FACTORS THAT INFLUENCE DISCLOSURE AND PROGRAM PARTICIPATION AMONG PREGNANT HIV-POSITIVE WOMEN: A MIXED METHODS STUDY IN LILONGWE, MALAWI

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ABSTRACT

Emily Anton Bobrow: Factors that influence disclosure and program participation among pregnant HIV-positive women: A mixed methods study in Lilongwe, Malawi

(Under the direction of Dr. Shelah Bloom and Dr. Linda Adair)

Background: Programs for the prevention of mother-to-child transmission (PMTCT) of HIV are increasingly available in low-resource settings. Challenges, such as HIV disclosure, impede participation by pregnant HIV-positive women. This study describes factors that influence women's willingness to participate in PMTCT programs and explores factors associated with HIV disclosure by pregnant women to their partners in Lilongwe, Malawi.

Methods: This study was conducted in three antenatal clinics from June 2006-May 2007. Qualitative interviews were conducted with 9 clinic nurses, 4 community nurses, and 30 pregnant HIV-positive women within a week of diagnosis. An additional twelve clinic nurses participated in two focus groups. A quantitative survey was administered to 300 HIV-positive women, using probability sampling.

Results: The common facilitator for participation identified by women and providers was women's desire to know their disease status. Providers believed women's high level of PMTCT knowledge contributed to participation. The main barrier to participation identified by women and providers was the culturally dominant role of partners in decision-making.

Despite provider's belief that HIV disclosure was a barrier to participation, most women (90%) disclosed their HIV status to their partner, and most (73%) did so early (day of diagnosis). Of women who disclosed, almost half (47%) told more than one person. Women who believed they were infected by their partner were more likely to disclose (OR=2.82, 95% CI 1.17, 6.81). Women who tested for HIV before their partner were more likely to disclose early (OR=2.26, 95% CI 1.14, 4.48) and to more than one person (OR=2.58, 95% CI 1.39, 4.78). Reasons women disclosed to their partners were often the same reasons nurses promoted in post-test counseling, specifically cultural obligation and communication norms with partners, belief the partner infected the woman, negotiation for condom use, and explanation for illness.

Conclusions: Participation can be enhanced through outreach to men and women to increase knowledge of PMTCT and to promote clinic services. Post-test counseling should encourage participation and HIV disclosure. Providers should be educated that HIV disclosure was high and that women's perceptions of the source of HIV infection and of testing before their partners were powerful motivators for disclosure.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral
BAN	Breastfeeding Antiretroviral and Nutrition
CAB	Community Advisory Board
CDC	United States Centers for Disease Control and Prevention
CI	Confidence interval
CTA	Call-to-Action
DHS	Demographic and Health Survey
HIV	Human immunodeficiency virus
IRB	Institutional Review Board
MCH	Maternal and Child Health
MMR	Maternal mortality ratio
MTCT	Mother-to-child transmission
NVP	Nevirapine
PMTCT	Prevention mother-to-child transmission
RTUF	Ready-to-use food
SEF	Social ecological framework
SES	Socioeconomic status
TFR	Total fertility rate
UNAIDS	The Joint United Nations Program on HIV/AIDS

UNC-CH	University of North Carolina at Chapel Hill
UNICEF	United Nations Children's Fund
VCT	Voluntary counseling and testing
WFP	World Food Program
WHO	World Health Organization

CHAPTER 1:

INTRODUCTION

Mother-to-child transmission accounts for over 90% of all pediatric HIV infections worldwide, with almost 420,000 infants infected and nearly 330,000 child deaths due to AIDS in 2007 (UNAIDS, 2007). Transmission of HIV occurs during pregnancy, labor and delivery and postnatally through breastfeeding (Newell, 2000). Without prevention interventions the rate of mother-to-child transmission (MTCT) is estimated at 35% (UNAIDS, 2005). The majority of cases occur in resource-poor countries, particularly in Africa, where HIV prevalence is high; and fewer than 10% of pregnant women have access to interventions designed for the prevention of mother-to-child transmission (PMTCT) (UNAIDS, 2004).

PMTCT programs are often linked to existing maternal and child health (MCH) clinics and to HIV voluntary counseling and testing (VCT) services. The coexistence of PMTCT programs on these other systems is often limited; for although many countries claim to prioritize PMTCT in their national HIV frameworks, few have programs beyond the pilot stage. In addition to the restricted scope of the programs, there are many public health challenges for engaging women in existing services and research designed to reduce MTCT (De Cock et al., 2000). In particular, HIV disclosure and involving male partners have been identified as major obstacles to women's participation (Medley, Garcia-Moreno, McGill, & Maman, 2004).

This dissertation explores PMTCT decision-making among women diagnosed with HIV during pregnancy in Lilongwe, Malawi. The research was designed to identify factors associated with women's willingness to participate in PMTCT interventions, and to determine which factors were related to HIV disclosure by women to their primary male partners. These findings will be used to make recommendations for ways to increase the proportion of women participating in PMTCT programs and HIV-related research studies while addressing women's concerns regarding HIV disclosure and PMTCT program participation. Additionally, findings will be utilized to ensure that post-test counseling enhances facilitating factors while identifying barriers to disclosure of HIV-positive serostatus by pregnant women to their partners.

Specific Aims

Aim 1: Describe factors that influence the willingness of pregnant HIV-positive Malawian women to participate in PMTCT research and programs.

Qualitative research, utilizing focus groups and in-depth interviews with various participant groups, explores how a range of factors influence decisions about participation in a PMTCT research study by pregnant women soon after being diagnosed with HIV.

Aim 2: Explore factors that influence HIV disclosure by pregnant Malawian women to their primary male partners.

Since HIV disclosure has already been identified as one major barrier for participation in PMTCT programs, qualitative and quantitative methods are used to gain further insight into what factors influence HIV disclosure.

Background and Study Setting

Prevalence of HIV/AIDS

As of December 2007, there were an estimated 33.2 million [30.6 – 36.1 million] people worldwide living with HIV. Of those, 15.4 million [13.9 – 16.6 million] were women, and 2.5 million [2.2 - 2.6 million] were children under 15 years (UNAIDS, 2007). Approximately 10% of the world's population lives in sub-Saharan Africa; yet that is where over 68% of adults and 90% of children living with HIV reside (UNAIDS, 2007). AIDS is the leading cause of death in sub-Saharan Africa where more than 76% of global AIDS-related deaths occurred in 2007 (UNAIDS, 2007). UNAIDS estimates that in sub-Saharan Africa there are 22.5 million [20.9 – 24.3 million] adults and children living with HIV (UNAIDS, 2007). Over half (61%) of the people living with HIV in sub-Saharan Africa are women from 15-49 years. Southern Africa is the most seriously affected region within sub-Saharan Africa, accounting for 35% of all people with HIV and 32% of all new HIV infections and deaths globally in 2007 (UNAIDS, 2007).

Malawi, a densely populated country in Southern Africa, has an estimated HIV prevalence of 12.7% among adults (UNAIDS, 2007). In antenatal clinics in the capital city of Lilongwe, the most recent HIV prevalence estimate was 15% (National AIDS Commission, 2006). HIV prevalence in Malawi varies throughout the country. The prevalence among pregnant women in Malawi ranges from just below 7% at a site in the Central Region to 33% in the Southern Region (Ministry of Health and Population Malawi, 2003). National prevalence estimates from the Ministry of Health and Population for 2003 come from antenatal clinics, where the prevalence has remained around 20% (Ministry of Health and Population Malawi, 2003). In rural clinics there has been an increase in the HIV

prevalence at antenatal clinics, from 12.1% in 1999 to 14.5% in 2003 (Ministry of Health and Population Malawi, 2003). The prevalence as of 2003 among young pregnant women 15-19 years old (15%) and 20-24 years old (20%) is particularly high (Ministry of Health and Population Malawi, 2003). One study in Malawi found that "HIV/AIDS is widely recognized as the most serious disease confronting society" (Zulu & Chepngeno, 2003).

Prevention of Mother-to-Child Transmission (PMTCT) Programs

Evidence-based interventions support the effectiveness and efficacy of PMTCT interventions incorporating access to antiretroviral (ARV) medications and nutritional counseling support to reduce HIV transmission (Gaillard et al., 2004; Guay et al., 1999; Nolan, Greenberg, & Fowler, 2002). In Malawi, MTCT was 27% in infants at 6 weeks of life without any intervention (Biggar et al., 1996). Using the HIVNET 012 regimen of ARV medications (Guay, 2001), only 16% of infants at 6-8 weeks of life were HIV-positive (Taha et al., 2006). A meta-analysis showed that with triple ARVs, MTCT can be reduced to <1% transmission (The International Perinatal HIV Group, 1999).

In order to identify pregnant HIV-positive Malawian women the Malawi National AIDS Commission issued a policy statement in 2004 that required antenatal clinics to test all pregnant women for HIV at their first visit unless a woman specifically "opts-out" (Malawi National AIDS Commission, 2004). The "opt-out" system of testing presumes that all women will be tested for HIV unless a woman specifically states that she does not want to be tested and she "opts-out." Consequently, reports indicate that since April 2005 almost all (99%) women attending Call-to-Action (CTA) antenatal clinics in Lilongwe have been tested for HIV (Moses et al., 2008). All women testing HIV-positive in these antenatal clinics received post-test counseling including information about PMTCT services and research

studies available as well as counseling to encourage women to disclose their HIV-positive serostatus to their partners. Data collection for this dissertation was conducted in CTA clinics in Lilongwe.

The Breastfeeding, Antiretroviral and Nutrition (BAN) Study

With more women being tested for HIV, PMTCT programs based on research findings need to provide interventions for all time periods of HIV exposure to infants, including pregnancy, labor, delivery, and breastfeeding. There is an absence of reported research on providing ARVs either to breastfeeding women or to their infants for PMTCT postnatally. For HIV-positive mothers, ARVs may provide a method of reducing transmission while still allowing the benefits of exclusive breastfeeding. The Breastfeeding, Antiretroviral and Nutrition (BAN) Study being carried out in CTA clinics in Lilongwe, Malawi was designed to explore these issues and is the only randomized trial currently underway designed to evaluate the efficacy of using ARVs beyond 6 weeks postnatally to mothers and to infants in a breastfeeding population (Gaillard et al., 2004; C. van der Horst, Fiscus, S. Piwoz, E., Corneli, A., Moses, A., Jones, D., Adair, L., Bentley, M., Hoffman, I., Kashuba, A., Shugars, D., Bandiwala, K., Tien, H., 2003).

The BAN Study utilized a design in which HIV-positive pregnant women who intended to breastfeed were randomly assigned into treatment groups based on a 2 by 3 factorial matrix (C. van der Horst, Jamieson, & Kazembe, 2003). Women were initially randomized to receive either a high-calorie, micronutrient fortified nutritional supplement or not (2-arm). A second randomization created treatment groups, in which either the mother, the infant or neither received long-term postnatal ARVs (3-arm). The end result divided the women and infants into six groups (Figure 1.1).

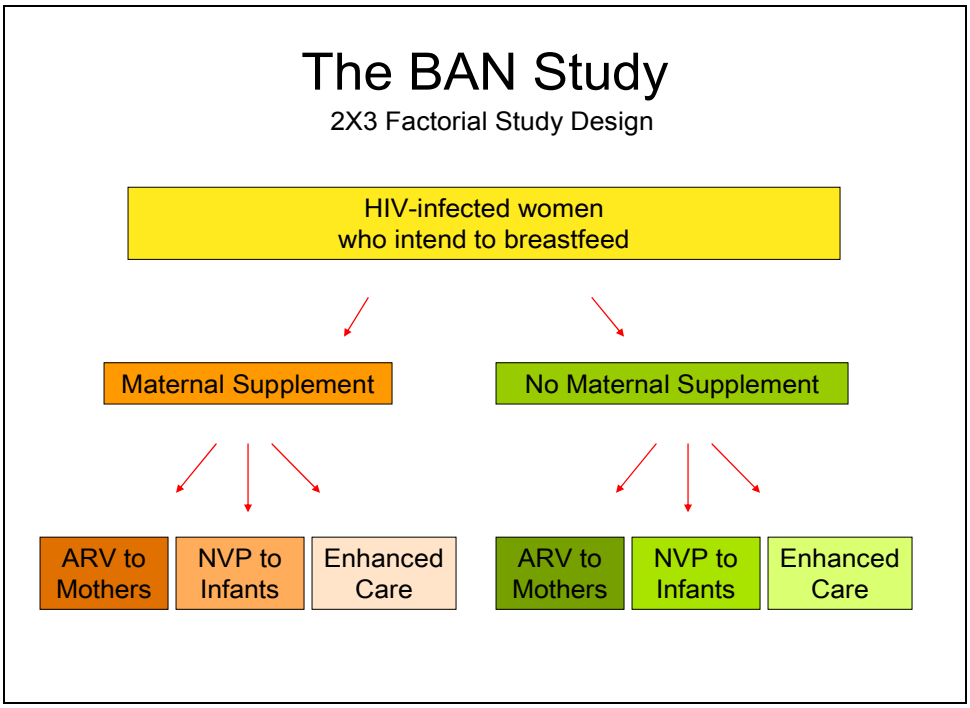

Figure 1.1. The BAN Study design.

In order to reduce the transmission of HIV in the intra- and peri-partum period, all BAN mothers received the HIVNET 012 regimen (single dose of Neviripine (NVP) [200mg] to the mother in labor and a dose of NVP [2mg/kg] to the infant within 72 hours). BAN women were offered other ARVs every 12 hours beginning at the onset of labor and up to 7 days postnatally. All BAN infants also received doses of ARVs for the same period. All BAN mothers were counseled to breastfeed their infants exclusively for 6 months, and were provided a breast milk replacement food for the infants. The ready-to use food (RTUF) was a locally produced energy-dense paste, somewhat like peanut butter, that has been used in Malawi for the rehabilitation of malnourished children both in hospitals and at home (Ndekha, Manary, Ashorn, & Briend, 2005). Women were counseled to feed the RTUF to their infants in addition to the usual weaning foods. The BAN study also provided an opportunity to study RTUF as a breast milk substitute and as a weaning food.

The BAN Study generated interest in an examination of facilitators and barriers to participation among pregnant HIV-positive women. The BAN Study aimed to enroll 15 pregnant women who met study eligibility criteria a week, yet weekly summary reports indicated that the actual number of eligible women deciding to join the study ranged between 5 and 8 per week (Chasela et al., 2005). Sufficient numbers of women eligible for BAN were at the recruitment sites; yet as of 2005 only 68% showed up for a follow-up screening visit after making an appointment. Preliminary evidence indicated that the main barriers to participation were the need to "consult the husband" and a reluctance by women to disclose their HIV status to their primary male partners.

Treatment and Care Options for Pregnant HIV-positive Women at the CTA Clinics

Figure 1.2 presents a flow diagram of choices available to pregnant women who test HIV-positive in the CTA clinics. Women chose to be tested for HIV, to join the BAN Study if they were eligible, to receive antenatal care, and to return to the CTA clinic for postnatal care. The research for Aim 1 focused on factors that influenced women's participation in the BAN Study. Quantitative research for Aim 2 was collected with women who had not joined the BAN Study and who returned to CTA clinics for postnatal follow-up care.

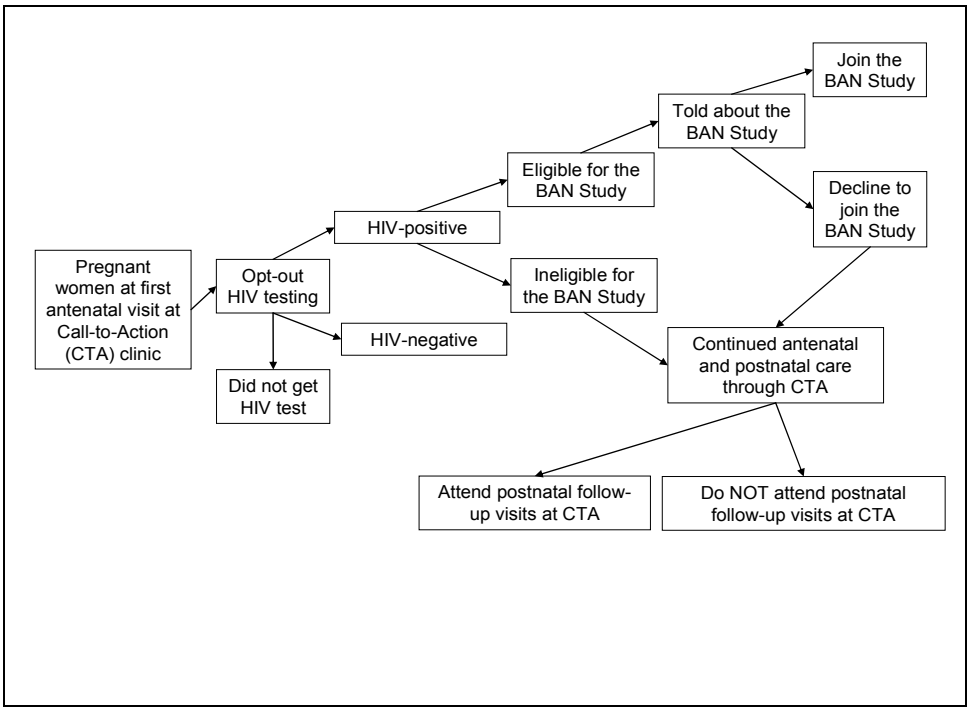

Figure 1.2. Flow diagram of possible decisions made by HIV-positive women tested at the CTA clinics.

Study Setting - Malawi

All of the research for this dissertation was conducted in the capital city of Lilongwe, Malawi. Malawi is a developing country in Southern Africa bordered by Tanzania on the north, Mozambique on the east, south and southwest, and Zambia on the west and northwest (see map in Appendix A). Although Malawi is landlocked, Lake Malawi occupies 475 kilometers along its eastern edge.

Malawi is one of most densely populated countries in Southern Africa with a population estimated at 13.2 million (World Bank Group, 2007) and total area of 94,276 square kilometers of land area (National Statistical Office and ORC Macro, 2001). Despite the high population density, the country is only 20% urban (National Statistical Office and ORC Macro, 2004) with an estimated 1.3 million people (10%) living in Lilongwe. The

economy is predominantly agricultural with tobacco, tea and sugar as the major exports. Maize and cassava are main staple foods produced domestically.

Malawi, previously called Nyasaland, was a British protectorate from 1891 to 1964 (Lwanda, 2005). In July 1964, Malawi was created as an independent state and became a republic in 1966. Dr. Hastings Kamuzu Banda was the first President of Malawi. In the course of his rule, he created a one-party state and declared himself President for Life. He remained in power until 1993 when a peaceful movement from inside Malawi and supported by the international community led to a referendum in which Malawians stated their desire to vote for a multi-party system. In 1994, Bakili Muluzi was elected President of Malawi and served two 5-year terms. In 2004, Bingu wa Mutharika was elected President.

While there are many tribes represented in Malawi, the predominant ones are Chewa (34%), Lomwe (17%), Yao (13%), Ngoni (12%) and Tumbuka (10%). Tribal structures, centered around the family, shape the social and cultural contexts in Malawi. Two types of lineage groups are found among Malawian tribes– matrilineal and patrilineal (White, Kachika, & Banda, 2005). Matrilineal groups dominate the Central and Southern regions of Malawi, while patrilineal groups live in the Northern region. These two kinship groups have many differences revolving around issues of marriage and property. Intermarriage used to be forbidden but has become accepted through recent trends in migration and changes of traditions.

In both the matrilineal and patrilineal systems, women are considered inferior to men (White et al., 2005). Women have no choice but to follow decisions made by men. The Malawian girl is socialized from birth to be "submissive, polite, put herself last and is subjected to motherhood roles at an early age, thus limiting her creativity" (White et al.,

2005). The Malawi Demographic and Health Survey (DHS) from 2004 found that the main household decision the majority of women (63%) made by themselves was what food to cook each day (National Statistical Office and ORC Macro, 2004).

The demographic and health indicators for Malawi demonstrate the effects of women's subordinate status in a resource-poor setting. The maternal mortality ratio (MMR) in 2004 was estimated as 984 maternal deaths per 100,000 live births (National Statistical Office and ORC Macro, 2004), one of the highest in the region. Almost half (45%) of women were anemic. Women living in Malawi had a total fertility rate (TFR) of 6.0.

Utilization of antenatal care is high in Malawi with the majority (93%) of women reporting having attended at least one antenatal clinic visit during pregnancy. Most (83%) women received antenatal care from a nurse or midwife (National Statistical Office and ORC Macro, 2004). Women tended to visit the clinic late in pregnancy with only 8% of women attending their first antenatal clinic visit before the fourth month of pregnancy. Half of births in Malawi were attended by a nurse or midwife, and 26% were assisted by a traditional birth attendant. Only 31% of women received medical care within 42 days after delivery (National Statistical Office and ORC Macro, 2004).

Nearly all (98%) of infants are breastfed. Just over half (53%) of infants under 6 months were exclusively breastfed (National Statistical Office and ORC Macro, 2004). The total median duration of breastfeeding was 23.2 months.

Mortality rates for infants and for children under five are very high. The 2004 Malawi DHS reported infant and under-five mortality rates of 76 and 133 deaths per 1,000 live births, respectively (National Statistical Office and ORC Macro, 2004). One in every eight children in Malawi dies before reaching their fifth birthday. Common causes of death in Malawian

children include acute respiratory infections, diarrhea, and malaria. All of these conditions are exacerbated by high rates of malnutrition. Nutritional status of children under five has not changed since the first Malawi DHS in 1992. In 2004, the prevalence of stunting (height-for-age z-scores) was 48%, wasting (weight-for-height z-scores) was 5%, and underweight (weight-for-age z-scores) was 22%. Anemia in children 6-59 months was 73% (National Statistical Office and ORC Macro, 2004).

Conceptual Model

The Social Ecological Framework (SEF) provides the structure for this research. It takes into account both individual and social influences on health. As formulated by McLeroy et al, there is a synergy between the social environment and changes in individual behavior (McLeroy, Bibeau, Steckler, & Glanz, 1988). The origins of the SEF stem from work by Bronfenbrenner on the ecology of human development (Bronfenbrenner, 1977). He explained that children develop within the context of the system of relationships that provide constant interaction. Through these interconnections or layers of environment, human development is supported and shaped.

Bronfenbrenner's work has been adapted in public health as a tool for understanding health determinants, interventions and evaluation. Multiple applications have incorporated individual and environmental factors and recognized the iterative processes and interacting levels (McLeroy et al., 1988). In the 2003 report by the Institute of Medicine entitled, Understanding Population Health and Its Determinants, the SEF is one of the main models proposed as a method to take into account the interconnected social determinants of health (Institute of Medicine, 2003).

Informed by the SEF, this research organizes potential factors related to women's willingness to participate in PMTCT programs as well as factors specifically related to HIV disclosure into levels of influence. Four levels have been identified – individual, interpersonal, institutional, and community (Figure 1.3).

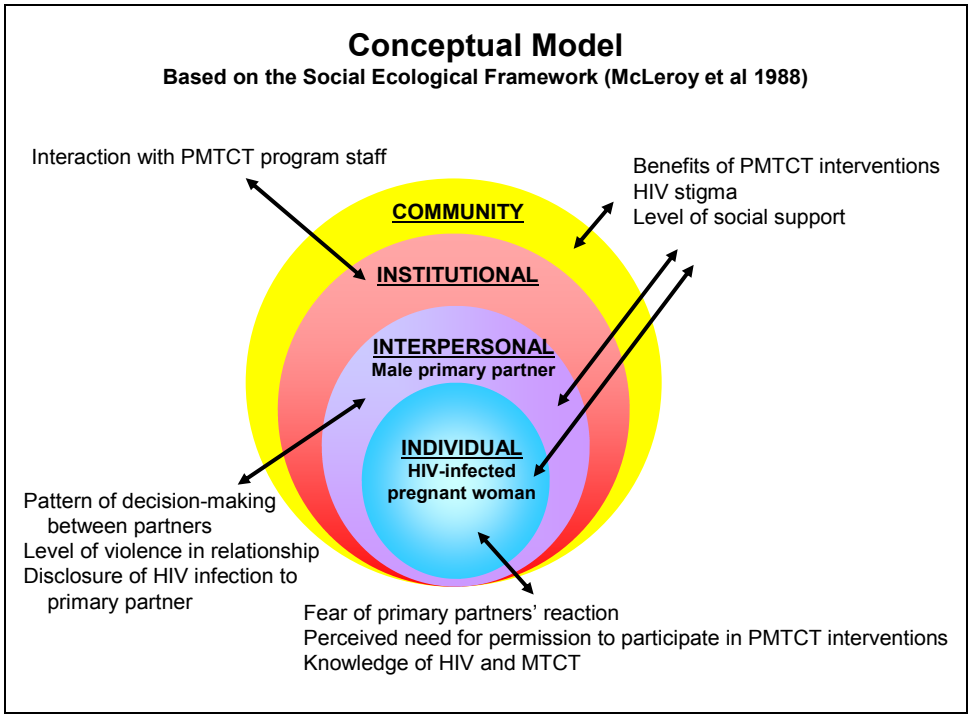

Figure 1.3. Conceptual model.

All of the factors listed on the conceptual model relate to women's willingness to participate in PMTCT interventions and to HIV disclosure by women to their primary partners. The following sections give more detail on each of the factors listed on the conceptual model.

Fear of Primary Partners' Reaction

On the individual level women feared the reaction of their partner to both HIV disclosure and to their potential participation in PMTCT interventions. In particular, women

feared violence and abandonment. In the summary paper by Medley et al, fear of negative outcomes was the main barrier to HIV disclosure (Medley et al., 2004).

Perceived Need for Permission to Participate in PMTCT

Reports from BAN staff indicated that the reason given most often for not wanting to participate in BAN was that women needed permission from their primary partners.

Knowledge of HIV and MTCT

Knowledge both of HIV as an incurable infection and of transmission of HIV from mother-to-child were important factors to explore. A study conducted in Botswana that examined the social consequences of women choosing to participate in PMTCT found that increasing information to the public about HIV and about PMTCT programs in general created an accepting environment in which more women felt free to participate in PMTCT interventions (Eide et al., 2006).

Pattern of Decision-making Between Partners

On the interpersonal level, the interaction between women and their primary partners was an important factor to explore. In terms of HIV disclosure a study in Tanzania found that women in relationships for longer periods of time (defined as more than 2 years) were more likely to disclose than women in shorter term relationships (Antelman et al., 2001).

Level of Violence in Relationship

Violence against women is both a cause and consequence of increasing rates of HIV. Violence as a cause relates to sexual violence experienced by women who are forced or coerced to have sex (World Health Organization, 2000). Once infected with HIV, women have an increased risk of becoming targets of physical, sexual and psychological abuse.

Studies have shown that HIV-positive women have more lifetime abuse than uninfected women (Maman et al., 2002).

Disclosure of HIV Status to Primary Partner

Disclosure of HIV status by women to their partners was a crucial deciding factor for women to gain access and engage in PMTCT. Research supported the fact that women who were confident and felt safe in their relationships were more likely to disclose their HIV serostatus (Medley et al., 2004). In the conceptual model, disclosure of HIV status was listed as a factor related to women's willingness to participate in PMTCT interventions, but many of the other factors on the conceptual model were related to HIV disclosure directly or indirectly. The influence of factors to HIV disclosure was explored through Aim 2.

Interaction with PMTCT Program Staff

On the institutional level, patient-provider interactions were critical in women's decisions whether to participate in clinic- based programs and studies with PMTCT interventions. The BAN Study was no exception. The interaction took into account the quality of the interaction, and the ultimate outcome of having the visit meet expectations. Social support issues also played a role in the patient-provider interaction.

Community Norms about the Benefits of PMTCT Interventions

On the individual, interpersonal and community levels, the benefits of PMTCT programs influenced participation by women in PMTCT interventions. If the community feeling was that PMTCT interventions were important, then more women were more willing to participate. Evidence from PMTCT in Zimbabwe supported the need for community support of PMTCT, even in a setting with well established MCH services (Perez et al., 2004).

HIV stigma in the Community

Fear of HIV stigma influences people not to disclosure their serostatus. The United Nations General Assembly Special Session on AIDS Declaration states that, ". . . stigma, silence, discrimination and denial . . . undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations and must also be addressed" (United Nations, 2001). UNAIDS made the statement that stigma fuels the HIV epidemic (UNAIDS, 2002) and that "HIV stigma and the resulting actual or feared discrimination have proven to be perhaps the most difficult obstacles to effective HIV prevention" (UNAIDS, 2005). Therefore AIDS stigma must be understood and reduced in order to change the course of the epidemic.

AIDS stigma is the result of the interaction between pre-existing sources of stigma and the fear of contagion and disease (Link & Phelan, 1995; Parker, 2002). Metaphors for HIV/AIDS, which equate the virus with death, horror, punishment, guilt, shame, and exclusion as "other," reinforce and legitimize AIDS stigma (Parker, 2002). HIV stigma is associated with lack of awareness and knowledge of HIV. This historical perception of HIV/AIDS that affects "others," particularly those who are already stigmatized due to their sexual behavior, gender, race or socioeconomic status, feeds the denial that some people feel. Some believe that they are not personally at risk or affected by HIV/AIDS (Parker, 2002).

Level of Social Support

Several supportive factors for disclosure, such as psychosocial support from family and peers, and husbands may enhance the likelihood that women will disclose their HIV status to their partners. Thus social support works on the individual, interpersonal and community levels. Women need acceptance and assistance in building and maintaining the

necessary skills and self-efficacy to follow the guidelines of the BAN Study (World Health Organization, 2003a). Yet international studies concede that there are few articles which address the supportive needs of HIV-positive women. Considerable evidence exists to support the reality that effective interpersonal communication is the key for people to absorb and understand new health information (World Health Organization, 2003b). Such strong communication must address emotional, psychological and personal needs in addition to providing the information necessary for women to feel ready to disclose their HIV status and have confidence in the response from their partner.

Social support has been categorized into four broad forms of supportive behaviors (Heany & Israel, 2002): emotional support (empathy, love, trust, and caring), instrumental support (tangible aid and service), informational support (advice, suggestions, and facts), and appraisal support (information to aid self-evaluation). All four of these forms of support may potentially be provided at the community and interpersonal levels. Social support can also be considered a part of the interaction with CTA clinic staff. On the individual level, social support is extremely important for HIV disclosure by women to their primary partners. In particular, a study in Tanzania found that women were more likely to disclose if they felt social support and if they personally knew someone with HIV/AIDS (Antelman et al., 2001).

Overview of Methods

The research was conducted in two phases. Phase 1 utilized qualitative research and findings from Phase 1 were used to inform the research in Phase 2. Phase 2 utilized quantitative methods. All of the data were collected by a team of trained Malawian field investigators. Data collection for Phase 1 began in June 2006 and ended in July 2006. Data collection for Phase 2 began in October 2006 and ended in May 2007. Table 1.1 displays an

overview of the research methods, eligibility criteria and recruitment locations for each participant group. In both phases, the primary sites for data collection were the CTA and the BAN Study recruitment clinics at Lilongwe Bwaila Hospital, Kawale Health Center and Area 25 Health Center.

The research for this dissertation included qualitative data including 8 focus group discussions and 54 in-depth interviews conducted among 7 participant groups and quantitative surveys with 300 HIV-positive women. For this dissertation, almost all of the data were included in the three manuscripts, except findings from focus group discussions conducted with Community Advisory Board (CAB) members, influential community members or primary partners of unknown HIV status. A number of observations were also conducted during community outreach activities and during support groups for women in the BAN Study and male support groups for the partners of women in the BAN Study. Many sections of the survey administered to 300 HIV-positive women in Phase 2 were included in this dissertation, although some data remains to be reported. Copies of all research instruments can be found in Appendices.

Table 1.1. Summary of data collected for dissertation.

Participants	*Sample size**	*Eligibility criteria*	*Recruitment location*
PHASE 1: Qualitative Data			
Community Advisory Board (CAB) Members	2 FGD	Participants in community advisory board for UNC projects	Invited all CAB members to participate and scheduled FGD with willing board members
Influential leaders in the community	2 FGD	Leaders of community organizations, committees and chiefs in areas where BAN women are recruited at Bwaila Hospital	Checked in BAN logbook for communities where BAN women recruited at Bwaila live; Chose 2 main communities with help from community nurses
Community Nurses	4 IDI	Employed by the Ministry of Health and Population as a Community Nurse in the BAN study catchment area	Targeted 3 main community nurses who worked with BAN women and 1 community nurse who provided outreach to men
Staff and nurses in CTA clinics	1 FGD 4 IDI	Employed as nurse in CTA	Recruited volunteers from Bwaila Hospital, Kawale Health Clinic and Area 25 Health Clinic
Staff and nurses in the BAN Study	1 FGD 6 IDI	Employed as part of BAN staff	Recruit volunteers from BAN site at Bwaila Hospital
Pregnant HIV-positive women eligible for the BAN Study	20 exit interviews (10 with women who decline to enroll into the BAN Study (women who need to consult husband and women who are not interested) and 10 with women who schedule a screening visit for the BAN Study) Follow-up in-depth interviews with the 10 women who scheduled screening visit for the BAN Study In-depth interviews with 10 women who consent to participate in the BAN Study	Pregnant HIV-positive women 18 years or older eligible for the BAN Study	Recruitment through the BAN study procedures at Bwaila Hospital – Identification of women by the BAN/CTA nurse
Primary partners of unknown HIV status**	2 FGD	Primary partners of unknown HIV status – men were not asked the HIV status of themselves or of their wives	In the 2 communities identified as main BAN recruitment areas – asked chiefs to invite men to a focus group
PHASE 2: Quantitative Data			
HIV-positive mothers of infants 12 months and younger	300	HIV-positive mothers 18 years or older with infants 12 months and younger who found out their HIV status during their latest pregnancy and who return to CTA clinics for follow-up care	CTA clinics at Bwaila Hospital, Area 25 or Kawale Health Centers

* IDI = In-depth Interviews; FGD = Focus group discussions (6-10 participants per FGD)
**Primary partner defined as married partner or partner in committed relationship for at least 6 months.

Description of the Manuscripts

The first manuscript addresses Aim1 and is entitled, "Perspectives of women and providers on factors that influence pregnant HIV-positive women's decision to participate a clinical trial in Lilongwe, Malawi." It presents qualitative findings from 25 health care providers and 30 pregnant HIV-positive women interviewed either on the day of diagnosis or within a week of diagnosis. Women and providers discussed facilitators and barriers to participation in the BAN Study. Findings are applicable to improving recruitment into PMTCT programs and research studies.

The second manuscript, entitled, "Factors associated with HIV disclosure patterns by pregnant HIV-positive women in Lilongwe, Malawi," addresses Aim 2 using descriptive and multivariable analysis of quantitative data from 300 HIV-positive women. The paper explores factors associated with HIV disclosure to partners, early (day of diagnosis) HIV disclosure to partners, and HIV disclosure to more than one person.

The third manuscript, entitled, "'Because he should know': Why pregnant women disclose their HIV status to their partners in Lilongwe, Malawi," addresses Aim 2 and provided in-depth qualitative results on perceptions of post-test counseling, reactions to disclosure, and reasons women did and did not disclose to their partners. This paper was based on interviews with 20 pregnant HIV-positive women interviewed within a week of diagnosis, 9 clinic nurses and 4 community nurses.

This dissertation study seeks to add to the knowledge and efforts to increase PMTCT program participation and to support women's efforts to disclose their HIV-positive serostatus to their primary male partners. Survey data described factors that influence HIV disclosure, and qualitative data provided context for participation and disclosure. The

combination of these findings obtained using mixed methods can guide the development of appropriate strategies to improve participation in PMTCT programs and to encourage HIV disclosure among pregnant women to their partners.

CHAPTER 2:

PERSPECTIVES OF WOMEN AND PROVIDERS ON FACTORS THAT INFLUENCE PREGNANT HIV-POSITIVE WOMEN'S DECISION TO PARTICIPATE IN A CLINICAL TRIAL IN LILONGWE, MALAWI

Abstract

Background: Programs for the prevention of mother-to-child transmission (PMTCT) of HIV are increasingly available in low-resource settings, yet challenges impede participation by pregnant HIV-positive women. Issues with participation emerged through the presence of the Breastfeeding, Antiretroviral and Nutrition (BAN) Study, which recruited women at antenatal clinics in Lilongwe, Malawi. Facilitators and barriers to participation were studied qualitatively from the perspectives of both women and health care providers.

Methods: Thirty qualitative interviews with pregnant HIV-positive women, and 13 interviews and 2 focus groups with health care providers (n=25) were conducted from June to July 2006, at three antenatal clinics in Lilongwe.

Results: The common facilitator for participation identified by women and providers was the desire by women to know their disease status. Women also indicated that the encouragement they received through counseling and their trust in the providers led them to participate. Providers believed the women's the high level of PMTCT knowledge contributed to their participation. The main barrier identified by women and providers was the culturally dominant role of the partner in decision-making. Women reported that being

shocked by their HIV-positive test result was also a barrier to participation in the trial. Providers identified additional barriers, including low level of PMTCT knowledge among women, misconceptions about the BAN Study, and fear of consequences from HIV disclosure to their partner. Barriers to continued long-term participation included: transportation, long waiting time at the clinic, and child care.

Conclusions: Findings highlighted the importance of post-test counseling that emphasized encouragement and promoted trust in the provider. General education for women regarding mother-to-child transmission (MTCT) and PMTCT services available also needs to be prioritized to improve participation. The cultural dominance of men identified as a barrier by women and providers needs to be addressed through outreach to men. Findings are applicable to improving recruitment into PMTCT programs and clinical trials following post-test counseling.

Background

Introduction

Children under 15 years are infected with HIV primarily through mother-to-child transmission (MTCT) that occurs during pregnancy or through breastfeeding (Newell, 2000). Interventions for the prevention of mother-to-child transmission (PMTCT) have been established and are increasingly available to women through the provision of routine antenatal care. These interventions are based on research from clinical trials conducted on reducing MTCT (De Cock et al., 2000; Gaillard et al., 2004; Guay et al., 1999; Nolan et al., 2002). In a review article, many public health challenges emerged for engaging pregnant HIV-positive women in existing maternal and child health services and for enrolling them in programs and studies designed to reduce MTCT (De Cock et al., 2000).

Barriers to participation in PMTCT programs and studies have been identified through previous research. In a comprehensive review article, HIV disclosure and involvement of male partners have been identified as major obstacles to women's participation (Medley et al., 2004). Challenges identified by health care providers in Uganda during a pilot PMTCT program were reluctance of women to be tested for HIV, loss to follow-up, non-disclosure and difficulties complying with infant feeding recommendations (Nuwagaba-Biribonwoha, Mayon-White, Okong, & Carpenter, 2007).

Facilitators to participation in PMTCT programs and research have been linked to social support from health care providers (de Paoli, Manongi, & Klepp, 2004; Eide et al., 2006). Social support has been categorized into four broad forms of supportive behaviors: emotional support, instrumental support (tangible aid and service), informational support, and appraisal support (information that is useful for self-evaluation) (Heany & Israel, 2002).

Social support has been found to increase the likelihood that women will disclose their HIV serostatus to their partners (Antelman et al., 2001) and may increase the willingness of women to participate in programs and clinical trials. Individual, private post-test HIV counseling with trained providers in a PMTCT program in Zimbabwe was critical to enable women to make the decision to participate (Perez et al., 2004). A review of literature documented the important effect of patient-provider communication on health outcomes (Roter & Hall, 1997).

Issues of participation are becoming more critical since there has been a huge increase in the number of women being tested for HIV during pregnancy, particularly in Malawi. Starting in 2004, due to evidence for reduction in MTCT and the increasing availability of PMTCT programs, national policy in Malawi mandated that all pregnant women be tested for HIV at their first antenatal clinic visit using the "opt-out" system of testing (Malawi National AIDS Commission, 2004). "Opt-out" testing means that the default option is to test everyone unless women specifically state that they do not wish to be tested. Starting in April 2005, due to "opt-out" testing, almost all (99%) pregnant women attending CTA antenatal clinics in Lilongwe, Malawi have been tested for HIV (Moses et al., 2008). The likelihood of these pregnant women being tested was high since 93% of pregnant women in Malawi receive antenatal care from a medical professional (National Statistical Office and ORC Macro, 2004).

The Breastfeeding, Antiretroviral and Nutrition (BAN) Study

Issues of participation gained prominence in the Call-to-Action (CTA) antenatal clinics in Lilongwe, Malawi through the presence of the Breastfeeding, Antiretroviral and Nutrition (BAN) Study, a prospective, randomized clinical trial of nutritional and

antiretroviral interventions designed to prevent HIV transmission via breastfeeding (Gaillard et al., 2004). In data compiled through BAN weekly recruitment and enrollment reports since May 2004, the most common reason given by eligible pregnant HIV-positive women for non-participation was their need to 'consult their husband', followed by 'not being interested' (Chasela et al., 2005). The need to address issues of non-participation in the BAN Study were targeted as particularly important since other research has documented the importance of addressing concerns about recruitment and enrollment rates in the early stages of a clinical trial (Haidich & Ioannidis, 2001).

Women were recruited for participation in the BAN Study following an HIV-positive diagnosis in the CTA clinics, where all women receive post-test counseling and information about the BAN Study. All of these women were asked to return to the CTA clinic for either continued antenatal care or, if they express interest, to learn more about the BAN Study. Enrollment in the BAN Study was predicated on fulfilling all of the eligibility criteria, which included being at least 18 years old, gestation of 32 weeks or less, intending to breastfeed, no previous use of ARVs, no tuberculosis or other serious illness (Gaillard et al., 2004; C. van der Horst, Fiscus, S. Piwoz, E., Corneli, A., Moses, A., Jones, D., Adair, L., Bentley, M., Hoffman, I., Kashuba, A., Shugars, D., Bandiwala, K., Tien, H., 2003). If women did not match all the criteria, they were still offered PMTCT program services through the CTA clinic.

Malawi Context

As shown by accounts from the BAN Study recruitment reports, women's decision to participate in the program or to join the trial depends on consulting their male primary

partner (almost always a husband) and gaining permission from him. In Malawi, the traditional value system assigns women limited power within their marriages (Musopole, 2006; White et al., 2005). Manifestations of women's subordination include acceptance of intimate partner violence, adultery, and lack of access to property. Men make the majority of the decisions in the household and women are socialized to think of themselves last (White et al., 2005). The majority (70%) of male partners are solely responsible for decisions for their wives' health care (National Statistical Office and ORC Macro, 2004). The family is an important structure in Malawian culture. Family includes the nuclear and the extended family which is linked by blood and by marriage. These family affiliations are also connected along tribal lines.

Tribal structures shape the social cultural context in Malawi. Tribes are divided into two lineage groups – matrilineal and patrilineal (White et al., 2005). Matrilineal groups dominate the Central and Southern regions of Malawi, while patrilineal groups live in the Northern region. These two kinship groups have many differences revolving around issues of marriage and property. In the matrilineal system the man moves to the wife's family. The children belong to the woman. In the patrilineal system the man pays for the wife and moves her to his family. Everything, including the children and all property, belongs to the man. The wife's independence is limited although she may have more security if anything happens to her partner since the man's extended family must care for her (Mvula & Kakhongwa, 1997; White et al., 2005). In the past, intermarriage between these two systems was not allowed. Due to migration and loosening of traditions in Lilongwe and other urban centers, more Malawians are intermarrying (White et al., 2005).

In both the matrilineal and patrilineal systems, women are considered inferior to men (White et al., 2005). Examples of practices based on cultural subordination that expose women to HIV, irrespective of tribal affiliation, include sex as a cleaning ritual before and after the death of a partner, women as property for male relatives after death of the partner, lack of property leading women to become sex workers, and polygamy which allows new wives to bring possible sexually transmitted infections (STIs) to a larger relationship (Kondowe & Mulera, 1999).

In Malawi, women's decision to participate in the program or to join the trial also depends on their interaction with nurses who provide post-test counseling. The support women receive through counseling is crucial in their decision to participate. A process evaluation with BAN Study nurses documented the fact that they provided appropriate information through counseling on infant feeding that was of high quality for women who joined the BAN Study (Ferguson, 2006). Nurses provided 90% of the information dictated by the study protocol. The nurses also adhered to non-verbal counseling elements, including maintaining eye contact, facial expressions and body postures expressing empathy. Although the health care providers who conduct post-test counseling are a different group and have not been directly evaluated, there are precedents for good quality and appropriate counseling in these clinics.

The aim of this study was to explore a range of factors that influence decisions about participation in the BAN Study by pregnant women soon after being diagnosed with HIV in Lilongwe, Malawi. The interaction between women and providers emerged as an important factor in previous research. Therefore, this paper compared perspectives of women and health care providers on facilitators and barriers to participation in the BAN Study. Findings

can also be applied to improving participation into PMTCT programs, where recruitment is initiated through post-test counseling.

Methods

Overview

This paper presents data from 30 pregnant HIV-positive women interviewed either on the day of diagnosis or within a week of their HIV diagnosis, and with 25 health care providers, 13 of whom participated in individual interviews and 12 of whom were part of two focus group discussions. The study participants were recruited between June and July 2006 from the CTA clinics at Bwaila Hospital in Lilongwe, Malawi using purposive sampling methods.

Recruitment and Eligibility

Ten pregnant HIV-positive women who expressed no interest in joining the BAN Study were interviewed on the day of diagnosis about barriers to participation. Ten pregnant HIV-positive women who were interested in joining the BAN Study were interviewed, once on the day of diagnosis and a second time within a week of diagnosis. Both of these interviews were conducted before the women were enrolled in the BAN Study. Data from the second interviews, conducted within an average of 5 days of diagnosis, were included in this paper. An additional ten women were interviewed on the day they consented to join the BAN Study, which was within a week of the day they were diagnosed with HIV. The timing was the same for the interviews with the women who scheduled follow-up interviews and with the women who were interviewed on the day of consent; only the method of scheduling the interview differed. The women were recruited either from the CTA clinic or from the BAN Study clinic.

A total of 25 health care providers participated in this research. Thirteen interviews were conducted with health care providers: 4 with CTA nurses, 5 with BAN Study nurses and staff members, and 4 with community nurses. In addition, 2 focus group discussions were conducted at Bwaila Hospital, one with 6 CTA nurses and one with 6 BAN nurses. None of nurses who were interviewed individually participated in the focus group discussions.

Health care providers were approached by research staff to schedule an appointment at a convenient time. The focus group discussions were scheduled on days convenient for all the participants.

Development and Content of the Interview Guides

The instruments were designed to gather information from different perspectives on facilitators and barriers to women's participation in the BAN Study. The content of interview and focus group guides was established after a review of the literature on participation in PMTCT programs and clinical trials. Informal discussions with BAN Study administrators also aided in creating appropriate instruments.

The interview guides for pregnant women included questions about women's responses to their HIV positive test result, knowledge of HIV and MTCT, facilitators and barriers to disclosure, social support, expectations and history of violence in their intimate relationships, interaction with the clinic, and specific aspects of the BAN Study. The instruments for health care providers focused on post-test counseling messages given to pregnant women about the BAN Study, knowledge and misconceptions about MTCT, advice given to women on HIV disclosure, and influence of partners and community members on

women's decision to participate in the PMTCT program. Demographic information was collected from all participants.

Data Collection Methods

All members of the research team were bilingual in English and Chichewa, the predominant language spoken in Central Malawi. One-on-one semi-structured interviews with women were conducted in Chichewa. Health care providers chose whether to be interviewed in English or Chichewa, and interview guides were available in both languages. The two focus group discussions were conducted English. All research was conducted at the clinics in private rooms. The interviews and focus group discussions were recorded with the consent of the participants. Pregnant women received a package of iodized salt and bars of soap for their participation. Health care providers received stationery and a beaded AIDS pin.

The research team was composed of field investigators who all had previous experience with qualitative research. Their skills were enhanced through a two week, in-depth training on research methods and on the methods related to this study. All the guides were pre-tested for understandability, and review sessions were scheduled throughout the data collection period to share experiences and to make necessary modifications to the guides. Each field investigator was responsible for creating an English transcript with field notes for the interview they conducted. For interviews conducted in Chichewa, each field investigator simultaneously transcribed and translated the interview. Moderators of the focus group discussions created the English transcript with notes. The entire research team read

and reviewed all transcripts for accuracy and discussed salient issues of cultural context that emerged from the data.

Data Analysis

A codebook was created, that included deductive codes based on the research questions. Transcripts were systematically read by investigators to identify common themes and to form conclusions regarding factors that influence participation. Two investigators independently analyzed each transcript and assigned codes. They met and compared their codes, coming to a consensus if there were differences. The recorded interviews and focus group discussions were coded using MAXQDA 2007 (Marburg, Germany, 2007). Inductive codes that represented themes that emerged from the data. The final codebook included both the deductive and inductive codes. Code reports for relevant codes were created for women and health care providers. Themes emerged from the reports on facilitators and barriers to participation. Additional codes and sub-codes were added through the iterative process of reviewing the coding reports. Illustrative text-based quotes were gathered to support each theme (Miles & Huberman, 1994; Ulin, Robinson, Tolley, & McNeil, 2005; Williamson, 2005). Initially results were written for women and providers separately. Then results were compared within groups and between pregnant women and health care providers, as presented in this paper.

The research was approved by Institutional Review Boards at the University of North Carolina (UNC) at Chapel Hill, the US Centers for Disease Control and Prevention, and in

Malawi by the National Health Sciences Research Committee in the Ministry of Health. Informed consent was obtained from all participants.

Results

Demographic Characteristics

Table 2.1 displays some general demographic characteristics of the pregnant HIV-positive women and health care providers who participated in this research. Women's average gestation at the time of the interview was 21.0 weeks. The participants' mean parity was 3.1 pregnancies, and their mean number of living children was 1.5. Most of the women (n=23) had no employment outside of their homes. The women had spent an average of 8.7 years living in Lilongwe. The majority of women's partners (n=27) worked in Lilongwe. Only one woman's partner had no job.

Only two of the providers were men. All of the providers were employed by UNC Project in Lilongwe and had been working for UNC for an average of 2.7 years. Only two of the health care providers worked at CTA clinics in Lilongwe other than the one at Bwaila Hospital.

Table 2.1. Demographic characteristics of pregnant HIV-positive women and health care providers.

	Pregnant HIV-positive women (n=30)	*Health care providers (n=25)*
Mean age (years)	25.2	35.0
Number married	29	24
Tribal affiliation:		
Matrilineal	24	8
Patrilineal	6	17
Religion:		
Christian	24	25
Muslim	6	0
Educational attainment:		
No education	2	0
Primary school	19	0
Secondary school	9	2
Above secondary school	0	23

Facilitators to Participation

The following themes were identified as facilitators to participation: 1) the desire to know disease status, identified by both women and providers; 2) women's high level of PMTCT knowledge, identified by providers only; and 3) encouragement through counseling and trust in health care providers, identified by women only. The following sections give more details about each of these themes.

Table 2.2 displays a summary of the facilitators and barriers to participation from the perspectives of the pregnant HIV-positive women and of the health care providers.

Table 2.2. Factors that influence participation in the BAN Study.

	Perspectives of pregnant HIV-positive women	*Perspectives of health care providers*
FACILITATORS	Desire to know disease status and progression	
	Encouragement through counseling and trust in health care providers	Women's high level of PMTCT knowledge
BARRIERS	Culturally dominant role of partner	
	Shocked reaction to HIV test result	Women's low level of PMTCT knowledge
		Misconceptions about the BAN Study
		Fear of consequences of HIV disclosure to their partners

Desire to Know Disease Status and Progression

Pregnant HIV-positive Women

The most common reason given by pregnant women for wanting to participate was a variation on the following response, "I wanted to know how I am in my body" (*Woman consenting to join the BAN Study*) indicating a general interest in what types of diseases, if any, they had. Women's initial reaction to their HIV-positive test result was disappointment coupled with a fatalistic attitude. Although very few women explicitly mentioned their

unborn child as a reason for participating, women did gain a sense of hope when they found out about their options for continued counseling and support, as illustrated by the following quote:

> When I was told that I am positive that's when I was worried, but when I thought about it later I knew I had done the best thing because I have known instead of just staying maybe I could have been ill on and off, but now I know that prevention is there (*Woman consenting to join the BAN Study*).

Women stated that they were thinking of the future and trying to make sure that if they needed help, they would have easy access to counseling support and medical care through the clinic. As one woman explained, " . . . when I know if there is any problem they should know how they can help me very quickly" (*Woman consenting to join the BAN Study*).

Health Care Providers

Health care providers felt that women wanted to participate to obtain medical care for themselves. One provider echoed a typical statement from the women by saying, "they come to know 'where am I'"(*Health care provider for the BAN Study*), by this, they meant that women wanted to monitor the existence and progression of any diseases they might have.

Women's High Level PMTCT Knowledge

Health Care Providers

Providers consistently stressed the fact that women who participated were those who had a high level of understanding of the rationale and advantages of the BAN Study. One community nurse stated that the women who participated were "those who have understood the benefits clearly" (*Community nurse*).

Providers felt that women participated specifically for the health of their unborn child and to prevent transmission of HIV from mother-to-child. One provider explained that, "their goal is they don't want to transmit the virus to their babies so this is what they are looking for" (*Health care provider for the BAN Study*). A few providers mentioned the appeal of breastfeeding counseling support for women, since according to recommendations from the World Health Organization (WHO) HIV-positive women in Malawi are counseled to exclusively breastfeed for 6 months and then wean the child (World Health Organization, 2001). Providers placed importance on their role to impart specific PMTCT information to women for them to be willing to participate.

Encouragement through Counseling and Trust in Providers

Pregnant HIV-positive Women

Women expressed their sense of feeling reassured through emotional support offered by the providers at the clinic. One woman explained that she received, "words of encouragement . . . so we try to be brave" (*Woman consenting to join the BAN Study*). For another woman, her initial reaction was to flee when she heard that she was HIV-positive, but then she was convinced to participate since the provider told her, "I've seen that a lot of people are being helped and [they] are having good babies" (*Woman consenting to join the BAN Study*). The women trusted that an HIV-positive woman could give birth to a healthy and HIV negative baby, "if you follow the advice from the hospital" (*Woman consenting to join the BAN Study*).

When women were asked in general about who supports them or counsels them, they often talked about family or other trusted people in their lives. One woman explained that she disclosed to her relatives, as the provider recommended, so that she would have support

from them if she were ill in the future. As she said, "maybe sometimes I can suddenly get sick while my husband is not there so [my relatives] should know about it" (*Woman consenting to join the BAN Study*).

Barriers to Participation

Both women and providers reported that the culturally dominant role of male partners was the main barrier to participation. Women talked about their shocked reaction to the HIV-test result as a barrier to participation. Providers believed that there were three additional barriers: women's low level of PMTCT knowledge, misconceptions about the BAN Study, and fear of consequences of HIV disclosure to partner. The following sections offer details about each of these themes.

Culturally Dominant Role of Partner

Pregnant HIV-positive Women

Barriers to participation were solicited from the ten pregnant HIV-positive women who were not interested in the BAN Study. Eight of these women said they needed to 'consult their husband;' as one woman said, "I can't do anything on my own without my husband knowing" (*Woman not interested in the BAN Study*). Some of these women said they planned to return to join the program if given permission by their partner. The other two women of this group simply said that they were 'not interested' and did not state a specific reason for their lack of interest. It is not known whether any of these women returned to the clinic to participate.

Among the 20 women who were initially interested in participating, five said that they had to gain permission from their partners. Despite their stated need to 'consult their husband,' these five women were willing to schedule an appointment for another counseling

session to find out more about the BAN Study. These five women did not have different demographic characteristics than the other women.

The status of women in Malawi, as determined by culture, dictated that women generally talked to their partners about most things. Women did reveal, with probing, that there are certain "things which I have only discussed with my fellow women" (*Planning to disclose to partner*). These things include childbirth and other gender-specific events.

Health Care Providers

Providers interviewed for this study concurred with previous reports that the main reason women stated that they did not want to participate was that the women "want to consult their husband" (*Health care provider for the BAN Study*). In Malawi, men are the heads of the household, as illustrated by the clinic nurses:

> In our culture the husbands are the decision makers (*Health care provider in the CTA clinic*).
>
> All the thinking is done by husbands. Even if it were something bad, and the husband gives it a nod, they will do it (*Health care provider in the CTA clinic*).
>
> Many of our women they are not empowered that they can do things on their own (*BAN Study nurse in the focus group discussion*).

One provider recommended that men come to the clinic to be informed of choices for their wives at the reproductive health clinics since "the mother can not make a decision on her own because the bread winner is at home" (*Health care provider for the BAN Study*). One provider talked about how women need bravery to decide about participating without consulting her partner; "There are very few women who are brave enough to make decisions

on their own . . . the majority rely on their husband's decision" (*Health care provider for the BAN Study*).

Providers felt that some women really did want to consult their partners, while others believed that women used this statement as an excuse since they feared consulting and disclosing their HIV-positive status to their partners. The following provider gave an example of this process:

> Usually those who say no they say they want to consult husband and so if they don't come back maybe the husband has indeed said no, or they had already made the first decision because they fear the husband (*Health care provider in the CTA clinic*).

Shocked Reaction to HIV Test Result

Pregnant HIV-positive Women

Women talked about how shocked and nonfunctional they felt on the day of diagnosis. One woman explained that, while she was interested in participating, she could not focus on the advice from the nurse:

> The nurse] advised me but I couldn't get what she was saying . . . I was thinking of many things . . . I was finding it hard in my heart . . . I didn't know what I would tell my husband (*Woman consenting to join the BAN Study*).

Women's Low Level of PMTCT Knowledge

Health Care Providers

Providers felt that women do not participate due to a low level of understanding and lack of information about MTCT. In particular, according to WHO recommendations for Malawi, HIV-positive mothers were counseled to engage in exclusive breastfeeding of their

infants for six months and then wean their children so that they do not breastfeed at all (World Health Organization, 2001). Low literacy level was mentioned, as well as misunderstanding about these infant feeding recommendations, as illustrated by the following series of quotes:

> Some people understand issues more quickly than others who take a bit of time (*Health care provider in the CTA clinic*).
>
> Illiteracy, that they are not educated so they can't make a concrete decision (*Health care provider in the CTA clinic*).
>
> So some don't join because of lack of understanding, as they keep saying, 'What will I give to my child when I stop breastfeeding?' (*BAN Study nurse in the focus group discussion*)

Women's lack of initial understanding of MTCT and PMTCT resulted in confusion when women told their partners about options for PMTCT at the clinic, including the opportunity to join the BAN Study. As one community nurse explained:

> We have noted is that our women do not explain the issues properly and usually on our visits the men say . . . had [she] explained like this we wouldn't have had the problem [with her participation] (*Community nurse*).

Thus this theme is tied together with the cultural dominance of the partner. If women were not able to explain why they should participate, then they had a decreased chance to obtain permission to join. One provider said that one partner told her, ". . . it is out of ignorance that other men resist" (*Health care provider for the BAN Study*).

Misconceptions about the BAN Study

Health Care Providers

Providers reported that women do not participate due to misconceptions and rumors about tests required as part of the BAN Study. This lack of accurate information was illustrated by two community nurses who said,

> Most of them, it's because of the misconceptions that they hear, especially that blood will be taken. Certainly they don't know the exact amount of blood taken (*Community nurse*).
>
> Some women don't give enough information and some of them give wrong information. This other woman told the husband that three [soda] bottles of blood will be drawn . . . So the husband said should this child develop anemia you should know that we will be parting ways (*Community nurse*).

Community nurses explained that they show women the small amount of blood needed for various tests, yet they acknowledge that seeking care during pregnancy and giving blood is strongly culturally influenced

Fear of Consequences of HIV Disclosure to Partner

Health Care Providers

The majority of providers believed that many women do not disclose their HIV status to their partners and that disclosure was a barrier to participation. Providers believed that women fear the negative consequences of HIV disclosure to their partners, as illustrated by the following quotes:

> Most of the women do not tell their results to their husbands. And if they come every now and then for visits the husband is very surprised and start asking so many questions, until he discovers that it is because of [his wife's HIV-positive status]. That's when divorce comes in (*CTA clinic nurse in the focus group discussion*).
>
> He will say, 'It's you who brought this HIV in this house.' In the end marriages break away and that is the reason some women don't disclose their result (*Health care provider for the BAN Study*).

Barriers to Continued Participation

Pregnant HIV-positive Women

Women did not anticipate barriers to their continued participation. The biggest obstacle foreseen by women was possible problems with transportation to the clinic. The very few women with employment outside of the home were not worried about missing appointments at the clinic due to their work schedule. A few other women were worried about missing appointments due to feeling sick or needing to attend a funeral.

Health Care Providers

Some barriers to continued participation were suggested by providers. These included problems with transportation, long wait times at the clinic and problems with care for other children. As one provider stated, "the best incentive we can give them is to respect their time, to make them stay at the clinic for the shortest possible time" (*Health care provider for the BAN Study*). Providers emphasized the efficiency of the clinic, even when women sought care when they were ill; "we also tell that even if they get sick, they will get medical help quickly and efficiently… without standing on the lines" (*Health care provider in the CTA clinic*).

Discussion

Though the research for this paper was focused on participation in the BAN Study, findings may also be applicable to recruitment practices into PMTCT programs. Both recruitment procedures are conducted through post-test counseling to pregnant HIV-positive women, and only one of the findings, the barrier about misconceptions, was specific to the

BAN Study. Even this finding can be applied to PMTCT programs since community perceptions of programs can be just as influential as those about research studies.

Increasing participation in PMTCT programs and in clinical trials requires enhancing facilitators and minimizing barriers, including those identified by both women and providers in this paper. In terms of facilitators, women and providers both saw the desire to know the woman's disease status and progression as a motivator for participation. A woman's interest in knowing if she had a disease may have been a motivator for testing; but, once a woman was diagnosed with HIV, then ascertaining other information about the disease progression and having access to preventive services were facilitators for participation. Findings from formative research conducted for the BAN Study found that women understood the link between infection and their health status (Bentley et al., 2005). Fortunately since July 2006 in the CTA clinics in Lilongwe, women have had access to CD4 count testing, which allows for staging of HIV and referral for treatment (Moses et al., 2008).

Women were attracted to participate in the BAN Study for the emotional support they received through post-test counseling. The promise of continued encouragement from a trusted health care provider facilitated participation. The importance of an encouraging attitude along with the delivery of appropriate information by health care staff was found to be a main component of a PMTCT program in Botswana (Eide et al., 2006). Providers need to be educated that the emotional support, defined as empathy, love, trust, and caring (Heany & Israel, 2002), component of their counseling with women is essential to a woman's willingness to participate.

In terms of barriers, women and providers agreed that the main barrier to participation was cultural dominance of their partners. This was evident in the stated need by women "to

consult their husband." Research with women in Botswana on the social consequences of participation in PMTCT programs found that only a third of the 52 women interviewed had support from their partners (Eide et al., 2006). Culturally in Malawi, power is assigned to men as the decision-makers in the household (White et al., 2005). Male dominance through culture "removes choice" from women (Lwanda, 2005). The majority (70%) of men have complete control over their wives' health care decisions (National Statistical Office and ORC Macro, 2004), yet there is also a woman's realm that is maintained and guarded by women; "women accept certain duties as traditional and they will be the first to object if those obligations and duties are interfered with, even if they are servile" (Lwanda, 2005). Post-test counseling could be modified to suggest that women schedule an appointment to learn more about the BAN Study without consulting their partners since this decision can be justified by being in the female realm related to pregnancy and childbirth. Then women could have the chance to 'consult their husband' and return to the clinic for more information.

Despite the belief by providers that women do not disclose, pregnant HIV-positive women do disclose their HIV status to their partners (Bobrow, 2008b). Findings from the 20 pregnant HIV-positive women interviewed for this paper who were interested in participating revealed that 13 of them had disclosed to their partners at the time of the interview, and of those 13 women 5 of them reported disclosing on the day of diagnosis. Of the 7 women who had not disclosed to their partner, 6 were planning to disclose. These Malawian women were not hiding their HIV-positive status and were not deterred by fear of violence. Partners may also be a source of support for participation in the program. As men have the power in relationships, PMTCT services and studies must also target them to gain their support for women's participation.

Outreach to men must be coupled with more education for women. The providers identified a high level of PMTCT knowledge as a facilitator and a low level of PMTCT knowledge and understanding as a barrier to participation. Formative research for the BAN Study suggested that women were well informed about issues of HIV, nutrition and infant feeding (Bentley et al., 2005); thus, the provider's perception about women's lack of initial understanding of MTCT and the BAN Study may be attributable to women's state of shock on the day of diagnosis. Nevertheless, providers believed that women's level of comprehension before coming to the clinic and their knowledge of the services available to them at the clinic may have played an important role in their willingness to participate. Outreach education to women by health care providers who are trusted as a source of information could address these barriers to participation. In addition, offering couples counseling at the clinic has been shown to increase the uptake of preventive interventions (Farquhar et al., 2004).

Outreach to women should also address the misconceptions and the need for blood specimens by participants in the BAN Study, both of which were seen as barriers by the providers. In Malawi beliefs around blood are very culturally powerful, particularly since people believe that a person only has a certain amount of blood and that a person can not make more (Mataya, 2007). Efforts to address misconceptions in the community about the quantity of blood needed as well as general misinformation about the BAN Study have been prioritized by UNC Projects with the initiation of community education sessions, male motivation sessions and peer support groups. These are perceived as being beneficial for addressing misconceptions and general issues of HIV stigma. These interventions have also

increased the knowledge of HIV testing in the antenatal clinics and participation in the PMTCT program at the CTA clinics.

The commonalities and differences in facilitators and barriers to participation identified by women and providers allow for appropriate targeting of interventions to each group to increase participation in PMTCT programs and research studies. Emphasizing training for providers who counsel women should be a priority since women value the connection and encouragement they received from providers as a facilitator to participation. Providers should also be trained to anticipate and manage the possibility of a shocked reaction by women to their HIV positive test result. Lessons from other counseling protocols on the management of delivering sensitive news could be applied to post-test counseling training for these providers. Enhancing the training for providers has the potential to build on the facilitators and address the barriers identified in this study. This belief is supported by the evidence from the process evaluation of infant feeding counseling conducted among BAN Study nurses which indicated that nurses follow their training and delivered 90% of the information required by the study protocol (Ferguson, 2006).

The PMTCT program in the CTA clinics in Lilongwe has been in existence since April 2002 (Moses et al., 2008). Trust in the program may have increased over time. Thus responses by both women and providers may have differed if this study had been conducted earlier. In addition, the BAN Study has had success in increasing recruitment and enrollment through community outreach activities and support groups (Bobrow et al., 2007).

The results identified barriers to continued participation in the BAN Study, specifically issues of transportation, long wait times at the clinic, and child care for existing children. These are important even though they are not barriers to initial recruitment and

enrollment. These obstacles to continued participation have been documented in a southern district in Malawi where the progressive loss to follow-up was up to three-quarters of the original cohort participating at 6 months after giving birth (Manzi et al., 2005). One proposed solution was to decentralize PMTCT services from the District Hospital to satellite clinics in order to reduce congestion at the hospital and to give women shorter travel time.

The findings from this study may be subject to a number of limitations. One omission in content emphasis was that women and providers were not asked specifically about the influence of current and previous illnesses on women's decision to participate in the PMTCT program. Illness could have been an important factor as women who had been ill with opportunistic infections may have been more likely to follow the instructions from the clinic and thus more likely to participate and disclose their HIV status. Another limitation may be variations in interviewing styles and depth of discussion for each emerging factor, even though the same interview and focus group guides were used for the various participant groups.

Future research on this topic may benefit from observations of the post-test counseling sessions to provide more evidence and context for effective counseling. Following this research, training and practice sessions for providers focusing on offering emotional support could be implemented and evaluated. In addition, this area of research would benefit from further exploration of participation by women in PMTCT programs in the context of voluntary counseling and testing (VCT) for couples, outreach for men and more education for women.

Another related topic for future research is the disconnect between women and providers about HIV disclosure in this context. It is interesting to note that women reported

disclosing their HIV-positive status to their partners, often on the day of diagnosis; yet providers believed that HIV disclosure was a major barrier to participation.

The findings highlight the influence of facilitators and barriers on women's participation in the BAN Study, which are applicable to PMTCT programs. The responses of the women and the providers have emphasized the benefit of post-test counseling that provides emotional support for women. The importance of the male partner as the decision-maker is a focal point for enhancing the facilitators and addressing the barriers. Recommendations and pilot programs that include male partners in couples' VCT for HIV (de Paoli et al., 2004; Eide et al., 2006) should be explored further.

This study highlighted the need for more education and encouragement of women by health care providers for their participation in PMTCT programs. After assessment, counseling needs to be targeted to address the needs of the women. Outreach to men should also be a priority for partners to encourage them to support women to participate. Findings from this study are applicable to issues of participation by women in PMTCT programs and in HIV-related research and clinical trials where women are recruited starting on the day of HIV diagnosis.

CHAPTER 3:

FACTORS ASSOCIATED WITH HIV DISCLOSURE PATTERNS BY PREGNANT HIV-POSITIVE WOMEN IN LILONGWE, MALAWI

Abstract

Background: Disclosure of serostatus by pregnant HIV-positive women to their partners is essential for increased support and participation in prevention of mother-to-child transmission (PMTCT) programs. Factors influencing the likelihood of HIV disclosure to partners, early disclosure to partners (on day of diagnosis), and disclosure to more than one person were examined.

Methods: Structured interviews were performed with 300 HIV-positive women with infants 12 months and younger who tested HIV positive in three antenatal clinics in Lilongwe, Malawi who returned between October 2006 and May 2007 for follow-up care. Women were selected as a probability sample and gave informed consent.

Results: Most women (90%) reported disclosing their HIV status to their partner, and many (73%) did so on day of diagnosis. Of women who disclosed their status, almost half (47%) told more than one person. Among women, 49% believed they were infected by their partner and 47% reported being sexually coerced by their partner in the past year. Women who believed they were infected by their partner were more likely to disclose to their partner (OR=2.82, 95% CI 1.17, 6.81). Women tested for HIV prior to their partner were more

likely to disclose early (OR=2.26, 95% CI 1.14, 4.48) and to more than one person (OR=2.58, 95% CI 1.39, 4.78). Women who perceived HIV stigma were less likely to disclose (OR=0.23, 95% CI 0.08, 0.67) or to disclose early (OR=0.54, 95% CI 0.30, 0.96). Women were more likely to disclose to more than one person if they were sexually coerced by their partner in the past year (OR=1.78, 95% CI 1.01, 3.11).

Conclusions: Participants had high rates of HIV disclosure to their partners, particularly on the day of diagnosis. Women's perceptions of the source of their HIV infection and of testing before their partners were powerful motivators for disclosure. Post-test counseling should concentrate on facilitating factors, such as enhancing good negotiation between partners, while identifying barriers, such as sexual coercion and HIV stigma.

Background

Prevention of mother-to-child transmission (PMTCT) programs are crucial in the worldwide fight against the spread of HIV. In sub-Saharan Africa, the world's most severely affected region, the epidemic disproportionately affects women, who comprise 61% of the adults living with HIV (UNAIDS, 2007). Consequently, the vast majority (90%) of HIV-positive children under 15 years worldwide live in sub-Saharan Africa (UNAIDS, 2007).

Malawi, a densely populated country in Southern Africa, has an estimated HIV prevalence of 12.7% among adults (UNAIDS, 2007). In antenatal clinics in the capital city of Lilongwe, the most recent HIV prevalence estimate was 15% (National AIDS Commission, 2006) an estimate which is likely to be accurate given that 93% of pregnant women receive antenatal care from a medical professional (National Statistical Office and ORC Macro, 2004). The prevalence of HIV among pregnant women in Malawi ranges from just below 7% at a site in the Central Region to 33% in the Southern Region (Ministry of Health and Population Malawi, 2003). The most recent Demographic and Health Survey (MDHS 2004) found that more adult women 15 to 49 years were HIV positive than men, in both rural (13%) and urban (18%) areas of Malawi (National Statistical Office and ORC Macro, 2004). Young women are particularly at risk.

Research has identified effective methods to prevent the transmission of HIV from mother to child, including targeted provision of antiretroviral medications (ARVs) and practices for infant feeding (Gaillard et al., 2004; Guay et al., 1999). Using ARVs (HIVNET 012 trial regimen (Guay, 2001)) for PMTCT reduced the mother-to-child transmission (MTCT) rate in Malawi from 27% (Biggar et al., 1996) to 16% (Taha et al., 2006). These proven interventions have become components of PMTCT programs.

The success of PMTCT programs is dependent upon identification of pregnant women with HIV. More pregnant women are being tested for HIV with the adoption of the "opt-out" system of testing, where the default option is to test everyone unless an individual explicitly "opts-out." In Malawi "opt-out" testing became national policy in 2004 for women attending their first antenatal clinic visit(Malawi National AIDS Commission, 2004) This change dramatically increased the number of women with access to HIV testing during pregnancy. Starting in April 2005 reports from the antenatal clinics in Lilongwe have indicated that almost all (99%) of women attending the clinics have been tested for HIV (Moses et al., 2008). Malawian women living in Lilongwe have more opportunities for HIV testing than women in rural settings and have the potential to access prevention services to protect their infants.

While more PMTCT programs exist now, challenges to engaging women in these programs and in HIV-related research studies have been identified (De Cock et al., 2000). Disclosure of HIV status by pregnant women to their primary male partners has been identified as a major barrier to participation in PMTCT programs (Medley et al., 2004). In antenatal care settings in Lilongwe, HIV-positive pregnant women are counseled on the day of diagnosis to disclose their HIV status to their partners and to others. This post-test counseling is designed to encourage women to participate in PMTCT programs available through the clinics.

A summary of studies on rates, barriers and outcomes of HIV status disclosure (Medley et al., 2004) found a wide of range (16.7% to 86%) in the disclosure rates reported by women in developing countries. In addition, a more recent study in the Ivory Coast found that only 46.2% of HIV-positive women tested during pregnancy disclosed to their partners

during a two-year interval after diagnosis. Among those who disclosed specific events led to HIV disclosure, including the end of pregnancy, weaning practices, and resumption of sexual activity (Brou et al., 2007).

In order to study factors that influence HIV disclosure, the social ecological framework (SEF) (McLeroy et al., 1988) provided the structure for this research. The SEF takes into account the interconnected social determinants of health (Institute of Medicine, 2003). These determinants are grouped into various levels: individual, interpersonal, community. The SEF is often visualized as a series of nested circles starting with the individual level and moving outward to the community level. The individual level includes characteristics and knowledge of the individual who is central to the framework. The interpersonal level focuses on factors related to social networks and support systems. The community level explores relationships and social interactions at the broader community level.

The SEF is particularly appropriate for Malawi, where the family is the dominant kinship group and women are considered inferior to men (White et al., 2005). Women are socialized to be subordinate and must follow decisions made by men. Unequal power dynamics exist in most marriages, leaving women less capable of negotiating for safe sex practices and allowing for the acceptance of culturally condoned abuse (White et al., 2005). Women are often economically dependent within their marriages, thus giving them few options to assert their autonomy. The Malawian cultural context is somewhat similar to those in other neighboring African countries where the SEF has been used to explore barriers to HIV testing and disclosure (Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001).

The SEF has been utilized in previous research to expose extensive barriers to both testing and disclosure. Individual level factors include age, educational attainment and socioeconomic status (SES) (Gaillard et al., 2004; Medley et al., 2004). Interpersonal level barriers include fear of partner's reaction, interaction between partners related to decision-making roles and communication norms, and the partner's attitude toward testing for HIV (Maman et al., 2001). At the community level, the importance of having a strong social network of family, friends and other trusted community leaders and counselors was essential in helping the women make decisions about both testing and disclosure (Maman et al., 2001).

Disclosure of HIV status to partners has many benefits, including: decreased anxiety; increased social support; increased access to PMTCT and to care, treatment and support programs; the ability to plan for the future; the chance for partners to be tested; and the opportunity to decrease risky behaviors (Medley et al., 2004). Couples can also make informed reproductive health choices that will reduce new infections and unintended pregnancies. Positive disclosure experiences reported in some studies included experiences of kindness, understanding/acceptance, and increased social support following HIV disclosure. Marriages became stronger; and women reported better access to services, including PMTCT, ARVs, and support groups (Medley et al., 2004).

Although barriers are perceived by women, they often do not match the reality of disclosure experiences. The majority of women reported positive responses to disclosing their HIV status to their partners (Medley et al., 2004). Only 3.5% to 14.6% of women experience a violent reaction to their disclosure.

This study contributes to the research on HIV disclosure during pregnancy by documenting patterns and influencing factors of disclosure by pregnant women to their

partners. This study explores through descriptive and multivariable analysis which individual/household, interpersonal and community level factors are associated with: 1) HIV disclosure to partners; 2) early (day of diagnosis) HIV disclosure to partners; and, 3) HIV disclosure to more than one person.

Methods

Sample Selection

From October 2006 to May 2007, in three Call-to-Action (CTA) clinics in Lilongwe, Malawi, all HIV-positive mothers of infants 12 months and younger returning for follow-up care offered to all HIV-positive women up to 18 months after giving birth were approached for this study. During the time period of recruitment, there was an on-going clinical trial, the Breastfeeding, Antiretroviral and Nutrition (BAN) Study, that was simultaneously recruiting women from the same three clinics utilized in this study. Recruitment for the BAN Study began in March 2004. The BAN Study was designed to investigate the safety and efficacy of antiretroviral and nutrition interventions among Malawian women in Lilongwe to reduce MTCT during breastfeeding (Gaillard et al., 2004; C. van der Horst, Fiscus, S. Piwoz, E., Corneli, A., Moses, A., Jones, D., Adair, L., Bentley, M., Hoffman, I., Kashuba, A., Shugars, D., Bandiwala, K., Tien, H., 2003). Women participating in the BAN Study were not eligible for this study.

Women were eligible for this study if they were at least 18 years old, had an HIV-positive test result during their most recent pregnancy, an infant between 0 and 12 months, and a primary male partner for the previous 6 months. Women were selected as a probability sample. As an incentive, all participants received a package of iodized salt and bars of soap for their participation at the conclusion of the interview.

Data Collection

Trained field investigators conducted face-to-face structured interviews to collect the study data. Women were screened for eligibility by the field investigators and if eligible, were interviewed in a private room at each clinic following their visit with a health care provider. All the participants and field investigators were women. Informed consent was obtained from each participant.

A review of all clinic records for demographic data was also conducted to assess whether the sample of women interviewed for this study was similar to all women attending the clinic. Data for the comparison were collected from women in the BAN Study and from women who tested HIV positive in antenatal care but who did not return for follow-up care.

Institutional Review Board approval was granted for the study by the University of North Carolina at Chapel Hill and the US Centers for Disease Control and Prevention, and in Malawi by the National Health Sciences Research Committee in the Ministry of Health.

Instrument and Measures

Survey development was informed by qualitative research conducted prior to this quantitative survey that focused on factors influencing participation in PMTCT programs, by validated instruments, and by items identified through a review of the literature. The survey was pre-tested by the field investigators. The survey assessed disclosure of HIV status and explanatory variables as defined by the organizing construct of the SEF at the individual/household, interpersonal, and community levels of influence. The outcome and explanatory variables are described below.

Disclosure of HIV Status

Disclosure was defined as the voluntary sharing of knowledge of HIV status by a recently pregnant HIV-positive woman with her self-identified primary male partner or to another person. Women were asked if and when they disclosed to their partner and to other people. The timing of disclosure by women to their partner was carefully recorded, particularly in relation to day of HIV diagnosis, day the infant was born, day infant was tested for HIV, and days related to choices regarding infant feeding. A woman's primary male partner was defined as a married partner or partner in a committed relationship for at least 6 months. Women were also asked if they knew the HIV status of their infant and if they had disclosed this knowledge to anyone.

Individual/Household Level Explanatory Variables

Data on the following individual level factors were collected: maternal age, educational attainment, marital status, tribal affiliation, employment status, religion, number of lifetime sexual partners, parity, number of living children, years living in Lilongwe, women's autonomy (multiple questions), knowledge of HIV and MTCT, and PMTCT activities related to ARVs and infant feeding. Data on characteristics of the child, including age, HIV status and health, were also gathered.

Socioeconomic status (SES) was represented by a factor score derived using the polychoric method, which is a variation on the principle component analysis procedure designed for use with dichotomous and categorical variables (Kolenikov S, 2004). Items in the analysis included a list of durable goods used in other surveys in Malawi (television, mobile phone, tape recorder, radio, bicycle, bed, mattress, table, chair, paraffin lamp with glass) and dwelling characteristics (material of floor, material of roof, type of sanitary

facility, source of drinking water, type of cooking fuel, type of lighting fuel). SES was divided into three tertiles representing low, moderate and high SES.

Interpersonal Level Explanatory Variables

Data on the following interpersonal level factors were collected: years with partner, employment status of partner, concurrence of tribal affiliation (matrilineal/patrilineal), believed source of HIV, who tested for HIV first, violent reaction to disclosure, involuntary disclosure, relatives with HIV, and relatives sick with AIDS. Two scales were also used on the interpersonal level, the Conflict Tactics Scale and the Social Support Scale, to measure factors identified in previous research on disclosure.

The Revised Conflict Tactics Scale 2 (CTS2) (Straus, Hamby, Boney-McCoy, & Sugarman, 1995) was utilized to measure the prevalence and frequency of conflict between women and their partners. Women were asked if their partner had acted in a certain manner and if so, the women were asked to approximate the number of times the action had occurred. The same series of questions were asked about two different time periods: the past year and prior to the past year, if the woman had been with her partner longer than one year. The CTS2 used in Malawi had 34 items divided into 4 subscales: negotiation (3 items), psychological aggression (16 items), physical assault (11 items), and sexual coercion (4 items). Scoring for each subscale followed the published guidelines for prevalence and frequency estimates (Straus et al., 1995).

The Social Support Scale used 12 items to measure the women's perceived availability of emotional/informational support (8 items) and tangible support (4 items) (Sherbourne & Stewart, 1991). Responses to all items were chosen from a Likert scale ranging from 1 (none of the time) to 5 (all of the time). The scoring of the subscales

followed the published guidelines (Rand Health, 2007; Sherbourne & Stewart, 1991) and resulted in two continuous scales where a higher score indicated more support.

Community Level Explanatory Variables

The HIV stigma scale was utilized to measure individually perceived community stigma and was the only community influence measured in the survey. It was adapted from an HIV stigma scale developed by the International Center for Research on Women (ICRW) (Nyblade, 2003). The original scale contained 17 items, but three items (lose customers, denied promotion, lose housing) were omitted as inappropriate for this population because women either did not work or their families did not own their home. Fourteen items remained in the final analysis. All items had response options on a four-category Likert scale, ranging from never to very often. Since there were no published methods for scoring the scale, the HIV stigma scale results were assessed for psychometric properties (DeVellis, 2003) using factor analysis. In the multivariable analysis, a dichotomous variable for HIV stigma based on the 14-item scale was utilized.

Data Management and Statistical Analysis

Data entry was conducted by one of the field investigators in Malawi using an Access database. The software package, STATA 8.0 SE (College Station, Texas), was used for data cleaning and analysis.

Descriptive statistics were used to obtain an overall depiction of the characteristics of the women and their patterns of HIV disclosure. Demographic data of the study participants were compared to demographic data of HIV-positive women in the BAN Study and HIV-positive women who did not return for follow-up care at the study clinics. Chi-square tests were conducted to assess for statistically significant differences between these groups.

Bivariate analysis on each of three disclosure outcomes used chi-square tests to assess statistical significance at the 0.1 level for every explanatory variable. Results from bivariate analysis provided a guide for determining the explanatory variables to be considered in the multivariable models presented. Explanatory variables for each model were retained based on a combination of statistical significance, conceptual relevance, variability and data quality.

Multivariable analyses included fitting a series of models using logistic regression on three outcomes, addressing three different aims related to HIV status disclosure. The first aim was to explore factors that influenced the likelihood of HIV disclosure by pregnant women to their partners. The second aim was to investigate the timing of the disclosure to the partner by exploring factors that influenced the likelihood of early (day of diagnosis) HIV disclosure by pregnant women to their partners. Finally, the third aim was to focus on the women who told at least one person, regardless of who they told, and examined factors that influenced the likelihood of HIV disclosure to more than one person. For each of the three aims, three separate models were constructed, each containing the variables within a single level (individual/household, interpersonal, community) that were found to be statistically significant in bivariate analysis. The final model was constructed for each aim that included variables from the previous models at all levels simultaneously.

Odds ratios with 95% confidence intervals were estimated from each model. To estimate the predicted probability of disclosure associated with each statistically significant factor in the three final models, each final model was re-fitted to two simulated datasets: one in which all women were assigned one value of the dichotomous variable, and one in which all women were assigned the opposite value. The original (observed) values of all other variables in these fits were maintained.

Results

Sample Characteristics

A total of 604 pregnant HIV-positive mothers were approached to participate in this study. Of these 604 potential participants, 287 did not meet the study eligibility criteria: 54.7% had an infant older than 12 months, 26.1% did not find out their HIV status in the previous pregnancy, 13.9% had no primary partner, and 4.5% were participants in the BAN Study. An additional 17 declined to participate, for reasons such as bad weather or not feeling well. A total of 300 women met eligibility criteria and consented to participate in the survey, representing a 95% response rate among eligible women.

The demographics of all women who tested HIV positive in the CTA clinics between January 2005 and October 2006 are presented in Table 3.1. For the demographic comparison, the women were subdivided into three categories: 1) those who returned for follow-up care and participated in this study, 2) those who did not return for follow-up care, and 3) those who enrolled into the BAN Study. The women interviewed in this study were more likely to be married, older and less educated than participants in the BAN Study. Women not returning for postpartum and follow-up care were younger than women participating in this study. Data on socioeconomic factors, specifically construction material of the floor and roof of the house, were similar among all three groups.

Table 3.1. Comparison of demographic data between HIV-positive women tested in Call-to-Action clinics: 2005-2006.

	HIV-positive women who returned for follow-up care and participated in this study (n=300)		*HIV-positive women who did not return for follow-up care (n=308)*		*HIV-positive women who joined the BAN Study (n=1390)*	
	N	**%**	**N**	**%**	**N**	**%**
Age group:						
15-29 years	201	67.0	229	78.7 [a]	1066	77.3 [b]
30-45 years	99	33.0	62	21.3	314	22.7 [b]
Martial status:						
Never/Not married	6	2.0	4	1.3	103	7.4 [b]
Married	294	98.0	303	98.7	1288	92.7 [b]
Educational attainment:						
No education	29	9.7	32	10.5	5	0.4 [b]
Primary school	171	57.0	158	51.8	737	60.6 [b]
Secondary school and above	100	33.3	115	37.7	474	39.0 [b]
Material of floor:						
Cement	211	70.3	230	75.4	837	69.9
Mud	88	29.3	75	24.6	357	29.8
Material of roof:						
Iron sheet	254	84.7	265	86.6	1007	84.1
Thatch	38	12.7	34	11.1	177	14.8

[a] Statistically significant at $p<0.05$ between women who returned for follow-up care and women who did not return for postpartum and follow-up care.
[b] Statistically significant at $p<0.05$ between women who returned for follow-up care and women who joined the BAN Study.

Other demographic characteristics of the women in the current study can be found in Table 3.2. All but 4% (n=12) of the women interviewed lived with the father of their youngest child. Marriage within the same specific tribe occurred among 44% of the women, and overall 66% of women married someone within the same tribal affiliation, either matriarchal or patriarchal. The participants' male partners had higher educational attainment and were more likely to have jobs outside of the home than the participants. Employment status was not significantly associated with age of the woman. The mean age of the infants at the time of the interview was 4.9 months (95% CI: 4.5 - 5.4). Overall, 46.7% (n=140) of the women had one or more of their children from a previous pregnancy die.

The participants' mean parity was 3.6 pregnancies, mean number of living children was 2.9, and mean number of sexual partners was 2.0. The women had been with their partners for an average of 6.5 years (95% CI: 6.1 – 7.0). Migration of primary partners was not found to be common among the women; only 20 partners (6.6%) worked outside of Lilongwe in the previous year.

Table 3.2. Additional demographic characteristics of the interviewed women, partners and infants.

	N	%
Characteristics of the HIV-positive women interviewed		
Religion:		
Christian	247	82.3
Muslim	52	17.3
No religion	1	0.4
Tribal affiliation:		
Matrilineal	212	70.9
Patrilineal	87	29.1
Employment status:		
Employed outside home	168	56.0
Not employed outside home	132	44.0
Total years living in Lilongwe:		
10 years or less	146	48.7
More than 10 years	154	51.3
Lived with partner at time of interview	288	96.0
Characteristics of partners		
Tribal affiliation:		
Matrilineal	205	69.3
Patrilineal	91	30.7
Educational attainment:		
No education	8	3.3
Primary school	93	31.1
Secondary school and above	175	58.3
Don't know	22	7.3
Employment status:		
Employed outside home	290	97.0
Not employed outside home	9	3.0
Characteristics of the infant		
Age of the child at the time of interview:		
0-6 months	196	65.3
Older than 6 months	104	34.7

Disclosure Patterns

Table 3.3 presents disclosure patterns among women interviewed. At the time of the interview, 90% of women (n=270) had disclosed their HIV status to their partners and 72.7% (n=218) had disclosed to their partners on the day of diagnosis (early disclosure). Another 14.7% (n=44) disclosed during pregnancy, sometime after the day of diagnosis. Only 2.7% (n=8) disclosed after giving birth. No significant differences were found in disclosure patterns by clinic site. Thirty women had not disclosed to their partner, and 15 of them had not disclosed their HIV status to anyone. Many women (67.0%; n=201) did not want specific people in their lives to know their HIV status. Only 4 (2.0%) of these women did not want their partner to know. Of the women who told at least one person, 88.8% (n=253) told their partner first, 8.0% (n=23) told a member of their family and 3.2% (n=9) told a non-family member. Of the women who disclosed to someone, 49.5% (n=141) told only their partner, 45.3% (n=129) told their partner plus one or more people and 5.3% (n=15) only told someone other than their partner. Involuntary disclosure, which is defined as disclosure of HIV status not controlled by or approved of by the HIV-positive person, occurred among 9% (n=27) of women.

Table 3.3. HIV disclosure patterns among women.

	N	*%*
HIV disclosure by women to their partners (n=300)		
Disclosed to partner	270	90.0
Do not disclose to partner	30	10.0
Timing of HIV disclosure to partner (n=300)		
Early disclosure (on day of diagnosis)	218	72.7
Late (after day of diagnosis) or not disclosed	82	27.3
Number of people told – if told at least one person (n=285)		
Told more than one person	134	47.0
Told only one person	151	53.0

Reasons women disclosed their HIV-positive status to their partner can be found in Table 3.4. The most common reason given was "because he should know," (40.4%), implying a sense of obligation. Other common responses, such as "because we are staying together," and "for him to be tested for HIV," and "protection for the future," indicated a practical impetus for disclosure. Strong negative emotions, such as fear, worry, and disappointment, also played a role in prompting women to disclose. Some women disclosed to stimulate their partners to be tested or to use condoms in the future. Prevention behaviors related to the infant were also reasons for disclosure. Some women disclosed because they knew their partner was the source of their HIV. Having a relative with HIV or AIDS was not a stated reason for disclosure, even though 27.3% (n=82) of women had a relative sick with AIDS and 15.0% (n=45) had a relative with HIV. Fear was the main motivator for not disclosing, although fear of violence was not often explicitly mentioned.

Table 3.4. Reasons women did and did not disclose their HIV status to their partners.*

	N
Reasons for disclosing (n=270)	
Because he should know	109
Emotional response by woman (scared, worried, disappointed)	48
Because we are staying together	44
For him to be tested for HIV	42
Protection for future	31
Because he infected me	21
Can't hide PMTCT behavior (ARVs, infant feeding, going to clinic often)	14
Advised to disclose by staff at clinic	13
Woman will need support in future	12
Fear of being accused of being promiscuous	6
Reasons for not disclosing (n=30)	
Fear marriage will end	12
Don't know how to tell him	6
Fear of being accused of infidelity	5
He will kill himself if either is HIV positive	5
Violence in relationship	4
Not available to tell	4
Want to be tested for HIV together	3

*Multiple responses were possible and thus the numbers do not total to the final n.

At the time of the HIV diagnosis, 44.7% of women and 29.7% of partners knew that the women would be tested for HIV at their first antenatal clinic visit. At the time of the interview, 41.3% of women reported that their partner had been tested for HIV (Table 3.5). Over half of the women (51.3%) knew that their partner had *not* been tested for HIV. These results differ significantly by age group with more women in the 20-29 years category reporting that their partners had not been tested. Of the women whose partners had been tested, 57.3% of their partners were HIV positive. Significantly more women who were of the same tribal affiliation as their partner knew that their partner was HIV-positive. The majority of women (60.7%) did not know whether they or their partner had been tested first. Of the women who knew that their partner had been tested for HIV, 55% of them believed that they had been infected by their partner, 38% did not know how they were infected, and 7% cited unspecified sources of their infection.

Table 3.5. Knowledge of partner's testing behavior and HIV status.

	N	*%*
Knowledge if partner has been tested for HIV (n=300)		
Partner has been tested for HIV	124	41.3
Partner has not been tested for HIV	154	51.3
Don't know if partner has been tested for HIV	22	7.4
Knowledge of partner's HIV status (n=124)		
HIV-positive	71	57.3
HIV-negative	42	33.8
Don't know	11	8.9
Who tested for HIV first (n=300)		
Woman tested first	79	26.3
Partner tested first	39	13.0
Don't know who tested first	182	60.7
Woman's belief in source of her HIV (n=300)		
Partner is source of HIV	147	49.0
Other source of HIV	33	11.0
Unknown source of HIV	120	40.0

Results of infant's HIV status and disclosure patterns by the mothers are given in Table 3.6. Mothers who tested positive for HIV during pregnancy were told to bring their

infants for HIV testing at 6 weeks postpartum. In the study, 72.5% (n=142) of infants who were 6 months and younger and 95.2% (n=99) of infants between 6 and 12 months had been tested for HIV. Of the 20% (n=59) of infants who had not been tested for HIV, 37.3% (n=22) were older than 6 weeks. At the time of the interview 26% (n=78) of women reported that their infants were sick.

Table 3.6. Knowledge and disclosure patterns of infant's HIV status.

	N	*%*
Knowledge of infant's HIV status (n=241)		
Positive	20	8.3
Negative	158	65.6
Don't know	63	26.1
Disclosure of infant's HIV status (n=241)		
Told no one	84	34.9
Told only partner	108	44.8
Told someone other than partner	6	2.5
Told partner plus another person	43	17.8

Partners' Reaction to Disclosure

Of the women who disclosed to their partner (n=270), positive reactions from their partner (48.1%, n=130) included support and understanding, a decision to be tested for HIV, and sadness or disappointment. Negative reactions from partners (13.7%, n=37) included panic, disbelief, blame, physical assault, and throwing the woman out of the house. Many women said their partner had no reaction (38.2%, n=103).

Results of Other Interpersonal and Community Level Explanatory Variables

All the women interviewed (n=300) responded to a series of questions on the Conflict Tactics Scale, on the Social Support Scale and on the HIV stigma scale. Results were divided among the subscales. Overall, 46.7% of women reported being sexually coerced in the past year, 76.0% experienced psychological aggression and 35.7% were physically assaulted. The majority of women (95.0%) said they negotiated with their partner in the past

year. The two social support scales remained as continuous variables. The emotional/informational support scale had strong internal consistent reliability with a Cronbach's alpha of 0.853. The scale loaded onto two factors accounting for 49.3% and 12.9% of the variance. The tangible support scale loaded onto one factor that accounted for 64.4% of the variance. The tangible support scale had a strong Cronbach's alpha of 0.808. Based on the HIV stigma scale, 53.5% of women reported perceiving stigma in their lives.

Multivariable Results

Table 3.7 displays selected results from the series of models addressing the first aim, which explored factors that influenced the likelihood of HIV disclosure by women to their partners. Table 3.8 presents predicted probabilities of disclosure associated with the variables found to be statistically significant in the final model.

Living in Lilongwe for 10 years or less increased the odds of women's HIV disclosure to their partners by roughly three times (OR=2.67). The probability of disclosure was 0.937 for those living in Lilongwe for fewer years, compared to 0.863 among women who had lived in Lilongwe for more than 10 years. Women who believed that their partner was the source of their HIV were also almost three times as likely to disclose (OR=2.82). These women, who suspected their partners of being HIV-positive, had a higher probability (0.939) of disclosure compared to women who did not know the source of their HIV infection (0.859). The perception of HIV stigma had a negative effect on disclosure (OR=0.23), which resulted in a higher probability of disclosure for women who did not identify HIV stigma in their lives (0.958), in contrast to the decreased probability (0.856) of disclosure if a woman did distinguish elements of HIV stigma in her life.

Two elements from the Conflict Tactics Scale also had influence on HIV disclosure to partners, however the 95% confidence intervals were wide and the p-values were $p<0.1$. Women who had negotiated with their partner in the past year were four times (OR=4.11) more likely to disclose to their partner. Women who had been sexually coerced by their partner in the past year were less likely to disclose (OR=0.41).

Table 3.7. Adjusted odds ratios from logistic regression models examining the likelihood of women's HIV disclosure to their partner at individual, interpersonal and community levels (n=300).

	Individual level	***Individual and Interpersonal levels***	***Individual and Interpersonal and Community levels***
Explanatory variables	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**
Individual & Household level factors			
Maternal age:			
Age group 15-29 years (ref)	1.0	1.0	1.0
Age group 30-44 years	1.63 (0.68 – 3.89)	1.61 (0.65 – 3.96)	1.48 (0.59 – 3.73)
Maternal education:			
No education or primary school (ref)	1.0	1.0	1.0
Secondary school and above	0.91 (0.38 – 2.18)	0.76 (0.30 – 1.92)	0.61 (0.23 – 1.60)
Total years living in Lilongwe:			
10 years or less	2.62 (1.14 – 6.02)*	2.67 (1.10 – 6.42)*	2.67 (1.10 – 6.48)*
More than 10 years (ref)	1.0	1.0	1.0
Socioeconomic status (SES):			
Low	0.55 (0.24 – 1.27)	0.59 (0.24 – 1.42)	0.57 (0.23 – 1.42)
Moderate and High (ref)	1.0	1.0	1.0
Interpersonal level factors			
Woman's reported source of her HIV:			
Partner is source of HIV		3.20 (1.33 – 7.67)*	2.82 (1.17 – 6.81)*
Other or unknown source of HIV (ref)		1.0	1.0
Conflict Tactics Sub-Scales:			
Negotiation in past year		3.40 (0.81 – 14.19)~	4.11 (0.90 – 18.70)~
Sexual coercion in past year		0.38 (0.16 – 0.92)*	0.42 (0.17 – 1.01)~
Tangible social support		1.01 (0.99 – 1.02)	1.00 (0.98 – 1.02)
Community level factor			
HIV stigma perceived			0.23 (0.08 – 0.67)*

* $p<0.05$; ~$p<0.1$

Note: Outcome variable: did not disclose to partner (n=30); disclosed to partner (n=270).

Table 3.8. Predicted probabilities of HIV disclosure by women to their partner for significant factors from final model.

	Mean predicted probability
Individual level factors	
10 years or less living in Lilongwe	0.937
More than 10 years in Lilongwe	0.863
Interpersonal level factors	
Partner is source of HIV	0.939
Other or unknown source of HIV	0.859
Negotiation with partner in past year	0.907
No negotiation in past year	0.748
Sexually coerced by partner in past year	0.866
Not sexual coerced by partner in past year	0.933
Community level factor	
HIV stigma perceived by woman	0.856
HIV stigma not perceived by woman	0.958

Note: Predicted probabilities for each level of each variable were calculated by re-fitting the final model to a simulated data set in which all women were assigned the specified value of a given variable, with no other simultaneous changes made in the dataset.

Table 3.9 contains selected results from the series of models exploring aim 2, which investigated factors that influenced early disclosure by women to their partners. Table 3.10 displays predicted probability results from significant factors from the final model.

Women with more education were less likely to disclose early to their partners (OR=0.43). More educated women had a probability of 0.621 of early disclosure compared to the higher probability (0.779) of early disclosure among less educated women. Women who believed they had been tested for HIV before their partners were over two times (OR=2.26) more likely to disclose early. The probability of disclosing early was 0.691 for women who thought their partner tested first or did not know if he had been tested. If a woman thought she was tested first, then the probability for early disclosure increased to 0.826. Perception of HIV stigma decreased the likelihood of early disclosure (OR=0.54).

Women who perceived stigma had a probability of 0.678, compared to 0.787 among women who did not perceive HIV stigma.

Two other variables that were statistically significant at $p<0.1$ influenced the likelihood of early disclosure. Women who had the same tribal affiliation as their partner were nearly two times (OR=1.69) more likely to disclose early. Women who reported being sexually coerced by their partner in the past year were less likely to disclose early (OR=0.58).

Table 3.9. Adjusted odds ratios from logistic regression models examining the likelihood of early (day of diagnosis) HIV disclosure by women to their partners at individual, interpersonal and community levels (n=300).

	Individual level	***Individual and Interpersonal levels***	***Individual and Interpersonal and Community levels***
Explanatory variables	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**
Individual & Household level factors			
Maternal age:			
Age group 15-29 years (ref)	1.0	1.0	1.0
Age group 30-44 years	0.88 (0.51 – 1.53)	0.80 (0.45 – 1.42)	0.75 (0.42 – 1.35)
Maternal education:			
No education or primary school (ref)	1.0	1.0	1.0
Secondary school and above	0.49 (0.28 – 0.86)*	0.48 (0.26 – 0.85)*	0.43 (0.23 – 0.78)*
Socioeconomic status (SES):			
Low	1.02 (0.56 – 1.85)	1.03 (0.56 – 1.89)	1.05 (0.57 – 1.95)
Moderate and High (ref)	1.0	1.0	1.0
Interpersonal level factors			
Same tribal affiliation		1.76 (1.02 – 3.05)*	1.69 (0.97 – 2.94)~
Who was tested for HIV first:			
Woman tested first		2.22 (1.13 – 4.37)*	2.26 (1.14 – 4.48)*
Partner tested first or unknown (ref)		1.0	1.0
Conflict Tactics Sub-Scales:			
Psychological Aggression in past year		0.60 (0.30 – 1.19)	0.68 (0.34 – 1.37)
Sexual Coercion in past year		0.54 (0.32 – 0.94)*	0.58 (0.34 – 1.01)~
Community level factor			
HIV stigma perceived			0.54 (0.30 – 0.96)*

* $p<0.05$

Note: Outcome variable: late disclosure to partner (after day of diagnosis) and non-disclosers (n=82); early disclosure to partner (on day of diagnosis) (n=218).

Table 3.10. Predicted probabilities of early (day of diagnosis) HIV disclosure by women to their partners for significant factors from final model.

	Mean predicted probability
Individual level factors	
Secondary school and above	0.621
No education or primary school	0.779
Interpersonal level factors	
Same tribal affiliation	0.761
Not same tribal affiliation	0.663
Woman tested for HIV first	0.826
Partner tested first or unknown	0.691
Sexually coerced by partner in past year	0.677
Not sexual coerced by partner in past year	0.773
Community level factor	
HIV stigma perceived by woman	0.678
HIV stigma not perceived by woman	0.787

Note: Predicted probabilities for each level of each variable were calculated by re-fitting the final model to a simulated data set in which all women were assigned the specified value of a given variable, with no other simultaneous changes made in the dataset.

A series of models were fitted for factors that influenced the likelihood of women disclosing to more than one person (Table 3.11). The community level factor was not statistically associated with the outcome variable and was therefore not included in this series of models. Predicted probabilities of significant factors in the final model are displayed in Table 3.12.

For the model including only individual level factors (column 1), age group and the number of years lived in Lilongwe had a statistically significant influence on disclosure to more than one person. These two factors did not reach statistical significance when taking into account the factors on the interpersonal level (column 3). Similarly, one factor on the interpersonal level, specifically involuntary disclosure, was not statistically influential in the model considering only interpersonal factors (column 2). This factor reached statistical

significance in the final model when factors on both individual and interpersonal levels were taken into account (column 3).

Women who knew they had a relative with HIV were approximately three times (OR=2.70) more likely to disclose their own HIV positive serostatus to more than one person. The probability for disclosure to more than one person was 0.439 for women with no known HIV-positive relative, compared to a probability of 0.641 for women with a known relative with HIV. Women who believed they tested for HIV before their partner were two and a half times (OR=2.58) more likely to disclose to more than one person. The differences in probabilities calculated illustrate the influence of women's belief that they tested first. Women who were sexually coerced by their partners in the past year were almost twice (OR=1.78) as likely to disclose to more than one person. Women not sexually abused had a probability of 0.414, compared to 0.527 in women who were abused.

Two factors reached statistical significance at $p<0.1$ in the final model. Women living in low SES households were less likely (OR=0.54) to disclose to more than one person. Women who had experienced involuntary disclosure were more likely (OR=2.65) to tell more than one person about their HIV-positive serostatus.

Table 3.11. Adjusted odds ratios from logistic regression models examining the likelihood of women's HIV disclosure to more than one person, among women who disclosed to at least one person, at individual and interpersonal levels (n=285).

	Individual level	*Interpersonal level*	*Individual and Interpersonal levels*
Explanatory variables	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**	**Odds ratios (95% CI)**
Individual & Household level factors			
Maternal age:			
Age group 15-29 years (ref)	1.0		1.0
Age group 30-44 years	1.77 (1.03 – 3.02)*		1.53 (0.85 – 2.77)
Maternal education:			
No education	0.52 (0.18 – 1.47)		0.62 (0.19 – 1.99)
Primary school completed	0.99 (0.57 – 1.73)		1.26 (0.67 – 2.36)
Secondary school and above (ref)	1.0		1.0
Total years living in Lilongwe:			
10 years or less	0.53 (0.32 – 0.87)*		0.63 (0.36 – 1.10)
More than 10 years (ref)	1.0		1.0
Woman employed outside of home	1.32 (0.79 – 2.19)		1.15 (0.66 – 1.99)
Knowledge that HIV-positive woman can have HIV-negative child	1.56 (0.78 – 3.11)		1.06 (0.49 – 2.26)
Socioeconomic status (SES):			
Low	0.69 (0.34 – 1.07)~		0.54 (0.28 – 1.02)~
Moderate and High (ref)	1.0		1.0
Interpersonal level factors			
Relative with HIV		3.00 (1.25 – 7.16)*	2.70 (1.09 – 6.69)*
Relative sick with AIDS		1.26 (0.65 – 2.42)	1.33 (0.68 – 2.63)
Involuntary disclosure to someone		2.57 (0.97 – 6.83)	2.65 (0.96 – 7.33)~
Who was tested for HIV first:			
Woman tested first		2.68 (1.49 – 4.82)*	2.58 (1.39 – 4.78)*
Partner tested first or unknown (ref)		1.0	1.0
Conflict Tactics Sub-Scales:			
Sexual Coercion in past 1 year		1.81 (1.05 – 3.11)*	1.78 (1.01 – 3.11)*
Emotional/informational social support		1.01 (1.00 – 1.03)	1.01 (1.00 – 1.02)
Tangible social support		1.00 (0.99 – 1.01)	1.00 (0.99 – 1.01)

* $p<0.05$; ~$p<0.1$

Note: Outcome variable: disclosed to only one person (n=151); disclosed to more than one person (n=134).

Table 3.12. Predicted probabilities of HIV disclosure to more than one person for significant factors from final model.

	Mean predicted probability
Individual level factors	
Low SES	0.386
Moderate & High SES	0.506
Interpersonal level factors	
Relative with HIV	0.641
No known relatives with HIV	0.439
Involuntary disclosure	0.644
No known involuntary disclosure	0.451
Woman tested for HIV first	0.609
Partner tested first or unknown	0.418
Sexually coerced by partner in past year	0.527
Not sexual coerced by partner in past year	0.414

Note: Predicted probabilities for each level of each variable were calculated by re-fitting the final model to a simulated data set in which all women were assigned the specified value of a given variable, with no other simultaneous changes made in the dataset.

Discussion

This study reports high rates of HIV disclosure by women to their partners, particularly on the day of diagnosis. These high rates of disclosure are encouraging and may signal a sea-change in Malawi. They also diverge from the lower rates of disclosure among pregnant women published in the past few years (Medley et al., 2004). Women's stated reasons for disclosing to their partners indicate a strong sense of cultural obligation.

The comparison of demographics of women testing HIV positive in CTA clinics can be explained by the varying eligibility criteria. Women in this study had to be 18 years or older and have a primary male partner for at least 6 months prior to the interview, whereas the BAN Study recruited women with a minimum age of 15 and did not recruit women based on characteristics of their partner relationships. The comparison between the study

population and women not returning for follow-up care is important because these women are more representative of the general population of women at other clinics where the BAN Study is not recruiting. The women who did not return for follow-up care were younger than women participating in this study. This finding can also be explained by the age-related exclusion criteria for this study. Therefore the overall results from this study can be generalized to women testing HIV positive through antenatal clinics in Lilongwe.

The first series of models explored factors influencing the likelihood of HIV-positive pregnant women disclosing to their partners. These data show that the main factors associated with disclosure were living in an urban setting, being infected by the partner, ability to negotiate, experiencing sexual coercion from the partner in the past year and perception of HIV stigma. It was not surprising that living in Lilongwe for 10 years or less was a factor associated with HIV disclosure. Women who are more recent urban residents may cling to the community connectedness from their rural roots. Only 20% of Malawi is classified as urban; thus, the majority of the population resides in rural areas (National Statistical Office and ORC Macro, 2004). In addition, the effect of urban living and of having a stable partner influenced the high rate of HIV disclosure.

The second series of models explored influences on early disclosure of HIV status by women to their partners. These data show that educational level, knowledge of previous testing of partner, lack of sexual coercion and lack of stigma attached to diagnosis influenced early disclosure.

Women who test HIV positive in antenatal settings are approached to join PMTCT programs or clinical trials on the day of diagnosis. Women are often in a state of shock on the day they are told of their HIV-positive status. They have been waiting at the clinic for

hours because each HIV positive result requires further testing to confirm diagnosis, and the women become nervous and are anxious to return home to fulfill their family responsibilities. These women are also sensitive to being seen waiting at the clinic, because others who see them may draw conclusions about their HIV status. In many ways, the day of HIV diagnosis is not an ideal time to engage women in a discussion of their options, but this may be the only time for counseling and for recruitment into programs and trials. Given the high incidence of early disclosure, this would also be important time for counseling to help women discuss specific options for disclosing to their partners.

The significant relationship between early disclosure and higher educational attainment were in contrast to results among pregnant women in Burkina Faso. The Burkina results showed that women with more education were more likely to share HIV results with partners than women who were illiterate (Issiaka et al., 2001). However, the Burkina results did not explore the issue of timing of disclosure, and therefore may not be truly comparable to results from this study. In Malawi the high level of educational attainment decreased the likelihood of early disclosure to partners only, but was not associated with incidence of disclosure to partner or disclosure to more than one person. However in the Burkina study, only 31.6% of women had disclosed to their partner after an average of 8 months.

The final series of models revealed that disclosure among HIV-positive pregnant women was influenced by knowledge of an HIV-positive relative, belief that the woman tested for HIV before her partner, sexual coercion in the past year, involuntary disclosure and living in a low SES household.

There were a few common significant factors across the three multivariable final models, although none on the individual level. On the interpersonal level, the influence of

the woman's knowledge that she had been tested for HIV before her partner was associated with an increased likelihood of early disclosure and of disclosing to more than one person. These findings coincide with the result that women who believed their partner was the source of her HIV were more likely to disclose to their partner. Women are generally more likely to be tested for HIV and to believe that they have been tested before their partners due to the high prevalence and frequency of childbearing in Malawi and to the "opt-out" system for HIV testing at first antenatal clinic visits. It is reassuring that these systematic interactions with the healthcare system led to a greater chance of being tested for HIV and have been shown to facilitate disclosure, early disclosure and disclosure to more than one person.

Women who had been sexually coerced in the past year were less likely to disclose or to disclose early, yet these abused women were more likely to disclose to more than one person. This finding may indicate that once a sexually abused woman decided to disclose, she accessed her social support network by telling more than one person of her HIV status. Fear of a violent reaction among women in already violent relationships may have contributed to decreased disclosure, even if the women did not state this fear and only a few women experienced a violent reaction to disclosure (7.3%, n=22). These findings correspond to results in the literature. Violence in the form of sexual coercion is a well-documented barrier to disclosure (Gielen, McDonnell, Burke, & O'Campo, 2000; Maman et al., 2002; van der Straten, King, Grinstead, Serufilira, & Allen, 1995). In another study, results from a logistic regression analysis indicated that women with a history of physical and sexual violence were significantly more likely to experience negative social and physical consequences when their infection became known to others, adjusting for age and the number

of people to whom women had disclosed, both of which were only marginally significant (Gielen et al., 2000).

Many of the significant factors for each of the final models were on the interpersonal level. This finding is linked to the sense of obligation women shared as the main reason for disclosing to their partner. In the multivariable analysis in the first series of models, one factor that increased the likelihood for women disclosing to their partners was negotiation with their partner in the past year. Good communication patterns among couples in Malawi has been documented in another study (Zulu & Chepngeno, 2003), which focused on communication related to risk and prevention of HIV within marriage and that asked about negotiation used to facilitate fidelity and safe sex. The impetus for discussion of those topics among couples was found to be the shared hope for lessening the consequences of HIV on their children. In this study, while the importance of protecting the infant was not stated as a reason for disclosure, the fact that the majority of women (88.8%, n=253) disclosed to their partner first highlights the closeness and sense of collective responsibility in the relationship.

On the community level, HIV stigma was statistically significant as a general barrier to disclosure and early disclosure, but had no significant effect on the pattern of disclosure to others. It was not surprising that HIV stigma is a barrier to disclosure, but it is important that HIV stigma did not have a significant influence on the number of people to whom women disclosed. Fighting the stigma of HIV is essential for reducing its influence as a barrier to disclosure.

The results of this study suggest avenues for intervention. Three factors – negotiation and communication between partners, lack of sexual coercion in the relationship in the past year, and timing of HIV testing of women compared to their partners – provide opportunities

for education, counseling, and intervention that could aid in keeping the disclosure rates as high as reported in this study.

Further research using qualitative methods will help explore reasons for disclosure and aspects of the counseling on the day of HIV diagnosis that may explain the higher rates of disclosure presented in this paper. In addition, further research on the role of sexual coercion and intimate partner violence is necessary in Malawi. Disclosure of infant HIV status by women to other people is another area for further research.

A number of study limitations are worth noting. The high disclosure rate was unanticipated and encouraging, but reduced the statistical power of the study. Given a larger sample, other important factors may have been revealed. Power calculations conducted prior to the survey were based on literature that presented lower rates of disclosure in similar settings. In this quantitative study, potentially important factors on the institutional level, such as patient-provider interaction, were not measured. In addition, the influence of the long-term presence and reputation of the University of North Carolina (UNC), which has been conducting research recruiting HIV-positive women at these three clinics in Lilongwe for many years cannot be measured. The continued presence of UNC may have contributed to the high rates of disclosure. The study was designed when the World Food Program (WFP) was conducting a targeted food distribution program for all women testing HIV positive in the three antenatal clinics utilized for this research. Thus all eligible women had been returning to the clinics for follow-up care and a monthly food basket. The WFP program ended prior to study recruitment. Issues of generalizability would have been minimized and the recruitment period would have been much shorter if the food distribution program had remained in place once data collection began. In addition, the recall period

could have been shortened by interviewing women with younger infants, minimizing recall bias of the disclosure event.

This study presents encouraging high rates of disclosure, even early disclosure, among pregnant women testing HIV positive during antenatal care. With more disclosure by women to their partners and to others, there is an increased chance of more women participating in PMTCT programs. Counseling should concentrate on facilitating factors, such as enhancing good negotiation between partners, while identifying barriers, such as sexual coercion and HIV stigma.

CHAPTER 4:

"BECAUSE HE SHOULD KNOW":

WHY PREGNANT WOMEN DISCLOSE THEIR HIV STATUS TO THEIR PARTNERS IN LILONGWE, MALAWI

Abstract

Background: Disclosure by pregnant HIV-positive women to their partners is essential for increased HIV prevention, treatment and care. This study aimed to explore reasons pregnant women disclosed and did not disclose their HIV-positive status to their primary male partners. Comparisons were made between reasons given by women and reasons nurses utilized in post-test counseling to encourage HIV disclosure by pregnant women to their partners. Reactions to disclosure by women and their partners were also documented.

Methods: This study was conducted in June and July 2006 at the Call-to-Action (CTA) clinic at Bwaila Hospital in Lilongwe, Malawi, where all women attending their first antenatal clinic visit were offered "opt-out" HIV testing. Individual semi-structured interviews were conducted with 20 pregnant HIV-positive women within a week of diagnosis, and with 9 clinic nurses and 4 community nurses.

Results: Of the 20 pregnant HIV-positive women interviewed, 13 of them had disclosed to their partners by the time of the interview and 5 of the 13 had reported disclosing

on the day of diagnosis. Of the 7 women who had not disclosed to their partner, 6 were planning to disclose. Only one woman had no intention of disclosing to her partner. Reactions to the HIV result by women and their partners varied from disappointment to acceptance. Among these women, expectations of anger from partners in reaction to disclosure did not appear to change their plan to disclose. Reasons women disclosed to their partners were often the same reasons nurses used to encourage disclosure in post-test counseling. These common reasons for disclosure were cultural obligation and communication norms with partners, belief that the partner was the source of HIV, the need to negotiate for condom use, and the need to explain current or future illness. Women also gave two additional reasons for disclosing to their partners: fear of disclosure from another source and prior knowledge of HIV testing available to all pregnant women attending their first antenatal clinic visit.

Conclusions: Nurses should be informed that many women are disclosing to their partners and that the reasons women disclosed to their partners are often the same ones that nurses emphasized to encourage women to disclose during post-test counseling.

Background

Prevention of mother-to-child transmission (PMTCT) of HIV depends on ensuring that pregnant HIV-positive women have access to treatment, care and support. These women need education and encouragement to follow PMTCT recommendations that are based on proven interventions including use of antiretroviral (ARV) prophylaxis and specific infant feeding behaviors (Gaillard et al., 2004; Guay et al., 1999). Part of the needed support includes counseling from health care providers and encouragement from family and friends. HIV disclosure to a trusted person is an important step for women to decrease their anxiety and to abide by PMTCT interventions (Medley et al., 2004). In Southern Africa, disclosure to a male partner is even more important, as it has been noted that a major cultural contributor to the spread of HIV is "women's weak societal position" (Lwanda, 2005).

The documented prevalence of HIV disclosure varies widely. Among women in developing countries, disclosure to their partners ranged from 17% to 86% as reported in a summary of studies on rates, barriers and outcomes of HIV disclosure (Medley et al., 2004). Studies of pregnant HIV-positive women revealed the lowest rates of disclosure. The timing of HIV disclosure also varied based on the setting. A qualitative study in South Africa with 31 women interviewed within a year of their HIV-positive test result during pregnancy found that virtually all of them (94%) had disclosed to someone, most often to their partner, within a week of their test result during pregnancy (Varga, Sherman, & Jones, 2006). In contrast, a recent study in the Ivory Coast found that only 46% of HIV-positive women tested during pregnancy disclosed to their partners during a two-year interval after diagnosis (Brou et al., 2007).

Fear of violence from their male partners is a well-documented barrier to disclosure (Gielen et al., 2000; Maman et al., 2002; van der Straten et al., 1995). Other barriers to disclosure include fear of abandonment coupled with loss of economic support, discrimination, being accused of infidelity, and upsetting family relations (Medley et al., 2004). A study in Tanzania documented barriers to disclosure and testing including fear of partner's violent reaction, interaction between partners related to decision-making roles and communication norms, and the partner's interest and acceptance of HIV testing (Maman et al., 2001).

Motivating factors for disclosure identified by the World Health Organization include increased time since diagnosis, poor health status of the woman, a sense of ethical obligation to partners, supportive relatives and friends, decreased anxiety and stress, and increased HIV preventive behaviors such as using condoms (World Health Organization, 2003a). Studies have also found an increase in the likelihood of disclosure associated with fewer sexual partners and personally knowing someone with AIDS (Medley et al., 2004). Health care providers play a critical role in encouraging women to disclose their HIV-positive status to their partners. In a study in Tanzania, social support from health care professionals was found to increase the likelihood of HIV disclosure by women to their partners (Antelman et al., 2001). Other research has found that women who are afraid of a violent reaction to HIV disclosure were helped to disclose by a health care provider (Gielen et al., 2000).

HIV disclosure has many documented positive outcomes (Kilewo et al., 2001; King et al., 2007; Maman et al., 2003). Disclosure has been found to be a mechanism for access to important resources (Norman, Chopra, & Kadiyala, 2007). A qualitative study in Uganda with 45 HIV-positive people found that positive outcomes of disclosure included risk

reduction, testing of partners for HIV, increased support, decreased anxiety, more communication about sex, and increased planning for the future (King et al., 2007).

The present study focuses on HIV disclosure in Lilongwe, Malawi, where HIV testing for pregnant women has become widely available in antenatal clinics. In Malawi, a small, densely populated country in Southern Africa, women are considered inferior to men; and, depending on the tribal affiliation of the family, women are often classified as being the property of their partners (Mvula & Kakhongwa, 1997; White et al., 2005). Despite tribal affiliations, women have little or no choice but to follow decisions made by their partners. From an early age Malawian girls are socialized to be obedient, well-behaved, and subservient (White et al., 2005). Women's lower status in Malawi has been documented through women's acceptance of cultural norms that allow men to beat their wives as a form of discipline (National Statistical Office and ORC Macro, 2004). This cultural conditioning affects how Malawian women interact and communicate with their partners.

Attitudes, behaviors and communication norms about HIV in Malawi have been changing over time. The prevalence of HIV in Malawi is high at an estimated 12.7% among adults (UNAIDS, 2007) and 15% among pregnant women in the capital city of Lilongwe (National AIDS Commission, 2006). One recent study found that "HIV is considered the most serious disease confronting society in Malawi" (Zulu & Chepngeno, 2003). The prevalence of HIV-related deaths in Malawi has helped bring the topic into everyday conversation. A study conducted in Malawi in 1998, among 2,606 participants, found that half reported that they had been to 1-4 funerals in the past month and the other half had been to more than four in the same time period (Zulu & Chepngeno, 2003). In comparing data from surveys in Malawi from 1998 and 2001, it was determined that HIV/AIDS has become

a frequent topic of conversation among married Malawians (Smith & Watkins, 2005). Increased awareness of the consequences of HIV and increased frequency of conversations between partners about HIV are positive influences for inducing HIV disclosure by women to their partners.

Many pregnant Malawian women in Lilongwe now have increased access to HIV testing and to PMTCT programs if they test positive for HIV. The PMTCT program in the Call-to-Action (CTA) clinics in Lilongwe screens 23,000 pregnant women annually (Moses et al., 2008). In April 2005 "opt-out" testing for HIV was introduced, meaning that all pregnant women are tested at their first antenatal clinic visit unless they specifically "opt-out." With the existence of "opt-out" testing, almost all (99%) pregnant women receiving care at the CTA clinics are tested for HIV.

All women who test HIV-positive receive post-test counseling from health care providers working in the CTA clinics. Women are given Nevirapine to take at the onset of labor using the HIVNET 012 regimen of ARV medications (Guay, 2001) that has proven to reduce mother-to-child transmission (MTCT) of HIV. Women are also given condoms during post-test counseling to use to prevent possible transmission to HIV-negative partners. In Malawi, as elsewhere, these interactions with health care providers have been found to be motivators for disclosure (Antelman et al., 2001; Gielen et al., 2000).

A survey in three CTA clinics in Lilongwe of 300 HIV-positive women who had learned their HIV status during their most recent pregnancy and had an infant 12 months or younger (Bobrow, 2008b) revealed that most women (90%) disclosed their HIV status to their partner and that many (73%) disclosed on day of diagnosis. Of women who disclosed their status, almost half (47%) told more than one person. Women had an increased

likelihood of disclosure to their partner if they were living in an urban setting, if they believed that they had been infected by their partner, and if they had good negotiation during a disagreement with their partner in the past year. Women had a decreased likelihood of disclosure to their partner if they perceived HIV stigma and if they had been sexually coerced by their partner in the past year.

The aim of this study was to explore using qualitative research methods, reasons pregnant HIV-positive women in Lilongwe disclosed and did not disclose their HIV-positive serostatus to their partners. Reports of reactions by women and their partners following disclosure were also described. Post-test counseling recommendations from nurses were recounted, and comparisons were made between perceived motivators from women and those that are highlighted by the nurses, since women's interactions with health care providers has been found to be a motivator for disclosure in other studies.

Methods

Overview

This study was the qualitative component of a larger mixed methods study on factors that influence disclosure to partners and program participation by pregnant HIV-positive women in Lilongwe, Malawi. In June and July 2006, a team of trained Malawian interviewers conducted individual semi-structured interviews with 20 pregnant HIV-positive women, 9 clinic nurses and 4 community nurses. All of these participant groups were recruited at the CTA antenatal clinic at Bwaila Hospital in Lilongwe using purposive sampling methods. Informed consent was obtained from all participants.

Recruitment and Eligibility

Pregnant women were interviewed within a week of their HIV-positive diagnosis. They were eligible if they were attending the CTA clinic for antenatal care, had tested HIV-positive for the first time within the week prior to the interview, were at least 18 years old and could give informed consent. Women were referred by clinic nurses to the team of field investigators carrying out this research.

Nurses worked at the antenatal clinic at Bwaila Hospital. Community nurses provided outreach activities and support to women attending the same antenatal clinics. Nurses were approached by research staff members to schedule an appointment at a convenient time.

Development and Content of the Interview Guides

The interview guides were semi-structured and were designed to collect and compare information on facilitators and barriers to HIV disclosure by pregnant women to their primary male partners. The guides were crafted after a review of the literature on disclosure.

Interview guides for pregnant women included questions about anticipation of HIV test results, reaction to HIV-positive result, interaction with health care providers at the clinic, disclosure patterns, social support, communication with partner, fear of violence, HIV stigma, autonomy, and willingness to participate in PMTCT programs and research at the clinic. The interview guides for nurses included questions on women's interaction with the clinic, community perceptions of services and research at the clinic, communication between partners, and perceptions of patterns of HIV disclosure. Demographic data were collected from all participants.

Data Collection Methods

Members of the research team were bi-lingual in English and Chichewa, the primary language spoken in the Central Region in Malawi. The research team was composed of four female and two male field investigators who had all completed secondary school and had previous experience with qualitative research.

Prior to data collection, the research team participated in an extensive training on the study design and methods. During the training, role play exercises were utilized to allow the team to become familiar with the guides and the informed consent process. All the guides were pre-tested for understandability. Review days were scheduled throughout the period of data collection to share findings and to make needed changes to the guides.

All of the interviews with the pregnant women were conducted by female field investigators in Chichewa. Nurses chose whether to respond in Chichewa or English. All the guides were available in both English and Chichewa. All interviews were conducted in private rooms in the clinic and were recorded with the consent of the participants. Pregnant women received a package of iodized salt and bars of soap for their participation. Nurses received a small gift of stationery and a beaded AIDS pin.

Written transcripts were created from all the interviews. Interviews conducted in Chichewa were simultaneously transcribed and translated verbatim into English. Transcripts were also created for interviews conducted in English. The interviewer who gathered the data was responsible to create transcriptions and translations as well as for writing field notes for each interview. Once the data were entered electronically, the entire research team reviewed every transcript to ensure accuracy and to discuss cultural context of the responses.

Data Analysis

A codebook was created after a review of study questions on disclosure. Data were carefully read to identify recurrent patterns and themes and to draw conclusions on influences and patterns of HIV disclosure. Two investigators coded independently and met to compare codes. Discrepancies were resolved through consensus. The interviews were coded using MAXQDA 2007 (Marburg, Germany). Code reports were produced for nurses and women separately. Themes emerged from the reports, and relevant text-based quotes were gathered from the reports to support each theme. Similarities between women and nurses were compiled through reading the coded reports. Descriptive summaries were written for each interview (Miles & Huberman, 1994; Ulin et al., 2005; Williamson, 2005). Summaries for women were compiled in matrices and grouped by disclosure outcomes. Relevant information on responses to disclosure and prior knowledge of HIV testing at the clinic were also recorded in additional columns of the matrix. Descriptive summaries for the nurses included motivators and barriers to disclosure.

The research was approved by Institutional Review Boards at the University of North Carolina (UNC) at Chapel Hill, the US Centers for Disease Control and Prevention, and in Malawi by the National Health Sciences Research Committee in the Ministry of Health.

Results

Demographic Characteristics

General demographic characteristics of the participants are displayed in Table 4.1. The pregnant women had a mean gestation of 20.7 weeks. Many of the women had been pregnant before, an average of 2.7 times; yet many women had also had a child die, as the average number of living children was 1.2. Five women had employment outside their

household. The women had spent an average of 6.5 years living in Lilongwe. Two of the nurses were male. The nurses had spent an average of 2.9 years working for UNC Project in Malawi, which conducts research and provides service in clinics in Lilongwe.

Table 4.1. Demographic characteristics of pregnant HIV-positive women and nurses.

	Pregnant HIV-positive women (n=20)	*Nurses (n=13)*
Mean age (years)	24.8	35.9
Number married	19	12
Religion:		
Christian	17	13
Muslim	3	0
Educational attainment:		
Primary school	13	0
Secondary school	7	2
Above secondary school	0	11

Disclosure Patterns

Of the 20 pregnant HIV-positive women interviewed, 13 (65%) had disclosed to their partners at the time of the interview. Five of these 13 (39%) had reported disclosing on the day of diagnosis. Of the 7 women who had not disclosed to their partner, 6 were planning to disclose; only one woman had no intention of disclosing to her partner. The women who had not disclosed had circumstances preventing disclosure, such as the fact that their partner was working far away or that their partner was someone else's husband.

Counseling and Support from Nurses

Women discussed the positive influence of the post-test counseling they received at the clinic and the importance of having proof of their HIV status from the clinic. These two factors assisted them in their decision to disclose their HIV-positive serostatus to their partners. Nurses provided their opinions on the influence of the post-test counseling they delivered and explained the components, the emphasis and the methods they utilized.

Pregnant HIV-positive Women

Women generally felt that the information they received at the clinic was helpful. As one woman said, ". . . everything they told me I felt is very useful to my life" (*Planning to disclose to partner*). Several of the women said that the nurses told them not to worry. As one woman explained, "the counselor encouraged me that I shouldn't get worried and I shouldn't be thinking too much" (*Planning to disclose to partner*).

Having proof of their HIV-positive status from the hospital was also important; "I feel like he can't believe me" but she says "he can believe it if he sees the paper" (*Planning to disclose to partner*). Another woman said that her husband "did not get angry since [the result was] from the hospital . . . it's the doctor who have said it" (*Disclosed to partner*).

Nurses

In contrast to the study findings, most of the nurses believed that women do not disclose to their partners. One nurse explained, ". . . it is really hard for our women to disclose and they have a tough time with this" (*Clinic nurse*).

Nurses in the CTA clinics were trained to conduct individual post-test counseling to encourage women to disclose their HIV-positive status to their partners. Nurses also gave specific recommendations on how to disclose. One nurse explained that the counseling included the "benefits of positive living" (*Clinic nurse*), which included information on interventions available at the clinic that, ". . . can prolong your life and also prevent HIV transmission to your child" (*Clinic nurse*).

Nurses used role play exercises and gave women specific advice on how to disclose. One nurse said that she tells women to ". . . start by preparing a good meal and then we tell her why don't you tell him this same day" (*Clinic nurse*). Another nurse gave an example:

> Sometimes they role play what will happen at home. For example I will give you this scenario. Where a husband has come from his work or business and he is greeted by the wife and have taken supper and then the wife starts telling as follows, when I went to the clinic the nurse told me that I should go for an HIV test and I decided to be tested (*Clinic nurse*).

Then the nurse provided various possible positive reactions from the partner, including his knowledge of his own HIV-positive serostatus or his desire to be tested in the future. These possible reactions from partners were ones that matched the reality of some women who reported back to the nurses at the clinic; thus, the role play prepared the women for what they might encounter. Nurses did not report using role play exercises to prepare women for a possible violent reaction from their partners.

Nurses also explained that they utilized stories and concentrated on the method of disclosure, since they feared that some women went home with a negative and accusing attitude that would provoke a defensive response in the partner. One community nurse gave an example:

> Some of them would just go home because they are angry or disappointed and so just say because of your behavior I am positive yet I have been telling you to stop this promiscuity. And so the husband would want to be defensive himself and say it is not me and would not accept, instead it is because of your behavior and that's why you went for the test (*Community nurse*).

Although the nurses advised women to disclose to their partners on the day of diagnosis, they let women choose if, when, and to whom to disclose:

> We advise them that it is up to them to decide whether to disclose or not to whoever they feel comfortable to reveal to. But we tell them that it is important that at least they disclose to one person especially the husband because all what we advise here

> needs to be implemented together with the husband . . . but it's not a must to reveal (*Clinic nurse*).

Reactions to HIV Disclosure

Women's Reaction

Women's reactions to news of their HIV-positive status varied from being worried ("I was thinking of many things") to being surprised ("I did not think that I would be found with HIV virus") to accepting the news ("after I heard I just accepted"). One woman said simply that, "I saw that my life changed" (*Disclosed to partner*). Often women who were not surprised by the result believed that their partner was the source of their HIV. One woman said that she "was worried but not very much because I was prepared" (*Planning to disclose*) since she suspected that her partner was HIV-positive. A few women felt that they would die that day or while giving birth. As one woman said, "I was thinking that that was the end of my life and that I will fall sick immediately after delivery" (*Disclosed to partner*). Many women were at least initially "disappointed" and then either said that they were encouraged by the nurse, or accepted the news in a fatalistic manner, as illustrated by the following quote:

> At first I was disappointed but later when I deeply thought about it I saw that there was nothing to worry about . . . it has already happened and there's nothing I can do about it (*Disclosed on the day of diagnosis*).

Partner's Reaction

Women who were planning to disclose often said they expected anger from their partner in reaction to their HIV disclosure, yet the expectation of an angry reply did not prevent their plan to disclose. They said that the anger would be purposeless. As one

woman said, “Even if he gets angry with it what will be the profit out of that?" (*Planning to disclose*) A few women reported that their partner did get angry; “he was angry, but not very, not more than two days” (*Disclosed to partner*).

Reactions by partners varied widely from those who were disappointed to others who just accepted the news. Women reported that their partners were disappointed, as illustrated by one woman’s account that her partner “. . . dropped his face in disappointment showing that he is concerned” (*Disclosed on the day of diagnosis*). Some partners were not surprised and accepted the news in a fatalistic manner, “when I told him, he just said ‘it has happened’” (*Disclosed on the day of diagnosis*). Another woman said her partner “. . . was not even disappointed because sometimes disease just comes when you are not expecting it” (*Disclosed to partner*). One partner was very practical and encouraging since, “he just said that I should follow the advice from the hospital” (*Disclosed to partner*).

A few women talked with their partners about being tested for HIV before they traveled to the clinic. These women knew that HIV testing was available at the antenatal clinic on the day of their first visit. For these women, disclosure was easier as they had already discussed the HIV testing with their partners.

Pregnant women and nurses were asked about reasons women did and did not disclose their HIV-positive status to their partners. The following sections provide themes from the responses to these questions.

Reasons Women Disclosed to Their Partners

The following themes were identified as reasons women disclosed to their partners. Many of the reasons women disclosed to their partners were the same ones that nurses emphasized to encourage women to disclose during post-test counseling (Table 4.2). These

common reasons were: disclosure because of the cultural obligation and communication norms with partners; the belief that their partners were the source of their HIV; the need to negotiate condom use; and the need to explain current or future illness. Women also gave two additional reasons for disclosing to their partners: fear of disclosure from another source and prior knowledge of HIV testing at first antenatal clinic visit.

Table 4.2. Reasons women disclosed to their partner and factors nurses emphasized in post-test counseling to encourage women to disclose to their partners.

	Reasons for disclosure to partners
Women and nurses	Cultural obligation and communication norms with partner Partner is source of HIV Need to negotiate for condom use Explain current or future illness
Women only	Fear of disclosure to partner from another source Prior knowledge of HIV testing at first antenatal clinic visit

Cultural Obligation and Communication Norms with Partner

Pregnant HIV-positive Women

The main reason women said they disclosed or were planning to disclose to their partners was out of a sense of obligation. One typical statement expressing this sentiment was; "because he should know," which in Chichewa is "*Kuti adziwe*" (*Planning to disclose*). Although many women talked about anticipating an angry response from the partner, they still disclosed because they felt obligated to their partners. The cultural reality that Malawian men are the decision-makers and have the power in the relationship appeared to outweigh fears of a possible negative response to disclosure.

Women's sense of obligation was coupled with other emotions. Women mentioned a history of support in their relationship with their partner; "we live by leaning on each other . . . it's supposed to be like that" (*Disclosed to partner on the day of diagnosis*). Others

revealed feelings of love along with obligation, as one woman said, ". . . because if we are staying together that means we are one" (*Disclosed to partner on the day of diagnosis*). Another woman explicitly mentioned love, ". . . because of the power of love I needed to tell him not for me to hide it from him" (*Disclosed to partner*).

Five women disclosed to their partners on the day of diagnosis. The main reason for this immediate disclosure was obligation and to avoid being questioned about a delay. Instead of being a barrier to disclosure, fear of the partner's reaction prompted early disclosure. The following quote illustrates these feelings:

> I told him the same day I came here and got tested. I told him because he is the one I am staying with so to keep quiet and tell him later he would ask, 'Why were you not telling me the same day?' So that's why I told him to see what his thoughts are (*Disclosed to partner on the day of diagnosis*).

Cultural roles also dictated that women generally talked to their partners about most things. The male dominance in relationships made women feel compelled to communicate with their partners. One woman said "I talk to him whenever something happens" (*Disclosed to partner*). Another woman said that her partner "gives me very good opinions" (*Planning to disclose to partner*).

Nurses

Nurses acknowledged the cultural obligation women have to their partners and the control men have over women, as illustrated by the following quotes,

> Most of the women are dependent on their husband . . . they have to go home and tell their husband that this is the situation I am found in (*Community nurse*).
>
> I strongly believe that these husbands have all the power (*Community nurse*).

One community nurse explained that when women do not disclose to their partners, ". . . it's like there is a communication breakdown between our women and their men" (*Community nurse*).

Partner is the Source of the HIV

Pregnant HIV-positive Women

Many women believed that their partner was the source of their HIV. These women tended to be disappointed, although not surprised, in response to their HIV-positive test result and felt justified in disclosing. As one woman explained, her partner, " . . . knows that it's him who transmitted this HIV to me" (*Planning to disclose to partner*). Only a few women disclosed or planned to disclose to encourage their partner to be tested for HIV. As one woman explained, she planned to disclose, ". . . for him to also see how his body is like" (*Planning to disclose to partner*).

Women were not asked specifically about their knowledge of discordant couples[1] and whether they could be in such a relationship, yet the concept emerged in a few of the interviews. When one woman was asked about this possibility, she was surprised that her partner could be HIV-negative. She said, if he was, then, "the marriage can end . . . because he would want to keep his life" (*Disclosed to partner*). It was not clear if she would have already disclosed within a week of her diagnosis had she known of the possibility of discordant couples. Another woman who knew about discordant couples said she was fearful that her partner could be HIV-negative and that "maybe we can divorce" (*Disclosed on the day of diagnosis*), but this fear did not stop her from disclosing on the day of diagnosis.

[1] Discordant couples are defined as a couple where one partner is HIV-positive and the other is HIV-negative.

Nurses

Nurses understood that many women believed that their partners were the source of their HIV. Nurses counseled women to encourage their partners to be tested. Women who disclosed often supported their partners; "They are usually encouraged to convince the husband to go for tests as well and [if needed] to try to get drugs and take them accordingly" (*Clinic nurse*).

Testing and counseling for couples was also available at the hospital. Nurses believed that couples counseling was a beneficial outcome to disclosure, as these two clinic nurses explained:

> If they disclose their status on their own, then they are motivated to bring the husband to the clinic for couples counseling (*Clinic nurse*).
>
> We tell those that are afraid to disclose to come with the husband to the hospital right away here or you should go together for testing and have the results together (*Clinic nurse*).

Need to Negotiate for Condom Use

Pregnant HIV-positive Women

Women were given condoms during post-test counseling and were told to insist that a condom be used each time she has sex in the future. One woman said, "What I saw very useful is that we should be using condoms" (*Planning to disclose to partner*). Suddenly changing the sexual interaction was an impetus for disclosure. As one woman explained, she was planning to disclose ". . . in order for us to use condoms whenever we want to have sex" (*Planning to disclose to partner*).

Nurses

In addition to promoting HIV testing for partners, nurses were trained to give all HIV-positive women condoms during post-test counseling sessions. They promoted condoms for HIV-positive women as a method for birth spacing since ". . . having children now and again can hinder their normal healthy life" (*Clinic nurse*). Condoms are also important barrier methods if the partner is HIV-negative. Nurses acknowledged that condoms would prompt disclosure, as illustrated by the following quotes:

> . . . it is impossible to hide the status to your husband and then ask him to use condoms at home, he will refuse unless he knows the status (*Clinic nurse*).
>
> . . . if the husband is not aware . . . he can ask, 'why should I use condoms now?' (*Clinic nurse*)

Explain Current or Future Illness

Pregnant HIV-positive Women

Specific questions and prompts on the influence of women's current health status on whether they disclosed to their partner were not included on the interview guides. This theme emerged from the data. A few women who had been ill before coming to the clinic explained that it is better to disclose their HIV-positive status since it clarified why they had been sick. They also said that they would disclose to others to ensure that they will have more support from trusted confidants if they become sick in the future; "they should know about it, [since] maybe sometimes I can suddenly get sick" (*Planning to disclose*).

Nurses

Nurses emphasized that women should disclose to their partners and to other trusted people in their lives to ensure that they have support if they become sick. Nurses talked about disclosing to supportive relatives in particular. These goals are illustrated by the following quotes:

> The women are encouraged to disclose their status at least to their husbands because if the husband is aware he can help (*Clinic nurse*).
>
> We also tell them that they should at least tell a relative because they are the ones to take you to the hospital in case you fall sick. They will understand you better in any problems that you go through (*Clinic nurse*).

Fear of Disclosure to Partner from Another Source

Pregnant HIV-positive Women

Fear of disclosure from another source was a prompt for disclosure because women wanted to ensure that the partner would not hear of the HIV-positive serostatus of his wife from another source. Women believed that they had been seen at the clinic and that people would think they were HIV-positive. One woman had not yet disclosed to her partner since he was temporarily working out of Lilongwe, but she planned to disclose as soon as he returned due to fear that someone else would tell him. She stated:

> Whenever anything happens I tell him so that he should live knowingly and not hear from some other people because he gets disappointed. So the first thing is to hear from me so that if he hears something from outside he shouldn't be disappointed; he should just say that I am already told by my wife (*Planning to disclose to partner*).

Prior Knowledge of HIV testing at First Antenatal Clinic Visit

Pregnant HIV-positive Women

Nine of the women knew that they would be tested for HIV during their first antenatal clinic visit. Ten women did not know. It is not clear from the data how many of the partners knew that their wives would be tested for HIV at the clinic. However, one woman reported that she disclosed to her partner on the day of diagnosis since, "He already knew that today at the antenatal clinic that I will have the HIV test so I wanted him to know the results" (*Disclosed on day of diagnosis*).

Reasons Women Did Not Disclose to Their Partners

Only one theme, fear of a negative reaction, was identified by women and nurses for non-disclosure.

Fear of Negative Reaction

Pregnant HIV-positive Woman

Only one woman stated that she had not and would not disclose to her partner. She feared his anger and being abandoned. She knew the HIV testing policy at the clinic and expected to be tested. She decided to be tested since she did not expect to be HIV-positive. She explained that she would trust and be supported by the clinic staff, since “I can be free with any of [them] because if I ask them, they can answer me” (*Not planning to disclose*).

Nurses

Many of the nurses believed that women do not disclose to their partners. The most common reason cited was fear of the partner’s negative response, which included fear of violence, divorce, abandonment and stigma. As one nurse said, it is “fear of the unknown”

(*Clinic nurse*) that frightens the women. A nurse recounted a story from one woman's disclosure experience with her partner. The man said, " . . . 'I don't know where you got that [HIV]. Please you should go where you got it'" (*Community nurse*).

Violent reactions by partners in the past prompted the community nurses to start outreach activities targeted to men. They also established support groups for men who had wives attending the PMTCT program at the antenatal clinic. As one community nurse explained, "There was gender-based violence because of disclosure status by the spouse; it's when we decided to start talking to these men" (*Community nurse*).

Discussion

Access to testing, counseling and treatment for pregnant women in Lilongwe may have had an impact on HIV disclosure. Almost all (93%) pregnant women in Malawi attend at least one antenatal clinic visit (National Statistical Office and ORC Macro, 2004); thus, there are few barriers for women to seek health care during pregnancy. In addition, the "opt-out" method has increased the number of women being tested for HIV at the antenatal clinics in Lilongwe (Moses et al., 2008). In addition, there was general knowledge among men and women that pregnant women were being tested for HIV at the antenatal clinics in Lilongwe, a finding which is supported by two of the reasons for disclosure identified by women but not by nurses. Women reported disclosing to their partners out of fear of disclosure from another source and due to prior knowledge that HIV testing was available at their first antenatal clinic visit. These findings highlight the importance of education in the community for both men and women to increase the knowledge of the availability of testing, counseling and treatment at antenatal clinics, thereby supporting HIV disclosure among pregnant women to their partners and to others.

The combination of factors in Lilongwe that seemed to prompt HIV disclosure by pregnant women to their partners was similar to findings among 31 HIV-positive South African women. Almost all of those women reported disclosing within a week of diagnosis. Findings emphasized the importance of the social context and the negative consequences of involuntary disclosure (Varga et al., 2006). The researchers believed that women disclosed due to self protective reasons, which matched findings in Malawi. Many of the reasons for disclosure identified by pregnant women in Malawi - specifically following the cultural norms, negotiating for condom use, securing support for future illness, and preventing possible involuntary disclosure - were self protective behaviors.

Nurses may not have framed the reasons for disclosure as being self-protective, but many of the reasons they emphasized in post-test counseling did correspond to the reasons women disclosed to their partners. These results demonstrated that post-test counseling was appropriate in this context, even though no direct association had been documented between post-test counseling and disclosure by women in Malawi (Bobrow, 2008b).

Nurses need to be educated that the post-test counseling they provided may have a beneficial and supportive influence on disclosure and that pregnant women do disclose their HIV-positive status to their partners, often on the day of diagnosis. Many nurses did not believe that women disclosed to their partners. Nurses often did not have the opportunity to ask women privately at subsequent antenatal clinic visits about their disclosure behaviors and reactions. If women experienced a negative reaction to their disclosure, then they may have been more inclined to tell a nurse at their next visit to solicit advice and support. Consequently, nurses may have heard more accounts of negative consequences of disclosure.

Although the post-test counseling was found to be appropriate, enhancements could be implemented because nurses in these CTA clinics have been found to adhere to their training protocols (Ferguson, 2006). A process evaluation of infant feeding counseling among clinic nurses, for a clinical trial at Bwaila Hospital which recruited women from CTA clinics in Lilongwe, found that nurses provided 90% of the information in the study protocol and that their counseling technique was of high quality (Ferguson, 2006). In addition, nurses could be trained to ask about disclosure at subsequent visits following the post-test counseling session. Post-test counseling should include tailored messages that correspond with reasons women disclose to their partners, in order to increase its relevance to women and potentially enhance its effectiveness in facilitating women's disclosure.

Other research conducted in these clinics support the findings in this paper. Quantitative results on disclosure in Malawi did support the dominance of cultural obligation as a motivator for disclosure. Results showed that the most common reason given for disclosing to the partner was "because he should know," (40.4%), implying a sense of obligation (Bobrow, 2008b). Women's feelings of obligation and responsibility for disclosure to their sexual partners has remained constant over time, even with the increased availability of ARVs, which have changed HIV more into a chronic disease to be managed rather than a death sentence (Siegel, Lekas, & Schrimshaw, 2005).

It is not surprising that women believed that their partners were the source of their HIV. There is a general belief in Malawi in "joint fates;" so that, if one partner is infected, then the other one will be infected as well (Zulu & Chepngeno, 2003). The authors also found that, "both wives and husbands believe that regular sex is a central aspect of marriage; both also believe that men and women (particularly men) may seek extramarital partners."

(Zulu & Chepngeno, 2003) This belief is further supported by the lack of knowledge of the possibility of discordant couples among women interviewed for this study. Condoms were not found to be suitable HIV prevention tools within marriages, but women encouraged their partners to use condoms in their extra marital affairs so as not to bring HIV into the marriage (Zulu & Chepngeno, 2003). While condoms were not considered as needed within marriages in Malawi as a preventive strategy, this study found that the way condoms are promoted in post-test counseling, as a family planning method, was a reason for disclosure.

Couples counseling and testing is available in Lilongwe. It may be that promoting couples counseling would be appropriate in the remainder of Malawi as well. Couples counseling was found to have long-term and beneficial effects on HIV-related communication in Rwanda (van der Straten et al., 1995). Educating men and women in the community about "opt-out" HIV testing for women at their first antenatal clinic visit should also be a priority, since prior knowledge of HIV testing through antenatal care helped women disclose to their partners.

Some women reported that they and their partners had a fatalistic response to finding out her HIV-positive test result. This sense of inevitability has previously been documented in a study in Malawi (Kaler, 2004). Men in particular often believe that HIV is in their future due to human nature. Although women did not explicitly list this factor as a reason for disclosure, some women may have known of their partner's feeling and not hesitated to disclose.

While communication norms may not differ throughout various parts of Malawi, access to HIV testing and treatment does. One of the study limitations is that the research

was conducted in the capital city of Lilongwe, where access to HIV testing in pregnancy and PMTCT programs are available. The same access is not found in rural Malawi.

Many areas for future research are suggested by this study. Future qualitative research on disclosure in Malawi could explore in more depth the cultural sense of obligation women feel for disclosing to their partners. Similar research could be conducted in rural Malawi, in a setting where HIV testing may be available through antenatal clinics, but where access to PMTCT services is limited.

This paper did not present findings from men. It would be helpful to include the voices and perspectives of men on women's disclosure. As more outreach activities are implemented to promote couples counseling and to increase the knowledge of HIV testing in antenatal clinics, an evaluation of the efficacy of outreach activities might also be beneficial.

The findings show that these women are disclosing their HIV status to their partners and that they have multiple reasons that prompt them to disclose, including existing cultural motivators and beliefs about the source of HIV. The findings highlight the need to inform nurses who conduct post-test counseling that the reasons they emphasize to encourage disclosure by women to their partners are the same reasons women report using to disclose. Outreach in the community should inform both women and men about "opt-out" HIV testing at antenatal clinics at the time of the first visit since prior knowledge of testing promoted disclosure and early disclosure.

CHAPTER 5:

CONCLUSION

Summary of Results and Implications for Practice

The purpose of this dissertation was to investigate factors that influence women's willingness to participate in prevention of mother-to-child transmission (PMTCT) programs and research and to explore factors associated with HIV disclosure by pregnant women to their primary male partners and other individuals. Qualitative and quantitative methods were utilized to provide a more complete understanding of participation and HIV disclosure in the research setting of antenatal clinics in Lilongwe, Malawi. Quantitative data were utilized to explore factors that influence HIV disclosure to partners, early disclosure to partners (day of diagnosis) and disclosure to more than one person. Qualitative data were used to compare reasons offered by health care providers and pregnant HIV-positive women for why women disclose to their partners and why they would participate in the Breastfeeding, Antiretroviral and Nutrition (BAN) Study.

This conclusion provides a summary of the findings for each of the two study aims and their implications for practice for each aim. Study limitations and directions for future research are also discussed.

Summary of Results for Aim 1

The first study aim was to describe factors that influence the willingness of pregnant HIV-positive Malawian women to participate in PMTCT programs and research. Research

was focused on participation in the BAN Study, but findings can be generalized to recruitment into PMTCT programs. Pregnant HIV-positive women and health care providers believed that the main facilitating factor to participation was the desire by women to know their disease status and progression. Based on the qualitative study, this was most often expressed as, "I wanted to know how I am in my body." Women also valued the trusting relationship they felt they established with providers during post-test counseling. Providers believed that women who understood issues of mother-to-child transmission (MTCT) and information on PMTCT during counseling were more motivated to participate. Women did not identify their knowledge of MTCT as a motivator for participation.

The main barrier to participation identified by women and providers was the culturally dominant role of men over women, which was consistently expressed by all married Malawian women despite their or their partner's tribal affiliation (both matrilineal or both patrilineal). Women reported that the recent shock of discovering their HIV-positive serostatus acted as a barrier to making an immediate decision about their participation. Providers identified other barriers to participation including a low level of PMTCT knowledge, misconceptions about the BAN Study, and fear of the consequences of women's disclosing their HIV-positive status to their partners.

Conclusions and Implications for Practice for Aim 1

Post-test counseling should be enhanced to emphasize emotional support while building on women's desire to know their disease status and progression. Providers should be trained to impart knowledge and treatment information in a supportive way to help minimize the shock of an HIV-positive diagnosis, while offering hope to women for their future health and the health of their children. Information about programs should be offered

to all women during post-test counseling and at subsequent antenatal clinic visits. Since men have the decision-making power, it is important that PMTCT programs and research studies target men to support women's participation. Outreach to men should be accompanied by education for both men and women about HIV testing for pregnant women at antenatal clinics, couples counseling and testing for HIV, MTCT, and PMTCT services available at the clinics.

These findings have important implications for Malawi. As more PMTCT programs are established in antenatal clinics in rural areas throughout Malawi, lessons learned from this study can be utilized to maximize women's participation in the programs to reduce MTCT. These programs have the potential to reach many women, since most (93%) pregnant Malawian women receive antenatal care from a medical professional (National Statistical Office and ORC Macro, 2004), and more pregnant women than ever are being tested for HIV using the "opt-out" system of testing (Moses et al., 2008), as mandated by the Government of Malawi (Malawi National AIDS Commission, 2004).

Summary of Results for Aim 2

The second study aim was to explore factors that influence HIV disclosure by pregnant Malawian women to their primary male partners. In the qualitative findings for Aim 1, health care providers asserted their belief that the need for HIV disclosure was a barrier to participation in PMTCT programs. Other research studies also supported this finding (Medley et al., 2004). Quantitative research was, therefore, utilized to examine the factors that influenced the likelihood of HIV disclosure by women to their partners. Almost all the 300 women who participated in the survey (90%) reported disclosing their HIV status

to their partner, and most (73%) did so on day of diagnosis. Of women who disclosed their status, almost half (47%) told more than one person.

Based on these results, multivariable analysis using logistic regression was conducted to explore factors that influenced three different, but related outcomes: disclosure to partner, early disclosure to partner (day of diagnosis), and disclosure to more than one person.

The main factors that increased the likelihood of a woman's disclosure to her partner were living in Lilongwe for ten years or less, her belief that she had been infected by her partner, and having negotiated during a disagreement with her partner in the past year. Factors that decreased the likelihood of disclosure were having been sexually coerced by her partner in the past year and perceiving a high level of HIV stigma.

The likelihood of early disclosure was increased by the woman's belief that she was tested for HIV before her partner and by sharing the same tribal affiliation (both matrilineal or both patrilineal) with her partner. Women with more education, those who had been sexually coerced by their partners in the past year, and those who perceived a high level of HIV stigma were less likely to disclose early to their partners.

Factors that increased the likelihood that a woman disclosed to more than one person included having a relative with HIV, believing that she was tested for HIV before her partner, fear of involuntary disclosure, and having been sexually coerced by her partner in the past year. Women with low socioeconomic status (SES) were less likely to disclose to more than one person.

Different factors were important in explaining the three outcomes. Perceptions of the source of women's HIV infection and of testing for HIV before their partners were powerful motivators for disclosure. Among the women interviewed, 49% believed they were infected

by their partner. Sexual coercion was associated with a decreased likelihood of disclosure and early disclosure, yet an increased likelihood of disclosure to more than one person. Overall, 47% of women reported being sexually coerced by their partner in the past year. A perception of a high level of HIV stigma was a barrier to disclosure and early disclosure to their partner, but had no significant effect on the pattern of disclosure to others. Overall, 54% of women reported perceiving HIV stigma in their lives.

Several of the conclusions from the quantitative research were supported by the findings in the qualitative research. High rates of HIV disclosure by women to their partners were evident among women interviewed for the qualitative research since 13 of the 20 women interviewed had disclosed to their partners within a week of their HIV diagnosis and 5 of the 13 had disclosed on the day of diagnosis.

The quantitative and qualitative results identified a common main reason for disclosure. Descriptive findings from the quantitative research showed that women disclose to their partners out of a sense of obligation. The women said they disclosed, "because he should know." The same phrase was noted as the reason for disclosure offered by the majority of women in the qualitative research. The obligation felt by women to their partners was coupled with good communication norms between partners. Good negotiation with their partners in the past year was also documented as a factor that increased the likelihood of women's disclosure.

The quantitative and qualitative results from women also both identify the women's belief that their partners were the source of their HIV infection as a reason for disclosure. A woman's belief that she was tested for HIV before her partner also increased the likelihood of early disclosure and disclosure to more than one person.

Within the qualitative findings, nurses revealed that they believed women disclosed to their partners for reasons that nurses used to encourage disclosure in post-test counseling. These common reasons for disclosure, identified by nurses and women, were cultural obligation and communication norms with partners, belief that the partner was the source of her HIV, the need to negotiate condom use, and the need to explain current or future illness. Women also gave two additional reasons for disclosing to their partners: fear of disclosure from another source and prior knowledge that HIV testing was available to all pregnant women attending their first antenatal clinic visit.

Qualitative findings on disclosure indicated that reactions to an HIV-positive result by women and their partners varied from disappointment to acceptance. Expectations of anger from partners in reaction to disclosure did not appear to change their plan to disclose. In contrast, quantitative results revealed that women were less likely to disclose and to disclose early if they had been sexually coerced by their partner in the past year. However, qualitative research with women did not specifically address women's history or expectations of sexual violence.

Conclusions and Implications for Practice for Aim 2

The finding that 90% of women disclosed to their partner and 73% of them did so on the day of diagnosis was unexpected, in light of reports by health professionals that reluctance to disclose HIV status was a main barrier to program participation. The high rate of disclosure by pregnant HIV-positive women in the antenatal clinics in Lilongwe, Malawi, is inconsistent with published literature. The access to testing, counseling and treatment for pregnant women in Lilongwe may be one set of reasons for this unexpected result. Almost all (93%) pregnant women in Malawi attend at least one antenatal clinic visit (National

Statistical Office and ORC Macro, 2004); thus, there is no barrier for women to seek health care during pregnancy. The "opt-out" testing method has also increased the number of women being tested for HIV at the antenatal clinics in Lilongwe (Moses et al., 2008). In addition, men and women in Lilongwe knew that pregnant women were being tested for HIV at the antenatal clinics, a finding which has been documented through this research. Women reported disclosing to their partners out of fear of disclosure from another source and due to prior knowledge that HIV testing was available at their first antenatal clinic visit. These findings highlight the importance of community education activities for both men and women to promote the knowledge of the availability of HIV testing, counseling and treatment for pregnant women at the antenatal clinics, thereby supporting HIV disclosure among pregnant women to their partners and to others.

Nurses in the Lilongwe clinics should be informed that the vast majority of women do disclose to their partners, and that their reasons were often the same ones that nurses emphasized to encourage women to disclose during post-test counseling. This is important evidence that supports what they are doing is effective in promoting disclosure. Such knowledge will increase the nurses' self efficacy as providers and reinforce their behaviors in post-test counseling.

Post-test counseling should continue to concentrate on facilitating factors for disclosure including following cultural norms, negotiating for condom use, securing support for future illness, and preventing possible involuntary disclosure. Although nurses did not frame these motivators for the women as self-protective, another study in South Africa (Varga et al., 2006), with a similar social context and prevalence of disclosure among pregnant women found that doing so may be a helpful tool to enhance post-test counseling.

Post-test counseling should also help women recognize and acknowledge barriers to disclosure, such as sexual coercion and HIV stigma. Women should be encouraged to have their partner access HIV counseling and testing. Improvements to post-test counseling for pregnant HIV-positive women could be easily implemented since other research indicated that nurses adhere to their training protocols for counseling (Ferguson, 2006).

Study Limitations

Several study limitations are important to note. Additional topics might have been included on the qualitative research guides. Women were not specifically asked for reasons they disclosed to their partners on the day of diagnosis because the trend for early disclosure was not known at the time of data collection. Specific questions about how current or future illness prompted disclosure were also not asked. These offer opportunities for future study.

For the quantitative research, power calculations were conducted with the assumption based on published literature from similar settings that fewer women would have disclosed to their partners. Thus, the statistical power of the study was limited and would have been enhanced with a sample size larger than 300 women. In addition, quantitative measures on the institutional level of the social ecological framework (SEF) (McLeroy et al., 1988) could have provided more insight into the influence of the patient-provider interaction, particularly since a number of qualitative findings were on the institutional level, including the main finding that reasons for HIV disclosure promoted by nurses in post-test counseling echoed the reasons women disclosed to their partners.

The University of North Carolina (UNC) Project in Malawi has been conducting research and providing care for HIV-positive women through antenatal clinics in Lilongwe for many years. Clinics supported by UNC are known as providing high quality care and

these clinics are busy. The impact of UNC's presence was not measured. UNC has a reputation for primarily providing care to HIV-positive persons; thus, people tend to think that individuals attending UNC affiliated clinics are HIV-positive. This could explain the high rates of disclosure among pregnant HIV-positive women.

Directions for Future Research

Data collected for this dissertation would allow for additional analysis related to participation in PMTCT programs and to HIV disclosure as well as other topics that are beyond the scope of this dissertation. In particular, data were collected during focus group discussions with Community Advisory Board (CAB) members, influential community members and primary male partners of unknown HIV status. Observations of community outreach activities and support groups for women in the BAN Study and for their partners were also conducted. Data from certain sections of the quantitative survey were also not reported but will provide important resources for future research.

One section of the quantitative survey for future analysis is intimate partner violence, including results from the Revised Conflict Tactics Scale 2 (CTS2) (Straus et al., 1995) which measured the prevalence and frequency of conflict between women and their partners in the past year and prior to the past year. Qualitative data could also complement these findings to help explain general beliefs about violence within intimate relationships in Malawi. In addition, research using a counseling intervention could be conducted to encourage male support of their HIV-positive wives.

Issues of HIV stigma were studied in-depth. The quantitative survey included an HIV stigma scale to measure individually perceived stigma. The scale was adapted from an HIV stigma scale developed by the International Center for Research on Women (ICRW)

(Nyblade, 2003). Analysis of these findings could be combined with qualitative data collected on HIV stigma specifically related to HIV disclosure.

When the issues of low participation in the BAN Study were noted, a number of efforts to increase participation were implemented, including community outreach activities, male motivation sessions in the community, and women's and men's support groups. These community efforts to promote participation in PMTCT programs were the basis of a presentation (Bobrow et al., 2007) and could be expanded for publication.

Focus group discussions with men and community leaders were conducted in the same two communities and utilized a narrative approach to gathering data using the same interview guide. Men's voices would be valuable to be heard on topics including HIV counseling and testing and HIV disclosure by their wives. Their perceptions could be compared with those of the women and health care providers. In addition, the men's responses could be compared with attitudes of influential community leaders to participation by women in PMTCT programs.

The quantitative manuscript explored factors that influenced HIV disclosure by women to more than one person. Qualitative results on disclosure to people other than primary male partners could be combined with these findings for additional understanding of reasons pregnant HIV-positive women disclose and do not disclose to more people.

Women were asked specific questions on the quantitative survey and in the qualitative research about their knowledge of infant feeding for HIV-positive women. These results relate to general knowledge and to participation in the BAN Study.

One interesting finding from the quantitative survey was that 35% of women did not disclose the results of the infant's HIV test to anyone. Research could explore factors that influence HIV disclosure of the infant's status to others.

Future research should concentrate on the accessibility of PMTCT services and perceptions of "opt-out" testing. Research on HIV disclosure among pregnant women in Malawi should be conducted in rural areas and should explore the cultural sense of obligation women reported for disclosing to their partners in more depth. In addition, as more outreach activities are implemented to promote couples counseling and to increase the knowledge of the availability of HIV testing in antenatal clinics, an evaluation of the efficacy of outreach activities might also be beneficial.

These findings provide hope for the future. While UNAIDS reported that fewer than 10% of pregnant women have access to PMTCT programs (UNAIDS, 2004) there are many countries with a high prevalence of HIV where PMTCT program efforts are increasing, including Malawi. As more of these PMTCT programs become available, particularly in urban settings like Lilongwe, there is a possibility that more pregnant HIV-positive women will be supported through effective post-test counseling and community outreach to disclose their HIV-positive status to their partners and to participate in the PMTCT programs.

APPENDIX A: MAP OF MALAWI

APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE FOR WOMEN – QUALITATIVE DATA

Date _____
Location _____
Name of interviewer _____
ID code _____

CTA enrollment ID __ __ - __ __ __ __ __

BAN temporary ID __ __ __ __ __

INFORMATION FROM CTA FORM

Has your partner had VCT? [1] Yes [2] No [9] Don't know
Result? HIV [1] Positive [2] Negative [9] Don't know

Gestational Age (in weeks) __ __

DEMOGRAPHIC INFORMATION

A1. Participant's age: _____(years)
A2. Participant's sex: [2] Female

A3. What is your marital status?
- [1] Married
- [2] Never married
- [3] Separated
- [4] Divorced
- [5] Widowed
- [6] Living with partner

A4. What is the highest level of education you ***completed*** at school? *(Circle response)*
- Standard 1 2 3 4 5 6 7 8
- Secondary school – Form 1 2 3 4
- Above secondary school
- Adult literacy only
- Never attended school

A5. How well can you read and write Chichewa?
[1] Very well [2] Well [3] Somewhat [4] Not at all

A6. How well can you read and write English?
[1] Very well [2] Well [3] Somewhat [4] Not at all

A7. What is your tribe?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

A8. What is your religion?

[01] Catholic
[02] Islam
[03] CCAP
[04] Anglican
[05] Seventh Day Advent
[06] Seventh Day Baptist
[07] Pentecostal/Revivalist
[08] Traditional
[09] No Religion
[88] Other (specify)_____

A9. What is your MAIN occupation?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] Housewife
[12] No job
[88] Other (specify)_____

A10. How many times have you been pregnant? __ __

A11. How many living children do you have? __ __

A12. How long have you lived in Lilongwe? __ __ years __ __ months

MALE PRIMARY PARTNER CHARACTERISTICS

A13. Are you living together with the man who is responsible for this pregnancy?

[1] Yes ***Go to question Q14***
[2] No ***Proceed to question Q13.1***

13.1. Are you living together with a man who is not responsible for this pregnancy?

[1] Yes ***Proceed to question Q13.2***
[2] No ***Go to question Q14***

13.2. How long have you been living with this man? __ __ years __ __ months

13.3. What is the tribe of this man?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

13.4. What is the highest grade level of this man? *(Circle response)*

Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school
Don't know

13.5. What does this man do to earn a living?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] No job
[12] Don't know
[88] Other (specify)_____

13.6. Where does this man work? [1] In Lilongwe [2] Outside Lilongwe [3] Both

13.6.1. How many months does the man spend outside of Lilongwe in a year? __ __ months

A14. What is the highest grade of school completed by the father? *(Circle response)*

Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school
Don't know

A15. What is the tribe of the father?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

A16. What does the father do to earn a living?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] No job
[12] Don't know
[88] Other (specify)_____

A17. Where does the father work? [1] In Lilongwe [2] Outside Lilongwe [3] Both

17.1. How many months does the father spend outside of Lilongwe in a year? __ __ months

HOUSEHOLD CHARACTERISTICS

A18. What kind of sanitary facility does your household use?

[01] Private flush toilet
[02] Communal flush toilet
[03] Private VIP latrine
[04] Communal VIP latrine
[05] Private traditional latrine with roof
[06] Communal traditional latrine with roof
[07] Private traditional latrine without roof
[08] Communal traditional latrine without roof
[09] Private Sanplat/Dome slab pit
[10] Communal Sanplat/Dome slab pit
[11] None
[88] Other (specify)_____

A19. What was your main source of drinking water over the past month?

[01] Piped water in dwelling
[02] Piped outside dwelling, personal
[03] Communal standpipe
[04] Personal handpump/borehole
[05] Communal handpump/borehole
[06] Protected spring
[07] Personal unprotected well
[08] Personal protected well
[09] Communal protected well
[10] Communal unprotected well
[11] River/spring
[12] Lake/reservoir
[88] Other (specify) _____

A20. The roof of the main dwelling of your household is predominantly made of what material?

[1] Grass
[2] Iron sheets
[3] Clay tiles
[4] Concrete
[5] Plastic sheeting
[8] Other (specify) _____

A21. The floor of the main dwelling of your household is predominantly made of what material?

[1] Sand
[2] Smoothed mud
[3] Smooth cement
[4] Wood
[5] Tile
[8] Other (specify) _____

A22. What are your sources of lighting fuel? **Multiple responses**

[01] Collected firewood
[02] Purchased firewood
[03] Grass
[04] Paraffin
[05] Electricity
[06] Gas
[07] Battery/ Dry cell/Torch
[08] Candles
[88] Other (specify) _____

A23. What are your sources of cooking fuel? **Multiple responses**

[01] Collected firewood
[02] Purchased firewood
[03] Paraffin
[04] Electricity
[05] Gas
[06] Charcoal
[07] Crop residue
[08] Saw dust
[09] Animal waste
[88] Other (specify)_____

Continue with the appropriate questionnaire.

APPENDIX C: INTERVIEW GUIDE FOR EXIT INTERVIEW FOR PREGNANT WOMEN
Referral from CTA nurse

Date _____
Location _____
Name of interviewer _____
ID code _____

CTA enrollment ID __ __ __ __ __

BAN temporary ID __ __ __ __ __

Start time _____
End time _____

Reminder: **Remember that the women who schedule a screening visit must agree to participate in the exit interview AND in a follow-up interview before their screening visit.**

Format: Introduce the field investigator. Explain that we are here to learn more about why women decide to join the BAN study or not.
Obtain informed consent. Explain the ground rules for the interview: (1) that the discussion will last about 15 to 20 minutes, (2) that everything they say will remain confidential, and (3) that their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the interview. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the interview.

Materials: Interview guide, notepad, pens, tape recorder, tapes, batteries, consent form, ink pad, demographic questionnaire for women.

1. Would you tell me what you have been told about the BAN study?
   What do you think about the information you have heard about the BAN study?
   Probe: if woman understood the information.
   Probe: if she thought the information was useful.
   Probe: how interaction with staff at Bottom/Bwaila Hospital was.

2. What do you think is the purpose of the BAN study?

3. Do you think you want to be part of the BAN study that was explained to you?
   [1] Yes [2] No
   a. If yes, Why? What makes you feel this way?
   b. If no, Why not? What makes you feel this way?

4. Do you think it is possible that a mother who is infected with HIV can give birth to a baby who is healthy and without HIV?
   [1] Yes [2] No [3] Not sure [4] Don't know
5. What makes you feel this way? (Depending on her answer, probe on whether it is always, sometimes, etc, and the reasons for what she feels.)

6. How do you feel about the having to take medicine as part of the BAN study? What problems do you anticipate encountering?

7. What do you think about giving your baby only breast milk for 6 months? What problems do you anticipate encountering?
   What do you think about giving your baby other foods and no breast milk after 6 months? What problems do you anticipate encountering?

8. What do you think about getting special food for yourself as part of the study? Would you share with anyone? If yes, with who? If not, why not?

9. **ASK EXITY – SKIP FOR EXITN**: You will be given an appointment to return to the clinic for BAN in one week (a first screening visit).

   a. What will make it easy for you to come to that visit? (Probe: transport money, food)

   b. What might make it hard to come to that visit? (Probe: distance, long wait time)

10. Will you tell anyone about your HIV status?
    [1] Yes [2] No
    a. If yes, then who? Why that person/people?
    b. If no, then why not?

11. Do you need to talk to someone before deciding to enroll into the BAN study?
    [1] Yes Who? Why? [2] No Why not?
    Do you need ***permission*** to enroll into the BAN study?
    [1] Yes From who? Why? [2] No Why not? ***Go to question Q13.***
    Who? (Probe: husband, mother, mother-in-law, others) Why that person/people?

12. If the person you discussed BAN with advises you not to join, what will you do? If the person you discussed BAN with tells you not to join, what will you do?

13. After learning all the details about the BAN study, what problems do you see in participating in the study?
    Probe: transportation problems
    Probe: long wait times
    Probe: other children waiting at home
    Probe: other children at clinic with you
    What will you do about these problems?
    How do you think BAN can help address these problems?

14. What concerns will other family members have for you to join the BAN study?
15. Anything else? Any questions?

Thank you!

For women who scheduled a first screening visit (EXITY):
DATE, TIME, and LOCATION OF THE FOLLOW-UP IN-DEPTH INTERVIEW (EXITYF):

_____

APPENDIX D: INTERVIEW GUIDE BEFORE SCREENING VISIT FOR PREGNANT WOMEN

Date _____
Location _____
Number of days since exit interview _____
Name of interviewer _____
ID code _____

CTA enrollment ID __ __ __ __ __

BAN temporary ID __ __ __ __ __

Start time _____
End time _____

Format: Introduce the field investigator. Explain that we are here to learn more about why women decide to join the BAN study or not.
Obtain informed consent. Explain the ground rules for the interview: (1) that the discussion will last about 1 to 1½ hours, (2) that everything they say will remain confidential, and (3) that their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the interview. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the interview.

Materials: Interview guide, notepad, pens, tape recorder, tapes, batteries, consent form, ink pad, demographic questionnaire for women.

HIV testing at the clinic

1. When you came to the clinic for your first antenatal visit, did you know that you would be tested for HIV?
   [1] Yes [2] No ***Go to question Q4.***

2. Before going to your first antenatal clinic visit, did you talk to anyone about the fact that you would be tested for HIV? (Probe: mother, mother-in-law, friends, religious leaders)
   [1] Yes [2] No

3. Did your husband know that you would be tested for HIV?
   [1] Yes [2] No
   a. If yes, what does your husband think about the fact that you have been tested for HIV?

4. How did you feel while waiting for your results? What were you thinking about while waiting for the results from the HIV test?

After the HIV results

5. How did you feel when you first found out that you are HIV positive?
   What thoughts were in your head when you first found out that you are HIV positive?

6. What did the counselor say to you?

7. What did you find helpful in what the counselor said?

8. What was NOT helpful in what the counselor said?

9. What do you think the counselor should have said?

Disclosure, social support, fear of violence

10. Could you tell anyone about your condition?
    [1] Yes [2] No ***Go to question Q16.***

11. Who could you tell? (Probe: husband, mother, sister, neighbor, friend)

12. Did you tell someone about your condition?
    [1] Yes [2] No ***Go to question Q16.***

13. Who did you tell? (Probe: husband, mother, sister, neighbor, friend) When did you tell them? Why did you tell them?

14. ***If the woman told her husband, ask:*** How did your husband react to your news that you are HIV–positive? (Probe: support, anger, violence)

15. Does he want to be tested too? [1] Yes [2] No [9] Don't know
    Why? Why not? ***After asking question, go to question Q18.***

16. ***If the woman did NOT tell her husband, ask:*** Can you talk to your husband about your test results? What do you think his reaction will be? (Probe: support, anger, violence)

17. Will he want to be tested too? [1] Yes [2] No [9] Don't know
    Why? Why not?

    Could you tell anyone else? (Probe: mother, sister, friend, neighbor)

18. Who do you turn to for advice or help? (Probe: husband, mother, sister, neighbor, friend) Why?

19. Who do you NOT turn to? (Probe: husband, mother, sister, neighbor, friend) Why?

20. How would other people react if they find out that you are HIV-positive? Why would they act this way? (Probe: husband's family, neighbors). Why?

21. Why do you think some people are unkind and judge others who are HIV-infected?

22. Is there anything that could or should be done to change this? What? Who should be involved?

23. What have you heard about ways to treat HIV?

Autonomy

24. What decisions about yourself can you make without consulting your husband? (Probe: health decisions)

25. What decisions about your baby can you make by yourself without consulting your husband? (Probe: health decisions)

26. What matters are you comfortable talking about with your husband? What makes you feel that way?

27. What matters are you uncomfortable talking about with your husband? What makes you feel that way?

28. Who makes decisions that involve money in your home? Can you make decisions about what to buy for your household without consulting your husband?
    [1] Yes [2] No

Perceptions of the BAN Study

29. What do you think about the information you have heard about the BAN study?

30. What do you think about having to take medicine as part of the study?
31. What problems do you think you might encounter when taking the medicines? How would you manage or cope with those problems?
32. What do you think about giving medicine to your baby as part of the study? How do you feel?
33. What would people say about this medicine? What would people say about the baby taking this medicine?

34. What do you think about giving your baby only breast milk for 6 months?
35. What do you think about giving your baby other foods and no breast milk after 6 months?
36. What do you think about getting special food for yourself as part of the study?
    Probe: sharing with others

37. Will you be able to return to the clinic often for follow-up examinations and to get more medicines? Why? Why not? What makes you feel this way?
    Probe: transportation problems
    Probe: long wait times
    Probe: other children waiting at home
    Probe: other children at clinic with you

38. How do you feel about having blood drawn on yourself and your baby? What makes you feel this way?
39. How do you feel about giving samples of your breast milk? What makes you feel this way?

Enrollment into BAN

40. Do you plan to go to the clinic for your first screening visit in a week?
    [1] Yes [2] No

    a. If yes, why do you plan to attend the first screening visit?
    b. If no, why do you NOT plan to attend the first screening visit?

41. What might help you come to the screening visit?
42. What might make you NOT come to the visit even after you have scheduled it? (Probe: influence of the transport money)

43. Do you need to talk to anyone about deciding to enroll into the BAN study? (Probe: husband, mother, mother-in-law) Who will make the decision?

44. If your husband is also infected with HIV, what will he think about you taking medicine? What will happen? What if he is not infected? What will happen?

45. After learning all the details about the BAN study, what concerns do you have about participating in the study? Who will you talk to about these concerns?

46. What concerns will other family members have for you to join the BAN study?

47. Anything else? Any questions?

Thank you!

APPENDIX E: INTERVIEW GUIDE AT SCREENING VISIT FOR PREGNANT WOMEN

Date _____
Location _____
Name of interviewer _____
ID code _____

CTA enrollment ID __ __ __ __ __

Made copy of first page of CTA form *(circle)* YES NO

BAN temporary ID __ __ __ __ __

Start time _____
End time _____

Format: Introduce the field investigator. Explain that we are here to learn more about why women decide to join the BAN study or not.
Obtain informed consent. Explain the ground rules for the interview: (1) that the discussion will last about 1 hour, (2) that everything they say will remain confidential, and (3) that their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the interview. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the interview.

Materials: Interview guide, notepad, pens, tape recorder, tapes, batteries, consent form, ink pad, demographic questionnaire for women.

Enrollment into BAN

1. Why did you agree to consent to join the BAN study?

2. Did you talk to anyone about deciding to enroll? (Probe: husband, mother, mother-in-law)

3. Who made the decision? (Probe: If someone other than the woman made the decision ask how she feels about that?)

4. What influenced the decision to join the BAN study?

5. What did you think of the screening visit you just had where you consented to join the BAN study?

6. After learning all the details about the BAN study, what problems do you see in participating in the study? (Probe: transportation problems, long wait times, other children waiting at home, other children at clinic with you) What will you do about these problems? How do you think BAN can help address these problems?

7. What concerns will other family members have for you to join the BAN study?

HIV testing at the clinic

8. When you came to the clinic for your first antenatal visit, did you know that you would be tested for HIV?

[1] Yes [2] No ***Go to question Q11.***

9. Before going to your first antenatal clinic visit, did you talk to anyone about the fact that you would be tested for HIV? (Probe: mother, mother-in-law, friends, religious leaders)
   [1] Yes [2] No

10. Did your husband know that you would be tested for HIV?
    [1] Yes [2] No
    a. If yes, what does your husband think about the fact that you have been tested for HIV?

11. What were you thinking about while waiting for the results from the HIV test?

After the HIV results

12. What thoughts were in your head when you first found out that you are HIV positive?

13. What did the counselor say to you?

14. What did you find helpful in what the counselor said?

15. What was NOT helpful in what the counselor said?

16. What do you think the counselor should have said?

Disclosure, social support, fear of violence

17. Could you tell anyone about your condition?
    [1] Yes [2] No ***Go to question Q23.***

18. Who could you tell? (Probe: husband, mother, sister, neighbor)

19. Did you tell someone about your condition?
    [1] Yes [2] No ***Go to question Q23.***

20. Who did you tell? (Probe: husband, mother, sister, neighbor) When did you tell them? Why did you tell them?

21. ***If the woman told her husband, ask:*** How did your husband react to your news that you are HIV–positive? (Probe: support, anger, violence)

22. Does he want to be tested too? [1] Yes [2] No [9] Don't know
    Why? Why not? ***After asking question, go to question Q25.***

23. ***If the woman did NOT tell her husband, ask:*** Can you talk to your husband about your test results? What do you think his reaction will be? (Probe: support, anger, violence)

24. Will he want to be tested too? [1] Yes [2] No [9] Don't know
    Why? Why not?

25. Who do you turn to for advice or help? (Probe: husband, mother, sister, neighbor) Why?

26. Who do you NOT turn to? (Probe: husband, mother, sister, neighbor) Why?

27. How would other people react if they find out that you are HIV-positive? Why would they act this way? (Probe: husband's family, neighbors). Why?

28. Why do you think some people are unkind and judge others who are HIV-infected?

29. Is there anything that could or should be done to change this? What? Who should be involved?

30. What have you heard about ways of helping people who have HIV?

31. Do you think it is possible that a mother who is infected with HIV can give birth to a baby who is healthy and without HIV?
    [1] Yes [2] No [3] Not sure [4] Don't know

Autonomy

32. What decisions about yourself can you make without consulting your husband? (Probe: health decisions)

33. What decisions about your baby can you make by yourself without consulting your husband? (Probe: health decisions)

34. What matters are you comfortable talking about with your husband? What makes you feel that way?

35. What matters are you uncomfortable talking about with your husband? What makes you feel that way?

36. Who makes decisions that involve money in your home? Can you make decisions about what to buy for your household without consulting your husband?
    [1] Yes [2] No

Perceptions of the BAN Study

37. What do you think about the information you have heard about the BAN study?

38. What do you think about having to take medicine as part of the study?
39. What problems do you think you might encounter when taking the medicines? How would you manage or cope with those problems?
40. What do you think about giving medicine to your baby? How do you feel?
41. What would people say about this medicine? What would people say about the baby taking this medicine?

42. What do you think about giving your baby only breast milk for 6 months?
43. What do you think about giving your baby other foods and no breast milk after 6 months?
44. What do you think about getting special food for yourself as part of the study? (Probe: sharing with others)

45. Will you be able to return to the clinic often for follow-up examinations and to get more medicines? Why? Why not? What makes you feel this way? (Probe: transportation problems, long wait times, other children waiting at home, other children at clinic with you)
46. How do you feel about having blood drawn on yourself and your baby? What makes you feel this way?
47. How do you feel about giving samples of your breast milk? What makes you feel this way?
48. Anything else? Any questions?

Thank you!

APPENDIX F: GENERAL DEMOGRAPHIC QUESTIONNAIRE – QUALITATIVE DATA

Date _____
Location _____
Name of interviewer _____
ID code _____

DEMOGRAPHIC INFORMATION

A1. Participant's age: _____(years)

A2. Participant's sex: [1] Male [2] Female

A3. What is your marital status?

[1] Married ***Go to Q4.***
[2] Never married ***Skip to Q7.***
[3] Separated ***Skip to Q7.***
[4] Divorced ***Skip to Q7.***
[5] Widowed ***Skip to Q7.***
[6] Living with partner ***Go to Q4.***

A4. What is the tribe of your spouse?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

A5. What is the highest level of education your spouse completed at school? *(Circle response)*

Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school
Don't know

A6. What is the MAIN occupation of your spouse?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] Housewife
[12] No job
[88] Other (specify)_____

A7. What is the highest grade you ***completed*** at school? *(Circle response)*

Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school

A8. How well can you read and write Chichewa?

[1] Very well [2] Well [3] Somewhat [4] Not at all

A9. How well can you read and write English?

[1] Very well [2] Well [3] Somewhat [4] Not at all

A10. What is your tribe?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

A11. What is your religion?

[01] Catholic
[02] Islam
[03] CCAP
[04] Anglican
[05] Seventh Day Advent
[06] Seventh Day Baptist
[07] Pentecostal/Revivalist
[08] Traditional
[09] No Religion
[88] Other (specify)_____

A12. What is your MAIN occupation?
[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] Housewife
[12] No job
[88] Other (specify)_____

A13. Do you work for UNC? [1] Yes [2] No ***Go to Q16.***
A14. How long have you worked for UNC? __ __ years __ __ months
A15. Where do you work for UNC?
[1] Tidziwe Center at Kamuzu Central Hospital
[2] Bottom/Bwaila Hospital
[3] Area 25
[4] Kawale
[8] Other (specify) _____

HOUSEHOLD CHARACTERISTICS

A16. What kind of sanitary facility does your household use?
[01] Private flush toilet
[02] Communal flush toilet
[03] Private VIP latrine
[04] Communal VIP latrine
[05] Private traditional latrine with roof
[06] Communal traditional latrine with roof
[07] Private traditional latrine without roof
[08] Communal traditional latrine without roof
[09] Private Sanplat/Dome slab pit
[10] Communal Sanplat/Dome slab pit
[11] None
[88] Other (specify)_____

A17. What was your main source of drinking water over the past month?
[01] Piped water in dwelling
[02] Piped outside dwelling, personal
[03] Communal standpipe
[04] Personal handpump/borehole
[05] Communal handpump/borehole
[06] Protected spring
[07] Personal unprotected well
[08] Personal protected well
[09] Communal protected well
[10] Communal unprotected well
[11] River/spring
[12] Lake/reservoir
[88] Other (specify) _____

A18. The roof of the main dwelling of your household is predominantly made of what material?

[1] Grass
[2] Iron sheets
[3] Clay tiles
[4] Concrete
[5] Plastic sheeting
[8] Other (specify) _____

A19. The floor of the main dwelling of your household is predominantly made of what material?

[1] Sand
[2] Smoothed mud
[3] Smooth cement
[4] Wood
[5] Tile
[8] Other (specify) _____

A20. What are your sources of lighting fuel? **Multiple responses**

[01] Collected firewood
[02] Purchased firewood
[03] Grass
[04] Paraffin
[05] Electricity
[06] Gas
[07] Battery/ Dry cell/Torch
[08] Candles
[88] Other (specify) _____

A21. What are your sources of cooking fuel? **Multiple responses**

[01] Collected firewood
[02] Purchased firewood
[03] Paraffin
[04] Electricity
[05] Gas
[06] Charcoal
[07] Crop residue
[08] Saw dust
[09] Animal waste
[88] Other (specify) _____

Continue with the appropriate questionnaire.

APPENDIX G: INTERVIEW GUIDE FOR BAN AND CTA STAFF AND NURSES

Date _____
Location _____
Name of interviewer _____
ID code _____
Start time of the interview _____
End time of the interview _____

Format: Introduce the field investigator. Explain that we are here to learn more about why women decide to join the BAN study or not.
Obtain informed consent. Explain the ground rules for the interview: (1) that the interview will last about 1 to 1½ hours, (2) that everything they say will remain confidential, and (3) that names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the interview. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the interview.

Materials: Interview guide, notepads, pens, tape recorder, tapes, batteries, consent form, demographic questionnaire.

Interviewer: Thank you for agreeing to talk about the current recruitment and enrollment procedures for the BAN study.

1. Please tell me a little bit about your job as it relates to BAN. What role do you play in recruiting and enrolling women into the BAN study?

2. What do you think about the recruitment procedures? What is working? What is not working?

   a. How has the recruitment procedures been changed over time?

   b. What effect have these changes made to the recruitment of women into BAN?

3. Are there any recruitment procedures that you think should be changed?

   a. If yes, tell me about them.

   b. If no, why?

4. Are there specific study recruitment sites that are working particularly well? Please tell us why you think things are working well at those sites.

5. Are there sites where recruitment is not working well? Why are they working poorly?

Interviewer: Now I would like to discuss some specific aspects about BAN study recruitment.

6. How many staff are involved with recruiting? Do you feel this number is enough?

7. What kind of staff are involved? Are these the right people?

8. How much time is spent on the recruitment process for women? Do you feel this is enough time?

9. What do you think of the information women receive during the recruitment process? Probe: Too much information? Too little information? Adequate information?

Interviewer: Now I would like to discuss procedures related to how women first hear about the BAN study.

10. What information is given to the women who hear about BAN from the CTA nurse? If they are not initially interested, are they told to come back and talk to a specific person? What would you do differently to encourage these women to come back?

11. Do they receive any documentation? If yes, what do they receive?

12. Do they have any incentive to return? If so, what is that?

13. What incentive do you think might work well with women to encourage them to schedule a first screening visit for the BAN study?

Interviewer: Now I would like to discuss procedures related to women who schedule a screening visit.

14. What kind of information is first given to the women who are eligible for BAN by the BAN nurses?

15. Why do you think some women schedule a first screening visit immediately?

16. For women who come for their screening visit, what do you think makes them come back?

17. For women who do NOT return for their screening visit, what do you think makes them stay away?

18. How do you think the recent increase in transport money from MK200 to MK500 has effected BAN recruitment?

Interviewer: Now I would like to discuss women who come back for the screening visit and consent to join BAN.

19. What do you think about the consent process for BAN? Probe: Is the consent process a barrier to recruitment and enrollment? Are women scared?

Interviewer: Now I would like to ask you about perceptions of the BAN study.

20. What are people saying about the BAN Study?

21. Why do you think that mothers are willing to participate in BAN?
    a. What makes you feel that way?

22. Why do you think mothers are NOT willing to participate in BAN?
    a. What makes you feel that way?

23. What do you think women mean when they say they "need to consult their husband" before joining BAN?

24. What do you believe is the influence of the husbands on whether women decide to enroll into BAN?

25. What kind of counselling do women get on disclosure of HIV status to family and friends? What tips do you give them on how to disclose?

26. What do men say about the BAN study?

27. What do men say about their partners participating in the BAN study?

28. What would others say about women participating in this study? (Probe: woman's mother, mother-in-law, neighbors, other family members, religious leaders, friends)

Interviewer: Now I would like to discuss BAN in the community.

29. How do you think the community education sessions are functioning to encourage women to enroll into BAN?

30. What is the impact of the community education sessions? What makes you say this? How could they be improved if at all?

31. How would you explain the community perception of the BAN study? What influences community perception of BAN? What more should be done or what should be done differently to improve community perception of the BAN study?

32. Which community members would provide relevant insight into the recruitment problems identified in BAN?

33. Anything else? Any questions?

Thank you!

APPENDIX H: INTERVIEW GUIDE FOR COMMUNITY NURSES

Date _____
Location _____
Name of interviewer _____
ID code _____
Amount of time working for BAN (months) _____
Start time of the interview _____
End time of the interview _____

Format: Introduce the field investigator. Explain that we are here to learn more about why women decide to join the BAN study or not.
Obtain informed consent. Explain the ground rules for the interview: (1) that the interview will last about 1 to 1½ hours, (2) that everything they say will remain confidential, and (3) that names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the interview. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the interview.

Materials: Interview guide, notepads, pens, tape recorder, tapes, batteries, consent form, demographic questionnaire.

After completing the informed consent process, say:
Thank you for agreeing to talk with us about ways to improve the current recruitment and enrollment protocol for BAN.

1. Please tell me a little bit about your job as it relates to the BAN study. (Probe: interactions with men in the community and with husbands of BAN women)

Awareness and perception of BAN Study
Interviewer: We would like to get your thoughts about the BAN study.

2. What are people saying about the BAN Study?

3. Why do you think that mothers are willing to participate in BAN?
    a. What makes you feel that way?

4. Why do you think mothers are NOT willing to participate in BAN?
    a. What makes you feel that way?

5. What do you think women mean when they say they "need to consult their husband" before joining BAN?

6. What do you believe is the influence of the husbands on whether women decide to enroll into BAN?

7. What do men say about the BAN study?

8. What do men say about their partners participating in the BAN study?

9. What would others say about women participating in this study? (Probe: woman's mother, mother-in-law, neighbors, other family members, religious leaders, friends)

Disclosure

10. What are some of the difficulties women face when approaching their partners to ask for permission to participate in the BAN study?

11. What helps women approach their partners to ask for permission to participate in the BAN study?

Community perceptions of HIV

12. What do men say about women who are HIV-positive?

13. What do men say about family members who are HIV-positive?

14. What do men say about other people who are HIV-positive?

15. What do women say about other women who they know are HIV-positive?

16. What key leaders do you think can have an impact on minimizing community-level HIV stigma? Why do you think so? Who do you think is most important?

17. What community groups or organizations can assist in minimizing community-level HIV stigma?

18. What key leaders do you think can have an impact on encouraging women to participate in BAN? Why do you think so? Who do you think is most important?

19. How should key leaders be involved in encouraging women to participate in BAN?

20. What community groups or organizations can assist in encouraging women to participate in BAN?

21. How should community groups or organizations be involved in encouraging women to participate in BAN?

22. What do you think about communities' level of awareness about prevention of MTCT? What do they know? What misconceptions exist? Do they need to know more? If yes, then what type of information needs to be passed to them?

Community sensitization activities

23. How do you think the community education sessions are functioning to encourage women to enroll into BAN?

24. What is the impact of the community education sessions? What makes you say this? How could they be improved if at all?

25. How would you explain the community perception of the BAN study? What influences community perception of BAN? What more should be done or what should be done differently to improve community perception of the BAN study?

26. Which community members would provide relevant insight into the recruitment problems identified in BAN?

Male involvement in BAN

27. What kind of outreach is being done to educate men about BAN in the community?

28. Where do you reach these men? (Probe: Are incentives provided? If yes, then what type of incentives are provided?)

29. What do you think of the existing male support groups for partners of BAN study participants?

30. How are these men contacted?

31. Why do these men participate?

32. Why don't some men participate?

33. Anything else? Any questions?

Thank you!

APPENDIX I: FOCUS GROUP DISCUSSION GUIDE FOR BAN AND CTA STAFF AND NURSES AND COMMUNITY ADVISORY BOARD MEMBERS

Date _____
Location _____
Name of moderator _____
Name of note-taker _____
ID code _____
Number of participants _____
Start time of FGD _____
End time of FGD _____

Format: Introduce the moderator and note-taker. Explain that we are here to learn more about ways to improve the recruitment and enrollment protocol for the BAN study.
Obtain informed consent. Explain the ground rules for the meeting: (1) that the discussion will last about 1 ½ to 2 hours, (2) that everything they say will remain confidential, and (3) that their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the discussion. All tapes will be destroyed after they have been transcribed.
Ask demographic questions and then proceed with the focus group discussion.

Materials: Discussion guides, notepads, pens, tape recorder, tapes, batteries, microphone, consent forms, demographic questionnaires.

Moderator: We would like to welcome everyone here today. During our time together we are going talk about ways to improve the current recruitment and enrollment protocol for BAN. We need everyone to participate. Okay?

Awareness and perception of BAN Study

1. What are people saying about the BAN Study?
   What else have you heard about the BAN study?

[Only ask Community Leaders question 2 – otherwise skip to Question 3]

2. From whom do you hear about the BAN study? Where did you hear about the BAN study?

3. Why do you think that mothers are willing to participate in BAN?
   a. What makes you feel that way?

4. Why do you think mothers are NOT willing to participate in BAN?
   b. What makes you feel that way?

5. What do you think women mean when they say they "need to consult their husband" before joining BAN?

6. What do you believe is the influence of the husbands on whether women decide to enroll into the BAN study?

7. What do men say about the BAN study? (Probe: if appropriate ask – what do husbands of BAN women ask you about the BAN study)

8. What do men say about their partners participating in the BAN study?

9. What would others say about women participating in this study? (Probe: woman's mother, mother-in-law, neighbors, other family members, religious leaders, friends)

Disclosure

10. What are some of the difficulties women face when approaching their partners to ask for permission to participate in the BAN study?

11. What helps women approach their partners to ask for permission to participate in the BAN study?

Community perceptions of HIV

12. What do men say about women who are HIV-positive?

13. What do men say about family members who are HIV-positive?

14. What do men say about other people who are HIV-positive?

15. What do women say about other women who they know are HIV-positive?

16. What key leaders do you think can have an impact on minimizing community-level HIV stigma? Why do you think so? Who do you think is most important?

17. What community groups or organizations can assist in minimizing community-level HIV stigma?

18. What key leaders do you think can have an impact on encouraging women to participate in BAN? Why do you think so? Who do you think is most important?

19. How should key leaders be involved in encouraging women to participate in BAN?

20. What community groups or organizations can assist in encouraging women to participate in BAN?

21. How should community groups or organizations be involved in encouraging women to participate in BAN?

22. What do you think about communities' level of awareness about prevention of MTCT? What do they know? What misconceptions exist? Do they need to know more? If yes, then what type of information needs to be passed to them?

23. How best can messages about BAN be imparted to the community? Please give some suggestions. (Probe: drama, community meeting with CAB, community nurses).

24. Anything else? Any questions?

Thank you!

APPENDIX J: FOCUS GROUP DISCUSSION GUIDE FOR MEN AND COMMUNITY LEADERS

Date _____
Location _____
Name of moderator _____
Name of note-taker _____
ID code _____
Number of participants _____
Start time of FGD _____
End time of FGD _____

Format: Introduce the moderator and note-taker. Explain that we are here to learn more about concerns about HIV/AIDS in the community, and that we want to learn from them in order to better design antenatal care, counselling and testing for HIV, and reproductive health programs for women and families.
Obtain informed consent. Explain the ground rules for the meeting: (1) that the discussion will last about 1 ½ to 2 hours, (2) that everything they say will remain confidential, and (3) that their names will not be used when reporting on the findings. A tape recorder is used only to facilitate the recording and analysis of the discussion. All tapes will be destroyed after they have been transcribed.
Ask demographic questions to each individual and then proceed with the focus group discussion.

Materials: Discussion guides, notepads, pens, tape recorder, tapes, batteries, microphone, consent forms, demographic questionnaires.

Narrative story:
Moderator: We would like to welcome everyone here today. During our time together we are going to be making a story together. We want you to help us with the story, but it should be realistic as though these were real people in your family or community. We need everyone to participate. Okay?

Let's imagine a young, married woman who is pregnant for the first time. Let's give her a name (ask group to name her). Let's give her husband a name too (name of husband). She lives with her husband, and her husband's sister and brother. (Name of character) is excited about her pregnancy. She goes to the clinic for antenatal care. When she gets to clinic she is told that everyone receives an HIV test at their first visit unless she refuses. She decides to be brave for her baby and to get the test. Still she begins to feel scared as she sits in the waiting room.

1. Why do you think she is scared?
2. What is she thinking about?

(Name of character) is nervous as she waits for her result, but she is determined to know her status and face the future. She is called into the counseling room, and the gentle and kind counselor tells her that she is HIV positive.

3. What is she thinking?
4. What do you think the counselor should say to her?

The counsellor tells her that there is a research study to try and find new ways to prevent HIV transmission during breastfeeding. To enroll in the study, mothers must agree to take medicine every day for 6 months OR to give medicine to their baby for 6 months after it is born. During this period mothers are instructed to exclusively breastfeed and then stop after 6 months. The research nurses will instruct her about what she needs to do. These mothers will have to return to the clinic often to be examined and to answer questions. Some blood will be drawn from mothers and babies for examination.

5. Should (name of character) enroll in this study? Why? Why not?
6. Will she need to consult anyone before deciding? Who? (Probe: husband, mother, sister, neighbour) Why?

(Name of character) returns home, her heart heavy with this new information.

7. What will she do when she returns home?
8. Would she tell anyone about her condition? Who? (Probe: mother, sister, neighbor) Why?
9. Who will she not tell? Why not?
10. Could she talk to her husband about her test results? Why? Why not? How would she tell her husband? What do you think his reaction would be? (Probe: support, anger, sadness)
11. Do you think she would be in danger from a violent reaction from her husband? Why? Why not? (Probe: danger of abandonment)
12. Would he want to be tested too? Why? Why not?
13. **Before** she tells her husband her HIV status, who would she turn to for advice or help? Who would she NOT turn to? Why?
14. **After** she tells her husband her HIV status, who would she turn to for advice or help? Who would she NOT turn to? Why?
15. How do you think her husband could be supportive? What do you think about him going to the clinic with her for her antenatal care?

16. How would other people act if they found out she was HIV-positive? Why would they act this way? (Probe especially on the husband's family, neighbors).
17. Why do you think some people are unkind and judge others who are HIV-infected?
18. Is there anything that could or should be done to change this?
19. What have you heard about ways to prevent the transmission of HIV from mother to child?
20. Do you think it is possible that a mother who is infected with HIV can give birth to a baby who is healthy and without HIV? What makes you feel this way?

21. After learning all the details, what other concerns will (name of character) have about participating in the study?
22. What concerns will other family members have about her participating in the research study?
23. Do you think her husband will give her permission to join the research study? Why? Why not?

Now we have to end this story. Let us give it an ending that provides (name of mother and father) with some love and support as she finishes her pregnancy and their baby is born. What kind of encouragement can we give to this woman and this man?

Wrap up the discussion after the story ends by asking participants if they have any questions about the discussion and the topics that were covered. Answer questions and provide basic facts to participants about HIV, mother-to-child transmission (MTCT), HIV counseling and testing, and antiretrovirals (ARVs).

Thank everyone!

APPENDIX K: SCREENING QUESTIONS TO ASSESS ELIGIBILITY FOR SURVEY QUESTIONNAIRE

ID Code __ -__ __ *(Only add ID if the woman is eligible for the research)*
Date __ __ / __ __ / __ __ __ __ **Clinic site _____**

My name is _____ I work with UNC. We are doing a research study involving women in CTA who have children within the ages of 0-12 months. So we are asking questions to know what women in Lilongwe think about being HIV positive, specifically about telling husbands/people their HIV status.

Dzina langa ndine _____ ndimagwira ntchito ku UNC. Tikupanga kafukufuku wokhudza amayi a ku Ndondomeko omwe ali ndi ana a miyezi yoyambira 0 kulekeza 12. Ndiye tikumafunsa mafunso kuti tidziwe zomwe amayi amu Lilongwe akuganiza pazakupezeka kwawo ndi kachilombo kamenaka ka HIV, makamaka momwe angafotozere za momwe magazi awo aliri kwa amuna awo kapena anthu ena.

1. How old is your child? ___ (months). Kodi mwana wanuyu ali ndi zaka zingati?
Only continue if the woman is the mother of the child and the child is between 0 and 12 months old

2. How old are you? (must be 18 years or older) __ __ (years). Panopa muli ndi zaka zingati?
Only continue if the woman is 18 years or older

3. Are you <u>currently</u> participating in the BAN study? Mukutenga nawo mbali mukafukufuku wa BAN?
   [1]Yes ***If yes – do not continue***
   [0]No ***If no – continue***

4. When the doctor told you your HIV status, how did you feel? Adokotala atakuuzani za momwe magazi anu aliri munamva bwanji?_____

5. When did you find out your HIV status? Munadziwa liti za momwe magazi anu aliri?
   [1] During previous pregnancy when tested at CTA clinic at first antenatal clinic visit
   [2] Before first antenatal clinic visit
   [3] During another pregnancy
   [4] Before recent pregnancy
   [5] After giving birth

Only continue if the woman found out her HIV status during her previous pregnancy (1)

6. Are you currently married? Panopa ndinu wokwatiwa?
   [1] Married monogamously (civil/religious)
   [2] Married monogamously (customary)
   [3] Married polygamously (civil/religious)
   [4] Married polygamously (customary)
   [5] Not married but living with sexual partner under one roof
   [6] Involved with a sexual partner but not living under the same roof
   [7] Separated
   [8] Divorced
   [9] Widowed
   [10] Does not have a current partner

Do not continue if woman is widowed or does not have a current partner

7. How long have you been with your husband/partner? Mwakhala nthawi yayitali bwanji muli ndi amuna anuwo kapena abambo omwe mumakhala nawo __ __ years __ __ months

Only continue if woman has been with husband or primary partner for 6 months or more

If a woman qualifies for the research by fulfilling <u>all</u> the eligibility criteria listed in these questions, then add an ID code to this form and proceed to the informed consent. If the woman completes the consent then proceed to the main questionnaire.

APPENDIX L: QUESTIONNAIRE FOR HIV-POSITIVE WOMEN WITH AN INFANT 0-12 MONTHS

Instructions to the interviewer:
Before starting this interview, please complete the screening questions to assess if the woman is eligible for the research. If she is eligible then obtain informed consent. Once consent is granted and the consent form is completed, then begin this interview.

ID code __ - __ __
Date of interview __ __ / __ __ / __ __ __ __ (dd/mm/yyyy)
Location of interview [1] Area 25 clinic [2] Kawale clinic [3] Bottom/Bwaila Hospital
Recruitment site [1] Follow-up clinic visit [2] Food distribution center [3] CTA support group
Name of interviewer _____
Start time _____
End time _____
Total time taken _____

CTA information

CTA enrollment ID __ __ - __ __ __ __ __ or circle not available

A. DEMOGRAPHIC INFORMATION

A1. Participant's age: Zaka za wotenga mbali: _____(years) (woman must be at least 18 years)
A2. Age of the child? __ months

A3. Where do you live now? Kodi mumakhalira kuti? _____

A4. Are you currently married? Panopa ndinu wokwatiwa? (women must be married or have a primary male partner for the past 6 months)
[1] Married monogamously (civil/religions)
[2] Married monogamously (customary)
[3] Married polygamously (civil/religious)
[4] Married polygamously (customary)
[5] Not married but living with sexual partner under one roof
[6] Involved with a sexual partner but not living under the same roof
[7] Separated
[8] Divorced

A5. How long have you been with your husband/partner? Mwakhala nthawi yayitali bwanji muli ndi amuna anuwo/abambo muli nawowo? __ __ years __ __ months

A6. What is the highest level of education you ***completed*** at school? Sukulu munaphunzira mpaka pati? *(Circle response)*
Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school

A7. How well can you read and write Chichewa? Kodi mumatha kuwerenga ndikulemba chichewa?
[1] Very well [2] Well [3] Somewhat [4] Not at all

A8. How well can you read and write English? Kodi mumatha kuwerenga ndi kulemba chingerezi?
[1] Very well [2] Well [3] Somewhat [4] Not at all

A9. What is your tribe? Ndinu a mtundu wanji?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____

A10. What is your religion? Ndinu a chipembezo chanji?

[01] Christian
[02] Islam
[02] Hindu
[04] Traditional
[05] No Religion ***Skip to A12.***
[88] Other (specify)_____

A11. How many times a month do you go to religious worship? Pamwezi mumapita kangati kopemphera?

[1] In a month I go _____ times
[0] Never attend

A12. What is your MAIN occupation? Mumagwira ntchito yanji?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] Housewife
[12] No job
[88] Other (specify)_____

A13. How many times have you been pregnant? Mwakhalapo ndi pakati kangati? __ __

A14. How many living children do you have? Ana a moyo omwe mulinawo ndi angati? __ __

A15. How long have you lived in Lilongwe? Mwakhala nthawi yayitali bwanji mu Lilongwe?

__ __ years __ __ months

B. MALE PRIMARY PARTNER CHARACTERISTICS

B1. Are you living together with the man who is responsible for this **infant** (the father)? Kodi mukukhala limodzi ndi bambo a mwana wanuyu? [1] Yes ***Go to question B2***
[0] No ***Proceed to question B1.1***

B1.1. Are you living together with a man who is not responsible for this **infant**? Kodi mukukhala ndi bambo yemwe sibambo ake eni eni a mwanayu (Omupeza)?
[1] Yes ***Proceed to question B1.2***
[0] No ***Go to question B2***

B1.2. How long have you been living with this man? Kodi mwakhala nawo nthawi yayitali bwanji bambo amenewa? __ __ years __ __ months

B1.3. What is the tribe of this man? Kodi bambowa ndi a mtundu wanji?
[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

B1.4. What is the highest grade level of education completed by this man? Maphunziro awo anafika nawo pati? *(Circle response)*
Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school
Don't know

B1.5. What does this man do to earn a living? Kodi bambowa amachita chani pa moyo wawo wa tsiku ndi tsiku?
[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] No job ***Skip to B2***
[88] Other (specify)_____-
_____
[99] Don't know

B1.6. Where does this man work? Kodi bambowa amagwira ntchito kuti, mu Lilongwe momuno kapena kunja kwa Lilongwe? [1] In Lilongwe ***Skip to B2*** [2] Outside Lilongwe [3] Both

B1.7. How many months does the man spend outside of Lilongwe in a year? Amatha miyezi ingati asali mu Lilongwe muno pa chaka? __ __ months

B2. What is the highest grade of school completed by the father? Kodi bambowo sukulu anafika nayo pati?
(Circle response)

Standard 1 2 3 4 5 6 7 8
Secondary school – Form 1 2 3 4
Above secondary school
Adult literacy only
Never attended school
Don't know

B3. What is the tribe of the father? Kodi bambowa ndi a mtundu wanji?

[01] Chewa
[02] Tumbuka
[03] Yao
[04] Sena
[05] Lomwe
[06] Senga
[07] Ngoni
[08] Tonga
[09] Nkhonde
[10] Lambia
[88] Other (specify)_____
[99] Don't know

B4. What does the father do to earn a living? Kodi bambowo amagwira ntchito yanji?

[01] Small holder farmer/subsistence farmer
[02] Tenant farmer
[03] Ganyu labour (agriculture)
[04] Ganyu labour (non-agriculture)
[05] Paid employment with salary
[06] Self employed (non farming)
[07] Fisherman
[08] Teacher
[09] Health worker
[10] Field Assistant
[11] No job ***Skip to C1***
[88] Other (specify)_____
[99] Don't know

B5. Where does the father work? Amagwirira ntchito kuti?

[1] In Lilongwe ***Skip to C1.*** [2] Outside Lilongwe [3] Both

B6. How many months does the father spend outside of Lilongwe in a year? Amatha miyezi ingati ali kunja kwa Lilongwe pa chaka? __ __ months

C. HOUSEHOLD CHARACTERISTICS

C1. What kind of sanitary facility does your household use? Kodi pa nyumba panu mumagwiritsa ntchito chimbudzi cha mtundu wanji? **Only one response possible**

[01] Private flush toilet
[02] Communal flush toilet
[03] Private VIP latrine
[04] Communal VIP latrine
[05] Private Sanplat/Dome slab pit
[06] Communal Sanplat/Dome slab pit
[07] Private traditional latrine with roof
[08] Communal traditional latrine with roof
[09] Private traditional latrine without roof
[10] Communal traditional latrine without roof
[11] None
[88] Other (specify)_____

C2. What was your main source of drinking water over the past month? Kodi pa mwezi wathawu madzi akumwa mumatunga kuti? **Only one response possible**

[01] Piped water in dwelling
[02] Piped outside dwelling, personal
[03] Communal standpipe
[04] Personal handpump/borehole
[05] Communal handpump/borehole
[06] Protected spring
[07] Personal unprotected well
[08] Personal protected well
[09] Communal protected well
[10] Communal unprotected well
[11] River/spring
[12] Lake/reservoir
[88] Other (specify) _____

C3. The roof of the main dwelling of your household is predominantly made of what material? Kodi denga la nyumba yanu linapangidwa ndi zipangizo zanji? **Only one response possible**

[1] Iron sheets
[2] Clay tiles
[3] Concrete
[4] Plastic sheeting
[5] Grass
[8] Other (specify) _____

C4. The floor of the main dwelling of your household is predominantly made of what material? Kodi pansi pa nyumba yanu panapangidwa ndi zipangizo zanji? **Only one response possible**

[1] Tile
[2] Smooth cement
[3] Smoothed mud
[4] Wood
[5] Sand
[8] Other (specify) _____

C5. What are your sources of lighting fuel? Kodi pa nyumba panu mumagwiritsa ntchito chani powunikila?

Multiple responses possible

[01] Electricity
[02] Gas
[03] Battery/ Dry cell/Torch
[04] Paraffin
[05] Candles
[06] Purchased firewood
[07] Collected firewood
[08]Grass
[88] Other (specify) _____

C6. What are your sources of cooking fuel? Kodi pa nyumba panu mumaphikira chani?

Multiple responses possible

[01] Electricity
[02] Gas
[03] Paraffin
[04] Charcoal
[05] Purchased firewood
[06] Collected firewood
[07] Saw dust
[08] Crop residue
[09] Animal waste
[88] Other (specify)_____

C7. How many people live in your household? Kodi m'nyumba mwanu mumakhala anthu angati __ __

Does your household have any of the following items? Kodi muli ndi china mwa zinthu izi pa nyumba panu? [1] Yes; [0] No

C8.	TV	TV	
C9.	Mobile phone	Telefoni ya m'manja	
C10.	Tape recorder	Wayiresi yotola mawu	
C11.	Radio	Wayilesi	
C12.	Bicycle	Njinga	
C13.	Bed	Bedi	
C14.	Mattress	Materesi	
C15.	Table	Tebulo	
C16.	Chair	Mpando	
C17.	Paraffin lamp with glass	Nyali yagalasi	

D. ATTENDANCE AT CALL TO ACTION (CTA) CLINIC

D1. Why did you come to the CTA clinic today? Ndi chifukwa chani lero munabwera ku Ndondomeko?

Multiple responses possible

[1] Was told to come by the CTA nurse for follow-up visit
[2] Want to have my infant tested for HIV
[3] Was told to come for medicine for me
[4] Was told to come for medicine for the baby
[5] Was told to come for medicine for both me and the baby
[6] My child is sick today
[7] I am sick today
[8] Me and my child are both sick
[9] I am here to pick up food allowance
[10] I am here to attend a CTA support group meeting
[11] I have come for other CTA services
[12] I have brought my husband for HIV test
[88] Other (specify) _____

D2. When your labor started, did you take drugs to prevent HIV transmission to your baby? Pathawi imene mumayamba kumva kuti muli pafupi kubeleleka munamwa makhwala kuti muteteze mwana obabwayo kukachilombo kamene kayambisa matenda a Edzi ka HIV?

[1] Yes [0] No [9] Don't remember

D3. Did your baby receive drugs to prevent transmission from mother-to-child within 3 days (72 hours) of birth? Kodi mwana obadwayo analandira mwakhwala oteteza kuti asatengeleko kachilombo koyambisa matenda a Edzi ka HIV kwa mayi ake pasathe masiku atatu (Pasanathe ma ola 72)?

[1] Yes [0] No [9] Don't remember

D4. When you were pregnant, were you ever told about the BAN study? Panthawi yomwe munali ndi pakati, munauzidwako za kafukufuku wa BAN?

[1] Yes [0] No [9] Don't remember

D5. Were you asked to join the BAN study? Kodi munafunsidwa kulowa mu kafukufuku wa BAN?

[1] Yes [0] No ***Skip to E1***. [9] Don't remember ***Skip to E1***.

D6. Why did you choose NOT to join the BAN study? Munachita kusankha nokha kuti musalowe mukafukufuku wa BAN yu?

_____

_____

E. KNOWLEDGE OF HIV AND MOTHER-TO-CHILD TRANSMISSION (MTCT)

E1. Have you ever heard that mothers can pass HIV to their babies? Kodi munamvapo kuti amayi angapatsire kachilombo ka HIV kwa mwana wawo?
[1] Yes [0] No [9] Don't know

E2. Do you think it is possible that a mother who is infected with HIV can give birth to a baby who is healthy and without HIV? Kodi mukuganiza kuti ndi zotheka kwa mayi yemwe ali ndi kachilombo ka HIV kubeleka mwana wa thanzi wopanda kachilombo ka HIV?
[1] Yes [0] No [3] Maybe, depending on the circumstances [9] Don't know

E3. Do you think a mother with HIV should breastfeed her baby? Kodi mukuganiza kuti mayi yemwe ali ndi kachilombo ka HIV aziyamwitsa mwana wake?
[1] Yes [0] No ***Skip to E5***
[3] Maybe, depending on the circumstances [9] Don't know ***Skip to E5***

E4. For how long should a mother with HIV breastfeed her baby? Kodi mukuganiza kuti mayiyu aziyamwitsa mwana wakeyo kwa nthawi yotalika bwanji? *Note: If the woman says that she follows the instructions from the clinic, then probe to specific time frame*
[1] Less than 6 months
[2] 6 months
[3] 6 months exclusively
[4] More than 6 months
[9] Don't know

E5. Is there anything an HIV-infected mother can do to prevent infecting her baby with HIV? Kodi pali china chili chonse chomwe mayi yemwe ali ndi kachilombo ka HIV angachite kuteteza kupatsira kachilombo ka HIV kwa mwana wake?
Multiple responses possible
[01] Take antiretroviral medications during labor and delivery
[02] Give your baby antiretroviral medications after birth
[03] Take antiretroviral medications after giving birth
[04] Stay healthy and strong
[05] Eat well
[06] Exclusively breastfeed for the first 6 months
[07] Do not breastfeed at all
[08] Wean your child after 6 months
[09] Listening to hospital advice
[10] Do not give blood to the baby, even if it is needed
[88] Other (specify)_____
[99] Don't know

F. HIV TESTING AND DISCLOSURE

F1.	When were you first diagnosed with HIV? Kodi kachilombo ka HIV anakupezani nako liti?	1. __ __ / __ __ / __ __ __ __ (dd/mm/yyyy) 99. Don't know
F2.	How do you think you got infected with HIV? Kodi mukuganiza kuti kachilomboka munapezeka nako bwanji?	1. My husband gave it to me 2. My boyfriend/sexual partner 3. My ex-boyfriend/ex-partner gave it to me 4. Raped 5. Blood transfusion at hospital 6. Injection 7. Traditional healer 8. Razor blade 9. Tooth brush 88. Other (specify): _____ 99. Don't know
F3.	How many sexual partners have you had? Ndi amuna angati mwakhala mukugonana nawo m'moyo mwanu?	1. Number of sexual partners __ __
F4.	When you came to the clinic for your first antenatal visit, did you know that you would be tested for HIV? Pamene mumabwera ku sikelo poyamba, Kodi mumadziwa kuti adzakuyesani magazi?	1. Yes 2. No – **Skip to F7** 9. Don't know – **Skip to F7**
F5.	Before going to your first antenatal clinic visit, did you talk to anyone about the fact that you would be tested for HIV? Musanapite kusikelo koyamba, Kodi munakambirana ndi wina aliyense zoti mukayesedwa magazi?	1. Yes 2. No – **Skip to F7** 99. Don't know – **Skip to F7**
F6.	Who did you talk to about being tested for HIV? Kodi munakambirana ndi ndani?	**Check all that apply** 1. Spouse/Partner – Circle [1]Yes on F7 if [1] Spouse is marked 2. Sister 3. Brother 4. Mother 5. Father 6. Female Friend 7. Male Friend 8. Son 9. Daughter 10. Female cousin 11. Male cousin 12. Aunt 13. Uncle 14. Female neighbor 15. Male neighbor 16. Neighbors 17. Relatives 18. Mother-in-law 19. Religious leader 88 Other (specify): _____
F7.	Did your primary partner know that you would be tested for HIV? Kodi amuna anu amadziwa mukayesedwa magazi?	1. Yes 2. No

F8.	Does your primary partner know you have been tested for HIV? Kodi amuna anu amadziwa kuti munayesedwa magazi?	1. Yes 2. No **- skip to F12**
F9.	Did you tell him the results of your HIV positive test? Kodi munawauza amuna anu zakupezeka kwanu ndi kachilombo ka HIV?	1. Yes 2. No – **skip to F12** 9. Don't know – **skip to F13**
F10.	What are your reasons for telling your primary partner about your HIV status? Kodi ndi zifukwa ziti zomwe zinakupangitsani kuti muwauze amuna anu?	**Check all that apply** 1. Because we are staying together 2. So that he should know 3. To hear his views 4. Maybe he can think of going for a test as well 5. Because I am sick 6. Because he is sick 7. Because the child is HIV positive 8. Other (specify)_____ 9. Don't know
F11.	How did your partner react when you told him about your HIV test results? Kodi amuna anu anatani mutawawuza zotsatira za magazi anu?	**Check all that apply** 1. Do not plan on telling my husband/partner 2. He showed support and understanding 3. He told me he was going to come for HIV testing 4. He did not react at all/Nothing 5. He felt sad/disappointed 6. He panicked 7. He blamed me for the results 8. He physically assaulted me 9. He told me to leave the house 10. He left me in the house 11. He did not believe me 88. Other (specify):_____ 99. Don't know **Skip to F13**
F12.	What are your reasons for NOT telling your primary partner about your HIV status? Kodi simunawawuze amuna anu zotsatira za magazi anu pa zifukwa zanji?	**Check all that apply** 1. Not available to tell (away for work) 2. Fear of being kicked out of his house 3. Fear of being accused of infidelity 4. Fear of losing financial support 5. It is difficult to meet since he is married 8. Other (specify): _____ 9. Don't know
F13.	Has your partner been tested for HIV? Kodi amuna anu anayesedwapo magazi?	1. Yes 1a. If Yes, when was this? __ __ /__ __ /__ __ __ __ 9. Don't know 1b. Date he told her __ __/__ __/__ __ __ __ 9. Don't know 1c. What were his results? [1] Positive [2] Negative [9] Don't know 2. No – **Skip to F16** 9. Don't know – **Skip to F16**
F14.	How sure are you about his HIV test results? Kodi muli ndi chitsimikizo bwanji pa zotsatira za magazi amuna anu?	1. Very sure 2. Somewhat sure 3. Somewhat unsure 4. Very unsure 9. Don't know

F15.	Who tested first, you or your husband? Kodi anayamba kuyezetsa magazi ndani inu kapena amuna anu?	1. I tested first 2. My partner tested first. 3. We tested at the same time 9. Don't know
F16.	Is your child sick? Kodi mwana wanu akudwala?	1. Yes 2. No
F17.	Has your youngest child been tested for HIV? Kodi mwana wanu anayesedwapo magazi?	1. Yes 1a. If Yes, when was this? __ __ / __ __ / __ __ __ __ 1b. What were his results? [1] Positive [2] Negative [9] Don't know [8] Results got lost 2. No – **Skip to F19** 9. Don't know – **Skip to F19**
F18.	Who have you told about your youngest child HIV status/test result? Kodi munauzako ndani zotsatira za magazi amwana wanu wang'ono	**Check all that apply** 0. No one 1. Spouse/Partner 2. Sister 3. Brother 4. Mother 5. Father 6. Female Friend 7. Male Friend 8. Son 9. Daughter 10. Female cousin 11. Male cousin 12. Aunt 13. Uncle 14. Female neighbor 15. Male neighbor 16. Neighbors 17. Relatives 18. Mother-in-law 19. Religious leader 88 Other (specify): _____
F19.	Have any of your relatives suffered from HIV/AIDS? Kodi alipo wachibale wanu aliyense amene anadwalako matenda a Edzi?	1. Yes 2. No 9. Don't know
F20.	Do you have any relative who is HIV positive? Kodi muli ndi m'bale amene ali ndi kachilombo ka HIV?	1. Yes 2. No 9. Don't know

F21.	Who did you tell about your HIV test results? Kodi munawuzapo ndani za zotsatira za magazi anu?	**Check all that apply** 0. No one – **Skip to F23** 1. Spouse/Partner 2. Sister 3. Brother 4. Mother 5. Father 6. Female Friend 7. Male Friend 8. Son 9. Daughter 10. Female cousin 11. Male cousin 12. Aunt 13. Uncle 14. Female neighbor 15. Male neighbor 16. Neighbors 17. Relatives 18. Mother-in-law 19. Religious leader 88 Other (specify): _____ 99. Don't know – **Skip to F23**
F22.	Please tell me in what order you told people about your HIV status? Pa anthu amene munawawuzakowa Kodi amene munayambira kumuwuza ndi ndani?	First _____ Second _____ Third _____ Fourth _____ 9. Don't know
F23.	Is there anyone whom you do NOT want to know your HIV test results? Kodi alipo yemwe simufuna kuti adziwe zotsatira za magazi anu?	1. Yes 2. No – **Skip to F25** 9. Don't know – **Skip to F25**
F24.	Who is/are this person/these people? Kodi amaneyu ndi ndani?	**Check all that apply** 1. Spouse/Partner 2. Sister 3. Brother 4. Mother 5. Father 6. Female Friend 7. Male Friend 8. Son 9. Daughter 10. Female cousin 11. Male cousin 12. Aunt 13. Uncle 14. Female neighbor 15. Male neighbor 16. Neighbors 17. Relatives 18. Mother-in-law 19. Religious leader 20. I don't want anyone to know 21. Anyone who is not my relative 88 Other (specify): _____
F25.	Has anyone learned of your HIV status without you wanting them to? Kodi pali munthu wina aliyense yemwe anadziwa zotsatira za magazi anu pomwe inu simunafune kuti adziwe?	1. Yes 2. No – **Skip to F28** 9. Don't know – **Skip to F28**

F26.	If yes, then who has found out? Ngati alipo ndi ndani?	**Check all that apply** 1. Spouse/Partner 2. Sister 3. Brother 4. Mother 5. Father 6. Female Friend 7. Male Friend 8. Son 9. Daughter 10. Female cousin 11. Male cousin 12. Aunt 13. Uncle 14. Female neighbor 15. Male neighbor 16. Neighbors 17. Relatives 18. Mother-in-law 19. Religious leader 88 Other (specify): _____
F27.	How did they find out? Kodi anadziwa bwanji?	1. Heard from a friend who also goes to the clinic 2. Found me at the clinic 3. Heard from one of the people I told 4. Heard from someone in the community 8. Other (specify): _____ 9. Don't know
F28.	Was anyone violent towards you when you told them about your HIV status? Kodi pali munthu wina ali yense yemwe anakuchitirani nkhanza mutamuwuza zotsatira za magazi anu?	1. Yes 1a. Who is this person?_____ 2. No one was violent 3. I didn't tell anyone – **Skip to G1** 9. Don't know
F29.	What happened to you after disclosing your HIV serostatus to people other than your husband/partner? Kodi chinakuchitikirani ndi chiyani mutawuza anthu ena osati amuna anu zotsatira za magazi anu?	**Check all that apply** 0. I have not disclosed to anyone other than my partner 1. I do not plan to disclose to anyone other than my partner 2. Increased emotional support from peers 3. Increased emotional support from family 4. Increased emotional support from employers 6. Disowned by family 7. Discrimination from health professionals 8. Increased emotional support from health professionals 9. Discrimination from employers 10. Estranged by peers 11. I felt relieved 12. Nothing happened 88. Other (specify) _____ 99. Don't know

G. TIMELINE FOR CHILD FEEDING AND HIV DISCLOSURE

Now I would like to find out a bit more about how you are feeding your child.

Date of birth -- -- / -- --/ -- -- -- -- **Age of Infant** ___ (months) Refer to A2.

(dd/mm/yyyy)

(Between 6 – 8 months)

HIV+ diagnosis date

-- --/ -- --/ -- -- -- -- (dd/mm/yyyy)

-- -- / -- --/ -- -- -- -- (dd/mm/yyyy)

Refer back to question F1 for date

Gestation in weeks at time of diagnosis

Date of Child's HIV test

-- --/-- --/-- -- -- -- (dd/mm/yyyy)

Or Not tested

Or age of child at time of result __

Date of interview

QUESTIONS FOR THE TABLE

G1. Was this child exclusively breastfed? Kodi mwana wanuyu amayamwitsidwa mwa kathithi?

Note: Exclusive breastfeeding means that the child is only fed breast milk – no water or other liquids and no foods. [1] Yes [2] No

If yes, for how many months? Kwa nthawi yayitali bwanji? __ (Mark on table)

G2. Is this child currently being breastfed? Kodi pakadali pano mwanayu mukumuyamwitsabe?

[1] Yes [2] No

G3. Is the child currently being fed solid food? Kodi pakadali pano mwanayu mukumamudyetsa zakudya zolimba [1] Yes [2] No

G4. Have you disclosed your HIV status to your husband/ primary partner? Kodi munawawuza amuna anu/abambo amene mukukhala nawowo za momwe magazi anu alili?

[1] Yes [2] No

If yes, when?Ngati ndi choncho, linali liti? (Mark on table) __ __ / __ __ / __ __ __ __

Or age of child at time of result __

Or number of months pregnant at time of result __

H. FOOD ASSISTANCE

H1. Were you receiving a monthly food package that was part of an HIV program?
Kodi mumalandira nawo chakudya pamwezi kudzera ku Ndondomeko kapena program iriyonse ya HIV?
[1] Yes
[0] No [9] Don't know *If no or don't know, then skip to H5.*

H2. How long were you receiving this food?__ __ months. Kodi chakudyachi mwakhala mukulandira kwa nthawi yatitali bwanji?

H3. Was receiving this food causing you to disclose your HIV status?
Kodi kulandira kwa chakudyachi kumakupangitsani kuti muulure zotsatira za magazi anu?
[1] Yes [0] No [9] Don't know

H4. Did receiving the food make you more comfortable to disclose your HIV status to people?
Kodi mmene mumalandira chakudyachi zimakupangitsani kukhala omasuka kuwulura zotsatira za magazi anu?
[1] Yes [0] No [9] Don't know

H5. Did your breastfeeding practices influence your choice to disclose or not disclose your HIV status to your husband? Kodi kayamwitsidwe ka mwana wanu kamakupangitsani inu kuti muulure kapena kuti musaulure zotsatira za magazi anu kwa amuna anu?
[1] Yes [0] No [9] Don't know

I. GENDER NORMS AND EXPECTATIONS/AUTONOMY

Can you tell me who usually does the following in your relationship you, your primary partner, both of you equally?
Kodi mungandifotokozere yemwe amakonda kuchita zinthu zotsatirazi pabanja lanu. Kodi ndi inu, kapena amuna anu kapena nonse pamodzi?

		Mostly Me	Mostly your partner	Both equally Tonse pamodzi	Does not apply (NA)
I1.	Who usually has more say about whose friends to go out with? Kodi ndi ndani amasankha abwenzi ocheza nawo?	1	2	3	9
I2.	Who usually has more say about whether you have sex? Kodi amaganiza ndani zoti mugonane kapena ayi?	1	2	3	
I3.	Who has more say about what you do together? Ndani amaganiza zoti mupangire zinthu pamodzi?	1	2	3	
I4.	Who usually has more say about how often you see one another? Kodi ndi ndani yemwe amayambitsa kuti muzicheza limodzi?	1	2	3	
I5.	Who usually has more say about when you talk about serious things? Nanga ndi ndani yemwe amayambitsa kucheza nkhani zofunikira?	1	2	3	
I6.	In general, who do you think has more power in your relationship? Kodi ndi ndani yemwe ali ndi mphamvu zambiri pa banja lanu?	1	2	3	
I7.	Who usually has more say about whether you use condoms? Kodi ndi ndani yemwe ali ndi mphamvu yonena kuti mugwiritse ntchito kondomu kapena ayi pogonana?	1	2	3	9 Don't use condoms
I8.	Who usually has more say about what types of sexual acts you do? Kodi ndi ndani amene amanena kuti mugonane mwanjira yanji?	1	2	3	9 No one

Do you need <u>permission</u> from your partner to do any of the following? (Read choices in order and only mark one per item) Kodi mumafunika kutenga chilolezo kuchokera kwa amuna anu kuti muthe kupanga zinthu izi?

		Never Ayi	Sometimes Nthawi zina	Mostly Nthawi zambiri	Always Nthawi zonse
I9.	To get health care for yourself when you are ill Kuti mupite ku chipatala mukadwala	1	2	3	4
I10.	To get immunizations for a child Kuti mwana wanu akalandire katemera	1	2	3	4
I11.	To get health care for a sick child Kuti mwana wanu apite kuchipatala akadwala	1	2	3	4

Do you talk to your partner about:
Kodi mumalankhula ndi amuna anu pa nkhani izi:

		Never Ayi	Sometimes Nthawi zina	Often Nthawi zambiri	All the time Nthawi zones
I12.	Events in the house or neighborhood? Zochitika pakhomo panu ndi oyandikana nawo?	1	2	3	4
I13.	Your feelings about daily life? Maganizo anu okhudza zochitika pamoyo wanu wa tsiku ndi tsiku?	1	2	3	4
I14.	Problems that arise in the household? Zamavuto okhudza pa khomo panu?	1	2	3	4
I15.	Worries connected to the children or other family members? Za madandawulo anu okhudza ana anu ndi a pabanja panu?	1	2	3	4
I16.	Worries connected to yourself? Madandaulo anu?	1	2	3	4

I17. Do you have the opportunity to talk with your primary partner alone? Kodi mumakhala ndi mwayi wokambirana ndi amuna anu panokha?

[1] Yes, very often
[2] Yes, but hardly ever
[3] No, never

I18. When do you most often talk serious things with your primary partner? Kodi ndi nthawi zanji pamene mumakambirana zofunikira ndi amuna anu kawirikawiri?

[1] At night before sleeping
[2] On a free time during the day within the week
[3] During week-ends
[4] I never have time to talk to my partner alone
[5] Any time
[6] Whenever it's necessary
[7] Out together alone
[8] Other (specify): _____

J. HIV STIGMA SCALE (from International Center for Research on Women (ICRW)

Since learning your test result, how often have you been afraid that . . .

Kuchokera pomwe munadziwa za zotsatira za magazi anu. Kodi mwakhalapo ndi mantha kuti….

		Never	Not very often	Sometimes	Very often	Does not apply (NA)
J1.	. . . you would be excluded from a social gathering (wedding, funeral, party, community association group) because of your HIV status? **. . . mutha kuchotsedwa pa zochitikachitika za pa gulu monga zikwati, maliro maphwando ndi zina chifukwa chakuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J2.	. . . you would be treated differently / shunned at a social gathering because of your HIV status? **. . . mutha kusalidwa pa zochitika chitika za pa gulu chifukwa chakuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J3.	. . . you would be abandoned by your spouse/partner because of your HIV status? **. . . mutha kusiyidwa ndi a amuna kapena akazi anu chifukwa chakuti muli ndi kachhilombo ka HIV?**	1	2	3	4	
J4.	. . . you would be abandoned by your family / sent away to the village because of your HIV status? **. . . mutha kusiyidwa kaya kutumizidwa kumudzi chifukwa choti muli ndi kachilombo ka HIV?**	1	2	3	4	
J5.	. . . you would be isolated in your household (made to eat alone/made to use separate eating utensils/made to sleep alone in your room) because of your HIV status? **. . . mutha kumasankhidwa pa banja panu monga kuti muzidya pa nokha kaya muzidyera mbale za nokha kapenanso kuti muzigona nokha chifukwa choti muli ndi kachilombo ka HIV?**	1	2	3	4	
J6.	. . . you would no longer be visited or would be visited less by family and friends because of your HIV status? **. . . mutha kuleka kuyendeledwa kapena mutha kumayenderedwa mwa patali patali ndi abale komanso abwenzi chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J7.	. . . visitors would increase to 'check out' how you are doing because of your HIV status? **. . . mutha kumayenderedwa pafupipafupi mcholinga chodzakuzondani chifukwa choti muli ndi kachilombo ka HIV?**	1	2	3	4	

		Never	Not very often	Sometimes	Very often	Does not apply (NA)
J8.	. . . you would be teased, insulted or sworn at because of your HIV status? **. . . mutha kumasekedwa kaya kunyozedwa chifukwa choti muli ndi kachilombo ka HIV?**	1	2	3	4	
J9.	. . . you would lose customers to buy produce / goods or lose a job because of your HIV status? **. . . mutha kutaya (lose) makisitomala amene amagula zinthu kaya katundu wanu kapena mutha kuchotsedwa ntchito chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	NA
J10.	. . . you would be denied promotion or further training because of your HIV status? **. . . mutha kulephera kukwezedwa pa ntchito kapena kutumizidwa ku maphunziro chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	NA
J11.	. . . you would lose housing or not be able to rent housing because of your HIV status? **. . . mutha kutulutsidwa m`nyumba kapena kusowa nyumba ya lenti chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J12.	. . . you would be denied religious rites/services (marriage, communion, burial, singing in the choir, prayer) or not be allowed to go to church or mosque because of your HIV status? **. . . mutha kuyimitsidwa mumpingo kapena kuletsedwa kupita ku tchalitchi kapena ku mzikiti chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J13.	. . . you would be given poorer quality health services (for example, passed from provider to provider or not given medicines, treatment or surgery) because of your HIV status? **. . . mutha kupatsidwa chithandizo chakuchipatala choperewera. Monga mwina kumangokusiyiranani kapena osakupatsani chithandizo kumene chifukwa chakuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J14.	. . . you would have property taken away because of your HIV status? **. . . mutha kulandidwa katundu wanu chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	

		Never	Not very often	Sometimes	Very often	Does not apply (NA)
J15.	. . . you would lose respect / standing within the family or community because of your HIV status? **. . . mutha kunyozedwa kaya kuchepetsedwa pagulu chifukwa chakuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J16.	. . . you would be gossiped about because of your HIV status? **. . . mutha kumanenedwa miseche chifukwa cha kuti muli ndi kachilombo ka HIV?**	1	2	3	4	
J17.	. . . you would be physically assaulted (hit, kicked or punched) because of your HIV status? **. . . mutha kumenyedwa chifukwa chakuti muli ndi kachilombo ka HIV?**	1	2	3	4	

K. SOCIAL SUPPORT SCALE (Medical Outcomes Study)

How often is each of the following kinds of support available to you if you need it?

Kodi zisamaliro zili mmusizi ndizopezeka kawirikawiri bwanji kwa inu mukazifuna

		None of the time Palibe	A little of the time Nthawi zochepa	Some of the time Nthawi zina	Most of the time Nthawi zambiri	All of the time Nthawi zonse
	Emotional/informational support					
K1.	Someone you can count on to listen to you when you need to talk Munthu amene mukhoza kulankhula naye ngati muli ndi zonena zina ndi zina	1	2	3	4	5
K2.	Someone to give you information to help you understand a situation Munthu amene angathe kukuwuzani zinthu zothandiza kuti mumvetsetse zinthu	1	2	3	4	5
K3.	Someone to give you good advice about a crisis Munthu yemwe angakupatseni uphungu wofunikira pa mavuto adzidzidzi.	1	2	3	4	5
K4.	Someone to confide in or talk to about yourself or your problems Munthu amene mukhoza kumasuka naye pomuwuza zinsinsi ndi mavuto anu.	1	2	3	4	5
K5.	Someone whose advice you really want Munthu yemwe uphungu wake inu mumawufuna kwambiri	1	2	3	4	5
K6.	Someone to share your most private worries and fears with. Munthu yemwe mungamuwuze zinsinsi zanu ndi mavuto anu onse	1	2	3	4	5
K7.	Someone to turn to for suggestions about how to deal with a personal problem Munthu yemwe mungafunseko nzeru zokhudza momwe mungathanirane ndi mavuto anu.	1	2	3	4	5
K8.	Someone who understands your problems Munthu yemwe amamvetsetsa mavuto anu	1	2	3	4	5
	Tangible support					
K9.	Someone to help you if you were confined to bed Munthu yemwe angakuthandizeni mutadwala nthawi yayitali	1	2	3	4	5
K10	Someone to take you to the doctor if needed it Munthu yemwe angakutengereni ku chipatala mutadwala.	1	2	3	4	5
K11	Someone to prepare your meals if you were unable to do it yourself. Munthu amene angakukonzereni chakudya inu mutalephera kutero.	1	2	3	4	5
K12	Someone to help with daily chores if you were sick Munthu yemwe angakuthandizeni zintchito za pakhomo inu mutadwala	1	2	3	4	5
	Additional item					
K13	Someone to do things with to help you get your mind off things Munthu yemwe mungathe kumachita naye zinthu zina ndi cholinga choti muthe kuyiwala mavuto anu.	1	2	3	4	5

L. CONFLICT TACTIC SCALE (CTS)

No matter how well a couple gets along, there are times when they disagree, get annoyed with the other person, want different things from each other, or just have fights because they are tired. Couples also have many different ways of trying to settle their differences, both positive and negative. I would now like to ask you some questions about your relationship and how your primary partner treats you. Please remember if you feel uncomfortable answering any of these questions we can skip to the next question and remember that there are No right and wrong answers to any of these questions.

Ngakhale banja litamayenda bwino bwanji sipalephera nthawi zina pomwe pamakhala kusamvana kwina kapena kupsetsana mtima kaya kufuna zinthu zosiyana mwinanso kungokangana pa zifukwa zina. Mabanjanso ali ndi njira zosiyanasiyana zothetsera mavuto a m`mabanja awo. Tsopano ndifuna ndikufunseni mafunso a momwe inu ndi amuna anu mumakhalira komanso mmene iwo amapangira zinthu zina pokhudzana ndi inu. Kumbukirani kuti muli ndi ufulu wosayankha funso liri lonse ngati muli osamasuka ndipo tilidumpha kupita kufunso lina komanso palibe yankho lokhoza kapena lolakwa. Ndifuna kudziwa ngati amuna anu anakuchitani zinthu zili m`munsizi:

		In the past 1 year						**Prior to the last 1 year**				
		Never	**Once**	**2-3**	**4-10**	**>10**		**Never**	**Once**	**2-3**	**4-10**	**>10**
L1.	Insulted or swore at you Kukutukwanani kaya kukunyozani	1	2	3	4	5		1	2	3	4	5
L2.	Twisted your arm or hair Kukupotokolani dzanja kaya kukukokani tsitsi	1	2	3	4	5		1	2	3	4	5
L3.	Showed respect for your feelings about an issue Anawonetsa kumvetsetsa maganizo anu pa nkhani ina yiri yonse	1	2	3	4	5		1	2	3	4	5
L4.	Made you have sex without a condom Anakupangitsani kugona nawo opanda kugwiritsa ntchito kondomu	1	2	3	4	5		1	2	3	4	5
L5.	Pushed or shoved you Anakukankhani mwa nkhanza	1	2	3	4	5		1	2	3	4	5
L6.	Used force (like hitting, holding down, or using a weapon) to make you have sex. Anagona nanu atakuopsezani njira ina iri yonse	1	2	3	4	5		1	2	3	4	5
L7.	Used a knife or some other weapon on you Anakubayani ndi mpeni kaya kugwiritsa ntchito chida china chili chonse pa inu.	1	2	3	4	5		1	2	3	4	5
L8.	Showed you he cared even though you had a disagreement Anawonetsa kuti amakuganizirani (kukulabadirani) ngakhale kuti simunagwirizane pa nkhani ina.	1	2	3	4	5		1	2	3	4	5

		In the past 1 year						Prior to the last 1 year				
		Never	**Once**	**2-3**	**4-10**	**>10**		**Never**	**Once**	**2-3**	**4-10**	**>10**
L9.	Insulted you or made you feel bad about yourself Anakunyozani kwambiri mpaka inu kuyamba kudzida nokha.	1	2	3	4	5		1	2	3	4	5
L10.	Punched or hit you with something that could hurt Anakumenyani ndi chibakera kaya china chili chonse choti chikhoza kukuvulazani.	1	2	3	4	5		1	2	3	4	5
L11.	Destroyed something belonging to you Anakuwonengerani chinthu chili chonse chanu.	1	2	3	4	5		1	2	3	4	5
L12.	Choked you Anakugwirani pa khosi	1	2	3	4	5		1	2	3	4	5
L13.	Shouted or yelled at you [IN PRIVATE] Anakukalipirani pa awiri	1	2	3	4	5		1	2	3	4	5
L14.	Shouted or yelled at you [IN PUBLIC] Anakukalipirani pa gulu	1	2	3	4	5		1	2	3	4	5
L15.	Beat you Anakumenyani	1	2	3	4	5		1	2	3	4	5
L16.	Grabbed you Anakukwenyani	1	2	3	4	5		1	2	3	4	5
L17.	Left the house during a disagreement Anachoka pa nyumba mutakangana	1	2	3	4	5		1	2	3	4	5
L18.	Slapped you Anakumenyani pama	1	2	3	4	5		1	2	3	4	5
L19.	Suggested a compromise to a disagreement Anapereka maganizo othetsa mkangano.	1	2	3	4	5		1	2	3	4	5
L20.	Burned or scalded you Anakuwotchani ndi moto kaya zamadzi zina zili zonse	1	2	3	4	5		1	2	3	4	5
L21.	Threatened to use a gun, knife or other weapon against you Anakuopsezani ndi mfuti, mpeni kaya chida china chili chonse	1	2	3	4	5		1	2	3	4	5
L22.	Threatened to hit or throw something at you Anakuopsezani kuti akumenyani kaya akugendani ndi china chili chonse.	1	2	3	4	5		1	2	3	4	5
L23.	Kicked you Anakumenyani theche	1	2	3	4	5		1	2	3	4	5

		In the past 1 year						Prior to the last 1 year				
		Never	**Once**	**2-3**	**4-10**	**>10**		**Never**	**Once**	**2-3**	**4-10**	**>10**
L24.	Used threats to make you have sex Anakuopsezani ndi mawu kuti inu mugone nawo.	1	2	3	4	5		1	2	3	4	5
L25.	Brought home girlfriends Anabweretsa zibwenzi ku nyumba	1	2	3	4	5		1	2	3	4	5
L26.	Prohibited you from going to work, selling or making money in any other way Anakuletsani ntchito kaya malonda omwe amakupezetsani ndalama.	1	2	3	4	5		1	2	3	4	5
L27.	If you had income, tried to take it from you. Anafuna kukulandani ndalama zopeza nokha	1	2	3	4	5		1	2	3	4	5
L28.	Forced you or your children to leave the house Anakuthamangitsani kaya kuthamangitsa ana anu pakhomo	1	2	3	4	5		1	2	3	4	5
L29.	Made you feel afraid Anakupangitsani kukhala ndi mantha	1	2	3	4	5		1	2	3	4	5
L30.	Belittled or humiliated you in front of other people Anakudererani kaya kukuchititsani manyazi pagulu	1	2	3	4	5		1	2	3	4	5
L31.	Threatened to hurt you or someone you care about Anaopseza kukuvulazani inu kapena munthu wina amene mumamukonda.	1	2	3	4	5		1	2	3	4	5
L32.	Made you do something sexual that you found un-natural or distasteful Anakupangitsani kugonana nanu mwanjira yomwe inu simunayikonde	1	2	3	4	5		1	2	3	4	5
L33.	Tried to restrict your contact with your family Anayesera kukuletsani kukumana ndi a pabanja la kwanu.	1	2	3	4	5		1	2	3	4	5
L34.	Came home late with No explanation Anabwera kunyumba mochedwa osafotokoza chifukwa	1	2	3	4	5		1	2	3	4	5

Any questions? Pali funso?

Thank you! Zikomo kwambiri!

Record any notes about the interview here:

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