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Prenatal HIV Screening of Pregnant Women in Ethiopia Using ‘Opt-out’ Approach: The Human Rights and Ethical Concerns

By

FANA HAGOS BERHANE

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Faculty of Social Sciences

School of Law

Declaration

I, Fana Hagos Berhane hereby declare that this thesis is my original work. Where information has been obtained from other sources, I verify that this has been revealed. I also confirm that it has not been submitted either in part or in full for any Degree or Diploma to this or any other university.

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Dedication

This doctoral dissertation is dedicated to my beloved mother, Azmera Haddis Dewel

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ABSTRACT

Following the recommendation of the WHO and UNAIDS the Ethiopian Government revised its guidelines on Prevention of Mother-to-Child Transmission to adopt a routine provider-initiated 'opt-out' HIV testing approach to all maternal health care services. The testing approach requires all pregnant women to be provided with HIV test unless they expressly decline it. This thesis examines the human rights and ethical implications of the implementation of this HIV testing approach within the maternal health care settings in Ethiopia to screen pregnant women. It argues that this HIV testing approach may be able to meet the pressing public health imperatives presented by the incidence of HIV in Ethiopia. However, a full understanding of the context in which this testing takes place reveals that, the implementation of this testing approach can result in the denial of pregnant women's rights to informed consent, to have access to adequate counselling and to ensure confidentiality of their HIV test results. This thesis argues that the implementation of routine provider-initiated 'opt-out' HIV testing approach in the maternal health care settings is affected by the weak health system, the feminization of poverty, and the persistence of HIV related stigma and violence as well as gender inequality.

The fieldwork undertaken in the Tigray region provided insights into the subjective experiences of women in relation to their ability to make autonomous decisions regarding the HIV test offered during their pregnancies. It involved in-depth semi-structured interviews with pregnant women and key stakeholders as well as non participatory observation. In addition, the normative and conceptual aspects of human rights and ethical principles inform the thrust of discussions and arguments in this thesis.

This thesis concludes that although the HIV testing approach adopted by the Ethiopian Government to screen pregnant women for HIV infections does not violate human rights requirements, its implementation in the context Ethiopian socio- economic, cultural and legal context raises serious concerns. The study therefore recommends that attention must be paid to balancing the scaling up HIV testing of pregnant women in Ethiopia to prevent vertical transmission of HIV and respecting the individual's rights to make their own medical decisions including refusing the HIV test.

List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
CEDAW	Convention on the Elimination of Discrimination Against Women
CSA	Central Statistical Authority
EDHS	Ethiopian Demographic and Health Survey
FDRE	Federal Democratic Republic of Ethiopia
HAPCO	HIV/AIDS Prevention and Control Office
HEP	Health Extension Program
HEWs	Health Extension Workers
HIV	Human Immunodeficiency Virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
M2M	Mother- to – Mother Support Group
MDG	Millennium Development Goal
MMR	Maternal mortality rate
MOH	Ministry of Health
MTCT	Mother-to-child transmission of HIV
NGO	Non-governmental Organization
NPEW	National Policy on Ethiopian Women
OAU	Organization of African Unity

PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
TBA	Traditional Birth Attendants
THB	Tigray State Regional Government Health Bureau
UDHR	Universal Declaration of Human Rights
UN	United Nations
VCT	Voluntary Counselling and Testing
WDA	Women Development Army
WHO	World Health Organization

Glossary of Tigrigna Terms

<i>Adetat Nadetae Gujelle</i>	Mother to Mother Support Group
<i>Be fitsum</i>	It can never happen
<i>Chikichek</i>	Argument/ quarrel
<i>Embiteгна</i>	Disobedient/ noncompliant
<i>Geat</i>	Porridge Like food
<i>Gelb</i>	Cultural ritual related to child birth.
<i>Guana</i>	A person with no blood relation
<i>Guejelle limeat Deki Anstio</i>	Women Development Army
<i>Kebelle</i>	Lowest Local Administrative Unit
<i>Lebam</i>	A reasonable/wise person
<i>Suk Ellie</i>	Nothing/ I have no reason
<i>Tikeat</i>	Violence
<i>Tserfi</i>	Insult
<i>Woreda</i>	District

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Starting from the early times of the Human Immunodeficiency Virus (HIV) epidemic there has been a strong public health impetus to decrease the spread of HIV by scaling up the provision of HIV testing that is believed not only to benefit individuals but also to reduce HIV incidence and prevalence. More importantly in the context of this study, HIV testing is the first crucial step in enabling pregnant women to take antiretroviral prophylaxis in order to substantially reduce the risk of transmission of HIV to their child if they tested positive to the infection. However, despite international, national and community led efforts it is estimated that a vast majority of pregnant women living with HIV do not know that they are infected with the virus particularly in countries severely hit by the epidemic.¹ In response to these realities there has been recent focus on the part of World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) as well as governments of many countries to the adoption of routine provider initiated 'opt-out' HIV testing approach to increase the accessibility of HIV testing particularly in high-prevalence countries.

¹ Joint United Nations Programme on HIV/AIDS (UNAIDS) *World AIDS Day Report 2012* (Switzerland: USAID, 2012). Available online at: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/jc2434_worldaidsday_results_en.pdf.> [Visited on 3 September, 2013].

This section of the chapter provides a brief summary of the way in which the various approaches of HIV testing have developed and in particular some of the main events that have influenced the discussion about routine provider – initiated 'opt-out' HIV testing approach.

Acquired Immune Deficiency Syndrome (AIDS) was first recognized clinically in 1981 in the United States of America (USA) and by 1985 as each region of the world reports at least one case, HIV/AIDS had become a global pandemic.² 1985 is also marked by the approval and the first use of a test for HIV in donor's blood in industrialized nations.³ From the outset, the manner of testing was controversial.⁴ Calls for mandatory HIV testing of 'high risk' groups (for example, gay men) were advanced within various contexts due to the enormous anxiety about the emerging AIDS epidemic.⁵ However, the lack of effective treatment combined with concerns related to HIV stigma, led to favouring of voluntary counselling and testing approaches where people are tested with procedures that fulfil the requirements of consent, counselling and confidentiality.⁶ This approach was later called 'HIV exceptionalism'. 'HIV exceptionalism' is a school of thought that distinguish HIV testing from screening for other communicable diseases in recognition of the

² T Tulchinsky and E Varavikova *The New Public Health*. 2nd Ed. (California: Elsevier Academic Press, 2009) 224.

³ Ibid.

⁴ See generally R Bayer and C Edington 'HIV Testing, Human Rights and Global AIDS Policy: Exceptionalism and Its Discontents' (2009) 34(3) *Journals of Health Politics, Policy and Law*, 301-323; R Bayer 'Sounding Board: Public Health Policy and the Aids Epidemic. The End to HIV Exceptionalism?' (1991) 324(21) *The New England Journal of Medicine*, 1500-1504; A Whiteside 'Is AIDS Exceptional?' Health Economics and HIV/AIDS Research Division, Working Paper number 25 (KwaZulu-Natal: University of KwaZulu-Natal, 2013). Available online at; http://www.aids2031.org/pdfs/aids%20exceptionalism_paper25.pdf. [Visited on 13 September 2013]; and MD April, 'Rethinking HIV Exceptionalism: The Ethics of Opt-out HIV Testing in sub-Saharan Africa', (2010)88 *Bulletin World Health Organization*, 703–708.

⁵ See R Knight *et al.*, 'Advancing Population and Public Health Ethics Regarding HIV Testing: A Scoping Review' (2014) 24(3) *Critical Public Health* 284.

⁶ Bayer above n 4 at 1502.

fact that, unlike some other infectious diseases, HIV/AIDS disproportionately affected populations who were already marginalized and attracted a deep social stigma against them.⁷

In 1994 it was established for the first time that HIV-infected pregnant women could reduce the risk of transmitting the virus to their infants by as much as two-third through the administration of zidovudine (ZDV).⁸ Furthermore, researches demonstrated that Mother- to- Child Transmission (MTCT) rates of HIV could be reduced below 2 percent in non breastfeeding populations and to 5 percent or less in breastfeeding populations by treating these women with potent combination antiretroviral (ARV) regimens that drastically reduce the viral load.⁹ On top of these, in 1996 at the XI International AIDS Conference in Vancouver, announcement was made on the availability of new albeit costly antiretroviral therapy to alter the clinical course of AIDS.¹⁰ The availability of these effective treatments with the prospect of preventing the birth of babies with HIV infection and of extending the lives of the already infected as well as the fact that the effective clinical management of HIV infection requires early identification, made some to call for routine HIV testing scheme to take hold.¹¹

In 2000 the XIIIth International AIDS conference in Durban called for acceleration of expansion of antiretroviral treatment worldwide, in particular, in counties hardest hit by the virus and for price

⁷ See generally R Jürgens *Increasing Access to HIV Testing and Counselling while Respecting Human Rights*, Background paper (New York: Public Health Program of the Open Society Institute, 2007). Available online at; http://www.soros.org/sites/default/files/increasing_20070907.pdf [Visited on 14 August, 2012]

⁸ M Yuen 'HIV Testing of Pregnant Women: Why Present Approaches Fail to Reach Desired Objective & the Unconsidered Option' (2007- 2008)14 *Cardozo Journal of Law and Gender* 186. Also see PA Clark, 'Mother-To-Child Transmission of HIV in Botswana: An Ethical Perspective on Mandatory Testing' (2006) 6(1) *Developing World Bioethics* 2.

⁹ World Health Organization (WHO) *PMTCT strategic vision 2010–2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goal* (.Genève, 2010) Available online at: http://whqlibdoc.who.int/publications/2010/9789241599030_eng.pdf. [Visited on 7 August, 2012].

¹⁰ Bayer and Edington above n 4 at 304.

¹¹ *Ibid* at 302.

to be cut.¹² WHO held consultation on new models of HIV testing and counselling services in 2001. At the consultation participants recognized the need for new models of HIV testing and counselling to rapidly scale up the provision, although they also underline that the new approaches should maintain the voluntariness and informed consent.¹³

In 2002 Kevin De Cock¹⁴ and his colleagues authored the widely cited paper titled '*Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century*'.¹⁵ De Cock *et al.* argued on the need for routinization of HIV testing in which patients would receive only essential information about HIV and routine testing should not require consent or pre-test counselling provided that all clients are informed that the testing is part of the package of services to which they are voluntarily attending.¹⁶ They claimed that enhancing access to testing represent a crucial first step toward realizing the rights of 'uninfected people to remain HIV negative, of infected individuals to benefit from treatment and prevention advice and of society to reduce the effects of HIV/AIDS'.¹⁷

In 2003, the WHO launched its '3 by 5 programme' with the goal of providing antiretroviral treatment to 3 million people by 2005.¹⁸ However, especially in developing countries the

¹² Whiteside above n 4 at 8.

¹³ See WHO Increasing access to knowledge of HIV status: conclusions of a WHO consultation, 3–4 December 2001 (Geneva: World Health Organization, 2001) 9. Available online at: http://www.who.int/entity/hiv/pub/vct/hiv_2002_09_en.pdf [Visited on 5 April, 2013]. See also Jürgens above n 7 at 11.

¹⁴ Kevin De Cock served as Director of WHO's HIV/AIDS Department from 2006 to 2009.

¹⁵ See generally K. De Cock *et al.* 'Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century', (2002) *Lancet* 68.

¹⁶ *Ibid* at 70.

¹⁷ *Ibid*.

¹⁸ See generally WHO *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector: Progress Report* (Genève, 2008). Available online at: http://www.who.int/hiv/pub/towards_universal_access_report_2008.pdf. [Visited on 9 September, 2013].

percentage of people who knew their HIV status was found to be very Low.¹⁹ To achieve this goal, as Bayer and Edington phrased it well, the necessity of radically scaling up HIV testing using the routine provider- initiated 'opt-out' approach became an 'article of faith'.²⁰

In 2004 Botswana, a country with one of the world's highest HIV/AIDS burdens became the first African country to launch the implementation of the new policy of routine provider-initiated 'opt-out' HIV testing approach followed by Lesotho and Uganda in 2005.²¹ Routine provider- initiated 'opt-out' HIV testing is an approach that requires health care providers to offer and conduct HIV testing to all persons who have contact with the health facilities, unless the person explicitly decline the testing.

In 2006 the Centres for Disease Control (CDC) in USA issued its *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Setting*.²² The revised CDC guidelines emphasized on achieving universal HIV screening during pregnancy and shied away from emphasis on counselling and voluntariness as essential components of prenatal HIV testing. In particular, the recommendations included the elimination of separate written consent for

¹⁹ *Ibid*

²⁰ Bayer and Edington above n 4 at 305.

²¹ See S Rennie and F Behets 'Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low- Income Countries' (2006) 84(1) *Bulletin of the World Health Organization* 54. Also see generally TL Creek, Successful Introduction of Routine Opt-Out HIV Testing in Antenatal Care in Botswana' (2007) 45 (1) *Journal of Acquired Immune Deficiency Syndrome*, 102-107 ; AP Clark 'Mother-To-Child Transmission of HIV in Botswana: An Ethical Perspective on Mandatory Testing' (2006) 6(1) *Developing World Bioethics* 1-12; and K Kenyon 'Routine HIV Testing: A View From Botswana' (2005) 8(2) *Health and Human Rights* 21-23.

²² Centres for Disease Control (CDC) *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, (Washington D,C : CDC,2006). Available online at; <http://www.cdc.gov/mmwr/PDF/rr/rr5514.pdf>. [Visited on 11 March, 2013].

HIV test by stating that "general consent for medical care should be considered sufficient to encompass consent for HIV testing."²³

In May 2007, the WHO and UNAIDS officially released a guidance- *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities* (herein after the 2007 WHO/UNAIDS guidance) to the global community recommending that routine provider - initiated 'opt-out' HIV testing approach be offered, in settings with high HIV prevalence, to pregnant women, people seeking services for other sexually transmitted infections and asymptomatic persons unless they explicitly opted out.²⁴ The 2007 WHO/UNAIDS guidance stated that the objective of scaling up provider-initiated HIV testing and counselling is to maximize the health and well-being of individuals through the timely detection of HIV, prevention of HIV transmission and subsequent access to appropriate HIV prevention, treatment, care and support services.²⁵

The guidance emphasize that WHO and UNAIDS do not support mandatory or compulsory testing of individuals on public health grounds by stating explicitly that 'endorsement of provider-initiated HIV testing and counselling by WHO and UNAIDS is not an endorsement of coercive or mandatory HIV testing.'²⁶ Furthermore, the guidance recognizes the need for adaptation to every country context, including: an assessment of the local epidemiology as well as the risks and benefits of routine provider-initiated 'opt-out' HIV testing and counselling, including an appraisal

²³ *Ibid* at 2.

²⁴ World Health Organization and United Nations Programme on HIV/AIDS (WHO/UNAIDS), *Guidance on Provider Initiated HIV Testing and Counselling in Health Facilities* (Switzerland: WHO/UNAIDS, 2007). Available online at http://www.who.int/hiv/who_pitc_guidelines.pdf. [Last visited 15 October, 2013].

²⁵ *Ibid* at 30.

²⁶ *Ibid* at 6.

of available resources, prevailing standards of HIV prevention, treatment, care and support, and the adequacy of social and legal protections available.²⁷

In 2007, the Ministry of health of the Government of the Federal Republic Democratic of Ethiopia revised its *guidelines on Prevention of Mother-to-Child Transmission* (here in after the 2007 PMTCT guidelines) to adopt and integrate the routine provider-initiated 'opt-out' HIV testing approach to all maternal health care services where all pregnant women would be provided with the test unless they expressly decline it.²⁸

By 2012 the routine provider-initiated 'opt-out' HIV testing approach was adopted by 42 (79.2 percent) of the 54 African countries to scale up HIV testing in their jurisdictions.²⁹ Though not a surprise, there are already 'success' stories on the increased number of pregnant women who tested for HIV in sub-Saharan Africa³⁰ including in Ethiopia.³¹ However, this aggressive expansion and espousal of the testing approach caused an alarm among those committed to human rights principles troubled by the potential for the new testing approach to pave a way for the erosion of

²⁷ *Ibid.*

²⁸ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother-to-Child Transmission of HIV* (Addis Ababa, 2007).

²⁹ See generally B. Hensen *et al.* 'From Caution to Urgency: The Evolution of HIV Testing and Counselling In Africa (2012) *Bulletin of the World Health Organization* 1. Available online at: <http://www.who.int/bulletin/volumes/90/9/11-100818/en/> (Visited on 30 February, 2012). According to this research findings Algeria, Angola, Chad, Egypt, the Libyan Arab Jamahiriya, Morocco, the Niger, Sao Tome and Principe and Tunisia are the countries that have not yet adopted the routine testing approach.

³⁰ See generally UNAIDS 2013 *Progress Report on the Global Plan; Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive* (Genève: UNAIDS, 2013) Available Online at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20130625_progress_global_plan_en.pdf [Visited on March, 2014].

³¹ *Ibid.* at 21. See also HAPCO *Report on Progress Towards Implementation of the UN Declaration of Commitment on HIV/AIDS* (Addis Ababa: HAPCO, 2010). Available online at: http://data.unaids.org/pub/Report/2010/ethiopia_2010_country_progress_report_en.pdf [Visited on 30 June, 2012].

the international human rights regime on HIV testing.³² The subsequent section proceeds to shed a light on the distinguishing features of routine provider- initiated 'opt- out' HIV testing approach.

1.2 Understanding Routine Provider- Initiated 'opt-out' HIV Testing Approach

HIV testing modalities can be broadly divided into two; Client-initiated counselling and testing (also called Voluntary Counselling and Testing) and Provider-initiated testing and counselling.

The Voluntary Counselling and Testing (VCT) approach involves individuals actively seeking HIV testing and counselling services that involve Counselling, Consent and Confidentiality (the 'three Cs'). The objective of VCT approach is prevention of HIV transmission and provision of emotional support of those who wish to consider HIV testing – to help the person make a decision about whether or not to be tested, and to provide support and facilitate decision making following testing.³³ VCT requires that individuals are notified that they will be tested, that they are provided with pretesting counselling to ensure fully informed consent, and that they will receive supportive post -test counselling for both negative and positive results, and that the results of testing will be kept confidential.³⁴

³² See E King *et al.* 'HIV testing for pregnant women: A rights-based analysis of national policies, Global Public Health' (2013) 8(3) *An International Journal for Research, Policy and Practice* 341, 326-341. Also see generally J Becker *et al.* 'Provider Initiated Testing and Counselling (PITC) for HIV in Resource-Limited Clinical Settings: Important Questions Unanswered'(2009) 3(4) *Pan African Medical Journal* 1-5; Bayer and Edington above n 4 at 302; Jürgens above n 7 at 32; and Rennie and Behets above n 21 at 54.

³³ A Strode *et al.* 'Scaling up HIV Testing in Resource Constrained Settings: Debates on The Role of VCT and Routine 'Opt-In or 'opt-out' HIV Testing' (2005) *The Southern African Journal of HIV Medicine* 47. Available online at, <http://www.ajol.info>. [Visited on 22 March 2014].

³⁴ Bayer and Edington above n 4 at 302.

An individual's right to know his or her HIV status motivate VCT and the onus is on the individual to access HIV testing services while clinicians must obtain informed consent and offer pre-test counselling services before commencing blood work. In some areas, people were even required to sign a separate informed consent form, which detailed the risks and benefits of being tested.³⁵ Since individuals freely elect to submit to HIV testing with the aim of knowing their HIV status, many argue that VCT is anchored in a human rights approach that respects individual autonomy, dignity, privacy and bodily integrity.³⁶

On the other hand, routine provider-initiated HIV testing approach refers to the HIV testing approach that is initiated by health care providers for persons attending health care facilities as a standard component of medical care.³⁷ In this testing approach any person who comes into contact with the health system is provided with an HIV test. Thus the testing becomes like any other test that can be recommended by the medical practitioner without requiring specific methods of counselling and informed consent before it was carried out. Hence, unlike VCT that relies on an individual taking the initiative to test for HIV, the routine provider initiated HIV test approach requires a health provider to make the initiatives by offering an HIV test to all patients in contact with the medical system, using each as a potential opportunity for HIV testing, diagnosis and linkage to care.

³⁵ King *et. al.*, above 32 at 339.

³⁶ M Njeru *et al.* 'Practicing Provider-Initiated HIV Testing in High Prevalence Settings: Consent Concerns and Missed Preventive Opportunities', (2011) 11 *BMC Health Services Research* 2. Available online at ; <http://www.biomedcentral.com/1472-6963/11/87> (Visited on 9 September, 2013).

³⁷ WHO/UNAIDS above 24 at 20.

Generally, the routine provider-initiated HIV testing approach can be described as; 'opt-in' and 'opt-out' of HIV testing. In cases of routine provider initiated 'opt-in' HIV testing approach, an HIV testing is available like any standard medical care service that will only be given if the person specifically requests it.³⁸ Often this means that only individuals who are worried about HIV (perhaps because they fit into a 'high-risk group') will agree to be tested. Crewe and Viljoen explain the meaning of 'opt- in' testing by identifying the pertinent questions that needs to be asked during testing. Accordingly, the question to the person to be tested is: 'Do you want to be tested?' rather than 'Do you refuse to be tested?'³⁹ The 'opt-in' testing approach is generally considered less effective than 'opt-out' testing approach because uptake tends to be much lower mainly due to the fact that such an approach exacerbates the common misconceptions among individuals that they simply do not need an HIV test and that health care providers will judge them if they do choose to get tested.⁴⁰

On the other hand, routine provider initiated 'opt-out' HIV testing approach is an HIV testing approach that presumes that anyone who enters a healthcare setting will be tested for HIV, unless the person actively declined the HIV test after the pre-test information is offered.⁴¹ In other words, the 'opt-out' HIV testing approach is a form of routine testing approach that requires health care professional to universally offer HIV testing to all individuals who have contact with the health

³⁸ See generally N Chingore 'Routine Testing of Individuals Attending Public Health Facilities: Are SADC Countries Ready?' in S Precious and F Viljoen (eds.) *Human Rights under Treat: Four Perspectives HIV, AIDS and the Law in Southern Africa* (Pretoria: Pretoria University Law Press, 2007) 55-92.

³⁹ M Crewe and F Viljoen *Testing Times Routine HIV Testing: A Challenge to Human Rights* (Unpublished , A Background Paper prepared for the International HIV Testing Email Group, 2005) [on file with the author of this thesis].

⁴⁰ Chingore above n 38 at 55. See also S Yeatman 'Ethical and Public Health Considerations in HIV Counselling and Testing: Policy Implications' (2007) 38(4) *Studies in Family Planning* 275.

⁴¹ H Jaffe, 'Increasing Knowledge of HIV Infection Status through 'opt-out' Testing 'opt-out' HIV Testing' (2009) 6 *Bioethical Inquiry* 230.

system while allowing them to decline the testing. Routine HIV testing differs from mandatory testing in that it implies a default policy of testing unless an individual specifically elects not to have it. Hence, clients or patients are required to actively 'opt-out' or decline the HIV test after pre-test information is provided by the health care providers. As put by a writer with 'opt-out', the default position is to be tested; with 'opt-in', the default is not to be tested.⁴²

The routine provider-initiated 'opt-out' HIV testing approach (herein after 'opt-out' HIV testing approach) is motivated by the objective of testing the greatest numbers of individuals possible, on the assumption that such testing will yield significant benefits in HIV prevention and treatment. Proponents of 'opt-out' HIV testing approach assert that the approach is crucial to achieve high coverage of HIV testing and prevention of mother-to-child HIV transmissions in the context of paediatric AIDS. In line with this argument, De Cock et al. have argued that the situation in Africa warrants a drastic response; hence, there is a need for emergency public health measures, which must be unencumbered by the 'need to protect individual freedom.'⁴³ De Cock et al. further argued that the emphasis on human rights in HIV/AIDS prevention has reduced the importance of public health and social justice, which offer a framework for prevention efforts in Africa that might be more relevant to people's daily lives and more likely to be effective.⁴⁴

⁴² K. De Cock, 'HIV Testing in the Era of Treatment Scale Up' (2005) 8(2) *Health and Human Rights* 33.

⁴³ See generally K. De Cock *et. al.*, 'Unfinished Business — Expanding HIV Testing in Developing Countries' (2006) 354(5) *The New England Journal of Medicine* 440 – 442.

⁴⁴ De Cock *et. al.*, above n 15 at 68.

Moreover, it has also been canvassed by proponents of routine 'opt-out' HIV testing approach that HIV testing is a 'gateway' to access to treatment.⁴⁵ The implication is that more and more people will be motivated to know their HIV status and to change their behaviour to prevent the spread of the epidemic to others and seek available care, support and treatment. For proponents of the 'opt-out' approach, relying on the traditional model of voluntary counselling and testing will not result in adequate numbers of people tested to meet treatment and prevention goals because it is client-rather than provider-initiated and is onerous in time and counselling requirements.⁴⁶

However, those who question the 'opt-out' HIV testing approach express their doubt about whether informed consent can be ensured in the context of routinely offered HIV testing under conditions of scarce human resources.⁴⁷ The unbalanced power relation in the provider-client relationship is also another area identified as a problem in enabling individuals especially those with lower social status to 'opt-out' HIV testing against the recommendation of the health care providers.⁴⁸ Others argued that women in particular are often unable to make HIV testing related decisions independently due to gender inequality and lack of knowledge.⁴⁹

⁴⁵ See generally UNAIDS *Current Debates on HIV Testing and Counselling* (Global Reference Group on HIV/AIDS and Human Rights, 2003). Available online at; http://data.unaids.org/Topics/Human-Rights/hrissuepaper_currentdebates_en.pdf [Visited on 20 August 2012].

⁴⁶ See De Cock above n 42 at 33.

⁴⁷ See O Ujiji *et al.*, 'Is "opt-out" HIV Testing' a real option among pregnant women in rural districts in Kenya?' (2011) 11 *BMC Public Health* 2. Available online at; <http://www.biomedcentral.com/1471-2458/11/151> [visited on 5 August, 2013]. See also R Bennett, 'Routine antenatal HIV testing and informed consent: an unworkable marriage?' (2007) 33(8) *Journal of Medical Ethics* 447; S Gruskin *et al.*, 'Provider-Initiated HIV Testing and Counselling in Health Facilities—What does this Mean for the Health and Human Rights of Pregnant Women?' (2008) 8(1) *Developing World Bioethics* 24.

⁴⁸ Rennie and Behets above n 21 at 54. Also see Gruskin *et al.* above n 47 at 26.

⁴⁹ See Ujiji *et al.*, above n 47 at 2. See also Bennett above n 47 at 447- 48; Gruskin *et al.* above n 47 at 27; and E Vernooij and A Hardon 'What mother wouldn't want to save her baby?' HIV Testing and Counselling Practices in a Rural Ugandan Antenatal Clinic, Culture, Health & Sexuality' (2013) 15(4) *An International Journal for Research, Intervention and Care* 554.

Furthermore, opponents of 'opt-out' HIV testing approach are sceptical that the scaling up of identification of HIV cases using the HIV testing approach would increase people's access to medical treatment.⁵⁰ They argue that mere conducting of HIV testing does not guarantee that the tested person will indeed receive ARVs, due to the unavailability of these medications in many settings and asking or demanding that people test for HIV without offering the benefits of ongoing treatment as needed is unethical.⁵¹

In this doctoral dissertation, I do not dispute the need to scale up access to HIV testing and counselling for pregnant women in Ethiopia to prevent mother-to-child transmission of HIV since it is both a human rights and public health imperative. However, my thesis critically assesses the human rights and ethical implications of the implementations of routine provider initiated 'opt-out' HIV testing approach to screen pregnant women for HIV in Ethiopia. It argues that the practical implementation of the 'opt-out' HIV testing approach is disconnected from enabling pregnant women to make their own informed decision regarding the testing due to the unbalanced power relation between the medical practitioners and the patients, social subordination of women, the under resourced and overburden health facilities and the persistence of HIV related stigma and violence.

1.3 Research Aims and Objectives

The aim of this study is to assess the human rights and ethical implications of the expansion of routine provider initiated 'opt-out' HIV testing approach in Ethiopia by drawing on the lived

⁵⁰ Crewe and Viljoen above n 39 at 6.

⁵¹ *Ibid.*

experience of women who tested positive to HIV during their access to maternal health care services. Hence, this study specifically aims to assess whether the scaling up of routine provider initiated 'opt-out' HIV testing approach in the maternal health care settings in Ethiopia would undermine the women's voluntary informed consent, their right for adequate counselling and the confidentiality of their HIV test results.

Specific objectives guided the data gathering process:

1. To review the existing human rights and ethical principles in relation to HIV testing enshrined under the different international and national human laws, policies and other binding documents to create a foundation for the following discussions;
2. To explore the nature of information provided to Ethiopian women during pre-test counselling under the routine provider initiated 'opt-out' HIV testing approach and the impact to empower the women to make an informed decision.
3. To determine if and how pregnant women visiting maternal health care settings are enabled to make their own informed consent regarding HIV testing under routine provider initiated 'opt-out' HIV testing approach;
4. To determine the influence of peer pressure on pregnant women's decision making in relation to HIV testing in the rural settings;
5. To determine the extent of the burden to disclose HIV positive results of the pregnant women and to assess the respect for confidentiality by the health care providers;
6. To determine on the negative social consequences of a positive HIV test result in the lives of the HIV positive women and their coping mechanisms;

7. To suggest ways by which the Ethiopian government can adhere to human rights principles and ethical standards while enhancing access to HIV testing in the context of PMTCT programme to ensure both public health and human rights objectives.

Research Questions

These objectives were formulated into the following research questions:

1. What are the distinguishing features of the routine provider initiated 'opt-out' HIV testing approach and how are they reflected under the 2007 Ethiopian PMTCT guidelines?
2. What are the human rights and ethical issues that are implicated in the process of the expansion and implementation of the routine provider initiated 'opt-out' HIV testing in maternal health care settings in Ethiopia?
3. How do the women perceive the contents of the counselling sessions under the routine provider initiated 'opt-out' HIV testing approach and the influence the messages conveyed have on the decision of the pregnant women to test for HIV?
4. How do the women perceive their experience of the decision making process under the routine provider initiated 'opt-out' HIV testing approach?
5. What are the Governmental structures at the grass root level in rural settings and how do they influence the individual decision to test for HIV during pregnancy and child birth?

6. What are the processes of disclosure for women who tested HIV positive under the routine provider initiated 'opt-out' HIV testing approach and the negative social consequence experienced by women?
7. What strategies can be suggested to balance the scaling up of the HIV testing uptake of pregnant women while respecting their fundamental rights and fulfilling the ethical requirements?

1.4 Contribution of the Study

The scaling up of prenatal HIV testing through adoption of the routine provider initiated 'opt-out' HIV testing that streamlined counselling and consent procedures has prompted debates among the ethics and human rights scholars. Critics questioned whether espousal of the routine provider initiated 'opt-out' HIV testing approach would threaten voluntary informed consent and counselling, whether confidentiality would be protected in overstretched health care facilities, whether clinical settings would provide adequate post-test counselling, support and linkages to treatment, and whether it contributes to the exposure of pregnant women tested positive for HIV to adverse consequence such as stigma, rejection and spousal abuse.⁵²

There are limited but growing body of empirical studies from African countries that assess the human rights and ethical concerns of the routine provider initiated 'opt-out' HIV testing approach. However, in relation to Ethiopia the researches have tended to concentrate on how to increase HIV testing uptake rather than to consider the extent to which the 'opt-out' testing approach is impinging upon the autonomy of women accessing maternal health care services. This study was

⁵² See generally Rennie and Behets above 21 at 52-7.

prompted by the limited nature in the literature of the human rights and ethical implication of the implementation of routine provider initiated 'opt-out' HIV testing approach in Ethiopia. It seeks to contribute to knowledge in two contexts.

First, this study will contribute to knowledge on the subject in sub-Saharan Africa and the discussion on the human rights and ethical concerns in relation to the implementation of routine provider initiated 'opt-out' HIV testing approach in the context of African countries severely hit by the HIV epidemic.

Second, the study will provide an in-depth understanding of the specific human rights and ethical concerns associated with implementation of the 'opt-out' HIV testing approach in Ethiopia by drawing on the lived experience of women who tested positive to HIV during their access to maternal health care services.

1.5 Structure of the Thesis

This thesis presents the findings of a study that examined the human rights and ethical implications of the expansion of routine provider initiated 'opt-out' HIV testing approach in Ethiopia by drawing the lived experience of women who tested positive to HIV during their visit to maternal health care services. The thesis is presented in nine chapters.

Chapter one begins by providing the background to and context for the HIV testing scheme in Ethiopia which is designed to prevent vertical transmission of HIV. It starts by providing a brief history to the various approaches to HIV testing. It explores the recent controversy over the different approaches of HIV testing and the influences that have led to the aggressive expansion of routine provider – initiated ‘opt-out’ HIV testing approach. The second section of the chapter discusses the distinguishing features of ‘opt-out’ HIV testing approach. It then presents the research objectives and research problems.

Chapter two discuss the situation of women’s vulnerability to HIV in Ethiopia by considering the different social, economic, cultural and legal factors that continue to exacerbate for the feminization of the epidemic in the country. The subsequent section in the chapter also provides overview of the HIV situation and health system of in Ethiopia followed by the discussion on the current status of the implementation of the PMTCT programme in Ethiopia. The third section assesses the legal and policy environment for the implementation of the new HIV testing approach to screen pregnant women for HIV infection in maternal health care settings in Ethiopia.

Chapter three builds on the understanding of the routine provide initiated ‘opt-out’ HIV testing approach and analyzes the theoretical frameworks of human rights and ethics that inform HIV testing. The purpose of the chapter is then to set the human rights and ethical standards in relation to HIV testing practice used as benchmark in evaluating the implementation of the routine HIV testing of pregnant women in Ethiopia in light of the data gathered from the field works. Hence relevant provisions of international and regional human rights instruments and their application are discussed under the first section followed by a discussion on the ethical concerns of the HIV

testing approach from the perspective of securing informed consent from pregnant women undergoing HIV testing.

Chapter four presents the methods employed in this study to answer the research questions. The purpose of the chapter is hence to provide readers a scientific justification for the research methods adopted in this thesis to collect preliminary data. It begins with a discussion of the approach taken to answer the research questions and the choice of research method. The second section sets out the research settings and sampling procedures adopted in this study including the discussion on the socio economic characteristic of the women who participated in this study. The third section presents the research process and the data collection tools employed in this study while the fourth and fifth section describes the post- fieldwork analysis and the writing up stage and the ethical considerations that were pertinent to this study. The chapter concludes with a discussion on the extent to which the methodological design was successful in generating data that were used to frame the debates in this thesis by facilitating the exploration of the lived experience of women in Ethiopia who tested positive to HIV during their pregnancies upon their visit to maternal health care services.

The findings are then presented in chapter five, six and seven. Chapter five begins by unpacking respondents' perception of the process of by pre-test counselling before they had the HIV testing at the maternal health care services. In doing so the findings presented under this chapter took readers from the point the women accessed the health facilities for pregnancy related health care service to the point where they have to agree or disagree to the HIV test offered to them. This chapter uses the data from the in-depth semi-structured interviews with women who took HIV testing in

relation to PMTCT and health care workers. Insights have also been drawn from the non participatory observations that were conducted in an antenatal care in Mekelle hospital.

Chapter six presents the findings related to how these women experienced the process of decision making for the HIV testing offered at the ANC or labour wards in order to have better understanding of how and why these decisions are made and if they meet the informed consent criteria. The first section of this chapter explores respondents' experience of HIV testing during their visit to health facilities for antenatal care. The section presents the findings of how and why the women who participated in the study decided to up take or refuse the HIV testing offered to them. The section also explores the process of decision making for pregnant women in rural settings and their exposure to peer-pressure through the informal local structure of WDAs. The second section examines the experience of the women who underwent HIV testing during their delivery. The third section presents the stories shared by participants to reveal the patient practitioner relationship in the context of HIV testing and its impact in the informed consent of the women while the fourth section deals with reports of clinic avoidance by respondents for fear of being tested for HIV. The last section provides a conclusion.

Chapter seven continues to present the findings of this study that shows the 'opt-out' HIV testing approach does not necessary address HIV-related stigma and intimate violence against women as contended by the PMCT guideline of the Ethiopia government. The chapter reveals that HIV related social stigma is still profound in Ethiopia. Information on the lived experience of the research participants in relation to the stigma and discrimination ranging from loss of friendships, rejection, negative reactions and domestic violence are presented.

Chapter eight provides an in-depth discussion of the findings of this study. The chapter discusses the main findings of the study that show how the scaling up of HIV testing using the routine provider initiated 'opt-out' testing approach in maternal health care setting in Ethiopia undermines the women's voluntary informed consent, their right to adequate counselling, the confidentiality of their HIV test results and that of the real exposure of women to violence and stigma due to their HIV positive results of the prenatal test.

Chapter nine provides the conclusion and recommendation.

CHAPTER – TWO

HIV, WOMEN AND PRENATAL HIV TESTING IN ETHIOPIA

2.1 Introduction

This thesis is primarily concerned with the human rights and ethical implications of the adoption of routine provider initiated ‘opt -out’ HIV testing approach to screen pregnant women for HIV infection. Mother-to-child transmission of HIV is the major cause of paediatric HIV infection in Ethiopia. To tackle this problem the Ethiopian Government launched PMTCT programme and has the goal to eliminate new paediatric HIV infection by 2015. However, MTCT prevention methods during pregnancy and child birth require knowledge of the mother's HIV infection in advance. As the previous chapter revealed Ethiopia has adopted routine provider initiated ‘opt -out’ HIV testing approach in all maternal health care services to screen pregnant women for HIV. Like their counterparts in sub-Saharan Africa women in Ethiopia face a number of vulnerabilities to HIV/AIDS that emanate from various social, cultural, economic, political and legal factors that contribute to inequality and violations of women’s human rights

This chapter begins with a discussion of the existing HIV situation and the health system of the country followed by a section that explores why women in Ethiopia are increasingly at risk from HIV/AIDS. This section discusses the position of women in Ethiopia and their overlapping vulnerabilities to both HIV/AIDS and human rights abuse to support the argument that Ethiopian women’s universal subordination and the systematic abuse of their rights need to be addressed fully in the development and

implementation of HIV- related policies and programs including HIV testing schemes that target women. The third section focuses on the different legal and policies frameworks adopted by the Ethiopian Government to address these issues and assesses their direct and indirect impact on reducing the vulnerability of women in Ethiopia to HIV/AIDS.

The fourth section introduces the current Government programme on prevention of mother-to-child transmission of HIV in Ethiopia. It describes its utilization and coverage as well as the policy measures being taken to scale up the number of pregnant women tested for HIV/AIDS. The last section assesses the legal and policy environment for the implementation of the new HIV testing approach. It argues that, since at least theoretically the routine provider-initiated 'opt-out' HIV testing approach allows for informed consent and the right to refuse for individuals who do not wish to test, the approach does not necessarily contradict with the existing legal and policy framework of the country. However, the full understanding of the context in which this testing takes place reveals that, the implementation of the 'opt-out' HIV testing approach can result in the denial of pregnant women's rights to informed consent, to have access to adequate counselling and to ensure confidentiality of their HIV test results.

2.2 HIV Situation and Health System in Ethiopia

This section provides an overview of the structure of the Ethiopian health system and the situation of HIV/AIDS in Ethiopia. It begins with a brief description and historical background to the country to enable the reader to appreciate the findings and discussions of this study in the broader socio-economic, cultural and legal context of the country.

2.2.1 Country Profile

Ethiopia is the oldest independent country in the world. Its history as an organized and independent polity dates back to the beginning of the second century with the formation of kingdom of Axum in the northern state of Tigray. The country extends to a 1,104,300 square kilometres. Geographically, making it the tenth largest in Africa, Ethiopia ranges from highlands with peaks of 4500 meters above sea level to the Afar depression, 110 meters below sea level (See Map: 1).



Map 1- The Map of Ethiopia (Source: <http://www.infoplease.com/atlas/country/ethiopia.html>)

Before 1974 Ethiopia was governed by a monarchy whose fall resulted in 17 years of military rule and Marxist dictatorship. After a prolonged and devastating civil war, in 1991 a coalition led by the

Ethiopian People's Revolutionary Democratic Front (EPRDF) ousted the military regime. This period marked the transition to democratic rule which has transformed the country from a single party state into a multiparty federal republic. Administratively, Ethiopia is a democratic country with a federal system government comprising of nine federating regional states (Tigray, Afar, Amhara, Benishangul-Gumuz, Gambella, Harare, Oromia, Somali, and Southern Nation Nationalities and Peoples Region (SNNPR)) and two Administrative Councils (Addis Ababa and Dire Dawa).¹ The capital city Addis Ababa is the largest city in the country, serving as the headquarters of the African Union. Ethiopia was a member of the League of Nations, a founding member of both the United Nations and the then Organization for the Africa Union (now African Union).

The population of Ethiopia in 2007 was estimated at 74 million.² In 2012, based on projections from the national census of 2007, it was estimated at 84 million making the nation the second most populous country in sub-Saharan Africa.³ According to the 2007 census, Ethiopia is one of the least urbanised countries in the world with only around 17 percent of the population living in urban areas.⁴ A mosaic of many cultures, the country is home to more than 87 ethnic groups each with their own language although Amharic is the official language of the country.

¹ The Federal *Negarit Gazetta*, The Constitution of the Federal Democratic Republic of Ethiopia Proclamation No. 1/1995 Art. 47 (1).

² See Central Statistical Agency of Ethiopia (CSA) *Population and Housing Census Report-Country* (Addis Ababa: CSA, 2007) 5.

³ Central Statistical Agency of Ethiopia (CSA) *Population Projections for Ethiopia 2007-2037* (Addis Ababa, CSA, 2013) 7.

⁴ CSA above n 2 at 7.

According to Government reports, Ethiopia's economy continued to grow rapidly for the last ten consecutive years registering a real GDP growth rate of 11.4 percent.⁵ However, the country is still ranked amongst the poorest countries in the world with per capita income, estimated at 235 USD per annum which is below the sub-Saharan average.⁶ Ethiopia's Poverty Head Count Index has declined from the 1996 level of 45.5 percent to 32.7 percent in 2007/08.⁷ Ethiopia's economy is heavily dependent on the agricultural sector even though the sector primarily consists of smallholder farmers who cultivate over 95 percent of the total agriculture land of the country.⁸

2.2.2 The Health System in Ethiopia

The 1996 Ethiopia's health policy states the democratization and decentralization of the health care system. The devolution of power to regional governments has resulted in largely shifting the decision making for public service delivery from the centre to the authority of the regions and down to the district level.⁹ Offices at different levels from the Federal Ministry of Health to Regional Health Bureaus and *Woreda* (district) Health Offices share in decision making processes, powers, duties and responsibilities. The Ministry of Health and the Regional Health Bureaus focus more on policy matters and technical

⁵ Ministry of Finance and Economic Development (MoFED) *Macroeconomic Developments in Ethiopia. Annual Report 2010/11*. Available online at: <http://www.mofed.gov.et/m/Resources/MEDR-EFY2003-AnnualFinal10012012-Final.pdf>. [Visited on 2 May 2012].

⁶ *Ibid* at 3.

⁷ *Ibid*.

⁸ See H Mohajan 'Ethiopia: A Socio-Economic Study' (2013)5 *Journal of Business Management and Administration* 66.

⁹ Federal Ministry of Health of Ethiopia (MOH) *Health Sector Development IV 2010/11-2014/15* (Addis Ababa: MOH, 2010) 4. Available online at : http://www.nationalplanningcycles.org/sites/default/files/country_docs/Ethiopia/ethiopia_hsdp_iv_final_draft_20102015.pdf [Visited on 3 August , 2012].

support while the *Woreda* Health Offices manage and coordinate the operation of the district health system under their jurisdiction.¹⁰

Ethiopia generally has poor health indicators and an inadequate health care system. The health status of Ethiopia's population remains poor, characterized by high rates of mortality and morbidity. The life expectancy for Ethiopians at birth was about 57 years in 2012 (59.21 year for females, 53.99 years for males).¹¹ Ethiopia's physician to population ratio is 1: 36,158 which remains well below the WHO standard of 1:10,000 and is over five times below the average for sub-Saharan Africa.¹² The exodus of health care professionals abroad due to poor working conditions and low salaries is an important factor in accounting for the critical shortage of health workers.¹³

Like in many sub-Saharan Africa countries, high maternal and infant mortality rate is one of the most intractable public health problems. Multiple sources estimate the maternal mortality ratio (number of maternal deaths per 100,000 live births) in Ethiopia to be above 650.¹⁴ This statistics that places Ethiopia among the top 3 sub-Saharan African countries for the number of maternal deaths and one of the six countries that contributes to about 50 percent of the maternal death worldwide.¹⁵ At a national level only 10 percent of births occur in a health facility and only 1.5 percent of births are caesareans.¹⁶ As a result, around 90 percent of Ethiopian births take place at home because most women live in remote rural areas

¹⁰ *Ibid* at 24.

¹¹ *Ibid*.

¹² See R Wamai 'Reviewing Ethiopia's Health System Development' (2009) 52(4) *Japan Medical Association Journal* 280.

¹³ *Ibid*.

¹⁴ Central Statistical Agency of Ethiopia (CSA) and ICF International *Ethiopia Demographic and Health Survey 2011* (Addis Ababa: CSA, 2012) 270 (here after EDHS 2011). See also M Koblinsky, 'Reducing Maternal and Prenatal Mortality through a Community Collaborative Approach: Introduction to a Special Issue on the Maternal and Newborn Health in Ethiopia Partnership' (online) (2014) *Journal of Midwifery and Women's Health* 3. Available online at: <http://onlinelibrary.wiley.com/doi/10.1111/jmwh.12174/full>. [Visited on 3 June, 2014].

¹⁵ Koblinsky above n 14 at 51.

¹⁶ *Ibid*.

where they cannot easily access health facilities at the time of child delivery. Access to family planning is one way to improve maternal ill health. However, in Ethiopia there are high unmet needs for family planning although progress has been achieved that the percentage of women aged 15-49 using contraceptive was reported to have grown to 28 percent in 2011 from 15 percent 2005.¹⁷

Furthermore, childhood mortality is also still among the highest in Africa: the under-five mortality rate was 104 per 1000 in 2009.¹⁸ Reports show that one in every 13 Ethiopian children dies before his or her first birthday, and one in 8 dies before age five.¹⁹ A preliminary comparison of levels of malnutrition in the 2005 and 2011 Ethiopian Demographic and Health Survey (EDHS) using the new WHO standard indicates that in Ethiopia stunting has declined from 52 to 44 percent and underweight from 34 to 29 percent.²⁰ Behind these high maternal and child mortality numbers in Ethiopia lie the problems of access, poor use of maternal health services and wide equity disparities in their use (for example the differences between urban and rural provision) that lead to the low rate of skilled care during pregnancy and delivery.²¹

To address this challenging environment, the Government of Ethiopia has recently established a policy of zero tolerance for home births which is expected significantly to decrease maternal and infant mortality rates over the long term. The Government is seeking to improve health care outcomes by targeting households and communities through its flagship programme the Health Extension Program

¹⁷ EDHS 2011 above n 14 at 96.

¹⁸ The United Nations Children's Fund (UNICEF) *Levels and Trends of Child Mortality: 2013 Report* (New York: UNICEF, 2013) 20. Available online at: http://www.childinfo.org/files/Child_Mortality_Report_2013.pdf [Visited on 14 September 2014].

¹⁹ Mohajan above n 8 at 64.

²⁰ UNICEF *Investing in Boys and Girls in Ethiopia: Past, Present and Future* (Ethiopia: UNICEF, 2012) 35.

²¹ F Hagos 'The Right to Survive Pregnancy and Childbirth Ethiopia' (2009) 2(1) *Ethiopian Journal of Legal Education* 70.

(HEP) which it launched in 2003.²² This programme aims to improve access to basic essential health services in severely under-served rural and remote communities, with the goal of achieving universal primary health care. The HEP service package mainly focuses on promotional and preventive interventions designed to tackle cultural issues, develop personal and social skills as well as increase health awareness that enables individuals to take action to promote their own health.²³ The HEP service package provides a family health service which includes family planning, antenatal care, prenatal HIV testing, assisted delivery, postnatal care and immunizations to address the high maternal and child mortality.²⁴ The HEP is said to have enabled Ethiopia to increase its primary health care coverage from 76.9 percent in 2005 to 90 percent in 2010.²⁵

Developing a cadre of Health Extension Workers (HEWs) who provide basic curative and preventive health service to every rural village is part of a distinctive strategy adopted by the Ethiopian Government to implement the HEP. HEWs are all Government-salaried women trained for one year and deployed into the rural community to promote health. By 2013 over 35,000 HEWs were working in rural areas throughout the country (except in pastoralist areas) recruited from their respective communities.²⁶ The majority of their time is spent conducting door-to-door visits to educate women about the benefit of seeking antenatal care, HIV testing during pregnancy and institutional child delivery, while performing outreach activities such as educating families to adopt a healthy lifestyle, especially improved hygiene and sanitation.²⁷

²² MOH 'Health Sector Development Programme' above n 9 at 12.

²³ *Ibid.*

²⁴ H Teklehaimanot and A Teklehaimanot 'Human Resource Development for a Community-Based Health Extension Program: A Case Study From Ethiopia' (2013) 11 *Human Resources for Health* 2.

²⁵ H Banteyerga, 'Ethiopia's Health Extension Program: Improving Health through Community Involvement' *International Journal of Cuban Health and Medicine* 46.

²⁶ MOH 'Health Sector Development Programme' above n 9 at 4.

²⁷ Koblinsky above n 14 at 51.

With the same objective of ensuring community engagement, ownership and social mobilization, the Government of Ethiopia has recently established a Health Development Army (HDA). This initiative is seen as a top priority. The formation of the HDA is facilitated by the HEWs and *Kebele* (local) administrations by establishing health development teams that comprise of up to 30 households residing in the same neighbourhood that would be further divided into smaller groups of six members, commonly referred as one-to-five networks.²⁸ The leaders of the one-to-five networks are selected by the team members based on the main criteria of being part of a model family and trusted by the members in mobilizing the community.²⁹

The formation of the health development teams and the one-to-five networks is facilitated by HEWs in collaboration with the *Kebele* administration. The performance of the HDA is monitored by a coordinating committee drawn from various Government sectors that meets every month and is chaired by the local administrators.³⁰ Although the gender composition of these HDAs is mixed in other parts of the country, in Tigray state (the study area for this doctoral study) the HDA is women-centred. It is known as the Women Development Army (WDA) and sometimes also referred to as the Women Health Development Army (WHDA). Members of the WDAs, with the technical support of the HEWs, discuss issues relating to healthy lifestyle among themselves during the weekly structured community dialogue sessions.

WDAs are instrumental in implementing health programmes deeper into communities, drilling all the way down to families by identifying and locating pregnant women in the villages and linking them to

²⁸ K. Admasu, 'The Implementation of The Health Development Army: Challenges, Perspectives and Lessons Learned with a Focus on Tigray's Experience' (2013) 5 *Quarterly MOH Health Bulletin* 4.

²⁹ *Ibid.*

³⁰ *Ibid.*

HEWs for antenatal check-ups and other maternal health care services. More importantly to the subject matter of this doctoral study, the HEWs and WDAs are instrumental in the enrolment of pregnant women in rural areas to PMTCT programmes as will be seen in chapter 5 to 7 of this thesis.

WDAs and HEWs have received commendation from the minister of the Federal Ministry of Health (FMOH) of Ethiopia for providing an unprecedented platform to improve maternal and child health service provision and utilization including PMTCT.³¹

2.2.3 HIV Situation in Ethiopia

In Ethiopia, HIV infection is thought to have begun in the early 1980s with the first AIDS case reported in 1986.³² The level of HIV spread in Ethiopia has evolved into a generalised epidemic (defined as more than 1 percent prevalence) leading the government of Ethiopia to declare a public health emergency in 2002. HIV/AIDS prevalence remained low in the 1980s but sharply accelerated through most of the 1990s, rising from an estimated 2.7 percent in adults (15–49 years age group) in 1993 to 7.3 percent by 2000.³³ Recent reports from UNAIDS reported that Ethiopia is one of 22 sub-Saharan African countries that succeeded in reducing their national rate of new HIV infections by 25 percent between 2001 and 2009.³⁴ Currently, according to the 2011 Ethiopian Demographic and Health Survey, the national adult HIV prevalence of the country is reported to be 1.5 per cent.³⁵

³¹ *Ibid.*

³² H Kloos and D Hailemariam 'HIV/AIDS in Ethiopia: An Overview' (2000) 7(1) Northeast African Studies 14.

³³ HAPCO and MOH HIV/AIDS Behavioural Surveillance Survey (BSS) Ethiopia (Addis Ababa: MOH and HAPCO 2005).

³⁴ UNAIDS, 'Global Report: UNAIDS Report on the Global AIDS Epidemic 2010', (2010) 8. Available online at http://www.unaids.org/documents/20101123_GlobalReport_em.pdf [Visited on 9 August 2012].

³⁵ EDHS 2011 above n 14 at 234.

Although HIV prevalence in Ethiopia is lower than many sub-Saharan countries, in 2009 it was estimated that there were 1,116,216 people living with HIV in Ethiopia, making the country one of the hardest hit by the epidemic in the world.³⁶ In the same year it was estimated that there were about 855,720 orphans in the country who have lost at least one parent due to AIDS.³⁷ In addition, annually approximately 131,154 new HIV infections were estimated to occur countrywide (57 percent female) and 44,751 AIDS-related deaths (57 percent female).³⁸ Therefore, HIV/AIDS is still a major public health problem in the country. HIV in Ethiopia is predominantly spread through unprotected heterosexual intercourse, which accounts for approximately 88 percent of all HIV infections.³⁹

HIV prevalence in Ethiopia is marked by its wide variation between urban and rural settings. The 2011 Ethiopian Demographic and Health Survey (EDHS) reported that urban adult HIV prevalence is 4.2 percent while the rural adult HIV prevalence is 0.6 percent.⁴⁰ Taking into consideration the fact that nearly 85 percent of the Ethiopian population resides in the rural settings, the reported low prevalence should not offer the Ethiopian Government a false sense of security. Besides, there are reports that show people living in peri-urban and small market towns are the most at risk segments of the population.⁴¹ The increase in HIV infection in small market towns suggests that there is potential for the disease to explode across Ethiopia's rural population.

³⁶ See HAPCO, *Report on Progress towards Implementation of the UN Declaration of Commitment on HIV/AIDS* (Addis Ababa: HAPCO, 2010) 13.

³⁷ *Ibid.*

³⁸ *Ibid.*

³⁹ K. Gilber et al. *Human and Financial Resource Requirements for Scaling Up HIV/AIDS Services in Ethiopia* (2004). Available online at http://www.abtassociates.com/reports/AB_PNADC109.pdf [Visited on 13 August 2012].

⁴⁰ MOH and HAPCO 2012 *Country Progress Report on HIV/AIDS Response* (2013) 10. Available online at <http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/GAP%20Report%202012.pdf> [Visited on 3 September, 2013].

⁴¹ WHO, UNAIDS, UNICEF *Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access* (2011). Available online at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20111130_ua_report_en.pdf [Visited on 14 August 2012].

The other feature of the HIV epidemic in Ethiopia is the fact that women are increasingly at risk of HIV infection. In sub-Saharan Africa, women account for a larger share of those directly affected by HIV/AIDS.⁴² In Ethiopia, the gender ratio of HIV infection started to change from male to female dominated rates around 1990.⁴³ Data from the 2011 EDHS shows that HIV prevalence is higher for women than men in most age groups indicating the feminization of the HIV epidemic in Ethiopia. The report shows that HIV prevalence is 1.9 percent among women age 15-49, while the prevalence among men of the same age range is 1.0 percent.⁴⁴ In urban areas, women are more likely to be infected than men (5.2 percent and 2.9 percent, respectively).⁴⁵ These estimates suggest therefore that HIV/AIDS has become more and more a disease of women in Ethiopia. The subsequent section of the chapter provides a discussion of the social mechanisms that make women vulnerable to HIV infection.

2.3 The Situation of Women in Ethiopia and their Vulnerability to HIV/AIDS

A range of factors contribute to the peculiar vulnerability of women to HIV/AIDS. Women in Ethiopia are victims of discrimination in their economic, social and political lives which directly or indirectly contribute to their exposure to HIV/AIDS. This section discusses the position of women in Ethiopia and their overlapping vulnerabilities to both HIV/AIDS and human rights abuse to support the argument that Ethiopian women's universal subordination and the systematic abuse of their rights need to be addressed fully in the development and implementation of HIV- related policies and programmes including HIV testing schemes that target women.

⁴² *Ibid.*

⁴³ H. Kloos 'The AIDS Epidemic in a Low – Income Country: Ethiopia' 2007 14(1) Human Ecology Review 42.

⁴⁴ EDHS 2011 above n 14 at 234.

⁴⁵ *Ibid* at 235.

2.3.1 The Position of Women in Ethiopia

Women in Ethiopia suffer from many forms of inequality, discrimination and marginalization. In 2013 the World Economic Forum ranked Ethiopia 118th out of 136 countries worldwide in terms of gender equality.⁴⁶ Women in Ethiopia have less access to land and resources, fewer opportunities of educational attainments and employment and face considerable risks of gender-based violence. They are also politically under represented. In the parliament, only 27.8 percent (152 of the 547 seats) of the House of Peoples' representative seats are held by women.⁴⁷ No woman candidate from the opposition parties was elected during the national elections held in 2010. Despite the recent double digit economic growth in the Ethiopian economy, almost one third of the population continues to live below the poverty line.⁴⁸ The burden of poverty in Ethiopia falls more heavily on women.

Significant progress has been realized in girls' education during the last two decades. However, in 2011 it was reported that around 60 percent of women in Ethiopia had no education and were unable to read and write.⁴⁹ This makes Ethiopian women seriously disadvantaged regarding educational attainment and hence underrepresented in the job market. Most women in Ethiopia are employed in traditionally female jobs in the informal sector.⁵⁰ According to the 2005 National Labour Force Survey among the employed population in Ethiopia 46.4 percent was women and 79.25 percent of them were illiterate.⁵¹ The breakdown of the federal government employees by occupational groups also indicated gender disparity.

⁴⁶ World Economic Forum *The Global Gender Gap Report 2013* (Switzerland: World Economic Forum, 2013) 10. Available online at: <http://reports.weforum.org/global-gender-gap-report-2013/> [Visited on 19 February /2014].

⁴⁷ See Concluding observations of the Committee on the Elimination of Discrimination against Women, Ethiopia (2011) CEDAW/C/ETH/CO/6-7, para. 244.

⁴⁸ UNDP *Programme Document for Ethiopia* (New York: United Nations, 2012). Available online at <http://Undp.Org/Africa/Programme.Shtml>. [Visited on 2, May, 2013]

⁴⁹ EDHS 2011 above n 14 at 40.

⁵⁰ Central Statistical Authority of Ethiopia (CSA) '*Urban Bi-Annual Employment Unemployment Survey*' (Addis Ababa: CSA, 2004).

⁵¹ Central Statistical Authority (CSA) 'Report on the 2005 national Labor Force' (2004) *Statistical Bulletin* 365.

In 2005, of the federal government employees found in clerical and fiscal type of jobs 71.3 percent were female, while the percentage of females in the administrative and professional and scientific job categories constitutes only 18 percent.⁵² This concentration of women in the informal sector and low level positions has serious implications for their income and hence their socio-economic status.

Gender based violence is also rampant in Ethiopia. The practice of early marriage persists in Ethiopia. For example in *Amhara* regional state about 80 percent of girls are married by the time they are eighteen, half by the age of fifteen; and the most common age for a girl to marry is twelve.⁵³ The latest EDHS revealed similar findings that marriage takes place relatively early throughout Ethiopia although an increase in the median age of marriage has been observed from 16.7 years in 2000 to 17.1 years in 2011.⁵⁴ Marriage by abduction is still culturally acceptable in some areas and in 2005 it was estimated that 8 percent of married women were abducted and forced into the marriage.⁵⁵ Marital rape is not considered as crime under the new criminal code since one element of the crime of rape is that the act should occur outside wedlock.⁵⁶ In some societies in Ethiopia widow inheritance (the practice of a widow of a deceased man being inherited by one of the man's brothers) is also widely practiced.

Although comprehensive data is not available on the magnitude of domestic violence against women in Ethiopia, smaller scale studies indicate that it is pervasive. The 2005 multi country study conducted by WHO revealed that in Ethiopia the proportion of women who had suffered physical or sexual violence

⁵² See CSA 'Urban Bi-Annual Employment'.

⁵³ B Rodgers 'Child Marriage In Ethiopia And Its Associated Human Rights Violations' (2012) *University of Washington Bothell Policy Journal* 15.

⁵⁴ EDHS 2011 above n 14 at 234.

⁵⁵ Central Statistical Agency of Ethiopia(CSA) and ORC Macro *Ethiopia Demographic and Health Survey 2005*(Addis Ababa: CSA and ORC Macro, 2005).

⁵⁶ The Federal *Negarit Gazzetta* of the Federal Democratic Republic of Ethiopia, The Criminal Code , proclamation No. 414/2004, article, 620.

by a male partner was 71 percent.⁵⁷ The same study also showed that Ethiopian women believe that a husband is justified in beating his wife if she disobeys him (78 percent) or if she is unfaithful (80 percent).⁵⁸ Similarly, another study reported that two out of every three women (68 percent) agree that a husband is justified in beating his wife for refusing sexual intercourse with him, or arguing with him, or going out without telling him or burning food.⁵⁹

2.3.2 Vulnerability to HIV/AIDS of Ethiopian Women

The links between gender inequality and increased vulnerability to HIV infection among women and adolescent girls have been well documented.⁶⁰ The 'feminization' of the HIV epidemic is fuelled by biological factors, which puts women more at risk of infection than men. It has now been established that women's risk of HIV infection from unprotected sex is higher than that of men.⁶¹ However, the vulnerability of women to HIV/AIDS of such a high magnitude cannot be explained solely by biological differences between women and men. The gender analysis of HIV/AIDS vulnerability is important as Doyal argued 'gender differences are especially significant for women, since they usually mean inequality and discrimination'.⁶² Women's disproportionate vulnerability to HIV infection and reproductive ill health stems from social, cultural, economic, and political realities at the international,

⁵⁷ See World Health Organization *Multi-country Study on Women's Health and Domestic Violence against Women*, (Genève: WHO, 2005) 6. Available on line at; http://www.who.int/gender/violence/who_multicountry_study/summary_report/summary_report_English2.pdf [Visited on 6 September, 2013)

⁵⁸ *Ibid.*

⁵⁹ EDHS 2011 above n 14 at 256.

⁶⁰ L Fuller, 'African Women's Unique Vulnerabilities to HIV/AIDS: Communication Perspectives and Promises' (New York: Palgrave Macmillan, 2008) 125. See also C Eyakuze *et al.* 'From PMTCT to a More Comprehensive AIDS Response for Women: A Much-Needed Shift' 2008) 8(1) *Developing World Bioethics* 34.

⁶¹ *Ibid.*

⁶² L. Doyal, *What makes women Sick , Gender and the Political Economy of health* (London: Macmillan , 1995).

national, and community level, not simply from their immune systems or biology.⁶³ The Committee on the Elimination of All Forms of Discrimination under its General Recommendation number 24 states in a clear language that the unequal power relations based on gender and the persistence of harmful traditional practices expose girls and women to the risks of contracting HIV/AIDS and other sexually transmitted diseases.⁶⁴ There is evidence from countries where data is available that economic inequalities between women and men play a role in increasing vulnerability and exposure to HIV.⁶⁵

Women constitute an economically vulnerable group within the Ethiopian society which prohibits them from being able to terminate a potentially dangerous relationship, to have access to information regarding HIV/AIDS and to negotiate the use of condoms in relationships. Evidence about the relationship of educational attainment and risk of HIV infection vulnerability in the context African women is documented.⁶⁶ The fact that fewer Ethiopian women are employed, have less job security and are paid less implicates women's lower socio- economic status and hence their dependence on men that prescribes an unequal role for women in sexual decision making undermine their autonomy, expose many to sexual coercion and prevent them from negotiating safe sex or use of condom. Research also indicates that economically vulnerable women are less likely to terminate a potentially dangerous relationship, less likely to have access to information regarding HIV/AIDS, less likely to use condoms and more likely to resort to high-risk behaviours for a source of income.⁶⁷

⁶³ S Gruskin, M Roseman and L Ferguson 'Reproductive Health and HIV: Do International Human Rights Law and Policy Matter?' (2008) 3(1) *International Journal of Sustainable Development Law and Policy* 72.

⁶⁴ See UN Committee on the Elimination of Discrimination Against Women, General Recommendation 24 on Women and Health UN GAOR Doc.No. A.54/38/Rev.1. para. 18.

⁶⁵ T. Turmen, 'Gender and HIV/AIDS' (2003) 82 *International Journal of Gynecology and Obstetrics* 415.

⁶⁶ Fuller above n 60 at 125.

⁶⁷ *Ibid.*

By the same token, violence against women especially forced or coerced sex increases women's vulnerability to HIV/AIDS by affecting their power and ability to negotiate the conditions of sexual intercourse. Culturally sanctioned gender roles that circumscribe women's sexual rights in and outside of marriage and the culture of silence that prevents women in Ethiopia from sexual negotiations renders them vulnerable to HIV infection.⁶⁸ Like many of their counterparts in the continent, Ethiopian women can face violence in the hands of their husband if they ask to use condoms due to the dynamic of gender relations.⁶⁹

Furthermore, the persistence of forced child marriage in Ethiopia exposes girls to whole range of harms including sexual abuse that make them susceptible to HIV infection. Young girls usually marry significantly older men, which creates a power imbalance.⁷⁰ Hence gender based violence coupled with other social and economic subordination of women in Ethiopia contributes to their vulnerability to HIV risks. These factors require special consideration in designing and implementing HIV related policies in the country.

2.4 Laws and Policies Addressing HIV/AIDS Vulnerability of Women in Ethiopia

The previous section argued that women's position within Ethiopian society underpins their overlapping vulnerabilities to both HIV/AIDS and human rights abuse. This section focuses on the different legal and policies frameworks adopted by the Ethiopian Government to address these issues and assesses their direct and indirect impact on reducing the vulnerability of women in Ethiopia to HIV/AIDS.

⁶⁸ Kloos above n 43 at 42.

⁶⁹ F Banda, *Women, Law and Human Rights an African Perspective* (Oxford: Hart Publishing, 2005) 193.

⁷⁰ Turmen above n 65 at 414.

Ethiopia is a state party to Convention on the Elimination of Discrimination against Women. To demonstrate its commitment to in eliminating gender/sex inequalities the Government of Ethiopia has adopted considerable legal reform measures. These include the promulgation of the 1995 Constitution of the Federal Democratic Republic of Ethiopia in 1994 which explicitly guarantees the rights of women as equal to those of men in all spheres.⁷¹ More importantly the 1995 Constitution of the Federal Democratic Republic of Ethiopia (here in after FDRE Constitution) entitles Ethiopian women the right to affirmative measures, the purpose of which is to provide special attention to women, so as to enable them to compete and participate, on the basis of equality, with men in social and economic life as well as in public and private institutions.⁷²

The principle of men and women having equal rights while entering into, during marriage and at the time of divorce is also enshrined in the constitution.⁷³ In light of this and other constitutional provisions the 1960 civil code marriage provisions were revised in 2000.⁷⁴ The Revised Federal Family Law recognizes the equal right of women and men freely to enter into marriage as well as equal rights and responsibilities of spouses during marriage. It also declared that marriage should be based on mutual respect, support and assistance of the spouses.

Moreover, the Revised Federal Family Law relaxed the grounds of divorce and denied legal recognition to marriages by abduction, early marriage and bigamy. Nonetheless, the application of the Revised Family Law is limited only to Addis Ababa and Dire Dawa city areas. The FDRE Constitution grants the power to regional states to enact their own family laws in conformity to the constitutional principles.

⁷¹ FDRE Constitution art 35.

⁷² *Ibid* art 35(4).

⁷³ *Ibid* art 34(1).

⁷⁴ The Federal *Negarit Gazetta* of the Federal Democratic Republic of Ethiopia, *Revised Family Law*, Proclamation No. 213/2000.

The CEDAW committee has repeatedly called upon the Ethiopian Government to harmonize federal, regional, customary and religious laws regulating marriage and family relations.⁷⁵

Another major area of Ethiopian law that has been recently (2005) revised to provide a positive contribution to the achievement of gender equality and reduction of vulnerability of women to HIV is the criminal law. The new law criminalizes various forms of violence against women including rape,⁷⁶ trafficking in women and children,⁷⁷ prostitution of another for gain,⁷⁸ physical violence within marriage or in an irregular union,⁷⁹ abduction,⁸⁰ FGM,⁸¹ early marriage⁸² and bigamy.⁸³ These new and revised provisions of the 2005 criminal law are directly relevant provisions to the protection of women's human rights in general and in the context of the HIV/AIDS pandemic in particular. However, despite these legal reforms aimed at the attainment gender equality, Ethiopia has a long way to go in terms of women's rights and equal participation as shown under the previous section. The Committee on the Elimination of All Forms of Discrimination expressed its concern over the slow progress of the implementation of the Convention and the national legislative frameworks.⁸⁴

In addition to the above legal reform, the Ethiopian Government has also adopted various policies that can be used to bring about gender equality and address HIV/AIDS among women in the country. However, it is questionable whether awareness of Ethiopian women's universal subordination and the

⁷⁵ CEDAW above n 47 at 244.

⁷⁶ FDRE Criminal Code art 620-28.

⁷⁷ *Ibid* art 597 & art 635.

⁷⁸ *Ibid* art 634.

⁷⁹ *Ibid* art 564.

⁸⁰ *Ibid* art 587-590.

⁸¹ *Ibid* art 565 - 66.

⁸² *Ibid* art 649.

⁸³ *Ibid* art 650.

⁸⁴ CEDAW above n 47 at 214.

systematic abuse of their rights are adequately informing policy and programme development in Ethiopia.⁸⁵ For instance, the Government adopted a National Policy on Ethiopian Women (NPEW) in 1993 that aimed to address gender inequality in the social, economic and political arenas and to devise strategies to address gender issues.⁸⁶ More specifically, the NPEW has the objective of eliminating harmful customary practices against women and guaranteeing the equality of men and women in the political, social, and economic domain by creating appropriate structures in government institutions.⁸⁷ However, the National Policy on Ethiopian Women is silent when it comes to addressing HIV in general and the gender dimension of the epidemic in particular. The NPEW not only fails to recognize the special vulnerability of Ethiopian women to HIV/AIDS but also to link this peculiar vulnerability with the traditional HTPs that was recognized by the policy seriously affecting women in Ethiopia.

The other policy adopted by the Ethiopian Government that can be used to bring about gender equality and address HIV/AIDS vulnerability among women in the country is the 1998 national HIV/AIDS policy of Ethiopia.⁸⁸ The national HIV/AIDS policy recognizes the contribution of gender inequality to the increased spread of HIV/AIDS in the country and the need for women to have access to information and services regarding HIV/AIDS.⁸⁹ It specifically recognizes that harmful traditional practices contribute to the spread of HIV and notes appropriate measures should be taken to stop HIV transmission through harmful traditional practices.⁹⁰ The policy states that one of its major objectives is

⁸⁵ See for instance F Merso 'Women and Girls and HIV/AIDS in Ethiopia: An Assessment of the Policy and Legal Framework Protecting the Rights Women and Girls and Reducing Their Vulnerability to HIV/AIDS'. Available online at; <http://countryoffice.unfpa.org/ethiopia/drive/WomenandGirlsandHIV-AIDSinEthiopia.pdf> [visited on 23 September 2013].

⁸⁶ The Office of the Prime Minister of Ethiopia, *National Policy on Ethiopian Women* (Addis Ababa: 1993).

⁸⁷ *Ibid.*

⁸⁸ Federal HIV/AIDS Prevention and Control Office (HAPCO), (1998) *Policy on HIV/AIDS of the Federal Democratic Republic of Ethiopia*, Addis Ababa.

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*

to empower women, youth and other vulnerable groups to take action to protect them against the epidemic.

However, the policy framework has failed to set out specific and workable strategies to address the link between HIV/AIDS and the peculiar vulnerabilities of women. Given the situation of women and HIV/AIDS in Ethiopia, a practical strategy that articulates clearly how women's peculiar vulnerability to HIV infection can be addressed should have been incorporated into the policy. The critics argue that subsequent programmes and guidelines developed for the implementation of the HIV/AIDS Policy also do not take into account gender issues nor seem to have specific strategy for addressing the vulnerability of women as well.⁹¹

As discussed above much has been done in Ethiopia in terms of putting in place a legal and policy framework that may have a direct or indirect relevance to addressing the vulnerability of women to HIV/AIDS. Nevertheless, in the light of the recent aggressive expansion of HIV testing, the question of whether the design and implementation of HIV related policies in Ethiopia are really being informed of the subordination and systematic abuse of rights of Ethiopian women remains contested. Assessing the implication of HIV testing policies on the vulnerabilities of women to HIV/AIDS and the human rights challenge women in Ethiopia face is of paramount importance both from human rights and public health perspectives.

⁹¹ Mersso above n 85 at 24.

2.5 Prevention of Mother-To-Child Transmission of HIV (PTMCT) in Ethiopia

Mother-to-child transmission of HIV is the primary cause of paediatric HIV infection globally and nationally. According to the 2011 Ethiopian Demographic Health Survey (EDHS), the HIV prevalence among pregnant women in Ethiopia is 2.3 percent.⁹² It has been reported that more than 90 percent of the paediatric HIV infection in Ethiopia is through mother to child transmission of HIV.⁹³ In 2012 it was reported that there were around 154,084 children below the age of 14 living with HIV/AIDS.⁹⁴ In the same year it was estimated that there were around 7,792 new HIV infections in children below the age of 15 years and 804,184 children below the age of 18 years had lost at least one parent to AIDS.⁹⁵ The following section provides background information on the implementation of PMTCT in Ethiopia. It begins with a brief discussion on how HIV is believed to be transmitted to children from their mothers.

2.5.1 Mother-To-Child Transmission (MTCT)

It is now well established that prenatal HIV transmission can take place *intrauterine* (in the uterus before labour and delivery), *intrapartum* (at the time of labour and delivery) or *postpartum* (after delivery) through foetal or infant exposure to infected maternal body fluids.⁹⁶ It is also scientifically proven that the rate of prenatal transmission can be decreased dramatically if an HIV-positive mother employs MTCT prevention methods. Prior to 1994 the risk of transmission from an HIV infected mother to her

⁹² EDHS 2011 above n 14 at 234.

⁹³ Federal Democratic Republic of Ethiopia Ministry of Health (MOH) *The National Strategic Plan for Elimination of Mother to Child Transmission of HIV (e-MTCT of HIV) 2013 – 2015* (Addis Ababa: MOH, 2013) 6.

⁹⁴ *Ibid.*

⁹⁵ *Ibid.*

⁹⁶ Canada HIV/AIDS Legal Network, 'HIV Testing and Pregnancy Medical and Legal Parameters of the Policy Debate' (1999). Available online at: <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=286> [Visited on 12 August 2012].

child ranged between 15 percent and 40 percent with the highest rates reported in the breastfeeding population.⁹⁷ However, in 1994, the results of the Paediatric AIDS Clinical Trial Group protocol 076 showed that HIV-infected women could reduce the risk of transmitting the virus to their infants by as much as two-thirds (from 25.5 to 8.3 percent) through the administration of zidovudine (ZDV or AZT) during pregnancy, delivery and by giving the newborns AZT for the first six weeks after birth.⁹⁸ In addition to AZT treatment, it is important to emphasize that an HIV positive mother can prevent risks of infant infection by other means, namely the election to undergo a caesarean section at time of delivery, passive immunization (with hyper immune globin or a neutralizing antibody), and washing the vagina and the baby at time of delivery as well as the use of breast milk substitutes after birth.⁹⁹ A caesarean section protects the baby from direct contact with an HIV-positive mother's blood and other bodily fluids, thereby diminishing the rate of transmission to uninfected infants.¹⁰⁰ By the same token, use of breast milk substitutes further reduces the probability of transmission, since HIV transmission through breast milk accounts for one-third of prenatal HIV transmission.¹⁰¹

However, the benefits of AZT treatment during pregnancy, labour and delivery cannot be meaningfully discussed without due recognition of the fact that the long-term consequences of babies' exposure to a medications to prevent HIV infections in *utero* are unknown. The limitations, risks and unknowns associated with the use during pregnancy of ZVD and other ARV remain significant.¹⁰² With regard to *risks* and *unknowns*, each of the ARV currently used present the risk of short-term and long-term

⁹⁷ P Clark, 'Mother-To-Child Transmission of HIV in Botswana: An Ethical Perspective on Mandatory Testing' (2006) 6(1) *Developing World Bioethics* 3.

⁹⁸ M Yuen 'HIV Testing of Pregnant Women: Why Present Approaches Fail to Reach Desired Objective and the Unconsidered Option' (2007- 2008) 14 *Cardozo Journal of Law and Gender* 187.

⁹⁹ J Cooper, 'The Politics of Pediatric Aids' (1996) 53(3) *Cardozo Women's Law Journal* 63.

¹⁰⁰ Yuen above n 98 at 191.

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*

adverse effects, quite apart from the complicating factor of pregnancy.¹⁰³ Important areas of concern when any of these drugs are used during pregnancy include the changes in drug *pharmokinetics* attributable to the many physiologic changes associated with pregnancy; the potential for *teratogenicity*, *mutagenicity* and *carcinogenicity*; and the *pharmokinetics* and toxicity of transplacentally transferred drugs.¹⁰⁴ While the demonstrated ability of this therapy to reduce the risk of prenatal HIV transmission and its devastating consequences is unquestionably significant, policymakers must therefore equally bear in mind the potential seriousness of known and unknown associated risks.

These preventive measures are promising, but all such methods require knowledge of a mother's HIV infection in advance or cannot be employed unless an expectant mother knows of her HIV status by getting enrolls in a PMTCT programme. This fact of the need of identification of HIV infection among pregnant women, as a result, has globally prompted intense debate surrounding the proper and justifiable approaches of screening women for HIV during pregnancy or delivery as depicted in the previous sections. The subsequent discussions focus on the implementation of the PMTCT programme in Ethiopia and the policy measures being taken to scale up the number of pregnant women tested for HIV/AIDS.

¹⁰³ R Jürgens, 'HIV Testing and Confidentiality: Final Report', *Canadian HIV/AIDS Legal Network & Canadian AIDS Society* (2001) 206. Available online at; <http://www.aidslaw.ca/Maincontent/issues/testing.htm#g> . [Visited on 3 August, 2012]

¹⁰⁴ *Ibid.*

2.5.2 Utilization and Coverage of PMTCT Programs in Ethiopia

According to the Government's estimate, in 2011, Ethiopia HIV prevalence among pregnant women was 2.3 percent with an estimated transmission rate of 30 percent.¹⁰⁵ Being part of the HIV/AIDS prevention strategy, the PMTCT programme in Ethiopia is aimed not only at preventing vertical transmission of HIV infection but also at enrolling infected pregnant women and their families into ARV treatment. In Ethiopia the first national PMTCT Guideline was issued in late 2001 and the service was introduced as a pilot project in four hospitals in Addis Ababa for the first time.¹⁰⁶ Ethiopia has adopted the WHO four pronged PMTCT strategy; (1) primary prevention of HIV infection, (2) prevention of unintended pregnancies among HIV-infected women, (3) prevention of HIV transmission from HIV-infected women to their offspring and (4) provision of care and support to women infected with HIV, their infants and families.

Recent reports from the Government show that the 'opt-out' HIV testing approach promoted by the 2007 PMTCT guideline, along with the expansion of health facilities and sites providing antenatal care services, has increased the number of pregnant women who are enrolled to PMTCT. In Ethiopia, the percentage of women who received antenatal care (ANC) from a trained health professional at least once for their last birth has increased from 28 percent in 2005 to 34 percent in 2009¹⁰⁷ and reported to have reached 89.1 percent in 2012 even though wide regional and urban/rural variations are observed.¹⁰⁸ For instance the regional Government of the State of Tigray (the study area for this research) reported a

¹⁰⁵ MOH (*e-MTCT of HIV*) above note 93 at 4.

¹⁰⁶ MOH National *guideline on the PMTCT of HIV in Ethiopia* (Addis Ababa: MOH, 2001).

¹⁰⁷ MOH and Ethiopian Health and Nutrition Research Institute (EHNRI) *Report on the 2009 Round Antenatal Care Sentinel HIV Surveillance in Ethiopia* (2011). Available online at : http://www.ehnri.gov.et/newsletter/ANC%202009_FinalReport.pdf [Visited on 3 March, 2012].

¹⁰⁸ MOH (*e-MTCT of HIV*) above note 93 at 4.

significantly higher percentage of ANC coverage for at least one visit. The report shows that in the year 2012 the percentage of pregnant women attending at least one visit was 99.7 percent.¹⁰⁹ However, although a generally higher increment on the percentage of pregnant women who received at list one antenatal care is observed at national level, the percentage of pregnant women attending at least four ANC visits during their pregnancy remains significantly low at only 19 percent in 2011.¹¹⁰

An increase in the number of health facilities providing PMTCT services has also been recorded. These increased from 32 in 2004 to 1,445 in 2011¹¹¹ and were reported to have reached to 2,044 in 2013.¹¹² As a result, by June 2013, 64 percent of all antenatal health facilities were providing PMTCT services and the PMTCT coverage reached 42.9 percent.¹¹³ Consequently, the number of pregnant women who received pre-HIV test counselling at national level has increased from 711,341 in 2009/10 to 1,261,752 by the end of June 2011.¹¹⁴ HIV testing coverage among pregnant women increased from 2 percent in 2005 to 26 percent in 2011 although this performance is less than half of the average coverage in high-prevalence SSA countries (48 percent).¹¹⁵

Similarly, the antiretroviral therapy coverage among Ethiopian pregnant women living with HIV has increased but remains low. In 2013 it was reported that only 38 percent (4 out of 10) eligible pregnant

¹⁰⁹ Tigray Regional health Bureau , *Annual health Profile of the Tigray region (2012/2013)*,(2014), page 25.

¹¹⁰ WHO *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector. Progress report*, (France: WHO , 2011). Available online at http://whqlibdoc.who.int/publications/2010/9789241500395_eng.pdf?ua=1 [Visited on 3 September, 2014]

¹¹⁰ MOH and HAPCO 2012 *Country Progress Report on HIV/AIDS Response* (2013) 31. Available on line at <http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/GAP%20Report%202012.pdf> [Visited on 3 September, 2013].

¹¹¹ *Ibid* .

¹¹² MOH (*e-MTCT of HIV*) above note 93 at 6.

¹¹³ *Ibid*.

¹¹⁴ MOH and HAPCO 2012 *Country Progress Report* above n 110 at 40.

¹¹⁵ WHO above n 41 at 15.

women living with HIV received antiretroviral therapy for their own health.¹¹⁶ Other sub-Saharan Africa countries have progressed more rapidly than Ethiopia in providing antiretroviral therapy to pregnant women living with HIV for their own health. For instance, UNAIDS report shows that the percentage of pregnant women who received antiretroviral therapy for their own health has reached 95 percent in Botswana, 94 percent in Namibia, and 86 percent Malawi.¹¹⁷

Notwithstanding the progress achieved by the government in the last few years, the overall coverage of PMTCT is lagging behind. In fact, performance data shows that among the pregnant women who were HIV positive around 75 percent were not provided with ARV prophylaxis to prevent Mother-to-Child HIV transmission.¹¹⁸ Coverage of paediatric ART in Ethiopia remains very low, although it was reported that the coverage increased from 11 percent in 2009 to 19 percent in 2011.¹¹⁹ Likewise, UNAIDS in 2013 reported that although more children are receiving ARV treatment than before, access remains unacceptably very low in Ethiopia where only 2 out of 10 eligible children are receiving HIV treatment.¹²⁰

Hence the number of new infections among children remains high despite significant reductions. In 2011, it was estimated 43,000 HIV positive pregnant women give birth with estimated transmission rate of 30 percent (13,000/42,900) including though breastfeeding.¹²¹ UNAIDS's report shows an estimate of 9500 new infections among children occurred in Ethiopia only in 2012.¹²² Some of the factors that contribute to this low performance are home delivery, inadequate awareness of the benefits and

¹¹⁶ UNAIDS 2013 Progress Report on the Global Plan; Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive' (Genève: UNAIDS, 2013) 21. Available Online at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20130625_progress_global_plan_en.pdf [Visited on March, 2014].

¹¹⁷ *Ibid* 12.

¹¹⁸ *Ibid* at 20.

¹¹⁹ WHO above n 41 at 52.

¹²⁰ UNAIDS note above n 116 at 20.

¹²¹ MOH (*e-MTCT of HIV*) above note 93 at 3.

¹²² *Ibid*.

availability of PMTCT services, high missed opportunities and dropout rates, inadequate access to ARV drugs and poorly equipped manpower.¹²³

Consequently, in 2012 there were 154,084 children under 14 years of age living with HIV/AIDS¹²⁴ out of which 73,000 children were reported eligible for antiretroviral therapy.¹²⁵ Taking consideration of these current trajectories of Ethiopia's PMTCT performance, the UNAIDS's 2015 target to eliminate new paediatric AIDS infections is unattainable. In recognition of the challenges and the need to scale up its PMTCT services in Ethiopia, in 2012 the Government developed PMTCT Accelerated Plan with main interventions including rapid site expansion, quality improvement and demand creation. The PMTCT Accelerated Plan is intended to rapidly increase the number of pregnant women who learn their HIV status, attend ANC and have institutional delivery. Under this Accelerated Plan, the Ethiopian Government has set a goal to eliminate new paediatric AIDS infections from the country by 2015.¹²⁶

However, such ambitious targets of eliminating paediatric AIDS by 2015 or just enhancing utilization and coverage of PMTCT programmes among pregnant women in Ethiopia requires identification of HIV status of pregnant women in advance. Accordingly, the government of Ethiopia is aggressively implementing a routine- provider initiated 'opt-out' HIV testing approach in all maternal health care services to enhance the number of pregnant women enrolled in PMTCT programme. The next section provides an assessment of legal and policy environment for the implementation of the routine provider initiated 'opt-out' HIV testing approach in Ethiopia.

¹²³ D Negese and B Megabiaw 'Mother-to-child Transmission of HIV and its Predictors among HIV-exposed Infants at a PMTCT Clinic in Northwest Ethiopia'(2013) *BMC Public Health* 6. See also A Adedimeji *et al.*, 'A Qualitative Study of Barriers to Effectiveness of Interventions to Prevent Mother-to-Child Transmission of HIV in Arba Minch, Ethiopia' *International Journal of Population Research* (2012) 2.

¹²⁴ MOH above note 93 at 6.

¹²⁵ UNAIDS note above n 116 at 20.

¹²⁶ MOH (*e-MTCT of HIV*) above note 93 at 4.

2.6 The Ethiopian Legal and Policy Environment for the Implementation of 'Opt-out' HIV Testing Approach to Screen Pregnant Women for HIV in Infections

According to the 2007 Ethiopian PMTCT guidelines routine counselling and testing using the 'opt-out' approach is recommended for all pregnant women seen within the context of maternal care (i.e. antenatal, labour, immediate postpartum). All pregnant women should participate in a HIV pre-test information group session or individually about HIV/AIDS and PMTCT. She should be told that her routine antenatal laboratory tests will include an HIV test. The provider also must inform the client that she has the right to say 'No' (to opt out), and this decision by no means affects the services she will receive from the health facility.¹²⁷

This section assesses the legal and policy environment for the implementation of the new HIV testing approach to screen pregnant women for HIV infection in maternal health care settings. It argues that, since at least theoretically the routine provider-initiated 'opt-out' HIV testing approach allows for informed consent and the right to refuse for individuals who do not wish to test, the approach does not necessarily contradict with the existing legal and policy framework of the country. However, the full understanding of the context in which this testing takes place reveals that, the implementation of the 'opt-out' HIV testing approach can result in the denial of pregnant women's rights to informed consent, to have access to adequate counselling and to ensure confidentiality of their HIV test results.

The 1995 Constitution of the Federal Democratic Republic of Ethiopia (hereinafter the FDRE Constitution) embodies several provisions on human rights most of which are adopted from the

¹²⁷ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother –to-Child Transmission of HIV* (Addis Ababa, 2007) 11.

provisions of the Universal Declaration of Human Rights (UDHR) that can be applied in the context of HIV testing. Specifically the constitution provides that every person has the right to privacy¹²⁸ and to security of the person, to liberty, the right to equality and equal protection of the law¹²⁹ and to seek, receive and impart information.¹³⁰ Moreover, Ethiopia has ratified many international and regional human rights instruments including: the International Covenant on Civil and Political Rights (ICCPR),¹³¹ International Covenant on Economic, Social and Cultural Rights (ICESCR);¹³² the Convention on the Elimination of Discrimination against Women (CEDAW)¹³³ and the African Charter on People and Human Rights.¹³⁴ The FDRE Constitution provides that all international treaties ratified by the country are integral parts of the law of the land¹³⁵ and requires the fundamental rights and freedoms it has recognized to be interpreted in a manner conforming to the international instruments ratified by Ethiopia.¹³⁶

The above mentioned constitutional provisions and human rights instruments to which Ethiopia is a party grants rights to enable individuals to make autonomous decisions regarding any medical procedures and to have control over their bodies. In addition, the 1960 Civil Code contains a general provision, not specific to HIV that states no health service may be provided to users without their consent. This specific law on the rights of individual on medical examination states that ‘A *person may*

¹²⁸ FDRE Constitution, art 26.

¹²⁹ *Ibid* art 25.

¹³⁰ *Ibid* art 29.

¹³¹ International Covenant on Civil and Political Rights (here in after ICCPR). Adopted by General Assembly Resolution 2200A (XXI) of 16 December 1966.

¹³² International Covenant on Economic, Social and Cultural Rights (here in after ICESCR). Adopted by General Assembly Resolution 2200A (XXI) of 16 December 1966.

¹³³ Convention on the Elimination of all Forms of Discrimination against Women (herein after CEDAW). Adopted by General Assembly resolution 34/180 of 18 December 1979.

¹³⁴ African Charter on Human and Peoples’ Rights (here in after ACHPR), adopted 27 June 1981 OAU Doc. CAB/LEG/67/3/Rev.5 (1982) entered into force 21 October 1986.

¹³⁵ FDRE Constitution, art 9(4).

¹³⁶ *Ibid* art 13(2).

at any time refuse to submit himself to a medical or surgical examination or treatment.'¹³⁷ Accordingly, under the Ethiopian law patients must give consent to any medical examinations. Since HIV testing is one of the medical procedures, from the reading of the above provision of the civil code, it can be rightly argued that individual do have the right to refuse the HIV testing and treatments if they do not want to have one. Similarly, the requirement of consent in the context of HIV testing is also enshrined in both the 2007 Ethiopian PMTCT guidelines and the 2007 guidelines for HIV Counselling and Testing (herein in after the 2007 HTC guidelines) that stated informed consent for testing shall be obtained in all cases, except in mandatory testing.¹³⁸ As discussed under chapter one of this thesis, the rational for the adoption of 'Opting-out' approach rather than the 'Opting-in' in these HIV guidelines is based on the recommendation of the WHO and UNAIDS.¹³⁹

Nonetheless, the 2007 Ethiopian PMTCT guideline is silent as to the issue of who has the capacity to give valid consent. In Ethiopia there are no specific laws that specify the age requirement to give a valid consent for medical examination and treatment. Hence health care providers under normal circumstances are expected to regard the age of majority which that is attainment of 18 years of age, as age of consent for medical treatment. However, in relation to HIV testing the 2007 HTC guidelines states that persons 15 years of age and above are considered mature enough to give informed consent for themselves.¹⁴⁰ On an exceptional basis the HTC guidelines also leaves room for children aged 13-15 who are married, pregnant, commercial sex workers, street children, heads of families, or sexually active

¹³⁷ Civil Code of Ethiopia, *Negarit Gazetta* (extra-ordinary issue), 19th year, No. 2, Proclamation .No. 0165 of 1960 art 20(1).

¹³⁸ HAPCO and MOH, '*Guidelines for HIV Counselling and Testing in Ethiopia*' (Addis Ababa, 2007).

¹³⁹ World Health Organization and United Nations Programme on HIV/AIDS (WHO/UNAIDS), '*Guidance on Provider Initiated HIV Testing and Counseling in Health Facilities* (Switzerland: WHO/UNAIDS, 2007). Available online at http://www.who.int/hiv/who_pitc_guidelines.pdf. [Last visited 15 October, 2013].

¹⁴⁰ HAPCO and MOH above n 138 at para 1.4.

to be regarded as 'mature minors' so that they can give a valid consent to HIV testing.¹⁴¹ Similarly, the 2007 HTC guidelines also state that HIV testing and counselling for a mentally impaired individual requires the knowledge and consent of his/her guardian, and should be for the benefit of the individual or patient.¹⁴²

The hierarchy between these two guidelines (i.e. the HTC guidelines and PMTCT guidelines) is not clearly stipulated in both documents, although the director general of the Federal HIV/AIDS Prevention and Control Office (HAPCO) indicated that the 2007 HTC guidelines is aimed to complement other guidelines to form a holistic approach to implementation of HIV/AIDS prevention, treatment, care and support.¹⁴³ Hence arguably since the Ethiopian 2007 PMTCT guidelines are silent on the issue of who can give a valid consent, the provisions of the 2007 HTC guidelines can be adopted for the purpose of requirement of securing consent from pregnant women for prenatal HIV testing.

The individual's right to refuse medical examination and treatment is not absolute under the Ethiopian legal system. The Civil Code enshrined a provision that states for the purpose of the public interest, laws and regulations can be enacted to force individuals to a physical examination of persons or their compulsory vaccination or other similar measures.¹⁴⁴ In the context of HIV antibody diagnosis, although in principle mandatory HIV testing is prohibited in Ethiopian legal and policy framework there are some exceptions. Mandatory testing of HIV testing is allowed in cases of voluntary blood, tissue and organ donors before transfusion or transplantation.¹⁴⁵ It can also be ordered by a court of law.¹⁴⁶

¹⁴¹ *Ibid.*

¹⁴² *Ibid at* para 1.5.

¹⁴³ *Ibid at* ii (forward).

¹⁴⁴ Civil Code above n 137 art 20(1).

¹⁴⁵ HAPCO & MOH above n 127 at para. 1.1

¹⁴⁶ *Ibid.*

The Criminal Procedure Code of Ethiopia under its article 34 states on issues of mandatory physical examination including blood test by the order of the court to that effect;

*'Notwithstanding to the provisions of article 20 of the Civil Code where an investigating police officer considers it necessary, having regard to the offence with which the accused is charged, that a physical examination of the accused should be made he may require a registered medical practitioner to make such examination and require him to record in writing the results of such examination..... Examination under this Article shall include the taking of **a blood test**.'*¹⁴⁷ (Emphasis added)

Therefore, although individuals have the right to refuse medical examination, when the situation requires it, the courts can order mandatory physical examination that may include a blood test. Such mandatory blood tests for HIV antibody is the usual order by courts in Ethiopia in cases of establishing the HIV status of sexual offenders. Mandatory HIV testing is also prohibited by other laws of the country namely the Federal Civil Servants Proclamation¹⁴⁸ and the Labour Proclamation.¹⁴⁹ These two legal instruments prohibit mandatory HIV testing as a condition for obtaining employment or remaining in it with the objective of preventing discriminatory acts based on HIV status.

¹⁴⁷ The Criminal Procedure Code of Ethiopia, *Negarit Gazetta* Proclamation 1961 Extraordinary Issue No.1 art 34.

¹⁴⁸ The Federal *Negarit Gazetta*, Labour Proclamation, No. 377/ 2003, art. 14 (2) (d). Article 14(2)(d) states that;

'[i]t shall be unlawful for the worker to, except for HIV/AIDS test, refuse to submit himself for medical examination when required by law or by the employer for good cause'.

¹⁴⁹ The Federal *Negarit Gazetta*, Federal Civil Servant Proclamation No. 515/ 2007, art.63(1) and art 17. In this regard, article 63 (1) of the Proclamation states that:

'[a]ny civil servant shall have the obligation to take medical examination, with the exception for HIV/AIDS, when required by the government institution on sufficient ground related to the service.'

Hence, since routine provider initiated 'opt –out' HIV testing approach, at least theoretically requires informed consent, it can be argued that there is no legal obstacle for the government of Ethiopia to introduce the approach in maternal health care settings. Thus, the significant issue is whether this new testing approach actually enables the pregnant women to give their consent for the HIV testing free from fear, coercion, fraud, undue influence and other subtle factors that may affect their autonomous decision making.

2.7 Conclusion

HIV/AIDS is a major public health problem in Ethiopia. In Ethiopia, over a million people lives with the virus making the country one of the world's hardest hit by the epidemic. Soon after the first report of HIV/AIDS case in Ethiopia, the Government adopted a national HIV/AIDS policy followed by the development of various strategies and guidelines for its implementation. According to the UNAIDS report, Ethiopia is one of 22 sub-Saharan African countries that succeeded in reducing their national rate of new HIV infections by 25 percent between 2001 and 2009. However, women remained disproportionately affected by the epidemic constituting the 57 percent of new HIV infection that happen every year in the country.

Women in Ethiopia suffer from the many forms of inequality and discriminations. They are victims of discrimination in their economic, social and political lives which directly or indirectly contribute to their exposure to HIV/AIDS. Women constitute an economically vulnerable group within the Ethiopian society which prohibits them from being able to terminate a potentially dangerous relationship, to have access to information regarding HIV/AIDS and to negotiate safe sex practice. By the same token,

violence against women especially forced or coerced sex increases women's vulnerability to HIV/AIDS by affecting their power and ability to negotiate the conditions of sexual intercourse. Hence, the chapter showed how these social, cultural, economic, legal and political subordinations of Ethiopian women contribute to the feminization of the HIV epidemic in the country.

It has been reported that more than 90 percent of the paediatric HIV infection in Ethiopia is through mother to child transmission of HIV. The overall coverage and utilization of PMTCT in Ethiopia remained very low leading the government to integrate the 'opt-out' HIV testing approach in all maternal health care services to expand the screening of pregnant women for HIV infections. However, there are human rights and ethical concerns on whether this new testing approach actually enables pregnant women to give their consent for the HIV testing free from fear, coercion, fraud, undue influence and other subtle factors that may affect their autonomous decision making. Ethiopian women's universal subordination and the systematic abuse of their rights need to be adequately considered in the development and implementation of HIV- related policies and programs including HIV testing schemes that target women.

The subsequent chapter provides an analysis of the application of human rights principles and ethical standards on issues of HIV testing in general and HIV testing of pregnant women in the context of prevention of vertical transmission in particular using the routine provider initiated routine 'opt-out' HIV testing approach.

CHAPTER THREE

CONCEPTUALIZING HUMAN RIGHTS, ETHICS AND ROUTINE PROVIDER-INITIATED HIV TESTING OF PREGNANT WOMEN

3.1 Introduction

Chapter three builds on the understanding of the routine provide initiated ‘opt-out’ HIV testing approach and analyzes the theoretical frameworks of human rights and ethics that inform HIV testing. Adhering to the three underpinning principles (Consent, Counselling and Confidentiality) during HIV testing has a clear foundation in human rights law and remains critical to the effectiveness of HIV prevention efforts. However, the implementations of ‘opt-out’ HIV testing approach in maternal health care settings often takes place in situations where women face unique challenges that impact on their ability to give informed consent, access adequate information and protect themselves from violence and stigma. The purpose of the chapter is then to assess the human right and ethical standards in relation to HIV testing practice which are used as benchmarks in evaluating the implementation of the routine HIV testing of pregnant women in Ethiopia. It provides the framework for the data gathered from the field work.

The first section of this chapter begins by discussing the distinction between moral and legal human rights and shows how the human rights we have contained in law are socially constructed. The section continues to discuss on the position of gender in the human rights discourse and summarise the development of the international women’s human rights movement. The subsequent section deals with the underpinning principles of HIV testing (sometimes called the ‘Three Cs’) namely Counselling,

Consent and Confidentiality and make an argument that the 'Three Cs' are interwoven with principles of human rights. Sections four discuss the human rights and ethical concerns raised by the adoption and implementation of the routine provider initiated 'opt-out' HIV testing approach and its application to screening pregnant women for HIV infection. This is followed by a discussion of the ethical principle of autonomy and its application in relation to HIV testing from the perspective of securing informed consent of women subject HIV testing.. The sections argue that the implementation of this testing approach to screen pregnant women for HIV in maternal health care setting poses serious human rights and ethical concerns.

The fifth section argues that despite their different approaches, public health and human rights imperatives can be complementary and mutually supportive in HIV prevention efforts including in the case of HIV screening schemes. The sixth section examines the debates relating to the 'maternal-foetal conflict' in the context of HIV testing. It argues that the principal decision maker regarding prenatal HIV testing should be the pregnant woman herself. The chapter concludes that respect for the principles of human rights and ethical standards in the process of HIV testing is imperative for obtaining both public health and human rights objectives including prevention of mother –to – child HIV transmission.

3.2 Women and Human Rights Law

The concept of human rights has been subject of much theorising. There is no universally accepted definition of the terminology, although it has been made familiar by its use in today's international politics. The contending views on the discussions of the nature of human rights are based on the distinction on the nature of human rights between legal and moral rights. The term 'legal rights' is

generally used to describe the rights that individuals actually hold, whereas the terms 'moral' or 'natural rights' are used to describe the rights that a particular group of people argue they need to fully participate in society but are denied by the law. Moral right or Natural rights theorists argued that all individuals were endowed by nature with the inherent rights which were their own and could not be removed or abrogated by the state.¹

However, natural rights theory was contested by some famous philosophers of the late 18th and 19th centuries like Burke with his abstraction and rationalism, Bentham with his utilitarianism and indeterminacy and Marx with his close link to class interests.² Bentham famously dismissed natural rights as not only *conceptual nonsense* and mere fallacies, but also they were mischievous and anarchical.³ On the other hand, legal rights are rights that can only be established by a recognized authority and hence be able to be tried in a court of justice. Positivists argued that the existence and content of rights could be derived exclusively from the laws and court decision of various countries. Hence although human rights had their origin in natural law, it took a system of positive law to provide a definite and systematic statement of the actual rights which people possessed.⁴

Most contemporary writers agree that human rights are not solely limited to the distinctions between legal and moral rights.⁵ Logically, the ideal is that legal rights should emerge from moral rights and that moral rights should be transformed into legal rights. However, the fact that different group has different conception of what is and is not moral and indeed of what moral rights are, makes the discussion on

¹ J Gordon 'The Concept of Human Right: The History and Meaning of its Politicization', (1998) 23(30) 23 *Brook Journal of International Law* 738.

² R. Haule Some Reflections on the Foundation of Human Rights – Are Human Rights an Alternative to Moral values? (2006)10(1) *Max Planck Yearbook of United Nations Law* 378.

³ *Ibid.*

⁴ *Ibid* at 380.

⁵ M. Ignatieff 'Human Rights as Politics and Idolatry' (Princeton University Press., 2001). Cited in PS. Jones, *AIDS Treatment and Human Rights in Context* (New York: Palgrave Macmillan, 2009) 58.

human rights based on the distinction of legal and moral rights to continue. Nonetheless, the modern understanding of human rights is not solely limited to the distinctions between legal and moral rights though. The modern conception of *human rights* is of ‘... *international moral and legal norms that aspire to protect all people everywhere from severe political, legal, and social abuses*’.⁶ Jack Donnelly, who is a ubiquitous presence in human rights studies, explains ‘... human rights are, literally, the rights that one has simply because one is a human being’.⁷

In general, human rights as they are discussed in this thesis are accepted as being socially constructed, recognizing that they are created and recreated in particular social conditions at particular times in history. Human rights consists rights which a person enjoys by virtue of being human and being vital element in national, international, and transnational struggles for social justice and human dignity. Just like the law as a whole, charters of human rights are ‘living’ documents in that they are always open to interpretation and reinterpretation. How they are interpreted, for what purposes, and by whom, vary between charters, but also over time and place.

Hence, since the advent of the Universal Declaration of Human Rights, human rights have been generally viewed inherent and universally applicable to all human beings irrespective of factors such as race, sex, nationality or jurisdiction and that they are principally concerned with the relationship between the individual and the state. Moreover, human rights function as high-priority norms or *prima facie* rights that imply duties for both individuals and governments, even if a person's own government has the main responsibility to protect and uphold a citizen's rights⁸

⁶ J. Nickel, *Human Rights*, *The Stanford Encyclopedia of Philosophy* (2003) [On-line Encyclopedia edited by E. N. Zalta]. Available at: <http://plato.stanford.edu> (Visited on October/2014).

⁷ J. Donnelly, *University Human Rights in Theory and Practice* (Ithaca: Cornell University Press, 2003) 10.

⁸ J W. Nickel, *Making Sense of Human Rights: Philosophical Reflections on the Universal Declaration of Human*

The human rights norms as we know them today have been institutionalized in the United Nations (UN) legally and morally binding human rights instruments including; the Universal Declaration of Human Rights (UDHR)⁹ and the two key international treaties: the International Covenant on Economic, Social and Cultural Rights (ICESCR)¹⁰, and the International Covenant on Civil and Political Rights (ICCPR).¹¹ Together these three UN human rights instruments make up the International Bill of Human Rights. The International Bill of Rights encompasses an expanding range of personal, legal, civil, political, subsistence, economic, social, and cultural rights.

Human rights scholars speak of three "generations" of human rights within the international context.¹² 'First generation' human rights, as embodied in the ICCPR, stress civil and political rights while the 'Second generation' human rights, embodied in the ICESCR, emphasize economic, social, and cultural rights. Under this Covenant, states are to take steps "to the maximum of available resources," with the objective of achieving progressively the full realization of designated rights.¹³ 'Third generation' human rights, the most controversial of international human rights, involve 'solidarity' among developing states as a group, and among states in general. They are said to be collective rather than individual

Rights (Berkeley: University of California Press, 1987) 3.

⁹ Universal Declaration of Human Rights(here in after UDHR), G.A. Res. 217A, at 71, U.N. GAOR, 3d Sess., 1st plen. mtg.,U.N. Doc.

¹⁰ International Covenant on Civil and Political Rights (herein after ICCPR) adopted 16 December 1966 entry into force 23 March 1976.

¹¹ International Covenant on Economic Social and Cultural Rights(here in after ICESCR) adopted 16 December 1966 entry into force 23 March 1976 993 UNTS 3.

¹² WJ Gregory *Human Rights in Theory and Practice: A Selected and Annotated Bibliography*, with an Historical Introduction (New Jersey & London: Scarecrow Press, 1995) 12. See also CR. Beitz *The Idea of Human Rights*(Oxford: Oxford University Press, 2006) Also M. Goodale, 'Locating Rights, Envisioning Law Between the Global and the Local', In M. Goodale and S. E. Merry (Eds) *The Practice of Human Rights Tracking Law Between the Global and the Local* (Cambridge , Cambridge University Press,2007)1-38.

¹³ ICESCR art 2(1).

The UN continued to adopt other international human rights instruments in particular contexts that including the International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)¹⁴ and the Convention on the Rights of the Child (CRC)¹⁵ among others. Regional human rights systems distinctively contribute to the promotion and protection of human rights. The African human rights system is based upon the African Charter on Human and Peoples' Rights (hereinafter the African charter) that entered into force in October 1986.¹⁶ The African Charter sets out an extensive range of human rights provisions that protect political, civil, economic, social, and cultural rights of citizens of the continent. Moreover, the African Union (AU) adopted a supplementary protocol to the African charter- the protocol on the Rights of Women in Africa (hereinafter the women's protocol) in 2005.¹⁷ This protocol recognises the rights established within CEDAW but roots these within the particular social political and cultural context of Africa.

From the beginning of the post World War II human rights movement, women have been formally included as holders of human rights. The Charter of the United Nations Organisation reaffirms *'faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations, large and small....'*¹⁸ This represents the first contemporary formal recognition of equality between the sexes. Subsequently, the United Nations Commission on the Status of Women (CSW) was established in 1946 within the UN system. The CWS influenced many landmark UN measures – the 1948 Universal Declaration of Human Rights (UDHR), the 1952 Convention on

¹⁴ International Convention on the Elimination of All Forms of Discrimination against Women (here in after CEDAW) General Assembly resolution 34/180 of 18 December 1979.

¹⁵ The Convention on the Rights of the Child (here in after CRC) Adopted in 1989 U.N. Doc. A/44/49 .

¹⁶ The African Charter on Human and People's Rights (here in after ACHPR) adopted 27 June 1981, OAU Doc CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982)

¹⁷ The Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa (herein after Women Protocol) O.A.U. Doc.,CAB/LEG/66.6 (2003) *entered into force* November 25, 2005.

¹⁸ See Paragraph 2 of the Preamble to the *Charter of the United Nations Organisation* [Emphasis added]. See also Article 1(3) of the UN Charter.

Women's Political Rights, and the 1967 UN Covenants on civil and political rights and on economic, social and cultural rights. UDHR is the basic foundation of the international human rights law. Articles 1 and 2 of the UDHR state that, 'All human beings are born free and equal in dignity and rights' and 'Everyone is entitled to all the rights and freedoms set forth in this declaration without distinction of any kind, such as race, colour, sex... The UDHR embodies the spirit of equal enjoyment of human rights between men and women and the principle of non- discrimination on the basis of sex has been clearly enshrined. In general, the early universal human rights documents claim women's rights on the basis of equality with men and use of gender-neutral languages. This, however, led feminists to argue that the instrument can be 'a double-edge instrument if is used to punish women for failing to conform to the conventional norms expected of men'.¹⁹

Since the adoption of the UDHR, various dimensions of women's situation have been addressed in a number of United Nations instruments, covenants, declarations and treaties. More importantly the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) was adopted in 1979. The CEDAW transformed the ideals contained in the UDHR into a legally binding instrument directed at the achievement of women's equality with men. Together with its Optional Protocol, adopted 2001, CEDAW constitutes a bill of rights for women and is departs from gender-neutral language to address women's rights issues. This makes CEDAW to be regarded as a remarkable stride; a clearly international legal instrument promoting the right of women to equality and non-discrimination as well as providing a framework or point of reference for policy-making, collective activism and lobbying. The CEDAW Convention explicitly deals with the issue of discrimination by defining what it means to discriminate. It covers both direct and indirect discrimination and the definition it provides, focuses on

¹⁹ S. Okin 'Feminism, Women's Human Rights and Cultural Difference, (1998)13(2) *Hypatia*, p.33.

the de jure (enjoyment by women of equality) and de facto (situation: i.e. the extent to which women in practice enjoy those rights).

While most states have ratified the convention, CEDAW has the most reservations on its recommendations than any other human rights treaty and states have been able to do so with relative ease in the name of 'cultural difference'.²⁰ In addition, with the exception of trafficking and prostitution, the issue of violence against women was completely missing from CEDAW suggests that this was because women's experiences were marginalized unless they were mirrored by or could be compared directly to men's experiences in public life. Despite decades of campaigning and the ratification of the principle human rights treaty for women, the distinction between women's roles in private meant that many women's human rights were still unprotected.

This poses a particular problem for the women's human rights project. A growing body of feminist human rights literatures argues that taking women seriously as equal human rights claimants with men requires considerable further rethinking of the concept of human rights.²¹ The male bias of human rights thinking and its priorities had to change for women's rights to be fully recognized as human rights. Catharine MacKinnon, for example, has claimed that the very character of human rights is a thoroughly masculinist construct, grounded in a series of concepts that systematically exclude women. Human rights principles are based on experience, but the experiences have not been those of women. What most often happens to women escapes the human rights net. Whether in war or in peacetime, at home or abroad, in private or in public, by our side or by the other side, man's inhumanity to woman is ignored.²²

²⁰ H Charlesworth, 'The Women Question in International Law' (2011) (1) *Asian Journal of International Law* 33.

²¹ Okin above note n 18 at 34.

²² MacKinnon, quoted in Anne-Marie Hilsdon et al., *Human Rights and Gender Politics; Asia-Pacific Perspectives* (London; Routledge, 2000) 14.

In addition, the questioning of the public/private divide has been central to the feminist movement. Legal discourse has tended to be most interested in formal juridical concepts of rights as inhering in the person; and that person has most often been conceived of as the male agent of western liberal modernity, located in the public sphere.²³ The core argument of the growing body of critical feminist legal theory rethinking human rights law and practice suggests that human rights law has concentrated on 'public' agents and ignored violations perpetuated by 'private' agents like family members. Feminists have argued that such public/ private dichotomy of human rights law has not only supported the oppression of women and served to exclude them from full citizenship, but also that the idea that life could be split into two distinct spheres was an untenable one. Many have pointed to the distinction made between public and private life as one of the principle reasons, if not *the* reason, why the human rights framework has been unresponsive to the human rights of women .²⁴ This is particularly evident in terms of domestic violence which has traditionally been seen as falling within the private sphere and outside the boundaries of state control is seen as in effect condoning masculine violations of women's rights. Until recently domestic violence has been constructed as a cultural , not a rights, issue. Its reduction requires the redrawing of boundary between what is deemed culturally acceptable (discipline of women) and what is not (abuse). Human right activities try to recast violent activities as unacceptable abuse that warrant state intervention through criminal sanctions and the granting of specific civil rights to those who experience such violence.²⁵

²³ *Ibid* 16.

²⁴ *Ibid* 14.

²⁵ A. Stewart, *Gender, Law and Justice in a Global Market* (Cambridge and New York, Cambridge University Press, 2011)45.

Ann Stewart sees human rights ideas relating to violence against women are the results of considerable transnational consensus-building that are adopted by national states and local communities.²⁶ For instance the 1993 World Conference became the focus of the Global Campaign for Women's Human Rights as an opportunity to bring women's rights to the forefront of the human rights agenda.²⁷ By declaring that women's rights are human rights, activists sought to highlight that widespread gender-based discrimination and abuse of women is a devastating reality that need an urgent redress as other human rights violations.²⁸ However, women and girls around the world continue to face multiple forms of discrimination and oppression every day. The female body and female sexuality still remain a battleground for control, and culture and religion are still allowed in practice to trump women's fundamental human rights to life, to freedom from torture and ill-treatment or punishment, and to health. In the context of women, HIV and AIDS the weak legal protection of women and the lack of women responsive approaches compound women's vulnerability to the disease.

3.3 Human Rights and HIV Testing

The first time that human rights were explicitly named in relation to HIV/AIDS was in the late 1980s, when the call for human rights and for compassion and solidarity with people living with HIV/AIDS was embodied in the first World Health Organization (WHO) global response to AIDS.²⁹ The HIV epidemic continues to confirm that there is a profound relationship between HIV/AIDS and human Rights. It is now clear that human rights discourse and practice continue to have an enormous value in

²⁶ *Ibid.*

²⁷ S. E. Merry *Human Rights and Gender Violence Translating International Law into Local Justice* (London, The University Of Chicago Press, 2006)22.

²⁸ *Ibid.*

²⁹ S. Gruskin and D Tarantola ' Health And Human Rights Overview ' in K Heggen and S Quah (eds) *International Encyclopaedia of Public Health* (Academic Press Vol. 3, 2008) 311

shaping a coherent ethical response to the pandemic because of their identification with reasoned argument about defined moral and legal norms.³⁰

Being HIV positive and the vulnerability for HIV infection among the disadvantage groups do have an impact on violations of human and in return, HIV is fuelled further by human rights violations. Human rights and HIV/AIDS activists have extensively argued that specific abuses of human rights as leading to HIV infection more importantly in relation to failure to protect women from gender based violence.³¹ The impact of HIV highlighted the inequities and vulnerabilities leading to increased rates of infection among women, children, the poor and marginalized groups. The widespread abuse of human rights and fundamental freedoms associated with HIV has emerged in all parts of the world in the wake of the epidemic.³² However, there is a growing recognition now at international level that the protection of human rights is essential to safeguard human dignity in the context of HIV and to ensure an effective and efficient response to HIV and AIDS. Moreover, the link between HIV/AIDS and human rights is based on the idea that protection of the rights of people living with HIV or vulnerable to HIV infection is deemed a fundamental element of the response to HIV.³³

The human right dimensions of HIV/AIDS epidemic ranges of civil, political, economic, social and cultural rights and fundamental freedoms of all people. At the global level, the human rights norms as

³⁰ L. Doyal, and L. Doyal, *Living with HIV and Dying with AIDS Diversity, Inequality and Human Rights in the Global Pandemic* (2013) 43.

³¹ *Ibid* at 20.

³² See generally M Crewe 'The HIV/AIDS Epidemic and Human Rights Responses' in M Robinson and A Clapham (eds) *Realizing the Right to Health* (Zürich: Rüffer & Rub, 2009) 277-558.

³³ *Ibid*.

we know it today have been institutionalized in the UN legally and morally binding human right instruments like treaties , courts decisions, declarations, statements , policies and ethical guidelines . Since the creation of the UN in 1945, numerous international human right instruments have been adopted even though to date there is no specific UN treaties that mention HIV or AIDS. Several provisions of these UN human right treaties, however, can apply to mitigate the impact of the epidemic and to promote the protection of rights in the context of HIV/AIDS. These include the right to life, to equality and non-discrimination, to privacy, to health, to liberty and security of the person and to seek, receive and impart information. The above mentioned women's protocol is the only human rights treaty to expressly address women's rights in relation to HIV/AIDS.³⁴ In addition to guaranteeing women's right to protection from sexually transmissible infections, including HIV/AIDS, the Women's Protocol guarantees women's right to adequate, affordable and accessible health services.³⁵

Thus the protocol recognizes the disproportionate effect that HIV has on women's health in Africa. In October 2012 the African Commission on Human and Peoples' Rights adopted the General Comments on article 14(1)(d) and (e) which clarified the meaning and scope of the provisions.³⁶ According to this general comment the right to self-protection and to be protected includes women's rights to access information, to education, to sexual and reproductive health services, to equality and non-discrimination,

³⁴ Ethiopia is one of the few countries that have not yet ratified the protocol. For discussion why Ethiopia as a member of the African Union need to consider ratifying the protocol see *Why Ethiopia Should Ratify the Maputo Protocol: The Instrument for the Right's Women in Africa* (online article) Pumazuka social forum, Nov/2010 website Available at <http://pambazuka.org/en/category/features/69059>.

³⁵ Article 14 (1) (d) and (e) of the women's protocol states that: 'States Parties shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted. This includes... (d) the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS; (e) the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognized standards and best practices.'

³⁶ African Commission on Human and Peoples' Rights, General Comments on Article 14 (1) (d) and (e) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.

to life and dignity, to self-determination, to privacy and the right to be free from all forms of violence.³⁷ The general comment also interpreted the provision to impose an overall obligation on the state parties to create an enabling, supportive, legal and social environment that empowers women to be in a position to fully and freely realise their right to self-protection and to be protected. This section of the chapter deals with the specific issue of human rights protection and HIV testing. The discussion is divided into two sub-sections: the first describes the underpinning principles of HIV testing (sometimes called the 'Three Cs') namely Counselling, Consent and Confidentiality and the subsequent section discusses the 'Three Cs' are interwoven with principles of human rights.

3.3.1 The Three Cs: Counselling, Consent and Confidentiality of HIV Testing

The HIV antibody test started to be available in industrialized nations at the time when there was apprehension about the emerging AIDS epidemic. Stigmatization, discrimination and social exclusions that emanated from the judgment of others about risk-behaviours and life-styles were often experienced by those who were tested positive by the HIV antibody test.³⁸ The fear of death from the disease due to the limits of clinical medicine coupled with the stigma linked to homosexuality, drug use and promiscuity led to public health measures such as mandatory testing, quarantine and isolations during the early responses to HIV and AIDS.³⁹ These were sometimes accompanied by calls to ensure that the HIV status of those who tested positive for HIV should be publicly known – in the worst cases, that

³⁷ *Ibid*.

³⁸ J Csete and R Elliott 'Scaling Up HIV Testing: Human Rights and Hidden Costs' (2006) 11(1) *HIV/AIDS Policy Law Review* 6.

³⁹ M Crewe above n 32 at 279.

these people be known in their workplaces and communities as HIV-positive, even that they be tattooed to show their status.⁴⁰

However, such aggressive calls for punitive and forcible testing sparked widespread concern about the effects of such strategies on individual rights and the spread of the epidemic.⁴¹ Some feared that if the screening was not voluntary, the growing pandemic could lead infected individuals to go underground for fear of discrimination, isolation or quarantine and not cooperate with public health officials.⁴² Others argued that HIV screening process should include intensive counselling before and after the HIV screening test to help interpret the significance of both negative and positive results.⁴³ It was also argued that the results of testing and the very fact that one was tested had to be kept confidential, not only because of the potential harm resulting from unapproved disclosure but also because the right to privacy had to be protected at all costs.⁴⁴

The pressures that existed at the time to make HIV testing compulsory or mandatory were curbed as most public health professionals came to understand that VCT was the most effective and rights-based approach to HIV testing.⁴⁵ Based on these grounds, the three underpinning principles of HIV testing (sometimes called the 'Three Cs') namely Counselling, Consent and Confidentiality were established as norms for the conduct of HIV testing of individuals.⁴⁶ Therefore, a broad consensus emerged that HIV

⁴⁰ Csete and Elliott above n 38 at 5.

⁴¹ R Jürgens 'Routinizing HIV Testing in Low- and Middle-Income Countries' (New York, Background paper, Public Health Program of the Open Society Institute, 2007) 9. Available at http://pdc.ceu.hu/archive/00003268/01/routinizing_hiv_testing.pdf [Visited on 13 November 2013].

⁴² *Ibid.*

⁴³ R Bayer and C Edington 'HIV Testing, Human Rights and Global AIDS Policy: Exceptionalism and Its Discontents' (2009) 34(3) *Journals of Health Politics, Policy and Law* 303.

⁴⁴ *Ibid.*

⁴⁵ *Ibid.*

⁴⁶ UNAIDS/WHO *Policy Statement on HIV Testing* (2007) 4. Available at : http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf. [Visited on 24 March 2013]

testing should only be undertaken with the individuals informed, voluntary and specific consent , pre- and post testing counselling and with respect to confidentiality.

3.3.2 The Linkage of the “Three Cs” and Human Rights

Testing with the ‘Three Cs’ (Counselling, Consent and Confidentiality) has a clear foundation in human rights law. What follows is a discussion of these interwoven- principles of HIV testing and human rights.

HIV counselling is a process that has long been considered an essential component of HIV testing with the objective of enabling individuals to make an informed consent to the testing. It contributes to the fulfilment of individuals having access to health information regarding the nature, purpose and potential risks of undergoing the testing. HIV counselling also helps individuals to be prepared emotionally and socially to receive their result using the two sessions of pre- and post- testing counselling. The ICCPR recognizes the right ‘to seek, receive and impart information and ideas of all kinds’.⁴⁷ In addition, according to the United Nations Committee on Economic, Social and Cultural Rights, the right to the enjoyment of the highest attainable standard of health includes the ‘right to seek, receive and impart information concerning health issues.’⁴⁸ Appropriate and sufficient information regarding the nature, purpose, benefits and risks of the HIV antibody diagnosis enables an autonomous person to make thoughtful choices.

⁴⁷ ICCPR art19(2).

⁴⁸ UN Committee on Economic, Social and Cultural Rights, General Comment 14(The Rights to the Highest Attainable Standard of Health (hear in after CESCR General Comment 14.) U.N. Doc E/C.12.2000/4 (2000) para. 12(b) (iv).

International human rights law protects the right of a competent adult to withhold informed consent to medical treatment, including diagnostic tests. This right to withhold consent to medical treatment derives from different rights including the right to health, right to liberty and security, right to privacy as enshrined under international and regional human right instruments. The right to liberty and security of the person guaranteed under article 9(1) of the ICCPR and article (6) of the African charter, demands that individuals to be able to voluntarily accept or refuse physical intrusions of any kind which gives them control over their bodies. Testing for HIV without informed consent is argued to represent an involuntary intrusion into bodily integrity, which is protected by the right to liberty and security of the person.⁴⁹ The International Guidelines on HIV/AIDS and Human Rights also noted that "...compulsory HIV testing can constitute a deprivation of liberty and a violation of the right to security of a person" and that "... respect for the right to physical integrity requires that testing be voluntary and that no testing be carried out without informed consent."⁵⁰ An essential element of the right to security and liberty is the right to informed consent prior to any medical procedure including HIV testing.

Moreover, the idea that individuals are entitled to the right to health is drawn from numerous international human rights instruments. The UDHR proclaims a right to "a standard of living adequate for the health and well-being of individuals and their families..."⁵¹ while the ICESCR recognizes "the right of everyone to the highest attainable standard of physical and mental health."⁵² The CEDAW also

⁴⁹ B. Anderson 'A Human Rights Approach to HIV Testing: A Voluntary, Mandatory or Routine? (2006) A *Publications of the AIDS Legal Network* 7.

⁵⁰ The Office of the United Nations High Commissioner for Human Rights (OCHCR) and UNAIDS *International Guidelines on HIV/AIDS and Human Rights* (Geneva: OCHCR/ UNAIDS, 2006) para.135. Available online at : <http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf> [Visited on 6June/2012].

⁵¹ UDHR art 25.

⁵² ICESCR art 12

obliges states to take all appropriate steps to eliminate discrimination against women in health care and to ensure women access to appropriate services in connection with childbearing.⁵³

HIV testing and counselling service is part and parcel of the 'highest attainable standard' of health. Csete and Elliott in framing HIV testing as a component to the right to health argue that;⁵⁴

‘ The authoritative comment on the right to health, from the UN committee that monitors governments’ progress on attaining this right, suggests that the right to health includes basic services, including HIV/AIDS-related health services, that are “scientifically and medically appropriate and of good quality,” as well as respectful of culture and medical ethics. We take this to include HIV testing.’

The UN committee on Economic, Social and Cultural rights interprets the normative content of the right to health by stating that ‘... the right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including ... the right to be free from interference, such as the right to be free from ... non-consensual medical treatment and experimentation.’⁵⁵ Hence, in health care settings the right of individuals to authorize or refuse medical treatment relies prominently on the right to health which is granted under different international and regional human rights instruments. However, for a person to truly exercise the right to informed consent, it requires provision of adequate information, the competence to understand the information and a voluntary consent to intervention free from undue influence, duress or coercion. In line with this the Special Rapporteur on the Right to Health has stated that:

⁵³ CEDAW art 12.

⁵⁴ Csete and Elliott above n 38 at 7.

⁵⁵ CESCR General Comment 14.

Guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy, self-determination and human dignity in an appropriate continuum of voluntary health care services . . . Informed consent invokes several elements of human rights that are indivisible, interdependent and interrelated. In addition to the right to health, these include the right to self-determination, freedom from discrimination, freedom from non-consensual experimentation, security and dignity of the human person, recognition before the law, freedom of thought and expression and reproductive self-determination.⁵⁶

Additionally, the right to privacy means that a person cannot be tested or treated for any diseases including HIV, without their knowledge and consent. Article 17(1) of the ICCPR states: "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence nor to unlawful attacks on his honour and reputation." The right to privacy encompasses respect for both physical privacy in the case of HIV testing without consent, and for privacy of information in the case of unauthorized disclosure of HIV status. The argument that unlawful HIV testing is a violation of the right to privacy under the ICCPR is reinforced by the International Guidelines on HIV/AIDS and Human Rights.⁵⁷

The third underpinning principle of HIV testing is confidentiality. Confidentiality refers to the patient's right to expect that health care professionals will not disclose personal health information without the person's consent.⁵⁸ It serves to promote human dignity by protecting intimate information, encourages

⁵⁶ Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Rep. to the General Assembly, para. 9, U.N. Doc. A/64/272 (2009) [*hereinafter* Rep. of the Special Rapp. on Health)], *available at* <http://www.ohchr.org/EN/Issues/Health/Pages/AnnualReports.aspx>, at paras. 18-19 (emphasis added). (last visited April/2013).

⁵⁷ OCHCR/ UNAIDS above n 50 at para 105.

⁵⁸ L. Gostin and Z. Lazzarin *'Human Rights and Public Health in the Aids Pandemic'* (Berkeley: University of California Press, 1997) 16.

and preserves trust between health care professionals or healers and patients, and increases the efficacy of public health programmes that depend on voluntary cooperation to effect lasting behavioural changes.⁵⁹

Maintaining confidentiality of test results and of the fact of seeking an HIV test is an integral part of respecting and protecting the right to privacy which is recognized under numerous international human rights instruments. Privacy is explicitly protected under art 12 of UDHR that ensures individual's right to protection from 'arbitrary interference with his privacy, family, home or correspondence.' Writers argue that the concept of privacy extends not only to private acts and the physical space within one's home, but also to personal information, including health information.⁶⁰ Similarly ICCPR also proscribes both arbitrary and unlawful interference with privacy and hence intentional or negligent disclosures of personal information without the person's consent may constitute a breach of privacy.⁶¹

HIV/AIDS policies that promote shared confidentiality and partner notification limit the right to privacy. Denying individuals the control of disclosure of personal information is contrary to the privacy principles as stated under different international human rights instruments. Therefore, the right to privacy encompasses obligations to respect physical privacy, including the obligation of health care providers to seek informed consent to HIV testing and privacy of information that requires confidentiality of all information in the case of unauthorized disclosure of HIV status.

In case of HIV/AIDS where local laws permit partner notifications, health workers usually contact persons who may have been exposed to HIV and offer them education, counselling, and testing although

⁵⁹ *Ibid.*

⁶⁰ Gostin and Lazzarni above n 58 at 16.

⁶¹ ICCPR art 17.

views differ regarding the appropriate design of partner notification programmes for HIV/AIDS. However, confidentiality of medical information including HIV test results has a paramount importance for human rights protections. Partner notification programmes which are consistent with human rights principles respect the informed consent of HIV-infected individuals and consider the unexpected consequences of disclosure of HIV test results to sexual partners.

In conclusion, therefore, adhering to the three underpinning principles of HIV testing has a clear foundation in human rights law and remains critical to the effectiveness of HIV prevention efforts. However, although basic human rights are inherent to all human persons and hence non-violable, at this juncture it must also be noted that, under a narrowly defined certain circumstance states may impose restrictions on rights where they pose a threat to the general welfare.⁶² The principle that certain rights can be restricted is enshrined under the UDHR where limitations are considered permissible to '... secure due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and general welfare in a democratic society.'⁶³ Similarly, Article 4 of ICESCR, for instance, states:

The states parties to the present Covenant recognize that, in the enjoyment of those rights provided by the state in conformity with the present Covenant, the state may subject such rights only to such limitations as are determined by law only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting general welfare in a democratic society.⁶⁴

⁶² The ACHPR has no a specific provision on limitation. However under article 27(2) of the charter the concept of 'duties' serve as a general limitation clause providing: 'The rights and freedoms of each individual shall be exercised with due regard to the rights of others, collective security, morality and common interest.'

⁶³ UDHR, art 29(2).

⁶⁴ ICESCR art 4.

Article 4 of the ICCPR also declares that when a public emergency which threatens the life of a nation arises and it is officially proclaimed, a state party may deviate from a number of rights to the extent strictly required by the situation a number of rights can under no circumstances be limited or derogated from. These include the rights to life, the right to juridical personality, the freedom of thought, conscience, and religion; the prohibition against torture and cruel or inhuman treatment; slavery; the principle of legality in the field of criminal law and imprisonment for inability to fulfil a contractual obligation.⁶⁵

Under the Ethiopian constitution there is no general limitation clause. However, most of the provisions on protected rights contain 'claw- back' clauses that limit rights to safeguard public security, peace, the prevention of crimes, public morality and the protection of the rights and freedoms of others.⁶⁶ Nonetheless, this discretion of Governments to restrict rights is not without limits. As spelled out under the *Siracusa Principles* (a non binding document adopted by the UN Economic and Social Council in 1985)⁶⁷ and the ICCPR any restrictions of rights must be strictly provided by law, neither arbitrary nor discriminatory, based on objective considerations, necessary to respond to a pressing social need, proportional to the social aim and no more restrictive than necessary to achieve the intended purpose.⁶⁸

⁶⁵ ICCPR art 4(2).

⁶⁶ See for example FDRE constitution, art. 26, 27, 29, 30 and 31.

⁶⁷ UN Economic and Social Council (ECOSOC), *The Siracusa Principles on the limitations and derogation provisions in the international covenant on civil and political rights*, (1985) UN Doc. E/CN.4/1985/4. The *Siracusa principles* provides relating to health related rights as follows: '...public health may be invoked as a ground for limiting certain rights in order to allow the state to take measures dealing with a serious threat to the health of the population" or of individuals. Such measures must be "specifically aimed at preventing disease or injury or providing care for the sick and injured...' (p.25)

⁶⁸ See generally Human Rights Committee, General Comment 29, States of Emergency (article 4), U.N. Doc. CCPR/C/21/Rev.1/Add.11 (2001).

Hence the protection of public health is a permissible justification for limiting rights recognized in the name of the need for communicable disease control. By the same token one may argue that restrictions of the human rights principles discussed above in the context of HIV testing of pregnant women is acceptable to prevent vertical transmission of HIV as one public health objective. However, such restrictions of human rights of pregnant women articulated in both the ICCPR and the ICESCR must be done in conformity and strict adherence of the *Siracusa* principles. Such discussions of allowing violations of the underpinning principles of HIV testing or pressuring pregnant women in order to procure a high uptake of HIV testing, need to be transparent and explicit and the reasons behind it stated and debated in a democratic society. As Bennett has argued it must be established that the evidence for the imposition of a policy of routine antenatal HIV testing is strong enough to warrant pregnant women being made a special case in which the usual gold standard of informed consent does not apply.⁶⁹

In many low and middle income countries the primary model for HIV testing has been the provision of client-initiated VCT services.⁷⁰ However, as shown in the previous chapter, these countries are increasingly espousing routine 'opt-out' HIV testing approach motivated by the objective of testing the greatest numbers of individuals as possible. The severity of the AIDS epidemic in sub-Saharan Africa and the potential benefit of testing in light of the advancement of medical treatment for the disease are usually invoked as a justification for the call to shift towards routine 'opt-out' HIV testing approach in an effort to expand testing massively.

⁶⁹ R Bennett, 'Routine Antenatal HIV Testing and Informed Consent: An Unworkable Marriage?' (2007) 33(8) *Journal of Medical Ethics* 447.

⁷⁰ World Health Organization and United Nations Programme on HIV/AIDS (WHO/UNAIDS), '*Guidance on Provider Initiated HIV Testing and Counselling in Health Facilities* (2007) para 6. Available online at http://www.who.int/hiv/who_pitc_guidelines.pdf. [Last visited 15 October, 2013].

However, the move towards expanding of the routine provider initiated 'opt-out' HIV testing approach in sub-Saharan Africa has resulted in the reopening of the assessment of the human rights and ethical implications of HIV testing policies on the continent.⁷¹ In the context of prenatal HIV screening of pregnant women to prevent vertical transmission of HIV 'opt-out' HIV testing approach aggressively in maternal health care services poses a threat to their human rights. The subsequent sections of this chapter discuss the human rights and ethical concerns raised by the routine provider initiated 'opt-out' HIV testing approach and its application to screening pregnant women for HIV infection.

3.4 Human Rights Concerns of the Prenatal Routine Provider - Initiated 'Opt-out' HIV Testing of Women

The espousal of the routine provider initiated 'opt-out' HIV testing approach that dictates all pregnant women to be tested routinely for HIV infection unless they explicitly decline the testing has ignited human rights concerns. For instance, as noted above adequate and appropriate counselling during HIV testing gives effect to the human rights imperative of the right to information as well as public health objective of prevention of onward transmission of HIV. However, one of the ongoing human rights debate in the case of the adoption of routine 'opt-out' approach to HIV testing revolves around the quality and adequacy of counselling and information about HIV given to women at the time of the HIV test offer.

⁷¹ M Crewe and F Viljoen *Testing Times Routine HIV Testing: A Challenge to Human Rights* (Unpublished, A Background Paper prepared for the International HIV Testing Email Group, 2005) [on file with the author of this thesis] 6. E King *et al.* 'HIV testing for pregnant women: A rights-based analysis of national policies, *Global Public Health*' (2013) 8(3) *An International Journal for Research, Policy and Practice* 328. Also see generally J Becker *et al.* 'Provider Initiated Testing and Counselling (PITC) for HIV in Resource-Limited Clinical Settings: Important Questions Unanswered' (2009) 3(4) *Pan African Medical Journal* 1.

As mentioned earlier, the 2007 WHO/UNAIDS guidance on provider initiated HIV testing and counselling (PITC) in health facilities, recommends '*simplified pre-test information*' instead of detailed pre-test counselling, although it also specifies minimum requirements when recommending HIV testing and counselling to a patient.⁷² The term simplified pre-test information indicates that provision of substantial levels of counselling is not required from health care providers before testing. The notification part of a routine programme requires that a woman be informed that she will be tested for HIV unless she expressly refuses. Such provision of notification does not necessarily impose an obligation on the health care providers for extensive disclosure of information regarding the benefits and risks of HIV testing nor to assist patient in determining what information is material to them. Consequently, the adoption of routine 'opt-out' HIV testing approach and thus the practices of 'simplified pre-test information' during HIV screening programmes has caused human rights concerns that the practice limits pregnant women's rights on access to information which could have enhanced their autonomy by providing them with information necessary to make the best possible choices.

HIV testing has serious social, legal and financial consequences in addition to its medical implication. In order for pregnant women accessing maternal health care service to give free and informed consent to HIV testing, adequate information regarding the purpose, risks and benefits of the testing and alternative options (including non-treatment) must be provided to enable them to understand fully the purposes, risks, harms and benefits of being tested, as well as those of not being tested, prior to performing an HIV test. A number of studies from different African countries have concluded that the quality and comprehensiveness of counselling varies widely: patients in antenatal care and other services are sometimes given inadequate information about their right to decline, the consent process and the

⁷² Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother-to-Child Transmission of HIV* (Addis Ababa, 2007) para 3. 6.

benefits and rationale for HIV testing, and they are not always given time to ask questions or make decisions.⁷³

The human rights concerns in relation to the issue of pre-test counselling in routine provider initiated 'opt-out' HIV testing approach is not only on the adequacy but also the content of the information provided. It has been argued that health providers' counselling practices are influenced by their perceived moral responsibilities as professionals, the need to promote and adhere to public health goals of preventing further infections as well as an underlying morality that health professionals are expected to know what is best for their patients.⁷⁴ Although the health care providers are expected to remain neutral when informing pregnant women about the HIV testing, they are tempted to 'sell' the clinical and public health benefits of HIV testing while playing down the right to refuse and glossing over the possible negative consequences of receiving a HIV-positive test result.⁷⁵

Pre-test information sessions that emphasis the moral responsibility of pregnant women to protect the unborn child but not on the patient's rights impose a moral obligation on pregnant women to take the HIV testing even if they do not wish to. Research in sub Saharan Africa suggests that pregnant women are unlikely to 'opt-out' of HIV testing due to the fear that it might signal to others that they disregard

⁷³ C. Obermeyer, *et al.*, 'HIV testing and care in Burkina Faso, Kenya, Malawi and Uganda: ethics on the ground'(2013) 13(6) *BMC International Health and Human Rights* 4.

⁷⁴ E. Vernooij, and A. Hardon, 'What Mother wouldn't want to Save Her Baby?' HIV Testing and Counselling Practices in a Rural Ugandan Antenatal Clinic, Culture, Health and Sexuality' (2013) 15(4) *An International Journal for Research, Intervention and Care* 563. Also see generally S. Rennie and F. Behets 'Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low- Income Countries' (2006) 84(1) *Bulletin of the World Health Organization* 54. Rothpletz-Puglia *et al.*, 'Routine Prenatal HIV Testing: Women's Concerns and Their Strategies for Addressing Concerns'(2012)16 *Maternal and Child Health Journal* 468. R Bennett, 'Routine Antenatal HIV Testing and Informed Consent: An Unworkable Marriage?' (2007) 33(8) *Journal of Medical Ethics* 447.

⁷⁵ S. Rennie and F. Behets 'Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low- Income Countries' (2006) 84(1) *Bulletin of the World Health Organization* 54.

the wellbeing of their babies.⁷⁶ In a study conducted in Uganda it was reported that the 'good for the baby message' during the pre-test information sessions by the health care providers left little room for the women to act otherwise.⁷⁷

It has been widely argued that in deciding to undergo HIV testing, a pregnant woman does take into account not only the health of her baby but also her own health, the potential social implications of a positive test result and her own prospects for accessing treatment, care and support services.⁷⁸ Hence, creating some sense of moral obligation on the pregnant women by emphasising the health of the unborn child during pre-test information causes women to take up the HIV testing although they are not sufficiently prepared for the possible negative consequences of the testing.

One of the core principles of the 2007 Ethiopian PMTCT guideline states that '... HIV counselling and testing services must provide adequate information and be done voluntarily following informed consent'.⁷⁹ Yet, the same guideline also declares that it promotes 'pre-test information' rather than 'pre-test counselling'. This can be inferred from one of the statements which states that '*...The client is given pre-test information in a group or individually on HIV/AIDS and PMTCT.*'⁸⁰ The espousal of pre-test information rather than counselling during HIV testing in relation to PMCT in Ethiopia is not incidental. It represents a deliberate response of the Government to the recommendations of the WHO and UNAIDS. As mentioned above the WHO/UNAIDS guidance on PITC in health facilities recommends

⁷⁶ N. Angotti 'Testing differences: The Implementation of Western HIV Testing Norms in sub-Saharan Africa'(2012)14(4) *An International Journal for Research, Intervention and Care* 372.

⁷⁷ Vernooij and Hardon above n 74 at 563.

⁷⁸ S. Gruskin *et al.*, 'Provider-Initiated HIV Testing and Counselling in Health Facilities—What does this Mean for the Health and Human Rights of Pregnant Women?'(2008) 8(1) *Developing World Bioethics* 28.

⁷⁹ MOH/HAPCO above n 72 at para.1.2.

⁸⁰ *Ibid*, para. 5.3.2 and 5.4.1.

simplified pre-test information instead of pre-test counselling.⁸¹ One possible explanation for the adoption the approach to provide 'pre-test information' rather than 'pre-test counselling' is the assumption that women already know about HIV and AIDS and they expect an HIV test upon attending maternal health care services.

However, in Ethiopia there are many effective health communication barriers including limited access to media and high illiteracy rate among women which precludes them from such knowledge. In fact, according to one cross-sectional study conducted among 422 women ANC attendees in Addis Ababa 21.3 percent of them revealed that they did not know the main reason why they were offered HIV testing at the health centres particularly when they were pregnant.⁸² These women were in the main from the most urbanized area of the country with a reasonable standard of living and access to information.

Correspondingly, researchers from different parts of Africa call for the improvement of counselling sessions in the case of prenatal HIV testing settings. For instance, according to a comparative cross sectional study conducted among ANC attendees from the Gambella region in Ethiopia with a sample size of 332 participants 80.7 percent suggested the need of improvement of pre-test counselling service being given to ANC attendees.⁸³ The practices of simplified pre-test information during HIV screening programs limit women's rights on access to information which could have enhanced their autonomy by providing them with information necessary to make the best possible choices. Reducing the use of pre-

⁸¹ UNAIDS/WHO above n 70 at para 36.

⁸² H. Ismail and A. Ali 'Pregnant Women's Satisfaction and Comprehension Level of Information Given during HIV Counselling and Testing for PMTCT in Public Health Facilities in Addis Ababa' (2011) 25(2) *Ethiopian Journal of Health Development* 129.

⁸³ W. Fanta and A. Worku 'Determinants for Refusal of HIV Testing among Women Attending for Antenatal Care in Gambella Region, Ethiopia' (2012) 9(8) *Reproductive Health* 2.

test counselling into pre-test information in the context of Ethiopia, makes 'opt-out' HIV testing approach to lose its power as a prevention tool as well.

Moreover, as noted earlier, under human rights law informed consent for any medical procedures is entrenched in the right to security of person or the right of a person autonomously to control what happens to her body. Although the underlying assumption of the routine 'opt-out' HIV testing approach is that the pregnant women are able to consent to HIV testing, there are concerns relating to the extent of the enabling environment for women to express their consent freely and voluntarily in reality. Those who question the consent process in the context of routinely offered HIV testing express concern that the approach could lead to uninformed and even forced testing, especially if the provider has limited time and resources.⁸⁴ True voluntariness in the context of HIV testing requires pregnant women to be able to say 'No' to an HIV test and that they have the confidence and power to make that choice.

Critics argued that in settings where there is a power imbalance between test provider and client, the voluntary nature of HIV testing could be compromised, as the client may feel compelled to consent to the provider's offer.⁸⁵ Taking into consideration the integration of gender inequality and power imbalance to the social fabrics of most societies in the developing world to which Ethiopia is no exception it is doubtful whether pregnant women may be empowered to exercise their right to informed refusal of HIV testing if they did not want to take up the test. As demonstrated by experts in health and human rights this unbalanced power relation is even more complicated in cases of pregnant women who want to exercise the informed right of refusal of HIV testing. Not only do these gender norms in many

⁸⁴ O. Ujiji *et al.*, 'Is "opt-out" HIV Testing' a real option among pregnant women in rural districts in Kenya?' (2011) 11 *BMC Public Health* 6. Available online at: <http://www.biomedcentral.com/1471-2458/11/151> [visited on 5 August, 2013].

⁸⁵ Rennie and Behets above n 75 at 54.

places marginalise women but also they lead to the fear that women will receive inferior care as a result of their 'incorrect' decision.⁸⁶

The unequal power relationships between women and their health care providers limit many women's ability to decline the test or defer testing until they feel more ready to deal with the results and manage personal risks. In describing the relationship of routine antenatal HIV testing and informed consent which she called '*the unworkable marriage*', Bennett argues that as the fundamental aim of routine testing is to secure the testing of those women who would not have specifically chosen to be tested, it seems inevitable that pressure will be put on women to accept the test.⁸⁷

The other concern raised over the 'opt-out' test approach is in relation to the language used to define informed consent in the policies. Absent or inadequate details on the provision of the consent process under HIV testing policies do not only raise concerns about whether clients' decisions to test will be sufficiently informed but also the health care provider is left with room for interpretation of how to render testing and counselling services. The 2007 Ethiopian guidelines on PMTCT clearly stipulate that HIV testing '... *must be done voluntarily following informed consent...*'⁸⁸ and that the women accessing maternal health shall be told that their routine laboratory check up includes HIV testing unless they say 'No' (opted-out).⁸⁹ However, the guideline does not define the concept of 'informed consent' nor does it state the details as to who can give a valid consent. The guideline also fails to give the minimal safeguards on how providers obtain consent from the women accessing maternal health care.

⁸⁶ Gruskin *et.al* above n 78 at 26.

⁸⁷ Bennett above n 69 at 447.

⁸⁸ MOH/HAPCO above n 72 at para.5.3.2.

⁸⁹ *Ibid.*

There are two elements to informed consent: *knowledge/information* and *consent*. Neither element on its own is sufficient to satisfy the requirement of informed consent. Hence, any medical procedure including an HIV test may only be lawfully performed under normal circumstances on an individual who has been fully informed of all relevant *information*, *understands* the information and has *freely agreed* to undergo the procedure.⁹⁰ Such absence of indication in the guideline as to how 'informed consent' should be understood, not only opens up the potential for conflicting interpretations but also the potential slippage in the practices from a routine offer of HIV testing to routinely imposed HIV testing.

Similarly, testing pregnant women for HIV during labour poses a host of human rights concerns. Sofia Gruskin and her colleagues argue that asking a woman who is overcome by uterine contractions to 'consent' to HIV test raises a host of questions including - whether there was pre-test counselling; how consent was obtained; how the test result was communicated; what sort of post-test counselling was provided and her access to antiretroviral therapy.⁹¹ There is a possibility that the manner of the HIV test offered to women in labour can be compromised due to the urgency to begin ARV treatment for a HIV-positive woman in labour in order to prevent vertical transmission.⁹² Despite the unique challenges of providing informed consent during labour, advocates of neonatal health increasingly promote HIV testing during labour and delivery.⁹³

⁹⁰ R. Faden and T. Beauchamp *'A History and Theory of Informed Consent'* (Oxford: Oxford University Press, 1986) 274.

⁹¹ S. Gruskin 'Reproductive Health and HIV: Do International Human Rights Law and Policy Matter?' (2008) 3(1) *International Journal of Sustainable Development Law and Policy* 91.

⁹² A. Ahmed, 'HIV and women: incongruent policies, criminal Consequences' (2011) 6(32) *Yale Journal of International Affairs* 36.

⁹³ See generally R. Armstrong 'Mandatory HIV testing in pregnancy: Is there ever a time?' (2008) 8(1) *Developing World Bioethics* 1–10. Available online at; doi:10.1111/j.1471-8847.2007.00214.x .[Visited on 4 February, 2012].

Research reports on HIV testing among pregnant women in Ethiopia are mainly focused on how to increase testing uptake rather than how the routine testing is impinging upon the autonomy of women accessing maternal health care services.⁹⁴ However, there are substantial studies from other sub-Saharan African countries that can be used to substantiate the above argued human rights concerns. For instance, a study in Uganda shows that although clinical officer acknowledged the right of pregnant women to opt out, in practice they did not emphasize patient rights, but rather the moral responsibility to protect the unborn child.⁹⁵ Another study that enrolled 245 pregnant women after pre-test counselling and prior to the collection of test results in Tanzania found that 52 percent of the participants felt that they lacked autonomy to make decisions about HIV testing because 'a refusal would have been conceived as a challenge to medical authorities.'⁹⁶ Similar studies in Uganda⁹⁷ and Malawi⁹⁸ have also reached the conclusion that, women who received ANC from health facilities that provided HIV testing on-site generally perceived testing as compulsory to access antenatal care. Hence, the human rights challenge of 'opt-out' HIV testing approach is that some pregnant women are unlikely to opt out of testing for the fear that their health care provider may react to them negatively for doing so.

⁹⁴ See generally M Malaju and G Alene, 'Assessment of utilization of provider-initiated HIV testing and counselling as an intervention for prevention of mother to child transmission of HIV and associated factors among pregnant women in Gondar town, North West Ethiopia'[Online] (2012) 12(226) *BMC Public Health* 1-8. Available online at; <http://www.biomedcentral.com/1471-2458/12/226> (visited on February/2014); A Lifson, *et al.*, 'HIV/AIDS stigma-associated attitudes in a rural Ethiopian community: characteristics, correlation with HIV knowledge and other factors, and implications for community intervention', [Online] (2012) 12(6) *BMC International Health and Human Rights* 1-8. Available online at <http://www.biomedcentral.com/1472-698X/12/6> (Visited on March/2013); Z Moges and A Amberbir, 'Factors Associated with Readiness to VCT Service Utilization among Pregnant Women Attending Antenatal Clinics in North western Ethiopia: A Health Belief Model Approach' (2011) 21 *Ethiopian Journal of Health Science* 107-116.

⁹⁵ Vernooij and Hardon above 74 at 563.

⁹⁶ S Maman, *et al.*, 'HIV-Positive Women Report More Lifetime Partner Violence: Findings from a Voluntary Counselling and Testing Clinic in Dar es Salaam, Tanzania', (2002) 92 *American Journal of Public Health* 1333.

⁹⁷ E Larsson, *et al.*, "'Opt-out' HIV Testing during Antenatal Care: Experiences of Pregnant Women in Rural Uganda' (2011) 1 *Health Policy and Planning* 5.

⁹⁸ N Angotti, *et al.*, 'An offer you can't refuse? Provider-Initiated HIV Testing In Antenatal Clinics In Rural Malawi' (2011) 26 *Health Policy and Planning* 312; See also A Hardon, *et al.*, 'Women's Views On Consent, Counselling And Confidentiality in PMTCT: A Mixed-Methods Study in Four African Countries' (2012) 12(6) *BMC Public Health* 1-9; and Vernooij and Hardon above 74 at 563.

Additionally, it has been stipulated by the WHO and UNAIDS in Geneva and by the national PMTCT guidelines in Ethiopia that as routine 'opt-out' HIV testing becomes more common and as the availability of antiretroviral therapy increases, HIV related stigma and discrimination will also decrease.⁹⁹ This assertion bases its argument on the critical review of the response to the school of 'AIDS exceptionalism' which argues that AIDS is a uniquely stigmatized disease that requires specific human rights protections and hence put a strong emphasis on informed consent and voluntary choice for testing.¹⁰⁰ Thus, supporters of routine HIV testing argue that the key to reduction of stigma associated with HIV is to begin to routine test for HIV in healthcare settings in a similar manner to other diseases.¹⁰¹

However, the fact that HIV-related stigma and discrimination are borne out of socio-cultural factors and may not necessarily be addressed by routine 'opt-out' HIV testing approach makes the above assertion disingenuous. Although HIV testing is a gateway to services, HIV testing is also a gateway to stigma and discrimination and thus HIV-related stigma and discrimination are rooted in socio-cultural practices of the people, which may not be necessarily be addressed by mere implementation of a particular testing method.¹⁰²

In fact, some commentators express their concern that routine HIV testing may fuel stigma and discrimination associated with HIV as more people especially women know their HIV status exposing

⁹⁹ See WHO/UNAIDS above n 70 at 36 and MOH/HAPCO above n 72 at 11.

¹⁰⁰ Csete & Elliott above n 38 at 13. Also see E Durojaye, 'The Impact of Routine HIV Testing on HIV- Related Stigma and Discrimination in Africa' (2011) 11 *International Journal of Discrimination and the Law* 195.

¹⁰¹ De Cock 'HIV Testing in the Era of Treatment Scale Up' (2005) 8(2) *Health and Human Rights* 32.

¹⁰² Durojaye above n 100 at 197.

them to negative responses including violence and rejection often associated with being HIV positive.¹⁰³ HIV testing occurs in a social context marked by unequal gender and power relations, thus, when tested positive, women are more likely than men to face judgemental attitudes or implicit accusation of promiscuity or other bad behaviours.

Although there is a paucity of research on the role of AIDS's related stigma on testing in Ethiopia, some research reports have shown the persistence of HIV related stigma in the country. A study that was conducted in North West Ethiopia reported that in a rural Ethiopian setting in which rapid scale-up of HIV treatment occurred, many respondents still characterized HIV as associated with shame or blame, or indicated that people living with HIV (PLWH) would be isolated or face discrimination.¹⁰⁴ According to this study that surveyed 561 participants from rural villages, 74 percent of them believe that HIV was God's punishment for bad behaviour while 41 percent responded with one or more negative responses associated with distancing themselves from PLWH, the most common being that they would not buy vegetables in the market from a person with AIDS.¹⁰⁵

Similarly, evidence from sub-Saharan Africa indicates that fears of negative reactions by partners pose important barriers to disclosure of HIV status to sexual partners. These studies report that pregnant women fail or defer disclosure of HIV positive status to their sexual partners due to fear of negative reaction like abandonment, being sent away from home, domestic violence and accusation of bringing HIV infection into the family.¹⁰⁶ It is also reported that in one community in Malawi, abandonment

¹⁰³ Csete & Elliott above n 38 at 14. See also S Mall, *et al.*, 'Changing Patterns in HIV/AIDS Stigma and Uptake of Voluntary Counselling and Testing Services: The Results of Two Consecutive Community Surveys Conducted in the Western Cape, South Africa' (2013) 25(2) *AIDS Care, Psychological and Socio-medical Aspects of AIDS/HIV* 200.

¹⁰⁴ Larsson, *et al.*, above n 97 at 3.

¹⁰⁵ *Ibid.*

¹⁰⁶ Mall above n 103 at 195. Also see generally W Sambisa, *et.al.*, 'AIDS Stigma as an Obstacle to Uptake of HIV Testing: Evidence From a Zimbabwean National Population-Based Survey' (2010) 22(2) *AIDS Care: Psychological and Socio-*

following HIV disclosure by pregnant women was so high that the community called the PMTCT service '*the divorce program*'¹⁰⁷ (emphasis added). A growing body of literature from Africa highlights that HIV testing in marriage are taken as a sign of infidelity or as an accusation of a partner's infidelity – both of which could result in tension or physical violence.¹⁰⁸

Furthermore, it is noted earlier in this chapter that any HIV testing policy that undermines valid and specific informed consent infringes upon the right to health of individuals. In line with this argument, there is a human rights concern that a routine 'opt-out' HIV testing approach is likely to undermine the trust between pregnant women and their health care providers, which in turn can cause pregnant women to avoid seeking medical attention if they fear that they will be pressured into having a test.¹⁰⁹ A study that surveyed 400 pregnant women from Gondar town in Ethiopia reported that around 17.8 percent of mothers in the study believed that provider initiated HIV testing approach would cause people to avoid seeing their health care provider for fear of being tested.¹¹⁰ A similar study conducted in *Arba Minch* city also showed that the high desperation to conceal their positive status from close family members compelled pregnant women to stay away from the facilities where they were diagnosed and to give birth either at home or in facilities where their HIV-positive status is not known.¹¹¹

medical Aspects of AIDS/ HIV 170-186; R Byamugisha, *et.al.* "Telling My Husband I Have HIV is Too Heavy to Come Out of My Mouth": Pregnant Women's Disclosure Experiences And Support Needs Following Antenatal HIV Testing In Eastern Uganda' (2012)15(17) *Journal of the International AIDS Society* 7.

¹⁰⁷ Obermeyer *et al.*, above n 73 at 10.

¹⁰⁸ A Conroy 'It means There is Doubt in the House': Perceptions and Experiences of HIV Testing in Rural Malawi, Culture, Health & Sexuality' (2014) 16(4) *An International Journal for Research, Intervention and Care* 407.

¹⁰⁹ E Flagler, *et.al.* 'Bioethics For Clinicians: Ethical Dilemmas that Arise in the Care of Pregnant Women: Rethinking "Maternal-Fetal Conflicts"' (1997)1156 (12) *Canadian Medical Association Journal* 1733.

¹¹⁰ Malaju and Alene above 94 at 7.

¹¹¹ A Adedimeji *et al.*, 'A Qualitative Study of Barriers to Effectiveness of Interventions to Prevent Mother-to-Child Transmission of HIV in ArbaMinch, Ethiopia' (2012) 2 *International Journal of Population Research* (2012) 4.

Studies in other sub-Saharan African countries also revealed the same concerns of avoiding medical attention for fear of HIV testing. For instance, a study in Kenya found that women give birth at home rather than at a health facility in order to avoid being forced to take an HIV test without their informed consent or have the confidentiality of their HIV test results breached. Another recent study in Kenya showed that pregnant women accept to be HIV tested but fail to return for the test results that are available within a quarter of an hour, and so failure to come for them strongly indicates that many women were not ready to face the consequences of a positive test result.¹¹² Further, a survey of 1,268 respondents in Botswana in 2004 found that while most participants reported being in favour of routine testing, 43 percent of participants believed that routine testing would lead people to avoid going to the doctor for fear of testing.¹¹³ Similar findings were also reported in a study from Malawi that rural women from Malawi do not perceive HIV testing in antenatal clinics as a choice and the consequence is that they may avoid government hospitals for antenatal services to escape what they perceive to be a mandatory testing requirement.¹¹⁴

Another important set of concerns in relation to the adoption of routine provider initiated opt-out HIV testing approach to screening pregnant women for HIV infection is that the practice may lead to a legal environment that makes women vulnerable to prosecution under criminal statutes. Criminalization of HIV refers to the use of HIV specific criminal law or non-HIV specific law (i.e. assault) to prosecute HIV transmission and exposure.¹¹⁵ Although several African countries have laws that create HIV-specific offences, as mentioned previously Ethiopia does not have such a HIV specific law. However,

¹¹² Ujiji *et al.* above 84 at 6.

¹¹³ S Weiser, *et al.*, 'Routine HIV testing in Botswana: a Population-Based Study on Attitudes, Practices, and Human Rights Concerns' (2006) 3(7) *PLoS Med* 4. Available online at ; <http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0030261>. [Visited on 4 June, 2011].

¹¹⁴ N Angotti, *et al.*, 'An offer you can't refuse? Provider-initiated HIV Testing in Antenatal Clinics in Rural Malawi' (2011) 26 *Health Policy and Planning* 312.

¹¹⁵ Ahmed above n 92 at 33.

article 514 of the Ethiopia criminal law states that acts of intentional spreading or transmission of communicable human disease is punishable by a rigorous imprisonment or in grave 'cases, with rigorous imprisonment for life or death.¹¹⁶ Although this particular provision of the criminal law does not specifically mentioned HIV/AIDS, courts in Ethiopia have applied it in many instances to transmission HIV/AIDS infection.¹¹⁷ Thus, the interaction of criminalization and routine 'opt-out' HIV testing approach has many implications for women. For instance, as mentioned earlier women are more likely to be tested first in family(before their partners) due to the prenatal testing, hence nondisclosure of positive HIV test results to a partner for fear of violence or abandonment can make a woman accountable for 'knowingly' transmitting or exposing a partner to HIV. On the other hand, HIV positive women who elect to carry a baby for nine months and deliver without preventive measures or who breast feed their children are potentially exposed to the possibility of criminal prosecution for transmission of communicable human disease i.e. HIV/AIDS.¹¹⁸

Therefore, the challenges and implications of the routine provider- initiated 'opt-out' HIV testing approaches on the human rights of pregnant women accessing maternal care services as discussed above are significant. The routine 'opt-out' HIV testing approach often takes place in situations where women face unique challenges that impact their ability to give informed consent, access adequate information and protect themselves from violence and stigma.

¹¹⁶ FDRE Criminal Code Article 514 states: '(1) Whoever intentionally spreads or transmits a communicable human disease, is punishable with rigorous imprisonment not exceeding ten years.(2) Where the criminal: (a) has spread or transmitted a disease which can cause grave injury or death . out of hatred or envy , with malice or with a base motive; or (b) without even the particular intent specified in sub-article (a) of this Article has spread or transmitted a disease which can cause grave injury or death; or (c) has transmitted an epidemic, the punishment shall be rigorous imprisonment not exceeding twenty year , or in grave cases, with rigorous imprisonment for life or death...'

¹¹⁷ See for instance *Public Prosecutor Vs Legesse Yirga Alaze* ,(2011) Federal fist instance court (Lideta) case no 337/2003 ; *Public prosecutor Vs Abdulkadir Yassin Ahmed* ,(2009) Federal fist instance court (Lideta) case no. 1235/2001 ; and *Public prosecutor Vs Getye Betru* ,(2013) Cassation court of the Amhara State Government Supreme Court , case no.43/2005.

¹¹⁸ See generally Ahmed above n 92. The author demonstrated how courts in the United States have addressed issues raised by HIV-positive women in the context of parenting and motherhood.

3.5 Ethical Concerns of Routine Provider Initiated HIV Testing

Several ethical concerns are also raised regarding HIV screening of pregnant women using the routine provider initiated 'opt- out' HIV testing approach. The concept of 'ethics' as a philosophical or theoretical discipline is concerned with morality, virtue, rationality and other principles or standards of conduct and seek to understand how human beings should act and what kind of life is best for people.¹¹⁹ In theory, under the routine 'opt-out' HIV testing approach, pregnant women retain their right to refuse HIV testing when offered by health care providers. In practice, however, there are many ethical concerns that need to be addressed to ensure pregnant women are serving their own ends by agreeing to be tested.

There are those who support the 'opt-out' testing policies from an ethical, moral and philosophical basis.¹²⁰ Generally, these perspectives have been informed by utilitarian ethical frameworks that are drawn from the work of John Stuart Mill. They argued that saying that 'opt-out' testing practices are a population health intervention that benefits future populations and are, therefore, morally justifiable.¹²¹ However, recently scholars have called for more robust population and public health ethical frameworks to inform how the health of populations and individuals ought to be improved through various approaches to HIV testing practices.¹²² This section argues that subjecting pregnant women to 'opt-out' HIV testing approach within the maternal health care setting poses ranges of ethical concerns.

¹¹⁹ M Slote "Ethics," *The Encyclopaedia of Bioethics*, 3rd edition Vol. 2. Ed. Stephen G. Post (New York: Thomson Gale, 2004) 795.

¹²⁰ See for instances K De Cock *et al.* 'Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century', (2002) *Lancet* 68.

¹²¹ R Knight *et al.*, 'Advancing Population and Public Health Ethics Regarding HIV Testing: A Scoping Review (2014) 24(3) *Critical Public Health* 285-290.

¹²² *Ibid* 283.

The provision of HIV testing has been considered as a means to benefit individuals, as well as a mechanism to improve population health by reducing HIV incidence and prevalence. Generally speaking the ethical acceptability of an opting-out HIV testing approach is equivalent with an opting-in approach only if pregnant women have sufficient liberty to say 'No' to the HIV test offer made by health workers. Decisions relating to HIV testing are complex and there are many reasons why pregnant women do not want to test for HIV including low risk awareness, fear of negative reactions from partners and lack of perceived benefits. Patient autonomy being the central ethical and legal principle in modern medicine, it is generally accepted that competent individuals should be allowed to choose whether to have diagnostic tests, including HIV testing. As discussed in the previous section, critics argue that while there can be significant benefits to both mother and foetus from HIV testing, the 'opt-out' approaches may involve a higher degree of coercion for pregnant women (For instance through subtle/overt pressure from partners, family and clinicians).¹²³

The legal doctrine of informed consent requires health care providers to obtain informed consent before they are legally entitled to administer medical procedures to a patient. This requirement is actually composed of two separate but related legal duties imposed on physicians; the duty first to disclose information to patients and the duty subsequently to obtain their consent before administering treatment.¹²⁴ In their comprehensive analysis, *A History and Theory of Informed Consent*, Ruth Faden and Tom Beauchamp define informed consent as an autonomous authorization, which relies on the principles of respect for autonomy.¹²⁵ In this sense, an informed consent is 'an autonomous action by a

¹²³ *Ibid* 289.

¹²⁴ JW Berg *Informed Consent : Legal Theory and Clinical Practice* (2nd ed)(Oxford: Oxford University Press, 2001) 12.

¹²⁵ Faden and Beauchamp above n 90 at 120.

subject or a patient that authorizes a professional either to involve the subject in research or to initiate a medical plan for the patient (or both).¹²⁶

Most writers draw the ethical justification of the concept of autonomy from the work of nineteenth century philosopher Immanuel Kant who argued that autonomy is feature of persons that makes them inherently valuable and self-legislating beings, unlike things in the world that are valuable only insofar as they serve people's ends.¹²⁷ On the other hand, John Stuart Mill, argued in his book titled *On Liberty*, that autonomy, conceived as a sphere of personal freedom, as the limiting factor on what may be required for the sake of the greater good.¹²⁸ Hence based on these ethical justifications autonomy is generally understood as a freedom from external constraints (Mill) and the capacity for self-determination (Kant) that permits individuals to pursue their own good in their own way.¹²⁹ To Beauchamp and Childress the basic prerequisites for a valid informed autonomous authorization are competence, disclosure, and voluntariness.¹³⁰

In the context of prenatal HIV testing, the woman not only must understand the information provided concerning the nature of HIV testing and the foreseeable consequences of consenting to or refusing testing, but also must be able to consider the information that she considers material to her decision to authorize testing.¹³¹ Another condition necessary for HIV testing of pregnant women to be ethically sound is the provision of adequate and accurate information regarding the benefits and risks of

¹²⁶ *Ibid* at 278.

¹²⁷ Berge above n 124 at 22. Also see TL Beauchamp and JF Childress ' *Principles of Biomedical Ethics* (4th Ed)(New York: Oxford University Press. 1994) 64 ; CN Manson and O O'Neill *Rethinking Informed Consent in Bioethics* (Cambridge: University Press Cambridge, 2007) 17 .

¹²⁸ JS Mill *On Liberty* (Indianapolis: Hackett Publishing Co, 1978) cited in JW Berg above n 97 at 21.

¹²⁹ Berg above n 124 at 24.

¹³⁰ Beauchamp and Childress above n 127 at 68.

¹³¹ G Geller and N Kass' Informed Consent in The Context of Prenatal HIV Testing' in Faden, Ruth R., Gail Geller, and Madison Powers, (eds.) *AIDS, Women, and the Next Generation: Towards a Morally Acceptable Public Policy for HIV Testing of Pregnant Women and Newborns* (New York: Oxford University Press, 1991) 190.

undergoing HIV test. As the term informed consent implies, the provision of information to individuals about the medical procedure to which they are being asked to consent is a basic element of informed consent.

However, the extent of the information a patient must be given has always been controversial in the discussions of the concept of disclosure of information and what constitutes enough information.¹³² Beauchamp and Childress give the following examples as (1) the facts that patients consider relevant when deciding to refuse or consent to the proposed intervention; (2) information the professionals believe to be relevant; (3) the professionals' recommendation; (4) the purpose for seeking consent and (5) the purpose and the limits of consent as an authorization act.¹³³ Hence generally speaking from a patient's perspective, informed consent (the process of information – giving and agreement –seeking) appears to be a right, while from the physician's viewpoint, it is a duty or obligation with the primary goals of protection of the patients welfare and the promotion of autonomy.¹³⁴

Some may still argue that the de-emphasizing of counselling and informed consent in the case of routine 'opt-out' HIV testing approach of pregnant women is morally justified in the belief that it benefits the foetus. However, when the issue is considered in its broader public health context such arguments are ethically indefensible because the prevention of vertical transmission of HIV infection is highly dependent on the cooperation of the mother. Public health objectives of preventing mother-to-child transmission of HIV can be achieved not by forcibly testing pregnant women for HIV but on securing the women's understanding and willingness to follow up the medications and return to the

¹³² See K. Kelly, 'Reducing Prenatal HIV Transmission and the Importance of Informed Consent' (2008) 22(2) *Public Affairs Quarterly* 163.

¹³³ Beauchamp and Childress above n 127 at 81.

¹³⁴ Berg above n 124 at 18.

health facility for further testing of their new born child, as well as their adherence to formula feeding or exclusive breast feeding.

The ethical and public health rationale for routine HIV testing depends heavily on the potential for diagnosis to lead to prevention and treatment.¹³⁵ As the previous chapters have demonstrated routine 'opt-out' HIV testing approach in many sub-Saharan Africa including in Ethiopia has led to increased HIV testing uptake among pregnant women. However, critics continue to ask whether more tests alone constitute a sufficient achievement without regard to the consequences of testing. The main objective of antenatal HIV testing is to identify the HIV status of pregnant women so that they could be lead to treatment, prevention of transmission of the virus to their unborn child and other supports and care. Unfortunately, the rapid scale-up of HIV testing in antenatal clinics is not matched with an equally scaled-up provision of Nevirapine prophylaxis to HIV-positive expectant mothers to protect their newborn children in many African countries.¹³⁶ In Ethiopia, because there is insufficient stock around 75 percent HIV positive mothers are not being provided with ARV prophylaxis for PMTCT.¹³⁷ This raises serious ethical concerns.

Lastly, the routine 'opt-out' HIV testing approach poses an ethical concern because when it de-emphasises informed consent, it denies pregnant women protection against the negative consequences of testing HIV positive. As we have seen HIV test differs from other kinds of tests in that it is associated with highly stigmatized activities like promiscuity or infidelity and can expose women to suffering

¹³⁵ Obermeyer above n 73 at 4.

¹³⁶ See generally UNAIDS 2013 *Progress Report on the Global Plan; Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive* (Genève: UNAIDS, 2013) 11-12. Available Online at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20130625_progress_global_plan_en.pdf [Visited on March, 2014].

¹³⁷ *Ibid*.

violence and abuse from the person's immediate social and/or familial support system. There is a substantial body of evidence from sub-Saharan Africa including from Ethiopia that indicates that fear of partner's negative reaction for HIV positive results is a major barrier for acceptance of HIV testing during antenatal care. The previously mentioned cross sectional study in Gambella regional state reported that the dominant reason for refusal of HIV testing by pregnant women was their perception that they would experience a negative partner response, such as a request for a divorce, if they tested HIV positive.¹³⁸ Similar studies in different parts of the country have also reported husband's approval as an essential factor related with willingness of pregnant women to test for HIV infection.¹³⁹

3.5 HIV Testing as a Right (The Right to Know)

As discussed in earlier sections of this chapter, individuals have the right to know their HIV status, without experiencing undue obstacles. This means that if they choose to undergo the testing they have the right to access an affordable and quality HIV testing service as part of their right to health. It is also argued that individuals have the right not to know their HIV status if they choose not to be tested. This section argues that it becomes problematic if this 'right to know' is automatically considered to imply that Governments have a duty to inform individuals of their HIV status.

Some argue that the state's duty to inform individuals of their HIV status even if they do not want to be informed can be logically deduced from the right to know one's HIV status.¹⁴⁰ However, as Csete argues

¹³⁸ Fanta and Worku above n 83 at 11.

¹³⁹ Malaju and Alene above 94 at 4.

¹⁴⁰ R Rajkumar, 'A Human Rights Approach to Routine Provider- Initiated HIV Testing' (2007) 7(2) *Yale Journal of Health Policy, Law, and Ethics* 320.

the duty of the state in relation to 'the right to know'[knowledge of HIV status] is to ensure that people have access to health systems with adequately resourced HIV testing protocols (for example, not only with money for rapid tests, but also money for sufficient counsellors and referral centres); adequate logistical resources to ensure privacy, confidentiality and sufficient time to make informed decisions; adequate funding to manage human resources and logistics; and the right to receive treatment and referrals to services and support networks, if needed after testing HIV positive.¹⁴¹

Therefore, knowing one's HIV status should not be considered as a duty imposed by the state over individuals but rather a right that constitutes the human rights to enjoy the 'highest attainable standard' of health.¹⁴² If the strong public health impetus to decrease the spread of HIV is to be achieved, then programmes in response to HIV epidemic need to respect and ensure the individual right to know and not to know one's HIV status. Ensuring access to HIV testing with counselling, informed consent and confidentiality is indeed well established as part of the human rights obligations of governments and hence the expansion of 'opt-out' HIV testing approach should not erode this right.

3.7 The Nexuses of Public Health and Human Rights in the Context of HIV/AIDS Testing

The issue of routine provider – initiated 'opt-out' HIV testing approach lies at the cross-roads of the public health goal to prevent HIV transmission and protecting human dignity as a human rights goal. Human rights seeks to protect individuals from coercive and non voluntary HIV testing while public health goals aspire to protect the collective good by detecting as early as possible those infected by HIV with the aim of prevention, treatment and care. The definition for public health has changed as public

¹⁴¹ Csete & Elliott above n 38 at 5–8.

¹⁴² ICCPR art. 12(1). Also see generally CESCR General Comment No. 14.

health has evolved, but common to most definitions is a sense of the general public interest, a focus on the broader determinants of health and a desire to improve the health of the entire population.¹⁴³ Generally through social, rather than individual actions, public health seeks to improve the well-being of communities.¹⁴⁴

As indicated in chapter one, the 'pro' and 'anti' debates on the adoption of routine opt- out HIV testing approaches are discussed in a rather polarized way, where the human rights requirements are seen to be contradictory to the public health requirements. However, increasingly, as shown below public health practitioners and human rights activists are arguing that the goal of both public health and human rights is to contribute to the advancement of human well being. The aim of this section is to show that despite their different approaches, public health and human rights imperatives can be complementary and mutually supportive in the fight against the AIDS epidemic, including in the case of HIV screening schemes.

Traditional public health measures have generally focused on curbing the spread of the disease by imposing coercion, compulsion and restrictions on the rights of those already infected or thought to be most vulnerable to becoming infected.¹⁴⁵ However, over time, human rights and public health are increasingly recognizing the vital role of the societal environment to the realization of both health objectives and human rights.¹⁴⁶ As Gostine and Lazzani argue a human rights approach is important not

¹⁴³ R Beaglehole, et al., 'Public Health in the New Era: Improving Health Through Collective Action' (2004) 363 *The Lancet* 2084.

¹⁴⁴ N Kass 'An Ethics Framework for Public Health' (2001) 19(11) *American Journal of Public Health* 1776.

¹⁴⁵ S. Gruskin and D Tarantola 'Health And Human Rights Overview' in K Heggenhougen and S Quah (eds) *International Encyclopedia of Public Health* (Academic Press Vol. 3, 2008) pp. 137-146 , 316.

¹⁴⁶ International Federation of Red Crescent Societies and Francios- Xavier Bagnoud Center for Health and Human Rights 'The Public Health – Human Rights Dialogue' in JM Mann *et al.*, *Health and Human Rights: A Reader* (New York : Routledge , 1999) 46- 53.

only because it promotes respect for individuals, but also because such respect is indispensable to improve public health.¹⁴⁷

Prevention of the transmission HIV/AIDS, which is communicable, incurable and especially in the developing world often a fatal disease, is a public health objective of vital importance. From the human rights perspective, this can best be accomplished by promoting and protecting the rights and dignity of everyone. The protection and promotion of human rights are necessary both to the protection of the inherent dignity of persons affected by HIV and to the achievement of the public health goals of reducing vulnerability to HIV infection, lessening the adverse impact of HIV and AIDS on those affected and empowering individuals and communities to respond to HIV.¹⁴⁸

In 1997 Jonathan Mann (the first director of WHO's Global Programme on AIDS) called for public health officials to go beyond the traditional public health approach (education and service-based efforts) to recognize that lack of respect for human rights as a societal level risk factor for vulnerability to HIV/AIDS.¹⁴⁹ Similar remarks were recently made by Clayton who argues that respect for human rights protects those who are vulnerable and marginalized, establishes trust for efforts to access populations that are hard-to-reach, promotes confidence in health services, and secures the cooperation necessary for preventing further transmission.¹⁵⁰

¹⁴⁷ Gostin and Lazzani above n 58 at 43.

¹⁴⁸ OCHCR/ UNAIDS above n 50 at 77.

¹⁴⁹ See generally J Mann 'Medicine and Public Health, Ethics and Human Rights (1997) 27 (3) *Hastings Centre Report* 6-13.

¹⁵⁰ S Clayton 'Public Health Law, Human Rights and HIV: A Work In Progress' (2010) 21(3-4) *Public Health Bulletin* 97.

However, concerns were aired that discovery of a biomedical intervention with substantial potential to prevent HIV infection, such as zidovudine treatment during pregnancy to reduce the risk of prenatal transmission, has provoked calls for routine HIV testing of all pregnant women and mandatory treatment of infected women.¹⁵¹ As Gruskin argues the debate about the correct approaches to HIV testing needs to be re-centred onto something that moves strategies forward towards sound public health and human rights practice, and away from a framing of public health and human rights as diverging or even antagonistic concepts.¹⁵² In recognition of this fact the UNAIDS/WHO state that, '... the global scaling up of the response to AIDS, particularly in relation to HIV testing as a prerequisite to expanded access to treatment, must be grounded in sound public health practice and also respect, protection and fulfilment of human rights standards.'¹⁵³ Integrating human rights principles in the HIV screening schemes can complement rather than contradict the public health objective of prevention of HIV transmission.

HIV testing and counselling can be implemented in a manner that realizes the mutually reinforcing objectives of public health and human rights which ensure both human dignity and social justice. Public health objectives of preventing mother-to-child transmission can be achieved not by forcibly testing the pregnant women for HIV but on securing the women's understanding and a significant degree of cooperation. This can only be secured properly through respecting their human rights. Prevention of vertical transmission involves an extended period of treatment before, during, and after child birth. It requires the HIV positive woman to follow up the medications of the child after birth; return to the health facility for further testing of their new born child; as well as their adherence to formula feeding

¹⁵¹ Gostin and Lazzani above n 58 at 71.

¹⁵² S Gruskin, *Its Time to Deliver Right! HIV Testing in the Era of Treatment Scale Up: Concerns and Considerations* (2006) (A Publication of the AIDS Legal Network September) 11.

¹⁵³ UNAIDS/WHO above n 70 at para 6

or exclusive breast feeding.¹⁵⁴ Taking note of these facts it has been argued that, conducting HIV testing in an environment that does not enable pregnant women to make their decisions regarding HIV testing and treatment could decrease the program's effectiveness since such practices discourage cooperation and trust between pregnant women and health care providers or causes women to avoid pre- or postnatal care.¹⁵⁵

3.7 Testing Pregnant Women for HIV: A Return to Maternal- Foetal Conflict?

The present study aimed to assess the human rights and ethical implications of the expansion of routine provider initiated 'opt-out' HIV testing approach in Ethiopia by drawing the lived experience of women who tested positive to HIV during their access to maternal health care. Hence the issues discussed in the thesis involve the health interest of the foetus and rights of a pregnant woman that can be easily framed in terms of the 'maternal-foetal conflict' relationship. The purpose of this section is, to shed light on the debates of the 'maternal-foetal conflict' and to argue that however difficult it may be, the principal decision make regarding prenatal HIV testing should be the pregnant woman herself.

The term 'maternal-foetal conflict' has now long been understood to refer to those situations in which there is discordance between the interests of a pregnant woman and the foetus she is carrying.¹⁵⁶ Most of the discussion of maternal-foetal conflict arises when the pregnancy is unwanted (and the woman wishes to have an abortion) although there are ongoing debates on the issue even when the pregnancy is wanted and the foetus is brought to term. Feminist's analysis has highlighted the way in which women's

¹⁵⁴ B Lo,*et al.*, 'Ethical Issues in Early Detection of HIV Infection To Reduce Vertical Transmission'(2000) 25 *Journal of Acquired Immune Deficiency Syndromes* 139.

¹⁵⁵ Gostin and Lazzani above n 58 at 81.

¹⁵⁶ L Post 'Bioethical Consideration of Maternal-Fetal Issues' (1996) 24(4) *Fordham Urban Law Journal* 758.

relationship to the state is altered by pregnancy and childbirth, especially when the state forces women to accept treatment they do not want or fails to make available the means by which women can make decisions about their reproductive lives.¹⁵⁷

The use of the term 'maternal-foetal conflict' is argued to be problematic for several reasons.¹⁵⁸ First, it situates the conflict between the pregnant woman and the foetus, whereas the conflict is often between the pregnant woman and others who believe that they know best how to protect the foetus. Second, the term 'maternal-foetal conflict' perpetuates the underlying but unfounded assumption that the problem involves opposition of maternal rights and foetal rights. It overlooks the important fact that these interests are inextricably linked. Finally, the term 'maternal-foetal conflict' is factually incorrect. The term 'maternal' suggests the existence of a parental obligation toward the foetus; whereas the woman is *yet to become* a mother to the foetus she is carrying. With this understanding, however, the thesis continues to use the term maternal-foetal conflict to indicate how the maternal and foetal interests are depicted as oppositional by the law without implying acceptance of this dichotomous construction.

One of the most recent and troubling manifestations of the issue under discussion here is the move to routinely screen women for HIV during pregnancy to prevent mother-to-child transmission of HIV/AIDS. Women have been the basic focus of HIV testing ever since it was first established that HIV could be transmitted from a mother to her child during pregnancy, labour and delivery, or through breastfeeding. As noted previously, currently countries severely hit by the HIV epidemic are increasingly turning to an HIV testing model that de-emphasises pre-test and post-test counselling and a requirement to obtain explicit informed consent from pregnant women who have contact with the

¹⁵⁷ R Spence 'Abandoning Women To Their Rights: What Happens When Feminist Jurisprudence Ignores Birthing Rights', (2012) 19(1) *The Cardozo Journal of Law and Gender* 108.

¹⁵⁸ Flagler *et. al*, above n 109 at 1733.

health system. Despite the fact that the routine HIV testing approach maintains that pregnant women have the right to refuse testing, there are significant concerns that forgoing the traditional informed consent procedure compromises women's rights and identifies HIV-infected women without their consent.

The maternal- foetal conflict in the context of pregnancy and HIV testing is complex. It involves the autonomy of a woman to make her own decision, including the right to decline testing if that is her wish, and the unborn child's need to be protected from the threat of HIV. When deciding whether to be tested for HIV, a pregnant woman must balance concerns related to prenatal transmission of HIV against other factors. For the pregnant woman the principal potential benefit of HIV testing is medical while the principal risks are social and psychological.¹⁵⁹ For women, a positive diagnosis of HIV can bring shame and anxiety, loss of friends, the need to make difficult decisions about to whom to disclose these findings, exclusion from employment, housing opportunities and health insurance. It can lead to various forms of stigma and discrimination and as we have seen all are significant and well-documented risks associated with testing positive for HIV.¹⁶⁰ Any one of these factors can prevent a woman from acting in the best interest of her foetus and can outweigh concerns related to prenatal transmission of HIV. Hence she must be allowed to come to her own conclusion regarding whether or not she wishes to undergo testing.

¹⁵⁹ L Waltes , ' Ethical issues in HIV testing during pregnancy' in Faden, Ruth R., Gail Geller, and Madison Powers, (eds.). *AIDS, Women, and the Next Generation: Towards a Morally Acceptable Public Policy for HIV Testing of Pregnant Women and Newborns* (New York: Oxford University Press, 1991) 276.

¹⁶⁰ K Kelly 'Reducing Perinatal HIV Transmission and the Importance of Informed Consent', (2008) 22(2) *Public Affairs Quarterly* 164.

3.9 Conclusion

The chapter has provided a human rights and ethical framework for the analysis of the implementation of the 'opt-out' HIV testing approach adopted in Ethiopia which is used to screen pregnant women. Prevention of mother- to- child HIV infection and providing pregnant women with access to HIV testing service by employing the 'opt-out' testing approach are both public health and human rights imperatives. Nonetheless, the practical implementation of the testing approach in maternal health care settings where the focus is very much on the accelerated reduction of new MTCT infections raises the concern that the public health objectives could override human rights and ethical imperatives.

Although a routine 'opt-out' HIV testing approach theoretically allows pregnant women to retain their right to refuse HIV testing when offered by health care providers in practice, however, there are concerns relating to the extent of the enabling environment for women to express their consent autonomously. Taking into consideration the extent of gender inequalities and the power differentials within the social fabric of most societies in the developing world to which Ethiopia is no exception it is doubtful whether pregnant women would be empowered to exercise their right to informed refusal of HIV testing if they did not want to take up the test. HIV testing occurs in a social context marked by unequal gender and power relations and women are more likely than men to face judgemental attitudes or implicit accusation of promiscuity or other bad behaviours, if they tested positive.

Consideration of the specific contexts therefore in which HIV testing is offered to pregnant women by health care providers and issues of how their consent is obtained in maternal health care settings in Ethiopia is essential. The thesis moves on to assess the way in which 'opt out' policies are being put into practice in Ethiopia and the extent to which pregnant women accessing maternal health care settings are able to exercise their human rights relating to HIV testing. The next chapter introduces the

methodology used to answer the research questions and to meet the objectives set out in chapter one of this thesis.

CHAPTER FOUR

METHODOLOGY AND DESIGN OF THE STUDY

4.1 Introduction

This chapter presents the methods employed in this study to answer the research questions. The purpose of the chapter is hence to provide readers with a scientific justification for the research methods adopted to collect data. It begins with a discussion of the approach taken to answer the research questions and the choice of research method. The second section sets out the research settings and sampling procedures adopted in this study including the discussion of the socio economic characteristics of the women who participated in this study. The third section presents the research process and the data collection tools employed while the fourth and fifth section describes the post- fieldwork analysis and the writing up stage and the ethical considerations that were pertinent to this study. The chapter concludes with a discussion on the extent to which the methodological design was successful in generating data that could capture the lived experience of women in Ethiopia who tested positive to HIV during their pregnancies upon their visit to maternal health care services.

4.2 Feminist Qualitative Research

There are many forms of feminist theoretical orientations and hence there is no precise definition of what feminism and feminist is. While all feminists are concerned with understanding why inequality between women and men exists and is the reason for the overall subordination of women, feminists do not all agree on where to find the causes of male domination nor how to combat this and achieve liberation for women. In elaborating this situation, feminist writers argue that feminism is not a

monolithic ideology, that all feminists do not think alike, and that, like all time-honoured modes of thinking, feminist thought has a past as well as a present and a future.¹⁶¹ However, whatever theoretical and epistemological position they hold, feminists share a common understanding that women have historically been devalued and denied full equality. Feminism therefore provokes questions about undeserved power differentials in society.

In view of that, there is also a debate on the existence of feminist research although many agree that there exists a distinct common research practices that are shared by feminists. Feminist researchers start with the political commitment to produce useful knowledge that will make a difference to women's lives through social and individual change. Letherby argued that any research may be considered 'feminist' which incorporates two main aims; a sensitivity of the role of gender within society and the differential experiences of males and females and a critical approach to the tools of research on society, the structures of methodology and epistemology within which 'knowledge' is placed within the public domain.¹⁶² Feminist research practice can be distinguished by the questions feminists ask, the location of the researcher within the process of research and within theorizing, and the intended purpose of the work produced. By documenting women's lives, experiences, and concerns, illuminating gender-based stereotypes and biases, and unearthing women's subjugated knowledge, feminist research challenges the basic structures and ideologies that oppress women.¹⁶³ Although there is no one single method, methodology, or epistemology that informs feminist research, feminists' writing on research methods generally identify the same key features, which include paying attention to the importance of gender as a

¹⁶¹ K. Sarikakis et al., 'Feminist Theory and Research' In DW Stacks and MB Salwen (eds.) *An Integrated Approach To Communication Theory and Measurement* (New York: Taylor & Frances, 2009) 513-516, 504.

¹⁶² G Letherby *Feminist research in theory and practice*, (Buckingham: Open University Press, 2003) 5.

¹⁶³ A. Brooks and SN Hesse-Biber 'An Invitation to Feminist Research' in SN Hesse-Biber et al., (eds) *Feminist Research Practice: A Primer* (1st edition) (London: SAGE Publications, 2006) 1-24, 4.

central element of social life, avoiding the exploitation of women as subject and objects of knowledge¹⁶⁴ and empowering women through social research.¹⁶⁵

In a similar way, Reinharz noted that a whole range of feminist methods can be employed in social research, including traditional methods of research such as survey, experimental and case studies, as well as original feminist research methods.¹⁶⁶ In fact, to unearth hidden aspects of women's lives and those of other oppressed groups, and to reclaim subjugated knowledge, some feminist researchers continue to develop new epistemologies, methodologies and methods of knowledge building altogether.¹⁶⁷ Hence many feminists do not believe one method of knowledge gathering is inherently better or worse than any other, because there are varieties of knowledge –gathering techniques used by researchers.¹⁶⁸ In fact one of the things that make feminist research is that many researchers use qualitative and quantitative approaches in research projects to gather knowledge from different perspectives.

Hence, feminist writers argue that different research techniques may be employed in a manner consistent with feminist values to undertake feminist research.¹⁶⁹ In order to address the topic of gender asymmetry using feminist epistemological assumptions, researchers have applied a variety of innovative approaches. At a practical level, feminists use many of the same methods as other researchers, but adapt them in ways that make them more consistent with feminist concerns. In many instances, this involves

¹⁶⁴ See generally M Fonow and J Cook 'Feminist Methodology: New Applications in the Academy and Public Policy (1987) 30(4)*Journal of Women in Culture and Society* 1987.

¹⁶⁵ S. Hardings and K Norberg 'New feminist approaches to Social Science methodologies : An introduction' (2005) 30 *Signs* 4 .

¹⁶⁶ S Reinharz *Feminist methods in Social Research* (New York: Oxford University Press, (1992) 238.

¹⁶⁷ Brooks and Hesse-Biber above n 163 at 4.

¹⁶⁸ Hesse – Biber *et al.*, above n 164 at 11.

¹⁶⁹ A Doucet and NS. Mauthner 'Feminist Methodologies and Epistemology' in CD Bryant and DL. Peck (Eds.)*Handbook of 21st Century Sociology*, (London: SAGE Publications, 2006), pp.36-42, 38.

adjusting the content and implementation of particular methods to incorporate gender, privilege subjectivity, avoid exploitation and empower women.¹⁷⁰ As Letherby rightly stresses, 'it is not the use of a particular method or methods which characterize a research or project as feminist, but the way in which the methods are used'.¹⁷¹

In this study, although quantitative data collection methods could provide useful information about how many women were able to exercise their right either by accepting or refusing the HIV test, use of quantitative method is not particularly suited to uncover the reasons and perception of women's individual experience in relation to exercising their autonomous decision making regarding HIV testing. Hence rather than focusing on broader social trends by using quantitative methods, I seek to gain insight into the subjective experiences of women in relation to exercising their autonomous decision making regarding the HIV test offered during their pregnancies by employing qualitative methods. According to Ramzanoglu and Holland, face-to-face in-depth interviews are associated with feminist principles of reciprocity, valuing women's personal experience and analysis of nuances of meaning and social relationships.¹⁷² Feminist researchers find interviewing appealing it offers researchers access to people's ideas, thoughts and memories in their own words rather than in the words of the researcher. In addition, the desired outcome of my project is not to obtain a representative sample that lends itself to generalisation of the findings beyond the group of study informants, but to inquire into individual accounts and hence adoption of qualitative in-depth semi-structured interviewing was considered appropriate for this study.

¹⁷⁰ *Ibid.*

¹⁷¹ Letherby above n 162 at 81.

¹⁷² C. Ramazanoglu and Holland *Feminist Methodology: Challenges and Choices* (London, Sage, 2002) 155.

Feminist researchers combine many methods in order to cast their net as widely as possible in the search for understanding critical issues in women's lives. Discussions of HIV testing approaches are complex and involve understandings of global policies, national legal frameworks, gender power relations and deep-rooted socio cultural norms. With the purpose of grasping this complexity and the meaning given by participants to their experiences, it was deemed necessary in this study to employ a semi-structured in-depth interview that allowed participants to talk about their personal feelings, opinions and experiences. In addition, the normative and conceptual aspects of human rights and ethical principles inform the thrust of discussions and arguments in this thesis. Hence, the thesis also relied on international and regional legal and normative standards, relevant scholarly articles, news, intergovernmental agency health reports, country reports, public health legislation and national and global HIV related policies.

4.3 Research Settings and Sampling

This section sets out the research settings and sampling procedures adopted in this study. It is followed by a discussion of the socio economic characteristic of the women who participated in this study project.

4.3.1 Social-political context of the Research setting: Tigray, Ethiopia

This research was carried out in one of the federating state governments of the Federal Democratic Republic of Ethiopia (FDRE) – the Tigray regional state. Tigray is located in the northernmost part of Ethiopia bordering with Eritrea in the north, Sudan in the west, Afar in the east and Amhara in the Southwest. The region is inhabited by around 4.3 million people (50.8 percent women) making up

roughly 6 percent of the total Ethiopian population.¹⁷³ Only 19.55 percent of the population of the Tigray region live in urban areas although this is larger than the average percentage of urban dwellers within the Ethiopian population (16.1 percent).¹⁷⁴ Around 95.5 percent of the Tigray population are followers of the Ethiopian orthodox church, 4 per cent Islam and 0.4 per cent the Catholic Church.¹⁷⁵ The regional state has several ethnic groups but the predominant one is the Tigrayan which make over 96.55 percent of the population.¹⁷⁶ (See Map-2 below)

The Tigray regional state is the home of the ancient Axumite kingdom and Adwa, the site of battle in which the independence of the country was defended from the invading Italian forces in 1896. In addition, the most recent devastating wars of the country were also fought in this area; the protracted civil war which ended in 1991 and the war with neighbouring Eritrea 1998-2000. These repeated armed conflicts coupled with centuries of environmental degradation due to deforestation and the recurrent drought and famine put Tigray people in a disadvantaged position. More than 58 percent of the total population in the region is living in absolute poverty (earning less than a dollar a day) which makes the region's situation more serious compared to the national average of 44.4 percent.¹⁷⁷

Over 30 percent of the households in Tigray are headed by women which is higher than the national average of 26 percent.¹⁷⁸ The high prevalence of female headed households is reported to relate to loss of male combatants in both the civil war and the Ethio-Eritrean border conflict.¹⁷⁹ The situation is also

¹⁷³ Census Central Statistical Authority Ethiopia (CSA) *Population and Housing Census Report (Addis Ababa: CSA 2007)*.

¹⁷⁴ Central Statistical Agency of Ethiopia (CSA) and ICF International *Ethiopia Demographic and Health Survey 2011* (Addis Ababa: CSA, 2012) 270 (here after EDHS 2011) 13.

¹⁷⁵ CSA above note 173.

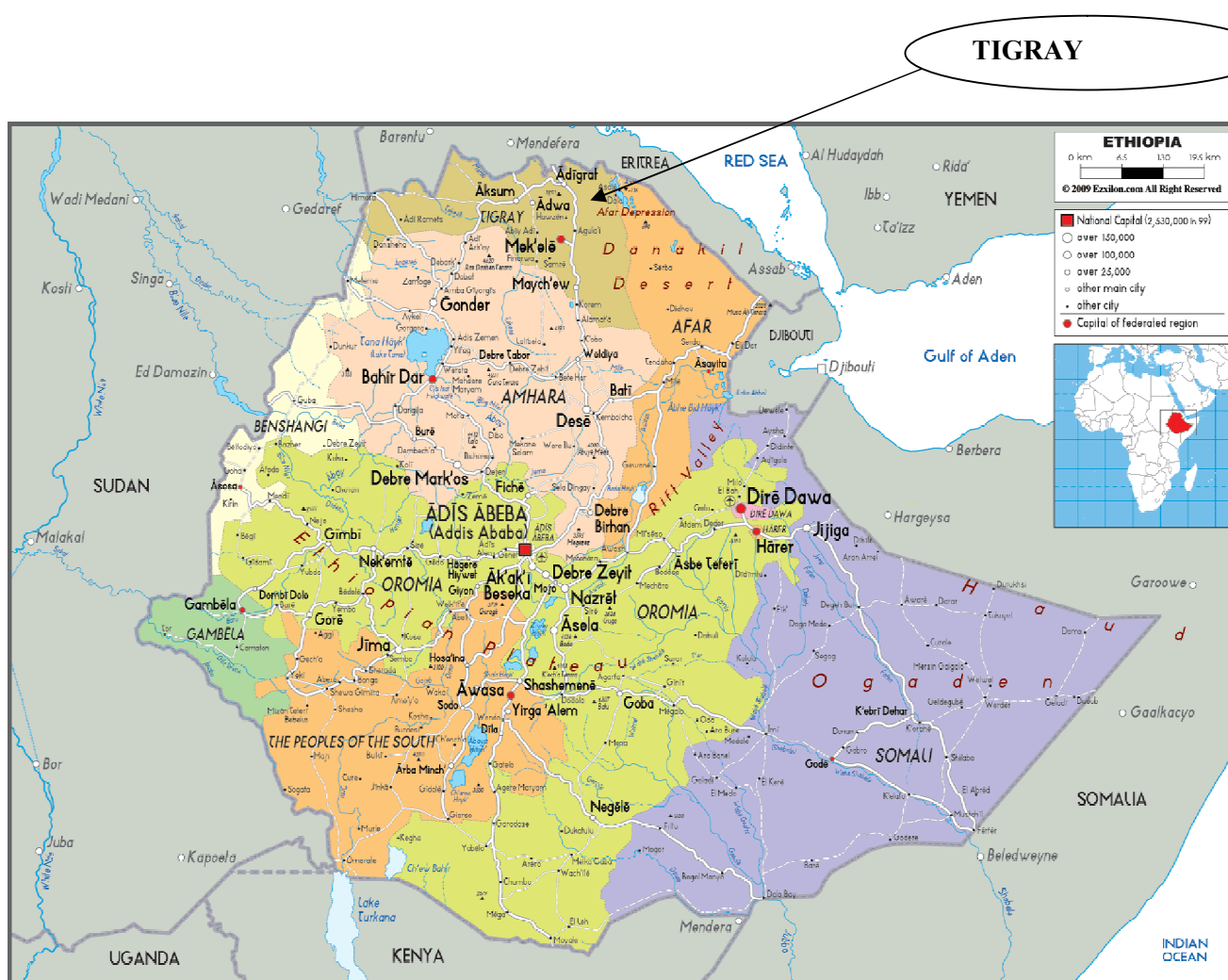
¹⁷⁶ *Ibid.*

¹⁷⁷ *Ibid.*

¹⁷⁸ EDHS 2011 above n 174 at 21.

¹⁷⁹ F Meehan, 'Female Headed Household in Tigray, Ethiopia A Study Review' (The Dry lands Coordination Group (DCG) report No.35, 2004)2.

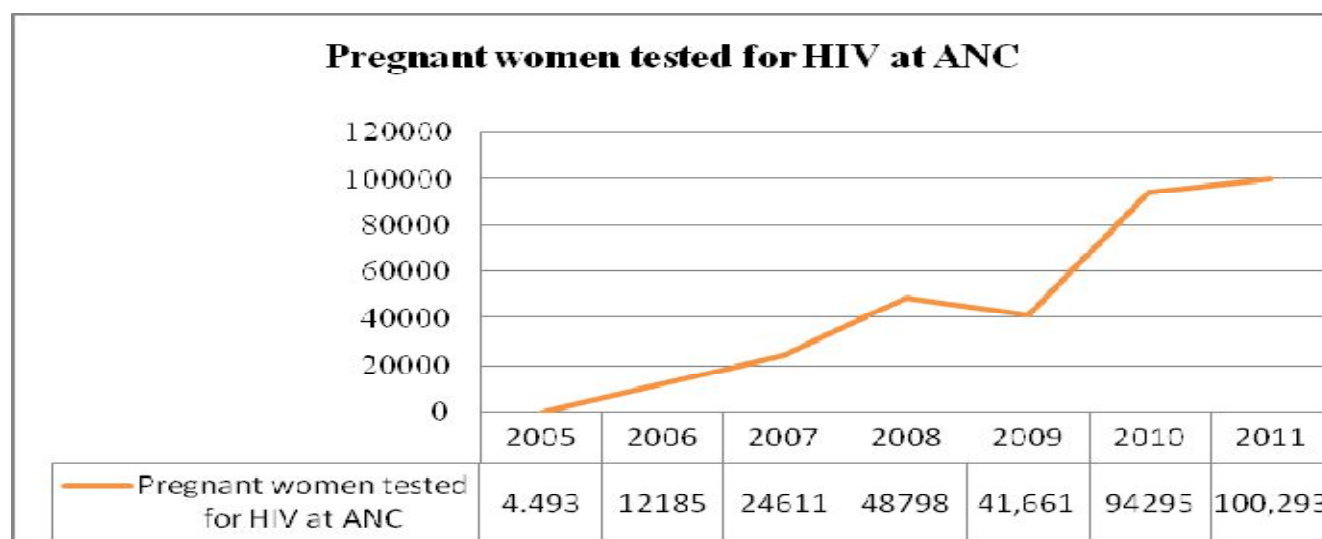
related to a traditionally high age gap between wives and husbands leading to a higher number of widows compared to widowers and traditional migration patterns, resulting in de facto female headed households even where legal marriage still exists. Women in these positions face a number of constraints which include having access to smaller landholdings and less household labour, and therefore greater difficulty in farming their own land. All these factors contribute to feminization of poverty in the region.



Map-2 location the state of Tigray on the map of Ethiopia. (Source-<http://www.idp-uk.org/Resources/Maps/Administrative%20Regions/EthiopiaRegions.gif> (Visited on December 2013).

According to the Health Bureau of the Tigray regional government HIV/AIDS is among the commonest health problems in Tigray region.¹⁸⁰ The 2011 EDHS estimates that the overall HIV adult prevalence (15-49 years) in Tigray is 1.8 per cent (1.9 percent women and 1.0 per cent men) which is slightly above the national average prevalence 1.6 percent.¹⁸¹

The PMTCT programme in the regional state was started only in 2002 in 3 locations which grew into 9 PMTCT sites by 2005 and 186 sites by 2011.¹⁸² Accordingly, the number of pregnant women who tested for HIV during ANC is reported to have grown significantly over the years as shown on the graph below (Graph-1). The Tigray health bureau (THB) credited this achievement to the Health Extension Workers (HEWs) and to the establishment of the women – centred one-to-five networking called the Women Development Army (WDA).¹⁸³ In rural settings of the Tigray region all women are expected to organise themselves in these groups with no exception.



Graph 1- pregnant women tested for HIV at ANC during 2005-2011. (Source: Tigray Health Bureau and Tigray HAPCO 2005 – 2011 reports and Tigray Regional State Synthesis of the HIV Epidemic and Response.)

¹⁸⁰ Tigray Regional Health Bureau (TRHB) *Annual Health profile of Tigray* (Mekelle: TRHB, 2012).

¹⁸¹ EDHS 2011 above n 174 at 189.

¹⁸² TRHB above n 130 at 2.

¹⁸³ Brief introduction of the HEWs and WDAs is given under chapter two of this thesis.

4.3.2 Research Sites

This study was conducted in both rural and urban settings. This was done to enable comparative analysis of the experience of pregnant women in the process of making the decision to uptake HIV testing within the different social settings. The specific locations of the study area are *Mekelle* (the capital city of the state of Tigray) to represent the urban setting and the *Ofla Woreda* to represent the rural setting.

The public health institutions Mekelle hospital in Mekelle city and Korem health centre in Ofla district are the specific health facilities where the study was conducted. The Korem health centre in Ofla district provides not only a skilled child delivery service but also access to PMTCT services including HIV testing, prophylaxis and antiretroviral treatments. In cases of complications during child delivery, patients are referred to Maichew comprehensive hospital located in the nearest city of Maichew . On the other hand Mekelle hospital is one of the oldest hospitals in the country and it provides comprehensive health care services. Both institutions have established the Mothers-to-Mothers support group (M2M) that were very pivotal during the data collection to access the participants as discussed in the subsequent sections.

4.3.3 Study Population

The study population included all women who tested positive for HIV during their pregnancy in relation to prevention of vertical transmission of HIV and the health care service providers directly involved in the implementation of PMTCT programme in the study areas. The inclusion and exclusion criteria were as follows.

The first criterion was that only women aged between 18-49 years were eligible to participate. I adopted a large age-range purposely in order to access respondents within the reproductive age. In addition, I consciously put the minimum age for the participation in the interview to be 18 years to exclude minors (married and already mothers) from participating in the interview who might be eligible based on their marital status or any other criteria. With this, I avoid the possible complications with issues soliciting valid consent from married minor participants in the research.

Moreover, I used other criteria to determine the participation of potential research subjects in the study project. Only those who tested for HIV in the context of PMTCT within the last twelve months of the field work period and tested positive were made eligible to participate. Participants self-reported the time and their HIV positive test results since diagnosis was not a part of the selection process. The reason for selecting women who had had HIV testing in the last twelve months was because I wanted to capture the proximity of their prenatal HIV screening experience.

The third criterion was that the women had to be in a marriage during the interview period. This criterion is relevant again because one of the objectives of the research is to investigate if the women feel that their HIV test result exposed them to violence and abandonment by their husbands. No document or evidence was asked to be produce by the participants as a proof for their age, HIV status or marital status and hence the inclusion of participant was determined based on participants self-reported of the facts.

On the other hand, only health care providers who had been working at the selected health facilities for the past 12 months directly on the PMTCT programme were included in the study.

4.3.4 Sampling Procedures and Sample Size

Purposive sampling was used to select participants for this study. Purposive sampling suits qualitative research well because it allows for the deliberate selection of people or units who will provide the most useful information – sampling with a purpose in mind. The original plan in this study project was to adopt a snowballing technique to access my research participants. Snowballing technique is a sampling technique where the researcher accesses informants through contact information that is provided by other informants.¹⁸⁴ This process is, by necessity, repetitive: informants refer the researcher to other informants, who are contacted by the researcher and then refer her or him to yet other informants, and so on.¹⁸⁵ Snowball sampling is often employed as a particularly effective tool when trying to obtain information on and access to ‘hidden populations.’¹⁸⁶ Since a study on HIV testing is a very sensitive subject and the fact of being tested for HIV and the positive results a very private matter with the potential of exposing study subjects to stigmas and marginalization, I thought that adopting snowballing techniques would enable me to access the study subjects who may not have responded to more ‘conventional’ methods.

However at the pilot study stage, I learned that I was not being referred to anyone. My respondents in the pilot study would not voluntarily refer me to their acquaintance. I was always forced to start again with my own network. Fortunately, in the course of the pilot study, I learned that the health facilities selected in this study have established and run a support group called (*Adetat Nadetae Gujelle*) Mother-to-Mother Support Group (M2M).

¹⁸⁴ C Noy ‘Sampling Knowledge: The Hermeneutics of Snowball Sampling in Qualitative Research (2007) *International Journal of Social Research Methodology* 3

¹⁸⁵ *Ibid.*

¹⁸⁶ *Ibid.*

The M2M in Mekelle hospital and Korem health centres enable women newly tested positive to HIV to have access to peer counselling and emotional support from other mothers those who have gone through more or less the same experience. The daily activities of the M2M support group is managed by its members called 'mentor mothers' who have been trained and hired for this purpose on a fulltime basis by the health facility. I also observed that the M2M support group enabled its members to meet one another and discussed matters relevant to their life after HIV positive test result with other members and the 'mentor mothers' over a coffee ceremony when they visited the facility to take their ARV either for themselves or their children which is dispatched on monthly basis by the health facilities.

Hence by taking advantage of this opportunity I took the M2M support group as a pool from where I drew the list of potential eligible research subjects for the in-depth interview using a purposive sampling technique. This technique is a method where respondents are made eligible to participate in the study based on their relevance to the research questions, theoretical position and analytical of the study as well as the argument or explanation being developed by the researcher.¹⁸⁷ From the list of potential research subjects, 30 actual research participants (15 from rural and 15 from urban setting) were selected using random sampling technique to minimize the biases associated with purposive sampling technique.¹⁸⁸

In addition to the 30 women participants, 9 health care workers also took part in the in-depth interviews; 2 nurse and 2 midwives from the selected health facilities, 3 health extension workers in Ofra district and 2 'mentor mothers' of the M2M support groups. All the participants of the expert

¹⁸⁷ J Mason *Qualitative researching* (2nd ed.) (London/New Delhi: SAGE Publication, 2002).

¹⁸⁸ *Ibid.*

interviews were directly involved on daily basis in the implementation of the PMCT programmes be it in the ANC units, labour wards or out in the villages contacting the women door to door.

4.3.5 The Gate Keepers and Recruitment of Study Participants

I conducted my field work during the period of April-December /2012. I started the work from the urban settings in Mekelle city. However, before I embarked into the fieldwork, I had to meet the relevant authorities and individuals from various levels in which the research was carried out. For this reason, in order to be able to access the people that I needed to recruit for the study, it was necessary to get an authorization letter from the Tigray Health Bureau (THB) as a permission to conduct the research. The letter of authorization was granted after I produced a letter from the Warwick School of law that explained the fact that I am doctoral student and another letter from Mekelle University from where I work.(see Section 4.6 of this chapter on ethical considerations) The letter of authorization from the THB was addressed directly to the health facilities selected as a research site in this study with a clear message that I should be provided with the necessary cooperation needed to conduct the research.

Having secured the above letters from THB, I had meetings on different occasions with the management of the two health facilities where I explained to them the reason for conducting the research, the main goals and methodology for the research. With the permission of the management of the study sites, I contacted the coordinators of the Maternal and Child Health department/units who in turn introduced me to the health care providers directly involved with the implementation of PMCT programme on daily basis and the 'mentor mothers' of the M2Ms.

As gatekeepers the help of the 'mentor mothers' in the M2M was indispensable to initially contact the potential research participants. I have mentioned earlier that the M2Ms are playing a significant role in peer counselling of mothers living with HIV virus on how to cope with HIV positive testing results, the disclosure and other relevant social issues. Taking advantage of their position and acceptance among the members, I asked the mentor mothers to help me in approaching the potential research participants that fulfilled the criteria set earlier. Members of the support group who came either to participate in the coffee ceremonies of the M2M or to get their monthly ARVs either for themselves or their children were then approached by the mentor mothers and the list of potential research subjects was drawn and used to recruit all my respondents.

I noticed that the 'mentor mothers' present themselves as if they are part of the health profession rather than just 'peers' to the HIV positive mothers who are members of the support group. For example, it was easy to note that the mentor mothers in both sites have a very close relationship with the nurses and midwives seemingly of colleague level. The mentor mothers also put on a 'white gown' which is widely used by health workers in public health facilities in Ethiopia and used by lay people like myself as the easiest (if not the only) way to differentiate between clients and health workers. I also noted from our discussions before the whole process of recruitment began that the mentor mothers used a number of medical terms and were ready to share the medical knowledge that they have in relation to HIV/AIDS. Even during the course of the interviews, respondents actually refer to the mentor mothers as '*Hakim*' which literally could mean a doctor or a nurse. This reinforced my suspicion that the mentor mothers might be taken as health care professionals to anyone who needed their services.

This created an anxiety that the potential research participants might feel obliged to participate if approached by the mentor mothers. Taking into consideration these facts, it was important for me to reassure the respondent that they were free to choose not to take part in the interview. I provided respondents with accurate information about myself, the purpose of the research, and future use of the data, and helped them understand what their participation in the project involved. On the other hand, as the recruiting process progressed I was reassured from my fear to see many women declining to participate in the study without fear by stating that they are busy and have no time for an interview when approached by the mentor mothers.

4.3.6 Socio- Demographic Characteristics of the Women

My analysis in this study is based upon 30 interviews with women who took the HIV testing at the time of their pregnancy or child birth and tested positive. The age range of these women with HIV of reproductive age was 19 - 41 with an average age of 29. In terms of religious affiliation, 4 women (13 percent) identified themselves as Muslim and the remaining 26 women (87 percent) were followers of the Ethiopian Orthodox Church. All the women interviewed spoke Tigrigna the local language as their first language.

In terms of family composition, all of the women had living children or were pregnant at the time of the interview. 3 were still pregnant and 27 already given birth to their children within the last 12 months. The three women were in their first time pregnancy during the interview time. The remaining participants, the number of children ranged from one to five children. Twenty three of the HIV positive

women who participated took the HIV testing during their pregnancy on their visit to the antenatal care and seven women had the testing during their child delivery.

The respondents who took part in an in-depth semi- structured interview shared a common characteristic in that all of them had no higher education, or specialist training linked to a profession and could be viewed as belonging to the lower class. Out of the thirty women I interviewed, eighteen of them had no education. There are many potential explanations for this. One is as shown under section 4.3.1 of this chapter Tigrean women's social status is in a subordinate position especially in terms of education, health and professional life. The composition of the group of women who participated in this study therefore could just be a manifestation of the reality for women in Tigray. The other potential explanation is that I have only accessed women who seek maternal and reproductive health service in public health facilities. Public health facilities are not mainly visited by those middle and upper class people who can still afford to obtain a service from the private health facilities. Furthermore, even for the middle income people who access the maternal service in public health facilities and learned about their HIV positive status it is less likely for them to be members of the mother-to- mother support group which I have used as a pool to recruit my respondents. The common practice is that mainly women who are in need of some psychological, financial and emotional support do join the M2M support group upon the communication of their positive HIV results. It happens that it is usually women of lower class that would join the M2M group to fulfil such needs at the expense of their privacy regarding the positive HIV test results. Therefore, within the above framework, I spent considerable time and energy identifying and accessing suitable participants so as to obtain a diverse group of research participants in both research sites.

At the time of interview, most of the women defined their occupation as 'housewife' even though many of them were also farmers, waitresses and petty merchants (like selling *Injera*, local beer, or vegetables ...) at the same time. Three women reported that they had worked as *Injera* bakers, and others had worked washing clothes and cleaning job for clients before their pregnancy and the HIV test. I also noted that the women worked in several jobs in order to make money even though the family's economic situation remained precarious.

4.4 The Research Process

The primary research technique in this study involved conducting in-depth semi-structured with women selected on the above discussed criteria and health care providers directly involved with PMCT programmes. This section gives a description of the research method and process.

4.4.1 The Method

A qualitative research method employs several methods that can be used to generate data including interview, (structured, semi-structured, unstructured), observations (participant and non-participant), documents and audiovisual materials. The current study aimed to assess the human rights and ethical implications of the espousal of routine provider initiated 'opt-out' HIV testing approach by the Ethiopian government to screen pregnant women for HIV by drawing the lived experience of pregnant women who tested positive to HIV.

This objective of the thesis suggested the adoption of a method that would facilitate the generation of data that represents the values, feelings, personal experiences and attitudes of the women who

underwent the HIV testing scheme. Hence, in-depth semi-structured interview was employed in this thesis as the main data collection tool. In addition, this study is also informed by data collected through non participatory observation and field notes gathered during the fieldwork period. Hence the study was shaped and refined with the data gathered from interview with women and other interviewees, observational data, field notes and themes identified from document reviews.

4.4.2. In- Depth Semi-Structured Interview with Women

As the current study aimed to assess the human rights and ethical implications of the expansion of routine provider initiated 'opt-out' HIV testing approach in Ethiopia in all maternal health care settings by drawing the lived experience of pregnant women who tested positive to HIV it was important to allow respondents the space within the interview to define these issues.

I. Interview Schedule

The interview schedule was developed based on the research questions as detailed under chapter one of this thesis. The questions on the schedule were open-ended. The schedule was designed to begin with rapport building and questions that would encourage the participant to open up.(Annex -C) The more personal questions were in the middle and the closing question was an open invitation to the participant to say whatever else they wanted to add. However, in practice the pattern of the flow of questions were not the same for all interviews and were mainly determined by the direction the participant took in their response to the first few questions.

I chose to conduct one-to-one in-depth semi-structured interviews, which included a number of key questions that had been prepared in advance, but remained sufficiently open-ended in order to explore information from interviewees. The key questions asked to all respondents were grouped into four categories; 1) general questions relating to demographic characteristics, 2) questions relating women's expectation and knowledge HIV testing, 3) women's experience and perception of the process of HIV test, and 4) questions relating women's life and experience after they learnt positive HIV test results. It was necessary to ask a combination of questions from the past and present life of respondents to uncover why and how the provider initiated routinely offered HIV testing for women during pregnancy and child birth affects women's human rights. There were a series of essential questions that were systematically asked as well as probing questions which were also used to explore deeper information. Apart from these questions, the researcher pursued other questions according to the direction and flow of information in particular situation.

II. Pilot Testing

At the early stage the field work was pilot tested through interviews with women. The main objective of the pilot testing was to create familiarity to the interview guides and the way of interviewing as well as to gain experience before going into the actual fieldwork. I interviewed four informants, two in each study sites, based on the in-depth interview guidelines. Each interview lasted 40 to 50 minutes.

I learned many lessons from the pilot testing. During the pilot testing it became clear that snow balling would not work. I changed my strategy of recruiting research participants. In addition, some questions in the interview guide were repetitions and others were unclear. All these were resolved by deleting the

repeated questions and clarity of the items was enhanced by re-phrasing the wordings of the question. Hence, before the actual data collection commenced the interview guideline was reviewed in relation to the refining the questions, the wording used in interview of sensitive matters and the way of probing method to find out additional information based on the data from the pilot interviews. Moreover, the pilot interviews were particularly of benefit in improving my confidence and familiarity with semi-structured interviewing. Lastly, based on experience of the pilot testing process I was able to develop a master plan for data collection in terms of recruitment of research participants, the time allowed for interviewing, transcribing and the analyzing stage.

III. The Interview Process

At the beginning of each interview I welcomed the participants, introduced myself and made sure that they were comfortable even though I knew that they were more familiar with the interview rooms than I was. Then the participants were given a description of the research by reading out the information sheet in order to obtain written or oral consent even though they were informally told about my project at the time of first contacts were made by the mentor mothers. I took care to be clear that their participation was voluntary and non-participation would in no way impact on whatsoever including their use and access to health care and services.

Respondents were made aware that the interview would involve informal conversation. The use of the word 'conversation' on the information sheets and consent forms was deliberate. I wished to portray the meeting as a dialogue between two people with a common interest, playing down the anticipated power

dynamics that would be at play in the interview. The information sheet (Appendix A) had also been carefully phrased to put emphasis on the informal conversation nature of the interview.

The original plan for the interview would take around one hour to conduct. However, in practice the duration of the interviews varied in length. Most interviews had a natural termination point where it was felt by the researcher that any further prompting would be intrusive or a repetition of what was already said. Some informants were limited by their own time constraints due to family and other commitments; therefore the initial proposal that interviews would last for approximately one hour, proved to be unrealistic. Consequently, the duration of interviews was largely determined by the informants. At no time was there any pressure exerted upon participants to remain beyond their limitations, neither was there any pressure exerted upon informants to disclose anything other than what they were willing to disclose.

All interviews were conducted in a sensitive and courteous manner, with the feelings of the informants regarded with the utmost respect. For instance during an interview with interviewee # 18 the session was interrupted after she emotionally breakdown during the interview and started to cry when she was telling me how drastically she was impacted economically due to HIV related stigma.

The interviews were conducted in the rooms dedicated for the M2M support group in both health facilities. The mentor mothers were cooperative enough to postpone whatever appointments they had with the members or to conduct them somewhere else until the interview sessions ended. The room in Korem health centre was very quiet and had no interruptions but in Mekelle hospital the M2M room was

located in a very noisy part of the facility where I was sometimes forced to close the door and windows after making sure that the respondents are comfortable with it.

Interviews were conducted with the support of a tape recorder recorded on audiocassette, but only with the express permission of the respondent. The consent form included the fact that the interview would be digitally recorded unless the interviewees objected to it. Eleven participants refused to be tape recorded, and in such cases the interview data comprised of field notes made by myself during the interviews and from memory after the interviews were completed.

In my experience of interviewing respondents the practice of taking time to engage with the respondents built trust and a level of reciprocity. Once I completed the interview and the tape recorders are off, I have always taken time to have un-recorded conversations with the respondents immediately after the end of the official interview sessions which helped me not only to know the participants in person and be in line with the cultural expectation but to avoid the sense of being used that could be felt by the respondents. This allows the respondents to talk at length with me on any matter of discussion they wished including my personal life and work, the research agenda and their own personal lives. For instance, one respondent (Interview #8) asked for my legal advice on her right to bring a case before the court on maintenance allowance for her son against her husband who left her upon positive HIV diagnosis. In addition many respondents discussed with me their concerns and worries in relation to discordant HIV test results with their husband, their feelings regarding the ARV treatment, health of their children and so on which provided greater insight and understanding into the respondents lives.

It was most important for me not to conduct my research in a manner that could be perceived as, or feel as if I were simply 'taking' information. Therefore, I was keen to extend the level of reciprocity beyond the period fieldwork. All respondents were given my contact details at the end of the interview if they wished to contact me after the period of fieldwork. I asked respondents if they would like to see copies of interview transcripts, or versions of papers that used the data. Most respondents declined the need for further information mainly because they said they were not particularly interested but for some it has also to do with their inability to understand English or not being able to read. It would be impractical to send copies of the research to all respondents, but I am still concerned about making my research available to the respondents who allowed me to write this thesis, should they wish to read it.

4.4.3 Expert Interviews (Key Informant)

The key aim of this study was to understand how women perceived and experience the health care provider initiated routinely offered HIV testing scheme for women during pregnancy and childbirth. However, it was also necessary to conduct interviews with key informants who are directly involved in the implementation of the PMCT programme in Ethiopia to describe the practice and relationships that shaped women's experience in their interactions with the health- care system.

Accordingly, in addition to the in-depth interview with the HIV positive women, 9 key informant interviews were conducted with key informants both in Mekelle and Ofla district (2 midwives, 2 nurses, 3 health extension workers). The perspectives provided by the health care providers are crucial for understanding the socio- political and cultural situations of the expansion and implementation of routine provider initiated 'opt-out' HIV testing approach in maternal health care settings. The expert interviews

were conducted towards the end of fieldwork to reflect on the findings from interview with women, and I have exerted maximum caution not to discuss the information collected from the women in the previous interviews. (See Appendix D) In Korem health centre interviews were made with the midwife (male) and a female nurse in the health centre who were responsible of handling both ANC and labour wards altogether while in Mekelle hospital one nurse from the antenatal care unit and one midwife (both female) from the delivery ward were interviewed. All of the in-depth interviews took place in their offices after work.

The letters that I had from the Tigray regional Bureau of Health and the authorization from the management of both health institutions facilitated my access to the experts although I was forced to endure many late hour cancellations of appointments by experts from Mekelle hospital. All expert respondents gave consent to be cited in the text, and where appropriate are cited by position. My first expert interview was with the midwife and nurse working in *Korem* health centre that have a direct responsibility of the implementation of the PMCT programme. During this interview with the health workers in *Ofla* district, I was confronted with unexpected events that they dictated me to conduct the interview together with a disguised that they have no time to do it separately. I agreed to their terms because I had already learned that there were only two of them in the health centre responsible for maternal health care and directly involved with the PMTCT services in the centre. Hence I had no chance to conduct the interview with others. The interview was conduct in late afternoon and took a total of two hours. During the course of the interview I noticed that the male midwife dominated the interview which made me to take conscious efforts to pose questions to the nurse participant to ensure that I did not missed any opportunity to gain two individual perceptions of the implementation of a routine 'opt-out' HIV testing approach in rural settings.

In addition, even though I thought I had made it crystal clear to the health care professional from Ofla district who participated in this research that I am just a doctorate student doing a research on issues of HIV testing for women during pregnancy and child delivery, I have noted that my key informant were not fully convinced that I have nothing to do with the health bureau or other organs of the regional government. As a result of this most of the information given by the experts were very much sensitized with the popular political terminologies and propaganda in the country. For example a statement '*because our government is a democratic developmental government ... we , as an army for development , are working day and night towards AIDS free generation...*' was commonly mentioned by the key informants which I later on started to understand as it is their way of being politically correct. Despite my concerns, analysis of expert respondents' interviews and their extended narratives revealed much about the ways in which the expert understood issues revolving HIV screening of women during pregnancy and delivery in rural settings from their own perspective.

The interview with health care professionals in Mekelle was conducted in a way I planned it. A midwife and a nurse participated in the interview individually. During the interview sessions I also noticed that they did not have any trouble taking me as just a doctorate student mainly due to the fact that I had had a prior social acquaintance with both of them. They already knew who I was. I believed that this has worked to my advantage.

As part of the key informant interviews, I also conducted an interview with three Health Extension Workers (HEWs). My first interview with the midwife and nurse in Ofla district opened access to conduct interview with three HEWs in relation to the HIV screening of women in the villages of that district. Without their help, it would have proven quite difficult to locate the HEWs, because the HEWs

normally work by visiting women door to door in the villages. Thus, the interviews with the HEWs was also fruitful as I was able to ask more specific questions about the follow up and mechanism adopted to ensure all pregnant women are screened for HIV in the rural areas.

4.4. 4 Field Diaries and Observations

I also generated data in the form of my field diaries. My field note comprises documentation and comment on the 'content' of the fieldwork, for example recording the time, location, respondent and key themes from an interview, alongside any additional comments arising from discussions taking place after the interview. I also documented the research process and used this to reflect on how the research project was progressing and on the possible reasons for any difficulties encountered. I found that my deconstructions of interviews recorded in the field diaries provided extremely useful both in the field and in the period of 'writing up' on return.

This study is also informed by data collected using non-participatory observation. I did the observation in Mekelle Hospital in the Integrated Maternal and Child Health Department. I sat in for seven ANC sessions to observe how HIV testing is offered to pregnant women as an integral part of the antenatal health care service and the way the pregnant women responded to the offer. Three of the pregnant women were first time ANC visitors and the remaining came based on their appointment. HIV testing was not discussed between the 4 women probably because they have already taken the test and there was no point of discussion for the nurses. But for the three first-time clients HIV testing was offered by the nurses and two of them accepted automatically but one tried to refuse the testing but gave up quickly as discussed in the subsequent chapters.

I used a standardised checklist to observe the activities and communications in the ANC room. Despite the limited participation I was able to observe the most visible elements of the routine offering of HIV testing to pregnant women visiting the ANC by health care providers. The data collected included the setting arrangements in the room, the greetings and reception of the clients, the words exchanged between the patients and the nurses, body languages and non-verbal components of interactions were taken account of during the observational data generation that fed into the analysis and interpretation of interview data.

4.5 Post Fieldwork Analysis and 'Writing Up'

The remainder of this chapter discusses the process of analysing, translating and writing up the findings generated during the period of fieldwork after return from the field. Following each interview, I transcribed the data into a complete text document and carefully edited all transcriptions by listening back to the recording. Transcription process allowed for greater understanding and familiarisation with interview contents. Because of the confidentiality risk present in this study, only I listened to the recordings.

After studying the data as a whole, thematic analysis was employed to reveal recurring themes from the data. This involved obtaining an overview of the material and identifying patterns and major ideas emerging from the interviews. Several steps were taken to identify and construct themes. Some were immediately apparent and others were discovered upon further analysis. Each theme was given a label descriptive of its content and this was reviewed several times in an effort to reduce the researchers own interpretations upon the findings.

The process of analysis begins immediately following the interview in the writing up of the interview notes and later by listening to the recording, transcribing and editing. I used highlighters to identify similar language and ideas that emerged and clarified those data blocks into themes. Interviews were compared to identify similarities and differences; to facilitate comparison I prepared summarised notes of findings from each individual according to the themes.

4.6 Ethical Considerations

Ethical considerations were very important in the planning, design, implantation and analysis of this research project. My research does not identify any individuals and participants in the study have been guaranteed the absolute in the research project. I have considered all the ethical issues generated by research study and have complied with the University of Warwick's Research Code of Conduct and Guidelines on ethical practices. Research permission/ authorization from the Tigray State Regional Government Bureau of Health and research ethics clearance from the Mekelle University College of Health Research Ethics Committee were also secured before the commencement of data collection. I also briefed the management teams in both the Mekelle hospital and Korem health centre on the purpose of the research and methods of data collection.

Moreover, all respondents were requested to consent their participation in the study in writing or verbally for those who cannot read and write. The information sheet was read out to all participants and verbal explanation of the research was given in each session before consent to participate in the study is requested. (See Annex A and B) Following the discussion, the information sheets were provided to respondents to keep it as a record or for my contact details. The study was described as being about HIV

testing women during pregnancy. Respondents marked on the consent forms or gave verbal consent to participate in the study.

In addition, respondents were guaranteed the anonymity of any data generated from their involvement in the project to maintain the confidentiality of the information collected. Where respondents are cited some general demographic data is given to outline the context in which women understand and attempt to exercise their rights, but not sufficient to be able to identify the respondent. This was particularly important to avoid any possible repercussion that could be inflicted on respondents in relation to their right to access to the health services be it in relation to HIV treatment or other services. However, I was surprise to find out that every time I communicated to my respondents that data given by them will remain anonymous, many objected expressly claiming that they have no fear of any kind even if their identity is disclosed since they will only tell the truth. A 27 old respondent from Mekelle said '*... I am going to talk about myself, my experience and I will only tell you the truth so ... there is nothing that I fear about even if you used my real name ...*' (interview # 3). However, even in cases of such clear statement of the participants I remained faithful to the ethical standard and collected the data anonymously by removing names of people and places.

However, obtaining traditional signed consent forms was less appropriate in my fieldwork with women in the rural settings, where many of my respondents were suspicious of the consent form and declined to sign the forms for undisclosed reason but with the disguise of not being able to read and write. Hence I only got their oral consent to participate in the research. 19 women mainly respondents from Mekelle signed the consent form after my explanation that the form is just in order to meet the ethical standard. Despite these difficulties with the consent form, I nonetheless experienced the issue of informed consent

to participate in research as an important tool with which to establish some of the basic principles of my research – such as confidentiality, anonymity, voluntary participation and the opportunity to withdraw – and to encourage participants to view the interview as a ‘guided conversation’ by asking me questions back during the interview.

Respondents were also given the opportunity to withdraw consent from the interview or the use of data generated at any point. However no respondents have withdrawn from the interview even though many of the respondents were indicating to me that they are in hurry want to finish the interview as quick as possible. This was understandable taking under consideration of the busy life of women in Tigray who shoulder all the burden of household chores.

4.7 Conclusion

Seeking to achieve the objectives of this study an approach was needed that would facilitate the generation of data that represents the values, feelings, personal experiences and attitudes of the women who took HIV testing during their pregnancies or child birth. Discussions of HIV testing approaches are complex subject that involves understandings of global policies, national legal frameworks, gender power relations and deep-rooted socio cultural norms. A qualitative approach was deemed well suited to such aim as it allows a more robust generation, description, interpretation and analysis of data that provide insight into the subjective experiences of women in relation to exercising their autonomous decision making regarding the HIV test offered during their pregnancies. Hence, in-depth semi-structured interview was employed in this thesis as the main data collection tool though this study is also

informed by data collected through non participatory observation and field notes gathered during the fieldwork period. In addition, the normative and conceptual aspects of human rights and ethical principles inform the thrust of discussions and arguments in this thesis. Hence the study was shaped and refined with the data gathered from interview with women and other interviewees, observational data, field notes and themes identified from document reviews.

The study was conducted in both urban and rural settings. Participants were recruited from members of mother-to-mother support group that function in health facilities as forum where HIV positive mother help each other. Interviews were conducted at the health facilities upon the recruitment of the research subjects based on the selection criteria. Before each interview, informed consent was sought from each participant. Following the interviewee with women who tested HIV positive during their pregnancies, key informant interviews were held with health care providers, health workers and mentor mothers of the M2M support groups. The following chapters of the thesis present the findings that framed the stud

CHAPTER –FIVE

FINDINGS I: HIV TESTING OF PREGNANT WOMEN AND THE COUNSELLING PROCESS

5.1 Introduction

This chapter begins by unpacking respondents' perception and description the process of pre-test counselling before they had had the HIV testing at the maternal health care services. The findings under this chapter are related to the pre-test counselling process that women who participated in this study went through before they had had the HIV testing at the maternal health care services. These findings took readers from the point the women accessed the health facilities for pregnancy related health care service to the point where they have to agree or disagree to the HIV test offered to them in order to assess the dynamics of consent and counselling. The chapter presents data collected from the in-depth semi-structured interviews with women who took HIV testing in relation to PMTCT and health care workers. Insights have also been drawn from the non participatory observation I conducted in an antenatal care in Mekelle hospital.

The current chapter, therefore, addresses the second objective of this study:

To gain perspectives on the extent of the pre-test counselling sessions provided to pregnant women under the routine provide initiated 'opt-out' HIV testing approach in Ethiopia to create enabling environment for the women to make an informed decision for the test.

The first section explores the respondents' prior knowledge on the integration of HIV testing with maternal health care services. The second section examines the experience of the women who participated in this study in the pre-test counselling sessions with specific focus on the content of the information provided by the health care workers. The third section presents the views of the health care workers on their role during the pre-test counselling sessions. Lastly, the chapter concludes that simplified, incomplete and inconsistent minimal information or just only a notification by the test provider hinder women from making a voluntary and an informed decision for the HIV test.

5.2 Prior Knowledge of the HIV Testing Scheme

The 2011 EDHS study indicated that the knowledge of AIDS is almost universal (97 percent of women and 99 percent of men)¹ indicating that the Ethiopian population is well aware of how HIV is transmitted and how it can be prevented. However, little is known about the extent of the knowledge of Ethiopian women about the integration of the routine offer of 'opt-out' HIV testing to all maternal health care services (that is, services that care of women during the antenatal period, labour and the immediate postpartum). Prior knowledge of women about the screening scheme is more likely to enable them to substantially understand the meaning and possible consequences of HIV testing. The subsequent sub-section sets out the process through which the women who participated in this study obtained information about the integration of 'opt-out' HIV testing approach in all maternal health care settings.

¹ Central Statistical Agency of Ethiopia (CSA) and ICF International *Ethiopia Demographic and Health Survey 2011* (Addis Ababa: CSA, 2012) 270 (here after EDHS 2011) 190.

5.2.1 Local Media as Source of Information

Local media like FM radio and TV² were mentioned by only a few of the respondents in this study as a source of information about the integration of 'opt-out' HIV testing approach. The following quotations are from such women participants:

'I saw on TV that women giving their testimony about testing for HIV at the time of pregnancy. I always do watch TV and there are some TV programmes on HIV testing that teaches about protecting the unborn child from HIV infection during pregnancy. They say women have to be tested for HIV during their pregnancy. So when I first visited the ANC I knew I would be asked to test for HIV.' (Interviewee # 13)

'I knew about HIV testing during pregnancy through FM Mekelle radio ... in the radio show they present women who tested for HIV during their pregnancy and gave birth to HIV free children ...so that is how I learnt about HIV testing during pregnancy.' (Interviewee #12)

In this study, local media namely TV and local FM radio was mentioned as a source of information predominantly by respondents from Mekelle though there were also respondents from the same study site who reported that mass media was not their source of information because they do not have access to these media outlets. For example, Interviewee#1 who is from Mekelle and had completed high school and repeatedly identified herself as 'educated' stated during the interview that '*... I live at the outskirts of the city... I do not have radio or TV ... because there is no electric power in my neighbourhood ...*' None

² There are only two FM radio in Tigray regional state both owned by the state government and there is only one national TV channel in the country which is also owned by the government.

of the participants in this study mentioned newspapers, magazines or any other printed documents as their source of information about HIV testing in general nor about its integration into all the maternal health care in particular.

5.2.2 Social Network as Source of Knowledge

In this study for those who had prior knowledge on the integration of the routine 'opt-out' HIV testing approach in all maternal health care settings, the main source of information mentioned was through social networking. For instance, Interviewee # 3 said

'... Even before my pregnancy I used to hear about HIV testing during pregnancy from some women in my neighbourhood who recently gave birth to their babies in hospitals...'
(Interviewee # 3)

Similarly, the experiences of other women from the sample suggest that social networks have been the main avenue for many of them to know about the integration of 'opt-out' HIV testing approach in all maternal health care settings. The statements of some of the respondents go on as follows:

'My sister- in-law gave birth to a child during the early months of my pregnancy and she was tested for HIV during her pregnancy ... so I learn from her that they [health workers] do that [HIV test] during pregnancy to all women in the ANC.' (Interviewee #20)

'I used to hear rumours from people that during pregnancy examination [ANC] these days they[health workers] do not let you go without checking your blood[HIV test]...' (Interviewee# 14)

Sometimes, both the local media and social networks were mentioned by respondents as sources of information. For instance, the above quoted Interviewee #13 who reported local media as her main source of information also mentioned social networks as her additional source of information. In her words;

'... I knew many friends and close relatives who went to the hospital during their pregnancies and they were asked to take up HIV testing. So I kind of remembered their experience of HIV testing the moment I knew that I was pregnant.' (Interviewee # 13)

Similarly, women participants from Ofla district are more likely to mention *Nay deki Anstyio Limieat Gujel'* (Women Development Army)³ as their source of information for their prior knowledge on the integration of 'opt-out' HIV testing approach to all maternal health care services. The statements of some of the respondents are as follows;

'Yes, I was aware of that there is an HIV test at the ANC. We [members of the WDAs] always discusses about HIV testing during child birth and pregnancies. So everybody knows.' (Interviewee # 15)

'During our meetings in the Gujille Limieat [WDA], HIV testing during pregnancy is always discussed in continuation to the benefit of going to clinics for ANC and child birth

³ Detail discussion about this new structure at grassroots level is provided in chapter two of this thesis.

in health facility. The HEWs teaches us the benefits of HIV testing to protect the child from HIV infection. '(Interviewee # 25)

Interestingly one participant from Ofla district reported that she was aware of the HIV testing scheme even before her pregnancy because of the information provided by the political party she is involved with.

' ... I am member of the party (TPLF- the Ruling Party) and we have been given trainings on HIV, transmission and prevention by the party , so that is how I happen to know about HIV test during pregnancy. ' (Interviewee # 6)

These respondents who reported that they had prior information either through mass media or other informal sources of information as mentioned above revealed that they were expecting that they would be offered an HIV test by the health care providers upon their visit to the maternal health care facilities. However, as presented below the story for the majority of women in my sample (n=19) was different as they did not have prior knowledge of the integration of HIV testing to the maternal health care service at the time of their first pregnancy related encounter with health care providers.

5.2.3 HIV Testing as a Surprise Extension to Pregnancy Test

The 2011 EDHS survey shows that the level of exposure to mass media is very low in Ethiopia where around 68 percent of women in Ethiopia are not exposed to any mass media.⁴ This fact of women in Ethiopia and their access to media has defiantly impact on their access to information relating HIV in general and HIV testing during pregnancy in specific. Hence, it was not unexpected that many of the

⁴ EDHS 2011 above n 1 at 42.

women who participated in this study (n=19) reported that they were caught with quite a surprised when HIV test was offered to them at the health facilities.

The common expression shared by the women participants who reported that they were not aware of the integration of 'opt-out' HIV testing approach to all maternal health care services was *'I went to the health facility to check if I was pregnant'*. Pregnancy testing tools are not widely available in Ethiopia outside health facilities and many women who would like to know their pregnancy status have to visit health facilities. Accordingly, women in my sample who sought a medical validation of their pregnancy reported that they were offered an HIV test immediately after the pregnancy was confirmed. For instance, Interviewee #17 said that she went to a health facility with the only purpose of pregnancy test in her words (*'to check if I was pregnant'*) to which it was confirmed that she was five month pregnant. She said that at the time she was also told by the nurses who attend her *'... now that you know you are pregnant you have to make the HIV test to protect your child from HIV/AIDS'* and Interviewee #17 reported that she was surprised by the question. In her own words:

'... I was surprised that she asked me for HIV test. I was not aware that there is HIV testing during pregnancy ... I did not know back then. So I told her [health worker] I need time to think about it and she said Ok.' (Interviewee #17)

Other respondents recounted a similar experience in the following way:

'I went to the hospital to check if I was pregnant [for pregnancy test] and the result showed that I have conceived ... the nurse now wanted me to take the HIV test ...I was very much surprised but I said OK. So I ended up taking both the pregnancy test and HIV test on the same day.' (Interviewee#4)

'... When my menstrual period stopped coming and I lost my appetite for food I suspected my body [for pregnancy]... I went to the hospital so that they [health workers] can help me to check if I was pregnant or not. I was told that am pregnant. Then nurse wanted to see [test] my blood for HIV and I was not expecting that kind of question back then so I said some other time ... It was only in my second visit for ANC that I agreed for the test. (Interviewee #2)

5.3 Women's Experience with the Pre-test information Session

As mentioned in the previous chapters, the 2007 Ethiopia's PMTCT guidelines mandate HIV testing and counselling to be offered as a routine component of standard maternal health care services. The guideline states that all women visiting health facilities for ANC, labour and delivery and post partum follow-up are to be given pre- test information on the benefits of PMTCT and HIV testing for mother and baby and should be told that their routine antenatal laboratory tests will include an HIV test unless they say 'No'. The subsequent sections present the content and the process of these counselling sessions as experienced by women who participated in this study.

5.3.1 Initiating Counselling through the 'Why Not?' Question

Women need access to adequate information about the HIV test before they make the decision whether to opt out or not. The findings of this study suggest that pregnant women are given pre-test information that is no more than the direct question: *'Now that you are pregnant, you know you have to test for HIV'*

rather than a detailed discussion on the benefits and risks of HIV testing. If the pregnant woman to whom the testing is offered declines, she will be required to justify her refusal and hence the question of 'why not?' follows.

'...He [health worker] asked me if I wanted to test for HIV ...I told him that I do not need one ...he asked why not? I told him that I am a married woman and I did not suspect myself for being infected with the virus. He now said 'if you do not have anything to fear then why did you refuse to take test?' ... and that is how I did the testing...' (Interview# 1)

'After writing down my names and address she [health worker] asked me if I had ever gone for HIV test before my pregnancy. I said 'No' and she continue with the question of if it is Ok to take my blood to test it for the virus and I said no, I do not want to . She asked 'Why not?' and I only said to her I will have to think about it...' (Interviewee # 24)

'She told me that I am a 2 month pregnancy. She now continues to say that I have to make HIV test as well.... I told her I do not want to test for HIV. Back then I truly believed that I do not have it [the HIV virus]. I never thought it can found me [to be infected with HIV]. And when I said I do not want to test for HIV, she asked me 'why not?' I simply said may be some other time....' (Interviewee # 14)

The findings presented above indicate that through the 'Why not?' question pregnant women who refused testing are subject to serious questioning and are required to give repeated explanations to the health care workers as to why they said 'No' to the testing offered to them.

5.3.2 The 'Good for the Baby' Message

This study found that *'the importance of having an uninfected baby as an advantage of HIV testing'* or *'the message that knowing one's HIV status was the best decision a mother could make for her unborn child'* was emphasized during the pre-test information session. This finding was reported both by the women and the health care providers who participated in this research. The danger with such a counselling approach that gives such a one-sided message about HIV testing is that it makes women feel some kind of moral obligation to take up the testing even if they did not want to. In addition, women may not be prepared for the possible negative consequences of testing, if the HIV pre-test counselling/information in the pregnancy context focus on the health of the child. In the course of this investigation into the content of the information provided during the pre-test sessions, a research participant health care provider reported that:

'... HIV testing counselling is given to all pregnant women before testing is conducted. We tell them that testing helps them to save their babies from HIV infection.' (Midwife, Ofla)

Another health care provider also reported similar experiences in providing pre-test information to women in labour wards:

'We always advise the pregnant women in our labour ward to seriously consider the health of their unborn child. We remind her that she has carried the baby in her womb for nine months to have a healthy child not a sick HIV infected child. We remind her that this could be her last child ... these things [child birth] are in the hands of God ... you know she might not be able to give birth to another child again ... so we tell her that to protect the health of the child that she is blessed with now and also for herself, she needs

to test for HIV. If in cases of a positive HIV result free medication is available to make sure that the child is born free from the virus ...' (Midwife, Mekelle)

More importantly, the emphasis on the 'good for the baby message' during the pre-test information session was also reported by women who participated in this study.

'... I was told by them (health care providers) that testing for HIV during pregnancy protects the baby from AIDS. I was told that if I took up the HIV test and the result showed positive, that they [Health workers] can help me to have to protect my child from being infected.' (Interview# 9)

'I was made to understand that a pregnant woman should test for HIV ... if I do not have it [if tested negative], then it is good - otherwise if it is found in my blood [tested positive] they told me that I can save my child from the infection ... after this advice I was tested for an HIV infection.' (Interviewee #12)

'I was told the benefit of testing for HIV. They have to see you [test you for HIV] so that they will save the child from the disease. They told me that they have medicine that helps to protect child from contracting the disease ...' (Interviewee # 27)

At the time of the fieldwork, the babies of the respondents were either unborn or below one year of age and hence it was yet clinically to be determined whether the babies were free from the infection. The success of the therapy treatment intervention in protecting babies from HIV is determined after a year of treatment. However, the respondents were very quick to mention that they have benefited by the testing because they had protected the health of their child:

'What makes me happy is that my son is free from the virus...' (Interviewee #1)

'Praise to God my son is safe... that is what matters ...' (Interviewee # 5)

'Thanks for the government for providing the medicine ... my baby is now safe From the disease.' (Interviewee # 7)

However, Interviewees #3 acknowledged that the HIV status for the baby was still to be determined but she confidently said that *'...but I am sure she [the baby] will be free from the virus.'* It was interesting to note that the discussion on the benefit of HIV testing with women in my sample was totally dominated by the *'good for the health of the child'* sentiment but no mention was made by the respondents on their own health status or the personal advantage for themselves from undergoing the HIV screening. The only exception was a respondent from Mekelle who claimed that even before her pregnancy she was very sick and when she tested positive for HIV, she was made to start the ARV treatment. She explained the situation as follows:

"...at the time of testing I was very sick. My CD4 count was found to be very low... and they made me start the medicine (ARV). Thanks to God, I am now well...." (Interviewee # 2)

5.3.3 The Right to Refuse HIV Testing Not Fully Communicated

The 2007 Ethiopian PMTCT guideline impose the obligation on health care provider to *clearly* inform the client (pregnant woman) that she has the right to say ' No' to (that is, to opt out) the offered HIV testing and that any refusal of testing by no means affects the services she will get from the health

facility.⁵(Emphasis added) Accordingly, this study aimed to investigate to what extent the right to refuse HIV testing was communicated during the pre-test information sessions.

Data gathered from the interviews with health care workers shows that there seems to be a confusion of the obligation to expressly communicate the right to refuse to clients with the obligation to ensure that clients take up the HIV test with their consent. For instance, the health care providers who participated in this study repeatedly responded when asked if they have the practice of clearly communicating the right to refuse testing to their clients with the following; *'It is not allowed to conduct HIV test without the permission of the patients'* and *'pregnant women are always asked for their authorization for HIV'* *'No woman is tested without her wanting to test for HIV'*. Similar but more argumentative statements were made by the nurse from Mekelle as quoted below:

'After making them [pregnant women] understand the benefit of HIV testing, we then proceed to ask for their agreement to the testing ... we do not force them to test without their will ... we always ask for their will... women know what is best for them .. They know how important HIV testing is during pregnancy ... they only need us to remind them and they agree for the testing ... we[health care provider] do not need to remind them that they can refuse ... because we do not force them to the testing and they know that'
(Nurse, Mekelle)

Health care providers who participated in this study avoided answering directly the question regarding their practice of clearly communicating the right to refuse HIV testing to the pregnant women visiting their health centres. The data collected shows that most of their responses revolve either on their practice

⁵ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother –to-Child Transmission of HIV* (Addis Ababa, 2007) 11 and 12.

of soliciting consent as indicated above or describing the worry that they have in communicating the right to refuse to their clients. One good example of such responses by the health care provider is presented below:

'You see sometimes communicating the right to refuse to the pregnant women can send the wrong message or wrongly understood that it is ok if she did not to test if she does not want to. That is what our daily experience tells us ... So we do not encourage women to skip HIV testing during pregnancy. Rather what we do is that we make them understand on the benefit of the testing and obtain their authorization for the testing.'
(Midwife, Ofla)

Similarly, women who participated in this study were also hesitant to answer directly whether or not the right to refuse HIV testing had been communicated by their antenatal care providers, although one can easily infer from their statements that the right to refuse might not have been communicated. This may be explainable as the respondents were very aware of their right not to be forced to be tested for HIV but not much awareness on the right to be clearly communicated about her right to refuse the testing if she does not wish to test. The quotation below captures this dimension:

Researcher: *'Were you told that you have the right to refuse the testing?'*

Respondent: *'... they [health workers] do not tell you that you can refuse but if you do not want to test you can refuse ... They asked for my permission, so it is not that I was not able to refuse If you want you can test if you did not then you can refuse.'* (Interviewee #2)

Researcher: *'I understand what you just said but I still want to know if the right to refuse was clearly communicated to you'*

Respondent: *'... I think you cannot expect them [health workers] to say that... it is like saying if you do not want to you may not test for HIV ... how can they say that? I do not think that will work. What they do is that they tell us [women/client] the benefits of HIV testing and if you do not want to test then they do not force you ...they will just try to make you understand the benefit.'* (Interviewee #2)

A much clearer preview of how the right to refuse HIV testing is communicated during antenatal HIV testing of pregnant women came from the non- participatory observation. During the observations at the antenatal clinic in Mekelle hospital, I noted that the right to refuse HIV testing without any consequence to their access to health care services was not explicitly communicated. The antenatal care providers were observed initiating the pre-testing counselling session by asking questions like *'Have you ever tested for HIV?'* *'Do you know that you have to take an HIV test during pregnancy?'* *'Have you considered HIV testing before your pregnancy?'* Then often follows the piece of information that emphasis the medical benefits of HIV testing in relation to the opportunity to prevent mother-to-child transmission of the virus. The ANC providers then proceeded to draw blood from the clients without explicitly notifying the clients of their right to refuse the testing as required by the 2007 Ethiopian PMTCT guideline. The following observed conversation between a pregnant woman and the antenatal care staff illustrates the above:

STAFF - *'Have you ever tested for HIV?'*

(Asked while still standing in front of the sitting patient after taking her blood pressure measures and looking down at her)

PREGNANT WOMAN – *'No.'*

STAFF – *'Why not?'*

PREGNANT WOMAN – *(silence)*

STAFF - *'You never heard about the benefits of HIV testing during pregnancy?'*

PREGNANT WOMAN – *(just an eye glance with silence)*

STAFF – *'... HIV testing will help you to know your HIV status so that you will be able to protect your child from infection if in case you have the diseases.'*

PREGNANT WOMAN – *(Just nodded)*

STAFF – *'Can I now take you blood for the test?'*

PREGNANT WOMAN – *'I can test, there is no problem'* and took out her finger for the test.

Such counselling sessions observed at the antenatal care sessions revealed not only that the right to refuse testing is not clearly communicated as required by the PMTCT guidelines but also the pregnant women were not given the time and the opportunity to reflect on the implications of the testing on their lives.

One respondent, the midwife from Mekelle, reported that pregnant women were actually told that they have no right to refuse the testing when the pregnant women explicitly ask if they have the right to refuse during the pre-test information sessions of HIV testing:

'Sometimes some women ask us [health workers] if it is a MUST to be tested for HIV ... we tell them yes it is MUST... then they agree for the test. We tell them it must, because we want to take the HIV testing. It is because we want to protect the health of the unborn children and for women's benefit ...' (Midwife, Mekelle)

5.3.4 Counselling Outside the Clinic Setting

The interview with health care providers who participated in this study showed that the process of convincing pregnant women to take a HIV antibody test does not stop when the women leave the clinical setting. Data mainly drawn from Ofla district reveals that the prevailing practice of convincing pregnant women in the villages to have a HIV antibody test involves people outside the health profession. The newly designed local structures at grassroots level, the Women Development Army (WDAs) is especially instrumental in 'convincing' the pregnant woman to take the test at different stages of the process. The health extension workers who participated in this study explained the importance of employing the WDAs to convince women to have HIV testing especially during pregnancy by stating:

'... when it is her [the pregnant woman's] neighbour or her friends in the WDA that is telling her about the benefits of HIV testing during pregnancy, women do have the tendency to agree for the test ... you know to them [the women in the village] we are the outsiders, hence women are more likely to believe the advice and words of their peers than ours. Hence, through the structure of WDAs we try to convince women to come to health facilities and seek medical attention during their pregnancy and child birth.'
(HEW₃, Ofla)

However, in some cases when the pregnant woman still refuse HIV testing even after counselling by the health extension worker and her peers in the WDA, the counselling by the non clinicians continues.

'In each village there are representative of the Woman Affairs Office [governmental structure], the chairwoman of the Woman Association of the village, the Woman's League [affiliated to the ruling party]. All these bodies work on the rights of women ... so we coordinate and involve all these bodies to convince a woman who refused to visit the antenatal clinics, to take HIV testing during her pregnancy' (HEW₃, Ofla)

5.4 Counselling During Labour

A routine provider initiated 'opt-out' HIV testing approach promotes the offering of HIV testing to women with unknown HIV status during labour and child delivery to prevent Mother-to-Child transmission of HIV infection. The rationale behind the provision of HIV counselling and testing in the labour wards is to provide women with the last opportunity to know their HIV status and in cases of positive results to provide therapy treatment to prevent MTCT. In this study seven out of the thirty women participants reported that they were tested for HIV during their labour or at the time of their delivery.

Health care providers who participated in this study both from Mekelle and Ofla recognized that there are some women who present themselves at labour wards with unknown HIV status. These women were described by the health care providers as women 'who came from other places', 'new comers' and 'visitors'. During the interview with the women who participated in this study and who reported that

they present themselves at labour wards with unknown HIV status, 'being new to the area' or 'being visitor' or 'new comer' was not mentioned as a reason.

Lack of antenatal care was the most common reason women gave as to why they showed up with unknown HIV status to labour wards. One example is the statement made by interviewee #7:

'During my pregnancy I have not been to the clinics neither for the ANC nor any other reason. That is because I have never been to any health facilities for my three previous pregnancies.... so I did not realize the need to have one in my last pregnancy too....'
(Interviewee #7)

Most importantly, the current study found that the unknown HIV status of women in the labour ward also relates to the deliberate action of the women to avoid medical attentions during their pregnancy for fear of HIV testing as discussed in detail under chapter six of this thesis.

'I heard from other women that they [health Worker] are testing all pregnant women for HIV during the monthly pregnancy examination [ANC] ... so I thought they [health workers] will force me to be test for the virus. Back then I did not really want to take the HIV test. So I did not come [visit health facility] for antenatal care ...' (Interviewee #23)

According to the women in my sample, the provision of pre-test counselling is highly dependent upon the stage of the labour at which the women present themselves at the labour ward. The women from Ofla district reported that in rural areas, pregnant women are generally advised to go to the health facility three or more days before their childbirth is due and wait for the onset of their labour. This is

mainly because it is very difficult for women to access health facilities once they are in labour due to the fact that most of the health facilities are located very far from their homes with no ambulances services. Hence, with the support of the HEWs, the government is encouraging pregnant women from rural villages to be hospitalized much earlier in order for them to get skilled birth attendants in an effort to reduce maternal mortality. Consequently, Interviewees # 19 and 21 reported that they went to the health facility days earlier and waited for their labour to start. This situation has given ample time for the health care providers to persuade the pregnant women from the rural areas about the benefits of HIV testing to prevent vertical transmission of HIV. The prolonged hospitalisation, however, also could be seen to limit the agency of these women to refuse testing. The following quotations from participants appear to support this:

' I was encouraged by the HEWs and my neighbours in the Guijel limeat [WDA] that as a first time pregnant woman I should give birth to my child at the health facility ... so I went there earlier and waited for the start of my labour for three days ... on the third day I delivered safely. ... During my stay they [health care providers] did all the testing for me including the HIV test I was told all the benefits of HIV testing. How the baby can be protected if I was found HIV positive ... So I agreed to the testing because it is for the benefit of myself and the child.' (Interviewee # 19)

I stayed there [health facility] for two days and the nurse advised me how important it is [HIV testing] to protect the baby from infection and I agreed to the testing. (Interviewee # 21)

However, another respondent from Ofla district reported that she went to the health centre after her labour pain started. She reported the conversation that she had with the health workers before the testing was conducted as follows:

'I was already in labour pain when I arrived in the health centre... they told me that I have to test for HIV ... I lied to them that I have tested before. I was asked to produce my paper form the monthly pregnancy examination [ANC] ... I have never been to the pregnancy examination [ANC] as well so that is how they know that I never took HIV test and they [health workers] told me that I have to test for HIV and I said OK.'
(Interviewee # 7)

The other woman in my sample who tested during child birth described her experience during the pre-test counselling session as something that can be understood as a 'mere notification' of the testing.

'...when I arrived at the labour ward she [health worker] said we have to test you for HIV first ...she was not interested to talk much about the testing ... she only said that my blood should be checked [tested for HIV]... I knew she would test me any way so I said Ok.' (Interviewee # 14)

5.5 The Health Workers' Views on the Counselling Process

All the health care providers who participated in this study made statements that regarded the PMTCT programme as '*decisive*', '*fundamental*', '*very important*', '*beneficial*' for the prevention of HIV transmission in paediatric AIDS. However, the pre-test counselling (pre-test information to use the terminology of the 2007 Ethiopian PMTCT guideline) was not perceived as a process of empowering pregnant women to make an autonomous decision but rather as a process of convincing or persuading them to take the HIV antibody testing. The quote below captures the above dimension well:

'Our government wants us to convince women to take HIV testing during their pregnancies. The government believes that here in Ethiopia we do not have a deaf [who do not accept advices] mother.... there is no deaf woman in our country. There is no mother who does not want to be benefited and avoid harm on herself and her family ... as long as we educated her, we showed her the right way, and we make her understand. I personally believe that this is true. What mothers need is that you need to teach them to the last [until they are convinced] and they will agree with the testing.' (HEW₁, Ofla)

This firm stand of health workers that if women are properly told they do accept medical advice was reflected throughout the interviews with all health workers who participated in this study. The following quotations from participants appear to support this:

*'... Those women who refused HIV testing are counselled up to the **last**... and eventually agree for the testing [HIV]...' (HEW₁) [Emphasis added]*

*'... a woman who refused HIV testing will repeatedly be told on the benefit of testing ... if she persist refusing that is an indicator for us [health workers] that the woman might already know that she is HIV positive ... so we advice and make her understand to the **last point** until she agree to take the testing ...' (midwife , Mekelle) [Emphasis added]*

5.6 Conclusion

Pre- test counselling has long been recognized vital in cases of testing women for HIV during their pregnancy to ensure that they understand the implications of a negative or positive test result, for

themselves, their partners and any future children.⁶ Nevertheless, the 'opt-out' HIV testing approach recommends 'simplified pre-test information' instead of pre-test counselling without necessarily imposing an obligation for extensive disclosure of information regarding the benefits and risks of HIV testing.

In this chapter I have explored the content of the pre-test information and the manner in which it was given to women in my sample as well as the perception of the pre-test counselling process by the health care providers who participated in this study. Accordingly, these data suggested that the pre-test information sessions are dominated by discussions of the 'good for the baby message' designed to make women feel some sort of moral obligation to take the test. In addition, the right to opt out of the offered HIV testing without affecting the care pregnant women receive from the health facilities was not clearly communicated and in some scenarios data gathered in this study suggested that pregnant women were actually told that they have no right to refuse the HIV testing. In cases of refusal of the HIV test during the pre-test information sessions, women were subjected to serious questioning and are required to give repeated explanations to the health care workers as to why they said 'No' to the testing offered to them.

Furthermore, in rural settings the HIV pre-test counselling of pregnant women does not necessarily stop within the clinical setting but other people, such as the WDAs, leaders of the women association in the village and local administrators often become involved in convincing her to take the HIV test. Moreover, the data suggested that the health care providers did not perceive the pre- test information

⁶ S Gruskin *et al.*, 'Provider-Initiated HIV Testing and Counselling in Health Facilities—What does this Mean for the Health and Human Rights of Pregnant Women?' (2008) 8(1) *Developing World Bioethics* 27.

session as a process of empowering pregnant women to make an autonomous decision but rather as a process of convincing or persuading them to take the HIV antibody testing.

The findings presented in this chapter, provides an analytical account for understanding the practices of 'simplified information' during HIV screening programs and its impact on limiting women's rights to access to information necessary to make the best possible choices. The following chapter explore how the pre-test counselling process discussed in this chapter frame the process of the decision making for HIV testing offered at the antenatal clinic or in labour ward to women who participated in this study.

CHAPTER –SIX

FINDINGS - HIV TESTING OF PREGNANT WOMEN AND THE DECISION MAKING PROCESS

6.1 Introduction

The previous chapter presented the findings related to the pre-test counselling/ information process women in this study experienced before they had the HIV testing at the maternal health care services. These findings illustrated the availability, content and adequacy of the information provided to women before they were asked for their consent to HIV testing during their pregnancies or child birth. The current chapter picks up from that point and presents findings related to how these women experienced the process of decision making for the HIV testing offered at the ANC or labour wards in order to have a better understanding of how and why these decisions are made and if they meet the informed consent criteria.

The findings of this chapter therefore address the third and fourth objective of this study:

- *To determine if and how pregnant women visiting maternal health care settings are enabled to make their own informed decision in connection to HIV testing under the routine provider initiated 'opt-out' HIV testing approach.*
- *To determine the influence of peer pressure on pregnant women's decision making in relation to HIV testing in the rural setting.;*

The first section of this chapter explores respondents' experiences of HIV testing during their visit to health facilities for antenatal care. The section presents the findings of how and why the decision of women to take or not take an HIV test is made and also explores the situation of women in rural settings

and their exposure to peer pressure. The second section examines the experience of the women who underwent HIV testing during child delivery. The third section presents the stories shared by participants to reveal the patient practitioner relationship in the context of HIV testing and its impact on the informed decision-making of the women while the fourth section deals with reports of clinic avoidance by respondents for fear of being tested for HIV. The last section provides a conclusion.

6.2 Respondents' Experience of Prenatal HIV testing

6.2.1 Assessing the Risk; 'I never thought I would be infected with HIV'

The perception that women in marriage are safe from HIV infection was commonly shared by the women in my sample. The following comments offered by respondents capture their perception of risk to HIV infection:

'...I have been married to my husband since I was fifteen and have been faithful to him. I never knew that married women can contract the diseases.' (Interviewee # 1)

'They [health care provider] asked if I suspect myself for being infected, I told them I am a married woman. From where would I bring the diseases? But the result showed positive and I did not trust any of the words they were saying...' (Interviewee # 30)

'As a married woman I did not suspect. I never thought that I might be infected with the disease... never (laugh) ... how could I suspect?' (Interviewee # 6)

'I never suspected I could be infected. When she [health worker] asked to see my blood [HIV test] ... I did not even hesitated to agree because I never thought I might have it in my blood [HIV positive].' (Interviewee # 10)

The above comments of the respondents indicate their beliefs that being in stable relationships like marriage eliminates the risks of HIV infection. But what is more interesting is that some women chose to believe that they were safe from the risk of contracting HIV even in situations where they were suspicious that their husbands might be infected by the virus. For example Interviewee # 15, who reported that she was given to a husband by her mother at a very young age when her father passed away, said that:

'...during the pregnancy examination [ANC] she [health workers] asked if I know about AIDS, I said yes and added I never tested for HIV. She asked why not and I responded that I am a married woman ... that I never needed to take the testing... I agreed for the test and tested HIV positive.....there were certain things that I could not foresee. My husband was sick for quite long time and I was very suspicious about the cause of his deteriorating health situation ... but it never occurred to me that I could get caught by the diseases through him... it is bad to be an illiterate woman.' (Interviewee # 15)

Other respondents also shared reports of the extra marital affairs of their husbands. Interviewee # 28 a mother of two who had been married to her husband for nine years expressed her awareness about his extra marital affairs. She said:

'I have heard from people that he is seeing another woman in the neighbourhood ... but I tried to ignore it thinking that he will come to his own sense and stop seeing her.' (Interviewee # 28)

Despite knowing about her husband's behaviour to which she had no control Interviewee # 28 said that she never thought that she could be infected and strongly believed that she was protected from HIV. In her own words;

'... how was I supposed to think that I could be contracted the virus while sitting at home... I thought it happens only to women who jump here and there [have multiple sexual partners].' (Interviewee # 28)

Interviewee # 1 also shared a similar story of low risk perception. She reported that her husband has already has a child with another woman but she forgave his act after he promised her he would not see the woman again. In spite of this, when Interviewee # 1 was offered an HIV test at the ANC, she reported that she resisted the offer by saying:

'... I do not need to test for HIV because I do not suspect myself of being infected. I am a married woman ...' (Interviewee # 1)

6.2.2 Respondents Prior Consideration of HIV Testing

To understand prior knowledge and experience of the respondents in relation to HIV screening I asked whether they had ever considered HIV testing before their pregnancies. Only one respondent confirmed to me that she actually did have HIV testing before her pregnancy.

'...five years ago I was tested for HIV. I was very sick and the doctors recommended me to do the testing but back then the result was negative.....' (Interviewee #6)

Among the women in my sample only four of them were in their first pregnancy when they underwent the screening for HIV. For the remaining women in my sample they had had prior experience of pregnancy and child birth even though I established from their responses that none of them had undergone HIV testing during their previous pregnancies. A respondent who said that she gave birth to her first daughter five years ago states that:

'... they (the health providers) started the testing recently ... there was no such thing [HIV testing] before. But these days they do not allow you to leave easily at the ANC without taking your blood for the test if you are pregnant ...' (interviewee # 4)

Similar comment was made by another woman from Mekelle who was pregnant at the time of fieldwork and who declared that she is member of the ruling party.

'... When I married my second husband I got pregnant immediately and I started my pregnancy follow up [ANC] when I was already a two month pregnant woman and I took the HIV test. Previously there was no HIV testing during pregnancy. The disease [HIV/AIDS] was found recently and woman used to give birth without knowing their HIV status and hence infect their children..... But now the time is good. The government is educating women – a teachings that even ones father and mother would not teach you ... So, No! I did not have HIV testing with my first child it is only with this one [touching her stomach] ... time has changed.' (Interviewee # 6)

The thinking that 'because *the disease started recently to spread and the need to test more women*' was also reflected by another woman from Mekelle during the interview:

'When I gave birth to my other three children [13, 10, 7 years old] there was no such 'testing' thing. I have done all the monthly pregnancy follows ups [ANC] and gave birth in hospital to all my children. There was no AIDS back then. It is nowadays that people are having it.... It is nowadays that we are hearing about testing for HIV during pregnancy. There was no such thing before.' (Interviewee #2)

6.2.3 The Process of Giving Informed Consent for Prenatal HIV Testing

Starting from the design stage of the interview questions, I was well aware of the problem of finding the direct meaning of the term 'Informed Consent' in Tigrigna (the local language). The word '*fikadegna*' is the closest word in meaning to consent. It is inclined to mean not coerced, not forced or a volunteer without necessarily indicating awareness of available information and the capacity to understand the information given as well as the consequence of the decision to be made. Hence, throughout the data collection period I employed the word '*fikadegna*' to connote informed consent cautiously and used different questions that related to it to avoid making assumptions about respondents' understanding of the term.

I. 'It is for my own Good': Dismissing Inquiry on Consent Issues

I found that the women in my sample were familiar with the word informed consent (*fikadegna*), but some were very quick to dismiss the relevance of discussing consent within the context of HIV testing during pregnancy by emphasising the benefit obtained from knowing ones' HIV status. For example, in response to a question asked about if they believed that they have freely consented to the HIV testing, interviewee # 6, who as mentioned previously identified herself as member of the ruling party in the country said:

'I think what matters most is that I now know my HIV status and I am being given medication that would help my child from the infection during child birth. My husband is also tested and he is HIV positive though he is still healthy and did not need to take the medication... So it is me and my family that ultimately got benefited from the testing, not them [health care providers] so it is for our own good. It does not matter whether I consented to the testing or not' (Interviewee # 6)

Another respondent also reflected a similar thought:

'In my early ANC visits I told her [the nurse] that I will think about it every time she mentioned HIV testing. But someday I did not meet the previous nurse but this new one [the nurse] I think she learnt from the card that I was not tested, she said many things that indicates that I am wasting a lot of time to decide and I said OK I will do it ... so if you asked me if I was pressurized to the testing? My answer would be yes! - But I see it as what you call ' a sisterly forcing' she tested me out of her deep concern for my health and for the health of the my child. So, I was pressured to test for HIV but it was all for my own good.'(Interviewee # 12)

However, the majority of the women in my sample who tested during their pregnancy stated that they agreed to the HIV antibody test but provided various reasons as to why they agreed to the testing which begs the question whether the 'opt-out' approaches creates an enabling environment for women to make an autonomous decision as discussed below.

II. The Rational for Accepting Offers of Prenatal HIV Testing

The women in my sample who tested for HIV during their ANC visits, commonly used statements like *'I said am Ok, go ahead', 'I said fine, I will test', 'I said you can test my blood', 'I said Ok and she took my blood for the test'*. At face value it would be easy to assume that just because the women reported that they said 'YES' for an HIV test then they might have made the decision on their own freely and voluntarily. However, as the discussion with the women in my sample probes more deeply into how and why they consented to the testing, the complexity for pregnant woman of giving voluntary and informed consent at the antenatal care service settings came evident.

This study found that the current set-up of prenatal HIV testing where health care providers are made to initiate HIV testing to pregnant women, actually is sending a message to some of the women that HIV testing is a prerequisite for obtaining ANC services. The following comments given by women in the sample captured the range of their experience in this regard:

'These days the nurses won't let you go without taking the HIV testing if you are pregnant ... they [Health workers] let you go only when they take your blood and test for HIV.' (Interviewee # 4)

'I went there [health facility] with my own will ... why would I say 'NO' to the HIV test ... they[Health workers] did not come to my house I went there [health facility] so that they will see if my pregnancy is healthy. So you do not tell them do this and do that or don't do this and do not do that. That is not how it works. If one does not want to be tested for HIV, she should stay at home because nobody is going to help her with her pregnancy at the clinic without the HIV test.' (Interviewee # 29)

'She [health extension worker] made me understand on the benefit of visiting health centre every month for the pregnancy follow up [ANC]. She also told me that the nurses in the clinic will see [test] my blood for HIV ... So when I reached the health centre as I was told they took my blood and told me that I have the virus in my blood after a while.' (Interviewee # 10)

As shown in the above conversations the women who participated in this study thought that HIV testing was a prerequisite for other antenatal health care services and did not consider that they could 'opt-out' of the testing without affecting their right to have access to the ANC. One respondent from Mekelle to whom HIV test was offered even though she was looking only for a pregnancy test, reported that she was told it is a ' must ' for a pregnant women to test for HIV. In her words:

'She [nurse] told me that all pregnant women that visited the hospital must take HIV testing...she made me understand that this obligation to test for HIV comes from the good intention of helping pregnant women to know who they are [HIV status]. It is about saving the child ... she told me all the benefits and I agreed to the test' (Interviewee # 12)

The other most common reason reported by respondents for agreeing to take up the HIV test offered by the health care providers at the ANC was because they were convinced that refusing the offer during ANC is meaningless as they were strongly convinced that the test will be imposed on them during child delivery. The following respondent from Ofla pointed out that:

'These days no one assist woman in labour at home for the fear of being punished 500 birr if they found about it.... This is now forcing women to opt for having their child delivered at health facilities ... therefore each woman will be caught at the delivery

room even if she avoided the HIV testing during pregnancy. At the time of child birth they forcefully get you tested...No one is allowed to give birth to child without it [HIV test]. So as to me those who decline HIV testing during pregnancy are just wasting their time.' (Interviewee # 11)

'I learnt a lot from our discussion in the Women Development Army ... that all women have to give birth in hospitals and be tested for HIV at the time of delivery ... so no use of avoiding it [HIV testing] during pregnancy. At the delivery HIV testing is a must.' (Interviewee # 15)

Similar views were shared by participants from Mekelle as well. Interviewee#13 said that she agreed to the HIV test offered during one of her ANC visits because she heard that women being compelled to test for HIV during child delivery. She explained the situation by saying that:

'... so I agreed for the HIV test during one of her ANC visits because I knew I will be made to test for HIV during child delivery any way ... whether I like it or not.' (Interviewee # 13)

Another respondent also articulated similar idea by saying that:

'... I think it is a must to be tested during delivery but during pregnancy it is fine [not mandatory]. There is a pressure on women to take the testing at delivery ... so there is no point of declining the test during pregnancy because it is a matter of time unless one plans to have home birth.' (Interviewee # 8)

6.2.4 The 'Publicization' of Pregnancy of Rural Women and the 'Peer' Pressure to Test

Society's new interest in foetal rights and in particular the new 'privileged status of the foetus' is really just a disguised 'assault' on women as mothers who are increasingly perceived as a major threat to unborn babies.¹ Writers observed that once a woman becomes pregnant, her life, her lifestyle and her medical options become subject to public control and scrutiny. Gallagher has called this the 'publicization' of pregnancy.² The field work data presented in this section seems to support this contention. The process of implementation of the routine 'opt-out' HIV testing approach with the aim of employing more women in the PMTCT programme in the rural setting considers a woman's womb as quasi-public territory as documented in this study.

The previously mentioned WDAs are very instrumental structures in this regard by directly providing the reproductive profile of each and every woman to the government through the health extension workers who have day to day contact with each group leaders of the WDAs. Hence, arguably every HEW in each village knows who is or is not a pregnant, who is or is not taking contraceptive pills, how many children each woman has and other similar decisions of reproductive rights matters. The government's campaign '*No woman shall die while giving life*' has the reduction of maternal mortality as the principal force behind it. Such an aim also drives the organized method of accessing every reproductive decision of every woman in a village. The following conversation with health care providers captured the argument of the increasing 'publicization' of pregnancy in rural Ethiopia:

¹ C Barnett 'The Forgotten and Neglected: Pregnant Women and Women of Child Bearing age in the Context of the AIDS Epidemic' 23 Golden Gate University Law Review 863 1993

² J Gallagher, Prenatal Invasions and Interventions, What Is Wrong with Fetal Rights, (1987) 1(9) *Harvard Women's Law Journal* 37, 9-58.

RESEARCHER: *How do you know if a woman is pregnant in the first place if the women are not visiting your health centre? You have to know that one is pregnant before you offer her an HIV testing, right?*

RESPONDENT: *What do you think is the job of the health extension worker in the village? She [HEW] has day to day contact with the leaders of the Women Development Army ... she has all the information about each and every individual woman in the village ... these days maternal health is under strict control of the government ... hence no woman is left behind... we know about each woman.* '[Midwife, Ofla]

As mentioned previously the rural women are expected to meet regularly in their WDAs to discuss issues including reproductive matters. In the meetings a woman is expected to disclose if she is pregnant but even if she does not the members in her group are attentive enough to take note of suspicious behaviours that indicate her pregnancy as expressed in the quote below.

'... Women easily detect the pregnancies of other women. new behaviours like refusing to drink coffee, avoiding food, withdrawal, nausea ... are the most common signals that woman usually use to assess pregnancy. Women say she is 'heavy' she must be pregnant just by looking at her body. ... So if they [WDA members] suspected that one of their group members is pregnant then they either directly ask her during their meetings of her intention about ANC or pass the information to us [HEWs]. Accordingly, we immediately contact the pregnant woman in her house during the door to door visit to educate her on the benefit of ANC, HIV testing and institutional child delivery'. (HEW₃, Ofla)

In addition to the above described mechanism of identifying a pregnant woman in rural settings, a health extension worker in Ofla district also reported other systems for identifying a pregnant woman. In her words:

'We have a list of names of all women aged 15-49 years old [reproductive age] in the village and if any of these woman did not attended to our health post for family planning [birth control contraceptives] ... then we visited her in her house and ask why she interrupted it [contraceptive]... if her reason was pregnancy then we start to talk about ANC and others services.' (HEW₁, Ofla)

Accordingly, by applying the above described methods a woman who becomes pregnant is traced and identified by the system. Hence as discussed once the pregnant women are brought to the spotlight their reproductive health related decisions including HIV testing are subject to public control and scrutiny.

6.3 Respondents' Experience of HIV Testing during Delivery

6.3.1 No Longer Voluntary: Testing For HIV in Labour Wards

All the respondents who reported being tested during delivery (n=7) mentioned that they either have never accessed antenatal care or have done it once or twice but avoided the service later on. These respondents reported that during their pregnancy period they were very much worried that they will be forced to take the HIV testing during child birth. The case of Interviewee#14 is a good example. As noted earlier though she was offered HIV testing when she came to the health facility for pregnancy test, she declined it and never came back again for another ANC visit. She explained her worries during the pregnancy as follows:

'.... Later on as the time for my child birth approached I regretted it. I started to hear from people that during child delivery they [the midwives] do stand on your throat [force you], and take your blood to see it if it has a virus [HIV test]...women told me that during child delivery it is must to take HIV test. I felt like I have killed my time for nothing ... I was so worried that they will strangulate my neck [force me] in the labour wards to take my blood and see it [test] for the virus even if I do not want to. I used to worry a lot.'
(Interviewee #14)

Interviewee#14 expressed her perceptions of testing for HIV during child birth by using terms like 'strangulation' and 'standing on a neck' to indicate the degree of coercion exerted by health workers on women in labour to subject them to HIV testing. Similarly, interviewee #3, who reported she of refused HIV test offered to her during her first ANC visit and avoided health facility altogether throughout her pregnancy, relayed a typical tale of fear and worry that health workers would force her to test for HIV during child birth;

'... During my pregnancy I was hearing from friends that HIV testing is a must if you happen to give birth in health facility.... and I used to fear that [the testing] a lot.'
(Interviewee #3)

On assessing whether she gave her informed consent for the HIV testing, Interviewee#7 reflected:

'When my labour pain started people helped me to reach the health centre ... as I reached there the midwife asked me for the pregnancy examination paper [ANC card] ... I told her I do not have it and she said you know we have to test you for HIV and then she proceeded to take my blood ... I did not say anything except watching her quietly. What else can I do?'(Interviewee #7)

A similar experience was recounted by Interviewee # 3, the only woman in my sample who tested for HIV after child birth. She said she was already at the last stage of her labour when she arrived at the hospital and hence the health care providers did not get the time to conduct the HIV test '*... I was in pain with labour pains and my water was broken.... so there was no time to do the testing*' However, even in such situation the respondent mentioned that the midwives did notice that she did not follow up the ANC. The respondent said that '*... she asked me why I didn't have a paper from the ANC... I told her 'Suk Ellie' [nothing/ I have no reason]...*' After the child birth Interviewee # 3 pointed out that she was only notified, not asked for authorization when her blood was drawn for an HIV test. In her own words:

'... Immediately after the child was out of my womb, she [midwife] took blood from my hand and told me that it is for HIV test'. (Interviewee # 3)

Likewise, the experience of interviewee # 14 illustrates the stark realities of HIV testing procedures at delivery rooms as follows:

'... it was at night and the Red Cross [Ambulance] brought me here [hospital] ... they [health care providers] put me on the delivery coach immediately ... then one of them she wanted to check my blood if in case I have it [HIV]. I already knew she will take my blood any way whether I said yes or no. It won't make any difference ... so I said Ok. They tested it but they did not tell me my test results instead they simply gave me a tablet and told me I should swallowed it. I did as I was told ... after a while the baby came out ... then that is when they told me that I have it [HIV positive result] ... right there when I was on the delivery coach...' (Interviewee # 14)

Other respondents were adamantly clear that they did not desire to test for HIV but ended up taking the HIV test at the labour wards mainly due to the lack of information regarding the routine provider – initiated ‘opt-out’ HIV testing scheme. This experience was reiterated by (Interviewee # 7) , who reported that she took up the HIV test offered during delivery because she believed that the only way that the midwives can help her is if they can protect themselves from infection, which requires knowing her HIV status. She explained that:

‘I went to health facility for child birth something that I never done with my previous children.... She [health care provider] asked me if I agree for HIV test... I said YES. What else can I say? ... I cannot expect them [health care providers] to assist me with the delivery without knowing what is in my blood... We all are humans, nobody wants to infected with the disease ... so they have to know what they are handling ... they have to know what is in my blood before they touch me.’ (Interviewee # 7)

A similar experience was recounted by respondent from Ofla who explained she agreed to take up the HIV test offer during child birth because she felt helpless about HIV/AIDS and the antibody testing procedures. She explained her experience in the following way:

‘ ... She [mid wife] asked me if I know my HIV status and I said ‘ No I do not’ she said many things on how I can protect the baby from infection if I tested for HIV and I agreed to the testing because I realized that ‘ Time’ has brought this disease [HIV/AIDS]over us [human beings] and The testing is also something that ‘Time’ has brought ... there is nothing one can do about it..... It is ‘Time’ that decides everything ... so I told her go ahead take my blood and tests it.’ (Interviewee # 21)

Home delivery is highly practiced in Ethiopia. With the intention of drawing more women to health facility for ANC and skilled birth attendance the government has cracked down on traditional birth attendants (TBAs) and hence the TBAs are not permitted to assist pregnant women to deliveries their babies at home. The quotes below capture the above dimension well:

'These days no one volunteered to assist you for home delivery. People fear of HIV infection so no one comes to help you. The local administrators are also saying that they will impose a fine of 500 birr [~15£] on any one who assisted home delivery in any way and women in my village have stopped giving birth at home because they know no one will assist' (Interviewee # 7)

'Together with the HEWs we have lists of pregnant women in the villages and the records when they are expected to give birth. The wish of the government is clear for every body ... that no woman should give birth at home. Everybody, the local administrators, the WDAs, women's associations, the HEWs and ourselves ... we all are working towards this goal [Reduce home birth].' (Nurse, Ofla)

6.3.2 During Labour Pain Women do not Refuse HIV Testing

Data collected from the interviews with the health care providers who participated in this study revealed that the saying *'Women in labour pain do not refuse testing'* was commonly shared statement among them. For instance the midwife from Mekelle hospital noted that;

'... I do not know if it is a deliberate decision or not but from my experience women in labour pain do not decline HIV testing.' (Midwife, Mekelle)

Similar expression was reflected by a nurse who participated in this study as the following exchange with the midwife in Ofla district captures it:

Researcher: *What if a woman refused to be tested for HIV expressly?*

Respondent: *She won't. Women in labour do not decline any offer for HIV testing. It is only during pregnancy that sometimes women refuse to test for HIV but if it is at the time of delivery they do not refuse because they care a lot for their child to be born healthy.*

Researcher: *Let us say the above scenario happened, so what would you do in such case?*

Respondent: *That is very difficult to say. So far we have never come across of such women in this health centre. Such things can never happen here.*

However, the staffs in Mekelle hospital labour ward seems to have much more clearer strategy and practice when they are faced with strong resistance for HIV test by pregnant women in the labour ward.

'From experience what I have learnt is that it is mostly a woman who already knew that she is infected by the virus or suspect herself to be so that refuse HIV testing . What I usually do is I do not give up on her so quickly when she refuses the testing... it could even take me the whole day ... but I convince her at the end of the day for the HIV test ... most of them [women in labour] at the end they do agree ... but if in case one still remain stubborn and refused after all the talking and convincing then I report her to the head nurse.... and I never came across a woman in the labour ward who refused an HIV antibody test offered by the head nurse.' (Midwife, Mekelle)

The midwife continues to note that:

'The only scenario that we [health workers] let a woman to have to child delivery without performing the HIV testing is when we are out of stock with the testing kits ... in such cases there is nothing we can do about it except helping the woman to deliver her baby safely.' (Midwife, Mekelle)

The above statement was also echoed during the interview made with health care providers in Oflla district. A male midwife who participated in this study used the term '*Be fitsum*' to connote '*That can never happen*' in responding if there was any woman who was given child delivery service in the health centre without screening her for HIV infection.

On another note, securing husband's permission was also reported as a reason for some women in the labour ward to refused HIV testing because such decision has to come from husbands. In explaining how sometimes it could get difficult for women in labour to make decisions of their own regarding HIV testing the midwife in Mekelle hospital said that:

'Some men also prohibit their wives in labour wards from taking HIV test. When we asked the women for the HIV test they tell us that we first need to secure permission from their husbands ... sometimes it can be very difficult [making the husband to agree for the HIV test] ... Some husbands would say that it [HIV test] is not necessary ... they have not done it with the previous children and there is nothing new in their marriage. It can get very difficult sometimes, you know. But at last we always manage to convince the husbands to test for HIV as well.' (Midwife, Mekelle)

6.4 The Patient Practitioner Relationship in the Context of HIV Testing

Throughout all the interviews with the health care providers who participated in this study, the commonly used term to refer to women who refused an HIV test offered was '*Embitegna*' which literary means 'disobedient'. The mechanisms and strategies employed by health worker in handling '*Embitegna*' women and pressurizing them to test for HIV will be identified and explored in the following section as indicated by the research participants.

In the rural settings, participants mentioned the existence of special referring system where the HEWs would advise the women who refused HIV testing during their door to door visit in the villages to consult higher practitioners in the health centre, namely the nurse and midwives. In such cases the health extension workers send a 'Yellow Card' with the patient to give the message to the nurses and midwives in the health centre that the patient holding the yellow card has refused HIV testing though a lot of effort has been done by the HEWs. Hence, the health workers in the health centre will now be ready to exert more effort in convincing the woman to take up the testing. This practice was described by a nurse in Ofla as follows;

'If a woman from the villages brings with her the 'yellow card' it is a signal for us [health care providers in the health centre] that the woman is 'Embitegna' ... so we take our time to give her adequate education on the benefit of HIV testing for herself and the baby ... at last she agree for the test ... in that way we put strict control to make sure that no opportunity to prevent paediatric AIDS is missed'. (Nurse, Ofla)

The other mechanism that was explained by the HEWs when they encountered a pregnant woman in the villages who declines HIV testing is that of the reporting system to the local administrators. The HEWs are required to make it known not only to her direct supervisors in the health sector but also to the local administrators of the area that a particular woman has refused the testing.

'... if women refused the testing we go to the extent of notifying the local administrators that a woman named so & so, a wife of so & so ... has refused the testing ... and we ask the administrators to help us with their leadership ... and we go to her house with these helping bodies including the representatives of the Tigray Women Association ... we mobilize all these people to make sure that all pregnant women are tested for HIV.'
(HEW₁, Ofla)

During the year when the field work took place the health care providers who participated in this study from Ofla mentioned that there were only two pregnant women who refused HIV testing in their health centre. According to the midwife from Ofla of these two women, one is still pregnant and she was 'repeatedly' offered a test for HIV but according to the midwife *'... she said she will not take HIV antibody test unless some kind of miracle happened.'* However, even with her clearly expressed refusal for the test the midwife noted during the interview that they have managed to take her blood under the guise of other blood testing and learnt that she is infected with the HIV virus. When asked what they are planning to do with the HIV positive test results that they obtained without the consent and knowledge of their client the midwife responded by saying:

'... we hope she will come for her next appointment [ANC visit] ... but if she did not, we know where she lives ... we have a plan to visit her house.' (Midwife, Ofla)

I also learned about the other 'Emibitegna' pregnant woman who I was told has already given birth at the time of the field work of this study. The midwife from Ofla narrated the story as follows;

' The other woman persistently refused the testing claiming that her husband will abandoned her if she tested positive ... she also knew that we will caught her [force her] for an HIV test during child delivery if she came to our health centre ... so she went to Maichew [the nearest bigger city] instead with the aim of avoiding HIV testing. But since the policy is the same everywhere, the midwives in Maichew hospital tested her and the result showed that she is HIV positive ... they gave her a medication for herself and the baby ...However by the time she was discharged from the hospital she left all the medication behind ... even the HIV medication for the baby. Immediately we were contacted by the Maichew hospital and we took another medication to her house.'(Midwife, Ofla)

In the urban settings, although the pressure on pregnant women might not equate to their counterparts in the rural setting: the imbalance of power relation among the patients and practitioner in the context of HIV testing is visible. The following extracts from the observation field notes illustrate how difficult it could be for some women to feel assertive enough in expressing what they want and did not want in the context of HIV testing. For example in the case of one of the pregnant woman who came in and sat on the chair quietly without any one caring to welcome her, she tried to express her refusal to the HIV testing with an objection that looks to me as a premeditated one but it was not good enough to be considered by the nurse. The pregnant woman gave up and agreed for the HIV test. While the nurse was still standing right in front of the setting patient, the patient- practitioner conversation continues as follows:

STAFF: *How long have you been pregnant?*

PREGNANT WOMAN: *Three months.*

STAFF: *Are you married?*

PREGNANT WOMAN: *No (after silence)... we are not married.*

STAFF: *Why did not he accompany you here [hospital]?*

PREGNANT WOMAN: *Silence*

STAFF: *He should have come with you. ANC is about family health.... we expected women to bring their husbands or fathers of the babies with them to the ANC at least once.*

PREGNANT WOMAN: *We do not live together.*

(The nurse started to be busy with some paper work while standing right in front of the sitting patient and then fetches the testing tools and put across the table closer to the patient.)

STAFF: *I will check your abdomen soon to see how your baby is doing -- emm-- however before that you know you have to test for HIV? Have you done it before?*

PREGNANT WOMAN: *I have already taken the test.*

STAFF: *Where? In this hospital?*

PREGNANT WOMAN: *No, somewhere else.*

STAFF: *But you have not taken the test in this hospital so I need to take your blood for the test (she already has the sharp tool in her hands)*

PREGNANT WOMAN: *Silence and looking down.*

STAFF: *Your fingers please.*

PREGNANT WOMAN: *She reluctantly gave her finger with a frown on her face.*

(While the nurse is putting the blood sample on the lab glass carefully the other nurse asked the patient to get up on the couch for physical examination and I was not able to see her face any more.)

This extract from the observational field notes clearly illustrates not only how information on the benefit and consequences of HIV testing is not provided as required by the 2007 PMTCT guideline but also how refusing HIV testing is difficult for pregnant women in ANC due to the patient/ health practitioner power imbalance at the maternal health care settings. Furthermore, during the interview with health care providers regrets were also shared that the legal system is not helping in prosecuting women who give birth with unknown HIV status.

' There is this woman I know who gave birth at home to avoid HIV testing against all the medical advice given to her. what do you do about these women who constitute 1 or 2 out of the hundredth ... she [the woman who gave birth without testing for HIV] was not jailed for this ...such act does not have a punishment by the law... even if women do have the right to make decision on their life, they should have been criminally liable for the life of the child... but there is no law for such acts ... This is the problem with the legal system.' (HEW2, Oflla)

I was also interested to learn from the interview with the HEW that to punish a woman who does not comply with the medical advice during pregnancy and child delivery, her husband was forced to resign from a public office.

'There was this man who was serving as one of the executives in the local administration ... but he and his wife refused HIV testing and she also gave birth for two children at home ... so far we do not know if children are infected with the virus or not because they refused testing ... in such cases what do you do there is no law that govern such act ... as a punishment the husband was made to resign from the public office. He cannot serve as a model citizen and lead the public if he keeps allowing his wife to give birth at home.' (HEW1, Oflla)

The recommendation of 'punishing *pregnant women who refuse HIV testing*' was also mentioned during the interview with key informants in Mekelle hospital.

'What do you do with this women who refuse testing while they know that they are already infected with HIV... we have come across women in our labour wards who hide their ARV in bags away from husbands and relatives while decline HIV testing ... there are women who leave behind the medication that was given to them to protect the new born from HIV infection on the hospital bed when they leave ... and continue to breastfed their newborns even though they were educated what they should and should not do to protect the child. What do you do with these women? They should be jailed? This is a serious problem and there should be a solution for this. (Midwife – Mekelle)

6.5 Report of Avoidance of Clinics for Fear of Being Tested

Fear of being pressured to take up HIV testing by women attending maternal health care services can make some women avoid seeking medical attention. Among the women in my sample who tested during delivery, several report the avoidance of medical attention due to fear of HIV testing. The following quotations from participants capture the above assertion well:

'... I never get back again near the hospital for another ANC visit or any other reasons ... until the child delivery. ' (Interviewee # 3)

'... I was very sick during my pregnancy but I have never been to the clinics ... I did not even do the monthly visit [ANC visit]...I just did not' (Interviewee # 23)

'I did not come for the pregnancy examination [ANC] ... I came only for the child delivery' (Interviewee # 14)

'... I started to follow up the ANC just the way I did in my first pregnancy ... but the nurses kept asking for HIV test even if I told them [Health care providers] that I will think about it and let them know ... and at last I dropped going for checkups all together until the day I was in labour pain ...' (Interviewee # 26)

The straight forward response commonly shared by the respondents as to why they avoided the ANC was just '*Suk Eile*' which could literary could be understood as 'I do not have a reason' even though the term is also commonly used by native Tigrigna speakers like myself when one do not want to answer the question directly. The term '*Suk Eile*' could be taken as a means of cooperating with the interviewer while avoiding a difficult admission or avoiding directly providing false information. As the conversation progress respondents started to get back again to the question of why they avoided the HIV test. Accordingly, Interviewee # 14 who reported that she attended ANC clinics during her three previous pregnancies but not with her last pregnancy said that the main reason she ended up with unknown HIV status to the delivery room was because she avoided ANC due to fear of the HIV test. She said:

'...I used to hear that even at the pregnancy examination [ANC] they [health workers] force pregnant women to test for HIV... I was fearful that I will also be forced to test for the virus [HIV] so I remained at home until the end [delivery]...I did not come here [hospital] for any checkups.' (Interviewee # 14)

She continues noting:

' .. but all these time of my pregnancy , I was worried that during child delivery they [health workers] will stand on my neck to force me to take my blood for HIV test ... I used to worry a lot and felt that I was wasting my time for nothing ... ' (Interviewee # 14)

Similar ideas were reflected by Interviewee # 3 who said *'I used to hear from women that there is HIV testing during pregnancy check up [ANC]'. After I did the pregnancy test I never come back again here even to the monthly pregnancy examination [ANC]... except for the child birth.'* Interviewee # 23 also related her experience to the story of avoiding medical attention during pregnancy to avoid HIV testing. She reflected:

'This is my second marriage. My first husband divorced me because I was not able to conceive a child ... So you know we [with her husband] used to argue on that a lot ... when I suspected my body that I might be pregnant I went to the hospital to take the pregnancy test and I was told that am pregnant and also informed about the benefits of HIV testing, attending the ANC and giving birth at health centre ... I agreed to take the HIV test on next appointment [ANC visit] ... but I never went back again.' (Interviewee # 23)

Researcher: Why not? What was the reason?

'Back then I was not sure what I would do if I have the disease. ..You know when you are with a second man [husband] it is difficult to know from whom you got it [HIV infection] ... So I stayed at home during pregnancy. It was only when my labour was prolonged that my husband brought me here [hospital] and they tested my blood for HIV.' (Interviewee # 23)

Likewise, Interviewee # 19 reported that almost immediately after her HIV positive test result was communicated to her while she was waiting in the rural health centre for the onset of her labour she said that she regretted not only taking the HIV testing but also the whole idea of giving birth at health facilities. In her words:

'I was not able to stop asking myself why in the first place did I went there [health centre]? Why did not I just give birth to my child at home like my mother's? ... For many days I was not able to stop asking my self... I regretted it very much.' (Interviewee # 19)

Such avoidance of clinics for fear of being tested was also mentioned during interviews with key informants. As captured in the quote below the midwife from Mekelle appreciated the problem of women avoiding medical attention during their pregnancies to avoid HIV testing but added that things are improving these days:

' Women used to avoid institutional delivery for different reason including fear of HIV testing ... but nowadays because of the campaign on maternal mortality more women are coming to health institutions for safe child delivery ... these days people have learnt a lot , even if they tested positive they now know that they can still continue to live ... they know if medication is taken the child can be protected ... so generally people are much aware now than ever on safe delivery and HIV testing ... ' (Midwife, Mekelle)

The HEW in Ofla district who participated in this study, although they shared similar views noted above on the increment of awareness of women and the public in general, reported similar experiences regarding their clients, that fear of being tested for HIV is becoming the '*new reason*' for home delivery.

HEW₂ from Ofla shared her experience about a certain woman who avoided ANC and delivery in health facilities so that she will not be tested for HIV.

'... There was this woman who during pregnancy we [HEWs] tried to convince her a lot to take the HIV testing ... she stubbornly refused ... we even involved the local administrators...they went to her house and talked to her.... but she made it clear that it is her life and only her makes the decision ... at the end she gave birth at homeand there was nothing we could do about it ...up until now we do not know if she has delivered a healthy child or not' (HEW2, Ofla)

Another HEW from Ofla district also shared her similar experience as follows;

' I know a woman who was prohibited from going to health post for delivery by her mother- in- law ... actually the woman delivered at home with the help of the mother – in – law ... the reason for the mother – in- law to prohibit her from seeking health professionals help during delivery was to protect the secret of her son if in case the woman is tested positive for HIV ... we know that the woman has delivered safely but we do not know if her child is infected with HIV or not...' (HEW3, Ofla)

I was also told similar story by the third HEW who participated in this study. The story was about a threat of attack against a HEW who happened to be a colleague to the story teller. In the words of the HEW:

' ... She [her colleague HEW] went to her [Client] house immediately after we [the HEWs] learnt that she is pregnant to provide her some medical advice in person on the benefit of ANC, HIV testing and delivery in health facilities ... But she made it clear that she will not take any of the medical advices given to her. My colleague did not give up hope easily and continue to visit her in her house ... and one day she [Client] told her

that she is unwelcomed in the house and threatened her not to come again. She made it clear that she wants to left alone ... at the end she gave birth to her baby at home without taking any HIV testing... and we do not know as of yet if the baby is infected or not... '(HEW2, Ofla)

According to the health workers who participated in this study, the avoidance of medical attention during pregnancy and child birth is even now readily associated with fear of HIV testing and avoidance of medical attention during child birth. This means that the public assume (sometimes wrongly) that women who give birth at home are suspected of HIV infection but those who give birth in health institutions are not. HEW₃ articulated her argument as follows:

'... It is easy for people to assume that if an expectant mother gave birth at home then there must be something that she wants to hide ... It is just like how it was with breast feeding, if a women did not breast feed her new born child everyone automatically assume that she tested positive for HIV ... a mother avoiding institutional delivery is suspected of something that she wants to hide and not to be found out by the health care providers.. That she could be HIV positive and don't want people to know about it'. (HEW3, Ofla)

Consequently the women in the community, friends and relatives are cautious about participating in cultural child birth rituals if they happen to know that the mother is HIV positive or just suspect as mention above. In Ethiopia, specifically in the state of Tigray there are many cultural rituals conducted mainly by women during child birth. One among these rituals is *Geleb*, which at the seventh day of giving birth women in the neighbourhood and relatives come together and wash all dirty clothes in the house and at last they eat special food called *Geat*. The whole process of the *Geleb* is very colourful

because the women sing and dance as a thanks giving to St. Mary for allowing their friend or relative to give birth safely. The washing of the dirty clothes in the house is also about helping the mother to take a rest without worrying about the house chores, which normally is the responsibility the woman in the house. However, this important and colourful ritual is now being challenged with HIV/AIDS that women are reserving themselves from participating if they suspected that the mother could be affected by the virus.

What is making the health extension workers worry is the new practice of using the 'place of delivery' to speculate whether a woman who gave birth to a child is an HIV positive or not. In the wordings HEW₃ *'Such thinking always worries me a lot ... in realty even those women who gave birth at the health facility could also be diagnosed with HIV infection.'*

6.6 Conclusion

As discussed under chapter one and other previous chapters in this thesis the prenatal routine provider initiated 'opt-out' HIV testing approach is an approach in which the pregnant woman is tested for HIV unless she expressly decline it after the pre-test information is provided to her during her visit to maternal health care services. It also been shown under chapter three that this testing approach has posed concerns that it may pave a way for the erosion of human rights and ethical principles related to HIV testing unless an enabling environment is created for pregnant women to make decisions for themselves freely and voluntary. This chapter explored the process of decision making for the HIV testing offered at the ANC or labour wards in order to have better understanding of how and why these decisions are made by the women who participated in this study.

Accordingly, findings presented in this chapter indicate that practical application of routine provider initiated 'opt-out' HIV testing approach in maternal health care settings in Ethiopia do not create an enabling environment for pregnant women to make an autonomous informed decision whether to take up the HIV testing or not. The fact that health care providers initiate HIV testing to pregnant women sends a message to women in my sample that HIV testing is a prerequisite for obtaining any maternal health care services during their pregnancies.

In addition, many were convinced that refusing the offer during ANC is meaningless as they strongly believed that the test will be imposed on them during child delivery as testing in labour ward is no more optional. Furthermore, the unequal power relationships between women and their health care provider limit women's ability to decline the test or defer testing until they feel more ready to deal with the results for the fear that their health care provider may react to them negatively for doing so. Routine 'opt-out' HIV testing approach is likely to undermine the trust between pregnant women and their health care providers, which in turn can cause pregnant women to avoid seeking medical attention if they feared that they will be pressured into having a testing against their wishes.

The following chapter explores the lived experience of the HIV positive research participants in relation to HIV- related stigma and violations of individual rights guaranteed in numerous human rights instruments.

CHAPTER – SEVEN

FINDINGS - CONFIDENTIALITY, DISCLOSING AND SOCIAL CONSEQUENCES OF POSITIVE HIV RESULTS

7.1 Introduction

The previous chapters presented the findings relating to the experience of women during the counselling session and the process of informed consent before the HIV testing. The argument that routine provider initiated ‘opt-out’ HIV testing approach will encourage more and more people to ascertain their HIV status and hence contribute to the reduction of stigma and discrimination associated with the epidemic was canvassed by proponents of the testing approach. This argument is also echoed expressly under the 2007 Ethiopian PMTCT guidelines. The guidelines states that ‘... compared with other approaches, routine provider-initiated HIV counselling and testing using the ‘opt-out’ approach for all pregnant women has resulted in greater acceptability, increased opportunity to prevent MTCT, and *minimized stigma...*’¹ (Emphasis added)

However, this chapter did not aim to measure the extent of the HIV related stigma and discrimination however it documented the stigma experienced by the women who participated in the study following their positive HIV diagnosis under the PMTCT programme. The chapter shows that the ‘opt-out’ HIV testing approach do not necessary address HIV-related stigma and intimate violence against women as contended by the PMCT guideline of the Ethiopia government. The chapter reveals the lived experience

¹ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother –to-Child Transmission of HIV* (Addis Ababa, 2007) 11.

of the research participants in relation to HIV- related stigma and violations of individual rights guaranteed in numerous human rights instruments of the women tested positive.

The findings of this chapter therefore address the fifth and sixth objectives of this study:

- *To determine the extent of the burden to disclose HIV positive results of the pregnant women and to assess the respect for confidentiality by the health care providers;*
- *To determine on the negative consequences of positive HIV test result in the lives of the HIV positive women and their coping up mechanisms.*

The chapter starts by presenting the reports of participants' experience of being diagnosed HIV positive during their prenatal HIV testing. The second section draws mainly on data that focuses on women's experience of disclosure of their positive HIV test results to their husbands, significant others and to the public. The third and fourth sections present the consequences of the disclosure of the positive HIV test result in the community and within the house which can be understood as HIV related stigma and intimate violence against women. The last section of this chapter argue that any prenatal HIV testing approach must allow pregnant women to come to her own informed decisions regarding whether or not she wishes to undergo testing after weighing the benefits and consequences.

7.2 Participants' Experience of Being Diagnosed HIV Positive

The emotional experiences of the women who participated in this study revealed that they were unaware of the medical advancement in HIV care and treatment as evidenced by their statements. Almost for all

the participants reported that death was the first thing that came to their minds when they learnt the positive test results: *'I thought I will never survive the next day', 'I kept saying to myself 'so I am dead now', 'every night I used to think that it was my last night', 'I thought I was done, finished and dead'* were some the commonly mentioned phrase used to expressed their feelings.

In addition, other terms were also used by participants to express their emotional experience: *'shocked', 'sadness', 'worry', 'stressed', 'could not stop thinking', 'confusion and disbelief'* ... as it was very difficult for them to accept the fact that they are infected by the virus. Interviewee # 3 who was identified in the previous chapters as the only woman in my sample, who tested for HIV after child birth, expressed her emotional situation as follows:

'...It was at late night that I finally gave birth ... I was still bleeding and tired ... there the midwife came closer to my side and she said I have the diseases [HIV positive] .. it feels like as if someone was cutting my spine with an axe. That is how I felt. I felt like my spine was cut into two... I was so shocked ...' (Interviewee #3)

Several other women have also expressed distressing emotional reactions to the news of positive HIV results. For example:

'... while I was in labour they[health care providers] took my blood [draw blood] and tested it for the virus. They found it in my blood [tested positive for HIV antibody test] ... They now told me that I have it [tested positive] before I gave birth ... and I was really shocked ...I thought I have gone crazy and my mind was not stable at all.'
(Interviewee #7)

' When they told me that I have it [tested positive for HIV antibody test] I was immediately changed into a lunatic ... I can see people talking but I cannot hear them ... I was not understanding what people were saying ... It seemed like I was dead , I stopped feeling anything ..' (Interviewee # 14)

Thinking what would eventually happen to their children when they die was most hurtful emotional distress as expressed in the quotes below:

'The first time I discovered my status that I am HIV positive, I thought I would die immediately. I worried a lot about dying ... about my children losing their mother... I was very concerned about who will look after my children when I die...' (Interviewee # 5)

'When I was communicated on the test results I was shocked and I thought I would die soon I cried and cried for my children,' (Interviewee # 2)

' .. I thought I was dead ... I felt sorry for my kidsI cried for them. I cried a lot. Leaving behind my children was what made to cry like that. It was not for me. It was for my children...' (Interviewee # 7)

In contrast, few participants reported that the positive HIV test result was not a surprise to them at all. Interviewee # 16 reported that *'I was not surprised'* and as she explained this was mainly because *'... my first husband was quite sick for long time before he died ... He never get tested but I was always suspecting that it could be AIDS that killed him.'* Similarly, interviewee # 15 reported that she was not emotionally disturbed and this was due to a family tragedy that at the time of testing she was mourning over the death of her son due to cancer. In her words:

'The test result did not bother me at all ... I said to myself so what? My son died of a disease that does not have treatmentso it was not a big deal whether am alive or dead ... I did not care that much.' (Interviewee # 15)

7. 3 Disclosure of Positive HIV Test Results and its Social Consequences for Women

Unravelling women's experiences of disclosure HIV positive results to their husbands is important to understand the social and legal consequence of positive HIV test result under the routine provider initiated 'opt-out' HIV testing approach. This section of the chapter examines whether or not the women who participated in this study disclosed their HIV test result to someone by analyzing to whom, how it was done, how long after the positive HIV test result and the response of the person or persons to whom the test result was disclosed. The study also collected information about the type of individuals to whom the respondents did not wish to disclose their test results and examines the implications of it.

7.3.1 The Process of Making the Decision to Disclose

All the women who participated in this study except for one participant have disclosed their positive HIV test results to their husbands voluntarily or involuntarily. The exception in this case is, Interviewee # 14 who reported that her reason for not disclosing to her husband during the interview period was that he was away from home;

'... he works in Humera [another town in Tigray]...I did not want tell him about this [HIV positive result] over the phone... when he gets back home I will tell him the news and advice him to test and to know his HIV status for himself.' (Interviewee # 14)

I. To Whom Did You Tell?

Most of the participants have kept their HIV status secret and only disclosing it to specific people whom they have trusted to keep their secret. The situation of keeping HIV status secret from the public was described by many respondents reporting that *'I have not told anyone'* (Interviewee # 3, 4, 5, 12, 16, 30, 29, 26). Similarly, Interviewee# 3, 13 and 14 said *'... not single person knows.'*, *'... in my neighbourhood people do not know that I am HIV positive.'* and *'... outside health workers nobody knows...'* respectively.

Interestingly but understandably, many of the respondents did not want their in-laws to know about their HIV status. This could mainly be due to the fear that disclosure to relatives of spouse risks accusations of infidelity and promiscuous behaviour. Hence interviewee # 1, 5, 6, 7, 9 and 12 all reported that their in-laws (*'his family'*) were not told about the situation though some respondents mentioned that the information was hidden from both the in-laws in both families.

'We [the respondent and her husband] did not tell any one ... not his family not mine ... for the time being that is what we have agreed but I feel that we have to tell them eventually ...' (Interviewee #1)

Although such is the case for many of the respondents, one woman from Mekelle (interviewee#13) reported that she and her husband have agreed to inform her brother-in-law but not her own brothers or any other member of her family. This was unusual but she described him as *'Lebam'* - a reasonable person. She said that she believes it is not a 'problem' to disclose her HIV test result to her own brothers but she felt 'unease' about it.

II. The Timing: When Did You Tell?

Since disclosure involves a process, I also examined disclosure in terms of the time elapsed after testing positive. Accordingly, very few respondents reported that they disclosed the same day they learned about their HIV test results, but others waited for a period of time (ranging I immediately called him n=1); I told him in the same evening (n=3), it took me weeks to speak to him (n=7). Another 7 of the respondents deferred the disclosure until they gave birth to their child and the remaining 8 stated that their husbands were approached by the midwives who disclosed the wives' positive HIV test results and counselled the husbands to test. One respondent had not disclosed to her husband until the time this field work was done.

When did you disclose your positive HIV test results to your husband?	
Immediately (I called him)	1
In the same evening	3
It took me weeks	7
It took me months but before birth	7
Only after I gave birth	3
The midwives informed him immediately	8
I have not yet disclosed to him	1

Table 1: Disclosure time

7.3.2 Reason for Disclosure

I. The Need for Support from Family/Public /Government

Support from Family

Some respondent said that they needed to disclose their positive HIV status because they needed as much support and help as they possibly could get from their community and family. Interviewee # 2, 4, 5, 6, 10, 16, 19 and 23 are examples of participants who reported of disclosing their HIV test results to their mothers while only one respondent (Interviewee#7) reported disclosing to her father, by saying ‘... *my father knows my secrets. I told him on the same day I heard.*’ These finding indicates that the respondents find it easier to discuss their health issues with their mothers rather than father which by itself could be the extension of the reflection of the traditional role of women in the Ethiopian society as care givers.

In general, the dominant reason as to why respondent decided to disclose their HIV status to their blood relatives is that once they become sick and bed-ridden due to AIDS , it will always be the family that will assume the responsibility of taking care of them. The response below from a respondent illustrates her motive for disclosing her status to family:

‘I have told my mother, brother and my children. They all know... I can’t just not tell my mother ... you do not need to tell to people who are not related to you by blood... otherwise disclosing my HIV status to the family is important because at the end it will be them who take care of me when the worst day comes. Who else is going to attend me when I get sick?’ (Interviewee # 2)

Similar story was also reported by another respondent (interviewee#12) that in addition to her husband she said she told her mother because she was advised by the health workers to do so. In her words;

'At first we [herself and her husband] did not want to tell to anyone but they [health workers] told me a lot of things can happen during child birth ... I could die during child birth living my new born behind ... Hence, I was told someone close should know ...and I told my mother who always took good care of me ... no one from my husband's family knows about this. We have agreed to keep it secret from them.' (Interviewee #12)

However, among the women who participated in this study some reported that they did not tell anyone.

'I did not tell anyone' said interviewee #3, who tested during delivery, and added *'... not even my mother, not my siblings, not my neighbours. No one is told.... no one knows.'*

Support from Public/Government

Examples of indirect disclosures were also evident from the reports of the respondents. Women who needed some financial and other support from the government believe that even if they did not purposely tell anyone about their HIV status, people knew anyway. Like for example in the case of Interviewee#11 who said *'... I am member of the association [the association people living with HIV virus]... so everyone knows, I do not have to tell them'*. She thinks it is obvious for people to know that she is HIV positive. Similar response was given by interviewee#18 who noted

'Being HIV positive cannot be hidden ... we [people living with the virus] are known and registered by the 'Kebel' [local administration] and we also get some help from the government on monthly basis. So everybody knows. AIDS is just a disease, it should not be hidden.' (Interviewee # 18)

As an illustration of involuntary disclosure, women from rural areas have more immediate reasons that would force them to disclose their HIV status to the public or to individuals outside the family circle. All farmers in Tigray State are required to participate in community work on soil and water conservation as free compulsory labour. Anyone who absented herself/himself from community work 'on unacceptable grounds' would be punished with a heavier workload than is usually accomplished in a day. Absenteeism due to sickness, pregnancy or travelling to another place for a funeral is normally considered as a legitimate reason for non performance of community work. The sick are required to provide evidence from health care providers, otherwise they will be penalized. In the context of the issue at hand HIV positive women who believe that they are sick and cannot participate in the free compulsory work on the soil and water conservation have to declare that they are HIV positive or face the harsh consequences. This situation was explained by respondents as follows;

'... I have told to every body ... otherwise I will have to go up and down to all the hills to work on the soil and water conservations... and in one hand I have the medicine [ARV] to take and on the other hand I am sick and always feel fatigue ... I just cannot do it [the compulsory work] ...So I told the local administrators about my HIV status...so that I will be relieved from the labour work.... I took the medicine [ARV] with me as evidence for my HIV positive status ...so that is how everybody in my village knew that I am HIV positive.' (Interviewee #15)

'...I am always tired. I cannot work heavy works any more. I do not feel healthy. The administrators understood my problem. I showed them my medicine [ARV] and they said it is ok even if I did not participate in the free labour work.' (Interviewee # 30)

However, the free compulsory works on soil and water conservation do not always make people to disclose their HIV status, as some participants from the rural setting Ofla district reported:

'So far I am healthy and I have no reason to ask for a relief from the free compulsory work on the water and soil conversation due to the disease [HIV]' (Interviewee # 21)

A similar idea was also shared by Interviewee # 7 in explaining that she did not need to disclose her HIV status to the local administrators because she said *'My eldest son covers up the working hours for me.'*

II. Partner Notification and Issue of Confidentiality

The Ethiopian HIV counselling and Testing (HCT) guideline does not in effect prohibit partner notification without the consent of the patient. The HTC guideline states that:

*'Clients shall be encouraged to disclose their HIV status to their partners. When a client fails to disclose positive status to his/her partner for any reason, the endangered partner has the right to know the positive partner's HIV status. In this case, the counsellor must refer the situation to senior staff who will then decide concerning disclosure to the affected partner. The person or institution involved in this way will have legal protection.'*²

² *Ibid* at 5.

For participants in this study who tested during their pregnancies, partner notification was not an issue as none of them reported of being accompanied by their husbands to the ANC clinics and the health workers did not bother themselves to trace the men except advising the women that they should disclose the test result to their husbands. In contrast, partner notification by the medic was an issue in cases of participants who have tested for HIV during child birth in the labour wards. Usually pregnant women are accompanied by their families including their husbands to the health facilities during child delivery. This situation has made things easier for the health workers to contact the husbands with each diagnosis of HIV infection of pregnant women in the labour ward with or without the consent of the women. This practice was expressed by the midwives from both study areas as follows:

' If the woman who came to our health centre found to be HIV positive upon the testing during labour or child birth , immediately we summon the husband to the office and provide him with counselling and he gets access to HIV testing. '(Midwife, Ofla)

'If the woman tested positive for HIV in the labour ward we immediately invite the husband to know his HIV status as well....' (Midwife, Mekelle)

The above practice was also reported by women in my sample who tested for HIV during child delivery.

' After I gave birth , she [midwife] asked him if I am his wife , he said 'Yes' and she asked if she can talk to him privately in office. I do not know what they talk about in the office , only God knows ... but I have my own suspicion that they might have told him my test result so that he will agree for HIV test ... he never told me what happened in that office any way. ' (Interviewee # 3)

'They told him [her husband] to give his blood [take HIV test] ... I think he agreed and he tested HIV positive ...' (Interviewee # 7)

'When he [her husband] came to visit us [the mother and new born baby] at the hospital they caught him [health workers tested him for HIV] ... the result was the same [positive]' (Interviewee # 19)

In addition, the midwife in Mekelle hospital mentioned during the interview that some women in the labour ward ask for their HIV result not to be disclosed to their husbands.

'Some married women ask for their positive HIV test results not to be disclosed to their husbands. They fear that if the men knew the positive result, they will chase them out from the house ... that marriage will be over...that they will leave them. Sometime these are real concerns for women ... You know, especially those women who does not earn their own income it could be difficult situation. However... you know... if this disease is to be eliminated or reduced all fears and worries associated with the virus have to be dropped. HIV results should be made known to everyone. It should not be a secret at all ... that is the only way how transmission of the virus can be prevented.' (Midwife, Mekelle)

Therefore, in situations where the woman strongly objects the partner notifications a mechanism usually employed was explained as follows by a midwife who participated in this study;

'... what we usually do is that we counsel the husband and wife together as if we do not already know the test results of the wife and we counselled them very well as to how they would handle if one of them have HIV infection ... then we do the test for both of them and communicate the result together ...that is how we solve the problem' (Midwife, Mekelle)

7. 3.3 Why the Deferral or Delay to Disclose to Husbands?

I. Fear of 'Violence' or 'Abandonment' by Husbands was not a Factor

The gender dynamics and power relationship between men and women is important aspect of the discussion of disclosure of HIV status and its social context. From literature and research reports women in Africa fear of violence and abandonment for disclosing their HIV test results to their husbands.³ Likewise, in Ethiopia studies shows that women expected their partner to react negatively towards a positive HIV test result.⁴ In this study as presented under section 7.5 of this chapter some participants of this research revealed that they have experienced some forms of violence in the hands of their husbands in relation to their HIV positive results.

However, this subsection examines whether fear of being accused for bringing HIV infection into the family or its consequences like '*Violence*' or '*Abandonment*' was an issue for them to seriously consider before disclosing their HIV status to their husbands. Some respondents rejected the idea right away saying that such fear was not the most important reason behind the decision to disclose or not. The quotes below capture the above dimensions quite well:

'I have been working all my life. I am an orphan my parents died when I was a little girl and all my life I have been working to sustain myself. So I do not need a man to live my

³ See for example J Rujumba et al. 'Telling my husband I have HIV is too heavy to come out of my mouth': pregnant women's disclosure experiences and support needs following antenatal HIV testing in eastern Uganda, (2012) 15(2) *Journal of the International AIDS Society* 1-10. Available online at:

<http://www.jiasociety.org/index.php/jias/article/view/17429> [visited on 2 September, 2014].

⁴ M. Malaju and G. Alene 'Women's Expectation of Partner's Violence on HIV Disclosure for Prevention of Mother to Child Transmission of HIV in North West Ethiopia'(2013) 6(93) *BMC Research Notes*. Available online at <http://www.biomedcentral.com/content/pdf/1756-0500-6-96.pdf>. [Visited on 1 January, 2014].

life ... if he [her husband] wants he can leave any time. I have never feared of being abandoned... that is not a problem to me. (Interviewee # 14)

'It was not that I feared that he might leave. That won't bother me... if we are not meant to be together he can leave any time ... fear of violence was not a reason for me...' (Interviewee # 12)

'That kind of fear was not in my mind ... I never feared he will be aggressive by the news [positive HIV test result].' (Interviewee # 1)

'... I was not feared of any thing ... I was rather angry ... at that time I really wanted him to leave' (Interviewee # 4)

This finding of the study was a surprise but as the discussion with the respondents goes on many of the women including some who made the above statement have reported that they themselves have suffered some form of accusation/violence/ abandonment in the hands their husbands in relation to their HIV positive test results as shown under section 6.5 of this chapter.

II. Anger and Resentment due to Sense of Victimization

Most of the respondent considered themselves as 'victims' of HIV infection by their husbands. Hence the discussion of why the deferral of disclosure of HIV positive results to husbands or delayed it for some quite time was mainly revolved on emotions of resentment and anger that originated from a belief that the husband brought the diseases to the family. A respondent from Ofla, Interviewee #30, states that '*... from where did I get ... he brought the virus to the house...I did not get it from nowhere.*'

Similarly a respondent reported earlier that her marriage was already having a problem because of her husband's sexual affairs with a woman in her neighbourhood, said that

'.... he brought the disease home .I have been married to him since I was 16 ... the virus did not come from the sky ...he brought the virus home.... I did not see it coming... I did not suspect this could happen... He infected me. ' (Interviewee #1)

Likewise, another respondent said that it took her weeks to tell her husband the positive HIV result of her testing because she was so angry with him and did not talk to him for many weeks. In her words:

' I completely stopped talking to him ... I do not even look at him for weeks and weeks ... and when we lastly talked I accused him for bringing the virus to the house. I was so sure he brought the virus ... from where else could it [HIV] come... ' (Interview #4)

A similar sense of victimization was reported by interviewee #18 as well:

'I thought I would be dead that night ... I was angry that he infected me with the Virus ... I told him on the same night and I was shouting on him to leave me alone and to leave the house ... I told him that I do not need him any more ... he called my sister and she bought peace to the house ..'(Interviewee # 18)

Interestingly, more or less similar reasons were also forward by the respondents who reported of disclosing their positive HIV test result to their husbands on the same day. A respondent from Mekelle who got tested for HIV during her ANC visit said that she called her husband immediately after she was told her positive HIV test results.

'I was sure that he brought the virus and I was very angry and could not wait until I go home.... and called him over the phone immediately and accused him of infecting me with the virus. I called him all the names that I knew....' (Interviewee # 4)

'When I went back home ... I told him everything on the same night. I told him that he killed me and that he should be happy now He said many things but it was no use ... he is the only man that I know in my life ... He brought the virus for me.' (Interviewee # 29)

In addition, husbands who already know that they were infected with HIV before their wives were made to take the HIV test in relation to pregnancy do not react violently to their wife's disclosure. The following quotations from participants appear to support this:

'I was in a huge shock with the result [HIV positive result] and on the same evening I told my husband the news ... he first kept quiet and later told me we shall help each other ... He then told me that he is also HIV positive . . . When he told me that I even felt worst and I could not stop crying for quite long hours ... I was annoyed with him for infecting me with HIV. ...' (Interviewee # 20)

III. To Avoid Argument of 'Who Brought the Virus Home?'

On the other hand there were also some respondents who expected some argument with their husbands upon disclosure of the positive HIV results and they delayed the news until the right time. A respondent from Mekelle described her reason as follows;

' ... I was already very sad by the news and I did not want to bring another argument as to who brought the virus to the family ... the pregnancy and the worries of HIV positive test result were already a lot to handle for me ... so I kept the test results for myself until I gave birth to my daughter. ' (Interviewee # 27)

The current study found that disclosing positive HIV status to husbands was particularly difficult to women who were in their second marriage during the interview. A respondent who reported that she lost her first husband during the border conflict between Ethiopia and Eritrea said that:

' It is not easy when you are with a second husband ... I was especially worried what my – in- laws would say ... that they will accuse me for bringing the virus ... so it was not easy at all to tell him that I tested positive and I kept it for myself until I gave birth ... After my daughter was born safely I accused him of infecting me with the virus ... he did not point back on me ... maybe he did infected me or may be my first husband did... these things are hard to find out ' (Interviewee # 9)

A similar experience was recounted by Interviewee#12 who said that, *' ... I was worried a lot as to what he is going to say about it...'* and added *'...if you are in the 1st marriage you know where you got the virus ...in second marriage such things are more complicated.'* The delicate situation of women in second marriages in relation to disclosing positive HIV results was appreciated by other respondents as well. For instance, Interviewee # 15 considered that she was not worried to disclose her positive HIV test result because:

' I did not have such fears of accusation or violence.... because such arguments happen when the woman is not with her first husband.... am still married to my first husband ...'
(Interviewee # 15)

7.4 Experiencing Social Exclusion and HIV Related Stigma in the Community

The participant women had only recently been diagnosed for the HIV positive (maximum of one year) and hence they have relatively short period of time in which to observe and report HIV related discrimination and stigma. Nonetheless, findings from this study suggest that concern over stigmatization upon diagnosis with HIV is still profound. Information was given by participants in relation to the stigma and discrimination they experience ranging from loss of friendships, rejection, negative reactions and people not wanting to be near them.

One respondent shared her experience of stigma by her landlord and the response of the local administrators against the landlord, though one still can question the legality of the local administrator's action. In her words;

'Once I was rented a house from a lady who has no clue as to who I am. One day I think somebody told her that I am positive and she now asked me to leave her house immediately before I infected her small children ... I tried to beg her to give me some more days until I find another house to rent but she insisted that I should leave immediately.... I complained about the situation to the Kebele [Local Administration] ... they put her in jail for days... in the meantime I found a house and I moved in there...'
(Interviewee # 2)

Similarly, interviewee # 13 recognized that there exist HIV–related stigma in the society even though she believes that *'... there is a progress in attitudinal changes it is much better than ever.'* However, even if she believes that stigma is better she also revealed that she has disclosed her status to no one in her neighbourhood for fear of stigma including to her land lords. She said *'... I myself live in house rent and I have not told my landlord anything about my HIV status.'* Likewise, interviewee #4 also has revealed her experience that she was once asked to give an explanation about her HIV status by her landlord *'...My landlord she asked me once if it is true that people are talking that I have that thing (HIV Virus) ... I told her, it is all a lie and I am free from the virus.'*

Similar stories were recounted by other participants as well as quoted below.

'...they gossip a lot of things about me ... but they never say it on my face ... I remained quiet ... because we [People living with HIV] ourselves used to do so to other people before we knew that we are infected by the virus...So yes it happens.' (Interviewee # 27)

'In my community I know many women saying and doing a lot of bad thing about people living with virus just to hurt their feelings ... I usually try to tell them what they said was wrong ... or they should not do this or that ... but without telling them that I live with the virus too.' (Interviewee #13)

Another commonly mentioned HIV related social exclusion and stigmatization experienced by the respondents is in relation to the cultural child birth ritual of *Geleb*.⁵ In the words of one respondent:

⁵ A brief description of the cultural child birth ritual of *Geleb* is provided under chapter six , section 6.5 of this thesis.

'Of course there is still stigma. People do isolate you if they suspect you are HIV positive. For instance, on the seventh day I invited my neighbours for the 'Geat' [to eat the porridge like food] as the custom requires... I didn't even want them to do the 'Geleb' [the washing] ... I already have washed everything by myself beforehand ... but nobody come to my house ... They didn't want even to eat my 'Geat'. That is very shameful... They thought if they eat from my house they will be caught by the disease.... it is their ignorance you know.' (Interviewee #15)

However, for interviewee #7 her disappointment was much less because her neighbours actually showed up for the 'Geleb' but she said '*... they asked me just give them clean clothes and they washed it [the clean cloth] for the purpose of fulfilling the culture ...*' Interviewee #7 emphasised that at last '*... they also eat the 'Geat', drink coffee, played and danced until late afternoon. They have done everything for me.*' In another story by interviewee #4, when the neighbours and friend show up on the seventh day, she took the initiative herself and gave them clean clothes and successfully avoided the discussion of what to wash or not. She said '*... My neighbours came for the 'Geleb' ... I quickly gave them clean clothes from the closet to be washed ... nobody asked why.*' Interviewee #4 also emphasised that '*... at last all the women eat the 'Geat.'*

Respondents took an action to conceal their HIV status from the public commonly by choosing breastfeeding to ensure that they are not identified as being HIV positive.

'Since I breast feed my child they [people in her circle] did not suspect that I have it [HIV positive] ... they usually tells me that I have given birth to child who looks like an angel.' (Interviewee # 4)

Respondents who do not breastfeed are subjected to suspicion of being infected by the virus.

Interviewee#1 who did not want to tell anyone outside her husband about her HIV status said that:

‘ I did not breastfeed my child ... I use formula milk ... my mother-in –law has observed this but has not said anything so far about it ... I believe she has already suspected...’
(Interviewee #1)

The isolation and exclusion have huge impact on some of the respondent’s livelihood specially those who have lower economic status. The following comments offered by a respondent captured the range of experiences by some women who faced HIV related stigma;

‘I used to earn money by making ‘injera’ [local food] and ‘Metka’ [ingredient for home made beer] all my life.... now nobody buys my ‘injera’ any more. I now totally depend on the support from government to feed my children.’ (Interviewee # 3)

7.5 Positive HIV Result and Intimate Violence against Women

The direct equivalent of the word violence in Tigrigna is ‘*Tikeat*’ even though the word ‘*Tikeat*’ may also be used to implicate some kind of victimization or weakness. The women who participated in this study were quick to disassociate themselves from experiencing violence in the hands of their husbands in relation to positive HIV results. This is probably due to the above mentioned usage of the word ‘*Tikeat*’ and its automatic implication in portraying women as victims those participants did not want to be associated with any kind of weakness. But as conversation goes on the participants were more

inclined to recognize that they experienced many of the forms of violence like arguments and chaos in family (*Chikichek*), insult (*Tserfi*), abandonment (*Hadiguni Keyedu*) and quarrel(*Mikueray*) without necessarily admitting that they were victims of violence. However, none of the participants in this study reported physical abuse by their husbands in relation to their HIV status.

7.5.1 'He Has No Reason to be Violent'

For some women who participated in this study their relationship with their husbands remains intact after their HIV positive test results. Interviewee#1 for instance who claimed that she was not afraid of her husband's reaction in relation to the disclosure said that '*... why would he be violent ... he is the one who infected me ... he has no reason to be violent...*' The following quotations from participants appear to support this;

'Nothing has changed ...our relationship is as it used to be before the HIV positive result ... our marriage has not changed in this regard.' (Interviewee # 13)

'I have not experienced any kind of violence from my husband because of my HIV status. Such problems most of the time happens to women who do not have a work [do not earn their own income]. I have observed many such HIV positive women falling in a lot of trouble. So far in this regard I am fine because I do work [earn my own income]' (Interviewee #12)

A respondent from Mekelle, who is a mother of 3, reported that she feared and worried a lot about disclosing her HIV test result to her husband. She said '*...I feared he will blame me for bringing the virus.*' However, when she disclosed to him at last about her HIV test result, she said she was surprised

that her husband was very 'quiet' that night and 'easily agreed' to go to the clinic with her to do the testing and at last the test result showed HIV positive. She explained the situation as follows:

'We went together and he tested ... he has it [HIV] ... I think he knew he was infected before the testing ... he was not surprised at all by the result... but he never admitted it any way.' (Interviewee # 9)

Similar experience was also recounted by Interviewee #9 who reported that she would have 'peace' in her marriage if it was not for her in-laws said that:

'Every time I accused him (her husband) of infecting me with the diseases (HIV virus)... he don't say a word. He never accused me for bringing the virus to the family.... But still I am not sure if I got it (the HIV virus) from him or my first husband ... It is very difficult to tell ... I can only say it is God's will.' (Interviewee # 9)

'... At first we used to fight a lot ... he started to call me bad names and blame me for bring the virus ... he became very aggressive and quarrelsome ... but later he tested for himself and learned that he is also infected... slowly he accepted his situation ... he now says it is Gods order... we have peace in the house now...' (Interviewee # 23)

7.5.2 Participants' Report on the Violence Suffered

Few participants in this study reported that their HIV positive results have caused serious effects on their relationship with their husbands. The current study found two cases of abandonment of wives by their

husbands due to positive HIV test results as reported by the participants. A respondent who tested during delivery in Mekelle hospital reported her experience as follows:

' ... I think she [midwife] told him about my HIV test result He left me right there in the hospital. After the midwives talked to him privately in their office , he was there next to my bed for a while ... he did not say anything , unusually very quite ... later on he left and never came back again...he left me alone with the children. I am raising my children by myself. I borrowed money from people to celebrate the feast on the baby's Christianity [baptism]. I am now about to celebrate the holiday [eastern] with empty house ... I do not even have a penny to buy bread for the kids' (Interviewee # 3)

The second case of abandonment was reported by a woman from Ofla. Interviewee #8 was tested for HIV during her pregnancy. She said she agreed to the HIV test offered *'... I did not fear of any bad result and agreed to the test because I thought I do not have it...'* But when the result showed HIV infection, Interviewee # 8 said her relationship with her husband was changed:

'... after that he became very aggressive ... we quarrelled a lot. He took me back to my mother's house and he left me there.... my mother sent him the village elders and our God father to talk to him but he said he does not want the marriage to continue ...that he has divorced me ... I am still staying with my mother. He is staying in the house. I do not have a land of my own so I am receiving food aid from the government.' (Interviewee # 8)

Extracts from my field notes based on some conversations I made with Interviewee # 8 after the interviewee was formally over also illustrate that she tried to bring a civil suit to a local court against her husband for the maintenance allowance to her child and also her share from the common property which

was in the hands of her husband. However, she said that she later on dropped her court case because her husband threatened to kill her if she continues to do so. She also added that her mother is preparing to send village elders that can talk to her husband so that he will accept his wife and child again.

The current study also found that verbal and emotional abuses were commonly reported mainly by women in a discordant couple relationship, i.e. that their husbands tested HIV negative. For instances, Interviewee #4, a housewife and a mother of three said it took her a week to disclose her test results to her husband. But when she did she accused him of bringing the virus home although he tested negative to HIV later. In her words:

' ... I accused him of bringing the virus home, that he infected me with it.... I told him that he made me a sick woman ... I have never been to any man outside him ... so I was sure that he bought the virus and I called him all the bad names I know ... He was so shocked with the news but he remain quite still and confident that night . He keep saying that it cannot be true and that we should be going together do the HIV testing again... we went together to the hospital the next morning to do the testing again ... when the result arrives I have it [HIV positive] but he was free [HIV negative]' (Interviewee # 4)

Following this Interviewee #4 said *' ... all the questions and the blame were now projected on me.'* She described her life after they found out they are discordant couples as follows:

'... You know he is not my mother's son. It is only your mother's son who truly cares for you and stands with you at hard times of your lifea husbands is 'Guana' [a person with no blood relation] and a 'Guana' is always 'Guana' ... He is free from the virus and I am not, so you can imagine. He has changed a lot ... He likes to make chaos in the house and blame me for being unfaithful to him. He insults me. He knows that he did not find me prostitutingI just lower my head and allow all things to pass because it is only

me who has the diseases [HIV]. There is no where I could go with the children ... I am waiting for my children to grow up ... otherwise I would have left him.” (Interviewee # 4)

The difficult situation of women in discordant couple relationship was also appreciated by another respondent in this study. In her words:

‘... I did not tell him until I gave birth because I did not want to be worried. I heard from the members of the Mother-to-Mother support group that some men can be free from it [HIV] while the wives are infected... that could be a nightmare... so I was not sure how to handle if he tested negative... so I waited until I gave birth. Men can get very difficult in such situation ... you know ... that why I kept it [HIV test result] secret from him all these time.’ (Interviewee # 1)

Another story from a respondent illustrates that HIV related violence against women (threatening a divorce in this case) also comes not only from husbands but also from the in – laws as well. In her words;

‘My first husband died at Bademe (Ethiopia- Eritrea War) ... and I remarried my second husband and I gave birth for this baby [referring to the baby she was holding] ... my in-laws blame me for infecting their son and are pressuring him to divorce me... but you see he was also married to another woman before me and divorced her because she developed fistula ... and we did not tested for HIV at the time of our marriage... we do not know for sure who brought the virus ... We could have lived in peace if it was not for his family.’ (Interviewee #9)

7.5.3 Health Workers' Report on their Awareness of Violence

Data collected from the interview that was conducted with the health care providers shows that they do not necessarily sympathise women's fear violence if tested positive to HIV. *'we hear that all the time'* said a nurse from Mekelle who participated in this study *'many women say that they fear HIV test because if tested positive then their marriage could be in trouble ... but when you counsel them repeatedly and patiently they agree for the test'*. She added *'I myself have never seen any man who left his wife because she is HIV positive.'* Similar reflections were made by the midwife from Mekelle hospital who participated in this study said that *'... there are some woman after they came here [labour ward] they get stiff when asked to take HIV testing saying that their marriage will disintegrate , husband will leave ... etc'* but said the midwife:

'I myself have never come with a single woman who suffered any kind of violence in the hands of her husband because of her HIV status. That is because we give them a thorough counselling as to how they should continue to live their life after HIV positive test result ... It is not always is easy what happen to such a family when they are back to their house ... but I just never heard of any such story' (Midwife, Mekelle)

Such practice of proving blind eye to worries of women who are expected to take HIV test under the 'opt-out' testing scheme was also shared by health workers in the rural setting. For example a male midwife from Ofla chose to think that such worries and fears of the women are 'unfounded':

'In our Woreda [District] we have not encountered a woman who has been abandoned by her husband because of her HIV test results. However, many pregnant women raised this as a reason for not taking HIV test. For example recently there was this patient who refused to test because she feared her husband will kick her out of house if tested positive ... we convinced her any way ... the result was positive. He did not divorced her or inflict any kind of harm on her. So most of the time such fear of violence if tested positive for HIV are unfounded.' (Midwife, Ofla)

However, the three health extension workers who participate have many stories to tell about women they knew who suffered violence at the hands of husband upon testing positive for HIV. Some of the stories I was told by the HEWs are quoted below;

'The husband was HIV positive and already under ARV treatment without the knowledge of his wife. Some day he interrupted his medication and I received his name from the health centre to track him down and to follow up his adherence to the ARV treatment. Accordingly, I went to his house and I noted his wife was pregnant.... he warned me if I came again or talk to anyone about it including his wife, that I will be a dead woman ... I was so worried and I have to save the unborn child but the man's message were clear for me... so now I went to the local administrator and told him all the story ... he said we should take the risk to save the life of the child... so he summoned the wife and she was asked to test for HIV ... she refused saying that her husband will kill her if she tested She tested positive any way at last ... during the birth we were able to save the child from HIV infection ... but the mother was divorced by her husband.' (HEW1, Ofla)

'I also know a woman who tested positive during one of our door to door visit in the village...her husband was very angry that she did the testing without his permission ... he divorced her ... so sometimes men can be a real problem to women ... but with this

woman I just told you, she has now married to another man who is also an HIV positive and she is living happily.' (HEW2, Ofla)

7.6 Conclusion

For pregnant women the principal potential benefit of HIV testing is medical while the principal risks are social and psychological can bring shame and anxiety, loss of friends, face difficult decisions about to whom to disclose these findings, various forms of stigma and discrimination in some case physical harm and even abandonment where she disclosed her HIV positive results to her husband. Hence any prenatal HIV testing approach must allow pregnant women to come to her own informed decisions regarding whether or not she wishes to undergo testing after weighing the benefits and consequences. This chapter resents the findings of the lived experience of the research participants in relation to HIV-related stigma and violations of individual rights guaranteed in numerous human rights instruments of the women tested positive. The data suggested that women in this research were subjected to different forms of stigma and discrimination as well various forms of violence including in some cases abandonments by their husbands due to the HIV positive test results.

CHAPTER – EIGHT

DISCUSSIONS

8.1 Introduction

This chapter discusses of main findings in relation to the specific objectives of the study. The inadequate and unclear pre-test counselling before screening pregnant women for HIV using the routine ‘opt-out’ approach and the implications are discussed first. The subsequent discussions focus on situations that are found to be resulting in violations of human rights and ethical requirements during the process of implementations of the testing approach at maternal health care settings namely – the perception of the compulsory nature of HIV testing among pregnant women, the power imbalance between the medical practitioners and pregnant women and the undue peer pressure to take up HIV test among rural women are presented. A discussion on the complexity of disclosure of positive test results and the persistence of HIV related stigma and violence is presented. The chapter ends with a brief discussion of the limitations of the research.

8.2 Discussion of Main Findings of the Study

8.2.1 Inadequate HIV Counselling and its Implications

HIV testing has social, legal and financial consequences in addition to the medical implications to women who tested positive. Hence HIV testing schemes in relation to PMTCT need to provide appropriate information to the pregnant women to empower them to make an informed decision.

Gruskin, et al., pointed out that insufficient pre-test information given to women in a routine 'opt-out' approach is detrimental to ensuring informed consent as well as to coping with a positive HIV test.¹

However, the fieldwork in this study demonstrated that pregnant women in the maternal health care services in Ethiopia are provided with inadequate information about the consequences and risks of HIV testing and about their right to refuse the testing without affecting their access to the other maternal health care services. The findings also revealed that pregnant women are not always given the amount of time to reflect that would allow them to make informed choices about HIV testing and subsequent treatment. The provision of inadequate information reported by the respondents as shown in the findings could be explained as the greatest inherent shortcomings of the 'opt-out' HIV testing approach. As discussed in the earlier chapters routine provider- initiated 'opt-out' HIV testing approach does not require health workers to disclose detailed information but only to provide a '*simplified pre-test information*' to pregnant women during the testing procedure. The finding therefore confirm previous studies in some parts of the country which have also identified the need of improvement of pre-test counselling service or pregnant women at maternal health care units to prevent vertical HIV transmissions.²

Moreover, the findings in this study also demonstrate that even the limited information being given to pregnant women in Ethiopia during prenatal HIV testing is dominated by one sided view of the positive

¹ S Gruskin *et al.*, 'Provider-Initiated HIV Testing and Counselling in Health Facilities—What does this Mean for the Health and Human Rights of Pregnant Women?' (2008) 8(1) *Developing World Bioethics* 27.

² Hussein Ismail and Ahmed Ali 'Pregnant women's satisfaction and comprehension level of information given during HIV Counselling and Testing for PMTCT in public health facilities in Addis Ababa' (2011) 25(2) *Ethiopian Journal of Health Development* 129.

consequence of HIV testing – *good for the baby message*. Emphasising the importance of having an uninfected baby tacitly imposes an obligation on the pregnant women to comply with the testing and makes it more difficult for women to act otherwise. The findings support the pattern of pre- test counselling identified in another published studies in some parts of Africa counties.³ Such one-sided pre-test counselling in the context of prenatal HIV testing has the effect of disempowered women from being prepared for the possible negative consequences of positive HIV test results.

What the findings in this study suggest is that under the new HIV testing scheme pregnant women in Ethiopia are not receiving the information and counselling that are supposed to accompany HIV testing in the effort to prevent vertical transmission. Hence their ability to make informed consent is being compromised. However, laws and HIV testing policies as well as guidelines of the county demand healthcare providers give pregnant women the information necessary to understand the consequences of a medical decision to undergo HIV antibody diagnosis, the risks and benefits of the testing procedure and the options including the right to opt- out of the HIV testing.

8.2.2 Prenatal Routine 'opt-out' Testing Approach and Violations of Informed Consent

The 2007 Ethiopian guideline on PMTCT requires voluntary informed consent as a condition for HIV testing within the context of maternal health care (i.e. antenatal, labour, immediate postpartum).⁴ The guideline also states that the informed consent is presumed unless the pregnant woman expressly decline

³ See O Ujiji *et al.*, 'Is "opt-out" HIV Testing' a real option among pregnant women in rural districts in Kenya?'(2011) 11 *BMC Public Health* 6. Available online at; <http://www.biomedcentral.com/1471-2458/11/151> [visited on 5 August, 2013]. N Angotti 'Testing differences: The Implementation of Western HIV Testing Norms in sub-Saharan Africa'(2012)14(4) *An International Journal for Research, Intervention and Care* 372.

⁴ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother-to-Child Transmission of HIV* (Addis Ababa, 2007) para. 5.3.2.

or to opted- out the offer for HIV testing made by health providers.⁵ This study found that the current set- up of prenatal HIV testing in Ethiopia, where health care providers are made to initiate HIV testing to pregnant women, actually is sending a message to pregnant women that the HIV testing is a prerequisite for obtaining antenatal or other maternal health care services. Hence, despite the fact that women in this research knew that they have the right to refuse, the fact that health care providers initiate a test and the burden to repeatedly justify their refusal to the HIV test offered to them by health care workers made them to perceive HIV testing a compulsory during pregnancy.

Previous study in other African countries has also reached in a similar conclusion that the pregnant women perceived HIV testing offered by health care provides during their ANC visits was compulsory test that it was an offer 'they cannot refuse'.⁶ Therefore, the perception of HIV testing during pregnancy as a prerequisite for accessing ANC or other maternal health care services by pregnant women demonstrated in the current study provides some merit to the concern that routine provider initiated 'opt-out' HIV testing approach do not necessarily enable pregnant women to make their own informed decision regarding the testing.

Furthermore, study participants in this research narrated how they were convinced that refusing the HIV test offered by health care providers during ANC is meaningless as they strongly believed that the test will be imposed on them during child delivery at the labour wards whether they wish it or not. In view of that the consent given for HIV testing during ANC by pregnant women is not voluntary since the

⁵ *Ibid* .

⁶ N Angotti, *et al.*, 'An offer you can't refuse? Provider-Initiated HIV Testing In Antenatal Clinics In Rural Malawi' (2011)26 *Health Policy and Planning* 312. See also A Hardon, *et al.*, 'Women's Views On Consent, Counselling And Confidentiality in PMTCT: A Mixed-Methods Study in Four African Countries'(2012) 12(6)*BMC Public Health* 6.

consent was given based on the misunderstanding of the equally optional nature of HIV testing in the delivery rooms as well.

The current study also found that, HIV testing of pregnant women in the labour ward is not voluntary and lack adequate pre-test counselling. Some participants in the research explained that HIV testing was not actually offered to them but they were '*notified*' that their blood is drawn for HIV test. Moreover, a participant who was hospitalized for childbirth without prior prenatal HIV test results reported that she not informed that she have been tested until after childbirth. The implementation of the provider initiated 'opt-out' HIV testing in the labour ward and the perception of the testing as a compulsory as reflected in the formulation "*Testing during child delivery is a must*" by participants of this study contradicts the current global and national guidelines on PMCT. Thus notwithstanding that the 2007 Ethiopian PMTCT guidelines put forth the right to decline HIV testing, Ethiopian women do not necessarily exercise this option once they put themselves in the labour wards.

According to the 2007 Ethiopian PMTCT, pregnant women do have the right to make an informed decision freely and willingly whether to make HIV testing that includes the right to refuse the testing. However, data in this study reveal that health workers strongly believe that pregnant women do not refuse an HIV testing offered to them during labour. The implication of this is that those women who chose to exercise their right to refuse HIV testing are not seen as someone who is exercising their autonomous decision but as deviants who need to make a lot of justifications for not following the recommendations of health care professionals.

The study also demonstrated the commonly held beliefs of health care workers that it is women who already knew their positive HIV status that refused the testing with the aim of hiding their HIV positive

status from their families and community. Consequently, as revealed by the findings in this study more pressure is exerted in the name of counselling to pressurize the women in labour to the screening with no exception.

Testing pregnant women for HIV without their consent has grave human rights implications that undermines constitutionally granted essential rights namely protection against unreasonable searches and seizures, protections of privacy and liberty. In the contrary to the current practice as revealed in the findings, pregnant women have the right to make an informed decision in relation to HIV testing free from any act of coercion, duress or deception. In addition, pressurizing pregnant women to uptake HIV testing has public health implication as it can diminish women's trust in the health care service that can have a serious potential to undermine the government's endeavours to scale up the use of PMTCT programme and enhance maternal health.

8.2.3 Power Imbalance in the Context of Routine 'opt-out' Testing Approach

Routine provider initiated 'opt-out' HIV testing approach raises grave concern regarding the question of how real is the 'opt-out' option. This concern is especially important considering the power imbalance between the health care provider and pregnant women in a situation where medical professionals have high social status, the scarcity of health care service and the arguably universal psychological tendency to obey authority.⁷ The power differential between health care providers and a patient is significant in a scenario where the uneducated poor woman on the verge of delivering her baby in the only available public health facility is offered an HIV test.

⁷ S Rennie and F Behets 'Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low- Income Countries' (2006) 84(1) *Bulletin of the World Health Organization* 54.

The data presented in this study indeed confirm that pregnant women who were asked to test for HIV testing during their child birth were not able to refuse the offer because they thought that the refusal would compromise their access to care. Exercising the right to refuse HIV testing offered by health worker either in delivery rooms or antenatal care services is particularly difficult for pregnant women since the refusal automatically imposes the burden to justifying the refusal on the pregnant woman. Hence saying 'No' to HIV testing offered by health workers in maternal health care setting requires a special effort that most pregnant women just succumb to the testing even if they did not intend to.

Moreover, the findings in this study demonstrated that the prevailing practice especially in the rural setting shows that the health care providers do often involve non-clinical personnel including local administrators and local leaders of the Tigray Women Association to whom the pregnant woman has to make justifications as to why she did not want to take the HIV testing. Despite the fact that the 2007 PMCT guideline expressly states that women do have the right to 'opt-out' the HIV testing if they do not want to take the testing such burden of repeatedly having to justify to health care providers and non clinical personnel including to local administrators heavily deny pregnant woman the autonomy to make decision free from coercion and duress.

8.2.4 Participants Report of Violence upon Disclosure of Positive HIV Result

One unintended consequence of 'opt-out' testing approach is that women are often the first to know their HIV status (mainly due to prenatal HIV testing) and hence frequently more likely to be blamed for the infection of their partners.⁸ Most of the women who participated in this study deferred disclosure of their

⁸ *Ibid* at 54.

HIV status to their husbands until after giving birth or until the husbands agree to take an HIV test and one participant did not inform her husband even though it was almost a year since she tested positive at the time of fieldwork. Such non-disclosure HIV status to husbands or sexual partners has an implication to the goals of the PMTCT as it precludes HIV positive women from adhering to PMTCT interventions, thus increasing the risk of HIV transmission to the infants.

The current study also found that some women who participated in this study reported negative outcomes following their disclosure of HIV positive test results to their husbands. These negative outcomes include abandonment, blame and accusation of bringing HIV infection into the family, threats of divorce and psychological abuse. As discussed in previous chapters the gender power imbalance and the subordinate social positions that women in Ethiopia occupy, expose them to domestic violence which only is being exacerbated by prenatal HIV positive test results. Findings in this study are suggestive of fact that subjecting pregnant women to routine provider initiated 'opt-out' HIV testing scheme in maternal health care settings in Ethiopia without consent and adequate information that can make them prepared for consequences of positive test results can further disadvantage women by exposing them to domestic violence. Some studies in other parts of the country have argued that fear of negative reaction including marriage disruption from their partners upon testing positive to HIV poses important barriers to HIV testing.⁹ The findings of this thesis very much strengthen this argument of women's economic dependency on men and their roles as mothers caring for children, forced women to

⁹ M Malaju and G Alene, 'Assessment of utilization of provider-initiated HIV testing and counseling as an intervention for prevention of mother to child transmission of HIV and associated factors among pregnant women in Gondar town, North West Ethiopia'[Online] (2012) 12(226) *BMC Public Health* 3. Available online at; <http://www.biomedcentral.com/1471-2458/12/226> (visited on February/2014). See also W Fanta and A Worku 'Determinants for Refusal of HIV Testing among Women Attending for Antenatal Care in Gambella Region, Ethiopia' (2012) 9(8) *Reproductive Health* 10.

think twice before they disclose their HIV status to their husbands particularly during the socially vulnerable period of pregnancy.

Such challenges faced by pregnant women with HIV positive test results not only violate their right to free from violence and fear but also from public health point of view such situation prevent women from adhering to PMTCT interventions properly. In addition the finding suggested that testing pregnant women in maternal health care settings without their consent and counselling and hence exposing them to violence and abuse makes the routine 'opt-out' HIV testing approach ethically unjustifiable.

The study also revealed that health care providers in the labour ward tend to disclose the positive HIV status of the pregnant women in their labour ward to their husbands/ partners without the consent of the women in an attempt to submit the husbands to HIV testing. In the study health care providers reported their beliefs that it is their duty to disclose HIV positive status of the pregnant women in their labour wards despite the existence of laws in the country that protect the right to privacy and medical confidentiality.

Disclosure of positive HIV test results to partners usually requires pregnant women to weigh a number of factors including the possible negative reaction of the husband. However, as data in this study illustrate that at times of child delivery husbands were informed their wives positive HIV status without the authorization or even knowledge of the women with the aim of encouraging men to undergo the HIV testing. The findings in the current study shows that maternity care providers found it undesirable not inform a husband who accompanied the wife to the delivery room, if his wife tested positive for HIV.

Such unauthorized releases of positive HIV test results are breaches of the right to privacy.¹⁰ As indicated earlier, confidentiality of positive HIV status is not only essential to protect the human rights of women but also such unauthorized disclosure of HIV positive test results exposes women to abandonment and domestic violence.

8.2.5 The Persistence of HIV Related Stigma against HIV Positive Women

HIV testing occurs in a social context marked by unequal gender and power relations and high levels of stigma. Nonetheless, among the major arguments forwarded by proponents of routine PITC is that that as routine testing becomes more common place HIV related stigma and discrimination will decline.¹¹ Following the trend, the 2007 Ethiopian PMCT guideline also justified the promotion of routine PITC for its role in contributing reduction of stigma and discrimination in the country.¹² However, this assertion is misleading given the fact that HIV-related stigma and discrimination are borne out of socio-cultural factors, which may not necessarily be addressed by routine HIV testing. In fact, fears are expressed by some commentators that routine HIV testing may fuel stigma and discrimination associated with HIV.¹³

As mentioned previously, the current study did not aim to measure the extent of the HIV related stigma and discrimination however it documented the stigma experienced by the women who participated in the study following their positive HIV diagnosis under the PMTCT programme. Accordingly, respondents

¹⁰ ICCPR art 17.

¹¹ J Becker *et al.* 'Provider Initiated Testing and Counselling (PITC) for HIV in Resource-Limited Clinical Settings: Important Questions Unanswered' (2009) 3(4) *Pan African Medical Journal* 3. See also K De Cock *et al.*, 'A Serostatus-Based Approach to HIV/AIDS Prevention and Care in Africa' (2003) 362 *Lancet* 1847.

¹² MOH/HAPCO above n 4 at 5.3.2.

¹³ E Durojaye, 'The Impact of Routine HIV Testing on HIV- Related Stigma and Discrimination in Africa' (2011) 11 *International Journal of Discrimination and the Law* 195.

in the current study have reported their personal experience of HIV related stigma that manifested in terms of expulsion from the house they rented, verbal abuse and exclusion for communities when their HIV positive status known or suspected. What the findings suggest is that in the Ethiopian society HIV/AIDS remains to be exceptional among infectious diseases associated with responses of severe stigmatization from individuals and communities. Thus, provision of detail pre-test counselling as a requirement of informed consent is necessary during prenatal HIV testing to ensure that women are forewarned that they are agreeing to a test of their blood that may expose them to one or more of these scenarios reported by participants of this study. Routine 'opt-out' HIV testing approach by itself cannot be expected to eliminate HIV- related stigmatizing attitudes that are deeply rooted in social structure that casts people living with HIV/AIDS as immoral. These findings also demonstrate the importance availability of adequate and detail pre and post test counselling service during the prenatal HIV testing for pregnant women to provide them with an opportunity to prepare for any adverse reactions that they believe might occur if they tested HIV positive.

8.2.6 Reports of Avoiding Medical Attention for Fear of HIV Testing

Routine 'opt-out' HIV testing approach also raises a concern that routine HIV testing causes pregnant women to avoid seeking medical attention to escape what they perceive to be a mandatory testing requirement.¹⁴ If women fear that they will be pressured into having a test, they may be less likely to use maternal health care services. The study demonstrated that women avoided ANC for the fear of being forced for HIV testing by the health care providers. Health care providers supported the view that pregnant women mainly from rural settings do avoid medical attention or are forced to do so by their

¹⁴ Angotti *et. al.*, above n 6 at 312.

husbands and mother-in-laws for fear of being subjected to HIV testing during child delivery. What the findings suggest is that undermine pregnant women's ability to make their own choice in the process of implementation of 'opt-out' HIV testing approach is likely to weaken the trust between pregnant women and their health care providers, which in turn can cause pregnant women to avoid seeking medical attention or decline those services normally attached to HIV testing.

8.3 Study Limitation

This study aimed to assess the human rights and ethical implications of the expansion of routine provider initiated 'opt-out' HIV testing approach in Ethiopia by drawing the lived experience of women who tested positive to HIV during their access to maternal health care services. This objective of the thesis suggested the adoption of a method that would facilitate the generation of data that represents the values, feelings, personal experiences and attitudes of the women who underwent the HIV testing scheme. Hence, in-depth semi-structured interview was employed in this thesis as the main data collection tool. In addition, this study is also informed by data collected through non participatory observation and field notes gathered during the fieldwork period. Hence the study was shaped and refined with the data gathered from interview with women and other interviewees, observational data, field notes and themes identified from document reviews.

A more general limitation concerns the generalizability of the findings. This qualitative study was based on a small purposively chosen sample within the purposively selected antenatal care facilities in the capital city of the Tigray region and one rural district. The study aimed at identifying a wide range of themes rather than getting a representative sample of the population of ante-natal care clients in the

country. The fact that the study was conducted in a limited geographic area in northern Ethiopia is also another limitation of study, although, I do believe that the findings of this study may reflect the situation of pregnant women other parts of Ethiopia.

CHAPTER NINE

CONCLUSION AND RECOMMENDATION

9.1 Introduction

Routine provider-initiated ‘opt-out’ HIV testing approach refers to the HIV testing that is initiated by health care providers for persons attending health care facilities as a standard component of medical care, unless the person actively declined the HIV test.¹ Following the recommendation of the WHO and UNAIDS, 42 (79.2 percent) of the 53 African countries had adopted this testing in their jurisdictions by 2012.² By the same token, the Ethiopian Government espoused the testing approach in 2007 upon revising its PMTCT guideline that integrated HIV testing to all maternal health care services in the country.

The testing approach has already proven to increase the number of pregnant women who undergo the testing within Africa.³ This study has sought to examine whether the adoption and implementation of this HIV testing approach which screens pregnant women in Ethiopia for HIV infection threatens to violate women’s human rights. Four issues have been the points of focus in this study: the issue of free and voluntary informed consent; access to adequate pre-test counselling; protection of confidentiality of

¹ Federal Ministry of Health (MOH) and Federal HIV/AIDS Prevention and Control Office (HAPCO) *Guidelines for the Prevention of Mother –to-Child Transmission of HIV* (Addis Ababa, 2007) 20.

² See generally B. Hensen *et al.* ‘From Caution to Urgency: The Evolution of HIV Testing and Counselling in Africa (2012) *Bulletin of the World Health Organization* 1-10. Available online at; <http://www.who.int/bulletin/volumes/90/9/11-100818/en/> (Visited on 30 February, 2012).

³ See generally UNAIDS *2013 Progress Report on the Global Plan; Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive* (Genève: UNAIDS, 2013) Available Online at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20130625_progress_global_plan_en.pdf [Visited on March, 2014].

test results and issues of protection from HIV- related stigma and intimate violence against women who have been tested under this approach.

This chapter is structured as follows. After this introduction, reflection on the methodology employed in this study is provided. The subsequent section of the chapter considers provision of access to quality and affordable HIV testing to pregnant women as both public health and human rights imperatives. The chapter moves on to provide concluding remarks relating to the human rights and ethical concerns raised on the practical implementations of the 'opt-out' testing approach in maternal health care settings in the context of Ethiopia's social , economic and cultural context. The final section draws together the overall conclusions from this study and makes recommendations.

9.2 Methodological Reflections

Methodologically this study employed qualitative research methods. The study aimed to assess the human rights and ethical implications of the 'opt-out' HIV testing approach by drawing on the lived experience of pregnant women who tested positive to HIV during prenatal testing. The aim was to bring to the fore the values, feelings, personal experiences and attitudes of the women who underwent the HIV testing scheme. It was therefore necessary to adopt a methodology which best facilitated this objective. As a result the study adopted a feminist approach which recognises the complex power relationships at play in such research. The study employed in-depth semi-structured interview as the main data collection tool although it was also informed by data collected through non participatory observation and field notes gathered during the fieldwork period. In addition, the normative and conceptual aspects of human rights and ethical principles inform the discussions and arguments.

This methodological approach enabled the examination of the complex interaction between the everyday lived experiences of women involved in the HIV testing and understandings drawn from global and national policies and legal frameworks. Hence, the use of qualitative methods enabled the thesis to explore the ways in which gender power relations, and the socio –economic and cultural contexts within Ethiopia affect the human rights and ethical implications of this testing regime. It therefore facilitated a socio-legal study of HIV testing.

9.3 The Need to Scale up Access to HIV Testing in Ethiopia: Not Disputed

In this doctoral dissertation, I do not dispute the need to scale up access to HIV testing and counselling for pregnant women in Ethiopia to prevent mother-to-child transmission of HIV. HIV testing is essential for the effective response to HIV prevention and an important gateway to treatment, care and support for those who test positive. Individuals have the right to know their HIV status, and this right entails access to quality and affordable HIV testing. More importantly in the context of this study, pregnant women's access to HIV testing service is crucial as knowledge of their HIV status enables them to prevent transmission of the infection to their unborn infants by employing the MTCT prevention methods that are now scientifically proven to decrease the risk significantly.

Reports from the Ethiopian Government indicate that the HIV transmission rate of pregnant women to their unborn children is unacceptably high and results in many hundreds of thousands of new HIV

infection among children every year.⁴ These facts justify the expansion of quality HIV testing and counselling among pregnant women in Ethiopia. Therefore, the question posed in this thesis is how the scaling up of HIV testing can be balanced with respect for the rights and informed decisions of the pregnant women to whom the HIV test is being offered within maternal health care settings. This thesis argues that the formulation of HIV policies that target pregnant women should take full account of the subordinate position of women in society. It should be attentive to their autonomy and privacy, the stigma and discrimination they may face as well as their health needs.

Analysis of the legal basis for the introduction of routine provider- initiated 'opt-out' HIV testing approach in Ethiopia is provided in chapter two. It is noted that since at least theoretically the testing approach allows for informed consent and the right to refuse for individuals who do not wish to test, the approach does not necessarily contradict the existing legal and policy framework of the country. However, I argue that the ethical and human rights implications of the implementation of the testing approach in maternal health care setting to screen pregnant women for HIV infection in Ethiopia cannot be fully understood without going beyond the formal provisions contained within the law. It requires a socio legal approach which takes full account of the social, economic and cultural context within which the testing is undertaken.

9.4 Implementations of 'Opt – out' HIV Testing Approach Raises Serious Concerns

The rationale behind the adoption of the routine 'opt-out' approach to HIV testing in Ethiopia and elsewhere in African nations is mainly motivated by the objective of testing the greatest numbers of

⁴ MOH *The National Strategic Plan for Elimination of Mother to Child Transmission of HIV (e-MTCT of HIV) 2013 – 2015* (Addis Ababa, 2013) 4.

individuals possible, on the assumption that such testing will yield significant benefits in HIV prevention and treatment. However, many authors have expressed concerns that routine 'opt-out' approaches to HIV testing pose human rights and ethical concerns.⁵ The data gathered in this study confirms these concerns that the practical implementation of routine provider initiated 'opt-out' HIV testing approach in maternal health care settings in Ethiopia undermines the ability of women to make informed and autonomous decisions.

Like in any other medical procedures, the ability of individuals to make an autonomous decision relating to HIV testing is rooted within ethical and human rights discourse. Informed consent stems from the concept of autonomy whereby patients have the right to health, liberty, security and privacy as enshrined under various international and regional human right instruments as noted in chapter 3. Nevertheless, it was evident from the study findings that the power imbalance between the medical practitioners and pregnant women, the perception of the compulsory nature of HIV testing among pregnant women, the undue peer pressure to test for HIV among the rural women through the structures of WDAs, and reports of HIV test in the labour wards being conducted without counselling and consent undermine the rights of women to give consent freely and voluntary.

The right to be informed of the benefits and risks of HIV testing is also of equal importance to the issue of consent. In this thesis I argue that the replacement of pre-test counselling with 'simplified pre-test information' under the 'opt-out' testing approach limits women's rights to access information which could have enhanced their autonomy by providing them with information necessary to make the best

⁵ See Gruskin *et al.*, 'Provider-Initiated HIV Testing and Counselling in Health Facilities—What does this Mean for the Health and Human Rights of Pregnant Women?' (2008) 8(1) *Developing World Bioethics* 24. See also Rennie and F Behets 'Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low- Income Countries' (2006) 84(1) *Bulletin of the World Health Organization* 54.

possible choices. Pre-test HIV counselling is vital for pregnant women to ensure that they understand the implications of a negative or positive test result, for themselves, their partners and any future children.⁶

The newly established Women Development Army groups (WDAs) are contributing to the violations woman's individual decision making on reproductive health rights matters including HIV testing and replacing it with communal decision. Within the WDAs women in rural settings interrogate each other and demand explanations from a member who declined HIV testing during her pregnancy. Any woman who refused the peer's consultation on reproductive health matters including prenatal HIV testing at the WDAs meetings will be reported to health workers for their strict follow ups. Such unduly peer pressure is prohibiting pregnant women in rural settings from making informed decision regarding HIV testing freely and voluntary. In addition, the WDAs are instrumental in bringing more and more pregnant women to the attention of health system so that the health workers will make sure that they gave birth at health institutions with aim of reducing maternal mortality rate. However, once these pregnant women are brought into the labour wards at health institutions, they are denied the right to make an autonomous decision whether or not to test for HIV infections.

It is generally accepted that under international human rights instruments, although implicitly, discrimination on the ground of HIV status is prohibited.⁷ It is noted that the social consequences of a positive HIV test results for women have been associated with negative outcomes including stigma and violence. In this thesis I argued that the adoption of an 'opt-out' approach to HIV testing in the context

⁶ Gruskin *et.al.* above n 5 at 27.

⁷ See generally the Committee on Economic, Social and Cultural Rights, General Comment 14 (The Right to the highest Attainable Standard of Health) paras 28-29 (2000).

of maternal health care settings to screen pregnant women for HIV cannot be justified if it exposes women to stigma and violence.

In the context of Ethiopia, inadequate legal protection against HIV related stigma and discrimination plays its role in the persistence of such negative social consequences in relation to HIV testing. Although the Ethiopian constitution guarantees equal protection to everyone, discrimination based on HIV status is not among the listed grounds upon which discrimination is prohibited.⁸ The country does not have specific legislation that offers protection against discrimination on the grounds of HIV status, with the exception of discrimination in areas of employment as noted under chapter 3. Such legislation which could play a vital part in the HIV response strategy to protect the public health as well as the human rights of people living with HIV

Moreover, studies have shown that domestic violence in Ethiopia is endemic.⁹ However, there is an insufficient legal protection relating to issues of domestic violence in the country. The 2005 criminal law under its section on harmful traditional practices provides a criminalization of the physical violence within marriage or in an irregular union to regulate domestic violence.¹⁰ This criminal law provision, however, falls short of providing a comprehensive definition of domestic violence that would include other forms domestic abuse like economic, psychological and sexual abuses as recommended by the CEDAW committee and now increasingly accepted as the internationally recognized definition. In

⁸ FDRE Constitution art 25.

⁹ Central Statistical Agency of Ethiopia (CSA) and ICF International *Ethiopia Demographic and Health Survey 2011* (Addis Ababa: CSA, 2012) 256.

¹⁰ FDRE Criminal Code art. 564 states that:

'The relevant provision of this code (Arts 555-560) shall apply to a person who, by doing violence to a marriage partner or to a person cohabiting in an irregular union, causes grave or common injury to his/her physical or mental health.'

addition, for the purpose of punishment the criminal code refers to the general assault articles thus indicating that the specific nature of domestic violence and its relation with gender power relations in society is not appreciated.

The persistence of stigma and violence associated with HIV in Ethiopian society is pertinent for the implementation of pregnancy related PMTCT programmes as women are more likely to experience routine testing than men. Mere expansion of HIV testing among the public using the 'opt-out' approach does not necessarily lead to a reduction of stigma and violence against HIV positive women as hypothesised by the national PMTCT guidelines in Ethiopia.¹¹ Unless specific programmes are designed and implemented to reduce stigma and violence associated with positive HIV test results, Ethiopian pregnant women will continue to be exposed to risks of significant harms as though the testing scheme will carry on increasing the numbers tested. As argued by Rennie and Behets downplaying the social consequence of being HIV positive for women in Africa helps to make the testing approach look attractive and less contentious.¹² Therefore, the findings in this study indicate that it is still essential to take account of the wider negative social consequences which flow from a positive HIV test, if women are to be empowered to make their own autonomous decisions regarding HIV testing whether they are pregnant or not.

¹¹ MOH/HAPCO above n 1 at 11.

¹² Rennie and Behets above n 5 at 54.

9.5 Simply Increasing the Numbers is not enough: The Way Forward

One of the WHO's four components of PMTCT is prevention of HIV infection among women, which is also adopted by the 2007 Ethiopian PMTCT guidelines.¹³ However, as noted in the thesis, Ethiopian women continue to be vulnerable to HIV infection with large numbers of new infections every year. These facts prove the serious failure of the Government not only in HIV prevention efforts but also with the wider perspective of ensuring an enabling environment for gender equality in Ethiopia that would have greatly contributed to reduction of HIV infection among women. While the public health goal of scaling up the number of pregnant women who know their HIV status through the expansion of access to HIV testing services is legitimate, human rights and ethical obligations require special attention to be paid to the vulnerability of women to HIV infection. Finding ways to protect women from HIV infections must be given the highest possible priority. As noted in the thesis the available data demonstrate that women in Africa are the poorest, least educated, most economically marginalized and compounded by violence against women. An overt recognition by the Ethiopian government is needed that this social position of women that renders them particularly vulnerable to HIV/AIDS.

Tackling gender inequalities and hence reducing the vulnerability of women to HIV infections will only be successful if there is a supportive legal and policy framework in place. Although not ratified by Ethiopia, the African Women's Protocol imposes an overall obligation on state parties to create an enabling, supportive, legal and social environment that empowers women to be in a position to fully and freely realise their right to self-protection and to be protected from HIV infection.¹⁴ The right to self-protection and the right to be protected are interpreted by the African Commission on Human and

¹³ MOH/HAPCO above n 1 at 3.

¹⁴ Africa women protocol , art.14 (1)(d).

Peoples' Rights as intrinsically linked to other women's rights including the right to equality and non-discrimination, life, dignity, health, self-determination, privacy and the right to be free from all forms of violence.¹⁵ Thus, ratification of this regional human rights instrument would definitely strengthen the legal environment for Ethiopian women to realize their self – protection and to be protected from HIV infections. It could then be used as the basis from which to develop a policy framework which recognised the gender power imbalances revealed within my field work findings.

Reports of the Ethiopian Government extol the significant increase in the number of health facilities providing PMTCT services and how the implementation of the health extension package has resulted in the increase in HIV testing coverage among pregnant women in the last decade.¹⁶ Nonetheless, access to antiretroviral therapy by pregnant women living with HIV both for their own health and for their unborn infant to prevent mother-to-child HIV transmission remains unacceptably low.¹⁷ As noted in chapter 2 of this thesis, in 2013 it was reported that only 2 out of 10 eligible children and 4 out of 10 pregnant women living with HIV received antiretroviral therapy treatment in Ethiopia.¹⁸ Such telling acts relating to the PMTCT programme in Ethiopia poses a range of serious questions relating to the ethics of subjecting pregnant women to HIV testing without a direct link to treatment, care and support. HIV testing is a means not an end in itself. The ends of HIV testing are the public health objectives of prevention of further transmissions of the virus and access to care, treatment and support for those who tested positive not just increasing the number of women who know their HIV status.

¹⁵ African Commission on Human and Peoples' Rights General Comments on Article 14 (1) (d) and (e) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa , para 10 and 11.

¹⁶ See generally MOH above n 4 at 2- 8.

¹⁷ See generally UNAIDS above n 3 at 20-21.

¹⁸ *Ibid* at 20.

9.6 Recommendations

The study raises some important themes and issues related to the adoption and implementation of routine provider – initiated ‘opt-out’ HIV testing approach in all maternal health care settings in Ethiopia to screen pregnant women for HIV and its human rights and ethical implications. It has generated knowledge by assessing the extent pregnant women in Ethiopia are enabled to make their own informed consent regarding the HIV testing by drawing upon the lived experience of women who tested positive to HIV during their access to maternal health care service. The study also provides insights into the negative social consequences of positive HIV test results for the women who tested during their pregnancies.

Finding ways to balance the scaling up of HIV testing of pregnant women in Ethiopia to prevent vertical transmission of HIV and respecting the individual’s rights to make their own medical decisions including refusing the HIV test should be a priority for the future efforts of prevention of paediatric AIDS which is both a human rights and public health imperative. The thesis concludes that the success of PMTCT program relies not on the mere increase in the number of newly diagnosed HIV positive pregnant women but by taking a concrete action to create an enabling environment to bring about gender equality in the country and also to uphold the rights of women (pregnant or not) to make their own informed medical decisions on their bodies regardless of their HIV status.

Therefore my recommendations are:

- The major recommendation springing out of the present work is that HIV testing at the maternal health care settings in Ethiopia should always be done based on respect for the human rights of

pregnant women to have access to adequate counselling, a well-recognised right to refuse HIV testing without this having any effect upon the provision of maternity care and confidentiality of test results;

- Adequate safeguards including the enactment of anti-discriminatory laws based on HIV status should be in place to protect of pregnant women from intimate violence and HIV related stigmatizations, as a prerequisite for the implementation of 'opt-out' HIV testing approach;
- Policy makers should introduce monitoring and evaluation mechanisms regarding the implementation of 'opt-out' testing approach to ensure the practice of offering and conducting the HIV test meets the human rights and ethical standards;
- Public health authorities should design and undertake a systematic outreach of public education targeting women (pregnant or not) on the significance of HIV testing as well as their right to counselling, to make informed consent and to the confidentiality of the results their HIV test. The public education campaign should strive to ensure that women are aware of the integration of 'opt-out' testing approach to all maternal health care services and that they do have the right to refuse HIV testing without affecting their health care needs;
- As part of the creation of enabling environments for gender equality and the transformation of gender relations in Ethiopia, the legislatures should introduce laws that protect women from domestic violence with a holistic approach that includes both criminal and civil remedies; and

- Several research questions have emerged from this current research that could be significant for further investigation in Ethiopia or in other countries with similar socio-cultural and economic characteristics. There is a need for large scale studies to consolidate much needed empirical evidence on systemic, social and economic challenges that undermine women's rights to make an autonomous decision on prenatal HIV testing. Moreover, there is a need for identification of suitable strategies and best practices that balance human rights and public health perspectives in relation to the negative consequence of positive HIV test in the Ethiopian socio-economic and cultural context.

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APPENDICES

ANNEX (A) – THE WOMEN I INTERVIEWED

Interviewee # 1

She was married at the age of sixteen. At the time of the interview she was twenty-one and has given birth to two children. She is a high school dropout. She lives at the outskirts of Mekelle city where many public services including electricity supply have not yet reached. She reported that this fact has greatly affected her access to information through media. She said she accepted the offer of HIV test during one of her antenatal care visit because she believed that she did not contracted the infection. She said she never thought that married women can be infected with HIV.

Interviewee # 2

A twenty one years old married woman with three children aged 13 years, 7 years and 9 months from Mekelle city. She tested for HIV during her pregnancy even though she reported that she rejected the HIV test offers many times before she agreed to take it. At that time she said she was very sick and the health worker made her to start ARV therapy because her CD4 count was very low. During the interview time she reported she felt healthy again and was grateful for the government for providing the medication.

Interviewee # 3

She is 27 years old women and lives in Mekelle city. She has two children. She tested for HIV infection at the time of child birth for her second child. She was aware of HIV testing was integrated to all

maternal health care services. She got the information from her friends. She reported she was offered an HIV testing during her pregnancy that she rejected and never came back again to the health facility except for child birth. At the labour ward she reported that a blood was drawn from her without notification and she was told that she as contracted the virus. Her husband who accompanied her to the hospital was immediately informed of her HIV status by the midwives. She does not know if her husband has taken the test for HIV but she has a suspension that the midwives have asked him to do the testing for himself. Ultimately she reported that her husband has abandoned her and the children because of her positive HIV test results.

Interviewee # 4

She has been married for nine years and has two children aged 5 years and 10 months. She lives in Mekelle and she identifies herself as a housewife. She visited a health facility to conduct pregnancy test but ended up taking HIV testing as well. When she was told that she is infected by the virus she automatically blamed her husband for bringing the disease to the family. But when he conducted the testing the result showed that he is negative to the HIV testing. During the fieldwork time they were living together as discordant couples however she reported that it is already too much for her to tolerate the verbal and other abuses by her husband because of her positive HIV status.

Interviewee # 5

A high school graduate lives in Mekelle and works as a waitress. She has three children from her husband. She has never visited ANC for her first two pregnancies and she also gave birth at home. But in her third pregnancy she visited ANC for the first time and the health workers keep asking her to uptake the HIV test. She then totally avoided visiting health facilities during her pregnancy but she went

there for her child birth. At the labour ward she agreed to test for HIV and the result showed that she is HIV positive. Her husband was automatically informed of her test results by the midwives but he refused to conduct the HIV test for himself.

Interviewee # 6

Twenty six years old married women. She lives in Ofla and identified herself as member of the ruling party in Ethiopia. During the fieldwork period she was in her second marriage and she was pregnant for her second child. She said her first husband died but they have one child together. Even though she never had the practice of visiting ANC services during her first pregnancy, she did it during her second pregnancy because of the training she go due to her membership in the political party. When she learnt her HIV status she reported she was shocked because she never thought that married women can infected of the HIV virus. She reported her husband has also tested positive to an HIV test and they were living together during the fieldwork period.

Interviewee # 7

A farmer from Ofla and has four children. She reported that she was married at a very young age. She never had any practice of visiting health facility during her previous pregnancies and child births except for her last pregnancy. She reported of being convinced by the extension health workers that she has to give birth at health institutions. However, at the health centre she reported that she was told that she need to test for HIV and the result showed positive. Her husband was immediately notified of her HIV test results and he was also made to agree to test for HIV that showed positive to the infection.

Interviewee # 8

She is an eighteen years old woman. She identified herself as a farmer and she was living in Ofla during the fieldwork period. She has only one child aged 11 months. She was tested for HIV infection during her pregnancy. She was advised by health extension workers and the women in her WDAs to visits ANC regularly. She does not know if her husband has ever tested for himself but she reported that he chased her away upon her disclosure of her HIV test results. She also mentioned that she does not have a land of her own and she went back to her mother with her child. During the field work time the mother of the interviewee was preparing to send village elders to the husband so that he will accept his wife again.

Interviewee # 9

She lives in Ofla. She is a farmer and has two children during the interview time. She said her first daughter is from her first marriage. Her first husband died during an armed conflict between Ethiopia and neighbour country Eritrea. She then married her second husband and they have a girl child together. She tested during pregnancy. Her current husband also tested positive as well. She reported they would have lived happily together if it was not for his family who blamed her for infecting their son. She reported that she has been threatened to be divorced by her mother-in-law repeatedly because of her HIV status.

Interviewee # 10

She is 44 years old woman who lived in Ofla during the fieldwork period. She reported to have four children from her husband to whom she married at a very young age. She tested for HIV during her pregnancy period and she reported she never taught that she could be infected with the virus as she was

marriage since her childhood. She reported of disclosing her HIV test results to her husband but she does not know if he has taken the test for himself or not.

Interviewee # 11

She is twenty four and a mother of three. She identified herself as a farmer and was living in Ofla during the fieldwork period. She has never visited health facilities during her first two pregnancies but she visited the health centre during her third pregnancy because of the recommendation of health extension workers. At the health centre she was asked to test for HIV to which she tested positive. Her husband was also tested positive afterwards. Both of them are now members of people living with HIV association.

Interviewee # 12

She is 35 years old woman who lived in Mekelle city at the time of the interview. She identified herself as a business woman and she was married with three children at the time of the interview. She reported that she was made to understand the advantage of testing for HIV during pregnancy to which she agreed and test positive. Her husband also tested positive to HIV infection. She reported that she never experience any kind of violence at the hands of her husband because of her HIV test results. She believed that such violence happens to women who are economically dependent to their husbands.

Interviewee # 13

A mother of two and married woman. She was living in Mekelle city at the time of the fieldwork. She reported that she was aware of the integration of HIV testing with all maternal health care services with the help of mass media. She also had friends who undergone HIV testing in relation to their pregnancies. She reported having agreed to up take the HIV testing during her pregnancy because she was convinced that she will be forced to conduct the testing during child delivery.

Interviewee # 14

A thirty years old married women with three children. She tested for HIV during child labour. She reported of visiting a health facility during her pregnancy only once. She was offered with the HIV testing but rejected it. At the time of child birth she showed up in the labour wards with unknown HIV status. When she was asked to test for HIV she agreed because she said she believed that they will do it wither she agreed or not. Her HIV result was withheld from her and not communicated to her until she was done with the child birth. However, she also reported that she was made to take a tablet that will protect her baby from HIV infection during the delivery.

Interviewee # 15

She is a twenty six year old married woman with four children (another one died of cancer). She reported that she was a farmer and lived in Ofla at the time the interview was conducted. She married her husband when she was fifteen. She tested positive for HIV during her last pregnancy. She reported that the death of her son was devastating to her that she did not even care whether she is HIV positive or

not. She also reported that her husband has also been quite sick for long time and was worried about the cause of his deteriorating health situation although it never occurred to her that she could contract the disease from him.

Interviewee # 16

Aged twenty-two, she is a mother of one child. She reported that she is a farmer although she does not have her own land. She was in her second marriage at the time the interview was taken. She reported that her first husband died after suffering for quite long time. He never tested for HIV so she does not know what killed him. After a while she reported of marrying her second husband and they have a child together. She reported of disclosing her HIV test results to her husband but he never told her if he had checked his HIV status for himself.

Interviewee # 17

She is in her mid-twenties and lives in Ofla with her husband and their four children. She was married to her husband at the age of 14. She reported that she took the HIV test during her pregnancy. She disclosed her test results to her husband and he also tested positive for HIV. She reported that the positive HIV test result has negatively changed their relationship with her husband that they are fighting more frequently and that makes her worry a lot.

Interviewee # 18

She is a thirty seven years old woman who lives in Ofla with her husband and five children. She got tested for HIV during her pregnancy during one of her ANC visits to the health facility. She communicated the test result to her husband. However when he conducted the testing for himself he

tested negative. They agreed to live together for the sake of the children. She described her relationship with her husband as discordant couples very difficult.

Interviewee # 19

She tested for HIV at the time of child delivery. She is a twenty two years old woman who lives in Ofla with her husband and three children. She never had the practice of visiting health facilities during her previous pregnancies, however during her last pregnancy she was advised by health extension workers and her peers at the WDAs to give birth at health centre. She said that she agreed for the HIV test with strong believe that married women cannot be infected with the virus but the result showed positive.

Interviewee # 20

A woman in her mid-twenties and lives in Ofla with her husband and three children. She never seek any maternal health care services during her previous pregnancies and child births. However during her last pregnancy she was told by health workers that it is must to give birth at health institution. She also reported that at the health facilities pregnant women undergone HIV testing from her sister who recently gave birth to a child. The positive HIV test result was a shock to her and she disclosed the fact to her husband with disbelief. However, her husband confessed that he was hiding his HIV status from her.

Interviewee # 21

She is an eighteen years old married woman who lives in Ofla with her husband and a son. She is a farmer although she do not own land by herself. She tested for during child delivery. She did not visit ANC during the period of her pregnancy but she was advices by health extension workers and her peers

at the WDAs to give birth at health centre. At the labour ward she was asked to take an HIV test to determine her HIV status and she agreed to the testing. The test result showed positive to HIV infection.

Interviewee # 22

She grew up in Ofla and was nineteen years old married woman who lives with her husband and a child. She tested for HIV during pregnancy and the positive test result was devastating to her. Her husband started to blame her for bringing the diseases home but as time goes he conducted the HIV testing and tested positive. Through time she reported that he is learning to accept their situation.

Interviewee # 23

She is twenty-two years old women and lives in Mekelle city. She has two children. She tested for HIV infection at the time of child birth for her second child. She was aware of HIV testing was integrated to all maternal health care services. She got the information from her friends. She reported she was offered an HIV testing during her pregnancy that she rejected and never came back again to the health facility except for child birth. At the labour ward she reported that a blood was drawn from her without notification and she was told that she as contracted the virus. Her husband who accompanied her to the hospital was immediately informed of her HIV status by the midwives.

Interviewee # 24

Twenty one years old married women with three children. She has completed high school and she has a plan join college. She does small business for a living and she lives in Mekelle with husband and their children. She tested for HIV during her pregnancy even though she reported that she rejected the HIV test offers many times before she agreed to take it. Her husband also tested HIV positive.

Interviewee # 25

She is a twenty years old married woman and lives in Mekelle with her husband and their two children. She reported that she was made to understand the advantage of testing for HIV during pregnancy to which she agreed and test positive. She communicated the test result to her husband. However when he conducted the testing for himself he tested negative. They were living together as HIV discordant couples during the fieldwork period.

Interviewee # 26

She is twenty-one years old woman and a mother of two (3 year old girl and 7 month body) and a housewife from Mekelle. She was married at the age of 17 and high school dropout. She said she visit the antenatal clinic in Mekelle hospital multiple times but did not want to test for HIV even if she offered with the test repeatedly. It was when she came to the hospital for child birth that she accepted for HIV test. The result for test showed positive and the midwives immediately tested her husband who accompanied her to the hospital for the delivery and his test result showed positive as well.

Interviewee # 27

Twenty-four years old marries woman with two children. She reported of taking the HIV test during her pregnancy. When she tested positive to HIV she withheld the information from her husband until she gave birth to her child safely in order to avoid arguments of who brought the virus in the family.

Interviewee # 28

She is 23 years old woman who lived in Mekelle city at the time of the interview. She identified herself as a business woman and she was married with two children at the time of the interview. She reported

that she was made to understand the advantage of testing for HIV during pregnancy to which she agreed and test positive. She reported having agreed to up take the HIV testing during her pregnancy. She expressed her awareness about her husband's extra marital affairs during their marriage but never thought of she might be infected with HIV. Her husband also tested positive to an HV test.

Interviewee # 29

She is a farmer aged 23 who lives in Ofla with her husband and their four children at the time of the fieldwork period. Although she never had the practice of visiting health facilities during her previous pregnancies, during her last pregnancy, she said she was advised by health extension workers and her peers at the WDAs to visit ANC. At the health facility she was offered with an HIV test to which she accepted. She believed that anyone who would not listen to the recommendation of the health worker shouldn't visit health facilities. Her HIV test result showed HIV positive.

Interviewee # 30

26 old woman from Ofla. She is a mother of three. She went to ANC for the first time at the 7th month of her pregnancy with advice of the health extension workers and the women development army. She agreed for the testing even she reported that she rejected the offer but was made to understand the advantage of testing by the health workers. When the test result showed positive result she reported of regretting not only taking the test but the idea of visiting ANC . Later on her husband also test positive to HIV infection.

ANNEX (B) - RESEARCH SUBJECT INFORMATION AND CONSENT FORM

This document informs respondents about Fana Hagos's PhD research at the Warwick University. It provides a general framework of the interview process, how information may be used, discusses issues of anonymity & confidentiality and potentials for future contact / feedback.

Upon agreement of participation, the interviewee shall sign the consent form.

The Interview Process

- Participation is voluntary & the personal choice of the individual.
- A respondent may decline to answer a question at any stage of the interview.
- There is no “correct” or “true” answer; questions are based on how individuals perceive & feel about the world around them. Answers are individual truths about daily life.
- I use an *interview guide* for “semi-structured” in-depth interviews. It is only a framework rather than an exhaustive list of questions.
- The interview will last approximately one hour.

The Interview as Dialogue

Interviewees are welcome to:

- Ask for clarification on questions.
- Ask me questions about myself, my project, etc.

- Correct me. If you believe I have missed an important aspect, said something inappropriate or inaccurate, please let me know. I welcome a dialogue.

What Will / Won't Information Be Used For?

- The data that I collect in this project will be used for my dissertation, journal articles, monograph and I hope to turn my dissertation into a book.
- Lectures/ presentations at conferences, seminars, courses & in my own teaching activities.
- Information, including quotations & transcriptions (see below) may be shared with my supervisors at Warwick for the purpose of discussion & analysis related to the PhD.

Anonymity & Confidentiality:

- I do not plan on using real names for my research. If you wish for your name to appear in the “acknowledgements” section, please let me know.
- A copy of the consent form will be given to take with you.

Tape Recordings & Transcriptions

As a qualitative researcher, recording & transcribing (writing the interview down word-for-word) is important to my research. If you allow me to record our conversation (as signed);

- I will personally transcribe the interviews word-for-word.
- When the recording is no longer needed for transcription, the recording will be deleted.
- Transcriptions will be stored in a locked space. Full names will not be listed on material.

- A respondent may request a copy of their personal interview transcription

Reporting of Results

If you are interested in hearing directly back from me with the results of the study, please provide some contact information. Please note that dissertation research may take years to complete, but I hope to have chapters or working papers available prior to the finished work.

ANNEX (C) - WRITTEN CONSENT AGREEMENT AND SIGNATURE SHEET

I agree to participate in Fana Hagos's interview. I do so willingly & acknowledge that my participation is voluntary. I am over 18 and eligible to participate in this study. I understand that the project is designed to gather information about academic work. I understand that I will find most questions to be interesting and thought-provoking. If, however, I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. I have read (or someone else has read it for me) and understand the information sheet provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

-
- I allow the interview to be taped: YES ☐
NO ☐
 - After the interview, I understand I am under *no obligation* for future contact. However, if an opportunity for future collaboration arises, I allow Fana to contact me so I may consider this opportunity:

YES ☐
NO ☐

If yes, contact information:

-
- I would like a copy of the transcription.
 - YES ☐ NO ☐

If yes, contact information (if not given above):

Respondent : Signature & Date_____

ANNEX (D) - INTERVIEW SCHEDULE FOR IN-DEPTH INTERVIEWS WITH WOMEN

[Brief introduction to the project, presentation of consent form to obtain written consent]

Preliminary Questions: ensuring informed consent

- Before we start, would you like me to explain any more details of my research, or do you have any questions about the research

General Questions

- Can you tell me a little bit about yourself?
- How many children do you have?
- For how long have you been married?

Questions about Interviewee's Previous Attendance of Prenatal Care and Child Delivery

- How did you learn about the benefits of antenatal care service?
- What were the reasons for you to access ANC during your last pregnancy?(delivery health care)
- What kind of service did you access at the ANC? Where did she gave birth and why?
- Could you tell me what you know about vertical transmission HIV testing?

Questions about Prenatal HIV Testing

- How did you learn the existence HIV testing scheme for pregnant women
- Could you describe your experience of HIV testing during pregnancy? (Child delivery)
- Did you expect that you will be offered with the HIV test in your fist visit to ANC?

(During child delivery)

- How do you describe your experience of the counselling session before you tested for HIV?
- How do you describe the consenting process at the time of the HIV testing?
- Did you feel that you could say no without any fear if you did not wish to test? If not, Why not?
Did you feel that it was hard to refuse? If Yes, Why?
- What made you decide whether or not to have the blood test? What was your husband /partner, family and others role in making such decision?
- Did you receive some medication to protect the child from being infected with HIV during pregnancy or child birth?
- Did you receive some medical treatment for your own health after the positive test result?

Questions Related to Positive HIV Test Results

- Do you think that there are any advantages for you of having a blood test for HIV?
(Which are the most important?) Are there any advantages for the baby?
- What does positive HIV result mean to you?
- How was the positive test result communicated to you? What was your reaction?
- Who knows about your positive test results? Who made the disclosure? Why?
- How did the positive test results affect your marriage?
- Do you believe you have experienced some sort stigma and discrimination because of your positive test results?

Wrapping up the interview

- In what do you recommend the HIV testing procedure during pregnancy/child birth to be improved? Why?
- Do you think that I have missed any important questions or issues?
- Is there anything you wanted to know about my research?
- Would you like to add any more comments?

ANNEX (E) - INTERVIEW SCHEDULE FOR IN-DEPTH INTERVIEWS WITH HEALTH CARE PROVIDERS

Preliminary Questions: ensuring informed consent

- Before we start, would you like me to explain any more details of my research, or do you have any questions about the research

General Questions

- Can you tell me a little bit about yourself?
- Can you tell me the kind of trainings (when and by whom) you have taken on PMTCT programmes and specially on HIV testing?
- In your personal understanding how do you assess the implementation of PMTCT programme in your Hospital (Health Centre?)

Questions about procedures of HIV testing of pregnant women

- What do you think is the main challenges of HIV testing uptake among pregnant women?
- How do you think is the new testing approach helping in addressing this challenges?
- Can describe to me the pre-test counselling sessions is being provided to pregnant women in your hospital/ health centre?
- Can you describe to me the consenting process of HIV testing during pregnancy?
- What do you think is the reason that many pregnant women tend to decline HIV testing upon group education and individual counselling?

- Do you think there is a particular difficulty of offering HIV test during child delivery to women with unknown HIV statuses
- What actions do you take if patient refused to test? Do you think you women need a Justification for refusal?
- In practice what do you actually do to convenience pregnant women who refused HIV testing during ANC? Which organs of the society, or government of family of the patients do you usually contact to convenience pregnant women who refused testing?

Questions relating to after HIV testing procedure conducted

- How is the positive HIV result communicated to the pregnant women?
- Who else do you believe should know about the result? What does the practice show?
- Do you appreciation of the potential negative consequences of testing HIV positive for women in their marriage or community? Does is differ depending on the socio-economic status of the woman?
- Do you think women are justified to refuse HIV testing if they fear violence in the hands of their husbands if test positive ?
- Do you think women tested positive for HIV need to be asked for their consent to administer the ARV treatments?

Other Questions

- What measures should be taken to scale up the program?

- External and internal factors of competence that limit health workers' ability to provide good quality service in the implementation of PTMCT programme
- How do you describe the role of health extension workers in the implementation of PMTCT and HIV testing of pregnant women?
- How do you describe the role of women health development programme in the implementation of PMTCT and HIV testing of pregnant women?

Wrapping up the interview

- In what do you recommend the HIV testing procedure during pregnancy/child birth to be improved? Why?
- Do you think that I have missed any important questions or issues?
- Is there anything you wanted to know about my research?
- Would you like to add any more comments?

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