they address these challenges. Information was gathered on women's understandings of their AIDS status and management of AIDS for themselves and their children; which aspects of

PMTCT programs were particularly challenging; what material, social, or religious strategies women employ as program participants; and who, in their social network, knows about their AIDS status and how they respond to this knowledge. Information was also gathered on patient demographics including age, marital status, number of children, number of household members, employment, and religious affiliation.

Plan B+ patients are prescribed medication regimen 5A immediately after testing HIV positive, regardless of their CD 4 count. (CD 4 cells are a type of white blood cell that protects the body from infection, and the CD 4 counts referred to here measure how well the body's immune system is responding to the HIV infection.) The 5A regimen includes the medications Tenofovir, Lamivudine, and Efavirenz.

Provider Interviews

A total of eighteen in-depth interviews were conducted with health care providers, consisting of nurse midwives, clinicians, PMTCT coordinators, and health services assistants (HSAs). Provider questions focused on the following topics: 1) perceptions of why some women are unable to complete the PMTCT program and why others successfully complete; 2) what is required of women as participants in this program; 3) what providers perceive as the responsibilities of women in PMTCT programs; 4) what strategies providers employ to promote completion; 5) how providers perceive successful program completion; 6) how these perceptions are conveyed to women as prescriptions for a treatment regimen; and 7) what recommendations providers have to improve program completion rates. These questions were designed to reveal how providers' and patients' expectations and program rationale diverge and where they overlap.

Community Interviews

A total of six semi-structured interviews were conducted with village chiefs, traditional birth attendants (TBAs), and church leaders. As noted above, I interviewed two church counselors from the Catholic community and the Church of Central Africa Presbyterian (CCAP) community. Church leaders were included in the sample because of the prominent role that religion plays in the daily lives of most Malawians, through which churches are powerful institutions within the community and play a significant role in imparting values and beliefs about gender roles and relations, and local understandings of women's roles within the family, kinship group, and community.

I interviewed two traditional birth attendants (TBAs) in the peri-urban Mpemba region who were recruited by snowball sampling. The HSA asked the village chief in Mpemba for the names of TBAs in the village. These interviews were conducted with simultaneous translation by my research assistant, and both TBAs were interviewed at their homes in one of the surrounding villages. TBAs were included because of their pivotal role in the reproductive health of women living in rural Malawi. Eighty-two percent of Malawi's population live in rural areas. TBAs impart ideas about women's reproductive health practices during pregnancy and delivery—two of the three phases of women's reproductive health targeted by PMTCT programs.

Patient demographics

I interviewed and conducted focus groups with a total of 71 patients between the ages of 18 and 49. The majority of women (75%) were between the ages of 26 and 40, 84% of the women were married, one woman was divorced and two women were widows.

Thirty percent had some secondary education, and 30% had completed only primary education. Most of the women attending the peri-urban PMTCT clinic had attended but not completed secondary school. I decided to collect data on women's level of education to better understand their ability to gain access to employment and other sources of economic support, as these factors may affect their ability to participate in PMTCT programs.

Patients' employment included women who worked in the professional sector as teachers or secretaries (13%), as small business vendors selling market produce (28%), or housewives who focused on domestic responsibilities of childcare, cooking, cleaning, water hauling, and collecting firewood (31%).

The majority of women who farmed subsistently lived in Mpemba. One woman sold charcoal prior to her illness, another worked as a sex worker. Guardians were interviewed on behalf of each of these women. The mother of the woman working as a sex worker participated in the interview. For the woman who sold charcoal, her mother completed two interviews after the daughter died suddenly before the end of the study period.

Most PMTCT patients were married (83%). One woman was divorced and two women were widows. The majority of patient informants from both urban and rural sites were of matrilineal descent (75%), whereas 25% were of patrilineal heritage. Although, as noted earlier, these descent and residence patterns were significantly altered in this urban context.

The most common ethnic affiliations were Lomwe (n=16) and Ngoni (n=13). The second most common ethnic affiliation was Yao (n=8). Eight were M'anyanga, four were Chewa, and three were Tumbuka. In this study community, women's experiences with gender inequalities and community-based stigma were found not to vary by ethnic affiliation. Women who reported

challenges to decision-making authority in marriage, and those who reported shared decision-making power in marriage represented the same ethnic groups—Lomwe, Chewa, and Ngoni.

However, a few health care providers and community members claimed that in some social contexts, patrilineal kinship groups leverage women's reproductive power in marriage. For example, community members and health care providers claimed women in patrilineal kinship groups experience greater stigma, arguing that these women were more likely to suffer from discrimination from mothers-in-law who may ill-treat them when they are unable to bear children or are sick. As I discuss in Chapter 4, health care providers and community members report that women from patrilineal communities experience greater stigma when unable to reproduce. Pressure from in-laws is most pronounced in patrilineal kinship systems where the social and material value of children weighs more heavily.

Contextualizing Kinship Demographics

While the majority of the men and women in this study come from matrilineal kinship groups, many of the gender relations described by informants reflect a shift in matrilineal kinship structures, where vestiges of the matrilineal system persist in the context of urbanization which has altered the practice of matriliney. The majority of the women interviewed in this study came from urban and peri-urban areas in the Blantyre district of Southern Malawi, where the matrilineal system and residence patterns have been changing over time (Phiri 1983; Desai and Johnson 2005) and matrilineal practices have broken down, thus reshaping kinship relations.

Phiri notes that the Chewa family system has been greatly affected by modern socioeconomic changes from colonialism and the capitalist economy which have shifted the structure of families in Malawi. He states, “Scarcely anywhere among the Chewa in central

Malawi today does the mother's brother exercise the kind of domestic authority he may once have had; the father has assumed that role..." (Phiri 1983, 257). A stronger relationship between wife and spouse delegitimized the household authority of the avunculate, or woman's brother (Phiri 1983), who traditionally held primary responsibility for the wellbeing of his sister and his sister's children, altering a primary source of material and social support available to women. As Phiri states:

In its ideal form, the Chewa family system is supposed to place considerable emphasis on the mother right, the avunculate, uxorilocal marriage, husband's subordination to wife's kin, and importance of female children as future reproducers of the lineage. In practice, however, there are a number of factors which have tended to mitigate the impact of these tendencies in the system, as far as men or husbands are concerned. These changes include changes in the marriage contract, family residential patterns, exercise of domestic authority, and control or custody of children. (Phiri 1983, 274)

My data demonstrate the malleability of matrilineal kinship structures, and illustrate how matriliney is functioning in peri-urban areas of Blantyre, where men and women have fewer opportunities to earn a living, particularly for those with little education. Consequently, these changes in matrilineal systems have heightened a woman's dependence upon the spouse for economic and social support.

The research methodology used at the three study sites, Blantyre, Ndirande, and Mpemba, are discussed in more detail in the next section.

Study Sites and Methods

Blantyre

Patients

Twelve interviews were conducted with current PMTCT participants at Queen Elizabeth

Central Hospital (QECH). All participants were purposively sampled. All patients interviewed were selected from the first cohort of PMTCT patients registered on Plan B+.

I attended weekly prenatal and postnatal clinics with my research assistant to solicit volunteers. Each woman registered at the clinics was invited to participate in a study on women's experiences with the PMTCT program. Those women who agreed to participate met the research team in a private room after receiving their initial check-up. Women's medical files were confirmed for Plan B+ participation after they agreed to participate. Four out of 45 patients declined to participate. Each participant received a 2kg bag of flour or 1kg bag of sugar for their participation.

Pregnant women met inclusion criteria if they were 18-49 years old, were HIV positive, and were initiated on the Plan B+ 5A medication regimen which began in July, 2011. 5A treatment was initiated at study sites after October 3, 2011. Women were asked why they had initiated treatment for themselves and for their child; household and familial responsibilities; challenges and supports to AIDS management; thoughts on why some women are unable to adhere; whether they had ever missed two or more consecutive PMTCT appointments and the reasons for doing so; experiences with HIV-related stigma; decision-making roles in the family/household; and reproductive decision-making and practice, including intended length of breastfeeding period.

A total of three focus group discussions were conducted with current PMTCT participants within the prenatal and postnatal clinics at QECH. I attended weekly prenatal and postnatal clinics to solicit volunteers. Each woman registered at the clinics was invited to participate in a study on women's experiences with PMTCT. Those women who agreed to

participate met the research team in a private room after they received their check-up. Focus group discussions began once a minimum of seven women volunteered.

Health Care Providers

Eleven in-depth interviews were conducted with health care providers at QECH. Interviews were carried out with nurse midwives, clinicians, PMTCT coordinators, and health services assistants (HSAs). Nine informants were female and two informants were male. To recruit health care providers, I applied a purposive sampling strategy (Marshall and Rossman 2006) and relied upon networking through my contacts from my initial pre-dissertation research conducted in 2010. Shortly after I received College of Medicine Research and Ethics Committee (COMREC) approval, I was introduced to the head of the PMTCT clinic at QECH. The PMTCT clinic manager then introduced me to PMTCT staff who were interested in participating in interviews.

Community Leaders

In Blantyre, I conducted one focus group discussion with teachers at a local secondary school. This discussion included a convenience sample of men and women who were working as full-time teachers and available to participate in the focus group during their lunch hour.

I also conducted semi-structured interviews with two church leaders, one from the Catholic Diocese and the Church of Central Africa Presbyterian (CCAP) church. Church leaders were selected through the process of snowball sampling. At one of the Catholic churches I attended during the fieldwork period, I asked for the name of the Church Counselor as I thought they would be more directly connected to the types of issues that emerge in their parishioners'

lives. CI Montford is the largest Catholic church in the Blantyre district, able to seat 2,500 parishioners. Sunday morning services include one service conducted in English followed by a service conducted in Chichewa.

I conducted one focus group discussion with female domestic workers and one focus group discussion with male domestic workers. These included a convenience sample of men and women who were employed at a nearby lodge as housekeepers, gardeners, and guards.

Ndirande

Four interviews were conducted with current PMTCT participants at Ndirande Health Centre. Patients were selected following the methodology employed at QECH.

Three in-depth interviews were conducted with health care providers at Ndirande Health Centre. These included a convenience sample of midwives, clinicians and health services assistants (HSAs). Two health care providers were female, one was male.

In the Ndirande community, I conducted one focus group discussion with teachers at a public secondary school. These included a convenience sample of men and women who were working as full-time teachers.

Mpemba

Patients

I conducted one focus group discussion with current PMTCT participants within the prenatal and postnatal clinics at Mpemba Health Centre. My research assistant and I attended weekly prenatal and postnatal clinics to solicit volunteers. Each woman registered at the clinics was invited to participate in a study on women's experienced with PMTCT. Those women who

agreed to participate met the research team in a private room after they received their check-up. Focus group discussions began once a minimum of seven women volunteered.

I attended the HIV/AIDS clinic in Mpemba for a period of five months. I spent an extended period of time in Mpemba because it became an ideal place in which to conduct participant observation. I was unable to conduct participation at the district hospital because there was little need for my volunteer assistance at the clinic. However, the clinic staff at Mpemba needed administrative support at the clinic, and asked me to participate. Further, Mpemba was the one clinic that was conducting outreach to follow-up with patient “defaulters,” and this recruitment phase took a significantly greater amount of time than the recruitment of active patients.

Patients Who Dropped

Perhaps the most sensitive aspect of the study was the process of identifying, locating, and interviewing patients classified as “defaulters.” Defaulters are defined by Ministry of Health guidelines as those patients who have not attended the PMTCT clinic for two consecutive months since their ARV medication has run out.

In Mpemba, a total of fourteen interviews were conducted with women categorized as “defaulters,” or those unable to adhere to treatment, to more directly explore specific supports and constraints from women most clearly challenged by the demands of PMTCT participation.

To identify patient defaulters, medical records were reviewed to create a list of patients whose records documented a “default” after October 3, 2011. These files were reviewed to determine eligibility: registered in PMTCT after October 3, 2011, between the ages of 18 and 49, and pregnant or new mother.

Patients who default are typically followed up by health center personnel. I learned that due to limited staff, only one health center in the Blantyre district, Mpemba, conducted outreach and health education in nearby villages to follow-up on defaulters. One HSA at this clinic was trained to conduct open-ended interviews with these women during their scheduled follow-up visits. For this reason, all interviews with patients who dropped out of the program (defaulters) were conducted at Mpemba Health Centre.

I had intended to hire a female for this sensitive position. However, I found one of the male HSAs, Esau, to have a quiet, nonjudgmental demeanor which seemed to place patients at ease. While volunteering at the health center at which he worked, I saw how he interacted with both male and female patients, and noticed that patients seemed very comfortable with him. I asked Esau to conduct a couple of pilot interviews, and he typically returned from the interviews armed with gifts each time—sugarcane sticks or bags of mangoes.

One of the biggest ethical concerns in this study was the risk of “outing” or forcing the disclosure of a woman’s HIV status with the presence of an HSA or myself at her home. Fortunately, Esau was responsible for conducting TB outreach to the surrounding villages and so combined these two goals in one home visit. To deflect any attention to him as a representative of the AIDS clinic, I asked him to say that he was conducting community health education if asked what he was doing in the village. Fortunately, his presence in the villages was so common because of his many non-AIDs-related activities, that he attracted little attention. I did not participate in these interviews, because of the tendency for my presence to attract attention from the villagers when I first accompanied Esau to follow-up with patients identified as defaulters. My goal was to not “out” any woman who had defaulted. I found that Esau’s presence in the community was expected, but as a foreign visitor, my presence was unexpected and was likely to

bring unwanted gossip from villagers toward the homes we visited. For this reason, I did not attend the interviews with these former patients.

Still, four of the 18 defaulters were not found, resulting in a total of fourteen women who qualified as defaulters and completed the interviews. Of the four women not found, we learned that one woman was a traditional healer who moved to the capital city, Lilongwe. While searching for the homes of the three remaining patients whose addresses were difficult to find, some villagers told Esau that sometimes at the time of registration, AIDS patients will change their name for the medical record so that they cannot be identified as HIV positive in their home villages. One woman is believed to have changed her name when reporting to the clinic, and was not found because she did not want to be found. I quickly dropped this patient from the study. The other two women lived several hours from the rural clinic. Because of the distance between the two villages and the clinic, it is likely that geography may be the reason for not returning to the clinic. When I spoke to clinic staff about the distance to these villages, they described them as “far-flung” and known to be areas where pregnant women chose to deliver at home with traditional birth attendants (TBAs).

Health Care Providers

Four in-depth interviews were conducted with health care providers at Mpemba Health Centre. Interviews were conducted with nurse midwives, clinical assistants, and health services assistants (HSAs). These included a convenience sample of three female informants and one male informant.

Community Leaders

In Mpemba, I conducted interviews and focus group discussions with teachers, church leaders, village chiefs, and traditional birth attendants (TBAs). I conducted one focus group discussion with teachers at a local secondary school. Participants included a convenience sample of men and women who were working as full-time teachers. In addition, I conducted one focus group discussion with church leaders. Mpemba had a CCAP church within walking distance of the health center at which I was based. I held a focus group with church leaders because they preferred to participate in a focus group rather than individual interviews.

I interviewed two chiefs from the Mpemba region, both selected through convenience sampling, one of whom was male and the other female. Both interviews were conducted through simultaneous translation. Village chiefs were included in the sample because they hold political authority within Malawian communities and are powerful social agents who handle household disputes between men and women when *ankhoswes*, marital counselors from within the kinship group, are unable to negotiate a resolution.

I interviewed two traditional birth attendants (TBAs) in the peri-urban Mpemba region who were recruited by snowball sampling. The HSA asked the village chief in Mpemba for the names of TBAs in the village. These interviews were conducted with simultaneous translation by my research assistant, and both TBAs were interviewed at their homes in the surrounding villages. TBAs were included in the study because of their pivotal role in the reproductive health of women living in rural Malawi; 82% of Malawi's population lives in rural areas. TBAs impart ideas about women's reproductive health practices during pregnancy and delivery—two of the three phases of women's reproductive health targeted by PMTCT programs.

Additional Methods Used

Member Checks

At the end of the study period, member checks were employed to validate study findings. Member checks involve bringing together a group of participants from the populations sampled—PMTCT patients and PMTCT health care providers separately—presenting preliminary themes, and soliciting feedback on the themes presented. Member check discussions were conducted in both urban and peri-urban study sites. Two focus group discussions were conducted with health care providers and two focus group discussions were held with patients from two of the three study sites to elicit feedback on initial findings from representatives of the study population. Health care providers confirmed the preliminary research themes. However, one theme that was understandably uncomfortable for health care providers was the apparent fear of negative interactions with some providers. Health care providers did not comment significantly on this theme.

After developing a list of preliminary themes to present to patients in the member check discussions, I realized that geography and lack of transportation never emerged as a barrier to care. This surprised me, as I had traveled throughout the region on foot and in a four-wheel drive vehicle to see where patients lived. Several times while exploring the rural region, I would find patients from the clinic who were physically impaired and struggling to walk home. I would deliver these patients home to assist them, and found the distances from the rural clinic to be unrealistic for patients who must walk long distances to the bicycle taxi stop. Furthermore, the bicycle taxi cost was prohibitive for many of the patients who frequented the clinic. These patients chose to walk the additional miles because of the cost. A third, but more expensive option in the rural region was the minibus which traveled on the paved highway, and not the dirt

roads that led to patients' homes and the health center at which I was based. In both provider and patient focus groups, people reminded me that walking long distances and not having the cash to access transportation on a regular basis was a normal process and likely not mentioned because this barrier emerged in all aspects of patients' lives and was not unique to their HIV/AIDS management.

Analysis

Transcripts were analyzed and analysis was conducted to answer the overall research questions examining the reasons women continue or do not continue treatment within PMTCT programs. Grounded theory was used to identify additional themes that emerged from the data to explore potential relationships between stated barriers, and to uncover barriers and supports not identified in the literature.

A common technique within grounded theory analysis is the application of the constant comparative method (Bernard 2000) to refine these theoretical constructs. Using this method, I continually compared units in the data to refine the core and secondary theoretical concepts. By continually comparing theoretical concepts to newly collected data, I was able to identify the dimensions of core and secondary concepts, explore their interrelationships, and integrate them into a coherent set of generalizations (Bernard 2000). This is an iterative process in which the analysis of data guides subsequent data collection (Bernard 2000). Comparisons were made against negative cases to assure all possible variations in the data were accounted for (Bernard 2000). Each interview was reread to determine whether interview responses fit into the existing theoretical concepts and continued until all data were accounted for.

To conduct the analysis, relevant text was selected that either related to my research questions or provided insight into my research participants' lives. Relevant text was coded using a name or phrase that I developed or stemmed from participant language. More focused coding was conducted with codes used most frequently. Codes were written as gerunds to eliminate premature analysis. To create higher level "parent" codes, I grouped these codes, along with the relevant text from transcripts, based upon how they related to each other—whether by causation, as consequence, etc. Codes were clustered based upon similarities, and clusters of initial codes were renamed as themes. In the final stages of analysis, I used participant quotes to write a "theoretical narrative" to tell a story about a particular aspect of participants' social lives (Auerbach and Silverstein 2003). Finally, I compared these theoretical narratives with the existing literature to answer my research questions and to explain other themes that emerged from the data.

Coding began once a number of interviews were conducted and patterns had begun to emerge from the data. Throughout the interview process, I used memoing to document potential codes and explore relationships among themes (Bernard 2000). Data codes reflect both the questions in the interview guide and broader themes that emerged from the interviews with patients and providers, focus groups with patients, and clinical observations.

Quantitative Survival Analysis

A quantitative survival analysis was conducted in the field to measure the frequency with which patients drop out or default from the PMTCT program at Queen Elizabeth Central Hospital (See Appendix A). The analysis was conducted to provide QECH with a record of patient adherence rates. Given that the focus of my study is on the social context of patient

defaulting within the primary PMTCT clinic in Southern Malawi, calculating specifically how many women are unable to remain in this PMTCT program allowed me to determine whether or not defaulting is a problem at my main study site, and if so, to calculate the extent of the problem. The quantitative analysis addresses the following research questions: 1) What proportion of women within the study population default within the study period, and 2) Does the likelihood of defaulting depend upon age of the patient? The survival analysis is included in the Appendix.

In Appendix A, Table 6 (Patient Profile) includes all of the methods used in the study as well as a summary of patient demographics. In the following chapter, I discuss the discourse and practices surrounding women's reproductive health in Malawi, and their intersection with PMTCT programs. I discuss the meaning of reproduction to the social identities of men and women within Malawian society, and to the family and kinship group.

Chapter 4:

Local Understandings of Reproduction and the Construction of Motherhood

For most women in Malawi, fertility is central to a woman's identity. Informants in this study construct a woman's ability to reproduce as essential to the production of family. As stated by one informant, "a house without children in Malawi is useless." As such, children enable women and men to enact social identities associated with motherhood and fatherhood.

This chapter is divided into three sections. In Part I, I discuss the meaning of reproduction to the social identities of men and women within Malawian society. Part II examines kinship and community responses to women's infertility. I demonstrate the centrality of women's motherhood role to her social identity by discussing the social significance of children to marriage, kinship group and community. Part III explores constructions of motherhood, primarily from the perspective of PMTCT patients. I discuss how women in this study enact this important social role by prioritizing the caretaking of their HIV-exposed child, conceptualizing compliance as key to their mothering role. Finally, I examine the social contexts that call upon women's identities as mothers, and the consequences to her competing social identity as wife.

This chapter will include a discussion of women's experiences with reproduction and infertility. A discussion of infertility is relevant to my larger discussion of women's experiences with HIV/AIDS treatment because both health conditions share common themes of a gendered stigmatization rooted in the social obligation to reproduce. Further, each of these health conditions, in signifying a woman's reproductive role, construct infertile women and pregnant women with HIV/AIDS as failing to conform to ideals of motherhood and wifehood.

In addition, I demonstrate that the reification of motherhood has its opposite in the marginalization of women who are infertile and cannot have children. Just as women with HIV/AIDS are perceived as promiscuous and immoral, infertile women are stigmatized and mocked for not conforming to the normative constructions of womanhood. In both instances the gendering of stigma and the gendering of infertility show how gender inequities become embodied in women's health outcomes. Women are constructed as the "cause of" infertility, and the "cause of" HIV/AIDS, which may affect how they are treated by spouses, family, and community.

For the PMTCT patients who participated in this study, caregiving for the family "inside the home" and the family "in the villages" anchors her identity as a mother within the household, kinship group, community, and larger Malawian society. Gender roles for women as mothers, wives, daughters, and community members maintain that women fulfill their reproductive role to the family, kinship group, and community. For the husbands of these women, enacting the role of family provider solidifies men's identities within the household, kinship group, and community. As in other sub-Saharan societies, childbirth in Malawi procures marriage, marks the transition to adulthood for men and women, and symbolizes the continuity of the lineage (Yeatman and Trinitapoli 1999).

The data presented in this chapter was drawn from interviews with health care providers and current PMTCT patients, and focus group discussions with community men and women.

Part I: Meaning of Reproduction to Local Femininities and Masculinities

Being a mother is central to the construction of womanhood in Malawian society. Fertility is both a biological and social process, assigning women greater status within the

community for their reproductive capabilities. The meaning of fertility becomes clearer, however, when looking at how infertility is conceptualized, and how infertile women are regarded. Women experience a range of negative responses from husbands, family and community when they are unable to meet these social pressures.

Informants describe infertility as a significant social burden to women. Health care providers, community members, and PMTCT patients claim that women without children are targets for a range of social responses from the family and community. Stigmatizing discourse towards infertility may include mockery and name-calling, with such expressions as the metaphor that the woman has “fallen from a tomato tree.” Similarly, “*Ulikutayiska waka ng’ombe za kwithu*” states that a woman “wasted my father’s cattle” denoting the social and economic value of fertility as a commodity to be exchanged between lineages. More derogatory statements include, “*Ukuzuzga waka chimbuzi pano* (you are here to only fill the toilet)” (Malawi Human Rights Commission 2005).

Among some matrilineal communities in Zambia, if a couple is unable to have children the woman may divorce the husband (Poewe 1980; 1981). This kinship structure thus confers power to women within the matrilineal system through women’s reproductive power. Poewe notes that some women enact procreative power by constructing gendered boundaries around the realm of reproduction, excluding men from attending the delivery. The “interference” of males in these social spaces is “not tolerated” and men are actively “kept away” from the childbirth site while women enact the cultural authority to inspect the child’s rights to live (Poewe 1981, 46).

Poewe notes that the Bemban and Luapulan communities explicitly differentiate between whether the infertility is conceptualized as the “husband’s problem” or the wife’s. Such opportunities to challenge the source of infertility were absent among the PMTCT patients I

interviewed in Malawi where fertility is gendered and a woman's procreative power can be mitigated by a lack of reproductive potential. The notion that infertility may be located in the reproductive potential of the husband was largely absent (see my discussion of "gendering of infertility" in Chapter 7). This denial of any possibility of the husband's role as the source of the infertility is the same as that discussed with respect to the women receiving treatment for HIV/AIDS who are blamed while the husband's role is not considered. I argue that the shared source of this disproportionate stigma is another example of how gender inequities become embodied in women's health outcomes.

These women lack the power to demand divorce and find another husband with whom to have children. Moreover, some women may be replaced by another wife or *fiisi* (male surrogate) if they are unable to have a child. If it is believed that a woman cannot provide a child for her husband, he will seek another wife, or negotiate to obtain the reproductive capabilities of her sister.

Women's reproductive successes and failures are often monitored, evaluated and situated as the subject of social commentary by the local community, thus demonstrating the diffusive nature of biopower as it operates through the monitoring eyes of the community. Just as the community monitors for HIV, the community monitors for infertility, thus exercising control over their social relations and marking deviance through various disciplinary mechanisms—mocking or community gossip, marking social spaces that include and exclude, and sanctioning the abnormal with medicalizing discourses of infertility and witchcraft (Foucault 1977). As noted by Foucault, "Mechanisms of power are exposed around the abnormal individual to brand him, alter him (Foucault 1977, 199)."

Just as “friends” may mock women for being diagnosed as HIV-positive, they also mock those women unable to bear children. Informants report that those most likely to deride women for not having children are their female peers. Community responses to women’s infertility include various forms of gossip with often disparaging comments, claiming that community members “Talk a lot... a lot.” Women unable to bear children are often constructed as deviants, located at the margins of society, although there is variation in this as the following statement from a health care provider illustrates. Below, the health care provider asserts class status by constructing those who mock infertile women as lacking in education:

They are mocked by their fellow women that they can't have children. It depends on the educational level of the people you are living with because when you are living with people who have gone to school, at least they understand. But in Malawian communities we have a lot of people that are not well educated so they MOCK at the woman saying she can't produce. She can't bear babies. And the woman has a really tough time with the relatives at the man's side. (Female health care provider)

A female health care provider says “Others laugh at them when they are there and make fun of them, like when women are chatting they may laugh at you indirectly.” Another health care provider conflates the social risk of infertility with the biological risk of HIV transmission, suggesting the cultural pressure to reproduce places men and women at greater risk of contracting HIV:

They will be shouted everywhere they go. Even small children will be pointing at them, saying, “this one doesn’t give birth, this one doesn’t have a child.” And this is one thing promoting HIV infection being highly transmitted because the husband will look for a child. They don’t know why the woman is not having a child and then they will keep on searching for other women and they’ll keep on spreading HIV if they are HIV-positive. (Female health care provider)

Part II: Community Responses to Infertile Women: Pregnancy, Secrecy and Social Risk

Some women marked as infertile are marginalized by their communities by community accusations that they are witches. Women's reproductive practices are thus further shaped by witchcraft discourse employed by community members whose watchful eyes reproduce the monitoring practices of the local clinic, thus ensuring the social and biological reproduction of society. The following statements were made during a focus group discussion I conducted with men from a rural study site:

Sometimes giving birth will take place in the villages because of delays. They say even though the woman is in pain, you cannot go to the hospital during the day. You see, they do come during the night. Because of that sometimes, they will give birth right in the village when they're not planning on it.

Maybe children are told that babies are born in the hospital. So they will try to have children not know that the mother had to leave for the hospital. So they leave during the night.

Why is it during the night? (Interviewer)

There should be some form of secrecy. Sometimes you avoid the witchcraft. People should not see them going because they took some necessities. That you took things for the delivery. If they see that certain things are taken, they know that this one is going to deliver. So witchcraft can happen. Giving birth is secretive.

Why is it secretive? (Interviewer)

Maybe it's part of culture.

So if you go at night, the community doesn't see you deliver, and you are less at risk for witchcraft.

Informants living in one rural region claim the secrecy of pregnancy is maintained by not going to the hospital during the day for fear of exposing oneself to witchcraft in daylight. In this community, informants maintain that women continue to use TBAs because of the distance to the health clinic and fear of negative attitudes of health workers at the nearest health clinic. These informants describe women's reproductive health practice as requiring forms of social protection such as privacy and secrecy. At the intersection of women's biological and moral

worlds, stigma, gossip, and witchcraft discourse reinforce and reproduce normative ideals of social and biological reproduction.

Witchcraft discourse may demonstrate state power as it constitutes its subjects through the reinforcement of reproductive ideals. Such discourse may also serve as a leveraging mechanism for members of the community with little social, economic, and political power to manage social inequalities within the community (Luedke and West 2006). In her study of traditional healing practices in Mozambique, Luedke explains the witchcraft discourse surrounding the sale of traditional healing services by *curandeiros*. When these healing services begin to replace free spiritual healing provided by local churches, anxieties about social competition and the commodification of the local economy emerge (Luedke and West 2006, 82). Luedke's findings support the narrative on the "witchcraft idiom in Africa" (Comaroff 1993, 92) in which witchcraft accusations emerge during times of commoditization and economic inequality (Ashforth 2005; Lwanda 2005).

In the following comment, a teacher from a rural community discusses his family's response to his sister's infertility:

I have a sister who...that one we do think she is a witch because we always wonder with her behavior. She always says anything against those people who have children. So sometimes I can tell maybe it's witchcraft. Sometimes it's because of abortions. Others say she is being bewitched. Some may wish that she does not have children.

Does your sister think that? (Interviewer)

Even myself I do think. Sometimes I won't get in the car with her. Apart from Malawians. If you don't have a child, people look at you with some eyes. At this age, she should have a child. They don't respect you. All sorts of insults would come to you. (Male teacher)

This pattern emerged primarily within one rural community where informants framed pregnancy as a social practice vulnerable to witchcraft. These informants described pregnancy as a "secretive" act in which community knowledge of a woman's pregnancy can be leveraged

against her, leaving her vulnerable to “witchcraft.” To protect themselves from witchcraft, pregnant women will travel to the traditional birth attendant (TBA) at night, in the dark to avoid the watchful eyes of the community. If pregnant women are seen carrying cloth, basin, and soap, it is believed they are going to the hospital for delivery. One community informant describes the practice below:

There should be some form of secrecy. Sometimes you avoid the witchcraft. People should not see them going because they took some necessities—that you took things for the delivery. If they see that certain things are taken, they know that this one is going to deliver. So witchcraft can happen. Giving birth is secretive. (Male teacher)

In her study of reproductive risk in Mozambique, Chapman (2012, 222) describes a similar pattern of monitoring practices against women unable to have children. Chapman found that pregnancy evoked jealousy and distrust among envious infertile women and inquisitive neighbors who monitor the allocation of good and ill-fortune within the community. Perhaps those targeted for witchcraft are not only targeted for the social wealth they will receive in childbirth, but also for material wealth they carry as the ability to afford the supplies demanded of them at the public facilities signifies access to scarce resources.

Stigma, gossip, and witchcraft discourse related to women’s infertility serve the social function of reproducing normative ideals of social and biological reproduction which further the continuity of family, lineage, and society. The critical role of reproduction to women’s social identities is signified by community responses to women’s reproductive capabilities and infertility. Below, an informant reflects upon the local manifestation of a global pattern of gendering infertility (Van Hollen 2013), placing the blame of being unable to bear children on the wife and not the husband:

Culturally, people think that it's usually the wife who has got problems. The one who receives a lot of stress as part of this whole thing... in the community... is the wife. 'Cause even the relatives to the man or the relatives to the wife, think she is not performing in the house, it's just the way our culture has brought us up. (Male health care provider)

Infertility as Gendered Embodiment

In many parts of the world, women are most likely to be blamed for infertility (Lock and Nguyen 2010). In this study, informants suggest that women, rather than men are most likely to be blamed for infertility. Such patterns point to the gendering of infertility, where normative ideals construct women's bodies as weaker while men's bodies are constructed as embodied with "ego strength," reflecting the inequalities in gender relations between men and women.

In men—in Malawi, when it comes to these reproductive issues, the woman is mostly the one to blame. The man is infertile, the woman can be fertile, but if there are no babies in the family, the first one to be suspected is the woman. (Female health care provider)

Unfortunately, the Malawian community tends to blame the woman and not the man—they say that the woman cannot have children. So it's not a nice experience. Some people tend to look down at you like you are a failure because you aren't able to have children. You have patients who are forty who are still hoping that one day they are going to have a baby. You cannot really offer them much... they still have to prove to the community that they can have children. They would never believe that infertility is a male's problem. (Male health care provider)

The belief that wives and not husbands bear responsibility for being infertile illustrates the concept of gendered embodiment—which captures the social process by which gender inequalities become internalized (Connell 2012). For women unable to reproduce, the inability to fulfill the maternal responsibility places them at the margins of society as they have failed to reach a critical sociocultural and developmental marker of womanhood.

Current PMTCT patients, health care providers, and community members link a woman's infertility to normative ideals of womanhood. In their own words, these individuals describe infertile women as "lacking in womanhood" or "not a lady." Particularly in rural areas, these women are conceptualized by members of the family and community as "girls" who have not experienced those sociocultural rituals marking critical transitions in the life cycle of women. Such local constructions are reproduced in community sanctions that forbid women from holding a child until they have fulfilled this social role, thus marking social spaces that include and exclude, and sanctioning the abnormal with medicalizing discourse of infertility.

Other informants frame infertility as a woman's failure to enact her ultimate social responsibility—the biological and social reproduction of Malawian society. When asked to describe how the community responds to women who don't have children, one PMTCT patient framed these women as lacking in purpose and social value. She reiterates the comments of other informants when I asked her what it meant to be infertile claiming, "It's not a nice experience. ... I mean... what's the use for you being there for? Being a woman for? Things like that."

One community informant I met during my first visit to Malawi, "Evelyn," was happily married at the time to her best friend from childhood. She had a vivacious personality, and was always quick to laugh. One day I found her in tears as she was performing her domestic work. As she worked, she told me about her inability to have children, and her husband's increasing pressure to bear a child so that they could build a family. She then discussed how much she feared losing her marriage. When she recounted her husband's comment, he situated their infertility within his wife's reproductive (in)capabilities, directly implicating her failure to fulfill her marital responsibility, claiming "I have provided you with a home, where is the child?"

When I returned to Malawi a year and a half later, Evelyn had still not given birth to a child. She appeared much more subdued, and although her personality recalled her earlier vivacity and playful nature, she was clearly burdened by her worries. When I asked her in private what was bothering her, she bowed her head. Her close friend confided to me that Evelyn's husband had gone to impregnate another woman, but did not yet want to end the marriage. Evelyn was overwhelmed by fear that the marriage would eventually end, and was devastated that her husband had fathered a child with another woman.

Enacting motherhood is central to the identity of the majority of the women in this study. A woman who has failed to reproduce does not have the social capital in which to enact her responsibilities within marriage, solidify social relations within the lineage or leverage respect within the community. Where family is central to the reproduction of society, women's inability to reproduce signifies a failure to fulfill their roles as wives, mothers, sisters and daughters. Women unable to provide children for their husband fail to fulfill one of the central tenets of wifehood—to provide children to carry the husband's name. Women unable to provide children for their uncle or older brother fail to provide a *bvumwe* over which he may expand upon his social wealth. To other women in the community, women with reproductive capabilities may serve as social threats as they are known to have greater marital potential.

Similarly, men experience the social pressure to reproduce and bear children. Within the PMTCT patient population in this study, normative ideals suggest children enhance men's status by ensuring a family over which he may provide social and economic security. Informants claim that men who are unable to have children are labeled as “castrated.” As I discuss in Chapter 6, normative ideals in the construction of masculinity suggest men embody “ego strength” which manifests as physical strength and virility. “Ego strength” may lead some men to delay seeking

medical treatment unless they are very ill. “Ego strength” may also signal a man’s virility or the ability to demonstrate fertility by producing children for the family and lineage. In the following quote, a male health care provider confirms the pressure placed upon Malawian men to reproduce:

Culturally if you are a man, you should show that you have children. You should have children, it's just the way we are trained, brought up. That you should see some children... running around... (Male health care provider)

Meaning of Reproduction to Family and Kinship Group

The shifting nature of power and gender relations is evident in the structure of the matrilineal kinship system and the significance of reproduction to the social and economic power of the kinship system. Within the matrilineal kinship system, a man’s biological children belong to the matrilineage. Therefore the status and labor power of children is granted to the larger matrilineal kinship system (Crehan 1997, 92).

When describing the meaning of reproduction, community members and health care providers equated having additional children with amassing greater social and economic wealth. As stated by one informant, having more children means social “richness.” Several informants situated reproduction within a religious context, claiming that having children signifies a family has received a “blessing from God.” When asked about family size and family planning, several informants employed religious discourse, claiming that whether they would have another child was “in God’s hands.” A current PMTCT patient stated, “It will depend on what God will offer me, if it’s one, that will be the only one and if its twins then it will be those two, because I had

one but it died.” Another said “I want to have two child(ren), I want to have two child(ren), but God gives this one... This is the last born.”

According to normative ideals within communities adhering to matrilineal practices, children expand the social wealth of the lineage and enhance the status of the uncle or *avunculate*. Within both the matrilineal and patrilineal kinship systems, children signify social and material wealth, and confer greater status to the lineage. Children do so by expanding the size of the lineage and by contributing the products of their labor to the kinship group with which they live. Within patrilineal kinship groups, the birth of a child sanctions the institution of marriage. The birth of children confers greater status to the husband’s family where children are likely to cultivate stronger bonds with the father’s kinship line (Van den Borne 2005).

In communities adhering to matrilineal practices, the birth of children confers greater status to the wife’s family where children are likely to cultivate stronger bonds. Uncles within matrilineal kinship systems become more powerful as size of the lineage is equated with social, political and economic power. Therefore, the uncle’s power grows as the size of his sister’s family grows, for the uncle has expanded the lineage by expanding his clan (Van den Borne 2005). These normative ideals suggest men achieve their status through the role of *malume* (uncle) rather than that of the husband (Mtika and Doctor 2002). The social status of the *malume* is augmented by providing him with a *bvumwe* over which he exercises political, social and economic authority. The uncle exercises economic authority by providing for his sister’s children, such as paying school fees and paying for wedding costs. One health care provider expands upon this social process, emphasizing the desirability of a larger clan to a matrilineage, stating:

It means... the uncle is a bit more powerful. The tribe is growing bigger. That man has got a clan... *Aphwanga*. So he has more status.

How about if she has only one child? (Interviewer)

He will look inferior. He doesn't have any power. (Female health care provider)

Having children contributes to the social status of the household *banja* and lineage.

Situating the social value of the child within both matrilineal and patrilineal contexts, the following health care provider describes the social wealth attributed to having children. The provider links marriage and reproduction as an opportunity for female children to amass bridewealth within the matrilineage:

Other parts of Malawi they would take that as a wealth. And more especially female children. And they would say if it's female children, once they are grown up, that's why they will make little children and get married quickly. Because they expect that girl to go get married and then give bridewealth to the family. This is for the Chewas. (Female health care provider)

In the following comment, the informant explains how in patrilineal kinship structures such as that of the Ngoni, greater social value may be placed on males as boys can inherit the wealth of their fathers:

But now we have one for the Ngoni's. The head of the family is like a son, so if the woman is giving birth to only girls then the husband has to go find another woman for him to have a boy. That when the father dies the boy should inherit the wealth. I'm half Ngoni. The very same thing happened in my family. We are three. We are all girls and now my Dad is looking for a boy. (Female health care provider)

Commodifying Infertility: Multiple Wives and Surrogate Sisters

She is saying sometimes, God created us but sometimes it happens that there are other problems that can make us not to have the gift of a child. We are married okay, but the gift of a child is not there. For such people, what do they do? (Female health care provider)

The social significance within marital and kinship relations of a woman's reproductive potential is made clear in the multiple strategies employed by spouses and kinship groups to ensure that a couple will reproduce.

Informants suggest the couple and the extended family may employ a range of strategies to ensure the reproduction of the family when a couple is believed to be infertile, including use of a male surrogate or *fiisi*, appropriating the reproductive capabilities of the wife's younger sister, use of multiple wives, divorce, use of drugs/medical treatment, traditional medicine, or prayer. *Fiisi* is a cultural practice in which a male member of the community is asked to impregnate a woman who has not become pregnant in her marriage. These men serve as surrogate fathers so that a couple may have children.

In rural communities, if the husband is suspected to be infertile, the family will secure a surrogate to provide a child for the couple. However, if the wife is suspected of being infertile, the family will call for the husband to divorce her. Thus, in these communities, women are more likely to lose the marriage. Given that women are most likely to be blamed for infertility, the risk of losing marriage is particularly high for them.

In some areas of Malawi, the use of *fiisi* is practiced. While discussing the social practice of *fiisi*, some community members framed the social practice as a means for women to "prove her fertility." *Fiisi* was actively practiced in one study community, but was more commonly referred to as a cultural practice that took place "only in the north."

They will just look for any woman. And some there are some other cultural practices. They'll be like the father... the husband—the wife is not becoming pregnant. They don't know what's the reason. They wouldn't go to the hospital. They would just go to another man whom they have seen that in his family he has children. They will call him, come heal my family. You should sleep with my wife and then you should impregnate my wife. They call it as a *fiisi*. If they do the sex unprotected, definitely they will do it unprotected

because they want a child. If that man is HIV-positive, and this one if she's not, then it's infected. Those are some other bad cultural practices. (Female health care provider)

Bearing children is essential to the foundation of family and the construction of local masculinities and femininities. Therefore, seeking pregnancy outside of marriage may be a coping strategy by which women preserve the stability of their marriage.

Female teachers interviewed within a focus group discussion claim that infertile women living in patrilineal societies have considerably less decision-making power in marriage and must negotiate greater social challenges. These women are more likely to have the husband find a replacement for the wife's infertility than to have the wife find ways to compensate for her infertility, or to be divorced:

In the patrilineal type of marriage, they will tell them that the woman has contributed to that and they will ask for a second marriage. Usually they will ask for a separate marriage, maybe the sister of the woman provides the children for the family. Sometimes it might not be a sister. They may look for somebody else to carry it. Sometimes the other family, they have a baby, and it becomes difficult for them to let you hold the baby. (Female teacher)

As noted in the example above, husbands may exchange the reproductive body of his wife for that of her younger sister if she fails to provide a child early in the marriage. These younger siblings either serve as a surrogate or join the marriage as a second or third wife. Husbands may also take on a second wife if the first wife is unable to provide children.

For many of the PMTCT patients in this study, husbands often decide where a woman will give birth—at home or at the hospital. Husbands also strongly influence the number of children in the family. In contrast, for many of the professionals and nurses in the study, husbands and wives shared the decision-making authority when making family planning decisions.

Decisions related to family size are not only made by husband and wife, they are also made by the kinship group. Kinship responses to a woman's infertility may be severe, placing a woman at risk of losing her marriage. Informants claim these pressures often come from "in-laws," mothers-in-law in particular. Pressure from in-laws is most pronounced in patriarchal kinship systems where the social and material value of children weighs more heavily. The following informant situates the meaning of infertility beyond the household to the larger kinship system:

She can't bear babies. And the woman has a really tough time with the relatives at the man's side. Because the mother in law—*aphongozi*. So when you are married they are looking forward that you should have a baby in some time and when you're not producing, they are asking you, or they even ask the man to leave you, that you should go to somebody else who can have babies. So it's really like a mockery. Being infertile is not good here in Malawi. (Female health care provider)

They can tell the son to look for another woman. Would he get a new wife? Yes, he would get a new marriage. You can even be in the house while another is having an affair. Why do they want babies? They just want babies. They want babies. They want children in this house. Why are children important? They are a big asset. A house without a child in Malawi is useless. (Female health care provider)

The social and economic value of the child to the lineage is evident in the following example of a failed delivery recounted by a female health care provider in which the mother-in-law seeks to control the outcome of her daughter in law's pregnancy. Ultimately she deploys her power within the lineage to enact violence on the young woman who is viewed as withholding a child from the family and patrilineage with a failed pregnancy.

Control of the young woman's birth process begins with the decision to seek medical care from a traditional birth attendant (TBA) rather than a hospital delivery. After two failed deliveries, the mother-in-law co-opts the assistance of the TBA to ensure a successful pregnancy. The quote provides an example of the sometimes violent forms in which reproductive pressures

may be experienced by women whose mother-in-laws exert control over their reproductive health to ensure the social and biological reproduction of the lineage. By ensuring reproduction, the *aphongozi* reinforces her status within the family when the son has brought children to the lineage.

I have one example. This patient, she came from Mulange. This was the third pregnancy. The first pregnancy she started labor. She wanted to go to the hospital. The mother-in-law said no you will not go to the hospital. You will go to the traditional birth attendant. They went there, the labor was not progressing. A stillbirth. The second pregnancy, the same thing. Now the third pregnancy, they were like, “You are not giving us babies, we will chase you.” Now she was pregnant... each and every time she is pregnant her mother-in-law takes her to the birth attendant. Next time around she went there, she labored, she labored, nothing. And then the ?(descent)? was high. The mother-in-law and the TBA took an *mpanga* (knife), they inserted it into the vagina, it will bring the baby down like this (demonstrates) but they failed and then the woman had ruptured the uterus. She bled. They went to the hospital because the woman was gasping. She arrived here with offensive discharges of the uterus. We kept her for almost two months. The mother-in-law didn’t come even a single day. She didn’t come to see her. The husband didn’t come to see her. They sent a message saying, “When you are back, we don’t want you coming here because you are not giving us babies. We gave MK 5000 to your mother and to your brother, but because you are not giving us babies, we will take your younger sister.” Now, this girl was only nineteen years. The younger sister was thirteen years. I asked, “Why is it that you can’t give back the MK 5000?” They said, “We don’t have money.” I asked, “Why can’t you take this issue to court?” They said, “No, according to our culture we don’t have to do that, this is a marriage issue.” So I think ignorance also leads to some of these problems. (Female health care provider)

In the above example, fertility becomes a commodity to be exchanged between lineages. When the productivity of one body fails, it is replaced by a younger sister whose fertility repays a social and economic debt with the promise of reproductive success. This “commoditization of reproduction” illustrates the social and material value of fertility for the continuity of the lineage and of society (Chapman 2012). The reproductive value of the anticipated birth goes beyond the 5000 kwacha, to the social and material power of the family and lineage, transacted through the exchange of one reproductive body for another. Forced delivery was not a common experience

among the women I interviewed. However, it illustrates how societal and kinship pressures to reproduce interact with gender inequalities and poverty, situating the young woman in a social context in which she has little agency to assert control over her own social and reproductive power.

While recruiting women to participate in the study, one woman appeared for an interview to talk about her experiences within the PMTCT program. She had heard that a researcher wanted to talk to mothers about their experiences in the program. I often began the interview with a discussion of the baby and his or her health to take the focus off of the mother until she was comfortable. When I began to ask questions of the mother, she hesitated, then nervously offered the information that she was not the mother of this child. The infant was in the PMTCT program, but she was not the mother. She then began to tell me the story of her younger sister who had died after initiating and then stopping ARV treatment within PMTCT. At eighteen years old, the young HIV-positive patient had been in an unstable relationship with the father of her baby, and tested positive in the antenatal clinic at the district hospital. However, she had been positive for some time, and was inconsistent in her use of the medicine. The younger sister then died in labor. At 38 years old, the sister explained that she had not yet been able to have a child, but she was now proud to be the child's mother.

These extended notions of kinship are not uncommon to families who have lost family members to HIV/AIDS (Lock and Nguyen 2010). The woman above signifies the growing responsibility placed upon family and kinship to assume parenthood for children whose HIV-positive parents have died. She also signifies the social status allotted to women who have enacted their reproductive responsibilities, even if through the ties of kinship. The woman above is unmarried, and offered that she may have her own child, but clearly believed she had assumed

her social role by mothering her sister's child. It is unclear why she stepped forward to join the cohort of HIV-positive mothers, but she seemed to glow when interacting with her sister's child. It appeared that this woman's participation in the study was a tool in which to leverage power performatively—as she aligned herself with the shared social identity of other new mothers despite the fact that she was not HIV-positive, and not the mother of her infant.

Monitoring Fertility: Family Planning Movements and Donor Support

The commodification of reproduction is also evident in the state and transnational efforts to manage reproduction through reproductive health and family planning initiatives. Ideas about family and population size drive the agendas of family planning and reproductive health policy of the state and transnational donors, demonstrating how relations of power are embedded within state and transnational interest in Malawian women's reproductive health.

Social scientists have brought attention to the plight of many women in sub-Saharan Africa who are burdened by infertility, suggesting support from social networks has declined because transnational donors increasingly link economic support to state control of population growth. While state support to treat infertility has weakened, clinics are provided with contraceptives to ensure population control. In many Southern African countries, social support mechanisms such as fostering have emerged—a form of reciprocity in which the extended family procures a child for households unable to have children. This same mechanism of reciprocity provides a support system for parents when they are older.

Women's health-seeking within PMTCT programs brings attention to the tension that arises as women enact the motherhood role, positioning women's reproductive power at the intersection of a woman's role as wife and as mother. PMTCT patients must negotiate these

contradictory social roles that call upon their desire to protect their child from mother-to-child transmission (MTCT) while preserving their marriage. Navigating these contradictory roles is all the more difficult when providers view women with HIV/ AIDS as “bad mothers” as will be discussed at the end of the chapter. Again, women are constructed as failing to conform to ideals of motherhood and wifehood, demonstrating how gender inequities become embodied in women’s health outcomes. In the next chapter I show how a woman’s primary identity of being a mother challenges her identity of being a wife when she discloses an HIV-positive status to her husband.

Women’s Responses to Reproductive Pressures

Health care providers and community women claim that some women will hide the infertility of their husbands by seeking other men with whom to become pregnant. Female health care providers shift the location of reproductive power by reframing this social process as “proving pregnancy.” Finding a surrogate male with whom to conceive was framed as both a strategy through which women hide the husband’s infertility, and a means by which a woman may prove her own fertility. Teachers within a community focus group discussion stated that women may try to become pregnant with other men, bringing the child into the family as though it were the child of her husband. Women seeking pregnancy outside the boundaries of marriage do so without the awareness of the husband. For those who do not tell their husbands, the intent may be to maintain the husband’s masculine identity and to preserve marriage. There is thus a causal link between these manifestations of gender inequities—responses to infertility and responses to women with HIV/AIDS shed light on the social obligation imposed upon families to have children.

In the comment by a female health care provider below, the discourse of “proving pregnancy” depicts an agentive wife challenging the location of reproductive “failure.” In doing so, the informant creates new social spaces for women to resist the cultural practices that point to her reproductive failure. Instead of a husband or extended family demanding she reproduce with a *fiisi*, the informant constructs women as going out to prove their own fertility. Such constructions of women’s reproductive agency challenge spousal and kinship authority by preventing husbands and family from monitoring, problematizing, and exchanging a woman’s reproductive potential.

If she goes out and proves she's pregnant...she will pretend that this pregnancy is from the husband. The reason why she is pregnant is that she wants to prove whether it's her problem or the husband. Sometimes they agree to have a second wife...or *fiisi*. (Female health care provider)

Part III: Enacting Motherhood: Maternal Sentiment and Prevention of Mother to Child Transmission

As of my side, the most important thing in my life is to have a healthy body so I can work and serve my children. (Current PMTCT patient, Blantyre)

The PMTCT patients in this study clearly prioritized their social role as mothers and shaped their health-seeking decision-making accordingly. When asked why they participate in PMTCT, women expressed an overwhelming acceptance of a positive status. Women pointed to the marked improvement in morbidity and mortality for PLWA (people living with AIDS) in recent years, highlighting how those diagnosed with HIV/AIDS “are now surviving” and “leading good lives.” HIV-positive women participate in PMTCT to gain access to medication—

prophylactic ARVs, postnatal Nevirapine, and antibiotics—to extend their lives, to prevent the HIV-exposed infant from acquiring the virus through mother-to-child transmission (MTCT), and to extend the infant’s life.

The perceived significance of women’s fertility has persisted despite the damaging nature of capitalist and colonialist social forces (Walker 1995). Christian and Victorian discourse on motherhood produced notions of the “good mother” as caretaker and “moral guardian” of the family, in service of the spouse and children. While the ideals of motherhood have remained stable, researchers note that the institution has shifted with an increase in the number of single mothers having children outside the institution of marriage (Walker 1995).

For the HIV-positive mothers in this study, consuming ARVs was described as a strategy to protect children from the HIV virus and nurture them well into their childhood years. The majority of the patients interviewed conceptualize their attendance at the PMTCT clinic as key to fulfilling their role as mothers, reporting, “I am here for her/him.” Women’s desire to care for the exposed child sheds light on their most significant social role—as mothers. In this study, the enactment of motherhood largely shaped women’s decision-making processes related to PMTCT participation and women’s daily lives.

By extending their own lives, women believed that they could protect the health of their exposed infant. Thus, they conceptualized their own health as a means to care for the child, with the health of the child as the ultimate goal; these women prioritized the health of the baby, viewing their own health as secondary. These conceptualizations of mothers—the idea that mothers’ health and identity is second to that of the child—is supported by similar research on HIV-positive motherhood (Long 2009; Van Hollen 2013).

Long (2009) argues that women's bodily subjectivity is consumed by the more central role of the baby's body in HIV-positive motherhood. This study predates the universal roll-out of ARV medication in Southern Africa. As a result, the study finds that mothers' subjectivity centers on the "infected body" and what the infected body means to an infant and mother's mortality. The study also took place at a time when PMTCT was newly available, and patient survival was not guaranteed. Van Hollen (2013) finds that mothers' desire to ensure ongoing care for her children involved securing alternative caregivers to take on the mothering role after her expected death. These mothers went so far as placing children up for adoption or in orphanages to ensure they would be cared for if they themselves did not survive.

The women in this study, while sharing the same maternal sentiment and enacting the same maternal practices of caretaking, enjoy the privilege of accessing ARV medication at a time when access to ARVs is no longer limited to the wealthy.

The prioritization of the mother's body over that of the child reflects the often contested discourse of motherhood that prevailed within PMTCT programs in recent years (AbouZahr 2003). Highlighting the importance of the health of the baby, these programs were criticized for constructing the mother's body as a vessel through which an infants' health could be promoted, contributing to an erasure of the maternal body (Long 2009).

When asked why women would not want to continue treatment within PMTCT programs, several health care providers claimed that women are more likely to discontinue treatment for themselves, but do not wish to withhold treatment from their child. One health care provider explains an encounter she had with a mother who came to collect her medication for the child, but not for herself.

There was this little one of nineteen years, she was saying, “But sister, I think you can just give the drug to my baby. Myself no.” I said to myself there is nothing to what I’m doing...? If I just give to the baby and not you it means you’re not cured. After counseling, she said, “I think it’s better for me to have the drugs for my baby so that my baby should not have the same problem. But myself—no need, sister. (Female health care provider, Blantyre)

Motherhood Discourse

The future and care of my children was my main concern, now I just believe and pray to God to grant me long life so that I can continue taking care of my children. (Current PMTCT patient, Blantyre)

Discourse on motherhood reflects the dominant “norms and values” within society that constitute the social identity of the “good mother” (Walker 1995). Both health care providers and patients constructed the good mother as a woman who is compliant with PMTCT/ARV adherence, aligning the roles and responsibilities within PMTCT with representations of the “good mother.”

Women who do not participate in PMTCT or are deemed “non-compliant” are viewed by other HIV-positive mothers as mothers who “do not love their children.” Such discourse demonstrates the construction of subjectivities that enable some HIV-positive mothers to align with the dominant caregiving practices of good mothers. Thus, when seeking treatment consistently, or being “compliant,” women’s enactment of her maternal identity aligns with her identity as a compliant patient. A similar pattern was discussed in Cornwall’s (2002) study of discourse on Nigerian women’s intimate relationships. Women who construct themselves as “respectable wives” construct single women as “wayward” and misbehaving, hoping to minimize

the competition for male “helpers” (lovers) who can “spend money” on a limited few (Cornwall 2002).

Health care providers I interviewed also maintain that women’s participation in PMTCT is a responsibility of motherhood, constructing the compliant mother as one who “loves her child” by participating in and remaining compliant with the clinical obligations within PMTCT programs. Below, health care providers equate the dominant motherhood discourse of child protection with a mother’s love, at once aligning the identity of the compliant patient with the good mother:

They have accepted, “I am HIV positive,” they have understood the importance of PMTCT to protect the baby, and they love the baby. (Female health care provider)

...So I think she (current participant) accepted, and she loved the child. Those people who have accepted and they have that feeling that my child should survive, they take the medication. (Female health care provider)

While women are blamed for being unable to reproduce, some health care providers blame HIV-positive women who fulfill this social role, again placing PMTCT patients in a double bind where they are blamed for being HIV-positive and for being pregnant. Informants suggest that with the arrival of the 5A regimen, HIV-positive women are reporting pregnancies that result in uninfected infants. This new medical intervention is expected to reduce mother-to-child transmission (MTCT) by up to 90% from the previous 50% (Schouten et al. 2011).

PMTCT policy advocates that women should be provided a choice whether to have additional pregnancies when found HIV-positive (Ministry of Health 2011). However, there is a significant difference between these national and transnational ideals and their actual practice by the health care providers who implement them. Some PMTCT patients maintain that health care providers convey the notion that they are placing themselves and their future child at risk

by having additional pregnancies when living with HIV/AIDS. The metaphor of the mother's body as infecting body (Long 2009) emerges when some HIV-positive women decide to have additional children despite their HIV-positive status.

The pregnancy itself it is a problem whether you are positive or negative. Then with the HIV it is worse. Because your immunity is still low then with the HIV it becomes worse. Because ARVs, ARVs it is not treatment, the viruses they are there but they're not active, as we know. So once you give birth, you need to take care of that baby carefully, preventing that baby so he cannot be infected. Because once the baby is infected it's also a problem. She'll be sick or you'll be sick on and off. Because of the low immunity the baby is prone to infections. Because you say I have to take care of this child. After the child is grown up to 2 years, you say you I should get another pregnant. You are still risking your life and also the life of the baby. (Female health care provider)

Employing biomedical risk discourse (Farmer and Kleinman 1989), female health care providers at several clinics asserted that patients may be exploiting greater access to ARVs to facilitate additional pregnancies by which they would otherwise not be capable. These health care providers suggested that women are leveraging the presumed efficacy and scientific legitimacy of ARVs in reducing mother-to-child transmission (MTCT) to justify their decision to have more children. Grounding their statements in biomedical risk discourse, these providers assume that HIV-positive women should not have more children because of the nature of their positive status.

But others they come because they want to get pregnant. So they know, I want to get another pregnancy. I will still be giving birth because there is a medication. They want to have more children. Which is bad, which is wrong. They say, "Ah! We can just be giving birth because we are told in PMTCT that we can even have babies that are not infected. Oh, we will go and get some medication for the treatment. Because we are told in PMTCT we can even have babies that are not infected. So if we get the medication... that means...[interruption]... I can have 2 or 3 babies, who are not infected, so I can be giving birth. There is no problem, because there is medication here—I will be treated." Not knowing that they are risking their lives. (Female health care provider)

Reports of negative attitudes toward women who are HIV-positive and continue to have children also emerged in discussions with current PMTCT patients during a focus group discussion when they were asked about whether they had ever experienced stigma.

Yes they talk about us. Yes, they say look at that one, they know they have the disease and they go ahead and have a baby when in fact we didn't know our bodies were like that, we knew of it here. (Current PMTCT patient)

I was once coming for the antenatal clinic and the nurse who was supposed to check my BP before going into the examination room. She was also impolite to me. When she saw my book [Health Passport], she asked "Why do you do this? You already know you are like that [HIV-positive], why do you do this? Do you not know others die? You are just giving birth? You will die as a result of that! That can make you suddenly sick. You see yourselves as though you are okay but you are not." She said a lot and I was not happy with it, without any love! ...Yes, we do not know that we are like that, so we get disappointed." (Current PMTCT patient)

Yes, to say the truth, that is *the* biggest problem we have here. Okay. Stigmatizing us. *Stigma? (Interviewer)*

Yes. In well expressed Chichewa!

What happens for you to know they are discriminating against you? (Interviewer)

Maybe when they take your book [Health Passport] and when they just read it, the way they handle your book, what they will do.

The way they react? (Interviewer)

Right! Your friends then immediately know that there is something wrong with you. That worries you to the point that I wanted to change where to get the medication. Maybe they have a different view of us because of our status. (Current PMTCT patient)

The HIV-positive mothers, they continue to become pregnant even if they know they are positive. After the child is grown up to 2 years, you say I should get another pregnant. You are still risking your life and also the life of the baby. (Female health care provider)

I too think with the coming of Nevirapine, medication provided to infants within PMTCT programs, they think that I can bear a child, he or she will be taking the drugs, so he cannot be tested positive. And some NGOs will assist you if you bear a child. They say you can get pregnant if you are positive. At the health facilities there are health workers to assist you. (Female health care provider)

Health care providers' commentary on the perceived abuse of ARVs as new biotechnologies demonstrates how government is exercised in the form of technologies that

generate objects for management as well as new knowledge (Agrawal 2005). As technologies of power, health workers embed assumptions about the “right” mother that reflect their own sociomoral interests. Not only do these health workers assume a woman’s individual responsibility for being pregnant, they are reworking who is deemed eligible to reproduce. Yet few of these women make the choice to reproduce independently. Husbands, members of the extended family, and societal pressures to reproduce all figure into this decision.

Such attitudes toward women’s decisions demonstrates how biomedical knowledge has transformed what it means to be HIV-positive and pregnant. Having additional pregnancies when HIV-positive reveal binary constructions of motherhood in which the “compliant” mother who doesn’t place her child at risk of HIV exposure enacts maternal sentiment through minimizing risk (Scheper-Hughes 1992, 36) whereas the non-compliant mother “choosing” pregnancy fails to do so. However, the above quotes assume a level of agency that is not within reach for many of the women in this study. Negotiation of condom use is often outside of the control of many of these women, particularly those with little decision-making authority within the marriage.

Risk discourse assumes a level of control over one’s reproductive health. Furthermore, risk discourse maps assumptions of individual choice and freedom onto the attitudes and practices of patients while erasing the social and cultural context of these practices (Farmer and Kleinman 1989). Yet many women in this study have little control over their own reproductive practices when they often must prove fertility to husband, kinship group and community. As a result, many women experience a double bind in which they are blamed when they are unable to reproduce, yet also blamed for deciding to reproduce when HIV-positive.

While the majority of current PMTCT patients women viewed taking ARV medication within PMTCT as a means to ensure child survival in future pregnancies, some current PMTCT

patients did not want to have children when HIV-positive. These women point to the shifts in how some HIV-positive women conceptualize their body as an “infected body” capable of imparting harm to the health of their child with mother-to-child transmission during gestation, birth, or breastfeeding (Long 2009).

Such discourse is reproduced in the larger community. Several current PMTCT patients I interviewed reported fear of illness or death during delivery because of their HIV status. As one informant states, the community members tell them “*mufuna wofera*” or you want to die, believing that it is a danger to a woman’s health. Such discourse may point to the medicalization discourse that continues to surround childbirth, framing childbirth as a high risk biological event, which requires “pathologizing the normal” (Lock and Nguyen 2010, 50). It may also reflect a perception of a dual risk to women’s health, with HIV/AIDS and fertility perceived as dual threats to women’s reproduction and the reproduction of society.

In the following examples, patients themselves reproduce risk discourse, highlighting their HIV status as a factor in determining family size, and choosing to limit the size of their family because of the assumed biological risks associated with pregnancy for HIV-positive women. The following women construct their HIV/AIDS diagnosis as a reason to no longer continuing to give birth:

Why have you decided that you will never fall pregnant again? (Interviewer)

On my part I never thought that I would one day be HIV-positive; therefore I find it justifiable never to have another child again. (Current PMTCT patient)

Why do you want this one to be the last born? (Interviewer)

It’s because I am positive. (Current PMTCT patient)

What actually disappointed you when were found to be HIV-positive? (Interviewer)

My worries were that, I was found with the virus when pregnant, how would I deliver? After being supported, I was told there is no problem, I needed to start medications after coming with my guardian and being counseled, and when the child will be born I will

have to take medications for the child until the child is six weeks and tested. (Current PMTCT patient)

I was also worried because a lot of people say when you have the virus, bearing children is dangerous, one can die, that worried me but also I had difficulties to find a guardian since all my relatives do not stay near, until one doctor volunteered to be my guardian and that's when I felt being free since I had now found a guardian. (Current PMTCT patient)

The discussion of a biological risk of mother-to-child transmission reveals an unexpected consequence of PMTCT interventions (Ferguson 1994). As development projects, health interventions such as PMTCT may rework social relations between husbands and wives, and health workers and patients, redefining the social categories of the biological and the social. From a biomedical perspective, HIV/AIDS as a biological and social process places a lens on the dynamics between men and women within marriage and the various kinship and community actors whose political, economic, and social interests lay at the intersection of these relations.

PMTCT patients who are scolded for having additional children when HIV-positive reveal the tension in women who desire to provide a child to the family and lineage, yet at the same time are framed as poor mothers because they have exposed their future child to additional medical risk of contracting HIV. In this context, women who comply with program recommendations by attending the program to access treatment are constructed as non-compliant patients, yet are simply enacting their caretaking role as mothers, illustrating the double bind of women's competing identities of mother, patient, and wife.

PMTCT patients who comply with the biomedical standards underlying their health care are at the same time asked to take on a set of ideas and practices that are closely tied to these medical recommendations, suggesting a medicalization and re-ordering of their family and social life. For example, in Information Education and Communication (IEC) sessions designed to

promote prenatal health, PMTCT nurses broker the boundaries of women's private lives. In the following discussion, one prenatal nurse attempts to debunk traditional beliefs about reproduction that are deemed harmful to the health of the mother and baby. In doing so, she takes the opportunity to provide marital advice to the young mothers, suggesting they continue to have sexual relations with their husbands, or risk losing them. The emphasis on women's duty to provide ongoing sexual relations during pregnancy highlights the unspoken fragility of marital relations, and the normative gender roles that reproduce the gender inequalities within many marriages that I discuss in Chapter 6.

In the following discussion, a health care provider asks a group of pregnant women, both HIV-positive and HIV-negative, about the local "myths" that surround pregnancy:

(Participant): A pregnant woman is not supposed to have sex, because it might harm the baby.

(Nurse): This is a common practice, when your husbands want to have sex, you deny for fear of this, is she lying?

(Participant): No.

(Nurse): You should think about the repercussions of this behavior with HIV/AIDS around, if you are denying your husband sex where do you want him to get it from? And after you give birth you are told to stay for some four months for you to get rid of disease, the disease which you don't even know, do you think a man will wait for all those months? The man will go out and find someone with a "bible" just like yours and if that other woman is caring do you think he will come back to you?

(Participant): No.

(Nurse): And if he comes back he might come back with STIs including AIDS, then you give birth to a baby with eye problems, you now start blaming hot chilies. Usually at times like these you find that there is no love between the two of you and this is one of the contributing factors, for example I cannot feed my husband with porridge only and expect him to be happy, because the food for his "thing" is my "Bible," so you cannot deny a man sex for 6 months just because you are pregnant. (Female health care provider, health education session)

In the above interaction, women's intimate relations is conflated with ideas about HIV prevention, demonstrating how reproductive health discourse is remade as providers interject

their own ideals related to marriage and family. Further, the message “Don’t follow everything you are told” employs gendered stereotypes of men as unable to live without sex to debunk local systems of knowledge, constructing the mothers as uneducated by distancing them from an objective “truth”. In doing so, the nurse “transforms the social into the biological,” demonstrating how “development discourse becomes localized (Van Hollen 2013)” and social processes medicalized. The social relations managed in this encounter evoke the intimate colonialism of the colonial era when political officials and health care providers imparted domestic advice on the sexual relations between men and women and the socialization of children to construct an imagined ideal citizen (Stoler 1995). This same process appears in the attitudes and practices towards men and women living with HIV/AIDS. HIV/AIDS discourse reproduces sociomoral ideals within the larger society, managing the sexual relations of men and women, shaming women for being HIV-positive as they were once shamed for carrying STDs.

Efforts to guide women through the psychosocial and sociocultural challenges of marital relations again emerge in health worker efforts to assist women unable to disclose to their HIV status to husbands, demonstrating the blurring of categories of the social and the biological. As discussed in Chapter 6, during semi-structured interviews, several health care providers offered that they often helped women to disclose an HIV status to their husbands. For those women who were afraid to tell the husband, health workers would offer to tell the husband herself:

Usually what we are doing here we encourage the woman to tell the husband or if she is not comfortable to tell the husband we advise her when the husband comes she can inform us and we can do the counseling together. (Female health care provider)

Conclusion

In this chapter, I have discussed local understandings of reproduction within Malawian

society, addressing the research question: How do the barriers and supports to pregnant women's HIV/AIDS management reflect the barriers and supports in Malawian women's lives? I examine the meaning of reproduction to the social identities of men and women within Malawian society and to the family and kinship group.

I discussed the meaning of reproduction to the social identities of men and women within Malawian society. I demonstrate the centrality of women's motherhood role to her social identity by discussing the social significance of children to marriage, kinship group and community. The birth of a child in Malawian society signifies social and material wealth within the institution of marriage and within the kinship network. According to normative ideals, childbirth anchors both women and men's abilities to enact the gendered responsibilities within marriage and the larger kinship system regardless of class, education, and rural vs. urban residence.

I then explored constructions of motherhood, primarily from the perspective of PMTCT patients, demonstrating how women in this study enact this important social role by prioritizing the caretaking of their HIV-exposed child and conceptualizing PMTCT participation as key to their mothering role.

I explore how women experience a range of pressures to reproduce by family and kinship relations, and state and transnational interests. As a result, women's reproductive power is managed by multiple interests—husband's, family and kinship relations. These pressures are most pronounced when a couple does not have children. However, gender roles, relations, and inequalities reinforce power inequities when women are infertile. When faced with infertility, it is often the wife who is blamed for her inability to reproduce. Therefore, the failure to reproduce has severe consequences to women—particularly poor women, who may risk losing their marriage.

In fact, their reproductive power is explicitly enacted in their efforts to protect their HIV-positive child. The pressures placed upon men and women to have children illustrate the political economic and sociocultural significance of reproduction in Malawian society. Importantly, these pressures point to the shifting nature of power relations in the realm of reproduction as women enact their social roles as wives, mothers, community members, and patients.

I argue that women are striving to be good mothers and do so by choosing to seek treatment within PMTCT programs. In the following chapter, I demonstrate how enacting the maternal identity conflicts with women's identities as wives.

Chapter 5:

Gender Roles and Relations in Malawi

In the previous chapter, I discussed the importance of motherhood to women's social identities. To understand how gender and power relations relate to pregnant women and new mothers' experiences with HIV/AIDS management, it is important to look at how HIV/AIDS is understood within the study community, and how these constructions of HIV/AIDS may confront women's social identities as wives, challenging their ability to enact the role of good wife and mother, ultimately shaping their coping strategies and health seeking practices.

In this chapter, I discuss how such constructions situate HIV-positive women outside the social categories of good wives, creating a tension in women's pursuit of motherhood and wifehood. This tension reflects a double bind in women's health care seeking. PMTCT patients seek to protect their child's health and publicly attend the clinic to receive HIV/AIDS treatment. Yet this enactment of women's maternal identity exposes the infidelities in her marriage when her HIV status is disclosed. I examine how HIV disclosure to husbands, the most commonly reported "barrier" to women's participation within PMTCT programs, reveals larger structural issues of gender ideals, relations and inequalities, and their intersection with women's identities as mothers and HIV/AIDS patients.

This chapter describes the power relationships within marriage which give greater authority to men in the realm of economic decision-making in the household and relationship power. This chapter further explores how these power relationships shape women's responses to a positive HIV/AIDS diagnosis and health-seeking practices in clinics; as will be discussed, women's dilemmas in health-seeking behavior are often linked to gender inequities in the marital

relationship. These power and gender inequalities constrain a woman's ability to preserve her social identity as wife, when her marriage may be threatened by a positive HIV/AIDS status.

This chapter addresses the following research questions: 1) What is the impact of gender relations on women's coping strategies and program participation? 2) How do the barriers and supports to women's HIV/AIDS management reflect the barriers and supports in Malawian women's lives? and 3) How can women's treatment-seeking be used as a lens to understand how gender roles and relations affect the lives of women in my sample? The information discussed in this chapter is drawn from interviews and focus group discussions conducted with PMTCT patients, PMTCT health care providers, and community members from the city of Blantyre and surrounding communities.

This chapter is divided into four parts. In Part I, I will discuss constructions of gender in Malawi and how these constructions are played out in women's social relations within marriage and within the community. In discussing constructions of gender, I explore how gender relations are understood in the context of matriliney. I focus on the gender roles, relations and ideologies related to women's social identities as wives and their role in women's identity construction around AIDS management, discussing the impact of social norms related to sexuality, marriage and fidelity on women's identities as wives. I highlight how gender and power relations in marriage play a highly significant role in women's HIV/AIDS management.

In Part II, I discuss how these constructions contribute to or mitigate against gendered inequalities within the institution of marriage. The barriers and supports women face with AIDS management within PMTCT programs shed light on the gender and social inequalities they experience in their daily lives. While many active participants claim to have disclosed an HIV-positive diagnosis to husbands, most also claim to know other PMTCT patients unable to do so.

Health care providers and patients assert that most women who attend PMTCT are afraid to tell their husbands of their HIV status, fearing the consequences of disclosure. For many women, a positive diagnosis signals problems within the marriage and the possibility of marital conflict and divorce (Bwirire et al. 2008).

Part III explores how these constructions are challenged or reproduced by the women who participated in my study: PMTCT patients and professional women living within the study community. I discuss the tension that is created in women's role as mother, patient and wife given the importance of marriage to a woman's social identity and economic security.

In the conclusion, I discuss the implications of these gender and power inequalities on women's ability to enact wifehood as HIV-positive pregnant women and new mothers.

Part I: Defining Gender Inequalities

To deconstruct the broad concept of gender inequalities, I draw upon the work of scholars whose research examines gender and kinship relations within Southern Africa (Conroy 2013; Crehan 1997; Jewkes and Morrell 2012; Poewe 1980; 1981). These scholars point to the multiple domains within gender relations in which gender inequalities emerge and the shifting nature of power relations as women leverage power in certain domains (Poewe 1981). Within this section, I discuss gender relations across the domains of economic and political relations—control over production, reproduction, political power (Crehan 1997; Poewe 1980; 1981) and relationship power (Conroy 2013; Jewkes and Morrell 2012). My goal is to provide a more nuanced and fluid understanding of the gender inequalities facing the Malawian women who participated in my study. The discussion focuses on a description of gender constructions in marriage in Malawi, highlighting ways in which these gender constructions shape participants' narratives about

management of a positive HIV diagnosis. To understand how gender constructions contribute to or mitigate against gender inequalities in marriage, I first discuss how household responsibilities and privileges are assigned to men and women in Malawi.

Scholars of African feminism argue that Western feminist assumptions of universal male hegemony are “ethnocentric,” claiming that such a unilineal view of male power fails to map onto the African social context (Oyewumi 2005, 100; Mohanty 2003; Steady 2005). These scholars suggest that western approaches assess gender relations through dualistic frameworks which map binary categories such as private/public and dominant/subordinate onto more nuanced cultural forms. Importantly, they point to the tendency to frame all African women as “powerless” as compared to an all-powerful African male. Such representations of a homogenous group of oppressed African women with the same interests and experiences fail to capture the diversity of women’s experiences. These scholars further argue that in the African context, the experience of women must recognize the larger North/South political economic power structures that frame the micro-level power relations between men and women (Mohanty 2003).

According to normative ideals reported by HIV-positive peri-urban women, gender roles for men suggest husbands’ responsibilities center on their role as financial provider for the family. Both male and female participants in my study assert that the husband has greater economic power within the household. Resources provided by the head of the household include basic necessities such as building the home in the village or paying rent in town, feeding the family, and paying school fees. In short, community participants reported that the husband is responsible for providing for the overall economic needs of his wife and children, “finding bread for the home” and “providing shelter.” As the “breadwinner” and “decision-maker,” husbands

secure control over household resources, leaving many women limited space in which to leverage economic power.

A husband's ability to perform his role as the household provider, however, has been influenced by larger political economic changes in Malawian society which have limited many men's ability to provide economic support for their families. Such changes may illustrate how macro-level political economic forces impact micro-level social relations.

Historical and contemporary political economic changes resulting in poverty and urbanization have widened the gap between gender ideals and men and women's lived experience. In the 1990s, structural adjustment policies and food insecurity fostered labor migration as heads of families struggled to secure employment. Men faced with few options for work migrate in search of *ganyu* or day labor, or to work on tea estates to provide for their families. These political economic processes constrain normative expectations of the *amfumu*, leaving many men unable to provide for the economic needs of their family (Bryceson 2006). (See Chapter 2 for a full discussion of the literature review).

When discussing the household responsibilities of men, one community member highlights the tension between normative expectations of the husband as the "breadmaker" and the lived realities of many low income men struggling to maintain their identities as husbands and fathers who are able to provide for their families. When asked about the husband's household responsibilities, the informant talks about his responsibility to provide for the family:

But the way things are in this country affect my family a lot. Without money a family cannot go on well, these days, money cements the family. (Male community member, Blantyre)

While these gendered divisions in decision-making and economic power structure enforce differentials between husbands and wives, there are “fractures” (Crehan 1997) within these power relations which offer women opportunities to leverage their decision-making autonomy related to household management.

Role of the Matrilineage

As noted in Chapter 2, although the south is recognized as a matrilineal area, many of these matrilineal practices have declined and no longer function in the highly urbanized setting of my study.

The matrilineal kinship system further shapes power differentials between men and women, demonstrating the fluidity of gender inequalities and the dynamic nature of gender and power relations between men and women in the Southern African context.

In Malawi, the historical context of gender and kinship relations reveals a complex and contested relationship between husbands and wives within marriage, and within the institution of marriage in relation to the larger matrilineal system. It appears that larger political, economic, and social factors historically shaped social relations within the matrilineage, including the relationship between husbands and wives and their relation to the wider kinship system. Specifically, Western notions of marriage and family structures were mapped onto African family structures at a time when political and economic forces favored these new marital forms. In Malawi, Christian conceptions of the ideal family (Phiri 1983) clashed with matrilineal notions of the relationship between husband and wife (Vail 1991). Marriage has been increasingly restructured as a relationship between the husband and wife rather than a relationship between respective families (Phiri 1983).

While husbands often have greater decision-making power within the household, members of the kinship network may counter this decision-making authority, particularly within matrilineal kinship systems. For example, marital support is often solicited from the *ankhoswe*—the marital advisor and wife’s brother or uncle—if problems emerge in the marriage. It is important to note that this is one of the few remaining roles for the *ankhoswe*. Most other roles are diminished in the favor of the husband. Community members and community leaders such as village chiefs explain that husbands and wives typically address marital problems by first attempting to solve the problem by themselves. If the couple is unsuccessful, they then seek counsel from the *ankhoswe*, or marriage counselor, or from marriage counselors within the church. If the problem remains unresolved, the couple seeks assistance from the traditional authority. The *ankhoswe* is known as the marital advisor within matrilineal and patrilineal kinship systems. These members of the kinship group have significant influence over marital relations. *Ankhoswe* are initially responsible for contracting the marriage through the exchange of gifts or *chikole*. The primary responsibility of the *ankhoswe* is to assist the couple with marital conflict. There are two marital counselors within a single household *banja*—one from each side of the family. If a husband is accused of causing problems, the wife will seek support from his *ankhoswe*. Similarly, if the wife is accused of causing problems, the husband will seek support from the wife’s *ankhoswe* (Van den Borne 2005).

However, while the majority of the men and women in this study come from matrilineal kinship groups, many of the gender relations described by informants reflect a shift in matrilineal kinship structures, where vestiges of the matrilineal system persist in the context of urbanization which has altered the practice of matriliney. The majority of the women interviewed in this study came from urban, peri-urban, and semi-rural areas in the Blantyre district of Southern Malawi,

where the matrilineal system and residence patterns have been changing over time (Phiri 1983; Desai and Johnson 2005) and matrilineal practices have broken down, thus reshaping kinship relations. My data demonstrate the malleability of matrilineal kinship structures, and illustrate how matrilineality is functioning in peri-urban areas of Blantyre, where men and women have fewer opportunities to earn a living, particularly for those with little education. Consequently, these changes in matrilineal systems have heightened a woman's dependence upon the spouse for economic and social support.

In this study, one of the matrilineal structures that has remained is the support from the woman's mother. For those PMTCT patients who disclosed their HIV status to their mother, and had not moved far from their matrilineal home, their mother often served as PMTCT guardian and were relied upon for emotional support.

Gender and Household Production

Female Gender Roles

Women's contribution to household production involves a range of activities that include caretaking, household maintenance or "work inside the home," and work on the farm or "work outside the home." Each day, a wife must start her day by preparing bath water and food for her husband before he leaves for work. She then prepares food for the children and prepares them for school. After caring for husband and children, she begins her daily chores, or goes to work if she is employed. Daily household chores may include a combination of the following: hauling water, cleaning dishes, sweeping, and gathering firewood, gathering or buying food. For women living "in the village" or the semi-rural villages surrounding Blantyre, a typical day may also include cultivating maize, cassava, ground nuts and other crops in small gardens during the growing

season from January to March.

Male and female informants construct the “good wife” as a woman who takes proper care of the children and husband with her domestic responsibilities, with women’s identities centering on their caregiving responsibilities. A woman’s primary caregiving responsibility is to ensure that husbands and children “are well taken care of.” Women are trained in domestic responsibilities as young girls. Informants explain that young girls are assigned childcare responsibilities to ease the caregiving burden of mothers with multiple children. Most girls learn caregiving and housekeeping responsibilities at a young age from the mother, who models these tasks. In addition to caring for their husbands and their children, women are responsible for providing care for sick members of the extended family—the family “in town and in the villages.” When deaths occur in the family, women are expected to attend on behalf of the *banja* to maintain linkages between the marital household or *banja* and the extended family or lineage.

Women’s work burden differs in rural and urban areas. Informants claim that household responsibilities are more likely to be shared in town, particularly if the wife is employed. In contrast, informants describe a significantly greater work burden for women living “in the villages.” Women in the villages spend more time with their children as they are less likely to have assistance with childcare.

Division of Labor

To understand the power relations between men and women in marriage in this peri-urban and urban area, it is necessary to first examine control over production³ and reproduction within the household. Division of labor within the study communities aligns with the concept of

³ I define control over production to include access to and control over resources such as land and labor.

sexual parallelism or complementarity in which men and women have separate, but parallel household responsibilities. This division of labor involves an interdependence between men and women as they rely on each other's skills to maintain the *banja* household. For example, in the households in my study, husbands are responsible for clearing fields for cultivation while women are responsible for cultivation. Similarly, it is a husband's responsibility to provide his wife a home in the urban area upon marriage while it is the wife's responsibility to care for the home. Women typically have control over domestic responsibilities, maintaining the home with domestic tasks such as cooking, cleaning, fetching firewood and water, and preparing water for baths (Crehan 1997). As reported by PMTCT patients, a typical day consists of prayer, cooking, cleaning, collecting and preparing water for baths, none of which is controlled by the husband.

The concept of sexual parallelism, therefore, reframes unilineal concepts of power by suggesting that men and women, in the domain of household division of labor, may have different ideologies and interests (Poewe 1981), offering a more nuanced understanding of power relations between husbands and wives in Malawi.

Access to Land

In matrilineal communities, women typically control key resources such as access to land within a matrilineage. In Malawi, women of matrilineal descent have rights to land through the *mbumba* or female members of the family. Women, husbands and children typically cultivate their land with some families hiring outside labor if they are financially able to do so. Women often manage the daily labor of children and outside laborers (Peters 1997). However, when land is scarce, women from matrilineal kinship groups with access to land do not benefit from these kinship rights rather than become more dependent upon members of the family who earn a wage

income (Davison 1988). This dynamic reflects a shift in political and economic relations in Malawi, in which land tenure reform coupled with the diminished size of landholdings restrict women's land rights where customary land rights have been upheld, creating a climate of "intense competition over land" (Peters 2013).

Gender Roles and Socialization

In this peri-urban and urban sample, gendered divisions in labor are often learned early in childhood when fathers typically mentor sons and mothers mentor daughters in gender normative attitudes and practices. Girls are expected to help mothers with cooking, fetching water, gathering firewood, and caretaking younger siblings. Boys, in contrast, are expected to learn the trade of their fathers.

These normative gender roles are then reproduced during the main rites of passage within Malawian society. In rural areas, girls learn gender ideals for women in initiation ceremonies such as *chinamwali*. Girls whose families no longer adhere to traditional *chinamwali* attend Christianized constructions of traditional *chinamwali* ceremonies within the local church.

Women's identities as future wives and mothers are produced within such social institutions as the *chinamwali*. *Chinamwali* are the rites of passage conducted for young girls at the nexus of childhood and adulthood, taking place at the onset of a girl's puberty. Community women described a range of values conveyed within the *chinamwali* ceremony which relate to a young girls' transition to womanhood. Sexual purity and personal hygiene were the most common values imparted during *chinamwali*. Particular attention is paid to young women's hygiene during menstruation. Christian-based ceremonies reinforce the importance of refraining from sexual relations with boys and striving to complete one's education. Both boys' and girls'

initiation ceremonies stress the importance of respect for elders, particularly parents, who are to be treated “as Gods.” The theme of purity within girls’ initiation rituals signifies the historical emphasis on women’s morality within Christian discourse discussed in Chapter 2.

Several community women framed young girls’ relationships with boys as interfering with the pursuit of education. However, for many of these women, poverty, kinship responsibilities and gender inequalities interacted to prevent their continued education. Community informants, enacting their roles as mothers, shared aspirations to reinforce the importance of education to their daughters. These women claimed to downplay early sexual relations when mentoring their young girls. While these women are reproducing the values espoused by the Christian church, they may also be reinventing their own lives that were once redirected due to limited economic opportunities within the family.

In urban areas, the “kitchen party” is a public ritual honoring future brides, in which members of the kinship group and friends celebrate the upcoming wedding of the bride and groom. A central component of the ceremony is the transfer of normative values and ideals for shaping the subjectivities of women as new wives. Women are provided with a range of proscriptions for their behavior as new wives. These reinforce the importance of women’s domestic skills within the household as well as the importance of being an attentive wife. Women are taught how to maintain a clean home, how to provide satisfying meals, and how to manage their finances. The importance of fidelity and strategies to ensure a husband’s fidelity are also disseminated and reproduced within this premarital ceremony. Often conveyed with humor, women are advised to maintain an attractive appearance in the face of potential threats to the marriage from single women. These single women are assumed to be “the secretaries” and

are cast as women who may divert the attention of one's husband, thus threatening a wife's ability to secure a stable marriage.

These rites of passage signal the critical role of marriage within men and women's lives within society. *Chinamwali* ceremonies prepare young girls for the next stages of their development, shaping their future roles as mothers and wives. By imparting values of respect for parents and other elders, young women are prepared for navigating future social relations within their own kinship group as well as the kinship group of their husband.

Proscriptions for behavior in marriage are again reinforced by marriage counselors within premarital counseling sessions at the church. At a private session prior to the kitchen party, church elders, *alangize*, or family elders, guide men and women to not stray from the marriage, provide "bedroom advice" on sexual relations within marriage, and suggest communication strategies to mitigate conflict. During this session, the future bride and groom are also instructed how to cultivate harmonious relations with in-laws and the wider kinship group.

Gendered Dimensions of Education and Employment

In Malawi, access to education is gendered, with boys having greater opportunity to pursue an education. This is particularly relevant in families with low socioeconomic status, where the ability to provide education to all children is limited (Government of Malawi 2011). In many cases, the education of boys is prioritized. As a result, girls' limited education results in fewer economic opportunities, thus positioning marriage as an opportunity for economic security.

These gender, kinship, and political economic dimensions to women's access to education were described by community women unable to finish their education. Women who

worked in domestic labor in Blantyre report that their education had been cut short due to poverty—parents who were unable to provide school fees for their daughters, and uncles unable to provide school fees for their *bvumwe*, or sister’s children. For these women, marriage opportunities arose when education was no longer financially attainable. These women lamented their shortened education, but remained confident in their agency to reinvent different life trajectories for their daughters, envisioning daughters who will complete their education prior to marriage, and intending to support their daughter’s education until they met this goal.

As a mother I have the responsibility of teaching my children about our culture, and good behavior. For the matured girls, I teach them how to dress well, more especially when they are in periods. I also tell my girls to avoid making friendships with boys because they can impregnate them and make them fail their school. (Female domestic worker, Blantyre focus group discussion)

In contrast to the experience of the PMTCT patients in my study, professional community women and PMTCT nurses describe more fluid gender roles that are structured by class. Many women “in town” have maids who assist them with childcare, cooking and cleaning while they are at work. Professional women participating in community focus group discussions claimed that when they return from their professional jobs, the maid may have already prepared the evening meal, whereas the woman in the village has to prepare the evening meal “even though she is tired.” Further, women in the villages are likely to carry their children “everywhere they go” on their backs, while they cultivate the fields, cook, and clean the house. These women also take on more responsibility for “looking for food” and “securing relish” for the family to eat. In rural areas, both male and female informants claim that women spend the majority of time on the farm.

Part II: Gender and Power

Control over Reproduction

Women may also derive power from their positionality as mothers (Long 2009; Walker 1995). This is particularly true for women in matrilineal societies where children become a major source of labor and political power for the matrilineage, and husbands have little control over reproduction. Among both the Bemba and the Luapula, if a couple is unable to have children the woman may divorce the husband and will take the children with her to her matrilineage (Poewe 1981). Poewe notes that the Bemban and Luapulan communities explicitly differentiate between whether the infertility is conceptualized as the “husband’s problem” or the wife’s.

Such opportunities to challenge the source of infertility were absent among the PMTCT patients I interviewed in Malawi, where fertility is gendered and a woman’s procreative power can be diminished if she is unable to reproduce. The notion that infertility may be located in the reproductive potential of the husband was largely absent (see Chapter 4, Part II: Infertility as Gendered Embodiment). These women lack the power to demand divorce and find another husband with whom to have children. Moreover, some women may be replaced by another wife or a *fisi* (male surrogate) will be solicited if they are unable to have a child. If it is believed that a woman cannot provide a child for her husband, he will seek another wife, or sometimes negotiate to obtain the reproductive capabilities of her sister.

For many of the PMTCT patients in my study, husbands often decide where a woman will give birth—at home or at the hospital because they live far from their mothers. Husbands also strongly influence the number of children in the family. For those women who disclose their HIV-positive status to husbands, husbands decide whether or not their wife will attend PMTCT programs to access ARVs. When asked why they discussed their reproductive health care

decisions with husbands, many patients claimed that husbands provided the money needed for them to pay for transportation and occasional hospital costs. These gendered divisions in marriage where husbands have greater control over household income contribute to women's health seeking strategies, most directly when women don't have money to get to clinics, as later discussed.

A woman's procreative power is further mitigated by kinship relations within patrilineal kinship systems. In patrilineal societies, husbands and mothers-in-law have greater decision-making power in regards to reproduction. Mothers-in-law within patrilineal societies may co-opt a woman's procreative power by asserting control over the reproductive practices of younger daughters-in-law. They may have direct influence over the number of children a woman has, and may decide where a woman will deliver.

Political Power

In many African societies, women derive power from leadership positions such as religious leaders, or village chiefs (Crehan 1997; Poewe 1980; 1981). Women also have access to political power within the community in their role as officiators of girls' initiation ceremonies. *Chinamwali* ceremonies are conducted by women as they alone are believed to have the cultural knowledge related to womanhood that must be imparted to future generations of young women.

In addition, in communities where traditional birth attendants (TBAs) remain revered, women in these positions are able to leverage status within the wider community not only in their role as healer, but also as spiritual leaders. Within many African societies, traditional African religious systems historically assigned political and spiritual power to TBAs and other healers due to their symbolic role in connecting the larger community with the ancestral world

(Livingston 2005). In recent years, TBAs have lost much of their cultural power as the Malawian state has censored their practice due to fears that TBAs contribute to the country's high rates of maternal mortality (Bisika 2008).

Relationship Power

Relationship power is another key domain within gender relations from which I analyze gender inequalities. Situated at the intersection of gender, sexuality, poverty, and decision-making authority, a woman's relationship power is a site in which gender inequalities are most pronounced and most relevant to an analysis of how gender inequalities interfere with the health seeking of HIV-positive mothers. Connell's (1987) theory of gender and power is a useful framework within which to analyze the relationship between gender and power in women's relationships in Malawi. I analyze relationship power across the three dimensions within Connell's (1987) theory: 1) "Labor" (economic dependence), 2) "Power" (decision-making dominance), and 3) "Cathexis" (social norms related to sexuality).

Economic Dependence

In the following section, I discuss the social structure "labor," (Connell 1987) which focuses on how gender relations shape and are shaped by women's economic (in)dependence. This dimension of relationship power demonstrates how gender inequities are produced by unequal access to education and employment, resulting in limited economic power within the household. I discuss women's economic dependence within marital relations, recognizing how kinship and class shape gender inequalities within marriage. While earlier in the chapter I discuss how within the families of PMTCT patients, men occupy separate, interdependent, and

complementary positions of power within the household division of labor, it is clear that for many PMTCT patients, a husband's decision-making authority is rooted in his control over access to economic resources, as movement to urban areas distances men and women from their kin. Many PMTCT patients claim they often rely upon husbands for access to money, linking household decision-making with economic power. Specifically, the majority of husbands provided transport money. For those women who disclose their HIV status to husbands, they must request "transport" from husbands to access care at the PMTCT clinic. Some women reported that husbands withheld transport money because they were angry that their wife was HIV-positive. Other husbands withheld transport money because the couple was discordant. For those who do not disclose their status, they must find alternative means to access cash. Husbands typically control access to cash in the household. Thus, the decision-making authority and economic power of husbands impedes a woman's ability to freely go to attend the PMTCT clinic. These gendered dimensions of women's treatment create a potential for conflict within women's marriages, particularly for women with few economic opportunities.

Among women participating in this study, economic dependence differed by social class, particularly differences in education and income level. Interviews with community members clarified the gendered dynamics of economic power within marriage. Women who work in income generating positions have more negotiating power in their relationship, and may be less fearful of divorce. For example, while discussing decision-making within the household, community members from the professional sector, who enjoyed greater economic freedom than many of my PMTCT patient informants, described "using charm" as a tool by which they leverage decision-making power and satisfy their material needs within their relationships. These women report using charm to co-opt the husband to satisfy a wife's desire for material goods or

“luxuries” such as special cloth or clothing, lotions, or soaps. The women who employed these strategies were professionals who reported having greater autonomy in their ability to make decisions within the marriage and their ability to demand divorce. Some of these women demanded divorces from husbands who physically abused them. As they displayed their scars to me, they recounted agency, their independent decision to leave the marriage and, eventually, secure new husbands whom they happily married. When asked who usually makes the decisions in marriage, these women answered:

It depends... mostly the husband, according to our culture the husband. Nowadays because of democracy... the woman is in charge. ... The women they use charm so they can make decisions. When I say I want my husband to buy a suit, it is just because of that charm that it is working. (Female teacher, focus group discussion)

These linkages between money and marriage were looked down upon by other community women who clearly disapproved of this behavior, and who constructed these wives as “thieves” whose marriages were lacking in love (Cornwall 2002). Those who employ persuasion to secure luxuries in marriage, take from their future husbands the money or status to promote their own personal mobility.

Sometimes in town people get married not because they love the person, but because of what the person has. There are such kinds of marriages where the person is just there to steal. (Female teacher, focus group discussion)

The relationship between intimate relations and money has been widely discussed in the literature on intimate relations among African men and women (Cole and Thomas 2009; Cornwall 2002; Jewkes and Morrell 2012). Women engage in affairs to access cash for basic needs, such as through transactional sex, or to secure “luxuries” such as lotions or soaps they are unable to obtain from their husband. Transactional sex has become increasingly normalized for

women unable to find sustainable work in an economy damaged by economic decline. In fact, transactional sex is one means by which some women can leverage economic power and social mobility (Watkins 2004; Jewkes and Morrell 2012) despite the challenges of the local political economy. This economic leverage becomes a way for women to gain immediate access to money without having to negotiate the macro-level barriers of low employment and micro-level barriers to household decision-making authority.

In Malawi, the differential access to education and income has contributed to a “competition for husbands (Peters 2013). In the previous chapter I argued that community-based stigma from female peers may reflect an economic strategy by which women seek to protect their marriages from potential threats. Non-HIV-positive women may be deploying stigma to their own advantage by preserving their position within the social hierarchy. The fear of losing one’s marriage may be rooted in the context of broader political economic changes that limit women’s economic potential and increase competition for husbands.

Research suggests that the focus on women’s marital and sexual relations reflects a growing ambivalence towards the “commoditization of love” or the monetary value placed upon intimate relations (Cornwall 2002). This ambivalence may reflect a tension between idealized values and beliefs within the institution of marriage and their lived realities. This tension may also reflect the changing structure of marriage in difficult economic times as both men and women seek alternative economic means to ensure the stability of the family, whether it is through migrant labor, *ganyu*, or transactional sex.

The blurring of boundaries between marriage and money again emerges in a recent study of the use of charm and other discursive strategies as leveraging mechanisms within marriage. In her study of Zanzibari women’s marital strategies, Thompson (2013) found that wives’ claims to

love for their husbands was equated with “valuing economic security.” These women co-opt the love of their husbands through persuasive discourse that may or may not reflect true emotion, illustrating the performative nature of love when money is at stake.

The notion that some women challenge the power inequities in relationships by deploying strategies that meet their material needs is supported in research on South African women’s agency in intimate relationships (Jewkes and Morrell 2012). Jewkes and Morrell describe a nuanced understanding of power inequities in intimate relations in which young women leverage control by managing multiple boyfriends and carefully selecting those relationships that procure their material needs and facilitate greater social mobility. These young women carefully leveraged relationship power by assessing their male partners on the potential for social mobility by the gifts they received and continued or discontinued their relationships accordingly.

Decision-Making Dominance

According to normative ideals within matrilineal settings, women’s control over productive resources confers decision-making power to women within the household (Crehan 1997; Poewe 1981). In Malawi, this decision making power increases with education level and wealth. Joint decision-making is more common among urban women living in urban areas, who have a secondary education, and women in higher income brackets. In this study, such decision-making power was more common to professional community women rather than PMTCT patients.

According to the Malawi 2010 Demographic and Health Survey, men who report that wives should participate in decision-making are most likely to be older, with higher levels of education, and have higher income levels. Decision-making is also influenced by education.

Women without any education are least likely to be the primary decision maker in the household (31%). However, 48% of women with more than a secondary education are the main decision makers in the household (Government of Malawi 2011).

Women's decision-making power is also impacted by income level. For women in the lowest socioeconomic bracket, 53% report that husbands are the primary decision makers. In contrast, only 24% of women in the highest quintile claim that husbands make the majority of decisions. In terms of how income is spent, 40% of women claim that husbands decide how their earnings are spent, whereas 68% of women whose husbands have cash income claim that the husband decides how his earnings will be spent. Regarding decisions related to healthcare, 44% of women claim that husbands make their health care decisions (Government of Malawi 2011). In a recent study of Malawian women living in a rural region of Southern Malawi, 85% of women reported a "male dominated" relationship (Conroy 2014).

In this next section, I discuss the social structure of "power," or decision-making dominance within women's marital relations as reported by study participants. (Connell 1987; Connell 2012). PMTCT patients in this study describe the husband, *bambo*, as the *anfumu*, or "king of the household" and "the overseer," particularly of household spending. When asked who makes these decisions, PMTCT patients and community members constructed men as the primary decision-makers. As one male informant responded, "Women are there, but they are there to listen to what the men say." Informants describe a "superiority" ascribed to men and an "inferiority" when describing women. This gendered power dynamic is particularly common in rural marriages where most patient informants held little economic power when compared to that of their husband.

Several informants legitimize the decision-making authority of the husband by invoking the Bible, employing Christian discourse on the institution of marriage. Representations of the wife as “the husband’s helper” and the importance of enacting respect for one’s husband were offered by both male and female informants.

For the PMTCT patients in this study, husbands are responsible for most household decisions, including aspects of women’s reproductive health care. Of PMTCT patients who participated in individual interviews, over 40% reported that husbands made the majority of decisions within the household.

It's like in our culture, a man is taken as an overseer of everything. The wife has to consult the man about what is taking place. Every decision is to be by a man. (Male community member, Blantyre)

Because here in Malawi, we women are supposed to respect our husbands. So the husband is the head of the family and the decision maker and the breadmaker. Whatever we do, we have to respect them. So even in the form of taking the medication we have to ask him first. If they say no then we are not taking them. (Female health care provider, Blantyre)

Some PMTCT patients redefined the decision-making authority of husbands, asserting that the husband provides the money for health seeking, but the wife “knows what to do.” Such agentive comments reflect some women’s ability to redefine normative ideals assigning the *amfumu* as the sole decision-maker, highlighting the potential gap between normative gender ideals and their lived realities. Such comments reflect women’s ability to negotiate the social spaces in which they may assert agency within their relationships.

Decision-making dominance is particularly useful in examining where power inequities intersect with women’s sexual relations and HIV/AIDs status—particularly a woman’s HIV disclosure to a spouse as a participant in PMTCT programs. This social structure helps explain

why many poor, peri-urban patients fear HIV disclosure, perceiving few options for social and material security outside the marital relationship.

Negotiating safe sex is widely discussed in the literature on gender and HIV/AIDs (Bwirire et al. 2008; Hunter 2007; Iliffe 2006; Jewkes and Morrell 2012; Schatz 2005; Susser 2009). While I did not include questions about safe sex in my interview guide, I noticed that the issue was of concern to some women who participated in the study. While conducting PMTCT patient focus groups, I noticed a pattern of questions from the women who participated. After focus group discussions concluded, women were invited to ask questions of the nurse interviewer. One question that commonly emerged was how to negotiate condom use with one's husband. While this question was not a part of my interview guide, it points to an inability for HIV-positive poor urban women to negotiate safe sex.

This inability to negotiate safe sex parallels a woman's fear of disclosing her HIV status to her husband, reflecting the absence of decision-making power with which to maintain control over the relationship. Both social contexts, in fact, require a husband and wife to discuss the possibility of outside partners. In both of these social contexts, a woman's relationship power is diminished in terms of her ability to communicate needs because of the potential for conflict, particularly divorce. When I asked PMTCT patients whether or not their husbands were HIV-positive, many (42%) did not know the HIV status of their husbands. Some of these women reported asking their husband to get an HIV test, but were unsuccessful.

Several informants noted the gendered consequences of divorce, highlighting economic consequences as central to women's fear of HIV status disclosure. Women may hesitate to disclose an AIDS status because they fear being "chased" or abandoned. Divorce for many women has both social and economic consequences, demonstrating the importance of women's

identity as a wife. The economic effects are most salient, as many PMTCT patients rely upon their husbands for economic security. Faced with financial hardship, many women have little means to fulfill their mothering roles. As a result, many leverage economic security for themselves and their children by positioning themselves within economically stable marriages. Health care providers and community members cited poverty and the need for material support to care for children as the number one reason women may discontinue with PMTCT treatment, claiming, in the words of one such provider, that “women have no options. Where are they are going to go with their children and have food to provide their children?”

Divorce here means the husband says I have nothing to do with you, you are not my wife. So the husband goes the other way and the wife goes the other way. The man is free to marry. The lady is free to marry. Usually the man can get another wife but the lady usually cannot have other children. She has other children, so no man would be happy to take care of another man's children... most of them it's hard to get another husband. It's very, very rare. (Female health care provider, Blantyre)

The thing is, the fact that most men are breadwinners and those ladies are just housewives, so they say, “What will happen if my husband leaves me. I will be useless, I will not have food for myself or for my children.” So to be divorced is disgraceful to women. (Female health care provider, Blantyre)

Women bear not only the economic burden of divorce, but also the social one. In rural areas, women who are divorced have a more difficult time getting remarried, as many men choose not to assume economic responsibility for the children of another man in their households. A woman's status declines with divorce while that of the husband is untarnished. If the woman was “culpable,” other men may hesitate to marry her, as providing for “another man's children” is deemed less attractive to prospective husbands. A woman who does secure a second marriage may be assigned a lower status, as that of the second or third wife.

The potential to remarry for men, however, is more closely linked to a man's economic power to support a family rather than to a history of infidelity. Men who have the financial means to support a new wife are deemed marriageable because of their economic power, potentially fulfilling local understandings of client-patron relationships. According to norms in many rural communities, men with economic power are often obligated to share their wealth with the community (Watkins 2004). Consequently, men who don't "share the wealth" are constructed by members of their community as "greedy."

Thus, the consequences of divorce may be greater for women living in peri-urban areas who have few economic resources in which to maintain the health and well-being of their family, without the economic support of their husband. This is particularly true in peri-urban areas where many women are more economically dependent upon their husband. As a result, women may lose a husband upon HIV status disclosure while husbands remarry with relative ease. The sexual freedom granted to men and corresponding sanctioning of women's sexuality reinforce the power differentials which constrain a woman's agency in marriage, limiting her negotiating power to remain in the marriage when asked to leave, to demand fidelity when the husband has strayed, and to secure social and economic support to manage AIDS within PMTCT.

Social Norms

Social norms are the final social structure shaping the balance of power within women's relationship power (Connell 1987). Social norms related to sexuality help explain the power inequities within many women's relationship power. Specifically, HIV disclosure invites discussion between husbands and wives of outside partners and questions of fidelity within the marriage.

Fidelity is a normative ideal espoused by most individuals and reproduced within major social institutions within society. There is a gap, however, between this cultural ideal and its everyday practice (Watkins 2004). The problem of fidelity within marriage emerged in several discussions with community members responsible for disseminating and reproducing ideals within marriage. When asked to comment on the most common concerns addressed in marriage counseling, church elders and village chiefs cite “outside partners” as the most common concern expressed by villagers and church-goers. These community leaders argued men “going out at night” and excessive beer-drinking are practices likely to foster a husband’s ability to access outside partners. Church elders cast “men who drink too much” and engage in multiple partnerships as disruptive to healthy marital relations. Similarly, women are advised not to engage in extramarital affairs. Church leaders and elders within one’s kinship group advise wives to not become entrapped in “affairs with bosses.”

In their discussions of marriage, community informants highlighted the normative value of fidelity between husband and wife. While fidelity is an aspiration for both men and women in marriage, a husband’s infidelity is more likely to be condoned while women’s infidelity is more likely to be sanctioned.

It’s more acceptable if a man cheats. It’s alright. He’s a man, he’s allowed to do it. But if a woman cheats, it’s the end of the marriage...we all forgive our men, it’s okay to cheat. The *ankhoswes* say, if a man has cheated, you must have done something wrong. Maybe you’re not doing something right, you’re not cooking right. You’re not giving the man what he wants. I thought it would go away but it’s still stuck with us. (Female health care provider)

What marital affairs mean about men and women’s moralities is gendered, contributing to gendered understandings of fidelity. Health care providers and community members consistently claim that having affairs is condoned for husbands. Yet women who have affairs

evoke disapproval, having done something “very wrong.” Gender inequalities allow husbands to “move about” without consequence, yet wives are blamed if they have affairs outside the marriage (Watkins 2004). In fact, some informants claim that men’s ability to secure multiple partners is a marker of masculinity (Kaler 2003).

The notion of *kawerekawere* or “moving about” connotes marital infidelity, which appears to have a double standard for many women. Informants offered that there is a double standard when assigning blame for affairs outside the marriage, claiming women can’t confront *bambo* about other women. One female health care provider stated, “If the wife does the wrong thing, she will be in problem. But if it’s the husband, she will just keep quiet and keep it a secret.” It appears that wives may keep a husband’s infidelity secret for the sake of preserving the family:

For example, if this one is my husband and he finds another girl and I know it, that he is doubling me, I don’t need to go out publishing that. I have to say, “It’s okay.” I don’t have any right to say, “Hey, you are doubling me.” I’m not supposed to do that. But if I’m caught... eesh! It’s very bad. The marriage can break... (Female health care provider)

But it is our culture for women to love their husbands more, and to keep their secrets to have a good family. If you have problems in the house—it’s okay, things will be okay next time. Anyway... he’s my husband. (Current PMTCT patient)

When the man is okay, (for) this lady, it’s the end of the marriage. On the part of the husband the lady can take care of the husband. On the part of the wife, it is the end of the marriage. They say this one is a prostitute while maybe she has caught this disease while taking care of other patients. But they say this one is a prostitute. (Female community member, Blantyre)

PMTCT wives fulfill their social role by “keeping the secrets” of the husband, hiding a husband’s affairs outside the marriage to preserve the integrity of the family. Maintaining secrecy about a husband’s outside partner may reflect a passive acceptance of local norms of

fidelity. However, it is more likely women's intentions are more agentic, seeking to protect the stability of marriage to secure the welfare of their children by maintaining a family structure that ensures continued economic support. "Keeping secrets" may be an effective strategy by which women leverage a husband's economic power to procure the material, and in some instances survival, needs of their children. Women's strategic preservation of marriage procures economic stability for her children, indexing the social leverage gained as women pursue identities associated with motherhood that are reinforced by moral discourse on infidelity (Jewkes and Morrell 2012). These women strategically recognize the pivotal social and economic role of their husband, and thus their identity as wife, encouraging women to avoid divorce at all costs.

Fidelity—Intersections with Local Masculinities

Fear of a wife's infidelity was discussed by community members and some patients as a reason husbands would not want their wife to attend the PMTCT clinic at the hospital. One patient classified as a defaulter asserted that her husband's fear of infidelity was the reason she did not continue with PMTCT. Claiming that her husband believed that she was meeting another man at the clinic, this patient became one of thirteen women defaulters. The assumption that some wives are not to be trusted emerged within a focus group discussion of community men who noted that women may be seduced by another man if not in the husband's presence.

It depends on the beauty and the way you trust your wife, you can let her go alone if you doubt her behavior. Some men escort their wives for fear of other men proposing love to them. Sometimes one needs to escort his wife depending on the end you want to achieve after attending antenatal services together with his wife. (Male domestic worker, Blantyre)

While local norms of masculinity grant husbands more freedom to pursue multiple partnerships, in certain social contexts, having multiple partners may be socially rewarded. In her study of cultural perceptions towards condom use, Kaler (2003) found that young men in rural Malawi make claims to being HIV-positive to their peers to assert their masculinity. These men gain currency with their peers when claiming to be HIV-positive, even if they have not been tested. Such claims point to the social pressure placed upon men at a young age to have multiple partners to enact masculine identities.

These cultural expectations may reflect the notion of “ego strength” expressed by informants. Both in discussions related to spousal participation in PMTCT programs and in discussions about men’s health-seeking practices, informants asserted that men are expected to uphold representations of physical strength when faced with ill health. Described as “ego” and “ego spirit,” informants cite the social and cultural pressure to maintain masculine identities associated with physical strength. Informants claim local masculinities link sickness with weakness, blaming the “ego spirit” when men fail to care for their personal health or refuse to attend antenatal clinics with wives seeking reproductive health care such as PMTCT.

Most of the cultures regard the woman as a little weaker than the man. If a man says he is sick, people will say you are strong even if he is feeling pain. (Male health care provider)

While gender ideals demand a woman accepts a husband’s infidelity, husbands are expected to be intolerant of a wife’s infidelity. As a result, gendered understandings of infidelity may lead some men to demand divorce when a wife has been unfaithful. A study conducted by Watkins (2004) on transactional sex in rural Malawi found that men who are aware of a wife’s infidelity are expected to leave the marriage and request a divorce. When asked why a husband

would be angry if his wife announced that she was going to the PMTCT clinic, one man responded:

Some think that the wife was unfaithful to him or else if the man was unfaithful to his wife he could think that he is the one who brought the virus in the family, but if you are sure that you were faithful to your wife, then what is likely to come to the husband's mind is that his wife was promiscuous because extramarital unprotected sex is the major way to transmit the virus. But this is not to underscore the fact that there are other ways of contracting the HIV virus. (Community men, Blantyre focus group discussion)

While men were more commonly cast as the marital partner more likely to engage in multiple partnerships, women may also have “male friends.” Community women of higher social class admitted greater freedom when discussing their sexuality as compared to PMTCT patients. Informants rarely discussed women as engaging in outside affairs, but when probed further some framed these women as those who act “against culture.” These women are described as those who “go outside their families” by having a man friend. Thus they are constructed as women who fail to adhere to normative gender ideals which ensure the preservation of the family.

Watkins (2004) argues that the disconnect between the cultural ideal of fidelity and the practice of multiple partnerships points to the cultural practice of ties of dependence, which involves reciprocal exchanges in which an individual with economic power provides material benefits to an individual in economic need. These relationships are locally understood as forms of social security, providing individuals with the social capital that may help them in times of need (Watkins 2004).

Because it's like, when a man has money, if he can support two or more women he can do that, it's okay, it's not a problem... When it happens to a man it's not taken seriously, unlike when a woman does go out and has an extramarital affair, that woman is not very serious. (Female health care provider, Blantyre)

Part III: Women's Responses to Gender Inequalities: Resistance and Accommodation

I have tried to demonstrate the shifting nature of gender and power relations by deconstructing gender inequalities across various dimensions of power: economic, reproductive, political, and relational. I have shown that power inequities for the women in this study differ across class lines, and emerge primarily in the social structure of relationship power in the context of a changing political economy. I have explored how these gender inequities at play in marriage help explain the attitudes and behaviors of the PMTCT patients interviewed in this study.

Resistance to idealized norms may be expressed in subtle ways. In this study, contact with women was primarily through the clinic, after which I was unable to contact them due to the sensitivity of their HIV/AIDs status. However, I did have an opportunity to interview domestic workers and professionals in the community through focus group discussions. While the majority of HIV-positive women I spoke with struggled with the power inequities in their lives, I encountered a handful of women who enacted agency by leveraging relationship power within marriage. These “fractures” (Crehan 1997, 231) and “counterpoint ideologies” (Crehan 1997, 231; Foucault 1977) occurred infrequently among PMTCT patients and more frequently among the small group of professional women I included in my focus group discussions. Below I discuss the social spaces in which these “fractures” in power relations emerged.

Higher-status professional community women with greater economic and decision-making power were able to more directly challenge potential power inequities within their relationships by deploying power discursively. These women divorced husbands when the relationship was not meeting their needs, employed discursive strategies to get their social and

economic needs met in the relationship, and exhibited greater freedom with discursive strategies, joking about husbands as we chatted before and after the taped focus group discussions. The Malawian notion of “feeling free” was clearly embodied by these women who occupied a much higher position within the social hierarchy as compared to PMTCT patients I interviewed.

Conclusion

In this chapter, I explored three research questions: 1) What can pregnant women’s HIV/AIDs management tell us about the daily lives of Malawian women? 2) How do the barriers and supports to pregnant women’s HIV/AIDS management reflect the barriers and supports in Malawian women’s lives? and 3) How can women’s treatment seeking be used as a lens to understand how gender roles and relations affect Malawian women’s lives?

To answer these questions, I reviewed the normative gender roles for men and women within Malawian society. I discussed how these constructions contribute to or mitigate against gendered inequalities within the institution of marriage. I argued that power differentials within marriage and the decision-making authority conferred to husbands lead many women to remain in marriages regardless of questions of infidelity. Yet the social and economic consequences of divorce reinforce a woman’s desire to secure her marriage, and preserve her identity as wife.

A woman’s ability to enact and preserve wifedom conflicts with her ability to enact her caregiving role central to her maternal identity. This chapter considers the tension that emerges in women’s pursuit of motherhood and wifedom. Many women conceptualize attendance within PMTCT programs as central to fulfilling the mothering role, yet fear being identified with a program associated with an AIDs identity. Consequently, PMTCT participation has a social cost in which women may risk losing their marriage—an institution which procures social and

economic security critical to caring for one's children, particularly for women living in poverty, who represent the majority of those in the study population.

Chapter 6:

Local Understanding of HIV/AIDS and Community-Based Stigma

To understand how gender and power relations relate to women's experiences in PMTCT programs, it is important to look at how HIV/AIDS is understood within the study community, and how these constructions of HIV/AIDS may challenge women's social identities as mothers and wives. In this chapter, I examine how community-based stigma, the second-most common theme related to women's participation in PMTCT programs, reveals larger structural issues of gender norms and inequalities and their intersection with social norms related to women's sexuality.

In my discussion of women's experiences with HIV/AIDS-related stigma, I explore how HIV/AIDS stigma affects women's enactment of motherhood and wifehood. PMTCT patients and community members report that HIV-positive women hesitate to disclose their HIV status to the community because of the stigma they experience. This stigma, manifested in gossip about these women, is fueled by local understandings of HIV/AIDS that construct women with AIDS as immoral or promiscuous. Exposing an HIV-positive identity within the public sphere may bring unwanted attention to the problems and conflicts within the household. HIV disclosure, therefore, may challenge a woman's ability to enact the sometimes conflicting identities of wife and mother, placing them in a double bind.

This chapter addresses two research questions: 1) How can women's treatment seeking be used as a lens to understand how gender roles and relations affect Malawian women's lives? and 2) How do the barriers and supports in pregnant women's HIV/AIDS management reflect the barriers and supports in Malawian women's lives? This chapter is divided into two sections:

Part I defines stigma and explores women's experiences with HIV/AIDS-related stigma in the community, and Part II discusses women's experiences with stigma within the clinic. In this chapter, I draw a link between women's experiences with colonial biomedical treatment of STDs and contemporary experiences with stigmatization and HIV/AIDS. I discuss the relationship between gender inequities and local understandings of HIV/AIDS as they intersect with and challenge women's identities as mothers and wives in the community. I then discuss women's experiences with HIV/AIDS stigma and their responses to stigmatizing attitudes and practices encountered in the household, kinship group, and larger community.

Part I: Defining Stigma

Stigma has been defined as a “spoiled identity”—when a member of a social group who embodies an attribute perceived to be different from the norm falls outside of culturally-constructed categories of normality (Goffman 1963). Goffman argued that attributes that are incompatible with culturally-defined categories of normality become sources of discrimination within society, framing those individuals as “deviant.”

Social scientists have criticized this classic sociological understanding of stigma for its essentialist focus on individualized traits of the stigmatized and individual practices of those who engage in stigma production. This essentialist perspective problematizes individual actions isolated from their larger social contexts, thereby erasing the processes by which stigma is produced.

Defining stigma more broadly, social scientists grounded in the theoretical constructs of structure and power argue that stigma must be recognized not as an entity, but as a social process in which certain social groups construct difference, thereby reproducing moral values within

society (Parker and Aggleton 2002; Sontag 1989). Drawing upon Foucault, Parker and Aggleton (2002) note that stigma production involves the leveraging of power against particular social groups with histories of marginalization. For persons with HIV/AIDS, associations with sexuality evoke a moral discourse directed towards individuals represented as sexually promiscuous. Within regions of the Global North, these narratives of blame have implicated homosexual populations for causing the HIV/AIDS epidemic (Parker and Aggleton 2002), while in the Global South such narratives are often gendered, centering on the supposed promiscuity of women (Nyblade et al. 2003).

Women's Experiences with Community-Based Stigma

I argue that women's experiences of gender inequalities at the household level interact with their identities as mothers and wives in the community to produce a "gendering of stigma" in which women are more likely than men to be at risk of being stigmatized, experience stigma differently and experience greater consequences of stigma, thus reproducing the inequalities women face in their daily lives (Van Hollen 2013). Women are more likely than men to be at risk for being stigmatized for several reasons. This is in part due to gender relations, power differentials within marriage, and colonial biomedical discourse related to women's reproduction and sexuality.

Women's fears of community gossip are consistent with local understandings of HIV/AIDS discourse in rural Malawi. With its roots in sexual practice, an HIV/AIDS diagnosis reveals family secrets—either the sexual promiscuity of the husband or wife. Participants in my study report that AIDS "exposes sinners," highlighting the complex sociocultural processes by which an AIDS diagnosis makes public the secret relationships conducted outside the intimate

spaces of marriage. Consequently, exposing such secrets may challenge women's social identity as a wife.

Women are more likely to be blamed for bringing AIDs into the family due to the different standards of sexual morality for men and women. As discussed in Chapter 2, these gendered standards may in part be due to historical constructions of the family rooted in Christian discourse on the nuclear family that compelled women to uphold the moral representations of their husband (Vaughan 1991). Several participants invoked Christian discourse, associating an HIV/AIDS identity with a husband or wife who has sinned. As one community participant stated, "When there is AIDS in the family... someone has sinned." Other informants related gender ideals to Christian discourse framing the wife as the husband's "helper." These ideals may result in women hiding the husband's infidelity to preserve the integrity of the family.

The feeling that people has is that if somebody is in this state, he or she is a sinner. She may have contracted that through sexual intercourse. So the feeling that people have about themselves and even other people who are living with that... People say, "Look at that one, they have that thing." So usually people will run away to other places so people cannot know their status. (Female community member)

Stigma and the Structure of PMTCT Programs

Women are also more likely to be blamed for bringing AIDS into the family because of the structure of PMTCT programs. Integration of PMTCT services within Reproductive Health Services requires that women "opt out" or refuse HIV testing if they do not wish to be tested for HIV during the initial prenatal care visit, leading most pregnant women to automatically receive testing. The "opt out" policy was implemented in recent years to increase the number of women

participating in PMTCT programs. This immediate provision of HIV/AIDS testing and counseling (HTC) at the prenatal clinic consequently provides women with a diagnosis often well before the husband has had an opportunity to be tested himself. Husbands are actively encouraged to accompany their wives to the clinic. However, few men initiate HTC. This was confirmed by over 40% of the participants in this study who did not know the status of their husband.

Encouraging husbands to accompany wives to the public prenatal clinic is reported by nursing and clinical staff to be an ongoing consistent challenge for many health facilities. As a result, most women who attend the prenatal clinic for health services become aware of their status, while the husband's status is not diagnosed, leaving many women vulnerable to blame and stigmatization as the only spouse within the marriage with a positive status.

Several informants reported that some men who claim to not know their status actually do know it, but do not disclose it to their wives. These men are believed to seek treatment at private health facilities that protect them from unwanted public disclosure. Thus men able to afford care at private facilities have a greater ability to manage the public exposure that contributes to stigma production, reinforcing the gendering of stigma.

That is the main problem in Malawi, they hide it. Most of the men go in private while we ladies go to Queens. Men go to private hospitals. (Female community member)

The majority of PMTCT participants express concern that attendance at the hospital means their private lives will be revealed. In their own words, several current PMTCT patients participating in a focus group discussion claimed, "Here (at the hospital) we are exposed." Women view the hospital as the site at which their HIV/AIDS status is first disclosed to the community. As a public facility, there are many opportunities for others to learn of their positive

status. Some women meet their neighbors when waiting in line at the ART clinic. Others attend the same church as health care providers at the hospital, and are inadvertently “outed.”

Moreover, the rooms that have been set aside for private one-on-one counseling are known by the patients at the hospital as the “rooms where one receives their ARVs.” PMTCT patients claim other pregnant mothers within the prenatal clinic gossip about why PMTCT mothers enter a different room to receive medication, claiming “Everyone knows what happens in Room X.”

Therefore, attending the PMTCT clinic greatly enhances the chances that a woman’s HIV status will be disclosed to the local community. Clinical observations confirmed the allegation that women’s AIDS identity is likely to be disclosed in the clinical setting. Despite integration of PMTCT into reproductive health services, some services dedicated to AIDS treatment remain separate from other clinical services, taking place on specific days, for example, or within a unique room dedicated to AIDS patients. As a result, PMTCT patients maintain that their identities are easily revealed. Enacting the caretaking responsibilities of future mothers places women at risk of being stigmatized for their positive HIV status:

Yeah of course we are coming to the antenatal clinic. They just take you from the room and they say come to that room. As for us, we don't feel good. Those people who are staying there, (they say) why do they go into that room? Because we Malawians, we don't reveal it everywhere, “I'm HIV-positive, I'm going into that room.” Those people ask themselves why are they going into that room. It needs privacy. (Current PMTCT patient)

The “Gendering of Stigma”

The gendered experience of HIV/AIDS stigma is supported by studies of women’s experiences within PMTCT programs in other countries within the Global South (Van Hollen 2013; Nyblade et al. 2003; Ogden and Nyblade 2005). Van Hollen (2013) found that rural Indian

women who were HIV-positive mothers experienced significantly greater stigma than their HIV-positive husbands. These women were committed to a shared goal of avoiding the social and economic costs of divorce. They employed a number of strategies to hide their positive status to preserve marriage and protect themselves from disapproving kin—mothers-in-law, in particular—who sought to protect the moral representations of the lineage and exercise newly-acquired status.

In India, efforts to dismantle the gendering of stigma have become institutionalized. Health officials have changed the name of this global program from Prevention of Mother to Child Transmission (PMTCT) to Prevention of Parent to Child Transmission (PPTCT) to hold husbands accountable for their role in HIV transmission (Van Hollen 2013). These changes recognize the pivotal role of gender in a woman's ability to access treatment for AIDs, highlighting the global nature of this problem.

A study of HIV/AIDS stigma in Zambia (Nyblade et al. 2003) found that community members point to HIV-positive women's inability to fulfill their caretaking role. These women are accused of violating normative structures of women as wives and mothers by failing to enact their caretaking responsibilities and requiring care for themselves. Family members who are no longer the recipients of women's caretaking complained of the extra work burden of having to take care of wives and mothers with HIV/AIDS. The study found that households experiencing poverty expressed the greatest stigma towards family members with HIV/AIDS (Nyblade et al. 2003). This study and others illustrate how stigma is produced when members of a kinship group are unable to meet their social obligations (Kleinman and Hall-Clifford 2008).

In this study, some participants spoke to the stigma experienced by women in patrilineal kinship systems, arguing that they were more likely to suffer from discrimination from mothers-

in-law who ill-treated them for bringing HIV/AIDS into the lineage and to their future offspring. Relationships with mothers-in-law are even more contested when women are unable to bear children.

Several women in my study report knowing friends who disclosed their HIV status to husbands only to be blamed for “bringing AIDS into the family.” This is in part due to the fact that power differentials within relationships shift the blame from husbands to wives. As one health care provider states:

Usually, HIV is linked to behavior in the family, so they think that if they tell the husband they are positive, they will think the wife is the one who is HIV-positive and is the one who infected the man. So instead of (disclosing) they just remain quiet. If she keeps it secret, she finds it difficult to say “bye,” to the husband, “I am going to the hospital.” (Female health care provider)

Thus, women’s fear of disclosure may be influenced by the likelihood that they will be blamed for bringing AIDS into the family. This gendering of stigma challenges a woman’s ability to enact wifehood, as she is likely to be blamed for bringing AIDS to the marriage. Accordingly, some women assume this blame without complaint, manifesting the gender inequalities that often led to the initial HIV exposure. This process of internalization becomes an embodiment of the inequalities women experience in their daily lives, as many are often not the partner responsible for contracting the virus.

When discussing the fact that many women are blamed for the HIV status within the couple, even if the husband introduced the virus to the relationship, a focus group made up of community men appeared shocked, and clearly did not identify with a husband who would blame his spouse. As one man stated, “That is just being stupid, why should you complain of something you are responsible for? The best way is to accept it.”

Gendered Embodiment and the Clinical Phenomenon of Discordance

The clinical phenomenon of discordance, in which one partner is tested positive and another negative, is an additional site upon which the gendering of stigma is reproduced. Informants report that discordance creates significant confusion and marital conflict around who has the virus and who does not, and more specifically who will assume blame for the virus. Health care providers and patients maintain that a woman positioned within a discordant couple is likely to be blamed for bringing the virus into the family if the wife has been found positive and the husband has not yet seroconverted, meaning that he has not developed antibodies to the HIV virus which allows for its detection.

Discordance often evokes fears of infidelity when both partners are not found positive. While conducting participant observation at a rural ART clinic, I met one couple who had received their HIV test results. The wife had brought the husband in for testing because she had questioned his fidelity. When the couple received their results, the husband tested negative and the wife positive, yet the husband had been the partner accused of infidelity. The wife appeared confused by the results, declaring they were not possible. When the health care provider explained how the virus seroconverts to demonstrate the “window period,” she remained unconvinced. The husband, looking surprised himself, proudly co-opted his test results with the biomedical knowledge that temporarily exempted him from further accusations of infidelity.

And also there is a problem with the discordant couple—the mother positive, the husband negative... so... to say that I’m going to the PMTCT clinic it’s difficult for the husband. But others they understand. You are negative, I’m positive.

Why is this a problem? (Interviewer)

They don’t trust each other. (They think) my wife is not faithful to me! Why am I negative? Maybe she is seeing somebody. So, to start using those condoms and the like because they are advised somebody is negative and somebody is positive... they cannot just be sleeping together. (Female health care provider)

Forms of Stigma

Participants in my study report multiple forms of discrimination toward women with HIV/AIDS. Common practices include ridicule and accusations that are often made public by members of the community. Several patients cited these forms of stigma as reasons to fear the public and private spaces where they may experience discrimination. These practices included mocking, name-calling, and pointing fingers. Other informants suggested that persons with living with AIDS (PLWA) experience various forms of social exclusion that deprive them of public services or benefits. These included exclusion from receiving fertilizer coupons, and exclusion from receiving loans to start small businesses.

Some women experienced social exclusion structured by fears of contagion. Women reported that some community members continue to fear contagion, forcing some PLWA to eat alone, and as observed within rural communities, some lose their homes when they are rejected by their families. While conducting participant observation within positive living support groups for PLWA, two women were seeking housing from anyone in the community. Family members had “chased” them from the extended family because of their positive status. Less commonly expressed, one woman reported that family members with which she lived would not address her medical needs, and even withheld food. Informants described the social exclusion associated with stigma by employing the concept of being “sidelined” or excluded from the social group and no longer considered as members of the community. Below a twenty-year-old informant speaks of her family’s reaction to her AIDS status. The quote illustrates both a social process in which she is moved to the margins of society and an altered identity in that she is no longer perceived to be a member of the kinship group and, at times, is treated as less than human:

I love my mother so much because when I am sick she doesn't leave the house, even if she receives a message from the church. She has a responsibility at the church. She tells them, "My child is sick." While my father works and he starts off early in the morning, leaving me groaning... and when he comes back he does not even care to come to see how I spent the day. The younger ones are the same. When my mother is away, I can spend three days without a bath, they eat their *nsima* right here without sharing with me, so I see that the person who loves me is my mother. (Female patient)

Men's experience of stigma is different from these forms of stigma experienced by women discussed above (Van Hollen 2013). As discussed in Chapter 5, local conceptualizations of masculinity allow men to engage with multiple partners. An HIV status for women, however, contradicts the normative moral representations they are expected to uphold. While exploring contemporary constructions of HIV/AIDS, I learned that a double standard of morality censors women's ability to have multiple partners, yet condones that of the husband. I found that the nature of HIV/AIDS as a sexually transmitted disease evokes ideas about sexuality, fidelity, morality, and relations between husbands and wives—concepts that are central to how marriage is understood and practiced within Malawian society. Connell's (1987) theory of gender and power explains how these social norms limit ideas about women's sexual behavior, as attending the PMTCT clinic signifies an HIV/AIDS identity to the community and subjects women to allegations of promiscuity from community members who perceive an HIV status as a violation of sociocultural norms.

According to health care providers and PMTCT patients, good mothers are compliant patients—they attend the clinic to collect their medication and treat themselves and their child. Yet these mothers must manage community-based stigma when their fidelity and morality are questioned upon HIV status disclosure, causing tension in their roles as mothers and wives. Women's fear of community-based stigma is well-founded, given local understandings of AIDS tied to women's sexual behavior and their intersection with the gender roles and inequalities

shaping women's sexual behavior. Informants suggest that women who are found to be HIV-positive are labeled as "prostitutes," violating local constructions of faithful wives and protective mothers.

The experience of stigma not only varies by gender, but also by class. Wealthier members of the community may have greater agency in their ability to hide their positive status from the larger community. Some informants discussed health seeking by professional men whose practices diverged considerably from the dominant demographic in this study—women with limited resources. "Well-known" members of the community enjoy greater privacy in their treatment seeking. One informant described two church members who traveled to South Africa to access medicine privately. Similarly, a health care provider described a patient who arranged for special services to attend the clinic during off-clinic hours to collect his ARVs. One dominant strategy that took place across class lines was the practice employed by all patients—accessing PMTCT or ART services at multiple clinic sites far from home to hide an HIV/AIDS identity.

Positionality, AIDS Gossip and Performing the Good Wife

PMTCT participants, health care providers, and community members stress the potential for community members to spread rumors or gossip about their AIDS status. PMTCT participants carefully defined those who were to be entrusted with knowledge of their status, and those who were not. The majority of women interviewed clearly articulated distrust of female "friends" and female community members. The majority of informants explained that the community members most likely to engage in stigma production are other women.

While holding a focus group discussion with current PMTCT participants, I asked women whether they told friends or members of the community of their HIV/AIDS status. A

chorus of all the previously quiet participants answered loudly with a resounding, “NO.” When questioned further, women claimed other women discriminated against, stigmatized, and “mocked” members of the community. Patients clarified that women who shared their HIV-positive identity did not mock them and instead were sources of support. These women are understood to be a potential source of social alliance not only in their capacity to not stigmatize, but in their shared identity as HIV-positive mothers. I witnessed this during the focus group discussion. Women who met each other for the first time at the focus group developed friendships, shared advice, and sometimes returned to the PMTCT clinic together.

PMTCT participants stressed their fear of being the target of stories discussed by “chatting” neighbors. Persons deemed safe enough for status disclosure were described as those who “can keep the secret.” The majority of participants admitted:

The only friends who know are only those that are also receiving medications too, because we keep each other’s secrets. These women are the only ones to be free with as others will just talk about you. (Current PMTCT patient)

No, we are unable to tell friends. You know Malawians, this is the way they feel. If you are shaking hands, (they say) she is HIV-positive, she can transmit it to us, so we shouldn't chat with her. Most Malawians do not reveal what has happened to them when we are talking of HIV/AIDS. That's what we Malawians do. (Current PMTCT patient)

Another participant described her shifting positionality on the boundaries of AIDS stigma production, admitting she once gossiped about other HIV-positive women until she was found HIV-positive. Claiming she was “one of these women who talk rubbish things,” she claimed she would never tell friends of her status, because she knows that “people talk.” From the perspective of one who “spreads the news,” she claimed, “Maybe I was too much talkative... meeting with other people in the church...”

Stigma production included various forms of “discourses of blame” (Van Hollen 2013). “Spreading the news” or gossiping was the most common form of stigma feared by PMTCT patients. Gossiping is described by informants as a rampant “problem within our communities.” Informants claimed people in their community “have a problem” by “talking a lot” and “spreading the news” of an AIDS status to other members of the community. These transgressors “broadcast when you have the virus” and were cast as individuals who “lack discipline.”

Manyazi or “shyness at being seen by others” was the most common discourse used to describe women’s perception of stigma or “felt stigma” production from the larger community:

There are so many things, even with those that you chat with in your neighborhood, the chatting starts to change, and one notices that change, and some may say, “Oooh you are on medications!” (Current PMTCT patient)

Spreading rumors about the sexual practices of other women may reflect the construction of HIV-positive women as a potential threat to one’s marriage. In a study of HIV-positive women living in urban Nigeria, Cornwall (2002) found a similar pattern of social commentary on women’s sexual practice in which community women engage in extensive gossip about the sexual practices of other women. These women would express dismay, problematizing and demeaning the “wayward women” found to be promiscuous. Such performances construct and reinforce a social identity of the good wife whose subjectivity is further realized when compared to the sexual practices of women who “stray” (Cornwall 2002).

Such “discourses of blame” pervade women’s gossip about the perceived sexual practices of their fellow women, creating social distance between the imagined and the “spoiled” identity (Goffman 1963). As an individual and collective process, the identity of women as mothers and wives intersect, and are either contested or reproduced by a woman’s presence at the PMTCT

clinic (Cornwall 2002). This intersubjective process allows certain identities, such as the unfaithful wife, to gain traction when witnessed by other mothers and wives.

Part II: Health Care Provider Attitudes within PMTCT Programs

“Even us we are not angels, but we try to help.” (Female health care provider)

Just as women fear being constructed as promiscuous by friends and members of the community, they fear accusations by the health care providers who serve them. It appears that social class interacts with stigma by positioning women living in poverty as the recipients of stigmatizing processes at the clinic. Poor attitudes and worker burn-out lead to interactions between health workers in positions of power and HIV-positive new mothers living in poverty that result in further marginalization of HIV-positive women. This mistreatment, while not rooted in stigmatizing attitudes about HIV/AIDs, ultimately contributes to stigma production, thereby reproducing inequalities. This mistreatment illustrates the double bind when health care providers expect women to comply with treatment, yet punish them for being compliant when seeking health care at the clinic.

Unlike the wider community, health care providers do not blame their PMTCT patients for being HIV-positive. Many health care providers maintain that women obtained the HIV virus from their husbands. Further, many appear devoted to their work, employing multiple strategies in which to assist their patients, going so far as to help women disclose their status to their husbands. These providers go to great lengths to assist women in maintaining confidentiality related to their status. Some nurses enact new identities when conducting outreach, disguising themselves as “relatives from the north” to minimize the likelihood that gossiping neighbors will stigmatize the woman in the community and disclose her status to the husband. However, the

sometimes “rude behavior” by other health care providers reproduces the very marginalization women experience when facing stigma in their communities.

Several women report negative interactions with some of the health care providers, claiming that nurses and other health care workers “sometimes do not talk to us nicely.” Participants admitted feeling “scared” coming to the clinic because of the manner in which they had been received by providers. Women report being shamed by nurses in front of other women, asserting they want to “feel free,” and “to be talked to with respect.” Some participants asserted they were “pointed at” and spoken to as though they were “the most sinful person.” During a focus group discussion, some participants reported that health workers were stigmatizing them, “in well-expressed Chichewa.”

In a similar vein, patients expressed disappointment in the attitude of health workers and how patients were treated when attempting to access ARVs. Several women maintained that workers were “angry” with them, revealing the pressures they face when managing a heavy patient load. One community member not only heard of such mistreatment, but witnessed it himself at a nearby clinic, noting that men are not immune to the stigmatization of AIDS patients. Below a teacher describes a conversation with a health care provider friend:

Nowadays it's just an assumption that sometimes these women stop taking these drugs because of the conduct of the staff there. (My friend says) “These are the people who are taking ARVs. All of your friends who are taking ARVs are there... they go over to that side!” So I was concerned with this message. Instead of keeping secrets, his was publicized. So sometimes even men, not only women, they stop taking the drugs because of the way they are handled by the medical person here. (Male teacher)

Women’s experiences seeking treatment for HIV/AIDS parallels women’s clinical experiences with STDs during the development of the biomedical health care system in Southern Africa. Health-seeking for the treatment of sexually transmitted diseases was a humiliating and

shameful process in which both men and women were ridiculed by colonial administrators for “naively” stepping forward to seek health services. A discourse related to African men and women with STDS as “lacking in shame” was reproduced in the attitudes and practices of colonial health officials who attributed this health seeking compliance as a “perverse African sexuality.” Colonial and missionary clinicians’ emphasis on cultivating shame in patients was deemed necessary for “a new moral code to succeed” within the British colony (Vaughan 1991, 148).

As discussed in Chapter 2, many of these attitudes persist today in the gendering of stigma experienced by PMTCT patients as mothers and wives living with HIV/AIDS. Local understandings of HIV/AIDS tied to morality and women’s sexuality are historically rooted in the history of STDs in colonial Malawi (Vaughan 1991). I argue that *manyazi* (shame) has been reproduced discursively and is well alive today in the treatment-seeking of these women living with HIV/AIDs.

PMTCT participants’ alleged mistreatment by health care providers emerged in one primary context: when the patient attends the clinic late or at a time outside of designated clinic hours. Informants claim that health workers sometimes mistreat PMTCT patients when they do not show up at the clinic at the designated time. Observations at one facility confirmed that patients were scolded by health care providers when arriving late to the clinic. With few resources available, clinics are often held in rooms with limited space. As a result, private conversations are a challenge. Patients waiting to be seen by health care providers often fell silent when other patients were scolded for clinical missteps, listening carefully to the nature of the accusations, perhaps to avoid future public shame.

Mistreatment of patients may signal the broader issue of resource limitations within government-funded health facilities. While many health care workers did not reveal the causes of their work stress, one theme that continued to emerge from interviews and clinical observations was the work burden faced by many health care providers within the government-run health care system. Often health care providers worked in circumstances in which staff numbers were lower than required.

PMTCT nurses work on the forefront of care for HIV-positive pregnant and lactating women. As those most directly involved in women's reproductive health care, they are one of the few with access to the intimate knowledge of a woman's HIV-positive status. These nurses play a critical role in women's AIDS management—brokering the boundaries of a woman's physical and psychological health. As agents within PMTCT programs, nurses are responsible for imparting all information related to AIDS management in HIV-positive women and their exposed children.

PMTCT nurses are powerful socializing agents. In addition to the health education provided to mothers, women are counseled on family matters that often intersect with a woman's participation in PMTCT. PMTCT nurses guide women through many of the major stages of motherhood: proscribing maternal practices during pregnancy, delivery, and breastfeeding. In addition to proscribing women's practice as mothers, nurses guide women through particularly sensitive issues within marriage—the discussion of one's HIV status and confrontation with infidelity. Claiming that many women refuse to share their HIV/AIDS status with their husband, nurses often guide women through the social and emotional challenges of communicating a positive status to their husband. For women who are afraid to disclose their status to their

husbands, nurses often offer to intervene on behalf of the mother and to tell the husband of his wife's status.

Finally, nurses “keep women's secrets.” Nurses are one of a select few individuals in a woman's life with knowledge of her HIV status and the marital challenges that often result from this status. For some women, the PMTCT nurse may be the only person that is aware of her condition. This sensitive role requires considerable trust in the health care provider and is often strictly guarded with professionalism. Thus, PMTCT nurses negotiate women's public and private worlds, aware of a woman's positive status despite women's desire to keep this knowledge secret.

While some PMTCT nurses evoke fear in patients, they also work diligently to promote the health of women and their infants. Many of these women have dedicated decades of their lives to a profession they deeply respect. Efforts to promote patient adherence are rooted in a professional and personal dedication to serve the health of HIV-positive women and infants. One nurse captures this sentiment in the following discussion of the struggle to serve HIV/AIDS patients in 2005—a time prior to the provision of free ARV medication. Her comment sheds light on provider awareness of the failures of transnational development processes such as the provision of pharmaceuticals, whose sustainability remains uncertain:

For most of us, there is poverty here in Malawi. (Before free ARVs) only those who were rich were able to live. Now... they are healthy. We just want to ask those who are giving us these drugs to continue. If they continue, we will thank them. Do you think it will continue? Because if it stops, Malawians will die. (Female health care provider)

Women's Coping Strategies

PMTCT patients in this study engage with and reinforce a “culture of secrecy” that surrounds the experience of patients with HIV/AIDS (Van Hollen 2013). Efforts to avoid stigma

included traveling to distant clinics where patients did not expect to encounter relatives, friends, or members of the community.

Unique to this group of women was the extent to which they strategized to keep their positive status from the watchful eyes of husbands, neighbors, and the kinship group. PMTCT patients in this study used a number of creative strategies to keep their positive status secret, hiding those “stigma symbols” that revealed their positive identity. For many of these women, the primary strategy employed to remain within PMTCT was to creatively hide a positive status and health seeking practices from husbands and their community, so that they could access treatment within PMTCT. Such strategies included hiding their ARVs in the flour bin or in holes in the ground outside the home, buying blank Health Passports (medical record books), and not selecting PMTCT guardians to accompany them to the clinic. The following practice was consistently reported by PMTCT patients and community members:

I understand due to some... maybe fears, people don't want people to know that they are taking the drugs. I have heard of people traveling from here to maybe (distant town) just to take the medications. Now just suppose that person has no money... their life goes on... They want to keep the secrets to themselves so they will need to travel to that place. (Male community member)

The most common strategy leveraged by women to avoid experiencing stigma and discrimination is the practice of hiding an HIV/AIDS status. Not disclosing an HIV status provides them with increased agency to negotiate the challenges of their daily lives. *Manyazi* or shyness was one of the most common responses to the question, “Why would a woman not want to attend PMTCT?” *Manyazi* may not so much reflect a fear of stigma, but a fear of losing control over one’s marriage, an institution that secures a woman’s social status, and, more immediately, ensures her economic survival.

Fears of unwanted disclosure were confirmed when conducting participant observation. At the beginning of the study period, PMTCT participants were provided with a 2kg bag of flour (*ufa*) for their participation. After consulting with local colleagues it was believed that a bag that was any smaller than 1kg would be insufficient as a token of appreciation. When participants were offered the 2kg bag, all refused the flour, despite the low socioeconomic status of many of the women. Only when the 2kg bag of flour was replaced with a smaller 1kg bag which would not attract attention, did women willingly accept the flour. Several women who had initially refused the flour returned over the next month to collect it.

PMTCT participants also remarked on the potential for stigmatization when carrying a Health Passport, patient medical files which bear the stamp of a positive status. Health care providers and community members claim that many patients buy an extra file—one contains information about the HIV-positive diagnosis while the other does not. Having two Health Passports allows women to control who has access to her HIV/AIDS diagnosis. When asked by clinic personnel why information is missing, some women claim to have lost their file. A patient remarks below on how the Master Card used at the clinic reveals her AIDS status:

We are given cards which we can't hide because they are big when they see us with these, they know we are here to receive medications. Just like how it is at the ART clinic, when they see you lined up, they know you are there to receive medications, I don't know how this can change. (Current PMTCT patient)

Several health care providers commented on the confusion created when a patient presented a Health Passport (medical file) without their HIV status—a file that had been bought for the sake of the current clinical visit. When I asked how women hide their status at the clinic, nurses and doctors claimed that patients buy multiple Health Passports, gaining some control

over their status disclosure. As stated by one nurse, “They have two books. Three of them. The other book they use antenatally. The other book is special for the ARVs.”

While stigma production as an obstacle to PMTCT participation remains formidable, women engage in a number of creative coping strategies to navigate barriers to PMTCT treatment. For some women, support from mothers, husbands, or church counselors provided the necessary support to ensure success with health seeking.

For those women who disclosed their HIV status to their mother, the mother served as a key means of social support. A few women maintained that mothers served as their PMTCT guardians, a buddy system in which PMTCT patients are asked to bring a family member, preferably one’s husband, to the clinic to ensure their adherence. Women shared their HIV status and their health-seeking at the PMTCT clinic with few individuals. In this study, patients cited their mother as emotionally supportive when disclosing their status, “encouraging” them when they needed support after receiving their diagnosis and initiating treatment.

Several current participants cited husbands as a source of economic support. This was most relevant for women living in the rural region who self-described as “housewives.” For those fortunate to have supportive relationships, husbands were a source of emotional support.

One current patient was unique in her claims to have been transformed by her HIV diagnosis. Moving from marital infidelity to marital harmony and religious atheism to religious devotion, she remains one of the very few informants strengthened by her HIV/AIDS diagnosis, and one of the few who expressed having a supportive spousal relationship upon disclosure. Citing support from a devoted husband, her relationship was transformed from one of marital infidelity to marital harmony after her husband confessed to having an extramarital affair. The

couple sought support from a local church and received marital counseling that strengthened their marriage and converted both husband and wife to religious practice.

Attending positive living support groups is another means by which PMTCT patients could cultivate support to counter stigmatizing practices in the community. While visiting one Positive Living support group⁴, I met a second patient who successfully remained within PMTCT. When asked about how her life was different now that she was on ARVs, the woman recalled her initial failed health, and a corresponding inability to cultivate her home garden because of her ill-health and immobility. Shortly after her husband left her, she joined a national support group for PLWA, claiming she “no longer crawled to the garden.” She met an HIV-positive man who soon became her husband. While describing her recent good health and well-being since starting ARVs, she demonstrated a vitality and gratitude for health through a celebration dance in front of her fellow PLWA.

While women appear to experience the majority of stigmatizing practices from other women, they seem to derive considerable emotional support from other HIV-positive mothers who share a collective identity as mothers and HIV-positive patients. Positive living support groups have emerged throughout Malawi to promote the principles of self-governance of PLWA by PLWA. Some of these groups provide, in addition to counseling by other PMTCT mothers, a forum in which HIV-positive new mothers can reconstruct shared experiences of gender inequalities, stigmatization, and other forms of HIV-related social marginalization. Focus group

⁴ Like other surrounding countries in southern Africa and across the global South, rights-based advocacy organizations (brought by NGOs) have emerged to challenge and mitigate the stigma experienced by many patients with HIV/AIDS. These organizations deploy community-wide campaigns to sensitize, mobilize and transform social perceptions towards HIV/AIDS. One of the underlying incentives of the programs is to encourage the community to test for HIV as well as to discourage stigmatizing perceptions toward the illness and more importantly towards persons living with HIV/AIDS.

discussions and conversations with these women were lively and often punctuated by women sharing information about employment opportunities and education opportunities.

Conclusion

In Malawi, as in other parts of the Global South, HIV/AIDS stigma has been a persistent social problem since the onset of the HIV/AIDS epidemic. Early representations of HIV/AIDS often linked individuals with marginalized groups such as sex workers, who were often blamed for perpetuating the epidemic. I have found that local understandings of HIV/AIDS continue to be linked with stereotypes of prostitution and unfaithfulness. These stigmatizing notions of AIDS may persist because of the historical context and discursive power of biomedical discourse towards the treatment of sexually transmitted disease as a condition associated with promiscuity. These historical processes—the production of an African women’s sexuality and its intersection with the history of STDS—contrast with historical and contemporary understandings of motherhood and wifehood, challenging these social identities. Consequently, the tension between these identities reinforce unequal power relations and community-based stigma toward mothers living with HIV/AIDS.

In this study, I found that PMTCT patients relied upon more subtle forms of resistance to the power relations that structured their PMTCT health seeking, deploying secrecy to evade marital conflict and community-based stigma. Such strategies enabled these women to preserve marriage and attend PMTCT to meet their maternal needs to protect the health and well-being of their child. Situated in the public sphere, it is clear that the infrastructure of the PMTCT clinic itself intensifies women’s vulnerability rather than protecting them from community-based stigma. While deploying secrecy may be understood as a passive reaction to power inequities, I

argue that it is a performative act that allows women to resist the power relations that threaten their ability to retain their marriage and protect their child. Buying blank medical files, seeking care at distant clinics, asking strangers to serve as guardians, and providing false addresses to health workers who visit them in their communities to ensure ARV adherence allows patients to creatively resist the biomedical and gendered dimensions of power that shape their social relations.

Chapter 7:

Dissertation Conclusions

While conducting clinical observations, I attended a PMTCT clinic in Lilongwe. I noticed a patient reject an intrusive gaze by a few health care workers as she interacted with the clinician. A well-intentioned clinician asked, “Why did you not take the ARVs?” At that moment, the boundaries between public and private sphere became blurred as the private world of the patient was met with the eyes of three health care workers who stopped their tasks to listen to the response. The woman’s eyes stayed focused on the clinician whose question initially flowed with the rhythm of a routine medical history-taking. After some silence, the woman offered an agentive reply: “*Ndataya pansi mankwala*,” or “I dropped them.” What had begun as a dialogic interaction between clinician and patient expanded to include a much wider audience as the eyes and ears of the greater community seemed to wait for the response of a woman who effectively resisted transgressions into the sanctity of the private sphere. Acknowledging the patient’s reconstruction of self as subject, the clinician accepted the subtle challenge to her authority. She then moved on, engaging the woman’s infant before continuing on with the routine medical history. The curious health care providers and community members who had turned to listen to the exchange returned to their tasks and conversation.

Stories of such acts emerged while conducting fieldwork in PMTCT clinics and various community settings in Malawi. Patients, community members, and health care providers reported a number of strategies women use to manage their social relations as HIV-positive pregnant women. As discussed in Chapter 6, patients and health care providers report that some women hide ARV medication from husbands, family, and the community. At home, some women hid

ARVs in the flour bin or in the ground outside the home. Nurses reported that after PMTCT clinics, they would find ARVs in the toilet and under pillows after women had delivered. Other women strategically bought new medical files that would not contain their HIV status so they could control who had access to this private information. Still others traveled to distant clinics to avoid the potential for stigma and marginalization that challenged their social identities and constrained their access to care.

I found that women employed secrecy as a strategy to manipulate the gender and power structures that challenge their social identities and health seeking practices within PMTCT programs. I argue that women's use of secrecy serves them in multiple ways, allowing women to meet their social and clinical needs. Secrecy is a coping strategy that allows women to leverage power and agency to negotiate the competing identities of mother, wife, and patient by minimizing the stigma and discrimination that challenges these identities. These coping strategies further allow women to meet their clinical needs to access treatment within PMTCT programs so that they can protect their HIV-exposed child, which is their ultimate priority.

This dissertation examines a research question that has concerned public health practitioners, clinicians, and social scientists in recent years—why do HIV-positive pregnant women drop out of PMTCT programs (Bwirire et al. 2008; Chinkonde et al. 2009; Van Hollen 2013; Van der Straten et al. 2014; Painter et al. 2004; Manzi et al. 2005; Weigel et al. 2012)? To better understand why HIV-positive women drop out of PMTCT programs, I examined the following specific research questions: 1) What strategies for AIDS treatment and management do pregnant and postpartum women employ? 2) How do broader social and gender relations affect women's participation in the program? and 3) Conversely, how does participation in the program affect women's social and gender relations? I explored these research questions through semi-

structured interviews, focus group discussions, and clinical observations with PMTCT patients, the health care providers who care for them, and various community members in the Blantyre district of Southern Malawi.

I began the dissertation with an account of the experiences of a young HIV-positive patient I met during the final stages of my study when I was interviewing women who had dropped out of PMTCT treatment. In the short time that I came to know Chitsulo, I learned that HIV-positive poor peri-urban women enjoy both supports and constraints in their daily lives as they negotiate social relations in marriage, the extended family, and the wider community as HIV-positive pregnant women and new mothers. Chitsulo's experience draws attention to the multiple social, cultural, and economic forces that shape the HIV/AIDS management of poor peri-urban women in one region of Southern Malawi. Chitsulo's experience, in particular, sheds light on the social forces produced in the interaction between gender and power inequities and local understandings of HIV/AIDS.

My study of the reasons why some women drop out of PMTCT programs reveals the multiple gender and power inequities that structure women's health seeking and social relations. My objective has been to show how these gender and power relations structure women's social relations in marriage and the community: challenging their identities as wives and mothers, and constraining their health seeking practice as patients in PMTCT programs.

Community-Based Stigma

This study shows that the HIV-positive women in this study experience multiple forms of stigma, discrimination and marginalization from spouses, family, and the larger community. Participants suggest local understandings of HIV/AIDS construct HIV-positive women as

immoral or promiscuous, situating them on the margins of being good mothers and wives. In this study community, an HIV/AIDS diagnosis means that someone in the relationship—the husband or wife—has been promiscuous. However, wives are more likely to be blamed because of a gendering of stigma that is produced by gender roles and relations and their intersection with social norms related to women's sexuality (Van Hollen 2013).

Despite continued efforts to provide confidential HIV services within the clinic, the PMTCT clinic further challenges women's vulnerability to stigma and discrimination. Given the public nature of the clinic, a woman's likelihood of meeting family and community members who do not know their positive status is enhanced simply by seeking care at the public PMTCT clinic. As a result, health-seeking at the clinic exposes an HIV-positive identity, bringing attention to the problems and conflicts within the household, which challenges women's social identities as mothers and wives.

Women are more likely to be blamed for being HIV-positive because of different standards of morality for men and women. Furthermore, as a sexually transmitted disease (STD), HIV/AIDS evokes ideas about morality that have been reproduced discursively in local understandings of HIV/AIDS. In Chapter 6 I draw parallels between women's experiences with colonial biomedical treatment of STDs and contemporary experiences with stigmatization. I discuss how *manyazi* was often experienced by men and women seeking STD treatment because inculcating shame in those seeking treatment for STDs was viewed by colonial officials as a means to instill morality in Africans (Vaughan 1991).

Local Understandings of Reproduction and the Construction of Motherhood

Just as women are stigmatized for being HIV-positive, they are stigmatized for their

infertility if they are unable to reproduce. I included a discussion of infertility in this dissertation to highlight the parallels between two health conditions that illuminate the gender and power structures that shape a woman's reproductive health and sexuality and construct women as failing to conform to ideals of motherhood and wifedom, fostering a tension between these competing social identities. Infertile women and women living with HIV/AIDS share a common experience of gendered stigmatization rooted in the social obligation to reproduce. In signifying a woman's reproductive role, the gendering of infertility and gendering of stigma demonstrate how gender inequities become embodied in women's health outcomes. In addition, both the gendering of infertility and the gendering of stigma reveal how women are constructed as the cause of their health condition. Yet, in each of these conditions, women have little control over having additional children, or negotiating safe sex.

I have attempted to show that many women in these clinics experience a double bind in which they are blamed when they are unable to reproduce, and also blamed for deciding to reproduce when HIV-positive. These constructions of HIV-positive mothers contrast with the attitudes and practices of women I met and interviewed who prioritized the health of their children and conceptualize PMTCT attendance as a means to ensure their child's survival and to extend their lives to enact the role of mother. I demonstrate, however, that this enactment of motherhood places women in a double bind where this critical social identity is contested by her identity as a wife.

Some health workers experiencing burn-out express negative attitudes towards PMTCT patients when they are late, miss appointments to collect their medication, "default," or simply are pregnant while knowing that they are HIV-positive. Others reproduce class-based power differentials in negative interactions with PMTCT patients. Other health care providers

stigmatize women for having additional pregnancies while HIV-positive. As discussed in Chapter 6, these health care providers redefine the social categories of motherhood, redefining who is eligible to be a mother and who is not. These attitudes demonstrate how biomedical knowledge of the perceived efficacy of ARVs transforms what it means to be HIV-positive and pregnant at a time when use of ARVs is expected to reduce mother-to-child transmission to less than 5% (Fasawe et al. 2013).

Gender Inequities in Marriage

At the same time that women are stigmatized for being HIV-positive by community members and health workers at the clinic, they experience challenges to their marriage when they disclose their HIV status to husbands. The most commonly reported “barrier” to women’s participation within PMTCT programs was the fear of HIV disclosure to one’s husband. This barrier to PMTCT participation reveals larger structural issues of gender ideals, relations and inequalities, and the double bind in women’s identities as mothers and HIV/AIDS patients.

My study demonstrates how gender and power inequities are reinforced in women’s AIDS management because HIV disclosure may lead to conflict between husbands and wives over sexuality and fidelity in marriage.

Applying the theory of gender and power, I argued that gender inequities most often emerge in PMTCT patients’ relationship power, which is constrained by women’s limited decision-making authority in relationships, limited economic ability to leave marriage, and historically-patterned social norms related to women’s sexuality and STDs. The majority of PMTCT patients in this study are poor peri-urban women with limited economic power. The

positionality of these women demonstrates how structural vulnerabilities are produced when particular positionalities intersect—gender, poverty, and a positive HIV status.

Recently, one of the largest HIV clinical trials conducted to test the efficacy of the prophylactic use of ARVs (PREP) was challenged by the women who participated (Van der Straten et al. 2014). After several years of expected success in discovering an effective HIV prevention drug, women's non-adherence led research investigators to end the intervention. Transnational researchers were baffled to find that 70% of the over 5,000 South African, Ugandan, and Zimbabwean women who participated had not taken the medication, yet told health care providers they had adhered—enacting adherence while secretly disposing of the medication, as Donald McNeil noted in a February, 2015 *New York Times* article. The narrative surrounding the ethics of this intervention were called into question, as many women were paid stipends that were disproportionate to local costs of living in Kenya. Most relevant to the present study, however, is that these women were able to collectively resist a health intervention with which they did not agree. Such acts reflect the performative nature of power. Again, subtle forms of resistance such as secrecy may appear to be “weapons of the weak” (Van Hollen 2013, 82), however, the above case demonstrates the collective power of multiple acts of resistance, and the agency of women who choose to not adhere to meet their own needs.

Double Bind: Negotiating the Competing Identities of Wife, Mother, and Patient

To my knowledge, social scientists have not studied the interaction of HIV-positive women's identities as mothers, wives, and patients in PMTCT programs, and how they may create a double bind for HIV-positive women when seeking HIV/AIDS treatment. Furthermore,

social scientists have not explored how these identities are specifically structured by gender and power inequities.

This dissertation reveals the importance of women's social identities to their HIV/AIDS management. I argue that gender and power inequities structure the social identities of HIV-positive pregnant women—situating women in a double bind as they negotiate the competing identities of mother, wife and compliant patient. The PMTCT patients in this study clearly prioritized their social role as mothers and shaped their health-seeking decision-making accordingly. When asked why they participate in PMTCT, women expressed an overwhelming acceptance of a positive status. Women pointed to the marked improvement in morbidity and mortality for PLWA in recent years, highlighting how those diagnosed with HIV/AIDS “are now surviving” and “leading good lives.” Women's desire to care for the exposed child sheds light on her most significant social role—to fulfill caregiving responsibilities is central to her maternal identity. PMTCT participation has a social cost in which women may risk losing their marriage—an institution which procures social and economic security critical to caring for one's children, particularly for women living in poverty, who represent the demographic of PMTCT patients in my study population.

Employing Secrecy: Mediating Competing Identities

Finally, few studies have explored the strategies women employ to negotiate health seeking within PMTCT programs. I have shown how in some instances, women respond to these social forces with subtle forms of resistance, employing secrecy to avoid marital conflict, minimize stigma, and address their health needs and those of their HIV-exposed child. I found

that women employed secrecy as a strategy to manipulate the gender and power structures that challenge their social identities and health seeking practices within PMTCT programs.

I find that women's use of secrecy is one strategy that reflects the "fractures" in the gender and power relations in the social relations of PMTCT patients, providing an example of "counterpoint ideologies" that are disguised and express themselves through discrete and veiled acts of rebellion (Crehan 1997).

Women employ secrecy to preserve their social identities and access PMTCT treatment for their child. Women also continue to have children while being HIV-positive. Some women may drop out, or not adhere to PMTCT, not because of the many barriers discussed in this dissertation, but by their own choice. It is possible that some women choose to avoid treatment in PMTCT programs to resist the discursive power embedded within health interventions and alter them to meet their own needs. These women may choose to drop out of PMTCT programs because they perceive these programs as another power structure to negotiate as it seeks to control their reproductive health and sexuality. Two such women are included in this study. As discussed in Chapter 6, two of the "defaulters" in this study explicitly stated they did not want to take the ARVs provided by the PMTCT program.

I argue that women's use of secrecy serves them in multiple ways, allowing women to meet their social and clinical needs. Secrecy is a coping strategy that allows women to leverage agency to mediate the competing identities of mother, wife, and patient, minimize the stigma and discrimination that challenges these identities, and meet their clinical needs to access treatment within PMTCT programs so they can protect their HIV-exposed child, which is their ultimate priority.

This study reveals the tension women experience in negotiating the conflicting identities of wife, mother, and patient as HIV-positive pregnant women and new mothers. The study illustrates the importance of women's social identities to HIV/AIDS management, and how gender and power inequities structure social identities of HIV-positive pregnant women. I have attempted to show that social and cultural obstacles rooted in gender and economic inequities may pose a far greater challenge than the clinical regimen demanded of patients within the PMTCT cascade. A better understanding of how gender and power work in women's lives may shed light on how best to implement these public health interventions.

Study Limitations

There are several limitations to this study. The study relies heavily upon the attitudes and experiences of health care providers who treat HIV-positive women within PMTCT programs. This clinic-based focus occurred because given the sensitivity with talking to HIV-positive women, my primary concern was to not disclose the status of women who participated in the study. To preserve women's confidentiality and prevent forced disclosure, I was unable to follow-up with women in their homes and communities. Therefore, I relied upon women's responses to interviews conducted only once and within the clinic setting. Interviews with community men and women were conducted to provide greater depth to the interviews conducted with PMTCT patients in the hospital.

Second, this study focuses on the experiences of HIV-positive women. Given the important role of gender relations and inequalities uncovered in the analysis, the perspective of men—specifically the husbands and partners of PMTCT patients—would provide a more balanced perspective on gender roles and relations.

Finally, interviews with women who had dropped out of the program were much less informative as compared to interviews and focus groups with women who remained in the PMTCT program. This is likely because these women were most at risk of negative consequences if their HIV/AIDS identity and “defaulter identity” was disclosed.

Gender and HIV/AIDS Research

As discussed in Chapter 2, the majority of the anthropological and public health literature on gender and HIV/AIDS focuses on prevention—specifically how gender inequalities may place women at greater risk of contracting HIV. However, few studies examine women’s social relations once they have begun treatment to understand why gender inequities may interfere with women’s participation. Studies that examine women’s social relations identify “limited social support” and stigma as potential reasons (Nyblade et al. 2003; Bwirire et al. 2008, Chinkonde et al. 2009; Kuonza et al. 2010; Van der Straten et al. 2014). For example, research conducted in Southern Africa (Nyblade et al. 2003) found that women were more likely to be stigmatized for being HIV-positive because they are believed to fail to fulfill their roles as caregivers to members of the extended family because of their illness from HIV.

Still, few studies examine the role that gender plays (Van Hollen 2013; Chinkonde et al. 2009) in women’s participation in PMTCT programs. Van Hollen (2013) is one of the first anthropologists to draw attention to the importance of gender in women’s access to HIV/AIDS treatment. In her study of HIV-positive mothers in India, Van Hollen draws attention to the fact that an HIV/AIDS diagnosis disrupts family and kinship relations, which may manifest in stigmatizing attitudes and practices toward women. Within the patrilineal context of her study, Van Hollen (2013) found that women were stigmatized by mothers-in-law who blamed them for

bringing HIV/AIDS into the marriage, thus threatening the moral integrity and continuity of the lineage.

Studies have been conducted on the impact of HIV/AIDS on women's experiences of motherhood. As discussed in Chapter 4, social scientists have examined the subjectivity of mothers with HIV/AIDS (Long 2009; Yeatman and Trinitapoli 2013) and the fertility desires of mothers with HIV/AIDS (Yeatman and Trinitapoli 2013). Social scientists have explored, from a phenomenological perspective, the subjective experience of HIV-positive mothers at a time when ARVs were not available to women who could not afford them. Long (2009) argues that women's bodily subjectivity is consumed by the more central role of the baby's body in HIV-positive motherhood. Similarly, Van Hollen (2013) discusses the impact of women's maternal responsibilities for women who were unable to access ARV treatment. Van Hollen found that mothers' desire to ensure ongoing care for her children involved securing alternative caregivers to take on the mothering role after her expected death.

In addition, while literature has drawn attention to the role of stigma in men's and women's HIV/AIDS treatment, few studies have explored the intersection of the meaning of HIV/AIDS with gender relations (Van Hollen 2013), and how it may affect the relationship power of HIV-positive pregnant women. This dissertation found that women are more likely to be blamed for their HIV/AIDS status rather than their husbands. Because the women in this study are more likely to be blamed for bringing HIV/AIDS into marriage and may be labeled "prostitute" if they leave the marriage, they are placed in a double bind with few options for accessing treatment other than secrecy or non-adherence.

Suggestions for Future Research

This study raises several questions that may be explored to address the challenges faced by PMTCT patients. First, how can PMTCT programs engage the support of spouses without reproducing the gender and power inequities HIV-positive women may experience in marriage? In recent years, spousal involvement has been identified as a potential strategy for encouraging women's adherence. This study suggests that unequal gender relations may in fact constrain these efforts. For many women in this study, spousal involvement may discourage their participation in PMTCT programs due to fears of marital problems and economic instability.

Addressing Gender Inequities: Increasing the Relationship Power of HIV-Positive Women

A robust strategy would involve increasing the relationship power of HIV-positive women—increasing women's economic power, decision-making authority and challenging the social norms that link women with HIV/AIDs to promiscuity. To increase women's economic power and decision-making authority in the relationship, gender mainstreaming may provide one potential strategy. Social interventions in the agriculture sector integrate “gender mainstreaming” into development interventions to involve men and women equally in economic strategies to ensure women's inclusion and minimize power differentials between men and women in the household (USAID 2012). Such strategies may provide women with the economic security to leave their marriage if forced to do so.

Challenging social norms that focus on the sexual practices of women, and deemphasizing the tendency to blame the husband or the wife may promote a more balanced perspective on HIV/AIDS as a disease that is the joint responsibility of husbands and wives.

Providing Social Support from Other HIV-Positive Women

Second, how can social support be provided to HIV-positive pregnant women and new mothers outside the clinic setting to help women negotiate the social, cultural, and economic barriers they encounter? In Southern Africa, support groups for HIV-positive mothers have been implemented to provide social support to HIV-positive women from other women living with HIV (Foster et al. 2014). By involving women with shared identities, these programs may provide social support and allow women to problem-solve with other women experiencing similar social, cultural, and clinical challenges. Such programs could be adopted to help women negotiate the social effects of PMTCT participation, such as marital distress and community-based stigma.

Minimizing HIV/AIDS Stigma through Service Delivery

Third, how can stigma and discrimination toward women living with HIV be reduced? Models of integrated care may provide confidentiality for women who avoid PMTCT clinics for fear of public disclosure by providing all clinical services at a single medical visit. For HIV-positive new mothers, such confidentiality would recognize the privacy valued by women living with HIV. This may promote treatment adherence and minimize the effects of gender inequalities and community-based stigma that prevent low-income women in resource-poor settings from fully accessing these programs. One such program has been tested in Kenya. Known as the “shopping model of care,” this program involves use of mobile clinics that provide all health-related services, including HIV/AIDS care, during one clinical visit. This structure would allow both men and women to seek treatment for HIV/AIDS privately while addressing other health needs (Andrews 2011).

Finally, a better understanding of the perspectives of patients involved in PMTCT programs may help to identify strategies to create PMTCT programs more responsive to women's needs. Further ethnographic research enlisting the strategies and suggestions of PMTCT patients themselves may provide answers to some of these questions. Further, given the strong presence of gender inequities in women's marital relations, ethnographic research centering on the attitudes and experiences of husbands of PMTCT patients would provide a more balanced perspective on how gender and power structures shape the social relations and health seeking of HIV-positive pregnant women.

APPENDICES

Appendix A:

Survival Analysis of Plan B+ PMTCT Patient Adherence

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Survival Analysis of Plan B+ PMTCT Patient Adherence

Quantitative Methods

Below I describe a survival analysis, conducted at Queen Elizabeth Central Hospital, to calculate the expected length of time patients remain on treatment prior to “defaulting” or being unable to adhere to ARV treatment during the study period. Data were retroactively collected from PMTCT registers at QECH to determine number of PMTCT appointments attended and appointments missed within the first 12 months of Plan B+, between October 3, 2011 and October 3, 2012. Data were entered into Excel and transferred to SPSS for the analysis.

The quantitative analysis investigates two research questions: 1) What proportion of women within the study population (for the quantitative study) default within the study period; and 2) Does the likelihood of defaulting depend on age as a covariate?

Quantitative Analysis

Data was retrospectively collected from PMTCT registers at QECH to determine number of PMTCT appointments attended and appointments missed within the first 12 months of Plan B+, between October 3, 2011 and October 3, 2012. Data was entered into Excel and transferred to SPSS for the analysis.

Patients included in the analysis represent the first patient cohort receiving the 5A treatment regimen under the current national PMTCT policy, Plan B+. This new treatment regimen was implemented by the Malawian Ministry of Health (MOH) on October 3, 2011.

Patient medical files were reviewed retrospectively to determine eligibility. All PMTCT patients registered between October 3, 2011 and October 3, 2012 were included in the analysis.

PMTCT programs last for a period of two years, or until the end of the breastfeeding period, as recommended under Plan B+ (Ministry of Health 2011). This analysis, which was conducted between October 3, 2011 and October 3, 2012, covers at most the first year of the program. Patients registered in the national PMTCT program are scheduled to return monthly for medication refills according to Plan B+ guidelines. Those patients who fail to return for refills two or more months after pill completion are defined as “defaulters” by MOH guidelines.

Survival Analysis Methods

Survival analysis assesses the proportion of a population that survive until an event of interest occurs. Literature on the use of survival analysis methods suggests this statistical method is most commonly used to assess patient survival after receiving medical treatment, or to measure time to disease relapse following the application of a new treatment regimen (Singh and Mukhopadhyay 2011). Survival data analysis has been increasingly used for other studies, such as retention within drug and alcohol treatment programs (Kelly et al 2011).

Following this trend, I employed survival analysis to model the amount of time patients remain on ARV treatment within PMTCT programs until the event of interest, or “defaulting.” This approach was used because it allows for an estimation of participants’ adherence to treatment in the presence of censored data. Censored data occur when the event of interest, in this case “defaulting,” is not observed for a participant during our specified time period. This is the case for many of the participants in this study.

Results for the 183 patients registered within the PMTCT program at QECH demonstrate that 65 patients experienced the event of interest, or “defaulting” during the study period, and

118 patients did not. Data were right-censored, indicating that the event of interest, defaulting, may still occur beyond the study period of one year or after transferring from the study. In other words, time to default for a censored patient is $>$ (number of days observed). Censored data in this study include transfers, or patients who transferred to other PMTCT clinics in the region to finish treatment as well as those who successfully completed treatment through the end of the study (October 3, 2012). For these patients, we know that their time to default is greater than the number of days they were followed in the study. Ninety-nine patients were still active at the end of the first year the program, and nineteen patients transferred during the study period, or chose to obtain treatment at a PMTCT clinic other than the district hospital. Consequently a total of 118 patients, or 64%, were censored or “not observed to default.”

A survival analysis was conducted using SPSS Version 21 (CITE) to calculate the length of time patients remain on treatment prior to defaulting. Survival analysis methodology was selected to assess the extent to which patients “default” from the program with a more robust statistic as compared to a simple probability ratio. A simple probability is more commonly used in the literature (Nachega et al. 2013) to assess adherence within PMTCT programs.

These statistics calculate the probability of defaulting by including in the numerator the total number of patients who default, dividing the number by the total number of patients started on treatment. For example, in this study, 65 patients defaulted out of a total 183 patients who were initiated on treatment. This simple frequency states that 35.5% of patients in the program defaulted, or failed to adhere to treatment. A simple extension of this logic may lead someone to the incorrect conclusion that 64.5%, or the remaining 118 patients, were still active or successfully engaged in the treatment at the end of the study. However, “did not default” is not the same as still active. The calculation of 64.5% includes in the numerator patients who were active at the end of the study and patients who transferred out of the study before it ended.

A survival analysis, in contrast, does not assume that transfers were still active at the end of the study period. Transfers instead are treated as censored observations and removed from the daily survival calculations illustrated in Table 1, a table of Kaplan Meier survival estimates (Clark et al. 2003). The Kaplan Meier Life Table (Table 1) shows the proportion of patients remaining within the program at each daily time interval, the number of patients who defaulted at each daily interval (“Number of defaults”), and the number censored. This table represents a daily summary of the full SPSS output.

Number exposed to risk represents the number of patients “at risk” of defaulting, or the number entering the program minus half of those patients who withdrew during the time interval. The *number of terminal events* or “patient defaults” represents the number of patients who defaulted in the given time interval.

The *number of censored events* represents the number of censored patients at each daily interval. These include patients who transferred or patients who successfully completed the first year of treatment.

The *daily proportion defaulting* represents the proportion of patients who default during the given time interval. The ratio is calculated by dividing the number of defaulting patients by the number of patients at risk of defaulting during the given time interval.

The *daily proportion not defaulting* represents the proportion of patients participating within the given time interval, and is calculated by subtracting the proportion of patients terminating by the given time interval from one.

The *cumulative proportion not defaulting* represents the cumulative proportion of patients not defaulting up to the given time interval.

For example, on Day 0, 29 patients defaulted, 18 patients were censored, leaving 136 patients “exposed to risk” of defaulting at the beginning of Day 1. These daily interval calculations remove all censored data from the calculation, including both transfers and patients still participating at the end of the study. Therefore, the Kaplan Meier survival estimate provides a more accurate estimate of the cumulative proportion not defaulting that continually adjusts the denominator for all censored observations, both transfers and those still active at the end of the study. As a result, the cumulative proportion of patients who did not default (.527) using survival techniques is lower than one might have inferred from the simple probability estimate (.645).

The survival probability is therefore the preferred calculation because it accounts for the uncertainty of patient behavior, such as whether or not patients who transferred out of the program ultimately defaulted. Because of the nature of censored data, it appears that survival probability is the most statistically robust assessment of patient adherence (Prinja et al. 2010).

Table 1: Kaplan Meier Life Table Daily Summary

Day	Number entering or exposed to risk	Number Defaults	Censored	Daily proportion defaulting	Daily proportion not defaulting	Survival estimate, cumulative proportion not defaulting	Standard Error
0	183	29	18	0.158	0.842	0.842	0.027
1	136	4	1	0.029	0.971	0.817	0.029
2	131	4	2	0.031	0.969	0.792	0.031
7	125	2	0	0.016	0.984	0.779	0.031
8	123	0	3	0.000	1.000	0.779	0.031
17	120	0	1	0.000	1.000	0.779	0.031
25	119	0	2	0.000	1.000	0.779	0.031
28	117	0	1	0.000	1.000	0.779	0.031
29	116	0	4	0.000	1.000	0.779	0.031
30	112	0	1	0.000	1.000	0.779	0.031
37	111	4	0	0.036	0.964	0.751	0.033
44	107	0	1	0.000	1.000	0.751	0.033
49	106	2	0	0.019	0.981	0.737	0.034
51	104	1	0	0.010	0.990	0.730	0.034
52	103	0	2	0.000	1.000	0.730	0.034
55	101	1	0	0.010	0.990	0.723	0.035
56	100	1	1	0.010	0.990	0.715	0.035
57	98	0	1	0.000	1.000	0.715	0.035
59	97	0	1	0.000	1.000	0.715	0.035
62	96	0	1	0.000	1.000	0.715	0.035
65	95	0	1	0.000	1.000	0.715	0.035
71	94	0	1	0.000	1.000	0.715	0.035
78	93	0	2	0.000	1.000	0.715	0.035

Table 1 (cont'd)

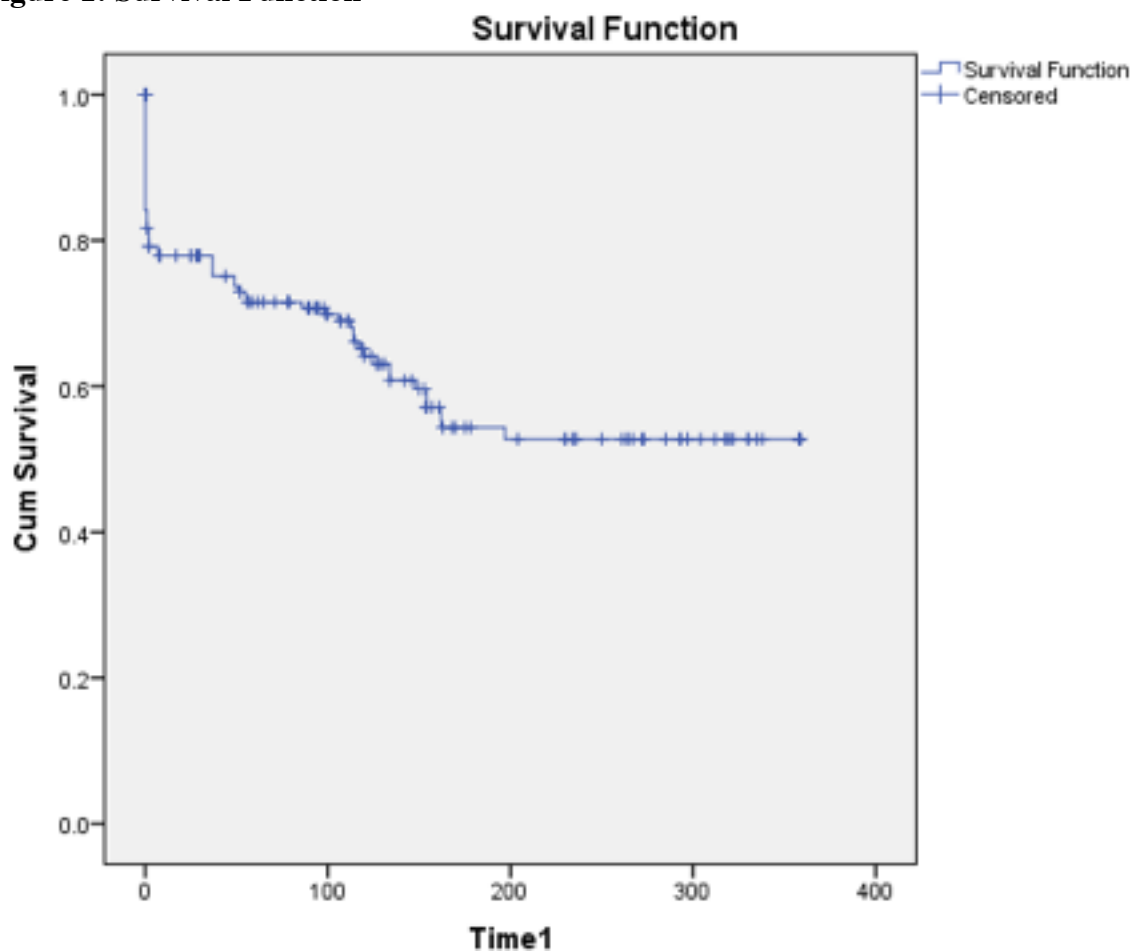
79	91	0	1	0.000	1.000	0.715	0.035
86	90	1	0	0.011	0.989	0.707	0.036
89	89	0	1	0.000	1.000	0.707	0.036
90	88	0	2	0.000	1.000	0.707	0.036
93	86	0	1	0.000	1.000	0.707	0.036
94	85	0	2	0.000	1.000	0.707	0.036
95	83	0	1	0.000	1.000	0.707	0.036
98	82	0	1	0.000	1.000	0.707	0.036
99	81	1	1	0.012	0.988	0.699	0.036
100	79	0	1	0.000	1.000	0.699	0.036
106	78	1	0	0.013	0.987	0.690	0.037
107	77	0	2	0.000	1.000	0.690	0.037
111	75	0	3	0.000	1.000	0.690	0.037
113	72	1	0	0.014	0.986	0.680	0.038
114	71	2	0	0.028	0.972	0.661	0.039
115	69	0	1	0.000	1.000	0.661	0.039
117	68	1	0	0.015	0.985	0.651	0.040
119	67	0	3	0.000	1.000	0.651	0.040
120	64	1	1	0.016	0.984	0.641	0.040
124	62	0	1	0.000	1.000	0.641	0.040
127	61	1	2	0.016	0.984	0.631	0.041
129	58	0	1	0.000	1.000	0.631	0.041
131	57	0	1	0.000	1.000	0.631	0.041
134	56	2	1	0.036	0.964	0.608	0.043
142	53	0	1	0.000	1.000	0.608	0.043
146	52	0	1	0.000	1.000	0.608	0.043
148	51	1	0	0.020	0.980	0.596	0.043
150	50	0	1	0.000	1.000	0.596	0.043
153	49	0	1	0.000	1.000	0.596	0.043
154	48	2	3	0.042	0.958	0.571	0.045
157	43	0	1	0.000	1.000	0.571	0.045
161	42	0	1	0.000	1.000	0.571	0.045
162	41	2	0	0.049	0.951	0.543	0.047
163	39	0	1	0.000	1.000	0.543	0.047
168	38	0	1	0.000	1.000	0.543	0.047
170	37	0	1	0.000	1.000	0.543	0.047
175	36	0	1	0.000	1.000	0.543	0.047
178	35	0	1	0.000	1.000	0.543	0.047
197	34	1	0	0.029	0.971	0.527	0.048
204- 359	Varies	0	33	0.000	1.000	0.527	0.048

Patterns in Defaulting

Another benefit to using Kaplan Meier survival estimates is that they reflect the pattern of defaulting and censoring as it occurs over time. The cumulative survival estimates are plotted over time in the cumulative survival function shown in Figure 1. The first vertical drop in the curve represents the event of interest, defaulting, occurring at the highest rate in the first ten days of the program. The rate is relatively higher again in the second month, as shown by the decrease in cumulative survival in the second month of the program, followed by a steady increase in the number of defaults (or a steady decrease in the survival function) from three to six months. The median estimated time to default is 218 days.

There were no patient defaulters after 197 days. This left 52.7% of patients still active at the end of the study.

Figure 1: Survival Function



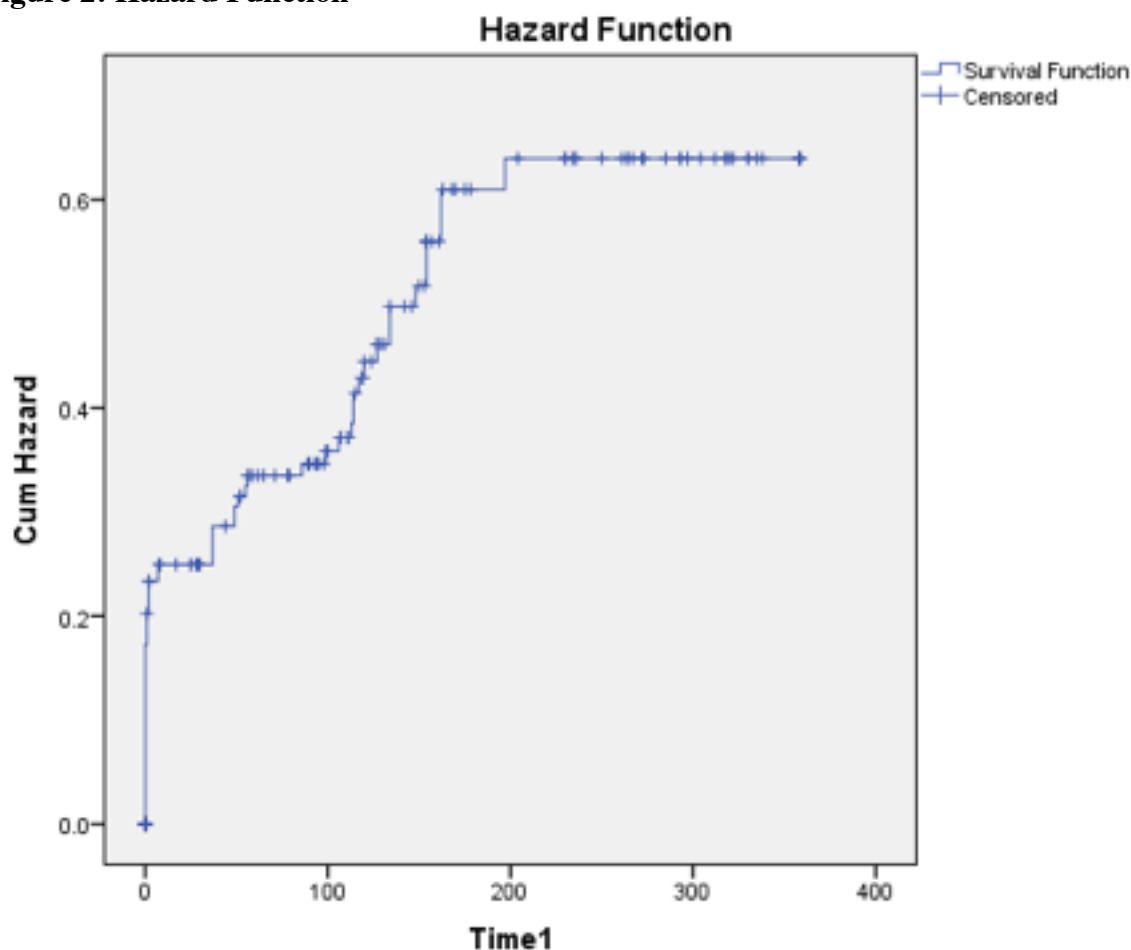
*Time 1=Days

Cumulative Hazard Function

The hazard function illustrates the relative risk that patients will default within the given time interval (Figure 2). While survivor functions emphasize the probability of not having the event of interest or defaulting occur, the hazard function emphasizes the probability of defaulting at the given time, and is based upon survival probability up to a specific point in time (Clark et

al. 2003). The shape of the hazard function also suggests the time of greatest risk of defaulting is in the first 10, and subsequently, 30 days of the program.

Figure 2: Hazard Function



*Time 1=Days

Discussion

Patients may default early in the program for a number of clinical, programmatic, and sociocultural reasons. Patients may not have experienced the clinical benefits of the medication, or have experienced initial side effects from treatment. Depending on the period in pregnancy, women may be forced to leave early on in the program. For example, women who begin treatment prior to delivery may choose to deliver at home, or through the use of a traditional birth attendant (TBA), which may lead some women to fear returning to the hospital for treatment. Further, women who begin treatment at delivery may delay return to the program because of the demands of the initial weeks of motherhood.

Importantly, because of the nature of censored data, it is unknown whether patients who appear to default have transferred to another facility without receiving an official transfer or have died. As stated in the qualitative component of the study, regardless of the point in the treatment trajectory, many patients may be unable to successfully adhere to treatment within PMTCT for a variety of sociocultural reasons, including lack of spousal and community-based support and the nature of HIV/AIDS stigma, as discussed in more detail in Chapters 5 and 6.

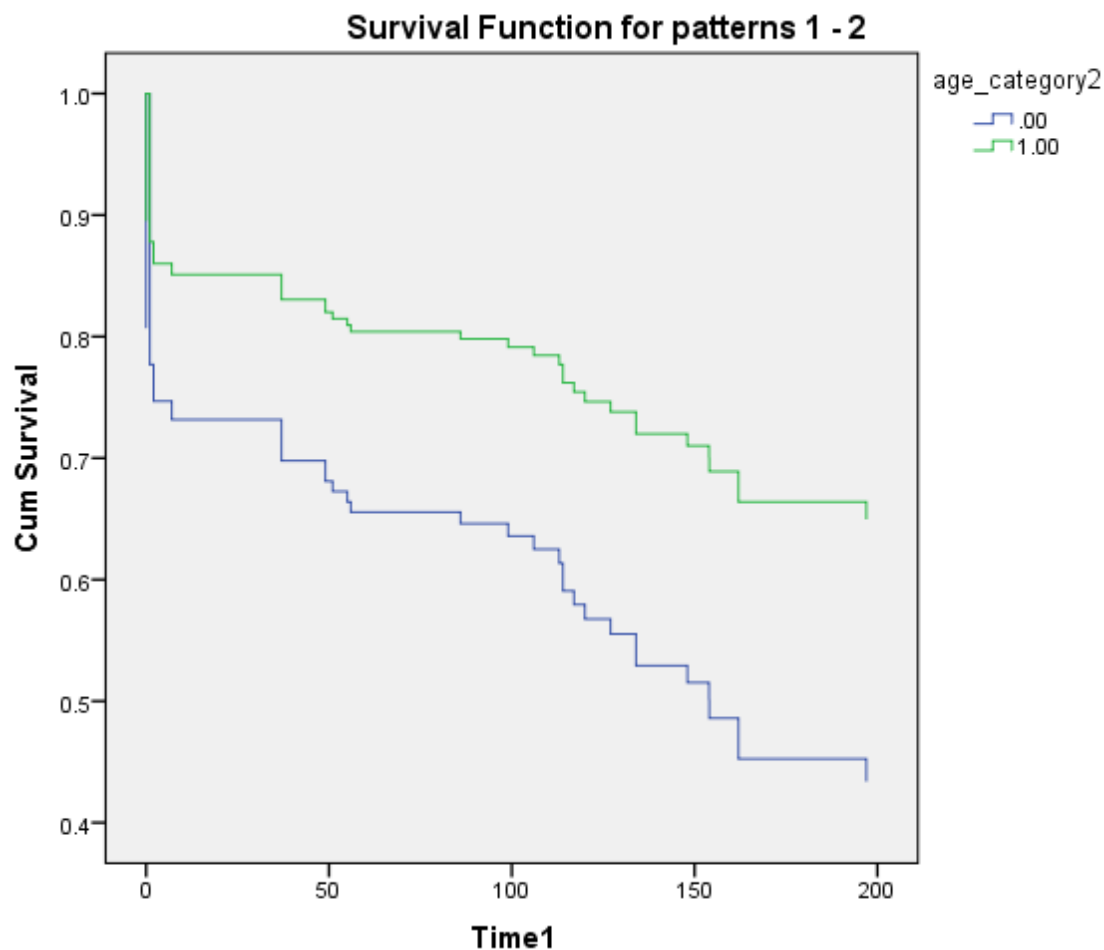
Covariate Analysis

Further analysis of the data suggested that age may be a predictive factor for likelihood of defaulting. We used the cox regression method of analysis to assess the effects of age on patient “defaulting” within this program (Bradburn et al. 2003).

Age was categorized into the following subgroups: 1) Patients over the age of 18 and under the age of 30 (n=112) and 2) Patients over the age of 31 (n=71).

The results of the cox regression are summarized in Table 2. We found a significant difference in default rates between the 2 groups at a 5% level of significance ($p=0.016$). The median survival time for older women in group was 330 days whereas the median survival for younger women was 158 days.

Figure 3: Cox Regression Analysis



*Time 1=Days

Table 2: Cox Regression Analysis Results

	B	SE	Wald statistic	df	Sig.	Exp(B)
Age category	.661	.275	5.790	1	.016	1.936

The above cox regression analysis shows that older women (ages over 31-45) (upper, green curve) have almost twice the likelihood of staying in the program as compared to women under the age of 30 (lower, blue curve). Similarly, women in the younger group have almost twice (1.936) the relative risk of not remaining within the program.

Appendix B:

PMTCT Core Services and Patient Profiles

Appendix B:
PMTCT Core Services and Patient Profiles

Table 3: PMTCT Core Services

PMTCT Core Services	
Step 1	Utilization of Antenatal Care
Step 2	Receive HIV pretest counseling
Step 3	Acceptance of HIV test
Step 4	Receive HIV test results and post-test counseling
Step 5	Use of ARV prophylaxis for mother and/or infant (for seropositive mothers)
Step 6	Use of labor and delivery services which include PMTCT interventions
Step 7	Postnatal follow-up with mother and infant, with HIV test for exposed infant and timely access to treatment, care and support

Table information sourced from Figure 1 in Marcos et al 2012.

Table 4: Patient Profile

	District Hospital (QECH)	Health Centre (Ndirande)	Health Centre (Mpemba)	“Dropped”	Total
18-25	12	0	1	5	3
26-40	33	4	7	6	50
NA				3	3
Total	45	4	8	14	71
Education					
None	0	0	2	0	2
Primary	3	3	6	9	21
Some Secondary	17	1	0	3	21
MSCE	20	0	0	0	20
College	1	0	0	0	1
NA	4	0	0	2	6
Total	45	4	8	14	71
Employment					
Farming	0	0	5	3	8
Business	13	0	1	6	20
Housewife	18	4	2	2	26
Professional	9	0	0	0	9
NA	5	0	0	3	8
Total	45	4	8	14	71
Husband HIV					
Positive	18	0	1	1	20
Negative	3	1	0	2	6
Not tested	9	3	7	8	27
NA	15	0	0	3	18
Died	0	0	0	0	0
Total	45	4	8	14	71
Marital Status					
Married	39	4	8	8	59
Single	2	0	0	1	3
Divorced	1	0	0	3	4
Widowed	0	0	0	0	0
NA	3	0	0	2	5
Total	45	4	8	14	71

Appendix C:

Interviews and Instruments Used

Appendix C: Interviews and Instruments Used

Table 5: Instruments Used

	Semi-structured Interviews	Focus Group Discussions
Current PMTCT Patients		
QE District Hospital	14	3
Ndirande Health Centre	4	
Mpemba Health Centre	0	1
Patient “Defaulters”	14	
Total	32	5
Health Care Providers		
QE District Hospital	11	
Ndirande Health Centre	3	
Mpemba Health Centre	4	
Total	18	
Community Leaders		
Teachers		2
Church leaders	2	1
Village Chiefs	2	
Birth Attendants	2	
Total	6	3

Patient Interview Questions (Chichewa)

Mphatikiri B: Chisanzo chamafunso ofunsidwa pokambirana ndi odwala:

Ena mwamafunso okhudzana ndi odwala okamba za zopinga zamatenda ndi njira zopezela chithandizo

Choyamba, ndikufuna kulankhula nanu zokhudza thanzi lanu m'mene muliri tsopano

1. Chonde mundilongosolorele m'men tsiku lanu lathunthu limakhalira. Kodi mumagwira ntchito? Kodi muli ndi ana angati?
2. Kodi mungalongosole bwanji za thanzi lanu tsopano?
3. Kodi mungandiuze zimene munachita pamene munamva koyamba kuti muli ndi matenda a HIV/AIDS? Kodi adokotala anakuuzani chiyani? Kodi inu munachita chiyani pamene munazindikira kuti muli ndi matendawo?
4. Kodi mubanja lanu, ndi ndani amene amakhala ndi mphamvu ya ulamuliro pokhuzana ndi chisamaliro cha moyo wanu? Umoyo wa mwana wanu?

Maganizo a odwala m'mene amaonera chilinganizo cha PMTCT:

Ine ndifuna kudziwa ntchito zimene muyenera kuchita monga m'modzi wotenga mbali mu chilinganizo cha PMTCT

1. Kodi mwakhala mukutenga nawo mbali muchilinganizo cha PMTCT kwa nthawi yayitali bwanji ku QECH/Kawale?
2. Kodi ntchito yanu ndi chiyani monga m'modzi wotenga mbali mchilinganizo cha PMTCT
3. Kodi zinthu zikukuyendarani bwanji? Kodi zinthu zimene mukuona kuti zimagwira ntchito ndi chani, kapena zinthu zimene sizimagwira ntchito ndi chiyani?
4. Kodi munayamba watenga nawo mbali muzilinganizo zina za PMTCT? Kodi ndi chifukwa chiyani munaganiza kusiya?
5. Kodi pali munthu wina amene amakuthandizani kapena kukupingani potenga nawo mbali?
6. Kodi mungachipititse bwanji patsogolo chilinganizo chimenechi?
7. Kodi munaberekera mwana wanu kuti? Kodi ndi chifukwa chiyani munasankha kuti kuti muberekere mwana ku QECH/kwina? Kodi pamene munaberekera mwana kunja kwa chipatala, zinakupangitsani mavuto otani kuti mulowe kapena musalowe nawo muchilinganizo cha PMTCT?

M'mene odwala amaonela zinthu zokhudzana chithandizo kuchipatala, m'munyumba mwawo, kapena m'mudzi:

1. Kodi anthu amadziwa kuti mumapita ku PMTCT?
2. Kodi ndi ndani amene amadziwa kuti mumapita ku PMTCT?
3. Kodi iwo amakulimbikitsani kapena kukugwetsani mphwayi? Ndi chifukwa chiyani mukuganiza choncho? Kodi mungakonze bwanji vuto limeneli?
4. Kodi mumabwera ndi ndani ku chipatala?
5. Kodi ndi ndani amene munamuuzapo zakudwala kapena kusadwala kwanu kwa matenda a HIV/AIDS? Anzanu? Abale anu?

M'mene odwala amaonela zinthu zokhudzana zopinga kuchipatala, m'manyumba mwawo, kapena mu umoyo wapamudzi:

1. Kodi ndi chiyani chimene chingapangitse chipatala cha PMTCT kukhala chosavuta komanso chabwino? Kodi ndi zinthu ziti zimene mumakonda m'chilinganizo cha PMTCT? Kodi ndi

- zinthu ziti zimene simumakonda m'chilinganizo cha PMTCT?
2. Ngati mutakhala ndi mwayi wosintha chinthu china pakalandilidwe kamankhwala mchilinganizo cha PMTCT, chingakhale chani?
 3. Kodi ndi zifukwa zina ziti zimene zingamupangitse munthu kuti asabwererenso ku chilinganizo cha PMTCT?
 4. Kodi munayamba mwalephelapo kupita kuchipatala panthawi imene munayenera kupita kumeneko? Kodi munalephera chifukwa chani?
 5. Kodi mukudziwapo mayi amene anasiyilatu kubwera ku chipatala cha PMTCT? Popanda kundidziwitsa dzina lake, kodi mukudziwa zifukwa zake zimene zinamupangitsa kulephera kubwerera kuchipatala cha PMTCT? Kodi mukuganiza kuti anachoka chifukwa chiyani? Chinachitika ndi chiyani kuti apange chitsimikizo kuti achokedi?
 6. Kodi alipo anthu ena amene amaoneka kuti sangamalize nawo chilinganizo cha PMTCT? Kodi mukuganiza kuti izi zili choncho chifukwa chani? Kodi munamvapo chani zokhudzana ndi nkhani imeneyi?
 7. Kodi ndi chifukwa chani amayi amatenga nawo mbali mchilinganizo cha PMTCT? Kodi ndi chifukwa chani iwo amasankha kuti amalize nawo chilinganizo chimenechi?
 8. Kodi munamvapo zakusankhidwa kapena kusolidwa kumene kunapangidwa kwa munthu amene ali ndi matenda a HIV/AIDS kapena kwa banja lake?
 9. Kodi mukuganiza kuti chingachitike ndi chani popeza njira yothetsa vuto losankha odwala ngati likupitilirabe masiku ano?
 10. Kodi ndi ziti zimene munamvapo kuchokera kumaphunziro a za umoyo zimene zakhala zofunika kwambiri pamoyo wanu? Izi zili choncho chifukwa chani? Kodi zilipo zina zimene munamvapo zimene ndizosakuthandizani?
 11. Kodi patakhala chinthu china chosiyana chimene chingakuchepetseni mavuto kuti muthe kudzisamale nokha ndi chiyani? Kapena kuti muthe kusamala mwana wanu amene ali ndi kachilombo ka HIV?

Mphatikiri C: Chinsanzo chamafunso ochokera kwa gulu la odwala:

1. Kodi ndi zifukwa ziti amayi amatenga nawo mbali mchilinganizo cha PMTCT?
2. Kodi ndi zifukwa ziti amayi amasiya kutenga nawo mbali mchilinganizo cha PMTCT?
3. Kodi ndi zifukwa ziti zimene zingapangitse amayi kuti amalize bwino potenga nawo mbali mchilinganizo cha PMTCT?

Mphatikiri D: Chinsanzo mafunso ochokera kwa anthu apamudzi:

1. Kodi ndani mayi wachisanzo chabwino? Kodi ndi zinthu ziti zimene zimaonetsa kuti mayi uyu ndi wabwino? Kodi ndi zinthu ziti zimene zimaonetsa kuti mayi uyu ndi woyipa?
2. Kodi chisanzo cha 'nthawi yayitali bwino' kuti mayi ayamwitse mwana ndi chani?
3. Kodi ndi ndani m'banja amene ayenera kupeleka thandizo kwa amayi lolimbikitsa munthu? Thandizo lazofunika mu umoyo wamunthu?
4. Kodi ndi ndani m'mudzi amene amayenera kupeleka thandizo kwa amayi lowalimbikitsa kupangira zinthu limodzi?
5. Kodi malo abwino kuti mayi angaberekere mwana ndi kuti?
6. Kodi ndi zinthu ziti zimene zipatsa mayi nkawa kwa mayi ndi chiyani?
7. Kodi muli ndi chiyembekezo chotani pa umoyo wanu komanso umoyo wa mwana wanu?

Patient Interview Questions (English)

General questions about the patients' illness challenges and its management:

First, I'd like to talk about your current health status.

- 1) Please describe your typical day to me. Do you work? How many children do you have?
- 2) How would you describe your current state of health?
- 3) Can you tell me when you first found out that you had HIV/AIDS? What were you told? What did you do when you found out?
- 4) Who in your family usually has the final say on decisions related to your health care? Your child's health care?

Patient perceptions of PMTCT program:

I'm especially interested in your responsibilities as a PMTCT participant.

1. How long have you been attending the PMTCT program at QECH/Kawale?
2. What are your responsibilities as a PMTCT participant?
3. How is it going for you? What do you find works and what doesn't?
4. Have you participated in other PMTCT programs? Why did you decide to leave?
5. Does anyone help or hinder your participation?
6. How would you improve the program?
7. Where did you deliver your child? Probe: Why did you choose to deliver at QECH/other? Has your delivery outside of the hospital affect your ability to participate in PMTCT?

Patient perceptions of supports within clinical, household, or community setting:

1. Do people know that you attend PMTCT?
2. Who knows that you attend PMTCT?
3. Do they support or discourage you? Why do you think so? How could you fix this?
4. Whom do you usually bring with you to the clinic?
5. With whom have you shared your HIV/AIDS status with? With whom might a woman typically disclose her HIV/AIDS status? Friends? Family members?

Patient perceptions of challenges, within clinical, household, or community setting:

1. What, if anything, would make the PMTCT clinic easier/better? Probe: What aspects of PMTCT do you like? What aspects of PMTCT do you dislike?
2. If you could change any aspect of your treatment responsibilities within PMTCT, what would that be?
3. What are some of the reasons someone would not return to PMTCT?
4. Have you ever missed an appointment? Why did you miss this appointment?
5. Can you think of a woman who has not returned to the PMTCT clinic? Without telling me who this woman is, do you know the reason why she was unable to return? Why do you think that is the case? What happened to cause her decision to leave?
6. Are certain people less likely to complete PMTCT? Why do you think that might be so? What have you heard about that?
7. Why do women participate in PMTCT? Why would they choose to complete the program?
8. Do you personally know of any examples of women who have begun a PMTCT program and were unable to continue? Why do you think that is the case? What happened to cause her

decision to leave? Do you know anyone else who has been unable to complete PMTCT?
What happened... What do you think of that?

9. Have you ever heard of a case of stigma or discrimination directed toward a person living with HIV/AIDS or their family members?
10. What do you think can be done to address the stigma that persists today?
11. Which information from the health education session has been most valuable to you? Why is that so? Has any information been not helpful?
12. What, if anything, could be different that would make it easier for you to care for yourself?
To care for your (HIV-positive) child?

Sample Patient Focus Group Questions:

1. What are the reasons women participate in PMTCT?
2. What are the reasons women drop out of PMTCT?
3. What are some factors that would make women better able to finish PMTCT?
4. What is an ideal mother? (Probe: What are the characteristics of a good mother? What are the characteristics of a bad mother?)
5. What is an ideal period of time for a mother to breastfeed her child?
6. Who in the family is most likely to provide women social support? Material support?
7. Who in the community is most likely to provide women social support?
8. Where is the best place for a woman to give birth? Why?
9. What are the main things that worry mothers?
10. What are your hopes for your future and that of your child?

Health Care Provider Interviews

General Research Questions

1. What strategies for AIDS treatment and management do women employ?
2. What is the impact of gender and kinship relations on women's careseeking strategies and program completion?
3. What is the impact of stigma on women's careseeking strategies and program completion?
4. How do community concepts of motherhood and ideas about breastfeeding practices affect women's careseeking strategies and program completion?
5. How do PMTCT program design and clinician attitudes impact women's program completion?

Sample Provider Interview Questions

1. Tell me about your professional background and training. How long have you been working at this facility? What are your main responsibilities? Could you describe a typical day at the PMTCT clinic for me?
2. What are the general characteristics of your patient population? How many doctors/nurses/midwives currently work within the PMTCT program?
3. What are the main components of your PMTCT program? What is the typical routine for a woman and infant who participate in the program?
4. How do you enroll women to participate in PMTCT?
5. What are the greatest barriers to providing PMTCT to women and their infants?
6. Why do you believe some women do not complete PMTCT? Why do you think that is so?
7. Why do you believe some women complete PMTCT?
8. At what point in the PMTCT process are women most likely to not return?
9. Please describe efforts made by PMTCT staff to track patients who are lost to follow-up.
10. How would you improve the program?

Sample Focus Group Questions

1. What are some reasons a woman would attend PMTCT?
2. What are some reasons a woman would leave PMTCT?
3. Where do most women typically give birth?
4. Can a woman deliver at home and still attend PMTCT?
5. How long should a woman breastfeed?
6. With whom does a woman share her HIV/AIDS status with? With whom might a woman typically disclose her HIV/AIDS status? Spouse? Family members? Friends within the community?
7. Who typically makes the decisions within a household?

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