Disclosure of HIV + status diagnosis: A qualitative study of pregnant women and lactating mothers experiences in PMTCT program in urban Dar es Salaam.

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Abstract.
HIV/AIDS remains to be a major public health problem worldwide over three decades now, with an estimated 36.9 million people currently living with HIV. Sub-Saharan Africa, is the most affected region with an estimate of 25.8 million people living with HIV, account almost for 70% of a global total of new HIV infections. Mother to child transmission of HIV, is the common way children become infected with HIV over 90% as a result of their mother being HIV positive. Viral transmission occurs during pregnancy, childbirth or breast feeding. About 2.6 million children under the age of 15 are living with HIV globally, 91% of them come from Sub-Saharan Africa. Prevention of mother-to-child transmission of HIV (PMTCT) programs are in many low and middle-income countries these days. The risk of viral transmission from a mother-to-child can be reduced to less than 5% if HIV-infected pregnant women and their infant starts and participate effectively in PMTCT interventions. Tanzania has the third highest number of HIV-infected children in Africa approximately 250,000.

Disclosure of HIV serostatus to a sexual partner is crucial and integral practice in a PMTCT program, this study aimed to explore HIV + diagnosis disclosure experience among pregnant women and lactating mothers enrolled in PMTCT program located at Muhimbili National Hospital in Dar es Salaam. In-depth interviews were conducted among 28 HIV+ pregnant and lactating mothers and a focus group discussion among the health care providers. Data analysis was done through thematic content approach. The results indicate, HIV+ test diagnosis was accompanied by shock, pain, confusion, denial and added an extra burden to pregnant women concerning the health prospects of the fetus. Fears of abandonment, being blamed as a source of infections, lack of communication about HIV were identified as barriers of disclosure to a sexual partner. Fear of HIV-related stigma and discrimination was found as a main barrier of disclosure to significant others. Couple HIV testing and counseling was identified as a facilitator of disclosure for participants who needed support. The majority of married participants disclosed their status to a sexual partner. Non-disclosure was mostly characterized with the unmarried participants. The findings, suggests more counseling towards unmarried participants along with economic empowerment programs, also in-depth education about HIV to the general population especially on different ways of transmission to overcome HIV-related stigma and discrimination.
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Finally, I have a lot of appreciation and gratitude to friends and colleagues, Martha Oshosen, Peter Kivumbi, Casius Bupe and Kevin Durand, for allowing me to pick your heads and your encouragement, in this study.
Dedication
I wish to dedicate this piece of academic work to my family and to my aunt and Uncle Ramsey A. Lyimo who has always inspired me, particularly on public health research.
Abbreviations and acronyms

AIDS: Acquired Immune Deficiency Syndrome
AFASS: Acceptable Feasible Affordable Sustainable and Safe
ANC: Antenatal Care
ART: Antiretroviral Treatment
ARV: Antiretroviral
CPT: Cotrimoxazole Preventive Therapy
DBS: Dried Blood Spot
DNA: DeoxyriboNucleic Acid
EFV: Efavirenz
EMTCT: Elimination of mother- to- child transmission of HIV
FBO: Faith Based Organization
HCT: HIV Counseling and Testing
HIV: Human Immune Deficiency Virus
MNH: Muhimbili National Hospital
NACP: National AIDS Control Programme
NVP: Nevirapine
MOHSW: Ministry of Health and Social Welfare
MTCT: Mother to Child Transmission
PLHIV: People Living with HIV
PMTCT: Prevention of mother- to- child transmission of HIV
RCH: Reproductive and Child Health
TDF: Tenofovir
TB: Tuberculosis
UNAIDS: Joint United Nations Program on HIV/AIDS
UNICEF: United Nations Children Fund
VCT: Voluntary Counseling and Testing
WHO: World Health Organization
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1 Introduction

1.1 Background
Globally, it was estimated that 36.9 million people equivalent to 0.8% were living with HIV by the end of 2014 (1). Sub-Saharan Africa is the most affected region with an estimate of 25.8 million people living with HIV accounting for almost for 70% of new HIV infections. Approximately 2.6 million children under the age of 15 are living with HIV globally, 91% of them come from Sub-Saharan Africa (1). In response to a reduction of HIV transmission from a mother-to-child, a global plan was launched in 2011 to accelerate the efforts of reduction of the numbers of new HIV infection from a mother-to-child transmission by 90% by 2015 (2). Transmission of HIV from HIV-positive mother to her child, is the common way children become infected with HIV over 90%, viral transmission occurs during pregnancy, childbirth or breastfeeding (3). Prevention of mother-to-child transmission of HIV (PMTCT) interventions, can reduce HIV transmission rate to less than 5%, if HIV-infected pregnant women and their infants, have access to and participate effectively in the full range of PMTCT services, without any interventions HIV transmission rate is about 15-45% (3, 4).

Prevention of mother-to-child transmission of HIV programs are now available in many low and middle-income countries (4), its comprehensive approach is comprised of four key elements (4, 5).

1. Primary prevention of HIV among women of childbearing age and their partners.
2. Prevention of unintended pregnancies among women living with HIV
3. Prevention of vertical transmission of HIV from mothers to their infants.
4. Provision of treatment, care and support to women living with HIV and their partners, infants and families

Interventions to prevent HIV transmission from mothers to their infants include the following:- routine HIV education, testing and counseling for pregnant women and their partners, comprehensive antenatal care (ANC), antiretroviral therapy (ART) and prophylaxis, safer delivery practices and counseling on safer infant feeding and care of the HIV-exposed infant (5). Tanzania has the third highest number of HIV-infected children in Africa approximately 250,000 (6).
Disclosure or sharing of HIV status with sexual partners is encouraged and is an integral practice in both voluntary testing and counseling (VCT) and the prevention of mother-to-child transmission of HIV (PMTCT) program (4, 5). The policy in PMTCT programs recommends that all pregnant women either HIV positive or negative to be empowered to disclose their HIV status to their sexual partner through counseling. HIV seropositive status disclosure to a sexual partner may results to improved involvement in HIV prevention and treatment programs, reduction of HIV transmission risks and increased opportunities to plan for the future (7). Also, disclosure may lead to, acceptance of an HIV seropositive status, use and adherence to maternal and infants ARV therapies, improved adherence to infant feeding methods selected, usage of co-trimoxazole prophylaxis, decreased mortality and increased survival and follow-up among HIV-exposed infants (8-12).

1.2 Research Questions

- What are the pregnant women experiences on HIV testing and counseling?
- What are the barriers of disclosure HIV+ status to a sexual partner?
- What are the facilitator experiences of disclosure of HIV+ status to a sexual partner?
- What are the perceived barriers of disclosure of HIV + status to significant others than sexual partner?
- How is the disclosure experience at the health care setting?

1.3 Structure of the thesis

This thesis is divided into five chapters, 
*Chapter one*, presents introduction which includes background information about global and local perspectives of the PMTCT program, followed by the research questions, a description of essential contextual information about the research setting (Tanzania) and a rationale for the study.

*Chapter two*, presents the following:- a literature review, starting with the descriptions of the theoretical framework that has been influential in this study, definition of key concepts related to this study, previous studies on prevalence and factors associated with HIV seropositive status disclosure and non-disclosure to a sexual partner and significant others and finally my thesis research objectives.
Chapter three, presents the research methodology including:- research design, rationale, study site, description of research participants, sampling strategy and recruitment, data collection process, (saturation, triangulation, transcription and translation), data analysis, (reflexivity, trustworthiness, ethical considerations) and finally a plan for disseminating the results.

Chapter four presents the research findings.

Chapter five presents the discussion of the key findings and offer concluding remarks and future recommendations.

1.4 Profile of Tanzania

1.4.1 Geographical location
Tanzania is the largest country in East Africa, which covers approximately 945,000 km², and shares a border with eight neighboring countries. Mainland Tanzania is divided into 30 administrative regions, 25 regions on the mainland and 5 in Zanzibar. The official capital of Tanzania is Dodoma which is located 309 kilometers west of Dar es Salaam. Dar es Salaam is the country’s commercial capital and it is also the main seaport for the country serving its landlocked neighbors (13).


1.4.2 A map of Tanzania

1.4.3 Population and demographic characteristics

The population of mainland Tanzania is approximately 43.6 million people (according to the 2012 population census) which have been growing at an annual rate of 2.7%. Nearly half of the population (48%) is below 15 years of age, (49%) are aged between 15-64 years and 4% are over 65 years. Tanzania Mainland accounts for 97% of the total population, of which 73% live in rural areas, and 27% live in urban areas. (14). The population is concentrated in the lake zone in the north along Lake Victoria, around Dar es Salaam, (the main business and trading centers along the coast) and in the southern highlands around Mbeya. The large rest areas of the country are sparsely populated.

The sex ratio in Tanzania Mainland is 95 males per 100 females, while that of Zanzibar is 94 (51.3% female, 48.7% male). The life expectancy at birth is 56 years for females and 53 years for males. Approximately half of Tanzania’s population is comprised of children under the age of 18 years (14).
1.4.4 Economy
Tanzania is among the developing countries. Its economy depends heavily on agriculture, which contributes for more than one-quarter of Gross Domestic Product (GDP), with the provision of 85% of exports, and employs about 80% of the workforce. The economy is also based on other service provision, including mining, tourism, small scale industries and construction (13, 14).

1.4.5 The situation of women
Gender imbalances still exist in Tanzania which hinders women’s meaningful participation in development programs and decision making. Female -headed household populations, still have high numbers with no formal education, (11.5%) in urban areas and (30.2%) in rural areas. Regardless of their lower socio-economic or educational status, approximately 40% of women do not have the final say in decisions regarding their own health, their children’s health, or their own daily household expenditure. Women remain the primary labor force for household food production in the nation (14).

1.5 Health system organization and management
The health system in Mainland Tanzania operates with technical coordination and in-service training of health care workers from the Ministry of Health and Social Welfare (MoHSW). The Prime Minister is responsible for the administration and supervision of health facilities including regional and local government authorities (14).

The health system is supported by different ministries departments, and agencies which provide different services that support health, ranging from actors in the legal framework that supports justice and gender rights, to those which are responsible for agricultural improvements and increased access to water. The health system is made of different actors, the public health sector and private which, includes:- faith-based organizations,(FBOs), community service organizations as well as other private sector actors, both formal and informal (14).

The human resources for health are produced by 135 pre-service institutions, including 62 governments, 47 faith -based organization (FBO), five private and ten university programs (14). The health system has a total of 6,342 health facilities, which include facilities owned by private, faith-based organizations and government institutions. As of December 2012, there were 4,914 health facilities providing PMTCT services, of which 1,404 provided full ART
services. Regarding distance to a health facility, 96% of urban households and 70% of rural households in Mainland Tanzania live within 5 kilometers of a health facility. Only 55% of health workers are serving a rural population, which represents 75% of the total population (14).

1.6 The national health sector response to HIV/AIDS Epidemic

HIV-related health services are provided by the Ministry of health through the coordination of the National AIDS Control Programme (NACP) as well as tuberculosis (TB), nutrition, and reproductive and child health (RCH) services. These services includes: the surveillance of HIV infections and other sexual transmitted infections (STIs), HIV care and treatment, the prevention of mother- to- child transmission of HIV (PMTCT), HIV Counseling and Testing, home-based care, and monitoring and reporting of the health sector response to HIV and AIDS (14).

The national health sector’s response to HIV /AIDS is faced with several challenges which includes:- coping with the rapidly expanding programmes, inadequate and unpredictable financing, weak procurement and supply chain management, shortage of skilled human resources for health, and poor infrastructure to provide HIV and AIDS services resulting in inadequate coverage of services (14).

1.7 Prevention of mother -to- child transmission of HIV (PMTCT)

1.7.1 Background

PMTCT services in Tanzania have been implemented by the Ministry of Health and Social Welfare since 2000 (5) In 2004 PMTCT service were scaled-up to cover all regions in the country. Implementation of these services was guided by the National PMTCT guidelines that were developed in 2004 and revised for the first time in 2007 (5). There are still some HIV-infected women, and HIV- exposed infants who do not access (PMTCT) services. In year 2011, approximately, 30% of all HIV- positive pregnant who women needed of ART in order to reduce the risk of mother -to- child transmission of HIV did not access PMTCT services at all (14). In addition, about 70% of health facilities, did not provide Early Infant Diagnosis (EID) services and 43% of HIV- exposed infants did not get any prophylaxis to reduce the risk of transmission of HIV from their mother (14). By 2014 HIV testing facilities have increased to (2137) with an integration of prevention of mother to child transmission into Reproductive
and Child Health (RCH) reaching to 96% of facilities (15). A recent report indicates, about 77% of HIV-positive pregnant women are receiving antiretroviral therapy (ART), and the national goal is to reach 90% by 2017 and 70% provision of prophylaxis to HIV-exposed infants (15). Despite this progress, more than 18% of children are born HIV-infected (15). This may be a result of insufficient supply regimens of a (single dose nevirapine) in some health facilities, poor adherence to treatment, drugs stock out or lack of access to PMTCT services during pregnancy (15). In addition to poor, service utilization patterns of RCH services by pregnant women and inadequate community and male partner involvement in PMTCT program (14). Promotion of Option B+ to all HIV-infected women is being used to address some of these service gaps.(14) ’

Option B+ is an ART prophylaxis regimen offered for life-long, among pregnant women living with HIV regardless of their CD4 count (16). This option was first developed and implemented in Malawi (2010), demonstrating successful results, with more than five-fold increase of pregnant women enrolled on ART during the first quarter of the wide national implementation (16). The success behind option B+, it is easier to be administered “one size fits all” and can be used by pregnant women living with HIV, even in a setting with poor access to CD4 count testing (16).

### 1.7.2 Current PMTCT statistics in Tanzania

According to data from the national resource center for the prevention of mother to child transmission of HIV (17). Approximately 97% of health facilities with RCH provides PMTCT services, where by about 98% of pregnant women attends ANC at least once, while only about 47% make at least 4 visits during their pregnancy. Approximately 90% of women who attend ANC in a RCH facility that provides PMTCT services are tested for HIV, but only around 26% of male partners of pregnant women test for HIV (17). The prevalence of HIV among women who attends ANC is 6.9% (17).

### 1.7.3 Service offered at the PMTCT programme

The guidelines for implementation of PMTCT services have been revised several times by WHO (18), in 2006, 2010, 2011, 2013 and most recently 2015, based on the new scientific evidence in the efforts to eliminate the number of new pediatric HIV infection. In Tanzania,
the fourth and the current national PMTCT guideline (5), was issued in September (2013) and was adapted from 2011 WHO new updates on ART for prevention of mother-to-child transmission of HIV and mother’s health. According to the guideline (5), services offered includes:

HIV testing, which is provider-initiated service, offered as a routine part of ANC in reproductive and child health (RCH) services. All women of reproductive age, pregnant women, and their partners are given pre-test HIV information during their first antenatal visit or any time a soon as possible. Opportunity to ask questions about the pre-test HIV information provided is also given. After pre-test counseling, HIV testing is then undertaken unless the woman refuses. Post-test counseling regardless of HIV status test results is also given in person, on the same day of testing. The Rapid test is the diagnosis tool used for HIV in adults through detection of HIV antibodies.

A definite diagnosis of HIV infection in children less than 18 months of age is done using (Deoxyribonucleic acid-polymerase chain reactions (DNA-PCR) conducted during 4th–6th weeks of age for all HIV-exposed infants. For 18 months of age children or older, HIV antibody tests, (rapid tests or ELISA or a combination of both), used the same way as for adults. For the breastfed infants, HIV testing is repeated during the six weeks after the complete cessation of breastfeeding.

Antenatal care (ANC) provided for women who are infected with HIV includes the same basic services provided for all pregnant women. However, further obstetric and medical care is administered to address the specific needs of women infected with HIV.

All pregnant and breastfeeding women who are HIV + are enrolled in a lifelong antiretroviral therapy (ART) composed of a fixed–dose single tablet regimen of tenofovir/lamivudine/efavirenz (TDF/3TC/EFV) taken once daily or given another alternative of first-line of ART regimen as recommended by the national ART guideline

ART for HIV + women is initiated at any time during pregnancy or breastfeeding period regardless of CD4 count or WHO clinical stage and continued for life
For infants born to women who are living with HIV, should receive daily nevirapine (NVP), as soon as possible after birth up to 6 weeks of age. This recommendation applies to all HIV-exposed infants regardless of the feeding options.

Cotrimoxazole Preventive Therapy (CPT) to prevent opportunistic infections among HIV-exposed infants should be given at the beginning of the fourth week of age or as soon as possible after that. CPT should continue until HIV is ruled out after complete cessation of breast feeding.

In addition to provision of ART to the HIV-infected pregnant women, health care providers should also maintain safer obstetric practices to reduce the risk of MTCT which include: practicing of standard precautions during all patient care, minimizing vaginal examinations, avoidance of prolonged labor, and artificial rupture of membranes, avoidance of unnecessary trauma during delivery, minimizing the risk of postpartum hemorrhage and using safe transfusion practices.

Exclusive breastfeeding for the first six months of infant’s life is recommended for women living with HIV. Complimentary foods should be introduced when the child reaches six months of age, while breastfeeding can continue up to 12 months of age. Exclusive replacement feeding for the first 6 months of infant life with commercial infant formula is recommended only when it is acceptable, feasible, affordable, sustainable and safe (AFFASS)

1.8 Rationale of the study
This study is in line with ongoing effort of reduction of HIV transmission from mother to child as addressed in global plan launched in 2011 (2) aimed at 90% reduction of the number of new HIV infection from mother to child transmission by 2015. A systematic review (7), about rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries, indicates 16%-87% of pregnant women do not disclose their HIV status to a sexual partner, with lower rates among women tested at VCT compared to women tested at ANC. The higher rate of disclosure to a sexual partner among the VCT clinic users may be due to a long period of thoughts about HIV testing, often talked with their partners about a decision to test, and high perception of personal risk for HIV (19).
Disclosure of HIV status to a sexual partner and significant others plays a significant role in overall four key approaches of PMTCT interventions (7). First, it helps both partners to start a discussion about HIV/AIDS raising both partners awareness of the risk of infection and may lead to behavior change (7). In the case of the serodiscordant couples, disclosure may prevent the risk of HIV transmission to an uninfected partner. Secondly, disclosure can be a good starting point for HIV-infected women to start a discussion about contraceptives use and reduce the number of unintended pregnancies. Besides, disclosure plays a significant role in women uptake of PMTCT program through their participation in treatment, care and support program (7). The optimal uptake and adherence of PMTCT program is difficult for women whose partners are not aware or supportive of their participation (7). Figure 1 below taken from (7) Summarizes

1.8.1 The role of HIV status disclosure in the prevention of HIV infections in mothers and infants

<table>
<thead>
<tr>
<th>WHO’s four -pronged approach to prevent HIV infections in mothers and infants</th>
<th>Role of women’s disclosure of HIV serostatus.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Reduction of HIV transmission to potential mothers</td>
<td>Initiate discussions among sexual partners that can lead to behaviour change</td>
</tr>
<tr>
<td>2. Reduction of unintended pregnancies among HIV-infected women and girls</td>
<td>Enables HIV-infected women to begin discussing the use of contraceptives with sexual partner</td>
</tr>
<tr>
<td>3. Reduction of mother-to-child transmission of HIV</td>
<td>Enables HIV-infected women to gain support from partners for participation in PMTCT programmes</td>
</tr>
<tr>
<td>4. Provision of care, treatment and support for mothers and their infants, partners and families</td>
<td>Enables HIV-infected women to gain support from partners for participation in treatment and support programmes</td>
</tr>
</tbody>
</table>

A recent cross-sectional study, (11) conducted in Tanzania (2013) indicate, only 41% of self-disclosure rate to a sexual partner among HIV-seropositive pregnant women enrolled in the PMTCT program. During literature review, no qualitative study was found about this topic, since 2000, when PMTCT services started to be implemented in Tanzania. Therefore, this study provides a more contextualized understanding of HIV + status disclosure experiences
among pregnant women and lactating mothers to facilitate better HIV care and treatment in PMTCT programs through prevention of further sexual and perinatal transmission of HIV infections.
2 Literature review and theoretical framework

2.1 Theoretical and conceptual framework

2.1.1 Reasons for HIV disclosure/Non-disclosure in close relationship: Testing model of HIV Disclosure decision-making

This study is informed by the integrative model of HIV disclosure decision making that describes the factors that contribute to the decision about whether or not to disclose HIV+ diagnosis to significant others (20). The first factor in the model focuses on the social environment in which the participant’s lives such as cultural attitudes about HIV, close relationship, and self-disclosure. HIV disclosure is less likely to occur in the communities that stigmatize someone with HIV.

The second factor in the model focuses on the relational, individual and temporal context in which someone with HIV lives. These contexts include social network based on availability and supportiveness of friends, intimate partners, co-workers, health providers progression and length of time living with HIV person, and network members characteristics (20). The nature of these factors, in turn, affects the endorsement of reasons for or against HIV disclosure.

Reasons for HIV disclosure or non-disclosure are divided into three categories (a) self (b) Other and (c) Relationship related benefits and risks. Self-focused reasons for disclosure include catharsis and seeking help. Other focused reasons for disclosure include a duty to inform and desire to educate others about HIV (20).

Relationship focused reasons for disclosure includes, being in an emotionally close and supportive relationship similarity with the other person and desire to test someone’s reactions (20).

Self-focused reasons for non-disclosure (20), includes (a) The right to privacy (b) Self-blame Self-concept difficulties (c) Fear of rejection and (d) Communication difficulties.

Other focused reasons for non-disclosure including (a) Protecting the other person and relationship focused reasons for non-disclosure includes (a) Protecting the relationship (20).
2.2 Definition of concepts

2.2.1 Disclosure
Disclosure is a neutral term, in the context of HIV/AIDS, it refers to the act of sharing of an individual’s HIV positive status to another person or organization (e.g. healthy authority, employer sexual partner, etc.) (21). An individual can disclose his/her own HIV positive status or someone can do it on his/her behalf with or without the individual’s consent (21). The purpose and the consequences of disclosure may either be beneficial or harmful. Beneficial disclosure involves occasions where an HIV + person informs a sexual partner about his/ her status for prevention purposes or inform family members or health care workers to share vital information and obtain support(21). Harmful disclosure involves cases, where disclosure is made without the consent of the person who is HIV + and leads to adverse consequences for that person such as stigma, abandonment loss of job, furthermore harmful disclosure may also impair prevention and care activities.

UNAIDS and WHO (21), encourages beneficial disclosure that is, a disclosure which is voluntary, respect the autonomy of the individual and the dignity of the affected individuals, maintain confidentiality as appropriate and leads to beneficial results for those individuals their families, sexual and drug- injecting partners. It also leads to greater openness about HIV/AIDS in the community and meets the ethical requirements in the situation where there is a need to prevent onward transmission of HIV. In my thesis research project, the concept has been used as the process of learning one’s HIV status, the living experiences with HIV and decisions towards informing significant others.

2.2.2 Stigma and Discrimination in the context of HIV/AIDS
Erving Goffman, (22) defines stigma as an “attribute that is deeply discrediting” and that reduce the stigmatized person “from a whole and usual person to a tainted, discounted one.” Stigma can be seen as the relationship between an “attribute and a stereotype”(23), where by as a “mark” (attribute) that links a person to undesirable characteristics (stereotypes). Link et al.(23), conceptualization of the term stigma, applies when the elements of labeling, stereotyping, separation, status loss and discrimination co-occurs in a power situation that allows the component of stigma to unfold.
HIV/AIDS-related stigma can be described as a “process of devaluation” of people either living with or associated with HIV and AIDS (24). It often stems from the underlying stigmatization of sex and intravenous drug use, two of the primary routes of HIV infection.

Discrimination follows stigma, it is the unfair and unjust treatment of an individual based on his/her real or perceived HIV positive status (24). It occurs, when a distinction is made against a person that results being treated unfairly and unjustly, on the basis of his or her HIV-positive status.

Ogden et al. (25), have identified four different forms of HIV-related stigma which includes, (a) Physical (b) Social (c) Verbal and (d) Institutional. Physical stigma can be grouped into isolation and violence experienced by PLWHIV from family and at the community level (25). It may be expressed through marking and separating eating utensils, public rejection, separation from children and abandonment by the family. Violence may include beating, arrest.

Social stigma can be grouped into social isolation, loss of identity, role, and voyeurism (25). Social isolation may be expressed through lack of invitation to significant family and community events.

Verbal stigma can be directly expressed by pointing fingers, insulting or blaming or more indirectly, through gossip and rumors (25). Gossip and rumors often focus on speculation about whether one is living with HIV or not, because of visible signs, behavior or association with, high-risk groups.

Institutional stigma occurs through different treatment in a defined institutional setting which leads to a negative outcome for the person living with HIV (25). It may be expressed through inability to secure livelihoods, housing, healthcare, education, waiting for a longer time for health services, bad depiction in the media.

The dimensions of HIV-related stigma includes, internalized/self-stigma, perceived or felt stigma and enacted stigma (26). Self-stigma/Internalized stigma occurs when people living
with HIV internalize negative attitudes that they perceive to exist in the society (25) These negative attitudes arises from the society’s values and norms concerning the nature of HIV and what it means to be living with HIV (25). Some of the expressions of internalized stigma includes:- loss of hope, feeling of worthless (suicidal feelings and inferiority) believing to be a person with no future (25).

Felt or perceived stigma, refers to the perceptions of stigma in the community (26). These perceptions are rooted in the society’s attitudes toward HIV.

Enacted stigma, refers to actual acts of discrimination and abuse towards people living with HIV (26). These discrimination acts can be expressed in different forms as I have indicated above.

2.3 Factors associated with HIV status disclosure / non-disclosure among HIV- infected pregnant women
A qualitative study conducted 2012 in Uganda (27), indicated that all HIV negative women had disclosed their status to their partner, but expressed the need for support to convince their partner to also test to learn their HIV status. Furthermore, the findings indicated, most of the HIV positive participants had not disclosed their status to a sexual partner due to fear of abandonment, violence and accusation of bringing HIV into the family. Most of the HIV+ participants deferred disclosure and requested health workers support in disclosure, those who disclosed generally experienced positive responses from their partners. Similar findings were reported in a qualitative study conducted (2013) in the neighboring country Kenya (28) with the title Facilitating HIV status disclosure for pregnant women and partners in rural Kenya. The findings, demonstrated that barriers of disclosure among couple included fears of abuse, disharmony in relationship and stigma. Additionally, participants explained the fears of abuse including being blamed for the infection, breaking up of the relationship and bodily harm were contributing factors on non-disclosure. While men, feared being accused of infidelity or being promiscuous, women tended to fear being blamed for bringing the infection into the family.

A systematic review (7), conducted in 2004, about, rates, barriers and outcome of HIV serostatus disclosure among women in developing countries, revealed that 16.7% to 86% of HIV + pregnant women do not disclose their status to their sexual partner, with the women
tested at Voluntary Testing and Counseling (VCT) more likely to disclose their HIV status to their sexual partner than women who were tested in the context of antenatal care. Barriers of disclosure to a sexual partner identified by the women in this review, included, fear of abandonment, rejection and discrimination, violence, upsetting the family members and accusation of infidelity. Women’s fear of abandonment was closely related to fear of loss of economic support from a partner. Majority of women who disclosed their HIV test results to their partner reported supportive reactions. Negative outcomes were less common which included, shock, disbelief, abandonment and violence. The trends and rates of HIV status disclosure reported in these studies is impossible to compare directly because, the studies differed on how they measured rates of disclosure and time frame used however it is clear the low rate of HIV disclosure were reported among women in antenatal care.

Similar findings have been reported in a mixed methods study conducted in four African countries (29), where 79% of the HIV + pregnant women in the study reported that, they kept their status a secret, and only 37% had disclosed to their husband, analysis of the open ended questionnaire revealed some of the disclosed women were divorced or widowed. In this study the non-disclosed pregnant women found difficult to tell their husband out of fear to be blamed, abused and abandoned.

Lessons were also learnt in another qualitative study conducted in 2010 rural Malawi(30), findings from this study shows partners disclosure played up fears of rejection among men given accusation of infidelity by the wives’ relatives, the situation which led many men to abandon their families. This situation left the HIV + pregnant women with the fear of HIV transmission to their infants but also the loss of income and support associated with a departed husband and social disgrace of a ruined family. In this context the PMTCT program was referred as a “the divorce program”

A cross-sectional study conducted (2013) in Addis Ababa Ethiopia (31), about disclosure experience to partner and its effect on intention to utilize prevention of mother to child transmission service among HIV positive pregnant women attending antenatal care, found that among 112 pregnant women who participated in a study, 107 (73%) women all married with one regular partner, had disclosed their status to their partner. Factors associated with disclosure of HIV status to a sexual partner identified in this study, included duration of
relationship with their partner, relationship before testing and prior discussion before testing. Strong association was found between prior communication about HIV testing with partner and HIV seropositive disclosure. Women who had prior communication about HIV testing with their partner were twelve times more likely to disclose their HIV status than those who had not communicated, likewise participants who had smooth relationship with their partners were six times more likely to disclose than the counterpart. Women who disclosed to their partner were almost five times more likely to participate in PMTCT than the non-disclosed. Out of 78 study participants 42 equivalent to 53% reported supportive reactions from their partner after disclosure, and felt free following disclosure, only 15% reported some negative reactions from their partner such as yelling, worried about his status, talked about divorcing.

Similar results were found in a cross sectional study conducted in 2013 at Morogoro region in Tanzania (11) about Predictors of HIV serostatus disclosure to partners among HIV-positive pregnant women. In this study a total of 250 participants were enrolled, 41% (one hundred and two) participants had disclosed their status to their partner. HIV disclosure to sexual partners was more likely among pregnant women who were less than 25 years, knew their HIV status before the current pregnancy, discussed with their partner before testing, secondary or higher education and had partner with higher or secondary education and high income. Participants who discussed about HIV testing with their partner before testing were six time more likely to disclose to their partner than the counterpart. Dependency on the partner for food, rent, had lower odds of disclosure.

A longitudinal study, about factors affecting disclosure in South African HIV positive pregnant women has identified more factors (32). This was a follow up study during pregnancy and at 3 months post-delivery among 293 women (62%). During enrollment 59% women had disclosed to their partner and 42% to others, which rose to 67% and 59% respectively by follow up. Logistic regression analysis identified being married, prior discussion about testing, having a partner with tertiary education and less experience of violence as factors associated with having disclosed to partner prior to enrollment. Increased levels of stigma decreased the likelihood of disclosure to a sexual partner while increased level of avoidant coping decreased the likelihood to disclose to others. Better housing, less financial dependency on the partner and knowing someone were associated with prior disclosure.
disclosure to others, women with financial support from their partner were less likely to disclose to others.

A cross-sectional study, spousal disclosure of HIV serostatus among women attending antenatal care in urban Nigeria (33), found that a majority of participants had disclosed their status to a sexual partner, (88%) equal to 146 participants out of 166 participants. Only 12% equal to 20 participants had not disclosed. Non-disclosure was significantly associated with nulliparous (women who have not delivered before) and women who were not married. Three common reasons for non-disclosure in this study were fear regarding spread of information, stigmatization and destruction of relationship with the partner. In this study there was no significant difference between both groups with respects to the level of education of the respondent or her spouse, age and mean duration of seropositivity. In this study the low rate of non-disclosure may be partly explained by the emphasis on adequate counseling by trained providers in many donor assisted PMTCT programs. Similar findings were reported in another cross sectional study conducted in the same country, (34) among 280 participants, 272 equal to 97% had disclosed their status, 90% disclosed to their husband, 23% to priest and 11.4% to a close family member. The only reason for non-disclosure to husband was fear of divorce. Partner reaction was supportive and understanding in all cases. Factors which significantly increased the likelihood of non-disclosure were being single low educational status, non-member of a support group. There was no significant association between ages, parity, knowledge of partner HIV status and duration of illness with the likelihood of serostatus disclosure. The higher rate of disclosure reported in this study was the likelihood of high rate of partner support which will encourage adherence to antiretroviral therapy and other PMTCT interventions.

2.4 Objectives

2.4.1 Main objective

- To explore the experiences of HIV + diagnosis and reflections among pregnant and lactating mothers enrolled in a PMTCT program made around disclosing their HIV status the perceived barriers and facilitators.
2.4.2 Specific Objectives

- To explore the experiences of disclosure of HIV+ positive test results.

- To understand and explore the perceived barriers on disclosure to sexual partner as experienced by HIV+ pregnant and lactating mothers attending ANC in Tanzania.

- To explore facilitator experiences of HIV seropositive disclosure among pregnant and lactating mothers to a sexual partner.

- To understand and explore the perceived barriers on disclosure to significant others as experienced by HIV+ pregnant and lactating mothers attending ANC in Tanzania.

- To understand the experiences HIV seropositive pregnant women, go through at the health care settings.
3 Methodology

This chapter will describe the research methodology including the followings: research design, rationale for the choice of methods, study setting, participants characteristics sampling strategy and recruitment, saturation, data collection methods, triangulation, transcription and translation, data analysis, reflexivity, trustworthiness, ethical consideration and dissemination of the results.

3.1 Research Design

This study is concerned with HIV+ status disclosure experience among pregnant and lactating women in a PMTCT program, and aim to explore and understand their experience with HIV+ test results, interaction with treatment and care and their thoughts and perceptions towards informing sexual partner and significant others about their status. These experiences can be understood better, by employing the phenomenological approach which aims to understand social phenomena from actors own perspective and describes the world as experienced by the subjects, with the assumption that reality is what people perceive it to be (35).

Disclosure of HIV+ diagnosis to significant others involves a decision-making processes related to different factors, (20) such as the social environment that the participants lives, close relationship, self-disclosure, contextual, relational, individual and temporal in which someone with HIV lives. Through the use of interpretive perspectives as a theoretical framework used in a qualitative design, it helps to understand the experiences of living with HIV+ as constructed by the participants through their interaction with each other and the wider social system and what influence the decision whether or not to disclose the HIV+ status to significant others.

Drawing on these experiences, feelings, thoughts and perceptions with respects to social cultural and economic conditions, provides a more holistic understanding of the phenomena. Therefore, qualitative research design was considered to be most appropriate for this study.

3.1.1 Rationale for the choice of methods

In-depth interviews and focus group discussion were the methods used for data collection. In-depth interview is appropriate, especially when a topic of exploration is sensitive, to provide complex textual descriptions of how people experience a given research issue, including contradictory behaviors, beliefs, opinion, emotions and relationship of individual
As I was exploring sensitive and private information, in-depth interviews were found to be an appropriate method.

One focus group discussion was conducted among health providers. Focus group discussions are useful for the exploration of collective understanding of a phenomenon, like beliefs, practices, and norms in a short period of time (36). This method was not considered to the participants (HIV+ pregnant and lactating mothers) to secure their privacy and confidentiality. HIV is still highly stigmatized and considered as sensitive and personal subject in Tanzania. From my field experience, the majority of participants who attended the clinic came from different places of the city, away from their residence to secure their privacy, it would have been difficult to recruit them in the focus group discussion, and that would also limit their freedom to share their experiences in a group setting. Unlike focus group discussions, in-depth interviews helped to protect the privacy and confidentiality of the participants. The focus group discussion with the health providers was considered during the course of the study to develop a rich and more in-depth understanding of the interviews data as one way of triangulation.

3.2 Study Setting
The study was conducted at Muhimbili National Hospital (MNH). Muhimbili is the largest referral and teaching hospital in Tanzania, situated in Dar es Salaam which is the country’s largest city. According to the 2012 National Population Census, the city had a total population of about 4.5 million people, with an annual growth rate of 5.6% . HIV prevalence in Dar es Salaam is 6.9%, (38). The overall, HIV prevalence in Tanzania among the age group 15-49 years is 5.1%, with higher prevalence among women, (6.2%) than men (3.8%). (38). HIV prevalence is also higher in urban areas compared to rural areas. This thesis research project was conducted at the Maternity Unit which is affiliated with MNH’s Department of Obstetrics and Gynecology. The unit receives referred pregnant women from nearby regions, districts and other hospitals in the city. According to the monthly report, the hospital receives about 200 newly pregnant women who start ANC each month with an average of 5-10 new cases of HIV. The hospital operates an open door policy where all pregnant women who go for delivery whether they have attended ANC or not at the hospital are received and managed regardless of their clinical states. Pregnant women who start ANC at the hospital are counselled and testate for HIV at PMTC clinic where each woman is given an ANC with
the test results. Positive results PMTCT-1, negative results PMTCT 2, followed by other procedures like body weight measurement, blood pressure, and medical consultation.

3.3 Participants

3.3.1 HIV-positive pregnant and lactating mothers
Participants who consented to participate in the study included: newly diagnosed HIV-positive pregnant women, who had undergone HIV testing and counseling, pregnant and lactating mothers (18-50 years old) who knew their status before the current pregnancy. HIV-positive pregnant and lactating mothers below 18 years were not included.

3.3.2 Health providers
Six health providers were included in the focus group discussion, with nursing titles as SANO (Senior Nursing Office) and PANO (Principal Nursing Officer) and one nurse attendant. Two of the health providers were working as counselors at the PMTCT clinic together with their attendant, and the other three were working in the labor ward. All participants were female and experienced nurses. The focus group discussion took place at the testing and counseling room after working hours.

3.4 Sampling strategy and recruitment
A purposeful sampling strategy was used. Purposive sampling is a technique commonly used in qualitative methods, which involves grouping participants according to preselected criteria relevant to research questions (36). This sampling technique allows a qualitative researcher to recruit participants who will provide rich information according to the variation of the sample research question. Since, I was not directly involved in the participant’s recruitment process (HIV+ pregnant and lactating mothers). Recruitment was conducted by two health providers working at the PMTCT clinic. After being attended participants were briefly introduced to the study in brief and invited to participate. Health providers were made aware that participation is on a voluntary basis, and they should let their clients know, that declining participation would not have any impact on their treatment and care.

Recruitment criteria were explained to the health providers, and an emphasis was put in variation is the socio-demographic characteristics during sample selection, in terms of marital status, level of income, education, duration of knowledge of HIV status, disclosed and non-disclosed participants. The age span of participants ranged from 18-56, educational background, ranged from primary school level 4 to a Master’s degree. Participants, who
agreed to participate, were introduced to the principal investigator by the health provider who later on gave further explanation about the purpose of the study and obtain their consent to participate.

Recruitment of participants in the focus group discussion took place on week 12 of data collection, starting with two health providers working as counselors at the PMTCT clinic, and their attendant followed by other counselors at the labor ward.

3.5 Data Collection Methods

3.5.1 In-depth interviews
An in-depth interview is typically an exchange between one interviewer and another respondent. During the interview the interviewer and participants become collaborators working together to achieve a shared goal of understanding (35). In-depth interviews were conducted among study participants (The primary source of data) by using a semi-structured interviews guide with the questions grouped into different themes related to the research questions. The semi-structured life world interview seeks to obtain descriptions of the life world of the interviewee with the respect of interpreting the meaning of the described phenomena (39).

The interview guide was reviewed by the health providers during the first week at the field site, to assess if the questions would not be offensive to the participants and if it covers all aspects of the topic. Small adjustments were, made for example the questions flow from a simple question to a more difficult one which allowed more space for probing.

Before the interviews, I spent a few minutes to establish a connection with the participants by introducing myself, and to obtain the informed consent. Consent to be audio recorded was also asked, many participants consented to be audio recorded. The language used during the interview was Swahili. Participant’s socio-demographic information was collected, including: the age, marital status, occupation, income and level of education. Participants were given an opportunity to ask any question before the audio recorder was turned on. The interviews lasted between 30 minutes to 1 hour. Many participants felt comfortable to be interviewed at the hospital and not at home or any other places. The interviews were conducted at the quiet and private place at the hospital with the exception of 3 interviews which took place of employment.
3.5.2  Focus group discussion

Focus group is a qualitative data collection method in which one or two researchers and several participants meet as a group to discuss a given research topic (36). Focus group discussion can produce a large amount of information in a short time and be useful in assessing a broad range of views on a specific topic (36). One focus group discussion was conducted among the health providers. The decision to conduct focus group discussion came during the week 10 of data collection, and the discussion took place during week 12. The method was useful for gaining an in-depth understanding of the interviews data since the health providers were directly involved with the study participants, their experience would provide a complete picture about the phenomena. Focus group discussion is one of the methods used to create a complete picture of how a given issue affects the community of people through assessment of their social and cultural norms and opinion about their own values (36).

Through the help of the health providers at the PMTCT clinic, I was able to recruit six participants for the focus group discussion. During recruitment, I had the chance to meet potential participants, introduced myself and briefly explain the main topics of the discussion and build rapport. It took about two weeks to recruit participants and schedule a meeting for discussion. The discussion took place at the testing and counseling room after working hours. Before the discussion, I introduced myself once again and reiterated the importance of privacy and confidentiality and how the data will be used. I also spent a few minutes explaining some of the rules to guide the discussion, such as further discussion after leaving the room was not allowed, the importance of respecting each other, freedom to express their opinion and that there is no right or wrong answer and speaking one at a time (36). Going through these rules was equally important since I was the moderator and the note taker. All participants consented to be audio recorded, during the discussion some participants were more talkative than others and sometimes spoke simultaneously. While this is a sign of good discussion, it was sometimes difficult to follow. Therefore, I reminded them to speak one at a time. Sometimes the discussion was interrupted for a while when someone else entered. Participants who were more silent were given a chance to express their opinion. The focus group discussion lasted for about one hour, and participants signed the informed consent document before leaving.
3.6 Data saturation
Saturation can be defined as data adequacy and operationalized as a collection until no new information is obtained (40). There are no published guidelines for sample size estimation required to reach saturation in qualitative research, rather the questions of saturation is left by a researchers evaluation depending on adequacy and comprehensiveness of the results (40). A total of 28 in-depth interviews were conducted of which 12 of the interviews were from non-disclosed participants. The interviews lasted from 35 minutes to 1 hour. One session of focus group discussion was done which lasted for about 1 hour. The saturation point was reached through an in-depth exploration of the phenomena, through triangulation of the data from the in-depth interviews and the focus group discussion. In qualitative research, the quantity of data is not as theoretically important to the process of saturation as the richness of the data that is derived from the detailed description, and not the number of times something is stated (40).

Though I would have liked to spend more time to get an opportunity to interview non-disclosed, married participants could have added more perspective about the barriers of disclosure to sexual partner, but this was less likely to happen because the majority of non-disclosed participants did not consent to participate from the beginning. On the other hand, I had already spent a longtime in the field, adding more time would have brought some discomfort to the participants regarding their confidentiality due to the chance of meeting them because they continued with follow-up visits at the clinic.

3.7 Triangulation
Triangulation involves using multiple data sources in an investigation to produce understanding, it is used to ensure the account is rich, robust, comprehensive and well-developed (41). Triangulation in this study was done through the use of different data sources including, in-depth interviews with research participants and one focus group discussion among health providers.

3.8 Transcription of the interviews and Translation
The audio recorded interviews were listened to several times and transcribed using Swahili language and later on translated into the English language. Several interviews were transcribed while I was still collect data.
3.9 Data analysis

Thematic content analysis was used for data analysis, which can be defined as a method for identifying, analyzing and reporting patterns within data (42, 43). With the flexibility approach of thematic analysis, several stages were applied to analyze the data (43).

Preliminary analysis, took place during data collection period, through notes taking of new ideas and observation of the emerging patterns in the interviews data as well by establishing the link between the interview data, previous studies, and theoretical framework.

The analysis process continued after all the interviews were transcribed when I got back to school. All the interviews transcripts were read through one by one starting with the longer interviews with rich descriptions and notes were taken to identify the general themes within each transcript. I also had the opportunity to share some of my interviews transcripts with my colleagues and my supervisor to get their impression of the data and compare with what I had previously identified.

Next, each transcript was read again and coded by using qualitative data analysis software Nvivo11. At this stage, several codes were developed through matching with the relevant content from the interview data. The codes were initially informed by the previously read literature, and observations of notes form my preliminary analysis during data collection for example, fear of abandonment, accusation of infidelity, stigma and discrimination, fear of violence were the most common apparent themes from the previous research, from the codes different themes were identified. At this level, semantic or surface meaning of the data was identified without looking anything beyond what has been said (42).

The developed codes were shared with my supervisors to be re-read again and reflected, some adjustments were made from the more silent themes and a reduction of number of categories, by collapsing some similar ones into broader categories for examples breast feeding dilemma, abortion, unwanted disclosure were grouped into dealing with HIV+ status and pregnancy category. Intention to disclose was changed to timing. Possible relation between marital status and disclosure was becoming apparent at this stage as a latent level. Latent level in a thematic analysis goes beyond the semantic content of data and start to identify or examine the underlying ideas, assumptions and conceptualizations and ideologies that are theorized as shaping or informing the semantic content of the data (42).
Previously coded transcripts were checked again with the newly identified codes and themes. Some adjustments were made, and presentation of the themes was guided by the study research questions. The key themes from the data were presented in a separate section with the discussion.

3.10 Reflexivity

Reflexivity is described as an attitude of attending systematically to the context of knowledge construction, especially to the effects of the researcher at every step of the research process (44). Through reflexivity, a qualitative researcher is obliged to observe and document his/her own roles in the research process including assumptions, biases or reaction that might influence the collection and interpretation of data (35). A qualitative researcher should examine on his/her own relationship to the respondent and how that relationship dynamics affects the responses to the questions (45), because knowledge is produced and reproduced in particular social, cultural and relational contexts where by the interview itself is one of that context of interactive knowledge creation. Who I am, my position and preconceptions would have an impact on the knowledge creation, with this in mind, I have been reflective throughout the study process.

Doing the research in my own country was an added advantage with prior knowledge about the context. To me, the fears of HIV-related stigma and discrimination seemed obvious. Despite this, I did not take things for granted. Instead I probed more to clarify participant’s explanations. For example, it seemed obvious to me that individuals would experience some pain and shock when diagnosed with HIV and directly associating it with death. However, this did not prevent me from asking probing questions about why it felt like that.

In the beginning, I thought being a male researcher and looking young would affect data collection since I was interviewing older women. I was concerned that they would not be open to share their personal issues. However being a male researcher had no impact on the data collection, most participants felt even more relaxed to share their experiences as a way of teaching me. I tried as much as possible to look professional by dressing up. My background as a sociologist was also beneficial when it came to interacting with the participants. It helped to cultivate good rapport.
I was also aware of the fact that, I was not directly involved, in the recruitment process, that there might be a selection bias and participants would be less likely to talk about the negative things about the hospital. To overcome this, health providers were reiterated the importance of voluntary participation and ensured privacy and confidentiality. I was also aware of the likelihood of participants to associate me with the hospital staff so during the introduction I made it clear that I was a student researcher and not working at the hospital. In addition, I was also careful with the environment where the interviews took place; I made sure it was a quiet and secure place to allow the participants to openly share their experiences.

3.11 Trustworthiness
The methods of evaluating the quality of the research findings differ between quantitative and qualitative research design. The standards of evaluating the rigor of qualitative studies are credibility, dependability, conformability and transferability are, (35) as common as internal validity reliability and external validity objectivity in quantitative design. According to Lincoln and Guba,(41) a fundamental criterion for a qualitative report is trustworthiness. These criteria have been applied during the stages of the study to ensure the quality of findings.

3.11.1 Credibility
Credibility also called truth value, is the corresponding criteria to judge qualitative findings which focus on the confidence in the truth of the findings, which include an accurate understanding of the of the context (46). Credibility can be examined through various aspects, including:- whether the narrative data is rich enough to support findings, if the study population consider the report to be accurate, and if the findings show a logical relationship to each other (46). Credibility can also be enhanced by prolonged engagement, persistent observation and triangulation, peer debriefing, negative case analysis and member checking (41).

Ensuring credibility is one of the important factors in establishing trustworthiness (41). To achieve credibility of the findings in this study, some considerations were taken. First of all, through the choice of relevant data collection methods, which were in-depths interviews and focus group discussion. In-depth interview are useful for gaining insights about particular phenomena and related experiences, feeling, opinions, especially when sensitive
issues are being discussed. In-depth interviews were used to gain insights about how disclosure of HIV+ status was experienced among the study participants.

By the establishment of good rapport and building a trusting relationship with the participants before the interview, many participants felt comfortable and were free to share their experiences. My background as a sociologist was useful during interaction with the participants. My previous experience of data collection through interviews was an added advantage. Since a sensitive issue was being discussed, the importance of privacy and confidentiality was set as a high priority. The information was over emphasized. I also made sure the place where the interviews were conducted to be private and quite. Additionally, during the interviews session, I listened carefully to participant’s experiences which allowed me to probe further to obtain detailed description and clarification. This was considered from the beginning because I was aware it would have been difficult to conduct member checking later on, due to the experience I had earlier when I started data collection as I tried to get some participants phone numbers in order to call later for clarification. When I tried to call them, they never answered, some participants were also not willing to give me their phone numbers. In addition, being a male researcher and interviewing female participants, I have a feeling they were more open to me.

Since, I was not directly involved in recruitment of the study participants; there might be bias in selection by a health provider. Keeping this in mind, health providers were reminded several times that participation is on a voluntary basis and that they should let their clients know declining participation in the study would not impact their treatment. This allowed getting participants who were willing to share their experiences without being forced. Additionally, participants were likely to associate me as a hospital staff and less likely to talk about negative things about the hospital. To avoid this, I made it clear to them that I was a student researcher and assured them confidentiality. Participants trusted me and were open even to report negative things about care and treatment.

The use of triangulation is considered useful to enhance the validity of the research findings (41, 47). Data from the focus group discussion among health providers was complimented with the data from the in-depth interviews to create a rich and comprehensive description. Furthermore, during recruitment maximum variation within the sample size was considered.
to avoid harsh generalization of the findings. Deviant case analysis was also made to enhance the credibility of the research findings, which involve searching for and discuss element of the data that appears to contradict with the patterns within the data (41).

Prolonged engagement is also considered as a way of producing credible findings (41). Since I was doing research in my own country, I had prior knowledge about the cultural, social, political, economic context which helped me to make sense of the data. But since I was not very familiar with the hospital settings, I spent one week and a half just getting to know the hospital, and building rapport with the health providers. I had several opportunities for informal conversations with health providers during lunch break to learn more about their work, especially issues related to HIV testing and counseling, I was also curious to know whether there was any ongoing research at the hospital particularly among pregnant women. I learned they had no any recent research about HIV disclosure among pregnant women. This helped me to make good preparations before data collection. The fact that there has not been any research recently, I expected that participants would be willing to participate in my thesis research project and share their experiences.

The interviews were conducted using my own language (Swahili) which helped me understand and follow the participant’s stories including the jargon. The audio recorded interviews were transcribed verbatim in Swahili and then translated into English. I had an opportunity to discuss several translated interviews with a Swahili and English speaker to assess whether the meaning and context was preserved in an English version.

The role of my supervisor as an experienced researcher has been equally significant in the whole process, from the study design, data collection and analysis through constant advice and feedbacks. During the analysis I had several occasions to discuss with my colleagues and my supervisor to review and assess if my previous identified codes were relevant to a particular theme and necessary adjustments were made to improve its validity, for example partner character as a barrier to disclosure to sexual partner was changed to fear of adverse reactions including violence. The involvement of my supervisor, have been useful to help see the phenomena in broader context as someone who comes from different context.
3.11.2 Dependability
Dependability is equivalent to the reliability concept in quantitative design. It refers to the extent to which the findings can be replicated (35). Qualitative research uses the term dependability instead of reliability. In qualitative research dependability assess whether the research is consistent and was carried out with careful attention to the rules and conventions of qualitative methodology (35), whether the research questions are clearly and logical connected to the research purpose and design.

Qualitative research was an appropriate design for my thesis research project that focuses on gaining a more holistic view of phenomenon. The main objective was to explore disclosure experience of HIV+ among pregnant women and lactating mothers. In-depth interviews were considered appropriate to explore this topic, complemented with a focus group discussion with health providers. The research design, methods of data collection and analysis have been well explained however replication in qualitative research with multiple phenomena and meaning cannot be applied as in quantitative design (46).

3.11.3 Conformability
Conformability generally implies maintaining distance between the observers and the observed by minimizing any possible influence of the researcher’s values on the process of inquiry (35). Objectivity is a traditional standard of quality in quantitative data while qualitative study to confirm means a way of knowing that, even being a co-participant in the inquiry, (the researcher) has to maintain the distinction between personal values and those of the study participants (35). This can be achieved through being carefully with bias or reaction that might influence the collection and interpretation of data. I have been reflexive throughout the study process from data collection to analysis as presented above. By applying reflexivity contributes to the conformability of the results (35). Conformability was also done through triangulation of different data sources as already explained.

3.11.4 Transferability
Transferability is the qualitative analogue to the concept of generalizability in quantitative studies (46). Generalizability in of the findings to the wider population is the goal of quantitative studies while the goal of qualitative research is to produce the data that is conceptually and not statistical representative of people in specific context (35).
Thick description is described as a way of achieving a type of external validity through description of a phenomenon in sufficient details so that one can evaluate the extent to which the conclusions are drawn and transferable to others times settings and people (41).

Since the context is the key influence in any qualitative, the researcher must account for contextual factors when transferring data from one situation to another (46). It was not my aim to make generalization to other settings, however thick description of the context has been explained so that other researches can better assess the transferability of the findings.

Transferability could have been enhanced more by the inclusion of different health settings where different experiences and perspectives could have been obtained and assessing similarities or difference.

### 3.12 Ethical Considerations

#### 3.12.1 Ethical approval Norway and Tanzania

The study was assessed for ethical eligibility by the Norway Regional Committee for Medical and Health (REK) See (Appendix 1) followed by then Norwegian Social Science Data Service (NSD) (Appendix 2) and finally Muhimbili National Hospital (MNH) Institution Review Board (Appendix 3), the permission to conduct the research was given by Head of teaching, research and consultancy coordination unit (Appendix 4).

#### 3.12.2 Informed consent

Informed consent entails informing the study participants about the purpose of the study, the main features of the design the possible risks and benefits of participating in the study (39), and voluntary participation. Due to the nature of the study which required a high level of confidentiality prior consent to participate in the study was first obtained through their health providers. I explained the informed consent procedure with participants who agreed to participate. The informed consent document was in Swahili and contained information about the background and the purpose of the study, potential risks and benefits, as well as privacy and confidentiality. Many participants gave an oral consent and other written, some signed the informed consent document and left their copy. Consent to be audio recorded was also obtained. More time was spent explaining the importance of recording the interviews and participants were assured of the privacy and confidentiality of the information and informed that the audio recording will be deleted after the completion of
the study. Many participants agreed to be audio recorded and no participant was forced to be audio recorded.

3.12.3 Confidentiality
In research, confidentiality means private data identifying participants should not be disclosed (39). Confidentiality was highly emphasized during all the stages of data collection and analysis due the fact that sensitive and personal issues were being discussed. To secure privacy and confidentiality, the study participants were identified through numbers instead of names and were also assured of the confidentiality of their information that was only to be used for the purpose of this research project. During the course of the interview, participants were constantly reminded of confidentiality as well. Participant’s numbers have been used in the data processing and reporting.

3.12.4 Data Storage and Handling
The audio recorded interviews, and transcribed interviews were stored on a password secured lap top known only by a principal investigator. Field notes were stored in a safe and secured place. Participants were assured that I was the only person who has access to the data and their information will be stored safely and securely and destroyed after the research project is completed.

3.12.5 Ethical dilemmas
The questions in the ethical guidelines, cannot be settled completely in the advanced stage of a research project, and can be conceptualized as a field of uncertainty (39), calling for a qualitative researcher to remain open to ethical dilemma ambivalence, and conflicts that will arise during the research process. Ethical dilemmas were encountered during the recruitment of the study participants, contrary to what was outlined in the research protocol addressing the participant’s rights to agree or decline to participate in the study through their health providers first. At some instance this procedure was not strictly followed as the period of data collection continued some participants were introduced about the study by the health provider with my presence I think that some participants wanted to see who was going to interview them in the end, many participants agreed to participate.

I also felt uncomfortable breaking the principal of confidentiality related to the HIV testing and counseling when I was invited several times into the HIV testing and counseling room by the health providers.
3.13 Dissemination of the results
The study findings will be presented as a Master’s thesis, for completion of Master of Philosophy degree in International Community Health. A copy of the thesis will be submitted to MNH Department of Obstetrics and Gynecological and one to the PMTCT clinic. I also hope to turn this Master’s thesis into an article.
4 Findings

In this chapter, the research findings will be presented according to the five research questions as referred to on introduction chapter page 11.

- What are the pregnant women experiences with the HIV testing and counseling?
- What are the perceived barriers of disclosure HIV+ status to sexual a partner?
- What are the facilitator experiences of disclosure to a sexual partner?
- What are the perceived barriers of disclosure to significant others than sexual partner?
- How is the disclosure experience at the health care settings?

4.1 Experience with the HIV testing and counseling

HIV testing and counseling is a provider initiated service and offered as routine part of antenatal care (ANC) and Reproductive and Child Health (RCH), it is also encouraged at all stages during pregnancy, labor and after delivery. Majority of the participants were aware that HIV testing and counseling are part of ANC care and learned their HIV status during their pregnancy period. However few participants learned their HIV status for the first time through their infant’s test results that indicated a HIV positive and eventually died. By the time of interviews, the duration of knowledge of HIV status among the participants ranged from less than a month to 18 years.

The PMTCT clinic where HIV testing and counseling took place was the first place where pregnant women encountered when starting the ANC clinic. Health providers encouraged the participants to do the HIV test first, in order to get a clinic card for their continuous ANC care.

Pretest counseling included:-assessment of participant knowledge about HIV, education about the expected types of test results, reactions towards the test results being good or bad, positive living coaching, medication adherence for their health and the baby, and the importance of knowledge of partner status. As described by a participant below:

R: I was told the results can be in three different ways. It can be positive for all, negative for all or one positive another negative. I was advised to accept the test results in whatever form they will be. All are the results in anyway and should just be accepted (Married living with a partner Int. No 7)
Clients, who were diagnosed HIV +, were provided with psychosocial support to deal with the HIV+ positive test results, by encouraging them to take it easy and accept it. Positive living was couched by the common phrase “to be living with HIV is not the end of life”.

Additionally, health providers often compared HIV with other diseases, like cancer or diabetes to foster positive living as more dangerous diseases, for example, a diabetic patient is more selective when it comes to diet and also required to take the medication every day. For some participants, who had a lot of negative thoughts due to their status and found it very difficult to accept it, were connected to other participants who have been on medications for some time and have accepted it, as described by a participant below:

R: In the beginning I was coming irregularly to the clinic to collect my drugs and sometimes I didn’t come at all, but the counselor used to call and scheduled me to a group of other HIV+ women who have accepted it, they counseled me a lot and I started to change my mind thinking how could they have the same condition as me but they have accepted it and doing fine. (...) now even when I see others feeling down about it I tell them to stop encourage them to take their medicines and move on (Unmarried not living with a partner Int. No 5)

Different feelings, reactions and concerns were expressed by the participants after learning about their status for the first time. It was shocking, painful and confusing experience to many. For some participants, it took some time to believe that were actual infected while others were still in denial. Participants who already knew about their status before testing at ANC were not greatly affected with their test results. Apart from being pregnant, HIV+ diagnosis added another burden to several participants.

4.1.1 Shock, pain and confusion
Many participants were shocked and experienced pain, when they learned their status as HIV positive for the first time. The shock was related to that they did not expect it to happen to them. They perceived that HIV was something one can hear happen to others.

R: I was shocked at first, it was so painful (...) i was shocked because I never expected such results. In my life I never expected one day I will be infected with HIV” is something you hear it as a story but you don’t expect to happen to you (Married living with a partner Int. No 9)
Though it was shocking and painful experience for many participants, accepting the test results was important because it has already happened, there was no way out to reverse the situation. Accepting the test results earlier was the decision several participants made to deal with the situation, deciding to start medication, as illustrated by one of the participant below:

R: It pained me, but it has already happened there is nothing you can do. I had to accept it. (...) since I found out, I haven’t taken it very seriously. Sometimes, I think about it then I ignore. But if I wouldn’t have accepted, it would be difficult to eat, drink, taking a shower, working you don’t like living anymore seeing yourself as a dying one. Yet you have another chance to live. (Married living together with a partner Int. No 23)

A sense of confusion towards the HIV+ test results was also expressed by several participants’ especially young ones. HIV positive test results felt like a death sentence, which put an end to life and dreams. Additionally it raised fears about what would happen once their status will be known to others, possible stigma and discrimination, thinking maybe they will be abandoned by their partners. As illustrated below by a young and unmarried participant:

R: The first time I tested positive, I was very confused... I thought I was already dead. I was thinking what people will think of me when they find out. In short I was only thinking about death. I prayed to God that it was better that I died from a car accident not from HIV. (Unmarried woman not living with partner Inter. No 19)

4.1.2 Disbelief and denial
Several participants reacted toward their HIV + test results with some disbelief as they never expected they could have been infected. This reaction forced the health providers to give additional counseling to help them dealing with their test results. The quote below demonstrates the reaction:

R: When I got my test results, I didn’t believe it. They had to lay me down for a while at the hospital. It was very hard for me to believe what they were telling me. I lied down for about 2 hours and then sister xxx asked me how I was feeling. I told her I was feeling better, and then she let me go. I felt like I was dying (Married living with partner int. No 6)
The attitude of disbelief compelled some participants to test twice after sometime, in order to be certain that are actually infected. As described by the participant below:

R: After about 3 months, I decided to come at MNH to start the clinic. When I was given my results at xxx Hospital, I didn’t believe if it was true (...) I was hoping to get different results at MNH being better hospital (...) I wasn’t shocked much because I had somehow started accepting the fact that I was infected after the first test although I would want to hear or see anything to do with HIV for example the adverts that said AIDS kill. (Unmarried not living together with a partner Int. No 19)

In addition, apart from being certain with HIV + test results and enrolled into care, several participants were still in denial finding it very difficult to completely accept their test results.

R: I accepted them but until today, I don’t believe it. I don’t want to believe it completely, it hurts me a lot. I know it has already happened and I am not the only one with this problem. I don’t know where I got it. This disease has a lot of things. Sometimes i convince myself it is not true but sometimes I think what should I do? I ignore it. (Married Living with partner Inter. No 2)

The attitude of denial was also expressed by the health providers working as counselors at labor ward and at PMTCT clinic, addressing it as one of the challenge they face at work. They had experienced attending some clients who have not accepted their status completely and still stigmatizing themselves and don’t want their status to be known by the health providers. They hide it, by changing their identity written in their ANC card which indicates they are infected. (PMTCT I- means HIV positive) (PMTCT II means HIV negative), while others possess two different cards.

Some change in the card when it is written PMTCT 1 they add another one to make it looks like two in roman number. (ii) (FGD participant 6)

Majority of the clients with such attitudes were the ones referred from other hospitals or health centers.
The attitude of denial towards one’s HIV + status was also expressed by the counselors working at the PMTCT clinic as described below:

*We have also experienced the same thing, you find a pregnant woman is referred here and she knows her status, but she wants to test again. When you ask her if she has started the clinic she say “no” when you test her it reacts positive. I have met one who has been using ARVs for 5 years, I asked her if she has tested she said no, I tested her when she came to collect her results she told me “Don’t give me the results which are different from what I know” now you wonder which results is she talking about positive or negative? When you ask her why? She say “she wanted to know if she is cured or not”? (FGD participant 4)*

4.1.3 Insensitive reactions

Some participants who already knew about their status through their former infant’s test results and during their previous pregnancy were not greatly affected towards the HIV + test results. Furthermore, the availability of better HIV service compared to the previous time, made it easier to receive the HIV+ test results easily. As described by a participant after getting her results during her third pregnancy:

*R: I took it easy, I was not shocked or cried that’s why I am still living until today. If I didn’t accept it I wouldn’t continue to give birth to my third child (...) It is a normal disease like others, I have accept it, that’s why I live, imagine I learned since 1997 as the days goes new medicines are discovered there were no medicines to prevent mother to child transmission of HIV before (...) there were no medicines to cure opportunistic infections either, but now these medicines are available just have to use them. (Married living with a partner Inter. No 21)*

The participant above, among others did not test during her previous pregnancy, she suspected she was infected for the first time after getting her six months old child HIV + test results which shocked her, thinking it was a joke.

Additionally, insensitive reactions towards HIV + diagnosis was also expressed by one participant with a nursing background who had tested herself and had a knowledge of her status for a while before seeking treatment at the clinic. Having seen other people living with HIV, leading normal life encouraged her. As illustrated below:
R: I already knew about my status (...), I have seen other people still living with the infections, I took it as normal condition I was not scared, that’s why I am still living up to now (Married living with a partner Inter. No 10)

4.1.4 Dealing with pregnancy and HIV infection
Learning HIV status during pregnancy was a big challenge to many participants which brought a lot of thoughts and concerns. In addition to handling their own situation as HIV positive, their concerns for the status of their fetus added more weight to their burden. Some participants expressed a desire to terminate the pregnancy, as illustrated by the quote below:

R: All I could think of at that time was to abort the pregnancy when they told me I could give birth to a safe child, I did not believe it. (Unmarried not living with the partner inter.no 19)

Furthermore, some of the participants who had just learned about their status recently, were still in a dilemma about their future unborn baby’s feeding options, whether they should breastfeed or not and for how long? The concern over child feeding options was to avoid involuntary disclosure of their status, if they will only be required to exclusively breastfeed for a certain period of time, affordability of the replacement feeding (infant formula) when deciding not to breastfeed, as well as the worries about passing the virus to the baby through breastfeeding. As illustrated by the participants below:

R: I am still thinking... I am a bit scared maybe I might transmit the virus to the baby when I breast feed. I was told I can do exclusive breastfeeding for six months (...) it is not a secret I am still in dilemma because for example maybe I have delivered and other people don’t know about your problem they will expect to see you breastfeeding your baby. But when you will feed the child with powdered milk they will start judging you and once they know your problem they will start gossiping (...) (Married living with partner Inter. No 18)

The worries about passing the virus to the baby, was also associated with the father’s sperm as one of the participants cleared her doubt by asking the health provider about it. Additionally, delay in learning HIV status at the later stages of pregnancy and suitable delivery methods was another concern to some participants. As illustrated by some participants below:
R: (...) when I was at home after about a week some issues were confusing me. Sometime I was thinking maybe I have delayed to test. I phoned sister xxx to ask if I was not delayed, maybe if I found out earlier it could help to protect the child but now I am delayed, will it really help to protect the child? Sometimes I am worried about the day I will go to deliver, when I will go to the clinic again I will ask my Doctor which method is better whether I have an option or not? (Unmarried living together inter.no 28)

This section concludes that, many participants knew HIV testing was important procedure when they started ANC and many learned their status while they were pregnant. However, a few participants learned about their status previously through their children. Participants reacted differently when they first learned about their status. Some were shocked, experienced pain and never expected to live with HIV. Several young participants and particularly those who were not married and recently married were confused looking at their test results as a death sentence, thinking what would happen to them once their status is known to other people. Among the participants who already knew about their status, who did not test during the previous pregnancy and were not greatly affected by their positive test results. Accepting the test results earlier was important decision several participants made as a coping strategy, however several participants found it difficult to accept their test results completely and were still in denial. Acceptance of HIV + test results earlier was not easy particularly in unmarried participants and had to test several times to confirm about their diagnosis. Dealing with pregnancy and HIV was a big challenge to several participants who had just found out about their status, which posed different questions about the risk of transmission to their future unborn baby and the child feeding options.

4.2 Perceived barriers of disclosure to sexual partner
Different barriers of disclosure to a sexual partner were expressed by the participants who were: married and living together with their sexual partners, unmarried sexual partners living together, unmarried sexual partners not living together, and ex married. The majority of participants who did not disclose their status to a sexual partner were unmarried partners not living together. Some of these participants were in relationship with other married men while others were still in a dating process. Common barriers expressed by the participants included:- fear of abandonment and losing economic support from the sexual partner, fear
of being blamed as a source of the infection and fear of adverse reactions from the partner including violence and lack of communication about HIV.

4.2.1 Fear of abandonment and losing economic support from a partner
Both healthcare providers, and the participants expressed, the reliance for economic support from the sexual partner, acted as a barrier to disclose one’s HIV status. The economic support from the sexual partner was important to cover their day to day costs of living like food, house rent and the associated costs of raising child. Disclosure of HIV+ results would lead to abandonment and hence loosing these supports. This fear was mostly associated with the majority of the participants who were not married, as depicted in the quote below by unmarried participant:

R. The counsellors have advised me that I should disclose to my partner but I told them, it will not be possible. To say the truth, I have not disclosed to him yet. I am worried, if I tell him, he might have a different reaction. It may be a reason for him to break up with me, considering that my child is still young, and still needs his support; I am not ready for that. They have advised me a lot to disclose but I have not. (Unmarried not living together Inter.no19)

In a similar way another unmarried participant stated:

R: I cannot tell my partner because first of all, he is not cooperative in child support. He gives me a lot of problems so if I tell him, he may get more reasons to stop providing child support so it’s best that I leave things as they are. I mostly take care of my child by myself so if I tell him about my status, he may have a reason to leave me. (Unmarried not living together Inter.no 5)

The concern for a lack of economic and material support seems to be perceived as more important than the concern for the health of their partner. It seems as there are different perceptions between women who are married and those who are not. For example, one participant who was married living with her partner disclosed for financial support, as described below:

R: I disclose to my husband because I thought if I don’t tell him, I will get problems, because for example you may be asked for some money in the hospital for treatment who will I ask first for? So I had to tell him about my condition (Married living together inter.no 6)
Likewise during the focus group discussion, health providers mentioned dependency of economic support from the sexual partner, hindered disclosure of the HIV positive status to their sexual partner. According to the health providers, women who are dependent economically on their sexual partners hesitate to make quick decision to disclose their status for the fear of abandonment unlike for the ones who are independent. A health provider added:

*It is difficult to disclose for those women who are depending on men, with small income to because when she will disclose it is over.* (FGD participant 1)

Furthermore, the fear of abandonment by a sexual partner was identified as one of the challenge that health providers’ face during counseling.

*For example you ask a woman to tell her husband about her status she responds “If I tell him and be abandoned what I will do?” Will you continue to talk about it? (...) you can’t she has said is someone who she depends on, you can’t continue. What you can do is to give her time to make her decision.* (FGD participant 4).

Health providers stressed that, women who are independent economically, the ones who can work and earn sufficient income to look after themselves and the child are more confident and can disclose more easily without caring much about the consequences, because they can look after themselves and the child. A health care provider added that, the dependency for economic support from the partner may lead someone who is not infected to even bear children with an infected partner when there is some sort of economic support.

Even though marriage seems to make it somewhat easier for women to disclose their status to their partners, this is not the same as marriage protecting the partner to stay in the relationship. During in-depth interviews, one participant was actually abandoned by her husband after disclosure. Her partner tested negative, she was married to him for three years. The participant learned her status during her third pregnancy.

Below it her experience

*R: (...) and he left me when I disclosed, before going to test he told me that will not leave me because our previous children are safe that(...) It is difficult for me to know how I got infected*
, but last year on June I had a miscarriage I think I was infected by their instruments they used to clean me(...) when we returned home after testing I was not happy he asked me to go to my parents’ place maybe I will be happy, I left with all my children. Later on things got bad my father called him to discuss but he came with the divorce paper he gave it to me in front of my father, (Ex married woman inter.no 25)

In the latter case, it appears that the former husband indirectly blamed the women as being responsible for being infected by HIV.

This chapter concludes that, fear of abandonment and losing economic support from a sexual partner played a significant role as a barrier of disclosure of one’s HIV status for several unmarried participants. Participants who were dependent for economic support from their sexual partner to cover their daily cost of living and their children found disclosure to be a difficult thing, fearing the partner would abandon them and hence losing economic support. As explained by health providers, participants who can work and earn sufficient income are in better position to disclose easily without fearing much about the negative reactions from the partner because they can take care of themselves and the child. One participant was actually divorced following disclosure as her partner was HIV negative. Lack of disclosure to protect economic support from the sexual partner was more attached to the women who were not married and not living together with their partners. The experiences described, indicate that disclosing HIV-status may have several serious consequences for the HIV-infected women in addition to living with the disease in itself.

4.2.2 Fear for being blamed as a source of the infection
Fear of being blamed as the source of infection, was also described as a barrier of disclosure of one’s status to a sexual partner, due to the prevailing perception that the one who disclose first is considered as the source of the infection. Health providers mentioned women often are the first ones to learn their status because they are encouraged to do a HIV test during pregnancy so that they can start using first medication if found infected. On the other hand, most men fears to get tested and are more likely to have sexual affairs with other women. Their earlier knowledge about their status made it difficult to disclose as they would be considered as a source of infection in the family. As illustrated with an example by a health provider below:
Women often test first, because they know, they are carrying a baby, without testing and starting medications it will harm the baby. So, when you counsel her well, she understands and agrees to test. But some men refuse to test. Now when her test result is HIV positive and you ask her to tell her husband she responds “When I will tell him he will say I am the one who brought it”. (FGD participant 1)

Similar argument was raised by an unmarried participant as seen below:
R: My husband is a difficult person. You can tell him about this problem instead of going to test as well he will start blaming you. Thinking maybe I am the one who went to fetch this problem and bring it, sometimes he might be the one who brought it I am living with him so I know him. I only told him that in the clinic we were asked to tell our husbands to go for a test as well (Married partner living together Inter.no 26)

In addition another unmarried participant stated:
R. This thing, you never know who infected the other, he may be the one who has infected me or I may be the one, who has infected him, but because of our beliefs, I may tell him first and he might think I am the one who brought it. We believe the person who test first and disclose is the one who brought the disease but it may not always be so. (Unmarried woman not living together, Inter. No 19)

Several participants did not disclose their status to their sexual partner when they thought they would not receive supportive reactions like partner agree to test as well. One participant who disclosed to her sexual partner confirmed this reaction. The quote below illustrates how her partner reacted after disclosure:

R: (...) He was just normal.... he said “if you are like that I will also be infected.” I told him “it doesn’t mean if I am infected, you will also be infected”. Since the day I told him he said he will go to test but he hasn’t I don’t know what he is scared of? (...) the Doctor told him he should not be scared he might not be infected but he didn’t test ,every time I ask him he says he will test but he has not (Unmarried living together inter.no 28)
This finding shows that a partner’s action is not necessarily to get tested immediately, even if he learns the status of his partner.

To summarize, the participants feared to disclose their status to avoid the blame as the source of the infection. Since many participants learned their status first due to the requirement of antenatal care there was a perception that, the one who disclose his/her HIV status first is likely to be the source of infection. This increased participant’s vulnerability and made them more prone to the blaming, which made it even more difficult for them to disclose. On the other hand men have negative attitudes towards HIV which prevent them from testing and would not want to be identified as the source of the infection.

4.2.3 Fear of adverse reactions including violence
Fear of negative reactions from the sexual partner was identified as another barrier of disclosure. Participants who suspected negative reactions from their partner including the possibility of violence and lack of emotional or physical support did not dare to disclose soon after they learned about their HIV status. Health providers also mentioned, that participants who suspected their partner will receive their HIV test result well, were more likely to disclose their status. One participant below expresses her fears:

R: I haven’t disclosed to him because I know his character (...) Ni “mtata” (he is troublesome). This case can turn back to me a hundred times and I will regret it. I will even find myself living early with my condition (pregnancy). You see... because I know him we are living together. Many things which happens in the house when I try to educate him, despite him being an accomplice it turns back to me. Then you regret why you have told him about his mistake. (Married living together Inter. No 23)

A similar account was described by another participant:

R: I have never considered disclosing to my partner. I wish I could tell him but I cannot to say the truth, the way I know him, he will not receive it well, He is an alcoholic, so I know how he thinks. The clinic staffs have counseled me to disclose but I gave the same answer, I have no thought of disclosing to him because I believe he will not receive it well. (Unmarried not living together Inter. No 3)
In conclusion, participants had to weigh the pros and cons before making a disclosure decision. Participants feared to disclose when they thought they would not receive supportive reactions from their partner. For participants who felt would receive supportive reactions from their partner, they were more likely to disclose their HIV status.

4.2.4 Lack of communication about HIV
The lack of communication about HIV between partners was also identified as barrier of disclosure of HIV status, not only for women but also for men. As pointed out by the health providers, men also struggle to disclose to their sexual partner even though he might have known it for a while and yet may react harshly towards his partner when she discloses her status first and sometimes may find a way to end the relation. A health provider added, due to inferiority of women to men it makes them easier to accept the accusations. As indicated below by a health provider with an example:

I have one case, a woman found out that her partner was on antiretroviral therapy but they were not married, her partner was hiding his medicines in a car boot, I don’t know what happened. One day she opened her partner’s car boot and saw a medicine bottle, she asked him “What are these medicines for”? He replied “I don’t know”. She took the bottle and investigated it and found out, later on she went to do HIV test and she had positive status. She decided to keep quiet, because she knew if she will tell him it will be worse. So everyone decides to hide it. People fears when they disclose it will bring problems in their relationship. (FGD participant 4)

The example above, tells another story which have been presented earlier. In this case the women do not need to fear the partner to leave her, because he is also infected. That they still do not communicate about it, suggests that there are also more general communication barriers between partners when it comes to talking about sensitive issues.

Lack of communication about HIV was also expressed by several participants during in depth interviews:
R: I have not disclosed to my partner, I think he is infected and hiding it from me too(...) I have a feeling he knows, because there are some of the information I don’t know but he knows, for example about breastfeeding the baby. He says, I can breastfeed for 3 or 6
months then stops so there is some information which he knows (...) I am not sure completely but I have also seen a sign on his neck, many people with that sign are infected by HIV
(Unmarried living with a partner Inter. No 13)

In the same manner another participant explained:

R: I was asked to disclose to my current partner, but I cannot because by any means I believe he knows .My first partner died from a car accident, my second partner used to be a truck driver but he went back to study, now he is married and working as an Engineer, even his wife gave birth and breastfed her baby for 3 months only 3, so I think her wife is infected as well. So I think he knows, he feels sorry to tell me and I feel sorry to tell him too. (Unmarried not living together Inter. No 5)

Similar experience was narrated by another participant who believed her partner to be a source of the infection, knew about his HIV status but failed to tell her. As she narrated her partner was married to another woman who died later but she did not know the cause of her death, either when they got back together with her former partner they did not test for HIV first. Below is her story

R: (...) he must have been aware about what was going on but don't know how to start telling me. He can't tell me because even when I ask him to come to the clinic with me he replied that he has a lot of work. He seems to be afraid of something. He fears, how should he start telling me? (...) I have seen him once taking the medicines I asked him, why he was taking the medicines every day? He responded “I am not feeling well”, but I have not seen any medicine bottle inside the house, he is the truck drivers he can leave the bottle in the truck (Married living with partner Inter. No 2)

Lack of communication about HIV between partners was also expressed by the health providers as one of the challenge they encounter during counselling, as depicted below: (...) another thing you can ask a pregnant woman what do you thinks about telling your partner? She responds “Since we have started our relationship does it mean he has never thought about testing for HIV”? He knows there is HIV, he has not asked me to test why I
should start? When he will decide to go for testing he will find out” it is one of the challenges which prevent you to continue, what you will do is to continue educating her until the day she will feel like disclosing. (FGD participant 4)

The lack of communication about each other’s HIV status may also be the results of a more general lack of open communication between the two. Particularly in the cases where the sexual partners are not married to each other, they may avoid talking to each other about sensitive issues in general.

In conclusion, communication about HIV seemed to be difficult among partners even if one person might suspect his/ her partner to be living with HIV. Difficulties to communicate about HIV maybe contributed to the fear of reactions from the other part which may not be pleasant.

4.3 Facilitator experiences of disclosure to a sexual partner
As we have seen, although disclosure seemed to be a big challenge to several participants, many were able to disclose their status to the sexual partner. Among the interviewed participants who disclosed their status many were in a marital relationship and living together with their sexual partner. Participants mentioned about the time and process of disclosure, reasons for disclosure and reactions after disclosure.

4.3.1 Time and process of disclosure to a sexual partner
Many participants, who were married, disclosed their status to their sexual partner on the same day after learning about their HIV status. Disclosure was done through face-to-face communication with their partners, while some participants needed assistance from a health provider through couple HIV counseling and testing (CHTC). As described below by a married participant below:

R: Immediately after getting my test results I went home and told him. I was so angry we had a fight at home. Now I think I didn’t react well, we decided to take a vacation to go somewhere and discuss it. Now he is even stricter when it comes in taking the medicines. He always insists and reminds me to take my medicines every day. (Married woman Inter. No 20)
In the same manner another married participant stated:

R: I gave him a call after leaving the hospital because he was still at work. I told him I have a problem please come back home. He listened and came back. When he came I told him. It took him a while to understand but when he saw me crying he sympathized with me and I advised him that he should also get tested, he agreed. The next day he did not go to work. I took him to the hospital (MNH) where he got tested and was fond to be HIV negative (Married living together inter. No 6)

But for some participants who were not married but living with the partner, it took a little while to disclose.

R: I disclosed to my partner, after sometimes, within a week, sister xxx was asking me if I have disclosed or not? I told her “not yet, it is difficult for me” but then I asked myself, how long will I keep it.? Because I was taking the medicines how long will I be in this condition? The medicines were torturing me, I felt dizzy, I thought it is better to be open so he should know as well (Unmarried living together inter. No 28).

In the case above it took some time for this participant to disclose because she wasn’t sure how her partner might react as she was not married.

Fear of being blamed as a source of infection made some participants to take even longer to disclose and feel free to disclose when a partner finds out by himself. This delay happened especially when a woman believe her sexual partner to be the source of the problem. As she narrated below:

R: (...) because my partner was still enjoying his youth(…) a truck driver spending many days away from home, I didn’t tell him anything since the time my first child passed away. He knew after I gave birth to my third child while my second child is in standard almost 7 years now. (...) He knew it by himself when he tested after getting heper zoster. I told him “Eeeh it is true, you were enjoying your youth, and we were both sick, now (...) my first and second child it was like this…. you are the one who brought it”. You know everyone has his own reactions when getting the results, it is better he knew it by himself (Married living with a partner inter. No 21)
In conclusion, the majority of participants disclosed their status to their sexual partner the same day. Many of them were married and disclosed through face-to-face communication. For some participants, who were not married yet, it took some time for them to disclose wondering what would be the partner reactions after disclosure. Fear of being blamed as the source of infection prolonged the disclosure decision.

### 4.3.2 Couple HIV Testing and Counseling

Couple HIV testing and counseling involves counseling and testing both partners and encouraging them to share their test results (mutual disclosure). Several participants who attended antenatal clinic with their sexual partner, received counseling and testing together and shared their test results. Some participants, who learned about their status for the first time alone, expressed the need for disclosure assistance from health provider through couple HIV testing and counseling, as it proved difficult to do it on their own fearing partner reactions. As illustrated by the participant below:

R: (...) when I first learned about my status, I didn’t disclose to him straight away, I told him the counselors have advised us to go together for testing, I brought him to the clinic where we tested and received the results together we were both infected. (Unmarried living together Inter. No 7)

In the same way another participant shared her experience:

R: I disclosed to him after leaving the hospital, it pained me a lot so I stopped by the friend of ours a Medical Doctor and I told him, then he phoned my husband, my husband came and the Doctor talked to him, he agreed to test and he was found negative (...) I couldn’t tell him alone because I didn’t expect he would accept it, because I was also shocked when I found out. (Married living together Inter. No 27)

This section concludes that, disclosure through face-to-face communication to a sexual partner seemed to be a challenge to some participants who were fearful about their partner’s reactions. Moreover, the generally lack of communication about sensitive issues, like HIV between couples, made it more difficult. Couple HIV testing and counseling was found to be a beneficial approach for facilitating disclosure and helping participants to deal with their fears through psychosocial support.
4.3.3 Timing
Apart from participants who disclosed their status to their partner right away, some participants were waiting for the right time to do it. Several participants explained that they would disclose if their partners would agree to test and share their test results as well. Some participants waited until after delivery, tested together with the partner, move in together and receiving the test results of their infants. The following extracts illustrate the point:

R: I will put effort to tell him when he decides to test as well, but if he continues to refuse I will not. I can tell him and he may think I am the source but when he test and found out by himself is okay. When he will share his test results with me I will also tell him now I am afraid. (Married living together Inter. No 26)

Another unmarried participant had this to say:

R: I plan on disclosing to him because we have plans to get married. He is not in the country now when he gets back, we will get married but before we get married we will get tested (Unmarried living with a partner Inter. No 13)

Another married participant mentioned that she will disclose after the delivery as described below:

R: It is even more difficult to tell him now with my condition, first when you have this one (HIV), then you are pregnant both carries weight, when you decide to add third one, to tell him will be very stressful for me and it might cause other problems. It will be easier when I have already given birth. I will ask him to attend the clinic with me so we can test together after I give birth, I will pretend I don’t know anything when we test together (Married living together Inter. No 23).

Even though waiting after delivery was perceived as convenient time for disclosure, in the case above convincing the husband to attend the clinic for counseling and testing together seemed to be another challenge, as explained further:

R: (...) first even to bring him to the hospital it needs extra efforts. I can’t just ask him “Mr. let’s go to test”. As I have told you he is very troublesome, (mtata) even to go for a Malaria test is difficult, what about HIV? When you ask him he might say. (High voice) “If you have it
(HIV) is you, I am not sick”. “Go yourself if you think you are sick, (Married living together Inter. No 23)

Similar scenario was described by another participant:

R: The clinic staffs have asked me several times to convince him to come with me to the clinic for testing, when I was still pregnant but he never attended. When I asked him he responded “I he cannot go to a place where there are many women”. (Unmarried not living with a partner Inter. No 19)

Achieving some sort of economic independence favored the right time for disclosure:

R: I am not ready yet, because I have a plan to move in my own house from where I rent now. When everything is ready in the house I will be able to test with him now I am not settled. (Unmarried not living together Inter. No 12)

In conclusions, although some participants disclosed their status to their sexual partner soon after learning, others were still thinking about it and preferred to disclose when they also knew their partner status either through testing together or a partner voluntary decision to disclose. Among participants who were still pregnant, it was even more difficult to disclose and one was waiting to test before getting married. Some participants felt it would be easier for them to disclose when they were financially independent from their sexual partner, like having their own house. Though some participants preferred couple HIV testing and counseling, it was also found not easy to persuade their partner to attend the clinic together.

4.3.4 Trustful relationship
Several married participants who believed to be faithful in the relationship with their sexual partners and therefore less likely to be blamed as the source of the infection were able to disclose their status in short period of time. As illustrated in the following quotes

R: (...) I was angry because at first I was okay. I tested in 2008 during my first pregnancy and I was okay. Even when we got married I was still at school but I had gone for a testing too and I was HIV negative (Married living together Inter. No 20).

Similarly another married participant stated:
R: I was confident on myself. I was not going out of my marriage. I lived with him for 15 years but I was not lucky to get children with him, but he has children outside the marriage. We are living together how can how long will I keep it by myself, how long will I hide the medicine, any day he can see them, is better I tell him whatever he decide should be early. (Married living together Inter. No 15)

Additionally, coping with the illness well, with the help of counseling was associated with disclosure to a sexual partner as stated a married participant below:

R: (…) I accepted the test results and felt confident that living with HIV is not the end of life. When you just test suddenly without counseling you might die. But when you are counseled you see whatever come it is okay. (Married living together Inter. No 8)

Many participants experienced supportive reactions from their sexual partner following disclosure, in terms of emotional and material support. A supportive reaction was also expressed among serodiscordant couples. Some of the male partners decided to go for HIV testing as well as depicted below by a married participant:

R: (…) “I have tested and the results shows I am infected, He asked how have I received it? I told him I have received it as it is, I don’t know how you take it? , He told me because you are my wife it is necessary for me to go and test. He tested the next day and was positive then we started using the medication (Married living with a partner inter. No 16)

For some participants whose sexual partners tested negative, (serodiscordant couples) were surprised about their results how come their partner is infected and they are not.

4.4 Perceived barriers of disclosure to significant others
Participants were asked if they have disclosed to any other person a part from their sexual partner. Probing questions were used to identify if the participants have disclosed to any family members or any other person. Many participants preferred to keep their status confidential due to the fear of HIV-related stigma and discrimination when other people will know their status. Protecting others from emotional harm was a common barrier to disclosing to family members, especially to parents.
4.4.1 Protecting confidentiality
Many participants feared to be hurt once other people know about their HIV + status. The motives to keep one’s status private were to maintain internal peace, by avoiding HIV associated stigma and discrimination. This is illustrated by the participant’s quote below:

R: I have not disclosed to any other person apart from my husband when you disclose to others you don’t know how they will react (…) you can tell someone and become the source of offending you more. But if you keep a secret between yourself you live well. “There is no a secret between two people”. When you disclose to another person it will not be a secret anymore (Married woman living with a partner Inter. No 11)

In this case the participant makes a clear distinction between what she discloses to her sexual partner, and what she discloses to others. From a health perspective one might argue that it is most important to disclose one’s status to sexual partners as there will be a risk that the other partner is infected and not the least that it is important for HIV-infected persons to take necessary protective measures. Disclosure to significant others, however may be motivated more from a mental health need for sharing and discussing concerns and thoughts.

4.4.2 Fear of HIV-related stigma and discrimination
Many participants feared to disclose to others due to potential negative attitudes from society and discrimination due to their status (Felt stigma). Fear to be labeled and gossip by others were common issues described by many participants when probed further why they preferred to keep their status a secret. By pointing fingers as described by participants’ indicates “Someone is infected, living with HIV” with an attachment of judgment. Participants also explained what could be the cause of stigma, its impacts in their life and came up with some suggestions against it. The extract below illustrates why participants preferred to keep their status confidential.

R: (…) you know, many people suffer more by seeing other people talking behind their back, everyone will gossip about you and when people start to gossip about you, you lose you internal peace and stressed as results your CD4 goes down, so to avoid that is better to keep a secret. (…) the problem with this disease is lack of peace. When you lose it became a
problem but when you take it normal there is no problem. (Married living with partner Inter. No 11)

Additionally participants explained what do people normal gossip once they know someone is living with HIV as illustrated below:

R: “A Sick, person, “marehemu mtarajiwa” (someone who is going to die soon) mean while we will all die regardless you have HIV or not (…) When people know you are living with HIV some people can even be scared to touch your hand, thinking you will infect them. They kind stigmatize you even when one cooks the food people will think twice about eating (Married woman Interview Inter No. 23)

Participants explained that the lack of in depth knowledge about different ways of HIV transmission, as it thought to be mostly through sexual transmission and perceived to be a shameful disease. Once someone has been infected, it is associated with bad behavior such as prostitution. Participants further explained that even if one has good intentions to disclose to someone, instead of that person going to test as well to know about his/her status will start pointing fingers at you and gossip.

A similar issue was also discussed by the health providers, that the negative perception towards people living with HIV is still prevalent in the community. To be living with HIV meant someone had bad behaviors and has got it through sexual intercourse, the assumption evolving even by educated people. Moreover health providers acknowledged in depth knowledge about different ways of HIV transmission is still lacking. The following quote illustrate this point:

For example you may ask a pregnant woman “Have you heard about HIV and AIDS?” she respond “Yes” what have you heard about it? AIDS they say “it the disease of prostitutes” that the answer she will tell you. But it is not true HIV can be transmitted through many ways, for example from mother to child, in the car accidents, but mother has that conception when people know she is living with HIV will think she is a prostitute. (FGD Participant 3)

Despite this, several participants suggested that people living with HIV should not be stigmatized as it prevents them to be open about their status. Furthermore HIV should be
perceived like any other disease and people should also know that not all people who have HIV have acquired it through sexual transmission. The following quote highlights this point:

R: My opinion people should stop stigmatizing people living with HIV that’s why many people fear to disclose. Some people once they know you are living with HIV think you can infect them even by sharing a cup with them, there is stigma even from some of the relatives in the family once they know, it becomes a problem they start discriminating you (Married living with a partner Inter. No 17)

In summary, many participants preferred to keep their status confidential due fear of HIV related stigma and discrimination. To be living with HIV was perceived as negative mark that one has acquired it through sexual transmission and associated it with bad behavior such as prostitution. Stigmatizing attitudes towards people living with HIV was considered to affect their health status, by losing internal peace and eventually dropping the CD4 counts. Participants suggested that people should stop stigmatizing people living with HIV and should perceive it as other chronic disease. More education is needed about different ways of HIV transmission.

4.4.3 Preventing emotional harm to parents
Apart from disclosure to a sexual partner, disclosure to a family member is important for prevention, treatment, care and support. In this context is equally important to prevent infection from loved ones because it is common for the pregnant women who give birth at the first time to be cared by their family members’ particular a mother or sister. Disclosure to a family member would also reduce the risk of transmission through mixed feeding to a child before six months of age if a mother decides to breastfeed. A common barrier to disclosure to a parent as mentioned by the participants was to prevent hurting or stressing them. Additionally, having older parents with blood pressure (BP) or diabetes would increase the stress level. Fear of disclosure to parents and other family members was less associated with HIV-related stigma and discrimination, as described by the following participant:

R: I have not disclosed my status to anyone not even my parents or relatives. I do not believe that if I tell my relatives, they would go tell it to other people. But what I fear is that I will
stress them. My mother for example is sick; she has diabetes and high blood pressure so I cannot tell her. (Unmarried not living with a partner Inter. No 19)

Apart from avoiding stressing the parents, the disclosure environment mattered as participants’ preferred face- to- face communication rather than through the phone:

R: I will tell my mother one day when I go home. She is living far from me, I cannot tell her through the phone (Married living with partner Inter. No 6)

Several participants disclosed to their family members had medical backgrounds like nurses or doctors. The majority of the participants who disclosed to their family members received good reactions such as care and support.

In conclusion, barriers to disclose to family members varied from each participant, many of them didn’t disclose to their parents to avoid stressing them, some wished to disclose but they preferred to do it face- to -face. Participants who disclosed to their family members experienced good reactions, care and support and some preferred to disclose only to a family member with a medical background.

4.5 Disclosure experiences at the healthcare setting

4.5.1 Disclosure support to a sexual partner

During the focus group discussion health providers were asked about the support they give to their clients (HIV+ pregnant women) when they fail to disclose to their sexual partner. Health providers explained that disclosure of the HIV status is a client decision and not of a health provider. The best they could do is continuous counseling until the client makes her own decision as described by a health provider below:

We ask them every time when they attend at the clinic have you disclosed to your partner?. What were the reactions? You have to remember there are new infection, maybe he is negative you can infect him you can also infect the baby. If he is positive and you continue the medicine will not work and you might transmit it to the baby. What will happen if your husband dies suddenly, you are using the medicine and he is not. But we are not forcing someone to disclose (FGD participant 4)
A health provider at PMTCT clinic noted disclosure whether to a sexual partner or a family is okay, but also mentioned it depends on the time and environment. Participants who tested positive at labor or after delivery were encouraged to disclose first to a close person who would be taking care of them after giving birth, a close person normally a mother or sister to prevent them from infections.

As shown earlier couple HIV testing and counseling is another approach health provider use to help clients who fail to disclose by themselves. As described by a health provider below

Some pregnant women come and tell you “I have failed sister” we ask her to bring him so you can test together, it reaches a time a woman pretends she has not tested at all. When they come together, you counsel and test them and encourage them to share their test results (FGD participant 4)

As explained further by health providers, couple HIV testing and counseling is also beneficial when it comes to decision making about the child feeding options. Whether the child should be exclusively breastfed for six months or given artificial milk? If there are complaints from the relatives as to why the child is not given complimentary food before six months, a child father can say that he has decided to be that way. A mother may have more difficult time hiding her HIV status. Moreover, the couple can also decide together who else to notify.

In conclusion, the decision to disclosure one’s HIV status to a sexual partner was left to a client to decide, depending on the right time and environment. However, continued counseling was the approach health providers used to educate their client about the advantages and disadvantages of hiding their status. Among participants who wished to disclose their status to their sexual partners but failed, they were encouraged to bring their sexual partner along so they could be counseled, tested and receive their results together. Among participants who recently learned their status during labor or after delivery, they were encouraged to disclose to the closest person who would be taking care of them during that period.

4.5.2 Interaction with health care providers

Many participants expressed a sense of satisfaction with the counseling services and felt comfortable to be attended by the healthcare providers. Participant satisfaction with the healthcare providers was favorable, as is evident in the following quotes:
R: *The service is good during counseling the nurses have a good sense of humor, they are very humorous, sometimes you even forget your problems when you get there. I am not saying this to please you but there are very humorous* (Married living with partner Inter. No 14).

Many participants had a positive experience with their health providers and were well cared during all stages, from pregnancy until delivery. These positive experiences are described below:

R: *I was attended well during delivery you can’t tell the difference because if the nurses were stigmatizing us it would be easier to know* (Unmarried not living with a partner Inter. No 12).

However, some participants mentioned that they had experienced stigmatizing attitudes from the health providers in another hospital as shown in the quote below:

R: *(...) in some hospitals, you may find the nurse stigmatizes you, for example the hospital where I gave birth, they pointed fingers at me and saying loudly that I was HIV+. I felt so bad but I leave it all to God,* (Married living with partner Inter. No 6)

### 4.5.3 Access to medicines

Several participants mentioned they do not get all the prescribed medicines at the hospital especially for those who do not have medical insurance. They requested to get all the prescribed medicines. As stated by several participants below:

R: *(...) when I tested me my CD4 was down the doctor recommended I should take one pill of vitamin B a day, now I have to take Septrin as well, I don’t get them here, I have to buy them sometimes you can’t even afford to buy. People who benefit the most, are the ones with health insurance, for people with exemption like me we only get the ARVs* (Married living with partner Inter. No 18)

### 4.5.4 Privacy and confidentiality.

Participants responded differently when asked about how they felt about the confidentiality of their information in the hospital. Some believed their information is kept confidential, others didn’t care at all, others didn’t know if their information is kept confidential or not. Others experienced some difficulties when there is someone whom they know who is
working at the hospital. As described by the participants below when asked how they felt about the confidentiality of their information

R: *I think it is okay after all I come here to get my treatment I don’t care much who will see me because even if you want to keep your privacy you can’t guarantee a lot of people come to the hospital* (Married living with a partner inter. No 17)

Some participants were very satisfied with the privacy at the PMTCT clinic as described by a participant below:

R: *They have good service, expensive one inside the room one by one, you are not required stay in a queue maybe someone will see you. When you sit outside in the bench people may think maybe you have just come to test but when you inter inside the room you finish your business and leave. The counselors are nice, charming and kind, they don’t stigmatize you.* (Married living with a partner inter. No 21)

However several participants who started treatment at the Counselling Treatment Care clinic (CTC) then shifted to the PMTCT clinic after becoming pregnant, mentioned they felt uncomfortable due to lack of privacy at CTC where they met many people and waiting for long hours to get service. This is captured in the quote below:

R: *For example at the PMTCT health provider attends you and you leave soon but at the CTC clinic, there are many people there and you have to wait for long time until your medicine prescription card has been entered in the computer, measure your weight then go to see the doctor for medicine prescriptions. After you have been prescribed the medicines you have to go and take your medicines in the pharmacy. In the (PMTCT) when you enter you show your medicine card you and you get your medicines unlike in the (CTC). At the CTC you have to take your number and you meet many people* (Married living with partner inter. No 18)

To conclude, many participants were satisfied with counseling and testing service at the PMTCT clinic. Health providers were described with a friendly care. However, several participants mentioned that they were unable to get all the prescribed medicines, especially antibiotic Septrin. They were required to buy it somewhere else, unfortunately it was not affordable to all. Many participants were comfortable with the privacy at the PMTCT clinic
compared to the CTC clinic where there is little privacy while waiting long hours in the queue and encountering many people.
5 Discussion

In this chapter, a discussion of the key research findings will be presented, followed by the study limitations and finally conclusions and recommendations. In an effort to increase the understanding of this study, the findings will be juxtaposed with other relevant studies and the theoretical framework. I begin by the summary of the key findings.

This study aimed to explore HIV + diagnosis disclosure experience among pregnant and lactating mothers enrolled in a PMTC program. The findings have revealed that the majority of participants (HIV+ pregnant and lactating mothers) were well informed about the procedures of HIV testing and counseling as one element of the ANC, administered as provider initiated service and routine. Pretest and post counseling was conducted by the health providers. The findings have shown, HIV + test results were experienced differently by the participants, accompanied with shock, pain and confusion, disbelief and denial. Some participants who already knew about their status were not greatly affected by their HIV+ test results. The finding also revealed that HIV+ results added another challenge for pregnant women concerning the health prospect of their fetus. In general, many participants experienced good reactions from their sexual partner following disclosure, with an exception of one divorce case.

Perceived barriers of disclosure to a sexual partner, varied from participant to participant which included, fear of abandonment and loosing economic support, fear of being blamed as a source of the infection, fear of adverse reactions including violence and a lack of communication about HIV. Disclosure of HIV+ status to a sexual partner was more likely to occur in a marital relationship. According to the findings many participants who managed to disclose their status to their sexual partners, did it on the same day through face- to- face communication. Additionally, couple HIV testing and counseling was also found to be a facilitator of disclosure for participants who failed to disclose on their own, while for others timing was important factor to consider before disclosure. Waiting until after delivery, or when one knows their partner’s HIV status, through counseling and testing together, or a male partner voluntary decision to disclose and being economical independent. Several participants who believed to be trustful in their relationships, early acceptance of the test results was also found to make it easier for disclose decision.
Perceived barriers of disclosure to significant others (family members and friends) differed from disclosure to a sexual partner. The identified barriers included: protecting privacy and confidentiality, fear of HIV-related stigma and discrimination and the expressed need to avoid stressing or harming the parents.

Finally, disclosure experience at the health care setting, where by couple HIV testing and counseling and individual continuous counseling from the health providers were identified as support given to facilitate discloser among the non-disclosed participants. Generally participants were satisfied with the counseling and testing services as well as privacy and confidentiality at the PMTCT clinic compared to the CTC clinic. Shortcomings reported included the lack of provision of all prescribed medicines, particularly antibiotic Septrin, and stigmatizing attitudes from the health providers reported in other hospitals.

5.1 Experience with HIV testing and counseling

5.1.1 Shock, painful and confusion reactions towards HIV + diagnosis
The findings indicate that, the news of HIV + test results was received with painful feeling and shock as they never expected to be found with a positive diagnosis especially with the pregnancy condition. This experience maybe interpreted as results of multiple stigma, first by having a HIV positive status and anticipated negative judgments for getting pregnant and increasing the risk of HIV transmission to the unborn child (48). Furthermore, the findings indicate some participants, especially the younger ones, reacted with a sense of confusion, wondering what would happen when other people finds out about their HIV status, associating the infection with shame and perceiving it as a death sentence. This phenomenon has been reported elsewhere by Bond et al. (49) as, a psychological impact of stigma that, makes people worried about the illness and about death, where by these negative thoughts shortening life expectancy. Deacon et al. (50) explain further the damaging effects of psychological impact of stigma, reduces a self-esteem which in turn affects the way a person respond to illness, discourage testing, disclosure and treatment seeking.

The findings also indicate that, several participants had to accept their test results since there was no way to change the situation. Other studies, have also reported the benefits of accepting the HIV + test results as an adaptive coping strategy, that foster positive living,
which has been found to increase medication adherence and may make it easier for the patient to disclose his/ her HIV + status (51-53). In addition, the findings have highlighted the benefits of psychosocial support to deal with a HIV + diagnosis. Peer group support was found to be, equally beneficial for participants who found had difficult time accepting their HIV status, which in turn affected their medication adherence due to irregular attendance at the clinic for medical refill. The beneficial role of a support group has been documented in previous studies (54, 55), which contributes to increased retention in the PMTCT program, as well increased knowledge and confidence among people living with HIV.

5.1.2 Denial
The findings also indicate that, some participants had difficulties in accepting completely their HIV + status with a tendency of stigmatizing themselves (internalized stigma) did not want the health providers to find out about their status by changing the status written on the ANC card. Similar finding have been reported by Turan et al. (56) stating that fear of stigma and discrimination contributed to the avoidance of HIV testing in the labor ward and throwing away of a ANC card with HIV+ test results. Lyimo et al. (51) state that, denial as one way of maladaptive coping strategy, results from a perceived stigma among people living with HIV. Denial and non-disclosure of HIV status have also been reported as obstacles of preventive efforts, as well as access to treatment, care, and support for people living with HIV (57).

5.1.3 Double burden HIV and pregnancy
The findings from this study reveal that, HIV + diagnosis added another burden for pregnant women concerning the health of their fetus. The findings indicate that HIV + diagnosis put participants in child feeding options dilemma, whether to exclusively breastfeed or not and for how long? This dilemma was partly to avoid other people learning about their status as well the affordability of the replacement milk. A study conducted in Malawi, (58) found that due to fear of involuntary HIV disclosure, stoppage of breastfeeding created or confirmed suspicion about a women’s HIV status, which resulted in negative reactions from the community. Another study conducted in Northern Tanzania (59), about counselors perspectives on ANC HIV testing and infant feeding dilemma, found that counselors believed that women who decide not to breastfeed risked the stigmatization of being identified as HIV infected. In addition, another study conducted in Kwa-Zulu Natal South
Africa (60) found that, in a community where breastfeeding is very normative, choosing replacement feeding would seem abnormal even prior to the HIV epidemic and hence opting for bottle feeding would announce one is HIV +.

The findings of this study also indicated that, the child feeding options dilemma was not only associated with involuntary disclosure of HIV status but also with the cost of replacement feeding (infant formula) as well as and the risk of transmitting the virus to a child through breast milk. These finding corroborate another study (60) that found the role of economic circumstance of the women played a role in decision making about child feeding options. Additionally this study found that, some of the mothers had a belief about HIV transmission through breastfeeding. According to WHO (2001), HIV and infant feeding guideline (61), replacement feeding is recommended when (AFFASS) criteria is met that is, acceptable, feasible, affordable, sustainable and safe. However regardless of the recommendation this criteria and exclusive breastfeeding has continued to be a challenge in Sub Saharan Africa due to the social consequences of non-breastfeeding (61, 62).

5.2 Perceived barriers of disclosure to sexual partner

5.2.1 Fear of abandonment and losing economic support
The findings indicated fear of abandonment and loosing economic support hindered HIV + status disclosure to a sexual partner, particularly for women who are economical dependent on their partner. This finding is line with several primary studies conducted in Tanzania and a systematic review (7, 27, 29, 63). Additionally the findings indicate that the likelihood of disclosure was higher among married participants compared to unmarried participants. This finding is supported by other studies(32, 33) showing higher disclosure rates among married participants, however the findings in this study have also pinpoint apart from being married one of the determinants of disclosure. Economic reasons had, an influence as one married participant mentioned she disclosed to get some support from her husband. The findings have also demonstrated an economically independent woman the one who can works and earn sufficient income, is more likely to disclose her status to a sexual partner. Therefore empowering women economically could be useful strategies to influence increased disclosure.
In general the findings indicated that, many participants experienced supportive reactions from their sexual partner couple following disclosure. Supportive reactions following disclosure to a sexual partner have previously been reported in other studies (27, 31). This could suggest that the fears faced by women sometimes are not realistic; however one divorce case following disclosure in a serodiscordant couple was reported in this study. This case is, in contrast to divorce cases, reported in a study conducted in Malawi (30), where male partners divorced their wife due to the fears of accusation of infidelity by their wives’ relatives.

5.2.2 Fear of being blamed as the source of infection
Findings from this study shows fear of being blamed, as a source of the infection prevented some participant to disclose their status to their sexual partner as it was believed that the one who test first and disclose is likely to be the one who brought the infection. A study by Ogden et al. (25), found that, women generally bear the strongest impact of stigma through blame as they expected to uphold the moral traditions of their societies. Similarly the gender norms in this setting penalize women for promiscuity and place them in socio-economic vulnerability make it even harder for them to disclose their status (26). The lack of HIV + status disclosure due to the fear of accusation of bringing the infection in the family has also been reported in other studies and systematic review (7, 27, 28). Moreover, the findings also indicate due to the fear of being blamed as the source of infection led some participants to take longer time to disclose, even when they disclose it is normally by the time a partner has already find out by himself. Earlier male diagnosis could be beneficial as, other studies show male partners are more likely to disclose to their sexual partner than female (64), in addition, knowledge of partner status may as well facilitate disclosure decision (65).

Findings from this study show some of the unmarried participants intended to terminate the pregnancy. This finding is related to having a child outside the marriage relationship, who might be infected and therefore signify the woman has been promiscuous and hence suffer community stigma and discrimination (66). The intention to terminate the pregnancy may be as well due to socio economic hardship in line with HIV positive status (66)
5.2.3  Fear of adverse reactions including violence
Findings from this study indicate that, fear of adverse reactions including violence made it harder for the participants to disclose their status. Findings supporting this phenomenon have been reported in other primary studies and systematic review (7, 27), others studies have reported that, participants who had a smooth relationship with their sexual partners without a history of violence, were more likely to disclose their status than the counterpart (11, 31, 32).

5.2.4  Lack of communication about HIV
This study found that a lack of communication about HIV between couples make it difficult for the disclosure process. Communication difficulties have also previously been reported as a reason for non-disclosure (20). Studies have documented prior communication with a sexual partner before testing, as a determinant of disclosure (11, 31). However, in this study the findings reveal that, poor communication between couples, particularly when it comes to a sensitive issue like HIV. This finding can be placed, in a gendered context which views sexuality as a taboo. Gupta Rao Geeta (67), asserts the culture of silence surrounding sex that indicates “good” women, are expected to be ignorant about sex and passive in sexual intercourse. This makes it difficult for women to be informed about the risk reduction of HIV transmission or even when informed, it still becomes difficult for them to be proactive in negotiating safer sex (67), on the other hand, the gendered norms of masculinity, expects men to be more knowledgeable and experienced about sex puts them at risk of infection because this norms prevents information seeking behavior or admitting their lack of knowledge about sex or protection. In addition, a variety of sexual partners as another norm to denote masculinity as essential to man, makes it harder to communicate especially when it comes to HIV+ test results for the fear of accusation of infidelity (28). Couple communication is equally important for HIV prevention considering the high rate about 6% of serodiscordant couples in this setting (14).

5.3  Facilitator experiences of disclosure to a sexual partner

5.3.1  Time and process of disclosure
Findings from this study, shows that many married participants disclosed their status, the same day through face- to- face communication with their sexual partner. Other studies have also observed disclosure time taking place within few days after testing (11, 68, 69).
Furthermore, the findings have demonstrated that, being unmarried prolonged the disclose decision. HIV + results may lead to relationship breakup. Thus, being married has the influence on both disclosure decision and time of disclosure.

The findings from this study reveal that, timing was an important factor to consider before making a disclosure decision. Some participants intended to disclose to their sexual partner when they knew about their male partner status. This finding is supported by another study conducted at Uganda (65) showing knowledge of the partner status as one of a predictor of disclosure. Additionally, the findings have announced disclosure after delivery with the help of health provider was regarded to be convenient time. This finding is supported by another study (8), showing disclosure taking place around the period of weaning or resuming sexual activity. In addition, the findings have reveal that being trustful in a relationship contributed to the disclosure decision to a sexual partner among some of the participants based on the fact they will be less likely to be accused as the source of the infection. This finding is in line with a study by Antelman et al. (63) indicating women who had fewer partner were more likely to disclose their status.

5.3.2 Couple HIV testing and counseling
This study found out couple HIV testing and counseling was used as an approach to facilitate the process of disclosure of HIV status to a sexual partner for some participants who couldn’t do on their own. Couple HIV counseling and testing at the health care setting have been reported to provides an opportunity for couple to be educated, counseled, tested and access to care and treatment (28, 70), which also contribute to improved understanding and communication between couples. Furthermore, the findings show that, couple HIV testing and counseling provide an arena for the couple, to make decisions on child feeding options since a child father has acknowledge the child feeding options, other relatives in the family will respect that decision as well. Similar findings have been reported by Msuya et al. (10) which showed that, the women male partners who have been involved in antenatal HIV testing and counseling were three times more likely to use Nevirapine prophylaxis, four times to avoid breastfeeding and six times more likely to adhere to infant feeding methods selected than those whose partner did not attend. Several other studies conducted in South Africa (71), shows women who have disclosed to partners and family members were supported to adhere to feeding options of choice, hence reducing the risk of child HIV
transmission through mixed feeding, as well as receiving psychosocial and material support from the sexual partner. In addition, a study conducted in Kenya (72), found that, seropositive women who attended voluntary counseling and testing with their spouses were three times more likely to report adhering to their treatment regimen during pregnancy and delivery than those who were counseled individually and five times more likely to report adhering to prescribed breastfeeding protocols.

The findings also indicated, apart from positive outcome of couple HIV testing and counseling, it was not easy for some participants to persuade their partners to attend the ANC clinic together, as ANC clinic was perceived to be place only for women. In addition, gendered norms leave little room for a woman’s voice, like making suggestions to attend the clinic together. Similar findings have been reported in other studies (73-75) showing that men perceived it to be problematic to attend a female oriented health care facility because they do not feel welcomed and comfortable as well as time constraints and perceptions among men that pregnancy and child rearing are women responsibility. A study by Eli et al. (76), conducted in northern Tanzania (2011) revealed that, women had no authority to request their husbands to test for HIV and the arena for testing was defined as a female domain where men were out of place. Masculinity has also been reported to make men view HIV/AIDS as a threat to their manhood and dignity resulting in a fear of the disease (77). This in turn, makes men avoid association with the disease and undermine their partner’s effort to access and adhere to ART.

Several studies have suggested strategies to improve male partner involvement in the ANC (74, 76), through creation of male friendly programs, by arranging service for men at an alternative time and location, sending invitations through invitation letters, policy development of a routine offer of HIV testing to men in maternity wards. A systematic review (78) about male involvement and the PMTCT in Sub Saharan Africa has pointed out further strategies, including men sensitization about ANC, (PMTCT), more focus on couple HIV testing and counseling, the development of health care service tailored to men’s needs, taking care of health care staff resources and community education about testing and safer infant feeding.
5.4 Perceived barriers of disclosure to significant others

5.4.1 Right for privacy and protecting emotional harm to others

The findings indicate some married participants preferred to disclose their status only to their husband and no need to tell others. This finding is supported in a model for HIV disclosure decision making (20) as a self-reason for non-disclosure, as right to privacy. Furthermore disclosure to a sexual partner is related to a partner’s health concerns (20), in order to avoid the risk of transmission to a partner if not infected by taking protective measures. Additionally, the findings have indicated that non-disclosure to family members particularly parents and siblings was the expressed need to preventing harming them emotionally, with the news perceived leading to stress through sharing their burden. In a model for HIV disclosure decision making this findings align with the other focused reason of for non-disclosure (20).

5.4.2 Fear of HIV-related stigma and discrimination

The findings indicate that, many participants preferred to keep their status confidential due to a fear of HIV-related stigma and discrimination. Felt or enacted stigma has been reported, leads to information management where by individuals may worry of disclosing their HIV status for fear of rejection,(79). This phenomenon is also supported by other studies and a testing model of HIV disclosure decision making (20, 29, 51, 52), which asserts fear of stigma and discrimination leads to the concealment of HIV status. Fear of verbal stigma was commonly identified in this study, which included labeling (marehemu mtarajiwa), pointing fingers, and gossip. Institutional stigma was expressed through mistreatment by the health providers due to one’s HIV+ status. These forms of verbal stigma have previously been reported in other studies conducted in South Africa, Tanzania, Zambia and Malawi (52, 80, 81). The findings also reveal that, the experience of HIV-related discrimination from the health providers through harsh treatment and publicly announcing that one is living with HIV. HIV-related discrimination in healthcare settings have also been reported in previous studies conducted in Nigeria, Ethiopia, and Tanzania. (52, 82-84).

Furthermore, the findings also indicate that, HIV-related stigma and discrimination is a result of lack of in depth knowledge about different ways of HIV transmission, as HIV commonly perceived by the community members to be sexually transmitted only. Similar perceptions have also been reported in a study conducted in Zambia, (49) which identified,
the main cause of stigma as ignorance and misinformation about how HIV is transmitted and what it means to be HIV positive. Additionally, the findings have revealed HIV is attached with immoral behavior such as prostitution and promiscuous. This phenomenon is supported by other studies in the similar context (49, 51, 80). HIV-related stigma and discrimination have considerable implications on overall HIV care and treatment services. Fear of stigma and discrimination has been reported as the main reasons why people are reluctant to get tested, disclose their HIV status and adhere to antiretroviral drugs (51, 82, 85). These impacts have also been reported in the context of PMTCT (26, 56, 86). HIV-related stigma may result in unwillingness to take an HIV test, leading to late diagnosis when the virus may have already progressed to AIDS (87), making the treatment less effective, increasing the chances of transmission to others and causing early death.

The findings of this study highlight an overall satisfaction with privacy and confidentiality at the PMTCT clinic compared to the CTC clinic. Maintaining privacy and confidentiality is equally important in HIV care and treatment. Several studies have reported on the negative impacts of lack of not maintaining privacy and confidentiality at health care settings, which may contribute to an avoidance of HIV testing, and a loss of follow-up to treatment (26, 58, 80).

5.5 Strength and limitations
Findings from this study should be interpreted in light of several limitations. This study was conducted at the referral hospital with better and qualified staff including the specialists’ doctors, the quality of care reported may not be representative of quality of care in other PMTCT programs at the district and regional level. Moreover, since most of the interviews were conducted within the health facilities and prior consent to participate in the study was obtained through the health providers, it is possible that the relatively high level of satisfaction reported in the study was caused by desirability bias. Other studies have shown that, clients are unwilling to express a negative opinion of services when interviewed at the health facility (88). To overcome this limitation voluntary participation was encouraged during the recruitment and participants were assured of privacy and confidentiality of the information.
Disclosure was self-reported in this study; therefore the findings may have been subjected to reporting bias. Moreover, the recruitment was done in a health facility, and may have been unable to capture the experiences of the women who never utilize a health facility. The findings may as well not be representative of the general population of pregnant and postnatal women. In addition, concerning issues related to HIV / AIDS-related stigma, participants talked more about how HIV/AIDS-related stigma and discrimination impacted others people rather than their own experiences. On top of that, many participants who attended at the PMTCT clinic came from different places away from their home. Barriers of disclosure to sexual partners among married couple may not have been fully explored as several participants did not consent to participate in the study.

Despite of the limitations, there are numbers of strength that are worth noting within this study. The use of in-depth interviews was especially useful, in exploring this sensitive issue with its flexibility it revealed different aspects of the phenomena. Also, the use of the focus group discussion with health providers as one way of triangulation resulted in creating a thick description of the phenomena.

The study site, being a big referral hospital has facilitated the recruitment of participants with a wider socio-demographic background that has resulted in a broader understanding of the phenomenon. In addition, the interviews conducted by a male researcher led participants to be more open in sharing their experiences more freely as a way of teaching the opposite sex. This study benefited from the use of qualitative research methods and data analysis, abiding to reflexivity, non-biased transcription, and reporting.

5.6 Conclusion and recommendations
Despite the fact the epidemic of HIV has been present over three decades now, the impact of HIV-related stigma and discrimination is still vital. Its impacts have several implications in PMTCT program when it comes to decisions about HIV testing, accepting the HIV+ test results, adherence to medications and recommended child feeding options as well as a lack of disclosure to a sexual partner and significant others for prevention, treatment, care and support purposes. In this study, its impacts have been demonstrated in the way, in which HIV + testing was received by the participants accompanied with shock, pain confusion, disbelief and denial and concern over adherence to recommended child feeding options.
(exclusive breastfeeding). Furthermore, lack of HIV status disclosure to a sexual partner was due to the fears of abandonment, being blamed as the source of the infection, fear of adverse reactions from a sexual partner including violence and lack of communication about HIV+ status between couples. One divorce case was also reported in this study.

Apart from fear of HIV-related stigma and discrimination, the findings have shown materials support mattered more than psychological support, to determine disclosure decision to a sexual partner, as majority of non-disclosed participants were unmarried compared to married ones. In addition, the findings have revealed some of the reasons that led to disclosure to a sexual partner, were, being faithful in a relationship, and adaptive coping with the illness. Additionally, for some of the non-disclosed participants, timing was found to be an important factor to consider before making a disclosure decision as some participants preferred to disclose after learning their partner’s status either through mutual disclosure or a male partner voluntary decision to disclose his status. This was highly associated with the fear of being blamed as the source of the infection in the family which has also resulted in prolonged time to disclosure to a sexual partner among some participants. Waiting after delivery and achievement of some sort of economic independence like living in one’s own house was also considered as a convenient time to disclose to a sexual partner.

To overcome the perceived barriers of disclosure to a sexual partner, mutual disclosure at the health care setting through couple HIV counseling and testing was found to be an effective approach. However, it has also been revealed that it is not always an easy thing to persuade a male partner to attend the ANC clinic together for couple HIV counseling and testing due to traditional gender roles.

The impact of HIV-related stigma and discrimination was also reported as a barrier of disclosure to significant others as participants preferred to keep their status confidential particularly when it comes to disclosure to a person who is not closely related to participants (friends). On the other hand, the lack of disclosure to family members was the expressed need to avoid stressing or harming them. The findings indicate that HIV-related stigma and discrimination came from the community, health care settings and at the family level in different forms such as pointing fingers, labeling, gossip and mistreatment at the health care settings through harsh treatment and name calling. The causes of HIV-related stigma and
discrimination have been identified as a result of limited HIV education. Not surprisingly, the findings indicate that the attachment of HIV with immoral behavior such as prostitution reinforced HIV-related stigma and discrimination.

Finally, the findings indicate that the majority of the participants were generally satisfied with HIV counseling and testing service at the PMTCT clinic compared to the Care and Treatment Clinic (CTC) with the lack of privacy which resulted in unwanted disclosure due to the interaction with so many clients. Furthermore, several participants without medical insurance expressed the need to get all the required medicines for their treatment in especially Septrin as antibiotic.

With regards to these findings (PMTCT) program can achieve its maximum potential through the following recommendations:

1. More counselling should be addressed particularly for women who are not in marital relationship alongside economic empowerment programs.

2. More involvement of peer support groups for dealing with HIV + diagnosis is needed such as mother- to mother to achieve better health outcomes.

3. Promotion of PMTCT education in a general population, including sexual partners and not only limited to pregnant women at ANC setting to increase the understanding of the purpose and benefits of PMTCT program.

4. More education about HIV, especially on the different ways of transmission to overcome the fear and moral judgments about people living with HIV as a way of addressing HIV-related stigma and discrimination.
Appendix 1: Regional Committees for Medical and Health Research Ethics in Norway letter (REK)

Amfinn Helleve
University of Oslo

2015/978 Åpnet om HIV-status blant gravide, HIV-positive kvinner ved en mor-havn klinikk i Tanzania.

RE Application received on the 12th of May 2015. The Regional Ethics Committee reviewed the project application at the meeting on the 11th of June 2015. The project was assessed by the Committee in accordance with the Norwegian Research Ethics Act of 30 June 2006 and Act on Medical and Health Research (the Health Research Act) of 20 June 2008.

Forskningsansvarlig: University of Oslo
Projektleder: Amfinn Helleve

Chief Investigator’s research project description

The research will provide an insight on experience of HIV seropositive status disclosure among HIV pregnant women and postnatal women enrolled in Prevention of Mother To Child Transmission program, what are the barriers and facilitator of disclosure of HIV status to sexual partner and family members. The knowledge will identify area which needs further support to improve uptake, retention and adherence in Prevention of Mother To Child Transmission to reduce HIV pediatric infections. Qualitative research design will be used with In Depth interview as data collection method. Qualitative design is good to explore people experience comprised of different beliefs, opinions, behavior, socioeconomic status, gender roles emotions. In depth interview is suitable for collecting data on individual personal histories, experiences, and perspectives especially on sensitive topic as HIV seropositive status disclosure experience.

The Committee’s evaluation of the project

The Committee considers that the aim of the project is not to generate new knowledge about health, disease, diagnosis or treatment, but to gain a better understanding of what the barriers and facilitators of disclosure of HIV status to sexual partner and family members are.

The project is therefore not considered to be taken in under the substantive scope of the Act on medical and health research (the Health Research Act), cf. § 2. The project can be carried out without an approval from the regional committee for medical and health research ethics in Norway.
Appendix 2: Approval for storage of information through the Norwegian Social Science Data Services (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Christoph Gradmann
Institutt for helse og samfunn Universitetet i Oslo
Postboks 1130 Blindern
0318 OSLO

Vår data: 24.07.2015
Vår ref.: 43893 / 5 / KS
Datoa data: 
Datoa ref: 

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 26.06.2015. All nødvendig informasjon om prosjektet forelå i sin helhet 17.07.2015. Meldingen gjelder prosjektet:

43893 Serostatus disclosure among HIV positive pregnant women enrolled at Prevention of Mother to child Transmission program at antenatal and postnatal care in Tanzania

Behandlingsansvarlig Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig Christoph Gradmann
Student Amen Remi Moshi

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være reguler av § 7-27 i personopplysningsforskriften. Personvernombudet tillår at prosjektet gjennomføres.

Personvernombudets tilrådende forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.


Personvernombudet vil ved prosjektets avslutning, 01.05.2016, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen
Knut Kalgraaff Skjåak

Katrine Utaaker Segadal

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.
Jotiproduksjon i Design Ottosien
OSLO NO (Universitetet i Oslo, Postboks 858 Blindern, 0316 Oslo 98, +47-23 85 57 11, nsd@nsd.no)
HENSÆTTELSER: Hugen teknisk naturvitenskapelige universitet, ZEFI-Institutt, tel. +47-51 36 36 01
HENSÆTTELSER: HUGEN SPH, Universitetet i Bergen, SPH Informat, tel. +47-55 56 84 35, nsdmedialavet.no

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Appendix3: Ethical clearance certificate from Muhimbili National Hospital Ethical Review Board

MUHIMBILI NATIONAL HOSPITAL

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: MNH/IRB/1/2015/05
Project Title: Sero status disclosure among HIV positive pregnant women enrolled at Prevention of mother to child Transmission program at antenatal and postnatal care in Dar es Salaam, Tanzania.
Principal Investigator: Amam Remi Moshi
Date of Approval: 24/07/2015
Expiration Date: 25/07/2016

On behalf of the Muhimbili National Hospital’s Institutional Ethics Review Board (MNH-IRB), I am pleased to inform you that ethical approval has been granted in respect to the undertaking of the above-mentioned project.

The Principal Investigator must ensure the following conditions are fulfilled:
1. Progress report is submitted to the MNH-IRB where applicable, annually, and final report at the conclusion of the project.
2. Amendments to the approved project (including change of personnel) are not effected before submission of request for amendment to MNH-IRB and a written approval from MNH-IRB.
3. Other Investigators are aware of the terms of approval and the project is conducted as approved by MNH-IRB.

We wish you well in your research

Dr. Samson Ndilo
Ag. Head of Teaching, Research and Consultancy unit

Dr. Hussein Kibangou
Ag. Executive Director

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Appendix 4: Permission to conduct research at MNH

MUHIMBILI NATIONAL HOSPITAL

Colleges

Telephones

Fax

Web

Postal Address

P.O. Box 62000
DAR ES SALAAM
Tanzania

In reply please quote:
Ref: MNH/IRC/R/035/393

Date: 03/08/2015

TO,

AMEN RENE MOSSI

RE: PERMISSION TO CONDUCT RESEARCH AT MNH NO: 393

You have been granted permission to conduct research at MNH.

| Name of Researcher | Amen Rene Mossi |
|-------------------|-----------------
| Research Title    | Prevention of Mother To Child Transmission Program at Antenatal and Neonatal Care in Tanzania |
| Type of Research  | Qualitative study |
| Valid Between     | 05th August, 2015 - 20th January, 2016 (6 months) |

Please note that:
1. Your report is expected to be submitted to the IRB Committee.
2. Publication of your findings needs permission from the management of MNH.

Sincerely,

Dr. COLOQO

Ag. Head, Teaching, Research and Consultancy Coordination Unit
Appendix 6: Informed consent form (Pregnant women and lactating mothers)

Jina lang ni ........................................mwanafunzi kutoka Chuo Kikuu cha Oslo Norway. Nimepata kibali kutoka Hospitali ya taifa ya Muhimbili cha kufanya utafiti juu ya mambo yanayochangia ushikikishi wa virusi vya ukimwi kwa wanawake wajawazito wenye maambukizi wanaohudhuria kliniki ya PMTCT hospitalini hapa. Dhumuni la utafiti huu ni kujua uzoefu wako wa kuishi na Virusi vya UKIMWI na ushirikishaji wa hali hiyo kwa mweza/mume/mtu wa karibu kuna vikwazo gani au nini kinachorahisisha ushirikishi hua. Taarifa zitakazo patikana kwenye utafiti huu zitasaidia Hospitali kuboresha huduma zitolewazo katika programu ya PMTCT.

Tutashukuru kutambua umuhimu wako kwa kujitolea kushiriki katika utafiti huu, uko huru kujitolea akyemani kama unakubali weka saini yako kwenye karatasi huu. Nimeridhia kushiriki katika utafiti huu wasiliana na mimi Amen Remi Moshi phone no +255 658 080 536

Kushiriki huku ni kwa hiari kama unakubali weka saini yako kwenye karatasi hii

Nimeridhia kushiriki katika utafiti huu

(Mshiriki) Tarehe .......................

Nimeelezea vizuri kuhusu utafiti huu

(Mtafiti) Tarehe .....................
Appendix 7: Informed consent form (Health providers)

Jina langu ni .......................... Mwanafunzi kutoka Chuo Kikuu cha Oslo Norway.


Kama unaswali, lolote, kuhusiana na utafiti huu wasiliana na mimi: Amen Remi Moshi phone no +255 658080536 arm.grets@gmail.com

Nimeridhia kushiriki katika utafiti huu

(Mshiriki) Tarehe ......................

Nimeelezea vizuri kuhusu utatifi huu

(Mtafiti) Tarehe ......................
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