

**Determining Factors that Affect Pregnant Women's
Utilization of PMTCT Services in Ethiopia: The Case of
Health Facilities at Nazareth/Adama**

**By
HaileMichael Tesfahun**

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By

HaileMichael Tesfahun

School of Social Work
Addis Ababa University

Approved by Examining Board

Advisor

Signature

Date

Examiner

Signature

Date

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Acronyms:

AIDS Acquired Immunodeficiency Syndrome

ANC Antenatal Care

ARV Antiretroviral

ART Antiretroviral Therapy

CSA Central Statistics Authority

HAPCO HIV/AIDS Prevention and Control Office

HIV Human Immuno-deficiency Virus

MOH Ministry of Health

MCH Maternal and Child Health

MTCT Mother-to-Child Transmission

OIs Opportunistic Infections

PLWHA People Living with HIV/AIDS

PMTCT Prevention of Mother-to-Child Transmission of HIV

PNC Postnatal care

STI Sexually Transmitted Infections

TBA Traditional Birth Attendant

TB Tuberculosis

UNAIDS Joint United Nations Program on HIV

UNGASS United Nations General Assembly Special Session on AIDS

VCT Voluntary Counseling and Testing

WHO World Health Organization

Abstract

Mother-to-Child Transmission of HIV (MTCT) has infected a large number of infants in Sub-Saharan Africa, including Ethiopia. However, the risk of MTCT has dropped to as low as 2% in developed countries since the introduction of anti-retroviral drugs. MTCT can occur during pregnancy, labor and delivery, and after birth through breast-feeding. The prevention of MTCT depends on the health care system and community based organizations and structures. The purpose of this qualitative and evaluative study was to find out the factors determining the seropositive mothers' PMTCT service utilization and know where the gap is. Findings revealed a number of factors for PMTCT service utilization. These center on lack of resource capacity at the health facilities to render necessary services, lack of coordinated care and support, lack of male partners' involvement, lack of home based care, safe-home birth practices, and lack of community involvement in the program. On provision of a range of services, the MTCT should not only focus on saving the child but also on the health and psychosocial well-being of the mother and the family.

Chapter 1

Introduction

1.1 Background and Problem Statement

Prevention of Mother-to-Child Transmission (MTCT) of human immunodeficiency virus, also known as vertical, prenatal, or parent-to-child transmission has become an important area of intervention on broader goal of HIV/AIDS prevention activities. Infection among women of reproductive age is undoubtedly on the rise, which underlies the potential for an increasing number of prenatal HIV infections (Lee, Cheung, Kwong, Wan, and Lee 2005). Mother-to-child HIV transmission bears a great impact of reversing gains in child survival and mortality due to childhood AIDS and orphaning millions of children, particularly in hard-hit countries.

Mother-to-child HIV transmission is the transmission of HIV from an HIV positive woman to her baby during pregnancy, in the birth process or by breast-feeding (Israel and Kroeger, 2004). Mother-to-child transmission causes more than 90 percent of all HIV infection in children under 15 years of age. Infants who acquire HIV infection from their mothers do so during pregnancy, labor, and delivery or after birth through breast-feeding. The risk of infection is now thought to be 5 to 10 percent during pregnancy; 10 to 20 percent during labor and delivery; and 10 to 20 percent during breast-feeding (DeCock, Fowler, Mercier, DeVincenzi, Saba, Hoff, David, Rogers, and Shaffer, 2000). Apart from the pregnancy, birth

process and breast-feeding, some literatures give explanation of non-MTCT transmission, though it is rare, can occur after birth through contact with infected blood and blood products or unsterile medical equipment.

In developed countries, the risk of Mother-to-Child Transmission of HIV (MTCT) has dropped to as low as two percent among the limited number of HIV-infected women since the introduction of use of ARV drugs to prevent MTCT (PMTCT) (Mofenson and McIntyre, 2000). In developing nations, however, particularly Sub-Saharan African countries where the vast majority of HIV-infected women of childbearing age live, MTCT rates remain high. Such high rates persist mostly because of the lack of access to existing prevention interventions, including HIV voluntary counseling and testing (VCT), replacement feeding, selective caesarian section, and antiretroviral drugs (Commission on HIV/AIDS and Governance in Africa, 2004).

In 2003, 1.5 million people, including 128,000 pregnant women and 35,000 newborn, were living with HIV/AIDS (AIDS in Ethiopia, 2004). In a country where, generally, there is low health service coverage, including antenatal care (ANC), crude 2003 site data suggest that 8.6 percent of ANC attendees were HIV positive (unadjusted for urban/rural proportion size) in the 15-24 years old age groups. Among children aged 0-14 years, there were 35,000 new HIV infections, 25,000 new AIDS cases and 25,000 AIDS death (Ministry of Health, 2004).

Therefore, the 2003 HIV prevalence is higher among women (5.0%) than men (3.8%) are. In addition, a large number of HIV positive pregnancies, HIV

positive births, and deaths of children (0-14 years of age) occurred in Ethiopia. Moreover, mother-to-child transmission of HIV remains as one of the biggest concern needs to be dealt with in taking effective preventive measures and maximizing treatment, care and support for needy HIV positive pregnant mothers in order to save the life of large thousand numbers innocent children in our developing country.

1.2 Rationale of the Study

Mother-to-child transmission (MTCT) is by far the largest source of HIV infection in children below the age of 15 years. The virus may be transmitted during pregnancy, childbirth, or breast-feeding (Lee et al., 2005). To date, globally 2.7 million children under the age of 15 have died of AIDS since the beginning of the epidemic. Over 9 in 10 acquire the infection from their mothers at birth or during breast-feeding (UNAIDS, 1999a).

AIDS threatens to reverse years of steady progress in child health and survival and has already doubled infant mortality in the worst affected countries. In Sub Saharan Africa, MTCT is contributing substantially to rising child mortality. In Ethiopia, an estimated 120,000 children under the age of 15 years were living with the virus in 2004 (UNAIDS, 2004). For many years, little was known about preventing transmission of HIV infection from sero-positive mother to her child. Recently, however, many advances have been made in developing effective and

affordable intervention that reduce the likelihood that a woman will pass HIV on her baby (UNAIDS/WHO, 2004).

Taking in to account the risk factors of MTCT, as well as increased availability of effective MTCT interventions, we now have a better opportunity to prevent children becoming infected with HIV from their mother. In continuum of HIV/AIDS interventions, preventing HIV infection in women of childbearing age will also limit the number of infants being infected by their mother. Support for prevention of unwanted pregnancies in HIV-positive women would have the same effect. However, programs to prevent MTCT are mainly delivered through the health care system, and are aimed at preventing an already infected mother from transmitting the virus to her child around the time of birth and in the following months. In fact, programs are lacking in addressing the psychosocial needs of the mothers.

Evidence shows that the risk of HIV transmission from an infected mother to her child can be reduced by 50% by giving antiretroviral drug during pregnancy and labor and by avoiding breast-feeding. In the absence of preventive measures, the risk of a baby acquiring the virus from an infected mother ranges from 25% to 35% in developing countries (UNAIDS, 1999; 2000). However, experience to-date in many countries show great variations in willingness to make use of the service that are available.

This study, therefore, is designed primarily to identify the factors determining pregnant women's PMTCT service utilization at the health facilities.

The result would be valuable in helping health care providers, public health officials, social workers, and policy makers to come up with measures so that PMTCT services do good to sero-positive pregnant mothers and their families and to contribute to further exploration of the area.

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1.3. Research Questions

The thesis will address the following research questions:

1. How are HIV infected pregnant mothers evaluated for ARV treatment and care?
2. What are the prenatal, during labor and postnatal care-giving supports delivered at the health institutions for HIV sero-positive mothers? Where are the gaps?
3. What are the determining psychosocial factors that affect the PMTCT service utilization?
4. How do the health institutions link the institution-based care-giving support to the home-based care?

1.4 Objectives of the Study

General Objectives:

- ◆ To identify determining factors that influence sero-positive pregnant women's utilization of PMTCT services at the health facilities that are providing PMTCT services.

Specific Objectives:

- ◆ To investigate how HIV infected pregnant mothers are evaluated for ARV treatment and care;
- ◆ To identify the prenatal, during labor and postnatal care-giving supports delivered at the health institutions for HIV sero-positive mothers; and determine where the gaps are, if any;
- ◆ To identify the determining psychosocial factors that affect the PMTCT service utilization; and
- ◆ To identify how the health institutions link the institution-based care-giving support to the home-based.

1.5 Strengths and Limitations of the Study

Strengths

There was no previous study conducted in the areas of PMTCT determining factors for service utilization in these institutions or other institution, and this study will provide information to similar studies that are going to be conducted in the future. Further, it may provide clue for *social workers* to intervene in the area of Prevention of Mother-to-Child HIV Transmission.

Limitations

The limitation of this study was the small sample size of the study participants and generalizability of the study.

1.6 Ethical Considerations and Communication of Findings

Ethical Considerations

Ethical clearance was obtained from Addis Ababa University Graduate School of Social Work by faculty reviewing and approving the research proposal. Participants participated based on their willingness and, written and verbal consents were obtained. The participants' privacy, confidentiality were maintained and benefits (i.e. incentives paid) explained. In addition, responsible officials and community leaders, who were directly or indirectly responsible, were informed about the study to get their support.

Communication of Findings

The result of this research work will be communicated to different responsible organizations and submitted to Oromia Region Health Bureau, Oromia Region HIV/AIDS Prevention and Control Office (HAPCO) and to local and international organizations who are working in the area of PMTCT. Efforts will be made to publish the paper in different journals and reserve in the library.

1.7 Definition of Terms

Mother-to-Child HIV Transmission - is when HIV positive woman passes the virus to the baby during pregnancy, labor and delivery or breastfeeding.

Prevention of Mother-to-Child HIV Transmission - is prevention activities that prevent women from being infected by virus, preventing unwanted pregnancy in sero-positive mothers, preventing the virus transmission to the baby during pregnancy, labor and delivery or breastfeeding and provision of care and support.

Vertical Transmission - is when the HIV virus passes from an HIV positive mother to her baby. This can happen during pregnancy, during labor and delivery, or during breastfeeding.

Chapter 2

Review of Literature

2.1 An Overview of MTCT

HIV has had a worldwide impact and there virtually are no areas that have not reported cases of infection. As of December 2001, an estimated 40 million people are living with HIV/AIDS. These include 2.7 million children less than fifteen years of age and 17.6 million women (Kennedy, 2003.) Hence, due to a high HIV prevalence rate in women and children, preventing mother-to-child transmission of HIV has become an essential element of the worldwide HIV/AIDS control strategy.

An estimated 2.1 million children worldwide are currently living with the virus and over 630,000 children became infected with HIV in 2003. The vast

majority of them acquire the virus during their mother's pregnancy, labor and delivery or because of breast-feeding (UNAIDS/WHO, 2004).

In Asia, prevalence rates among pregnant women are mainly below 5% but due to enormous population of the region (60% of the world population), the percentages are of grave concern. Low national prevalence rates do not reflect localized epidemics in many places, such as China and India (UNAIDS, 2000). A study in women and infants, shows that a probability of 27% for in-utero transmission in the USA, while in Kinshasa 23% infants were thought to be infected in-utero, 65% intrapartum or early postpartum and 12% in late postpartum (WHO/UNAIDS, 1999).

In low and middle-income countries, there is at least a 30% likelihood that an HIV positive breast-feeding mother will pass the virus to her newborn. From a study in Kenya and Malawi, the absolute transmission rates from breast-feeding were estimated to be 3.5% at 6 months, 7% at 12 months and 10.3% at 24 months (DeCock et al., 2000).

Africa is the region seriously affected by HIV/AIDS epidemic. Of ten countries world wide with the greatest number of infected children, the top nine are all in Sub-Saharan Africa, ranging from 140,000 in Ethiopia to 90,000 in Nigeria (Piot and Coll-Seck, 1999).

In 2003 an estimated 630,000 children worldwide become infected with HIV; the vast majority of them during pregnancy, childbirth or breast-feeding. Africa remains by far the region worst affected by the HIV epidemic. The HIV

prevalence varies considerably across the continent ranging from less than 1% in Mauritania to almost 40% in Botswana and Swaziland. More than one in five pregnant women are HIV infected in most southern Africa countries, while elsewhere in Sub-Saharan Africa median HIV prevalence in antenatal clinics exceeds 10% (UNAIDS/WHO, 2004).

UNAIDS 2004 reported that in Sub-Saharan Africa by the end of 2003, 25,000,000 people are living with HIV of which 13,100,000 (52%) are women of childbearing age (15-49) and 1,900,000(7.6%) are children (0-14). The severity of the MTCT problem in Sub-Saharan Africa is due to high rates of HIV infection in women of reproductive age, a large total population of women of reproductive age, high birth rates, and the lack of effective MTCT prevention interventions. Rates of infection in women are high in sub-Saharan Africa and growing rapidly

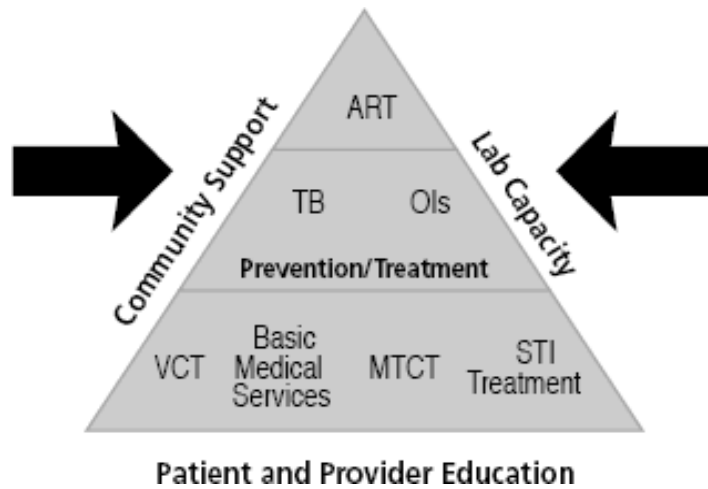
Preventing mother-to-child transmission of HIV has become an essential element of the worldwide HIV/AIDS control strategy. The declaration of commitment adapted at the UN General Assembly Special Session on AIDS (UNGASS) set a goal of reducing the proportion of infants infected with HIV by 20% by 2005 and by 50% 2010 (United Nations, 2001). The data available so far reveals that MTCT is one of the major serious problems, about which little has been done especially in developing countries in the Sub-Saharan Africa.

In 2004, around 640,000 children under 15 became infected with HIV mainly through mother-to-child transmission. About 90% of these MTCT infections occurred in Africa where AIDS is beginning to reverse decades of steady progress

in child survival. In high-income countries, MTCT has been virtually eliminated thanks to effective Voluntary Counseling and Testing (VCT), access to antiretroviral therapy, safe delivery practices and the widespread availability and safe use of breast milk substitutes. If these interventions were used worldwide, they could save lives of thousands of children each year (UNAIDS, 2004).

Currently, in limited resource settings and higher disease burden, the foundations of HIV care are services to provide basic medical care, treat sexually transmitted infections (STIs), identify HIV infection through VCT, and provide primary and secondary HIV prevention services, including prevention of Mother-to-Child Transmission. Prevention and treatment of tuberculosis and other opportunistic infections are needed as patients with HIV become more immunosuppressed, but require greater resources in terms of medications, laboratory monitoring, patient and provider education and training, and community engagement. In settings with few resources, the ability to use antiretroviral drugs is still limited due to cost, accessibility, and health care infrastructure, but this is beginning to change with the growing global consensus that there is a moral imperative to provide these life-sustaining therapies. The Clinical Services Pyramid (Figure 1) (John Snow Inc. /World Education Inc. Center for HIV/AIDS, 2001) illustrates the inter-relatedness of the community, laboratory infrastructure, and patient and provider education that is essential at all levels of HIV care. These components of the health care system must exist and be strengthened for both prevention and care and treatment services to succeed and use of anti-retroviral therapy (ART) to reach those most in need.

Figure 1. Clinical Services Pyramid



Source: John Snow, Inc. /World Education, Inc. Center for HIV/AIDS. Boston, MA 2001

Risk factors for mother-to-child transmission, besides socio-economic factors, include high plasma viral load in the mother; choriodecidual inflammation; obstetric factors such as vaginal delivery (caesarean delivery is protective) and preterm delivery; and breastfeeding. Mixed feeding (i.e. breast milk plus other foods and liquids by mouth) appears to account for substantial transmission risk via this route in the first six month of life (Preble and Piwoz, 2001). In addition, the use of antiviral therapy for the mother and for the baby is one of the most significant factors to positively effect vertical transmission (Kennedy, 2003).

The contribution of each of these routes to over all transmission has not been quantified exactly but it appears that in-utero transmission is less frequent,

and substantial proportion occurs at the time of delivery or late in pregnancy (WHO/UNAIDS, 1999).

Reports on prevalence of HIV infection among pregnant women show that Southern Africa remains the worst affected region in the world. Data from antenatal clinics in urban areas in 2002 showed that HIV prevalence of over 25% following a rapid increase from just 5% in 1990. In Swaziland, the average prevalence among pregnant women was 39% in 2002 showing an increase from 34% in 2000 and only 4% in 1992. In Botswana antenatal prevalence has been sustained between 35 and 37% in the period 2001-2003 (UNAIDS, 2004).

In Kenya, Malawi, Namibia, Rwanda, South Africa, the United Republic of Tanzania, Zambia, and Zimbabwe, over 10% of women attending antenatal clinic in urban areas were reported to be HIV positive, with a rate of almost 60% in some sites. In Thailand, prevalence among women in antenatal clinics has climbed from 0% in 1989 to 2.3% in 1995 and continues to rise. Similar increases were reported from some Indian cities, Latin America and the Caribbean (WHO/UNAIDS, 1999).

In summary, the above discussed issues and figures show that mother-to-child HIV transmission has a great disease burden in childhood HIV/AIDS and threatening child survival in Africa with interwoven and multidimensional problems, which thereby affect the quality of life of the sero-positive pregnant mothers, in general.

2.2 Mother-to-Child Transmission: Mechanisms, Timing, and Risk Factors

2.1.1 HIV Transmission during Pregnancy

In most HIV-infected women, HIV does not cross the placenta from mother to fetus and the placenta actually shields the fetus from HIV (Anderson, 1997). This protection from the placenta may break down, however, if: a) the mother has a viral, bacterial, or parasitic placental infection during pregnancy; b) the mother becomes HIV-infected herself during the pregnancy, and hence develops a very high level of the HIV virus for a short time; or c) the mother has severe immune deficiency associated with advanced AIDS. Thus, maternal conditions including untreated placental infections (particularly malaria), recent HIV infection, and advanced HIV disease have been cited as risk factors for MTCT (WHO, 1999). In addition, in some literatures it is found that malnutrition during pregnancy may indirectly contribute to MTCT and poor nutrition, anemia, and vitamin A deficiency may lead to preterm labor and early separation of the placenta that in turn increase the risk of HIV transmission.

Adequate maternal and child health (MCH) services are the cornerstone of any intervention to prevent MTCT. However, most African countries provide only limited MCH services, facing managerial, financial, and human resource constraints. Uptake of available services is also low on the continent. Upgrading and expanding MCH services, as well as increasing uptake of these services, therefore need to be central to PMTCT programs.

2.2.2 HIV Transmission during Labor and Delivery

Infants of HIV-infected mothers are at great risk of becoming infected with HIV during childbirth. During this single event, between 10 and 20 percent will become infected if no steps are taken to prevent transmission. Most infants who acquire HIV during labor and delivery do so by sucking, imbibing, or aspirating maternal blood or cervical secretions that contain HIV. The duration of membrane rupture (often deliberately performed to augment or induce labor), acute chorioamnionitis (resulting from untreated STDs or other infections) and invasive delivery techniques that increase the baby's contact with the mother's blood have been associated with higher risks of MTCT during labor and delivery (Preble and Piwoz, 2001; WHO, 1999).

Evidence suggest that artificial rupturing of the bag of waters increase transmission rates about 2% for every 24 hours of the bag being ruptured and delivery should happen with bag intact whenever possible (European Collaborative Study, 1994). Episiotomy, cutting of the birth canal opening, is routine in many settings, although there is no research that shows its benefit in routine birth. In fact, episiotomy increases the mother's risk of excessive bleeding, infection and painful healing. There is evidence that the exposure to the mother's blood from episiotomies may increase MTCT (WHO, 1999).

In addition, various studies show that continuous labor monitoring and support, looking for signs of infection, minimizing vaginal exams and lacerations,

reduce use of forceps and vacuum extractors, cord care and planned cesarean section reduce risk of MTCT during labor and delivery by 50 percent. Moreover, prompt and timely provision of anti-retroviral drugs is some of the core factors for prevention of MTCT during labor and delivery (Israel and Kroeger, 2003).

Potent antiretroviral (ARVs) administered around the time of delivery have proven to reduce the risk of MTCT by between 30 and 50 per cent (Preble and Piwoz, 2001). Administering short-term courses of ARVs has its own sets of challenges, including cost, health system capacity, and risk of resistant strains of the virus developing. However, this is still found to be a cost-effective way to prevent transmission of the virus from mother to baby during birth, and presently a number of initiatives are put in place to increase ARV availability for PMTCT (Preble and Piwoz, 2001).

2.2.3 HIV Transmission through Breastfeeding

On average, about 15 percent of babies born to HIV-infected mothers will become infected through sustained breastfeeding (24 months or more). The risk of MTCT is believed to double (to about 30 percent) if the mother becomes reinfected with the virus while breastfeeding (Dunn et al., 1992).

A child born uninfected to an HIV positive mother has a 5-15% chance of acquiring the virus from the mother's milk, if exclusively breastfed. The risk of transmission is much higher if breastfeeding is mixed with other feeding. However,

not breastfeeding in resource-constrained settings may also entail health risks for the baby if breast milk substitutes are unaffordable, clean water unavailable, or sterilization impossible. The World Health Organization recommends not breastfeeding only when bottle-feeding is acceptable, feasible, affordable and sustainable, and safe. Counseling on breastfeeding is increasingly included in PMTCT services (Commission on HIV/AIDS and Governance in Africa, 2004).

2.3 Voluntary, Counseling and Testing (VCT) as an Entry Point for PMTCT

Knowledge of HIV status is a gateway to AIDS treatment and has documented prevention benefits, however the current reaching of HIV testing service is poor and up take is often low because of several factors (UNAIDS, 2004). Voluntary HIV counseling and testing (VCT) for pregnant women is a starting point for instituting a mother to child transmission (MTCT) prevention program. This strategy promotes adequate treatment for HIV positive women and has a positive impact on mother-to-child (MTCT) HIV transmission rate. For HIV negative women it provides opportunity for education and behavioral change (DeCock et al., 2004; UNAIDS, 2004). Nevertheless, experience to-date in many countries show great variations in willingness to make use of the service that are available (UNAIDS, 1999b).

According to a study done on the VCT service use by pregnant women in 14 urban sites in Africa and Thailand in 1997, the acceptance rate of VCT were high; median being 92% ranging from 77 to 99.7%. Over all acceptability of VCT (i.e. women coming for both test and result) was about 69%. The most common reasons to refuse testing were the need to discuss with partner, fear of HIV positive status, and fear of loss of marital security, domestic violence and confidentiality. The study has also reported that better-educated women refuse to test more often than others (Trapper, 2000).

Voluntary Counseling and Testing (VCT) helps women explore options and make decisions regarding testing, as well as infant feeding and other central issues. As women have to know their HIV sero-status in order to know whether MTCT interventions are merited, VCT is an important entry point into these interventions and related services. VCT is also a critical and possibly under-utilized opportunity to inform and counsel women (and men) on HIV.

2.4 Mother-to-Child HIV Transmission in Ethiopia

In Ethiopia, as in any Sub-Saharan African country, the problem of mother-to-child HIV transmission is one of a widespread problem that breaks inter-generational link. The 2003 HIV prevalence is higher among women (5.0%) than men (3.8%) and is higher in urban (12.6%) than in rural (2.6%) population (MOH, 2004) and also on children under 15. Ethiopia's population is young with 44 percent under 15 years (Central Statistics Authority, 1994).

The prevalence of HIV infection among pregnant women in Ethiopia was found to be 17.8%, 17.5% and 15.1% in 1996, 1997 and 1999 respectively yielding an average of 16.8%. In urban Ethiopia the average prevalence of HIV among pregnant women is estimated to be 13% (MOH, 2001).

In Ethiopia, over 80% of the cases of HIV are found between the age of 20 and 49 years, the most economically active group of the population. A survey from the Ministry of Health showed that certain population groups are at higher risk than others. Commercial sex workers, long distance truck drivers and the military were found to have been the most severely affected. In addition, sero prevalence data based on ANC surveillance in Addis Ababa among 15-24 years pregnant women showed that HIV prevalence is about 11% in 2003 after having a peak at approximately 24% in 1995 (MOH, 2002).

In 2003, a total of 128,000 HIV positive pregnancies and an estimated 35,000 HIV positive births occurred. Among children aged 0-14 years, there were 35,000 new HIV infections, 25,000 new AIDS cases and 25,000 AIDS deaths. Besides, crude 2003 data suggest that 8.6% of ANC attendees were HIV positive (unadjusted for urban/rural population) in the 15 – 24 years old age groups and national adult prevalence is 2003 to be 4.4% of which 12.6% is urban and 2.6% rural (MOH, 2004).

Of the urban sites reporting, Dubti Hospital in Afar (24%), Bahir Dar Health Center in Amhara (20.2%), and Gambella Hospital in Gambella (18.7%) reported the highest prevalence of HIV among antenatal mothers. Adama Health Center,

which renders services to the general public, reported 10.8% prevalence among antenatal mothers. Among the rural sites, the highest prevalence was reported by Haik Health Center (11.9%), Tenta Health Center (11.5%) in Amhara, and Dello Health Center in Oromia (8.5%).

In summary, enormous evidence ascertain that the mother to child HIV transmission can occur at periods of pregnancy, during labor and delivery and at early and late postnatal periods including breast-feeding. In order to address all these ranges of risk times the health facilities do have a great responsibility to deal with. At the health facilities, where PMTCT services are provided, there is a need to come up with a substantive work performance in the area of PMTCT.

Hence, the goals of PMTCT are prevention of HIV infection in parents-to-be; to prevent babies from acquiring HIV from their infected mother and provision of treatment, care and support for those infected and affected by the disease. To achieve the intended goals; there is need to investigate the factors affecting pregnant women's utilization of PMTCT services at the health facilities.

Chapter 3

Methodology

3.1 Study Area

This study was conducted in Nazareth/Adama town at the health facilities where PMTCT services are available. The reason for selecting this town is the reported highest HIV prevalence rate of 10.8 percent, according to Adama City Health Office and HIV/AIDS Prevention and Control Office, and higher report for high prevalence of HIV positive pregnancies (10.8%) (MOH, 2004).

Nazareth/Adama town is found in Oromia Regional State, 99 km east of Addis Ababa on the main road from Addis to Djibouti. The town has 14 Kebeles with one zonal hospital, and three health centers (two governmental and one non-governmental). According to Central Statistics Authority of Adama branch, the total population of Nazareth/Adama is 218,110, of which 108,990 are male and 109,120 are female. Women of childbearing age (15-49) are estimated at 50,165, of which estimated pregnant women are 8,389, according to Adama City Administration Health Office.

The maternal and child health care unit (MCH) provides PMTCT service to pregnant women attending antenatal care. The unit includes antenatal, labor/delivery and postnatal care, family planning and STI service, voluntary confidential counseling and testing, anti-retroviral drug therapy for prevention of

MTCT and pre and post-test counseling. The service was started in April 2004 with six counselors in the two institutions; in about two years time more than one thousand pregnant women were counseled and about 400 tested for HIV.

The PMTCT services have been provided only in two health facilities in Nazareth/Adama, namely Adama Hospital and Adama Health Center. Adama Hospital is a Zonal referral hospital in East Shoa Zone. In both health facilities, the PMTCT service/program started in 2004 with support of NGOs.

Since the commencement of the PMTCT service through January 2006 program 6156 pregnant women attended ANC, 1780(29%) of them were counseled for PMTCT VCT, out of them 1223(69%) were tested for HIV. Of the tested pregnant women who passed through ANC, 144(12%) were sero-positive and 1079(88%) were tested to be sero-negative. Within these three years period of time 108 (75%) mothers, who were found to be pregnant HIV positive, took the ART drug Nevirapine. At the hospital where gynecologists/obstetricians are available, no elective caesarean sections are preferably done for needy mothers unless the labor and delivery is complicated as any emergency obstetric problem. At Adama health center, until January 2006, 6601 pregnant women attended ANC, of which 2801 (42%) women were counseled for PMTCT/VCT. However, 1837 (65%) pregnant women gave blood for HIV test and 1699 (92%) negative for the test. In general, of the total sero-positive pregnant mothers who were utilizing PMTCT follow up, only 45% HIV positive pregnant mothers gave birth at the health center taken Nevirapine. Thirty-five babies born at home from HIV positive mothers got Nevirapine after birth; however, their sero-status was unknown.

3. 2 Study Design

In this study, a qualitative method was employed to evaluate the factors determining pregnant women's PMTCT services utilization. Samples of pregnant mothers were selected by non-probability or purposive sampling selection method. Prior to actual data collection, the questionnaires were tested in the study area. Then, in-depth interviews and focus group discussions were conducted to gather the needed primary information. To back up the primary data, secondary data was collected from the health facilities (hospital and health centers), regional and zonal HAPCO , health bureau and other organizations.

The source population for this study was: a) pregnant women in child-bearing age, 15-49, who have been attending ANC and VCT. This age range is taken because in epidemiological calculations, fertility rates, in general population, are calculated by considering womens' age of 15 to 49, b) HIV sero-positive and negative pregnant mothers, c) sero-positive mothers who gave birth under PMTCT program, PLWHA, d) health professionals at different levels at the health facilities of Nazareth/Adama, and e) local and regional actors/stakeholders and community members.

Inclusion Criteria

- ✓ Pregnant mothers who had voluntary HIV counseling in the current pregnancy and are sero-negative,
- ✓ Those pregnant women who had HIV counseling and are sero-positive for PMTCT service,
- ✓ Those pregnant sero-positive mothers who gave birth under PMTCT program utilization (i.e. not more than six months after delivery), and
- ✓ Those pregnant women who are above 15 years old.

Exclusion Criteria

Women who did not satisfy the inclusion criteria and were not able to give an informed consent and those who were unable to communicate for different reasons were excluded from the study.

3.2.1 Focus Group Discussion (FGD)

The FGD session encouraged participants to generate ideas on factors at the health facilities that affect pregnant women to utilize the PMTCT services despite the expanded flow of information. The focus group interaction with the respondents stimulated richer responses and allowed new and valuable thoughts to emerge. This included pregnant mothers attending ANC at each health, community leaders, elders, and knowledgeable group of the population. Hence,

the heterogeneous composition of the group in terms of social class, age, sex, marital status, educational level and cultural differences were maintained. The smaller the group size the greater the depth of response from each participants and each group. Thus, each group had a maximum of six members. Each session had a time span of one and a half hours. In addition, there was an arrangement to uphold privacy and comfortable situations and location. Skilled recorders were assigned to record important points raised. The total focus groups were two with total size of 12 individuals (i.e. six individuals in each focus group).

The moderators were selected based on their experience of conducting such interviews. A male moderator moderated the male group discussion and female moderator moderated the female group discussion. The role of the moderators was to stimulate and control the discussion process. An effective and experienced recorder recorded points raised in the discussion.

Finally, in order to analyze and interpret, the transcript was read, themes that emerged regarding the topic area were identified, different positions and dimensions that emerged were summarized and analyzed in the final write up. In addition, as regards ethical consideration, we informed participants about the aim of the study and they participated based on their own willingness. Privacy, confidentiality, and benefits were maintained.

3.2.2 In-depth Interviews

In-depth interviews were conducted with the health professionals involved in PMTCT service delivery, VCT and antenatal care and with sero-positive pregnant and postnatal sero-positive mothers who were beneficiary of the PMTCT program in both health facilities. The postnatal mothers were mothers who utilized the PMTCT service up to six months period after giving birth. These mothers, both antenatal and postnatal sero-positive, were contacted for interview through their address, while coming for follow-up, care and support. The total number of in-depth interview conducted was *twelve*. The main ideas were recorded and merged with data found from FGD and the analysis was done by categorizing the obtained data in to issues as listed on the questionnaires. Then, the number of respondents the under the listed issues was tallied for analysis.

Table 1. Summary of Sample Framework

Instruments	Number of Participants	Organization they come from
1. In-depth Interview <ul style="list-style-type: none"> • Health Workers 	6	3 individuals from each Health facilities
<ul style="list-style-type: none"> • PMTCT Service Users (pregnant and postnatal sero-positive mothers) 	6	3 individuals from each health facilities
2. Focus Group Discussions <ul style="list-style-type: none"> • ANC Attendees (FGD1) • Community Leaders (FGD2) 	6 per a group 6 per a group	3 from each health facilities 3 females <i>Baltina</i> and 3 males <i>Idir</i>

3.3 Conceptual Framework

Mother-to-child HIV transmission, as most health problems, includes factors that can be viewed from a medical perspective as well as the socio-economic and cultural factors that contribute to vertical transmission of HIV.

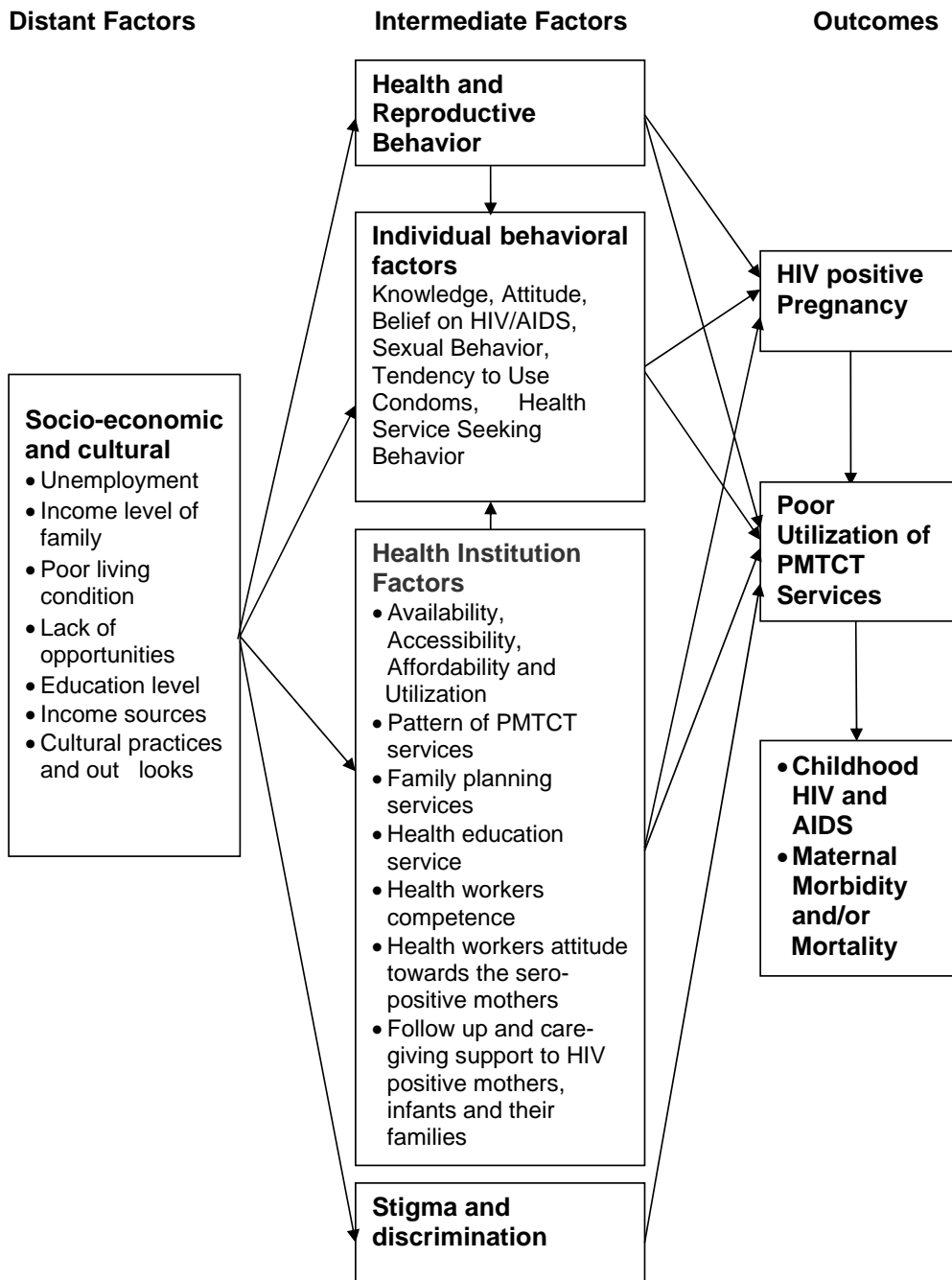
In PMTCT programs addressing “root” factors of mother-to-child HIV transmission could be important at one end and focusing on the immediate factors is another approach. Certainly, these diverse approaches are not mutually exclusive. However, in order to have a coherent picture, what we need is a conceptual framework that encompasses all of the major factors that determine PMTCT service utilization and its outcomes when failed to use the services.

Figure 2 shows the conceptual framework of the determinants of PMTCT service utilization and its outcomes. This framework considers that to reduce mother-to-child HIV transmission by improving socio-economic and cultural status. First, socio-economic and cultural factors are first shown to have an effect on at least one of the intermediate factors: Health and Reproductive Behavior; Individual Behavioral Factors; Access to health Services; or Stigma and Discrimination of the sero-positive pregnant mothers. Furthermore, the chain of effects then is extended to one more of the three outcomes: HIV Positive Pregnancy; or Poor Utilization of PMTCT Services. Lastly, these outcomes lead to childhood HIV and AIDS (child morbidity and mortality due to HIV/AIDS) and maternal morbidity and/or mortality. Hence, these three outcomes are sequential, e.g. HIV positive births cannot occur without first having HIV positive pregnancies.

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Therefore, in order to address all the determining factors of the PMTCT service utilization, in this research the instruments were developed to look upon the distant and intermediate factors and outcomes of these factors. Accordingly, Focus Group Discussions were conducted with Community Based Organizations (CBOs) and ANC clients and In-depth Interview was conducted with health professionals who are working on areas of PMTCT and direct PMTCT service users (sero-positive antenatal and postnatal mothers).

Figure 2. Conceptual Framework on Determinants of PMTCT Service Utilization



Chapter 4

Findings

4.1 Findings of In-Depth Interviews of Health Workers Working in PMTCT/VCT Service

Subjects:

A total of six health workers participated in the in-depth interviews. Three of them were from Nazareth/Adama Hospital; one of the nurses was PMTCT program coordinator and PMTCT counselor and the second one was the head and service provider at MCH department and the third one was a mid-wife nurse trained in PMTCT and harmonizing PMTCT services at labor and delivery ward. The other participants of this study were three health professionals who are directly involved in PMTCT program at Adama Health center. These were: a medical doctor (General Practitioner) who is trained in PMTCT and rendering medical care services for sero-positive pregnant women and two of them were nurses; one was trained PMTCT coordinator and counselor and the other was a midwife nurse and counselor at MCH department. Almost all these health workers, at both health institutions, are directly involved working in ANC, labor/delivery, postnatal care and counseling units for sero-positive pregnant mothers.

Education and Training:

Regarding the strengths and shortcomings of the PMTCT training, given as an in-service training, most of the trained participants declared that the training adequately prepared them for the job. However, some were feeling in the contrary. The weaknesses of the training mentioned by them were short time allocated to general PMTCT service provision training, infection prevention, and PMTCT counseling (i.e. breast-feeding, nutrition and family planning). The teaching methodology was generally good but it was to be acquainted with demonstration and practical attachment to relate the theoretical teaching with practical one.

Health workers' sources of information, and knowledge about MTCT, as to majority of the health workers, responses were trainings, television and radio, internet, booklets of MOH, UNICEF/WHO, magazines, and information shared from trained persons mentioned as their source of information about recent issues of MTCT and prevention modalities. Only few of the participants mentioned the absence of sources of recent information about MTCT and related information. Almost all of the participants stated that the main ways of MTCT of HIV (trans-placental, during delivery, and through breast-feeding). The means of prevention of MTCT of HIV stated by most of them were infection prevention in mothers and prompt diagnosis and treatment of certain infection (like Malaria and Chorioamnionitis), short-course ART (Nevirapine) prophylaxis administration for

the mothers before delivery, appropriate feeding of the infants, safe delivery practice, providing short-course ART (Nevirapine) to the infants after delivery.

In both institutions, according to the respondents, in average around eight to ten mothers are counseled as an individual or group pre-test counseling, majority of them tested, except few most of them come back for post-test counseling. However, as to the counselor's point of view, it is worthwhile to mention that the number of mothers from the starting of PMTCT/VCT counseling up to receiving/declaring the results, the number of mothers in the process of PMTCT service was decreasing from step to step. Some mothers even sent their babies for retroviral therapy after giving birth at home (for example, 35 babies took Nevirapine). On post-test counseling, one in ten is usually positive for HIV and mostly these mothers are not willing to tell to their husband all about their sero-status.

For example, in this unit (PMTCT counseling unit) a mother was counseled and tested for HIV without the knowledge of her husband, since she is afraid of her husband for many reasons like verbal and physical abuse, and firing out of home, she will not disclose her HIV status to her husband. This is a stumbling block for us to provide the service (a PMTCT counselor).

Almost all respondents replied that on executing the PMTCT service periodical lack and shortage of basic equipments and supplies have been experienced at all steps of service provision. Since most of the health facilities do not allocate budget specifically for such services as the PMTCT Program,

sometimes it is confusing as to who is responsible for the program but supported by humanitarian organizations.

As to the PMTCT counselors and coordinators, for those mothers who are sero-positive for HIV, the services like ANC follow-up and counseling including breast-feeding, diagnosing and treating opportunistic infections and other infection which risk the mother-to-child transmission, and referral to NGOs (like OSSA, MedanAct and Save the Children/USA) for care and support for needy mothers, are given. Moreover, safe delivery with ART (Nevirapine) provision to the mother and baby, and postnatal care and counseling are offered.

For most of the mothers who are sero-positive there is almost no care and support from the NGOs in timely and coordinated way, there are almost no free drugs available for treating opportunistic and other predisposing infections. Even the available free drugs, provided as an aid from humanitarian organizations, will be available only for a very short period. On referral to care and support to locally available NGOs, sometimes the mothers do not get immediate acceptance for care and support. *"I can say"*, said one of the respondent, *"the mother is neglected in many ways"*. Another participant added:

The mother is neglected in the PMTCT program, which might lead to motherless child that sum up to already high number of orphans due to HIV/AIDS. Even for the child, emphasis is given only to prophylaxis ART not on care and support. There is, for example, no free and adequate drug for them to treat opportunistic infections. Unless the concerned bodies working intensively on care and support aspect, what has been done till now is not good enough in PMTCT intervention.

Thus, the health workers (counselors) were emphasizing the importance of availing care and support for HIV positive women and their infants in the health institutions where VCT/ PMTCT services are provided which can be managed by the health institutions themselves.

Concerning the readily availability of Voluntary, Counseling and Testing (VCT) and getting the ART at the time of need, for example, for the mother on labor, there is no service that immediately respond to the need of the mother at the time of request. A respondent working at labor and delivery ward said:

To increase service utilization, the rapid tests should be available even at the labor ward, if the mother has not been received PMTCT service previously and convinced to do so.

The majority of the participants forwarded that services like labor and delivery is provided for all mothers equally whether she is HIV positive or not. However, for sero-positive mothers there will be special attention to prevent infections and reduce invasive delivery or obstetric practices. Sometimes due overburden of the work and shortage of utilities like gloves and others, the staff may show misconduct to their clients on laboring and delivery.

Home-based care is mandatory for pregnant woman who is living with the virus, if it is provided for the sake of palliative care and psychosocial support only during the pregnancy period. However, I, personally and as a mid-wife nurse, recommend every mother to give birth at the health facility under professional assistance. Because there are so many things, that might be unpredictable, to happen on labor and delivery which predisposes the baby to HIV virus infection and the mother to birth related complications and death (like vaginal tear, hemorrhage or infections etc) (a mid-wife nurse).

Almost all the participants forwarded that, though, home-based care providers and working with the traditional birth attendants community is a good thing, the care should not include labor and delivery attendance, because there is a shortage or lack of necessary equipments/supplies and inadequate supervision to attend the delivery and timely monitoring of the home-base delivery attendants. Yet, respondents felt that there should be formal linkage between the health institutions and home-based care providers like that of traditional birth attendants, health extension workers, family members and other trained groups for better PMTCT service utilization. Moreover, the health workers argued that with ART (Nevirapine) sometimes the Nevirapine is given, under some instances for a pregnant term mother who may not come to the health facility for delivery for many reasons, to take it home and have it on times of laboring. Nevertheless, respondents underlined that such a practice should be terminated because the mother may not take the drug at appropriate time while laboring. In addition, the need to have intensive social sensitization and mobilization is compulsory for home-based care might provoke victimization because majority of the mothers do not disclose their sero-status to their partner or family for fear of violence and stigma.

Since the introduction of PMTCT program, providers report that some of the practices have changed. To mention some: infection prevention mechanisms, avoiding or reducing doing episiotomies and forceps delivery, safe delivery

practices, cord care, provision of VCT for all pregnant mothers as a component of pregnancy follow-up.

Summary of Challenges in PMTCT Service Provision for HIV Positive Pregnant Mothers and Possible Solutions Suggested by the Participants:

I. Challenges:

1. High workload due to additional responsibilities they had in the institutions/units. This affected the quality of PMTCT services (short time spent during counseling) and some times, they are not able to do it,
2. Inadequate number of trained health professionals on PMTCT /VCT,
3. Trained health workers were not assigned in relevant units in the hospital and health center,
4. Delay in laboratory test results since lab technicians were not assigned only for HIV testing in the health institutions. It leads to prolonged waiting time of mothers, and mothers once they left home, most didn't come back for post-test counseling (to collect their HIV test result). Thus, it results missed opportunity,
5. Fear of violence of husbands (verbal abuse and physical beating) and stigma in the community,
6. Male-partners were not involved counseling and HIV testing, and

7. Absence of care and support for needy mothers on pregnancy follow up, delivery and post delivery.

II. Suggested solutions by the respondents:

1. Support for poor HIV positive mothers who decided to use PMTCT services,
2. Increase in number and quality of PMTCT service providers and counselors to integrate the service to all activities of the health institutions,
3. "PMTCT-Plus" care should be present (i.e. care and support for HIV positive mothers, the children and family with free drugs for opportunistic infections and free long term ART service),
4. The health facilities should work on the community sensitization, and mobilization on PMTCT to reduce or halt victimization, to increase partners' involvement in the program and make use of community resources so as to maximize PMTCT service utilization and,
5. Few of the participants suggested strengthening and systematizing internal (within the health facility) and external care and support referral system (with the NGOs and other health facilities) in the way it protects confidentiality, doing rapid testing by the counselor himself or herself and refreshment course for the formerly trained staffs, as vital solutions.

4.2 Findings of In-Depth Interview with HIV Positive Pregnant and Postnatal Mothers

Participants in PMTCT:

The demographic data of the PMTCT service utilizes give the following profile. Three mothers were from Adama Hospital and three mothers from Adama Health center. Two mothers from each health facility who were sero-positive pregnant mothers and one who were gave birth at both health facilities under PMTCT program. The average age of the respondents was 25. The educational status of the majority completing the primary school and only one respondent completed high school education. Regarding the marital status majority of them are married, among the married two of them were separated due to their sero-status, three of them living with their male partner/husband but do not disclose their sero-status to their partners. The average family size of the respondents is four.

Knowledge about HIV/AIDS:

Except for a few respondents, the majority of the mothers do have a good knowledge/awareness on HIV/AIDS. The majority of the mothers explained the difference between HIV and AIDS--carrying the virus with in the blood that can be transmitted but stay healthy, executing their daily activities for HIV. They explained AIDS as transmitting the virus and the severe stage in which the person

become seriously ill and the major illnesses could be seen on the person and may be unable to execute his daily activity or bed ridden. Regarding the modes of transmission and means of prevention of the virus majority of the respondents stated that at least three major modes of transmission and means of prevention. Few participants who are PMTCT service users hardly explain the modes of transmissions and prevention of the virus.

Response to PMTCT Counseling and MTCT Prevention:

As to the respondents, almost all of them recruited to PMTCT services on the pregnancy follow-up sessions especially on the first attachment at the health facilities as a part of pregnancy follow-up. Despite the fact that the recruitment for service was a good thing, most of the mothers were complaining that the process of counseling and testing was too time taking, and too boring and mothers with many responsibilities are expected to wait for about six hours to know her sero-status.

Pertaining to who suffers from the consequences of HIV/AIDS, for example, the ideas of most respondents coincide with the below respondent's idea.

In the community I came from it is the woman who is mostly affected with Virus and suffer the consequences of HIV/AIDS. Woman is economically dependent on their male partner and our tradition also undermines women's right, all these related factors predispose women to be more susceptible to the virus and affect by HIV/AIDS related problems (a sero-positive respondent).

Regarding how to prevent the baby from being infected by the virus, majority of the respondents forwarded that a mother need to have a pregnancy follow-up at the health facility (where she became tested and know her sero-status); give birth at the health facilities (where retroviral drugs for sero-positive mothers is available). In addition, having a distinct option on the breast-feeding under counseling are some of the preventive measures forwarded by the mothers as a means of prevention. Moreover, one mother argued that a mother should have a routine follow up and medical check up to reduce some infections that might hasten in-utero transmission. Another woman has a very limited knowledge though she is with in PMTCT service utilization.

Condom Use and other Prevention Efforts:

The majority of the mothers agreed that a pregnant woman needs to use a condom while having a sex with her husband or male partner for reasons condom could prevent re-infection and viral exchange between either partners. But, according to the respondents, the mother has no power to decide on reproductive or sexual life matters including using condoms. Therefore, it is practically impossible to influence their male partners to use condoms at time of pregnancy, because most of the mothers do not disclose their sero-status to their partners. Concerning the commencement of retroviral therapy, almost no respondents

started to have the retroviral drugs and they usually check their status at the hospital.

Services Provided for Sero-positive Pregnant Mothers:

Almost all mothers replied that pregnancy follow-up, counseling, medical diagnosis, referral to NGOs, and post-delivery care and counseling are some of the services available to the mothers. Few women argued that sometimes health facilities provide free drugs but the drugs prescribed are all the same for almost all sero-positive mothers. However, they further elaborated that free drugs are available at the health facilities on temporarily basis and only for short time. Moreover, some women do not use these drugs because they feel that getting free drugs is bureaucratized and for the fear of breaking of confidentiality in between while they are going through different offices or units to have stamp that declare fee-exemption and/or signature to get a free drugs. One of respondent told that she was told by one of the health professionals to have balanced food rather than looking for a medication, which might be beyond their reach for they are already economically deprived mothers. As to most of the respondents there is no free drug for most needy mothers who are economically deprived unless the mother go to locally available NGOs which about majority of the mothers complains of 'found out' and very delayed response to their immediate care and support. Although the health facilities refer their needy clients to NGOs and faith-based organizations,

who provide care and support, there is no easy and organized referral system, prompt care, and support provision.

Disclosure and Relationship with Partners:

Half of respondents did not disclose their sero-status to their husbands or male partners. Few of the respondents, who were disclosed their sero-status, are separated from their male partner, fired out of home or the male partner run away after knowing that they are HIV positive and were physical abused/assaulted. Only few respondents who disclosed their sero-status to their male partners have lived in stable relationship with their partner. To sum up, almost all mothers were counseled and tested alone (with out the involvement/knowledge of their male partner).

A few respondents explained that after getting their blood result and knew they were HIV positive the health workers gave them a letter that notify the male partner voluntarily to come for counseling and test. However, the partner became aggressive against them and run away from the home. Most of these mothers are under direct support from the care and support providers because they are surrendered to socio-economic problems. One of the mother said, *"It was better not to disclose my sero-status to my husband than suffering from the consequences including hunger."* To add more, breast-feeding perspectives from the family, neighbor, and community is also one of the factor to which direct stigma is attached like formula milk feeding. A mother who does not breast-feed her baby

considered as a 'cruel mother' who do not love her baby. Due to this attached stigma and cultural influence the woman prefer to feed her baby or doing what is expected to be done as per perception of the community. Further, the majority of the pregnant mothers living with the virus responded that community involvement in the process of prevention and support as a key potential area of intervention. A young respondent argued:

In order to prevent mother-to-child HIV transmission, the concerned body needs to work on preventing the community not to stigmatize the people living with the virus. For example, this is my first pregnancy. I am told by the health professional the signs of labor, when I will feel the pushing down pain, even I will not tell to my husband whether the labor started. Simply, I will call a taxi and go to the health facility where I have follow up through out my pregnancy period. Because, I afraid that they might know my sero-status while I am laboring and they may stigmatize me then after.

Abortion Options:

As regard to the need of having abortions for pregnant sero-positive mothers, under legal conditions, almost all mothers disagreed and expressed their fear in that the abortion has bleeding related problems and my end up on the some gynecological related infections, which may latter affect the health status even death of the mothers. For most of them it is better to give birth having HIV than an abortion.

Care-giving Support to Sero-positive Pregnant Mothers:

Almost all mothers strongly agreed that all pregnant mothers need to know their sero-status to ensure that the generation of the concerned family shall continue or intergenerational link would continue and preventing the transmission of the virus from parent to their children. Regarding the respondents idea that in order to have good health status of the mother, most of the health facilities should render care and support services that are provided by the humanitarian organizations for disadvantaged mothers. Most of the mothers are socio-economically deprived and dependent on their male partner for self-support. For fear of 'found out' by some one and violence of the husband, most of them did not disclose their sero-status to their partners. Thus, most of them forwarded that the health facilities should integrate, if possible, care and support just as a component of PMTCT services. The majority of the respondents argued that the care and support provided through referral from the health institutions to the locally available NGOs and faith-based organizations are not easily accessible to the clients for reasons quota or lack of resources at the organizations. In addition, most of the respondents reported that while they are going here and there to seek for care and support, they were anxious that the confidentiality might be broken which is already concealed even from the partners. Moreover, there is a fear of found out by someone.

To sum up, some mothers experienced ill-timed response for their medical care and other supports and was obliged to be registered and waiting for positive response under the waiting list. One woman argued that the care and support

system from the organizations side is bureaucratized and there is a need to pass through different offices to get the needed services both at the health facilities and at the supporting organizations themselves.

Victimization Issues:

For some of them who disclosed their sero-status, victimization affect their socio-economic conditions even up to forcing to leaving the house they rented and some of the neighbors who knows their sero-status stay away from buying their food items they sold - *Baltina* products. Moreover, these add up for failing to utilization of PMTCT the service.

Victimization affects my lives even up to forcing my family and me to leave the rented house and dysfunction my social relationships (a sero-positive postnatal respondent).

Pregnant women are already victimized by their husband most cruelly and by the family, neighbors and the community as well. Therefore, this stigmatizations especially from the male partners is one of the most predominant factor for mother-to-child HIV prevention service utilization at the health facility (a pregnant sero-positive respondent).

Moreover, another woman argued differently and she replied that some health workers did victimize the sero-positive mother in pregnancy follow-up, delivery, as well as a post delivery follow-up. She shared her experience that two health workers who were attending the night session at labor/delivery room were nagging to each other as to who should attend the delivery after knowing her sero-status on her follow up card (ANC card). The condition traumatized her mind.

Finally, her husband asked her why they were arguing and she preferred to keep quiet than saying anything else because he did not know her sero-status. Another woman, who is sero-positive and gave birth two months back, added that she was attending pregnancy follow-up at one of the health facilities and she gave birth at home and sent the baby for retroviral therapy to the health facility for the fear of stigmatization during labor and delivery from the health workers' side.

Preferred Care Models:

Almost all mothers agreed that institution-based care should be linked with the home-based care to maximize care and support at the home-environment and reduce the workload at the health facilities, which are already congested. However, majority of the mothers argued that the home-based care itself might provoke the stigma because majority of the mothers, who are sero-positive, do not disclose their sero-status even to their male partner. For almost all respondents, home-based care is indispensable to maximize the care for those pregnant mothers living with the virus who are already deprived of socio-economic problems. However, most of the respondents argued that the community needs to have extensive awareness about parent-to-child transmission and its consequences prior to home-based care promotion.

Home-based care, in our country, needs a meticulous work at the community level because women are dominated by their male partners. Male partners usually feel ashamed if found out with their pregnant partner at the health facilities. For example, I did not tell my sero-status to my husband and for fear of stigma, I do not want to

disclose my sero-status to my family as well as neighbors. So that if home-based care to be promoted my husband in first place, then family, and other may ask me why these service providers come to my home (one of the respondents).

Attitude towards PMTCT Services:

Majority of the mothers shows positive attitude about the PMTCT services provided at the health facilities. However, they complained that the process of service delivery through which the mother is expected pass is too boring and long time taking. As to the respondents the staffs overburdened on rendering services for their clients (both sero-positive and negative mothers) because they are not assigned only to PMTCT services. Yet, some health workers are misbehaving as showing mal-treatment for sero-positive mothers. In addition, some respondents replied that staffs, with whom they are familiar with, are repeatedly shifted to other rooms and it might alleviate their anxiety if they may find the health professional that they know well. In addition, confidentiality of the case is another pertinent issue from health care system.

Lastly, for better PMTCT service utilization, majority of the service users underlined that male-partner involvement and community awareness as a crucial determining factor. Hence, community education on the area prevention of parent-to-child transmission at different occasion like *Idir*, *Baltina* and religious gatherings are among some of intervention for the betterment of PMTCT program activity. In addition, unethical responses of few of the health professionals also another issue forwarded and need to be considered as well.

From the challenges they faced while attending PMTCT services, the sero-positive mothers recommended;

1. The counseling and testing time needs to be revised because it takes too long times for a mother with HIV and shoulder many responsibilities,
2. Availing and accessing drugs for opportunistic infections treatment and care provision is vital,
3. There should be easy referral system and making it out in the way it respect confidentiality and sensitive to pregnant women's need and considering care and support provision by the health facilities themselves,
4. Male-partners involvement in PMTCT program is critical areas that require interventions for effective service provision, and
5. Community involvement to alleviate or stop stigma and its consequences and provision of care and support for needy mothers is vital.

4.3 Findings from Focus Group Discussion with ANC Attendees

FGD Respondents:

The demographic characteristics of the focus group discussants provide the following profile. All of the respondents were pregnant women who have at least visited the health facility twice for pregnancy follow-up. The average age of the

respondents was 27. Except one respondent, all were married but one was separated. Regarding religion, the group comprises Orthodox, Protestant and Muslim religion followers. Among the respondents majority of them were Orthodox followed by Protestant. Except one of the respondent, all other discussants found to have basic education that enables them to write and read. In a majority of the cases, the respondents have lower education below grade six. However, one of the respondents was a college graduate and holds diploma in Agriculture. Concerning the occupation of the respondents except two of the focus group discussant majority of them were with no occupational engagement and were economically dependent on their male-partner, a breadwinner. A few of them were engaged in petty trade, which is not good enough to satisfy the basic need of the household.

Impacts of HIV/AIDS:

Concerning the impact of HIV/AIDS within the community, majority of the mothers replied that HIV/AIDS does have disastrous effect on the local community they live in. The effects were explained as increasing the number of orphans (losing of one or both of their parents), and older people are forced to take care of their children, who are HIV positive and become bed-hidden. In addition, the grandfathers and grandmothers who expected that care would be provided for them experienced a reversal, in that they provide care for their children and grandchildren. Hence, HIV/AIDS does have multidirectional effects. Further they

explained that some of the neighbors who were professionally experienced and wealthy and doing many development activities in their beneficial business have passed away leaving enormous socio-economic problems.

Moreover, the majority of the respondents replied that MTCT as being a serious problem in the community, because there are babies who are dying at their early age and the mother and father followed soon. Sometimes, the mother dies first and the child follows because of lack of care and support for the mother and child. As to the respondents, therefore, mother-to-child HIV transmission becomes a serious problem. One respondent woman stated:

I know that one of my neighbor, whose husband is a military, she became pregnant and tested for HIV and she become sero-positive. After knowing, she has HIV in her blood, while she told to her husband all about her sero-status. He had bitten her and then he run away from home. Until now, she does not know where he is. Now the mothers gave birth under many economic problems. Even we, as a neighbor, contributed for post- delivery care and needed expenses like house rent. The health facilities referred the mother to one of NGOs and now she got periodically a sort of money, around 100 Eth. Birr for her living expenses.

Another woman added that one of her neighbor who was from the well to do family, gave birth knowing that she was HIV positive under PMTCT service utilization (but kept secret her sero-status). She was advised not to breast-feed her baby. One of the family members then asked her why she did not breast-feed her baby. She gave a sort of reason but he did not believe that. This debate ended up in stigmatization by the family members, including her husband. This mother killed

her two-month baby and developed a mental health problem. This mother is now under a psychiatric care at one of psychiatric hospitals in Addis Ababa.

Factors for PMTCT Service Utilization

As to majority of the mothers the attracting factors for better PMTCT service utilization are:

1. Acceptance of the PLWHAs as an integrated whole and socio-economically productive because victimization of these people, from the family, neighbors and community, could end up as a barrier for service utilization,
2. Educating the mothers, at community level, on services and options in PMTCT since women who do not come to the health facilities may not know all about the services,
3. Health facilities and professionals need to be receptive and fully capacitated to render the service for needy mothers, and
4. Community based organizations, community and male-partners should be involved in systematic and culturally sensitive way in the PMTCT service program.

Home-based Care Issues:

Almost all the focus group discussants agreed and forwarded ideas as the home-based care as a good thing to be promoted for sero-positive mothers. Because it is the area of intervention, as a critical point to render care and support at the home environment. As to the respondents, the husband, family, neighbor or community already stigmatizes majority of the mothers in one way or another. Mostly, as stated, they have no one to help them in their need (those who disclosed their sero-status) and economically are deprived. Actually, the family and neighbors are the ones who should provide the care. If this is not possible, the organized groups should provide the care such as home-based care providers. However, the fear of the participants was home-based care may provoke stigmatization from the community side. Most of the mothers, for fear of their husbands and stigmatization from the community, do not declare their sero-status. Hence, home-based care may end up in victimization or making the case known to others for whom it did not concern. However, as a solution, they suggested that securing the care as a secret and Traditional Birth Attendants (TBA) could handover the care. Another woman argued that safe home delivery along with home-based care should be promoted because majority of the pregnant woman in their locality give birth at home for many reasons as there may to be a time the mother need care.

Comments of Focus Group Discussants for Better PMTCT Service Utilization

To maximize the PMTCT service utilization respondents felt there is a need to:

1. Contact the sero-positive pregnant mothers who discontinued their pregnancy follow-up through their address: telephone, house number etc, is essential to minimize the risks in missing periods, and to provide counseling and support since the mother may discontinue for many reasons. This again may create a good relationship between the health service provider and the mother and build confidence of the mother in the service,
2. There should be positive consideration to sero-positive pregnant mothers from the health professions side and
3. The community should normalize the HIV/AIDS and do the best to support the family in times of problem. Thus, there should be intensive community education.

4.4 Findings from Focus Group Discussion with Community Based Organizations (CBOs)

Impacts of HIV/AIDS:

Regarding the consequences of HIV/AIDS in their locality, the majority of the respondents replied that: firstly, economic problems for the sick person and his

or her family because earnings goes to the medical care expenses of the sick and the problem is worse if the sick is the husband, because usually it is the husband who is a breadwinner. Secondly, older people gave care for their children and grandchildren, in this case, the care is reversed because in our tradition the offspring are expected to give support to their family (mother father and grandfathers and mothers). Thirdly, children became orphaned and the number of orphans increased from time to time. Finally, death of experienced and productive male and female community members and children were the critically raised issues.

As reported by one of the respondents, the problem of HIV/AIDS is a countrywide problem. However, the disease does mostly affect the economically deprived community members, though it also affects the well-to-dos. Moreover, economically well-to-do community members do have a broad chance of transmitting the virus to others. Even some these people not disclose their case they go other areas like Addis Ababa to seek medical care and treatment whenever they got a medical problem.

A few women expressed their fear that mother-to-child HIV transmission has a threat that break intergenerational link of the family if the baby born from sero-positive mother becomes HIV positive. Some women do not know their sero-status but their husband died due to the HIV/AIDS. In the meanwhile, if they have a baby, then it may die. Hence, due to lack of knowledge about HIV/AIDS, the family members consider it as 'curse' or called as *Irgiman* in Amharic. Moreover, no one says that the baby died due to HIV/AIDS or mother-to-child transmission.

Thus, all these mentioned conditions cumulate to come up with negative impact in the community they live in.

Determining Factors for PMTCT Service Utilization:

Concerning the determining factors for PMTCT service utilization, almost all of the focus group discussants expressed the following points:

1. Fear of victimization from the husband, family, neighbor, and community,
2. Maltreatment from the few health professionals at the health facilities especially at the labor/delivery unit,
3. The counseling methodology and long waiting time may incite fear among the counselees, needs to be adopted in culturally sensitive way with out losing its standards,
4. The economic problem from the social–economically deprived women or family because there may be a problem to afford to pay for delivery services at the health facilities,
5. Male–partner influences on women that affect women who do not disclose themselves for fear of their husband. Even those who disclose their sero-status pointed to each other as to who brought the problem. This may end up in corruption or separation, and

6. Finally, due to low coverage of health education, community sensitization or mobilization low awareness on the PMTCT, the majority of the mothers give birth at home with untrained traditional birth attendants' assistance. This might contribute to high rate MTCT and low PMTCT service utilization.

Home-based Care Issues:

Concerning the home-based care, almost all discussants strongly agreed on home-based care service provision and expressed on the need to introduce and work with it to reach the needy mothers. On the other hand, the discussants, forwarded that educating the community to create awareness and mobilization on PMTCT is an area of intervention for the success of the care and support. One of the *Baltina* leaders said:

We do have a tradition of helping each other or caring for the sick from the family members up to the neighbors. Hence, I believe that home-based care is a good thing but the care provision should start from the family members, informally, where the maximum potential emanates; they need to be trained how to give care and support for the sick without risking themselves. In addition, the trained home-based care providers should be involved in back up the service in formal way.

Another *Idir* leader added that for the sustainability of the home-based care, the close family members and the community need to handle the service as their own concern. He forwarded, as an example, that one organization started to work at home-based care for PLWHA but the organization worked for few months but

disappeared. On top of this another *Idir* leader argued that start to work with the community through handling the community leaders is very easy but the problem comes on the sustaining the work, the very difficult task. The respondent summarized that while starting to consider home-based care for HIV positive pregnant mothers, the sustainability is a key question. To do so, provision of training for families how to give care and community mobilization for stigma alleviation and community resource utilization needed to be put into consideration.

The community leaders cited the partners influence as one of the issue in PMTCT service utilization. In response, one of the *Idir* leaders responded that the influences of male-partners, especially the fear for disclosing their sero-status to each other emanates from low awareness or knowledge about the problem. As to the respondent's suggestion, even the husband and wife were to discuss about their sero-status before conception. Awareness deliverance is a key issue in preventing HIV from parents to their baby. In addition, another *Baltina* leader stated,

Females are dominated by their male-partners, even the tradition influences so, mostly, economically females are dependent on men and usually tested alone for HIV with out the knowledge of their husband. These and other factors influence woman not to share sensitive problems, like being HIV positive. Mostly, women, if they are HIV positive they will not disclose their status to their male-partner because, the male, rather than accepting what happened he pointed at woman as if she is responsible to brought HIV to him and this condition may lead to other complicated problem in their marriage relationship. Therefore, due to fear, if they are pregnant and HIV positive, woman will not disclose to their male partners (a respondent, *Baltina* leader).

Finally, the listed below are comments from the community leader (*Idir* and *Baltina*) on how to improve the prevention of transmission of HIV from the parents to their children:

1. Developing the tradition of free discussion on reproductive health issues from both sides (in male and female partnership),
2. There should be a strong networking or referral system between community leaders or CBOs, health workers, health facilities and other NGOs so as to make use of community resources,
3. Train the traditional birth attendants on home-based care, delivery techniques and identifying emergency obstetric problems for prompt referral to the health facilities for sero-positive pregnant mothers. Because majority of the mothers do give birth at home through assistance of TBA, and finally,
4. Providing training for family members so that they can handle the care provision because they spend more time with the victims.

Chapter 5

Discussion

Findings revealed that MTCT prevention can have a significant effect on saving children's lives and secure child's right to survive and ensure quality of life of the mother and the family. Effective MTCT prevention interventions demand broader reaching efforts to improve overall health service deliverance system and community involvement in the prevention, care, and support of sero-positive mothers, their children, and the family. However, challenges in PMTCT service provision occur in both the health facilities and the community. The health facilities or service providers need to ensure confidentiality in testing, counseling and providing care (Israel and Kroeger, 2003). In addition, the health workers need to show a positive regard to needy service users in using the safest obstetric procedures or techniques that are addressing the care for PMTCT and providing psychosocial support. Because, a woman's lifetime risk of dying during pregnancy or childbirth is greater than *one in ten* in countries such as Mozambique, Mali, Niger, Ethiopia, and Burundi (Save the Children, 2000).

Findings in this research show that more attention is given towards protecting the baby from being infected by virus. Hence, the attention of the service providers goes only to prevent the baby from HIV infection during pregnancy, delivery/labor, and breast-feeding. However, the health and life of the mother is neglected in the spectrum of services. Preventing children from

becoming infected is clearly important, but the exclusive focus on preventing infection in the child may be missing the point. If the care is not given for the mother, she gets sick and dies; the child also suffers from the consequences, whether HIV infected or not. The death of the mother is a high risk factor for child morbidity and mortality. The imperative should, therefore, be on keeping the mother healthy. This is beneficial to the child and the family unit. Preventing the massive growth in the number of orphans also helps to ensure stability and further intergenerational knowledge formation on a societal level (CHGA, 2004). Also in rendering the service, the programs need to be systematized in the way that does not over burden the care providers or facilities beyond their capacity and organizing *in* and *out referrals* in a way the referral includes the needed services.

Most women have their babies at home, by their choice, or because there are no alternatives, or because the health facilities are not positive options or due to costs, distant location, poor staff attitudes and/or facility conditions (Israel and Kroeger, 2003). In this study, it was found that the majority of the sero-positive mothers were socio-economically deprived and some of the mothers give birth at home and send their babies for retroviral therapy to the health facilities. Hence, economic factors, lack of decision-making power within the household as well as their pessimistic regards towards the health professionals and institutions could have the factors that contribute to poor utilization of institutional pregnancy, care and delivery.

This study identified that the majority of the pregnant sero-positive mothers lack decision-making power with in the household and are economically

dependent on their male partners. Studies show that women's relative lack of decision making power, education, and economic independence in many parts of the world affects their ability to both protect themselves from HIV infection, and seek and receive treatment and support. According to the United Nations figures, women represent 58 percent of all people living with HIV/AIDS in Sub-Saharan Africa; young women in the region are now six times more likely than young men to be infected; and women, in general, die faster from the disease than men (Kiragu, 2001).

Regarding the stigma or victimization, findings in this study paint a comprehensible picture of the consequences of stigma or victimization in PMTCT service delivery. The majority of the respondents pointed out that victimization are among the stumbling blocks for PMTCT service utilization; as it affects their social relationship, economic gain and their own health care. HIV stigma - the perceived shame or ostracism faced by someone known or thought to have HIV/AIDS – is shown to be one of the most difficult barriers to slowing the spread of the disease. Stigma from the family, neighbor, or community poses challenges to integration or if providers are hesitant to offer services to PLWHA, or if clients do not want to be affiliated with a facility that also provides HIV/AIDS service or general service for PLWHA (Israel and Kroeger, 2003).

Concerning counseling and testing most of the mothers, especially in their first visiting the health facilities for the pregnancy follow-up, counseled and tested as a voluntary requirement for pregnancy follow-up. However, this study has identified that women who were counseled, tested, and found to be HIV infected,

communicating information about their sero-status to their sexual partners is very difficult and the majority of them do not disclose their sero-status to their male partners for fear of violence and stigma or anticipated negative responses from their partners' side. Studies (e.g. Preble and Piwoz, 2001) suggest that fear of violence (physical beating) and break-ups of relationships among women who are found to be HIV positive are not uncommon (Maman et al., 2001; Gaillard et al., 2000; The Voluntary HIV-1 Counseling and Testing Efficacy Study Group, 2000). In this study, women who disclosed their status faced problems like physical beating, firing out of home, separation and few experienced the run out of home of their husbands. Those mothers who did not disclose their sero-status suffered socially and psychologically because these people at least need to have emotional support. Hence, to fill such a gap and for effective PMTCT work, the health facilities, or the counselors need to consider factors related to disclosure and its consequences and devise the means to cope with it. Hence, receptive client oriented counseling, community awareness raising/mobilization and involvement of male partners are critical.

Another important set of findings was concerning home-based care for mothers living with HIV/AIDS. This study found out that this area has not yet been integrated in the health care system. For example, one PMTCT client argued that the home-based care is a good thing but it should include home birth practice for those needy sero-positive mothers because for many reasons the majority of the mothers give birth at home. Some of these reasons are economic problems, pessimistic regards about the health facilities or professionals, and so forth.

Another respondent, who is a mid-wife nurse trained in PMTCT, argued differently, he proposed that home-based care has many benefits for PLWHA and the participation of TBAs. However, this nurse disagreed with participation of TBAs in home delivery, for reasons of emergency obstetric problems like Cephalo-Pelvic Disproportion (CPD) and hemorrhage, and birth environment sanitation.

I would like to argue that home-based care should be rendered to needy mothers along with safe home birth services with the involvement of TBAs. The need to intensively train the TBAs on promotive and preventive health issues, normal labor/delivery, on emergency obstetric problems and prevention of vertical transmission and home-based care giving, is crucial point to be considered in the first instance. Further, home-based care giving support, such as palliative care, nutritional support/cooking, keeping personal hygiene, house cleaning and so on, should be supported and provided by the government and/or humanitarian organizations in a coordinated way. Furthermore, safe home birth with trained TBAs needs to be promoted under adequate provision of necessary materials and utilities and proper supervision. In supporting the above idea, some researchers recommend that if home-birth attendants trained in PMTCT, they could provide links between families and facilities and serve as a tributary from the community to the health facilities for PMTCT service utilization. If possible, the institutional health care and delivery is the best practice. However, in developing and resource poor countries, where institutional delivery is at its lowest (not more than 9% in Ethiopia), effective PMTCT programs can promote safer home-birth for mothers

living with HIV/AIDS and need to target traditional birth attendants (TBAs) and others who attend births at home (Israel and Kroeger, 2003).

On top of services rendered by the home-based care providers, some researchers advise encouraging pregnant women, living with HIV/AIDS, to take part in their own health care and the need for empathic relationships with service providers to breakdown the interpersonal gap and hierarchical relationships between the provider and PMTCT client. Collaborating with the PMTCT clients and empowering them should be the goal of all facilities providing PMTCT services (the counselors, MCH nurses, mid-wife nurses and others). To empower these women, however, it would be more promising if the male partners and the community are participating in the program. To effect on care and empowerment of women, each community has different types of community-based organizations (*Idir, Baltina*, etc) and personnel (TBAs, traditional healers and religious leaders) that are resources to be utilized for better PMTCT program execution and to provide effective home-based care and home life saving services for needy mothers.

Strong linkages between community and facility services are the foundation of an effective PMTCT program, and fully integrating PMTCT services including developing linkage between the two (Israel and Kroeger, 2003). Hence, formal connection between community-based personnel (TBAs and other organized groups) with health facilities provide a smooth continuum of care each enhancing and complementing to render comprehensive service for the mother and family. Hence, in order to come up with effective MTCT prevention, community

organization/mobilization and networking are critical factors to support efforts for better PMTCT service utilization. Further, some literatures suggest that involving the family and community is a key to both designing appropriate service delivery as well as increasing demand for services. Some PMTCT programs have already started doing this through activities such as fostering couple and community discussion on HIV/AIDS, and by working with community structures and local organizations to normalize HIV counseling, testing, and care. These activities need to be further integrated into PMTCT activities and be scaled-up (CHGA, 2004).

Community involvement and strengthening the referral system between the community-based organization and the health facilities should perhaps be encouraged to provide a better quality of home-based care and service utilization for PMTCT. Here, the *social work* practices play a great role in exerting effort to reach the needy mothers in provision of care-giving support and ensure its quality. If humanitarian organizations that are involved in provision of care and support want to promote home-based care for sero-positive mothers; they should participate and collaboratively work with community-based organizations. This is significant for the sustainability of the prevention of vertical transmission of the virus. It could also minimize the over utilization of costly facility services, broadens the way of support and service available and minimizes the number of mothers and babies who may fall through the cracks of the formal health care system in the process of PMTCT service provision. Thus, while we start to consider home-based care and referrals for HIV positive pregnant mothers, its sustainability is a key question. To do so, provision of training for families (on the care provision) and

community mobilizations for stigma alleviation and community resource utilization should be considered to consolidate the service.

Regarding services rendered to sero-positive mothers at the health facilities, though the majority of mothers hold a positive look upon the services, it is not without complaints. Findings revealed that the health facilities are suffering from periodical lack/shortage of drugs to treat opportunistic infections, and equipment and supplies, and lack of care and support provision for needy mothers. For example, an ANC client counseled and tested for HIV should wait for about six hours for the declaration of their blood result for the laboratory technicians are not only assigned for PMTCT/VCT. Hence, it is important to work on and make accessible a range of services like locally adoptable VCT for PMTCT, secure adequate ARV provision at the strategic health facilities, treating opportunistic infections, safe delivery at the health institutions and providing baby health care system including breast-feeding. In addition, every effort should be made to work on keeping sero-positive mothers healthy and psychosocially competent citizen.

A key lesson learned from this study is that postnatal HIV transmission through breast-feeding remained almost neglected. All attention goes to prevent the baby from HIV infection around the times of pregnancy and labor/delivery and there is a very weak follow-up on the postnatal period. The postnatal risk prevention of vertical transmission of the virus through breast-feeding is limited only on counseling of the mothers. In this study, this is one of the gaps found out in continuum of prevention of vertical transmission. The breast-feeding counseling

demands practical provision of care and support to mother in safe infant feeding. The World Health Organization (WHO) discourages breast-feeding only when bottle-feeding is acceptable, feasible, affordable and sustainable, and safe. However, in developing and resource poor countries like Ethiopia not breast-feeding may bring up risks of postnatal vertical transmission because breast milk substitutes are costly, lack/shortage of clean water and unsanitary conditions are prevalent problems to promote breast substitutes. Thus, exclusive breast-feeding is recommended as an option but the mothers should have practical care and support and keep the mother healthy to benefit children from safe exclusive breast-feeding. For example, only 31 percent of children in sub-Saharan Africa experience the benefits of *exclusive* breastfeeding (UNICEF, 2000). Therefore, to come up with maximum MTCT HIV prevention in the continuum of PMTCT service, postnatal and psychosocial support services for the infant feeding method of choice is essential. This is critical because; firstly, to help the mother overcome any difficulties she is having with her feeding choice; secondly, to ensure that the chosen method is practiced safely and effectively to minimize MTCT through breastfeeding; and ensure that the health and nutritional benefits of her method of choice are achieved (Preble and Piwoz, 2001)

In addition to the above, a number of other findings of the study, related to breast-feeding, are worthy of mention. The majority of sero-positive mothers replied breast-feeding perspectives from the family, neighbors, and community as one of the factors attached to direct stigma. A mother who does not breast-feed her baby is considered as a 'cruel mother' who does not love her baby. Due to this

attached stigma and cultural influence, usually the woman preferred to breast-feed her baby or doing what is expected to be done as per perception of the community. As cited in Preble, E. and Piwoz, E., (2001) understanding attitudes and practices related to breast-feeding and perceptions and stigma associated with not breast-feeding are critical for the development of appropriate interventions to reduce postnatal transmission of HIV. Many African cultures have historically stigmatized women who do not breastfeed as “bad mothers.” The emergence of HIV in Africa has enhanced this stigma, as described in studies in Botswana, Cote d'Ivoire, Zambia, and Zimbabwe. Hence, there should be a concrete work on the area of raising the community awareness on infant feeding options as an area of PMTCT work to alleviate or stop the attached stigma.

In the range of services offered in PMTCT program, the data available shows that from initial contact at ANC unit, through VCT, returning to the health institution for labor /delivering, receiving treatment and postnatal counseling and care for both mother and infant, declining at each steps of the processes. This shows low uptake of even the available services in PMTCT program. Such a pattern is cited on CHGA, 2004, background paper as a ‘*cascade*’ effect on service uptake. The above-discussed factor that were found out in the data and that supports the conceptual framework, could play a significant role as determinants for low service uptake.

Finally, the social work practice aimed at enhancing human well-being and helping meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in

poverty (National Association of social Workers, 1999) are among the needed issues to be considered in PMTCT. Social work interventions that promote social justice and social change with and on behalf of PMTCT clients are indispensable. Because, pregnant HIV positive and postnatal mothers, and their families are suffering from stigma and discrimination, and lack of provision of proper attention to their medical, economic, psychosocial and other related problems. Hence, provision of care-giving supports and advocacy services on behalf of these groups of people is an important area of intervention in PMTCT as a part social work practice in HIV prevention and care.

Chapter 6

Conclusion and Recommendations

6.1 Conclusion

This study revealed that MTCT prevention focused on health care system within the health institutions. The health institutions are providing services to reduce vertical transmission of the virus around the time of pregnancy and childbirth but postnatal vertical transmission is neglected and only breast-feeding counseling is given with no resource provision to the needy mothers. In addition, the way to find out those mothers who fail to visit the health facility for many reasons, at the postnatal follow-up, is of paramount importance. PMTCT services, at the health institution, are too female oriented because the services are linked with maternal and child health services. This may lead to lower participation of men in the PMTCT program. Men may further lose their support for program success that bears distinctive significance. It is worth mentioning that though services are too female focused, all the attention is on saving the baby from HIV infection, in this regard, the mother is most neglected in the spectrum of services; the greatest missing point!

Although PMTCT services are available in both institutions for a number of reasons, there is a low uptake of services. The main reasons are: firstly, women's fear of disclosing their sero-status to their male partners for fear of violence and marital relationship break up; secondly, stigmatization or victimization from the

family, neighbors and community and also fear of being discriminated against by the health workers and lack of coordinated and easily accessible care and support that ensures confidentiality.

MTCT prevention, as a continuum in HIV/AIDS intervention, for example, primary prevention (protecting the mother from HIV), preventing unwanted pregnancies among the sero-positive mothers, safe infant feeding support and provision of care and support to PLWHA are areas of intervention that demand due attention to effect on positive outcome of PMTCT. Moreover, the activities like designed program for health and child survival, reproductive health and family planning options, nutrition, health sector strengthening and reform in the way it is sensitive to women and food security needs to be integrated in PMTCT program.

If care and support are rendered, by health facilities and humanitarian organizations, in a timely and organized way, they could positively effect on PMTCT. This is because it serves as entry point at the community level for PMTCT interventions. In addition, provision of effective home-based care giving support for sero-positive pregnant mothers could comprise dual benefits; utilizing the resources for sustainability of the service and raise hope and lead to empowerment of the community to fully participate in MTCT prevention. Furthermore, safe home births with trained TBAs need to be further integrated with home-based care to increase PMTCT service utilization and coverage. However, community sensitization/mobilization should come first prior to home-based care and safe-home delivery promotion for sero-positive mothers. Hence, the formal

link between the institution based care and community based care is mandatory for sustainability and maximum coverage of the services.

Finally, since collaborating with the PMTCT clients and empowering them, and provision of psychosocial support are fundamental concern in PMTCT program, involving the health workers, social workers, family, and community is a key to both designing appropriate service delivery, as well as increasing demand for services. For this reason, empowering sero-positive women and intensively working with or mobilizing the community and community-based organizations is very important in PMTCT.

6.2 Recommendations

- Male partners' involvement, family focused treatment, care and psychosocial support should be integrated to increase uptake of PMTCT services.
- Creating a strong formal linkage or networking between health facilities, community based organizations, and community personnel like TBAs is fundamental to maximize the service coverage and program impact. Hence, from MTCT prevention point of view, activities such as fostering couple and community discussion on HIV/AIDS and working with community structures and local organizations are central parts to normalize HIV counseling,

testing, and care. These activities need to be further integrated into PMTCT activities and scaled-up.

- Working on and promoting home-based care, safe home birth and provision of care and support with especial emphasis on sero-positive pregnant mothers is of paramount importance.
- Health facilities should provide comprehensive MCH services, respecting confidentiality in VCT and PMTCT follow-up, care and support, safe infant feeding, quality and safe obstetric practices, provision of ARV therapy and family planning services. In the spectrum of services, the mother should not be neglected. Hence, considering human right to better life, health and non-discrimination to services is a central point.
- Primary prevention of HIV/AIDS in women of reproductive age and preventing unwanted pregnancy in sero-positive mothers should be a critical area of interventions to bring safe sexual behavior.
- In the continuum of Mother-to-Child HIV prevention, the *social work* practice is indispensable in addressing *bio-psycho-social* needs of sero-positive mothers and their family.

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Appendix 1

Characteristics of Core MTCT Prevention Intervention

INTERVENTION	PROBABLE IMPACT ON PREVENTION OF MTCT	RELATED RISKS	PROBABLE FEASIBILITY	OTHER RELATED BENEFITS
Improving comprehensive MCH services	Essential for delivering effective MTCT prevention interventions	No risks assuming services are delivered appropriately	Feasibility depends on how extensive the necessary improvements are	Significant reduction of maternal and child morbidity and mortality
VCT	High if combined with all other interventions	Consequences of possible violations of confidentiality; psychological stress & stigma or violence against HIV+ women	The relative high cost (for training, staffing, supervision, lab support, etc.) diminishes feasibility	Enables early treatment, facilitates planning for future, promotes primary prevention
Support for safe infant feeding	Not yet precisely quantified, but theoretically high (depends on the quality of the counseling, and on feeding decisions and practices)	If infants are breastfed, there is a risk of HIV transmission. If infants are not breastfed, there are risks associated with unsafe preparation and use of replacement feeds/infant formula. These include increased malnutrition, morbidity, and mortality. A "spillover" effect is another potential risk of introducing replacement/formula feeding.	Safer breastfeeding is feasible if health workers are trained and women appear for ante- and postnatal care. Safer replacement feeding is less feasible, as it requires adequate funds for formula, safe water supply, mothers who receive full information and support for safe feeding, fuel, additional time, etc.	Improved infant health and survival if implemented properly
Improving obstetrical practices	Not yet precisely quantified, but theoretically high	Safety is high; no risks (except potentially from C-section, if provided)	Feasible if training and supervision of health workers, sterile equipment, and improved guidelines are provided	Benefits both HIV-positive and HIV-negative mothers and infants. Prevents occupational HIV transmission to birth attendants
Short-course ARV prophylaxis	High but diminishes, depending upon method & duration of breastfeeding	Results of clinical trials to date indicate safety is high and risks are few, if any	VCT and adequate MCH services are essential requirements	None known
Family planning counselling and services	Theoretically high	Possible side effects of contraceptives	Very feasible systems exist in most countries, but are sub-optimal and not linked with VCT	Improved maternal and child health

Source: Adapted from Prevention of Mother-To-Child Transmission of HIV in Africa: Practical Guidance for Programs, Washington, DC, June, 2001

Appendix 2

Addis Ababa University

School of Graduate Studies

In-depth Interview Guide - 1

Respondent: Health Workers working in the Prevention of Mother-to-Child Transmission (PMTCT) of HIV program in Nazareth/Adama health institutions, Nazareth/Adama, Ethiopia, and March 2006.

Introduction: Hello, I am HaileMichael Tesfahun, I came from Addis Ababa University, School of Graduate Studies. I am here to interview health workers about PMTCT service delivered in the health institutions of Nazareth/Adama town. We would like to ask your opinion of PMTCT service utilization, in general. All comments, both positive and negative, are welcome. No harm is apparent as a result of participating in this project. If you are unable to continue an interview, I may stop the interview process at any time. I would like to assure you that confidentiality for your comments will be respected and will be used only for research purpose. Are you willing to participate in the interview? I greatly appreciate your taking time to speak with me.

If yes, proceed ;If no, thank and stop here.

(Signature of interviewer certifying that respondent has given informed consent verbally)

Section I. Identification Data

Name of health Institution: _____

Date of interview: _____

Position of respondent: _____

Section II. Interview Guiding Questions

2.1 Training and Preparation

2.1.1 What is your profession? And Where do you currently work?(*Probe: Gynecologist/Obstetrician, Physician(MD), Health Officer, Midwife/Clinical/MCH/Public Nurse, Laboratory Technician or if other specify; And place of work: ANC room, labor room, post-natal ward, VCT unit, well baby clinic or any other PMTCT related department*)

2.1.2 What do you think about the transmission of HIV from infected mother to her baby?

2.1.3 Have you ever taken training on PMTCT? *If yes, ask whether the training was taken during professional training (pre-service) or after professional training (in- service) and, whether he/she feels adequately prepared to conduct counseling and rendering PMTCT services after the training.*

2.1.4 In your opinion, what are some of the weakness in your training? (*Probe; time allocated content of the training, or teaching methodology*)

2.1.5 What are your sources of information on recent issues of HIV/AIDS particularly MTCT?

2.2 Clinical Experience and Procedures

2.2.1 Approximately, how many pregnant have you counseled(pre-test) during working hours every day as an individual, couple or group counseling and in other

way if available in the last one month? (*Probe as to how the pregnant mother referred to VCT and PMTCT services in the site, and whether the point of discussion about PMTCT services is at pre test, post-test, at delivery or other*)

2.2.2 How many HIV positive pregnant women have you counseled for PMTCT service utilization during working hours on daily, weekly or monthly basis? and how do you protect the confidentiality of your PMTCT clients?

2.2.3 Do you have basic equipments and supplies to carry out PMTCT and related services? Where do you get these equipments and supplies?

2.2.4 What are the services you provide for HIV positive pregnant mothers on your PMTCT program? (*Probe for the preventive measures of MTCT of HIV*)

2.2.5 What are you doing for a woman at the *labor and delivery* have not been tested for HIV or do not know their sero-status but wish to have ART (NVP)?

2.2.6 Do you think that you equally give care or treat the PMTCT clients and other pregnant mother who disclose her sero-status or who do not know their sero-status(at ANC, labor/delivery or PNC)? If no, mention why?

2.2.7 Do you think that institution based care need to be linked with the home based care for PMTCT service clients? If yes why? If no, why?

2.2.8 Is there any other PMTCT services you think that is not included for HIV positive mother at your site (during ANC visit, on labor, post-natal and on going follow-up)? (*Probe: Why? for all mentioned services that are not included*)

2.2.9 What are some of the changes you observed in your medical practice or procedure after introduction of PMTCT program at this health facility(at ANC, labor/delivery or PNC)?

2.3 Factors for PMTCT Service Utilization

2.3.1 From your observation at your site, during counseling and/or PMTCT services, what are some of the common complaints forwarded by your clients on your service?

2.3.2 In your opinion, from health practice perspective, what are some of the prominent problems or factors that affect sero-positive pregnant women while rendering the PMTCT services (*at ANC, VCT, labor room, post-natal and follow up*)? (*Probe: which are the most important and need immediate solution? Why immediate/urgent solution is needed*)

2.4 Stakeholders Involvement and Advocacy in PMTCT Program

2.4.1 Do you advertise or promote the PMTCT program in any way to the community? If yes, describe some of the activities.

2.4.2 What do you think the reaction of the community to pregnant HIV positive woman?

2.4.3 To support the PMTCT program, Is there any community support groups or organizations for pregnant HIV positive woman? If yes, mention them.

2.5 Challenges and Solutions

2.5.1 What challenges (constraints) have you faced in providing PMTCT services? (*Probe for workload, number of trained staff, staff turn over, lack/shortage of equipments, supplies and other resources.*)

2.5.2 Do you have any suggestions, that you think are solutions, in how the PMTCT services could be *improved and better utilized* at your health facility? If yes, describe them

Appendix 3

Addis Ababa University

School of Graduate Studies

In-Depth Interview (IDI) Guide – 2

Respondent: In-Depth Interview (IDI) guide to pregnant and postnatal women who have participated in the Prevention of Mother-to-child transmission of HIV/AIDS program, in Nazareth/Adama health institutions, Nazareth/Adama, Ethiopia, January 2006.

Introduction: Hello, I am HaileMichael Tesfahun, I came from Addis Ababa University. I am here to interview women who have participated in the Prevention of Mother-to-child transmission of HIV/AIDS program about PMTCT service delivered in the health institutions of Nazareth/Adama town. We would like to ask your opinion of PMTCT service utilization, in general. All comments, both positive and negative, are welcome. No harm is apparent as a result of participating in these project. If I am unable to continue an interview, I may stop the interview process at any time. To ensure the quality of the data collection, I will use tape recorder. I would like to assure you that confidentiality for your comments would be respected and will be used only for research purpose. Are you willing to participate in the interview? I greatly appreciate your taking time to speak with me.

If yes, proceed

If no, thank and stop here.

(Signature of Interviewee)

Part I – Background of Respondent

Age _____ Sex ____ Marital Status _____ Educational Level _____
Occupation _____ Address _____

Part II – Knowledge of HIV/AIDS

- 2.1 What is the difference between HIV and AIDS?
- 2.2 What are the modes of transmission of HIV/AIDS?
- 2.3 What are the methods of prevention of HIV/AIDS?
- 2.4 In the community you are living in who is the most affected and suffer the consequences and/or infected by HIV/AIDS?
- 2.5 How can a pregnant woman prevent her baby from becoming infected if she is HIV infected?
- 2.6 Do you think that an HIV positive woman who is pregnant needs to use a condom when having sex with her partner? If yes, why?

Part III – General Information

- 3.1 What are the services you get from this health facility pertaining to PMTCT?
- 3.2 Does your current partner know his HIV status? If yes, where? (Probe whether there was couple pre-test and post test counseling)
- 3.3 Do you think that the law allow pregnant woman who know they are HIV positive to have an abortion? If yes, why?
- 3.4 In your opinion, do you think believe that all pregnant woman should routinely take an HIV test? If yes, why?
- 3.5 If you were sick, where do you go for treatment and care? Why (Probe for free treatment and care or special exemption for PLWHA)
- 3.6 Are you currently on ARVs? If yes, which type?

3.7 Do you think that institution-based PMTCT care needs to be linked with home-based care? If yes, Why?

Part IV – Factors that Affect PMTCT Service Utilization at the Health Facilities

4.1 How were you recruited for PMTCT services? Were there problems that occurred during this process? How do you cope with it? If so can you discuss them?

4.2 What types of services are provided for HIV positive pregnant woman in this health facility? *(Probe whether there are services needs to be improved, among the mentioned. If so, why?)*

4.3 In your opinion, what are the factors that affect pregnant women's PMTCT service utilization at the health facilities?

4.4 Were you satisfied about how you found out about PMTCT services and got enrolled in the program? Were there problems that occurred during this process? How do you cope with it? If so can you discuss them? *(Probe whether the mother faced problems on process of VCT, ANC follow-up, labor, delivery, PNC and other PMTCT related services at the health facility)*

4.5 In your opinion, what are the conditions that facilitate the PMTCT service utilization in your locality?

4.6 In your opinion, what are the factors at the health facilities that prevent others in your locality to use PMTCT services?

Part V - Stigma

5.1 How do you have been treated by the clinical health and supportive staffs professional in this health facility (starting from gatekeeper up to health professionals rendering the service)?

5.3 Have you felt victimized because of your HIV status? If yes, How and by whom? (*Probe whether it has happened by health professionals, family members, neighbor, or others.*) If yes, ask the following;

5.3.1 How has victimization affected you? (*Probe its effect on the medical care at the health facility, social relationship etc*)

5.3.2 What are the coping mechanisms that you employed to deal with the situation?

Part VI - Perceived Quality of Service

6.1 What do you appreciate most while you use the PMTCT service? (*Record all answers; probe Using any thing for the following- examination services received, Privacy(Voice and vision) and comfort during Physical examination and counseling services, provision of free drugs for OIs, and easy referral to other care and services*)

6.2 Which type of health service providers do you prefer? Why? (*Probe male or female nurses, physician, mid-wife, Obstetrician/Gynaecologist etc*)

6.3 What should be improved at this health facility and/or PMTCT program to provide quality services to clients of community?

6.4 In your opinion, who is responsible for this PMTCT service improvement?

Appendix 4

Addis Ababa University

School of Graduate Studies

Focus Group Discussion (FGD) Guide

Respondent: Focus Group Discussion (FGD) guide to ANC/PMTCT service users and community leaders, Nazareth/Adama, Ethiopia, March 2006.

Introduction: Hello, I am HaileMichael Tesfahun, I came from Addis Ababa University, School of Graduate Studies. I am here to open discussion as a group with ANC/PMTCT service users and community leaders on Prevention of Mother-to-child transmission of HIV/AIDS program or all about PMTCT service delivered in the health institutions of Nazareth/Adama town. We would like to ask your opinion of PMTCT service utilization, in general. All comments, both positive and negative, are welcome. I would like to assure you that confidentiality for your comments will be respected and will be used only for research purpose. Are you willing to participate in the discussion? I greatly appreciate your taking time to speak with me.

If yes, proceed

If no, thank and stop here.

(Signature of interviewer certifying that respondents has given informed consent verbally)

1. What kind of impact does HIV/AIDS have in your community?
2. Do you think that Mother-to-Child HIV transmission is a serious problem? Why?

3. PMTCT service is given at the health facilities in Nazareth/Adama, do you think that most beneficiaries are utilizing this service? If yes, what are the pulling factors to these services? If not, what are the pushing factors? Why?
4. Do you think that home-based care is need to be promoted as a component of Prevention of Mother-to-Child HIV transmission? If yes, what are some of the state of affairs expected from the community? If no, why?
5. To maximize the PMTCT service utilization what do you recommend.

Appendix 6

Statement of Informed Consent

In-depth Interview Respondents for the health workers

Determining Factors that Affect Pregnant Women's Utilization of PMTCT Services in Ethiopia: The Case of Health Facilities at Nazareth/Adama

I, _____, am being asked to participate in the study of PMTCT service utilization of pregnant women's' with HIV/AIDS. HaileMichael Tesfahun, a student, Addis Ababa University School of graduate Studies, is conducting this study.

Purpose of the study

I understand that the general purpose of the study is to determine how the PMTCT services systems of care currently function to meet the need of pregnant women's living with HIV/AIDS and to identify the determining factors for PMTCT service utilization at the health facilities. The researcher hopes to gain an understanding of these issues by interviewing persons knowledgeable of these systems of care.

Explanation of the procedures to be followed

I understand that as a participant, I have the right to withdraw from the interview process for any reason. I understand that I will participate in an interview that will take an hour. The interviewer will ask me a question about existing PMTCT services, gaps in these systems, development needs, and recommendations for change.

Description of benefits

I understand that by sharing this information, I will assist the study in making recommendations as to how future PMTCT programs can better meet the needs of sero-positive pregnant women utilizing the service.

Description of risk and discomforts

No harm is apparent because of participating in this research. If I am unable to continue an interview, I may stop the interview process at any time.

Confidentiality

I understand that I will be sharing information and option with researcher. Great precaution will be taken to ensure that this information with remain confidential. Any reports or recommendations which are written as a result of the study will never refer to specific individuals by name.

Voluntary participation

Participation this study is voluntary. Refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled. I understand that I may discontinue participation any time with no penalty to me.

I have been given the opportunity to ask any questions, and I have received a copy of this consent form. By signing this document. I freely and voluntary consent to be interview as a participant in this project.

Signature of the participant

Date

Printed Name of participant

Signature of Witness

Date

Printed Name of Witness

Declaration

I, the undersigned, declare that this thesis is my original work, has never been presented in this or any other university, and that all resources and materials used herein, have been duly acknowledged.

Name: HaileMichael Tesfahun

Signature _____

Place: Addis Ababa University, Ethiopia

Date of submission:

This thesis has been submitted for examination with my approval as a University advisor.

Name: Professor Nathan L. Linsk (PhD)

Signature _____