

Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV

**AN ASSESSMENT OF THE NEEDS
OF WOMEN LIVING WITH HIV IN THE
AMHARA AND SOMALI REGIONS OF
ETHIOPIA AND THEIR UPTAKE OF SERVICES
FOR THE PREVENTION OF VERTICAL
TRANSMISSION AND SEXUAL AND
REPRODUCTIVE HEALTH AND RIGHTS**

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Acronyms

| | |
|---------------|--|
| AIDS: | Acquired Immune Deficiency Syndrome |
| ANC: | Ante-natal Care |
| ART: | Anti -Retroviral Treatment |
| ARV: | Antiretroviral |
| CBO: | Community Based Organization |
| FGD: | Focus Group Discussion |
| GNP+: | Global Network of People Living with HIV |
| GO: | Governmental Organisation |
| HAPCO: | HIV and AIDS Prevention and Control Office |
| HIV: | Human Immunodeficiency Virus |
| IEC: | Information, Education and Communication |
| M2M: | Mother to Mother group |
| MCH: | Maternal and Child Health |
| NEP+: | Network of Networks of HIV-Positive People in Ethiopia |
| NGO: | Non- Governmental Organisation |
| NNPWE: | National Network of Positive Women Ethiopians |
| OI: | Opportunistic Infections |
| PLHIV: | People living with HIV |
| PMTCT: | Prevention of Mother to Child Transmission [preferred terminology is the prevention of vertical transmission] |
| PVT: | Prevention of Vertical Transmission |
| SRHR: | Sexual and Reproductive Health and Rights |
| VCT: | Voluntary Counselling and Testing |
| WHO: | World Health Organisation |

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Executive Summary

The National Network of Positive Women Ethiopian (NNPWE) in collaboration with Global Network of People Living with HIV (GNP+) and Network of Networks of HIV-Positive People in Ethiopia (NEP+) conducted this study. The main objective of this study was to assess the services on the prevention of vertical transmission and sexual and reproductive health services that were being provided in the rural areas of Amhara and Somali regions and identify the factors that hinder HIV-positive women from being able to access these services.

This study is an addition to the same study conducted by NNPWE in Adama and Addis Ababa two years ago. The rationale to scale up the research was to build more evidence on the prevention of vertical transmission, HIV and reproductive health services, their uptake and accessibility at grass root level. Based on this, the research was conducted in Amhara region (Kuta ber, Dur bate and Gonder) and in Somali region (Jijiga town).

In order to ensure the implementation of the GIPA principle and build the capacity of HIV-positive people and their associations, the research was carried out by staff working in NEP+, NNPWE and Wogagen (from Gonder), Yemilinium Raey (from Dessie) and Berhan (from Jijiga) associations of women living with HIV.

This study report is divided into four chapters. The first chapter is a literature review which provides an oversight of HIV prevalence and related issues in Ethiopia and the rationale for the research. The second chapter presents a general description of the research process, methodology, and demographic characteristics of the respondents and limitations of the study. The third chapter outlines the main findings of the study and presents a discussion. The outcomes of the study are discussed under four major topics: Policy implementation, available interventions, service delivery, levels of awareness about the prevention of vertical transmission, ANC and HIV, and barriers which hinder HIV positive women from accessing services to prevent vertical transmission. The final chapter summarises the conclusions and recommendations of the study.

Study methodology

The research was qualitative; and the data collection method involved focus group discussions (FGDs) and one-to-one in-depth interviews. A total of four FGDs (each group consisting of 8 people), 17 in-depth interviews with women living with HIV, 8 interviews with men living with HIV, and 16 interviews with government officials and health care providers and, were conducted. In total, data was collected from 73 people through FGDs and one-to-one interviews.

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Summary of main findings and conclusion

The current national HIV and AIDS, PVT and reproductive health policy is well designed and addresses the issues of prevention of vertical transmission and the sexual and reproductive health and rights of women living with HIV. The PVT guidelines were developed based on WHO standards. However, the implementation of policy at community level is problematic. This is due to a lack of resources, infrastructure and limited knowledge of policy among implementers at community level.

There are a variety of interventions on HIV; the prevention of vertical transmission and SRHR are being implemented by GOs, NGOs, CBOs, 'anti-AIDS' clubs, M2M groups and associations and networks of people living with HIV. These interventions, whilst encouraging, still need better coordination, integration and need to ensure sustainability and quality.

The main interventions being implemented are: awareness-raising activities on HIV prevention, prevention of vertical transmission of HIV, family planning and VCT, capacity building, care and support, outreach services by health extension workers, community conversation and different treatment options for HIV. PVT services are offered by health centres. The majority of HIV-positive women interviewed mentioned that they benefited considerably from the services given by M2M groups to access health facilities for ANC and the prevention of vertical transmission.

The quality of services to prevent vertical transmission, provide sexual and reproductive health advice and other HIV services vary from region to region and within also within the regions; the quality decreases in rural areas. The main factors for low quality of services are shortage of human resources, laboratory equipment, medication and absence of some essential services. The shortage of qualified doctors is identified as a major impediment in ensuring the delivery of adequate services.

The level of knowledge on the prevention of vertical transmission, sexual and reproductive health and rights, family planning, ANC, child feeding, and HIV medication has improved among women who accessed PVT services, whereas the level of awareness remains low among the general public.

The key causes of the low uptake of services to prevent vertical transmission and the effectiveness of treatment are a lack of awareness about SRHR, ANC, the prevention of vertical transmission and HIV treatment and their availability in health care facilities. Although the level of HIV-related stigma and discrimination varies over time and is experienced differently among people living with HIV, stigma remains a key barrier to accessing HIV treatment, care and support services. Misconceptions about HIV, based on religious beliefs, are a significant barrier for accessing HIV treatment especially amongst the Muslim community.

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The significant distance between health facilities and the homes of people living with HIV is another barrier to accessing HIV services. As most health facilities are in urban areas, women living in rural areas cannot access professional health care because of lack of transportation and lack of money to afford these services.

Gender inequality is another factor preventing women from accessing health services. As women in the areas of study are often economically dependent on their husbands, they often lack the power to make decisions on family planning and their own sexual and reproductive health. The participation of men in services to prevent vertical transmission and ANC services is very low in both of the study sites. This is mainly due to a lack of awareness on the issue and rigid patriarchal power structures within families, which affect decisions made about family planning.

Recommendations

A. Integration of services to prevent vertical transmission, sexual and reproductive health and HIV services.

There is a need for continuous efforts among government bodies and different stakeholders and donors to ensure that national HIV policy, programs, strategies - and their implementation, are assimilated in SHRH services to prevent vertical transmission. The HIV treatment, care and support program-package should also include sexual and reproductive health service provision, economic empowerment and services to prevent vertical transmission. The issue of gender should be mainstreamed throughout the aforementioned national programs to prevent vertical transmission and promote sexual and reproductive health and rights.

B. Evidence based advocacy for the promotion of quality services to prevent vertical transmission

Different stakeholders, including people living with HIV, their associations and networks, should continue their advocacy efforts to influence policy makers, donors and the government to allocate more resources and prioritise prevention of vertical transmission, promotion of sexual and reproductive health and rights, and addressing gender inequalities. Advocacy work should be evidence based and reflect the reality of practices at available services on grass root level.

C. Scaling up community based programs to prevent vertical transmission

A scale up of community based initiatives would enable a greater access to PVT-, ANC- and PICT- services by women and their partners. Rural areas would particularly benefit from

scale up of M2M groups, community education programmes and health care extension through outreach workers. Community based programs improve uptake and access to PVT-, ANC-, and family planning services.

D. Continuous awareness raising campaign

A continuous awareness raising campaign, especially at grass root level should be supported. This campaign should be led mainly by community based organisations, health centres and PLHIV associations. The types and number of IEC materials used to promote the prevention of vertical transmission should be increased and widely distributed at grass root level.

E. Access to services to prevent vertical transmission should be included in the major HIV prevention strategy

Conventional approaches to HIV prevention which have been used to educate the public on HIV prevention methods should be revised in light of current HIV prevalence and services available in the country. PVT and sexual and reproductive health should be included in public awareness programmes.

Chapter One: HIV and AIDS related issues in Ethiopia

1.1 Literature review

Women living with HIV have had to repress poor health and systemic discrimination when trying to overcome challenges relating to HIV. In the last decades, women living with HIV have experienced various stigma and discrimination from community members and state institutions in Ethiopia. Most women living with HIV have limited knowledge about their basic rights to information and access to sexual and reproductive health services, as well as prevention of vertical transmission services. Moreover, earlier studies showed that those women living with HIV who have access to information often refused to use these services because of barriers such as long distances to service facilities, poor quality and integration of services to prevent vertical transmission within MCH services, and the fear of stigma and discrimination.

Vertical transmission of HIV, which can occur during pregnancy, delivery or breastfeeding, accounts for over 90 per cent of paediatric infections. Sub-Saharan Africa, where women constitute 61 percent of adults living with HIV, represents 90 percent of the 420,000 children newly infected with HIV in 2007¹. Without any interventions, one in three children of women living with HIV will be infected with HIV.

The risk of paediatric infection is higher in countries with high HIV prevalence in women. Despite the reported decline in HIV prevalence among young pregnant women attending antenatal clinics in many sub-Saharan African countries, prevalence remains high in some countries.

The Government of the Federal Democratic Republic of Ethiopia has shown commitments to overcome challenges faced by women living with HIV. The national HIV and AIDS policy was enacted in 1998; and in 2001, the National HIV/AIDS Council declared HIV a national emergency. The National HIV and AIDS strategic framework had outlined a multi-sectoral response, guaranteeing rights of all people living with HIV and. Moreover, the national guidelines on the prevention of vertical transmission, and the National Reproductive Health Strategy have been endorsed by the government of Ethiopia to facilitate the supply and integration of SRH and PVT services².

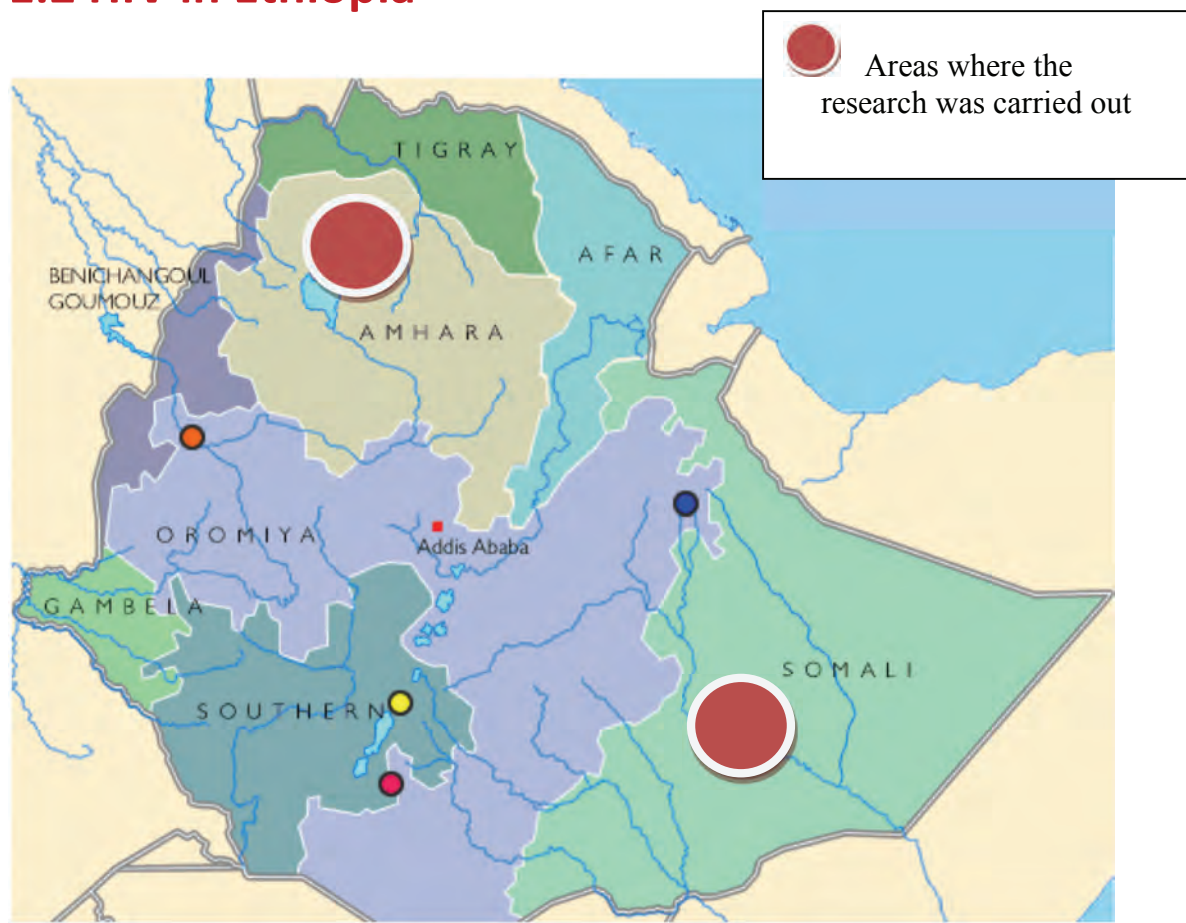
¹ UNICEF 'Children – HIV and AIDS' – document last updated 2010

² HIV/AIDS Prevention and Control Office, Ministry of Health (2007) 'Guidelines for Prevention of Mother-to-Child Transmission of HIV in Ethiopia',

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Various recent studies have reported that the level of uptake of PVT services among women living with HIV remains low in comparison to other HIV care and support services. This is due to, among other reasons, lack of awareness among women of the availability of these services, low economic status, poor implementation of existing HIV and AIDS policies, lack of resources and HIV related stigma.³

1.2 HIV in Ethiopia



Across the country, the epidemic is generalised. However, urban areas and women are more affected than rural areas and men. Urban HIV prevalence was 7.7% in 2009 and this accounted for 62% of the total PLHIV in the country, while rural HIV prevalence was 0.9% in 2009, which accounted for 38% of total PLHIV population in the country. The estimated national adult HIV incidence of 0.28% in 2009 translates to over 131,000 new HIV infections. There is variation in the prevalence among regions both by urban and rural settings. The HIV prevalence in urban areas ranges from 2.3% in Somali region to 10.8% in Afar region. There is also variation in the urban HIV prevalence among big regions: Oromia (6.1%), SNNPR (7.2%), Amhara (9.9%), and Tigray (10.7%); whereas the rural HIV prevalence ranges from

³ HAPCO (2009) Annual report

0.4% in Somali region to 1.4% in Amhara region. Small towns are becoming hot-spots and can potentially bridge further spread of HIV epidemic to rural settings. Addis Ababa and four regions: Amhara, Tigray, Oromia, and SNNPR account for 93.4% of the total PLHIV population in the country. According to the universal access targets, it is expected that 80% of HIV positive mothers attending ANC should have received PVT services in 2010⁴. Currently, however, only 8.3% of HIV positive mothers in ANC received ARV prophylaxis.⁵

1.3 Policy Environment

The Ethiopia Constitution states that “...Women shall have equal rights with men in the enjoyment of the rights and protections guaranteed by this Constitution to all Ethiopians... The State has the duty to guarantee the right of women to be free from the influence of harmful customary practices. All laws, stereotyped ideas and customs which oppress women or otherwise adversely affect their physical and mental well-being are prohibited... Women shall have the right to demand that their opinions be heard on matters of national development policies, on plan and project implementation, and in particular, on projects affecting their interests. Women shall have the right of access to education and information on family planning and the capability to benefit thereby so as to protect their good health and prevent health hazards resulting from child birth.”⁶ This creates great potential for the development of maternal and child care programs. The national health policy also identifies that due consideration is needed for mother and child health, emphasizing inter-sector collaboration for family health and population planning.

The national HIV and AIDS policy was enacted in 1998; and in 2001, the National HIV and AIDS Council declared HIV a national emergency.⁷ The National HIV and AIDS strategic framework calls for a multi-sector response, guaranteeing the rights of all people living with HIV and AIDS, and facilitating the supply and use of antiretroviral drugs. Ethiopia has adopted the WHO/UNICEF/UNAIDS 4-pronged PVT strategy as a key entry point to HIV care for women, men and families. Technical interventions, including antiretroviral medications, satisfactory obstetric care, effective health system management and resource allocation, as well as addressing gender bias, are all part of the comprehensive national PVT program. Addressing all four prongs has the potential to impede systemic failures in PVT efforts.

⁴ FHAPCO: Multi-sectoral HIV/AIDS Response Annual Monitoring and Evaluation Report, July 2008 - June 2009

⁵ Report on the progress towards implementation of the UN Declaration of Commitment on HIV/AIDS, 2010

⁶ Translation of the Ethiopian Constitution - http://www.africa.upenn.edu/Hornet/Ethiopian_Constitution.html

⁷ National Family Planning Guidelines Ethiopia

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According to the annual HIV and AIDS multi-sector response, 2009-2010, the Federal HIV and AIDS prevention and Control office reports that due to the expansion of HIV services in the health facilities is focal, it has been possible to expand services to prevent vertical transmission and support mothers in health facilities. The number of health facilities that provide vertical transmission services has grown from 32 in 2003/4 to 1352 in 2009/10. However, because the number of health facilities that provide vertical transmission services is still below 50% of the total number of health centres that could provide PVT services, greater efforts are needed to ensure and expand availability of such services. In places like Addis Ababa, where many private health facilities provide maternal and child health services, it is recommended to integrate PVT in the private health sector as well.

Chapter Two: Background to the research

2.1 General objective

The aim of this study is to assess the delivery of services to prevent vertical transmission and promote sexual and reproductive health and rights in the areas of focus. The research also seeks to identify factors that prevent women living with HIV from accessing these services in the rural parts of Amhara and Somali regions.

2.2 Specific objectives

- Assess the implementation of policies, programs and guidelines at grass root level to prevent vertical transmission.
- To assess the delivery of services to prevent vertical transmission and promote sexual and reproductive services.
- Identify the factors/barriers that prevent women from accessing these services.

2.3 The research process

The research was conducted in five phases. These include: designing the research framework, data collection tool development, training for data collectors, data collection, coding and analysing the data collected and preparing the final report.

2.4 Research design

In order to develop a road map which guides all the research activities a research framework which explains the objectives of the research, target group, the methodology and tools of data collection, population size, areas where the data would be collected, who the data collectors are, and action plan, was developed. The plan was developed by the research team and NEP+ project coordinator.

2.5 Methodology

Both primary and secondary data collection methods were used. The primary data collection methodology used in this research were: focus group discussions, in-depth interviews and observation.

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2.6 Data collection tools

Based on the objectives of the research, methodologies and the target population's characteristics the research team developed four different data collection tools which are:

- FGD guiding questions for men living with HIV who have a partner accessing services to prevent vertical transmission.
- FGD guiding questions for women living with HIV who are accessing services to prevent vertical transmission.
- Semi structured in-depth interview questionnaire for women living with HIV who are accessing services to prevent vertical transmission.
- Guiding interview questionnaire for health care providers, case managers and government officials, policy makers and implementers.

2.7 Training and orientation for data collectors

In order to inform the data collectors about the objectives, topic and methodology of the research, target population, and the data collection tools, a one-day training was provided for members of the research teams. The training was delivered by a health care professional who is experienced in issues related to the prevention of vertical transmission and sexual and reproductive health; and staff members of NNPWE who are well experienced in conducting similar research. The topics of the training included basic information on the prevention of vertical transmission, data collection methods, how to conduct an interview, explanation on each of the data collection tools and how to transcribe the interviews etc. The members of the research team were selected from the following PLHIV associations and networks.

| S.No | Name of PLHIV association that participated in the research | Number of persons that participated | Sex |
|------|---|-------------------------------------|---------------------|
| 1 | NEP+ | 1 | Female |
| 2 | NNPWE | 6 | 4 Females & 2 Males |
| 3 | Wogagen association of PLHIV -Gonder | 2 | 1 Female & 1 Male |
| 4 | Birihan association of women living with HIV. | 1 | Female |
| 5 | Wogagen association of women living with HIV -Gonder | 1 | Female |
| 6 | Yemilinium Raey association of women living with HIV | 2 | 1 Female & 1 Male |
| 7 | Birihan association of women living with HIV | Project coordinator | Male |

2.8 Data collection

Data was collected from two regions of Ethiopia. In the Amhara region, data was collected from Dessie, Bahirdar and Gonder. In the Somali region, data was collected from Jijiga towns. A total of four FGDs (8 people/group), 17 in-depth interviews with women living with HIV, 15 interviews with government officials, 7 interviews with health care providers and 8 interviews with men who are living with HIV. In total, data was collected from 79 people through FGDs and one to one interviews.

Age Composition of PLHIV respondents

| AGE Group | 25-30 | 31-35 | 36-40 | 41-45 | 46-50 | 51-55 | 56-60 | TOTAL |
|-----------------------|-----------|-----------|-----------|----------|----------|----------|----------|-----------|
| FGD MEN | 1 | 2 | 2 | 1 | 0 | 2 | 1 | 9 |
| FGD WOMEN | 11 | 6 | 5 | 1 | 0 | 0 | 0 | 23 |
| PLHIV WOMEN INTERVIEW | 11 | 4 | 2 | 0 | 0 | 0 | 0 | 17 |
| PLHIV MEN INTERVIEW | 4 | 2 | 2 | 0 | 0 | 0 | 0 | 8 |
| TOTAL | 27 | 14 | 11 | 2 | 0 | 2 | 1 | 57 |

Composition of sex of respondents from government organisations and health facilities

*This information was not documented for all government organisations and health facilities interviewed. It was documented for 16 out of the 22 respondents.

| OFFICES | GENDER | | TOTAL |
|-----------------------------|----------|-----------|-----------|
| | F | M | |
| HAPCO | 0 | 3 | 3 |
| Finance & Economic | 1 | 3 | 4 |
| Health Bureau | 0 | 3 | 3 |
| Health Bureau/Case Managers | 3 | 1 | 4 |
| Women Affairs | 1 | 1 | 2 |
| TOTAL | 5 | 11 | 16 |

2.9 Limitations of the study

- A few of the respondents did not actively participate in the FGDs. They were passive during the discussion.
- It was challenging to find the appropriate person in some of the government offices. In Jijiga the data collectors could not get representatives from HAPCO as the person was not available at the time of the data collection.
- The interview and FGDs were conducted amongst people living with HIV who had accessed services to prevent vertical transmission.

Chapter Three: Results and Discussion

The findings of this study are discussed under four major topics. These are: policy implementation and existing interventions, service delivery, level of awareness on the prevention of vertical transmission, ANC and HIV, and barriers that prevent women living with HIV from accessing services to prevent vertical transmission.

3.1 Policy Implementation and existing interventions

3.1.1 Policy implementation

The regional HAPCO and health bureau are the primary actors working to ensure the implementation of the national policies and programs in the two regions. A majority of respondents from these two organizations stated that the national HIV and AIDS-, prevention of vertical transmission and reproductive health policies are well designed but there are still gaps in implementation: *‘Implementation at kebele and grass root level also has a lot of problems that need to be addressed as the direct targets live at that level’ (Gonder HAPCO, interview)*

According to this interview, one of the reasons for the gaps in services to prevent vertical transmission is, *“[i]n our region and city administration, I think the problem was that we have started very late to implement ART and [PVT] services. That gap created the lag in disseminating the service”*.

The majority of HIV-positive women interviewed did not have clear knowledge about existing national HIV-, PVT and sexual and reproductive health policies.

3.1.2 Available HIV, PVT and related interventions in the research sites

Almost all respondents said that different interventions on HIV, the prevention of vertical transmission and sexual reproductive health are being implemented by GOs, NGOs, CBOs, anti- AIDS clubs, M2M groups, PLHIV associations and their networks. The major interventions mentioned by most respondents are awareness raising activities on HIV prevention; the prevention of vertical transmission; family planning and VCT, capacity

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building, care and support, outreach service by health extension workers, community conversation and different medication on HIV and the prevention of vertical transmission by health facilities.

“We have three pillars in our activities. The first is prevention, the second focuses on care and support and the third core activity is capacity building... The PMTCT is another area we work on. Our programs target any community woman to seek testing. Pregnant women are encouraged for antenatal care and VCT and to deliver in health facilities.” (Amhara regional HAPCO).

3.2 Service Delivery

3.2.1 Types of service being given by health facilities

Almost all respondents from health Bureau, health facility, HAPCO and majority of PLHIV interviewed mentioned the following types of HIV, prevention of vertical transmission and sexual reproductive health services are being given by health centres, hospitals and clinics available in the respective sites.

- **Prevention of vertical transmission of HIV:** which includes voluntary counselling and testing (VCT), provider initiated counselling and testing, pregnancy testing, child testing, home to home counselling, antenatal care, post natal care, pregnancy follow up, and prophylaxis.
- **Awareness and education in health facilities and outside:** This includes education on PVT, HIV prevention, treatment, family planning and sexual reproductive health.
- **Provision of treatment:** The major medicines given by health facilities are ART, prophylaxis, AZT for the three ones, 3TC and Nevirapine.
- **Family planning services:** These include counselling on family planning, provision of contraceptive pills, distribution of condoms, JD for three years and 5 years and intrauterine devices (IUD).

3.2.2. Quality of services

According to most respondents there is a shortage of qualified human resources/ medical staff, laboratory equipment and shortage of medicines. Some basic and essential services are also lacking.

“There are instances where the professionals are overcrowded and we are asked to wait [considerably] longer than expected. I had [that] experience when I delivered my baby. Because the doctor was very busy. I had to wait for him and I started bleeding which should not normally happen when you are about to deliver. It could be fatal and my baby had to be [undergo treatment] for days because of that” (FGD,F,Desse).

The majority of women living with HIV who participated in the study also highlighted the problem of medication for opportunistic infections not being free of charge.

*“We have major problem with OI treatment, if we do not have money we do not buy.”
(Female FGD participant, Jijiga).*

There are also times when ART stocks run out *“I go to the hospital, I use 1.50 birr for transportation but now it has gone up. ART used to be given for three month but these days they only give us for a month” (FGD,F,Gon).*

In some health facilities there is no clearly written policy regarding confidentiality *“There is no written policy in the hospital but as a professional you are obliged to keep patients information confidential. We are sworn to secrecy” (int, Midwife nurse, Gon)*

Lack of laboratory equipment is also one of the factors which affect the quality of services *“For example today we have attended to 20 women and sent them to laboratory section for testing but the laboratory is not capable of doing all tests for all the [referred] cases.”(int, midwife nurse, Gon)*

Very few of the respondents expressed that they experienced an improvement in the quality of services *“Here in Gonder there is a Hospital, Poly and Family guidance, the care for mother and child is good. Especially family guidance does not ask for a chart they provide the service both for the mother and the child, they tell you the result in 30 minutes, and they order medicine.”(FGD ,F, Gon)*

3.3 Barriers that prevent PLHIV from accessing services

3.3.1 Lack of awareness, misconceptions, attitudes and cultural and religious beliefs

Most of the respondents identified lack of awareness on SRHR, ANC, prevention of vertical transmission and HIV treatment and services available in health centers as a significant barrier to uptake of PVT services.

“Almost nonexistent awareness of ART and [PVT] services in the population in earlier times. We have build up the awareness over time but still women prefer home delivery [over delivery within] health facilities’ (GONDOR, HAPCO, and interview).

In addition to the aforementioned, traditional and religious beliefs are recognised as

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obstacles for the service delivery in PVT. *“One reason could be cultural upbringing. Mothers have long been giving birth at home with the presence of all family members and traditional customs. Exposing themselves to somebody else in a health facility would be very strange for them. So they would not get encouraged to leave those old customs and seek medical observations” (Gonder HAPCO, interview).*

The attitude some women have towards treatment is still unchanged *“One challenge is even after the women know their HIV status and understand the need for a medical follow up; they refuse to come to facilities just because they are not interested. This kind of attitude is a problem”.* (Gonder, Health Bero).

Religious beliefs, especially in Giggiga, remain a problem for HIV treatment access. *“The Christians are ok, they get educated and become aware [of the issues]... but the Muslim society, even if they get the education they [are reluctant to accept it]. They do not want to come to PMTCT services, they say ‘what’s the need to go to the service? It is Allah’s will that we got pregnant and we will give birth if he wants it, there is no need to go to the hospital.”*(FGD, F, Jijiga)

The majority of the interviewed women living with HIV are those who have accessed services to prevent vertical transmission and have children who are HIV-negative. Most of them said that as a result of accessing services to prevent vertical transmission, their knowledge on the PVT, reproductive health, family planning, ANC, child feeding, HIV treatment has improved.

“When a woman decides to get pregnant, first she consults her doctor and if her CD4 count is low she would start ART and if she decides to use family planning she would be given choices about the methods she uses, there may be implants, pills, etc.”(FGD ,F, Gigiga)

Another woman from Gonder also shared what she gets from the service to prevent vertical transmission *“I think reproductive health has to do with spacing children according to our economy, preventing oneself from STIs using condoms and teaching HIV prevention”*(FGD, M,Bah)

Although public awareness levels have improved over time, HIV positive women still give birth at home.

“Sometime even professional and educated women want to deliver at home and the interest to attend antenatal care is at times very low’ (Gonder HAPCO interview)

The sources of information for the majority of respondents are associations of PLHIV, M2M groups and information disseminated at health facilities

“The mother support group provide information in the morning to the crowd of women who come there for treatment, whether positive or negative, about condom and family planning in general, using this opportunity, the women would get the information”(FGD, F,Gigiga).

Some also mentioned different treatment literacy trainings given by NGOs as important source of information. The media is also mentioned as another source of information

“A lot of information we hear from radio, TV and posters help us to some extent in changing the attitude as well. We have a number of experiences with many women who have changed their attitude and complied with the required treatments with these inputs in the association.” (FGD, F,Desse)

3.3.2 Stigma and discrimination

Although the level of HIV-related stigma and discrimination decreasing from time to time, changing its forms, it still remains a barrier for HIV treatment, care and support services. Most of the respondents mentioned that stigma is also a barrier for the uptake of services to prevent vertical transmission.

“The stigma is also there. A pregnant woman who is positive would not risk being isolated from her partner, neighbours, family and friends. So she prefers staying at home and avoids visits to the health facility.”(Amhara, HAPCO, int)

Stigma and discrimination is often internalised but also comes from the community and health care professionals: *“Some health professionals have unethical attitude towards HIV positive women. Some even insult us. My friend... stormed out of the health center and swore to never come back because a nurse treated her badly.” (FGD ,F, Dessie)*

The forms of stigma have become different from earlier experience: *“There is stigma and discrimination, but it is not straight forward, they do not come at you and say that you are HIV positive. Most people live in a rented house, they do not participate in a social event like IDIR, if I tell you from my own experience, I am part of an IDIR it was my turn to chop onions, one of the women came and told me to wash the dishes rather than chop onions. It is good that she [was honest] and told me her fear, which is that I might cut myself and contaminate the food”(FGD,F, Jijiga)*

Levels of stigma and discrimination also vary between Christians and Muslims; being higher among the Muslim population: *“stigma and discrimination is not severe in the Christian society because of the church education, there is a bit of sign which is seen in the Muslim society but I do not face that, I have IDIR, everyone knows me” (FGD,F,Gigi).*

3.3.3 Distance and accessibility of health services

As most of health facilities are found in urban areas women living in rural areas cannot access the services because of lack of transportation, some even cannot afford the cost: *“A number of health facilities are built to assist these women but there is a problem with accessibility as they are a bit far from where they live. Some of them are even difficult for us [to reach] when we want to visit them for some supervision. Most women walk to these facilities and that may create problems’ (Gonder HAPCO).*

There are women who had been following ANC and educated to give birth at health facility but because of the long distance to health care center they gave birth at home *“The new neighbourhood I live in is very difficult to walk, especially if it rains. My neighbour had to walk to the hospital as she suspected labour but they told her that she had to come back after 3 days. The next morning it was time for her labour, but she could not walk that muddy road. So she had to give birth at home without professional care” (FGD, F , Dessie)*

There are also instances when some women do not benefit from follow-up as a result of long distances. *“there are some who stopped coming here due to the distance and referred to another clinic or hospital, if they want they are transferred, but most of them will stop coming and go to another health facility.” (int, midwife nurse, Gon)*

3.3.4 Lack of involvement of men

As women are economically and socially dependent on their husbands the lack of participation of men in services to prevent vertical transmission, ANC and family planning is a factors for the low uptake of these services: *“All this and other reasons come down to lack of adequate knowledge. Husbands and men in general think their responsibility is just on the field and providing means for the family. So they do not want to accompany their wives [to seek services] even if she wants to go. They also do not want their wives to get tested as this implies disrespect”. (Gonder, HAPCO interview).*

As a result of this most women do not come to the available services *“My husband refused to test and stopped me from accessing the service and that is why I had to raise HIV positive child”(FGD, F, Dessie).* Some women still are not able to negotiate on their sexual and reproductive health and rights:

“I was this kind of man. I want everything my way. When I wanted a child, she says no. I deliberately stopped her from taking contraceptives and she was pregnant with my second child.” (FGD, Men, Bah)

Ethiopia

Couples from rural areas access services more than couples from urban areas:

“The couples who are from the rural parts come together, the women are brought by their husbands, if the women are from the cities, their husbands do not come. Even when they are HIV positive and worried to tell their husbands we ask her to call her husband so that we can tell him for her but they refuse to come, that’s the problem. There is lack of awareness.” (int, midwife nurse, Gon)

Chapter Four: Conclusions and Recommendations

4.1 Conclusions

- The National HIV and AIDS, prevention of vertical transmission and reproductive health policy is well designed and addresses the issues of the prevention of vertical transmission and sexual and reproductive health and rights of women living with HIV. The PVT guidelines were also developed based on the WHO standards. But there are implementation gaps at community level. These are due to a lack of resources, infrastructure and limited knowledge of the policy among implementers at community level.
- Different interventions on HIV, the prevention of vertical transmission and SRHR being implemented by GOs, NGOs, CBOs, anti- AIDS clubs, M2M groups, PLHIV associations and their networks are encouraging. However, they still need coordination, integration, and it is important that they are sustainable and of high quality.
- The major interventions being implemented are awareness raising activities on HIV and AIDS prevention, prevention of vertical transmission, family planning and VCT, capacity building, care and support, outreach service by health extension workers, community conversation and different treatments on HIV and PVT are given by health facilities. Majority of beneficiaries mentioned that they benefited largely from the services given by M2M groups.
- The quality of vertical transmission, sexual reproductive health and other HIV services vary from region to region and within the two regions where the research was carried out and the quality decreases in rural area. The major factors for low quality of service are shortage of human resources like professional health care providers, laboratory equipment, medicines and lack of some essential services. Shortage of professional doctors has a major impact on the quality of services available.
- The level of knowledge on the prevention of vertical transmission, reproductive health, family planning, ANC, child feeding, HIV medication is improved among women who passed through PVT services, whereas the level of awareness remains low among the general public.

Ethiopia

- The major factors accounting for the low uptake of the prevention of vertical transmission and effectiveness of the treatment are; lack of awareness about SRHR, ANC, vertical transmission and HIV treatment and their availability in the health facility. Though the level of HIV-related stigma and discrimination has decreased over time, it still remains a barrier for accessing HIV treatment, care, and support services. Misconceptions about HIV resulting from religious beliefs remain a major barrier for HIV treatment especially within the Muslim community in one of the research areas, Gigiga.
- The long distance between health facilities and the homes of beneficiaries is another barrier to access HIV services. As most of health facilities are found in urban areas women living in rural areas are unable to access the services because of lack of transportation and shortage of money to afford the services.
- Gender inequality is another factor preventing women from accessing health services. As women in the areas of study are often economically dependent on their husbands, they often lack the power to make decisions on family planning and their own sexual and reproductive health. The participation of men in services to prevent vertical transmission and ANC services is very low in both of the study sites. This is mainly due to a lack of awareness on the issue and rigid patriarchal power structures within families, which affect decisions made about family planning.

4.2 Recommendations

A. Integration of services to prevent vertical transmission, sexual and reproductive health and HIV services

There is a need of continuous efforts among government bodies, stakeholders, and international donors to ensure that national HIV policies, program strategies and their implementation integrate sexual and reproductive rights and health services to prevent vertical transmission of HIV. HIV treatment, care and support programmes should also meet the needs for sexual and reproductive health, economic empowerment and services to prevent vertical transmission. The issue of gender is pivotal in national services to prevent vertical transmission and delivery a high quality of SRHR programs.

B. Evidence based advocacy for the better quality services to prevent vertical transmission

Different stakeholders, including people living with HIV, their associations and networks should continue to develop their advocacy efforts to influence policy makers, donors and the government to allocate more resources and give priority for the issue of the prevention of vertical transmission of HIV, sexual and reproductive health and rights, and promote gender equality. Advocacy work should be evidence based and reflect the reality of practices at available facilities on grass root level.

C. Scaling up community program to prevent vertical transmission of HIV

A scale up of community based initiatives would enable a greater access to PVT-, ANC- and PICT- services by women and their partners. Rural areas would particularly benefit from scale up of M2M groups, community education programmes and health care extension through outreach workers. Community based programs improve uptake and access to PVT-, AND-, and family planning services.

A continuous awareness raising campaign, especially at grass root level should be supported. This campaign should be led mainly by community based organisations, health centres and PLHIV associations. The types and number of IEC materials used to promote the prevention of vertical transmission should be increased and widely distributed at grass root level.

D. Access to services to prevent vertical transmission should be included in the major HIV prevention strategy

Conventional approaches to HIV prevention, which have been used to educate the public on HIV prevention methods should be revised in light of current HIV prevalence in the country. PVT and sexual and reproductive health should be included in community/public awareness programmes.

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