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Challenges facing women living with HIV in Upper Egypt

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CHALLENGES FACING WOMEN LIVING WITH HIV IN UPPER EGYPT

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Abstract

This research aims to identify challenges that face women living with HIV in Upper Egypt in order to help policy makers and different stakeholders to overcome those challenges. Interviews with women living with HIV from different governorates in Upper Egypt were conducted. In addition, this research included interviews with national AIDS program officials and NGOs managers to obtain different perspectives about the condition of women living with HIV.

Women represent half of people living with HIV around the world. The burden of disease on women is even more challenging in many countries due to gender inequality. The effect of culture in Upper Egypt on women living with HIV was an added value to this research as there is shortage in researches that tackled this problem in this particular area in Egypt. Despite efforts to fight HIV in Egypt and to reduce stigma and discrimination, women living with HIV in Upper Egypt face many challenges. What are those challenges and how can Egypt overcome them? Main findings included that women living with HIV in Upper Egypt need a stigma free reproductive health services. They need to disclose about their illness without fear of stigma. Women face many difficulties to access reproductive health services upon disclosure about their status. Women might transfer the virus to their children due to mismanagement of their cases or lack of proper services in health care provision during child birth.

Moreover, there is a shortage in the services provided for PLHIV in Upper Egypt including medications' distributing centers and laboratory tests. Finally, there is a pressing social stigma against PLHIV which results in low utilization of testing services.

Key words

HIV, AIDS, Women, Upper Egypt

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List of Acronyms

HIV	Human Immunodeficiency virus
PLHIV	People living with HIV
AIDS	Acquired Immunodeficiency Syndrome
NAP	National AIDS Program
MoH	Ministry of Health
WHO	World Health Organization
MARPS	Most at risk populations
MSM	Men who have sex with men
IDUs	Injecting Drug Users
WLHIV	Women living with HIV
HCV	Hepatitis C Virus
HBV	Hepatitis B Virus
ARV	Anti Retro Viral
CS	Cesarean Section
VCT	Voluntary Counseling and Testing

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Chapter One: Introduction

"Let us give publicity to HIV/AIDS and not hide it, because [that is] the only way to make it appear like a normal illness." - Nelson Mandela (Seoka and Osman , 2014).

Mandela statement summarizes the complications that surround HIV in many countries. It explains that Human Immunodeficiency Virus (HIV) is not only a disease that kills millions of people around the world but also a social problem that affects all aspects of life for those who live with the virus. People living with HIV (PLHIV) suffer from a pressing social discrimination due to stigma surrounding this virus. Many people relate HIV to criminalized actions or social taboos like injecting drugs or homosexuality. As a result, PLHIV face further obstacles to live as normally as other people who have “normal” illnesses. Denial of services, firing from work and even family exclusion are among discriminative practices that face PLHIV when others know about their status. On one hand, HIV medications are available in many countries and people can live normally for many years without complications. On the other hand, stigma and discrimination still the main complain of PLHIV.

According to the National AIDS program (NAP), Egypt has low prevalence of HIV among general population (less than 0.1%). UNAIDS program in Egypt estimate that there are (4800-12,000) PLHIV in Egypt but many of them do not know their status. PLHIV in Egypt can know their status through a confirmatory test which is available only through Ministry of Health (MOH) central labs. Medications are available for free for those who need it in Egypt through NAP. Counseling centers are open in many governorates to provide PLHIV with the proper information about their situation.

One of the major problems regarding HIV in Egypt is the stigma against PLHIV. This stigma leads to discrimination in family, work place and in service provision. Stigma against women is further more complicated. In many conservative communities, women face unequal treatment regarding mobility and access to services.

Upper Egypt is a conservative region in Egypt where women cannot easily talk about their problems due to many social and cultural constrains. People might accuse women who are infected with HIV that they did unacceptable sexual behavior. This misperception about HIV discourages women from knowing their status and pursuing the necessary treatment. As a result, many women do not know their status, which jeopardizes their life.

This research aims to identify challenges that face women living with HIV (WLHIV) in Egypt in order to help policy makers and different stakeholders to overcome those challenges. Interviews with women living with HIV from three different governorates in Upper Egypt were conducted. In addition, this research conducted interviews with national AIDS program manager and NGOs managers to obtain different perspective about the situation of women living with HIV.

1.1. HIV global and local situation

HIV is a major global hazard that infected 2.3 million new cases in 2012 in addition to 35.3 million PLHIV around the world. Since it began, it has claimed around 36 million live. An estimated 1.6 million people died from AIDS related causes in 2012(CDC, 2014).

Egypt has low prevalence of HIV among general population. A cumulative of 6228 cases was reported until the end of 2013 (GARPR, 2014). UNAIDS estimates that there are (7400-12,000) people are living with HIV in Egypt which represent less than 0.1% of the population.

However,MoH has reported that there was a remarkable increase in the new reported cases in 2013 to almost the double numbers of the previous year. In addition, Egypt face a concentrated epidemic of HIV in most at risk population (MARPS) which includes men who have sex with men (MSM) and injecting drug users (IDUs).

Egypt initiated the national AIDS program (NAP) to lead the national efforts addressing HIV in Egypt since 1987 as part of MoH. Moreover, many civil society organizations and international agencies are working on HIV programs in Egypt. World Bank estimates external fund that Egypt has annually to support HIV programs with 4,150,000 USD. Despite all of these efforts, Egypt has increasing numbers of new cases. There are concerns from PLHIV regardingthe medications, service denial, poor follow up systems and many other problems.

1.2. Women and HIV

Women represent half of the people living with HIV around the world (WHO, 2014). The burden of disease on women is even more challenging in many countries due to gender inequality. Women face many difficulties to access reproductive health services upon disclosure about their status. In addition, they might transfer HIV to their children due to mismanagement of their cases or lack of proper services in health care provision during child birth.

Among the reported cases in Egypt, the ratio of females who live with HIV to malesis (1:4) (GARPR, 2014). This is unexpected as the global ratio is around (1:1). One of the authoritative explanations is that women have less access to testing services. Women living with HIV in Egypt are more likely to face stigma and discrimination due to cultural misconceptions.HIV is misperceived to be indicator for unacceptable sexual activities, women

who live with HIV in Upper Egypt struggle to keep their status secret and some of them prefer to die rather than inform their status.

1.3. Upper Egypt

Upper Egypt is the least developed part in Egypt. The poverty rate is highest in Upper Egypt and specifically rural Upper Egypt (51.5 %), followed by urban Upper Egypt (29.4 %) and it is the least prevalent in Urban Governorates (9.6 %); the same applies to the poverty gap and the squared poverty gap(CAPMAS, 2011). Poverty is the key root for many social and health hazards including HIV.

Stigma in Upper Egypt is more influential. Social structure is much stronger than other places in Egypt which means that people have less privacy and individuality. Tribes and extended families play a significant role in people's life in Upper Egypt. Accordingly, Womenhave restrictions in terms of social life. It is very important to investigate the effect of living with HIV on women in theseconservative communities. This research focuses on women living with HIV in Upper Egypt specifically. It is vital to investigate social norms, poverty, shortage of services and gender inequality and its effect on women.

Chapter Two: Research Approach

2.1. Research problem

According to World Bank, Egypt spent 7,593,000 USD on HIV programs in 2008 for both internal and external resources. With low prevalence of HIV in Egypt, it was expected to achieve great results in prevention programs. However, number of reported cases of HIV positive increased by 268% from 1990 to 2010 (BBSS 2010). Moreover, while world is getting to achieve the objectives of (zero new infections, zero stigma), Egypt in 2014 reported over 800 new cases which considered a large number comparing to low prevalence among general population (NAP 2014). The number of women who accept to be tested is still very low. Accordingly, the reported number of women living with HIV will continue to be low unless the challenges that face women living with HIV is seriously tackled. Culture of silence and fear can lead to serious consequences on the community.

Moreover, stigma and discrimination are common concern among PLHIV especially women. Denial of health services and persecution are major problems that face PLHIV which increase their silence and add more complications to the problem.

The research problem can be concluded as, despite efforts to fight HIV in Egypt and to reduce stigma and discrimination, women living with HIV in Upper Egypt face many challenges regarding access to services, social mobility and risk of raising their children. What are those challenges and how can Egypt overcome them?

2.2. Research objectives

This research aims to determine the situation of women living with HIV in Upper Egypt. In order to do this, the research identifies current efforts from government and NGOs that address

women living with HIV needs in Upper Egypt. This step helps to gauge the current situation in terms of services provided.

Moreover, the research determines challenges that face Women living with HIV in Upper Egypt in and the impact of these challenges on them and on the community. Firstly, the research highlights the overall challenges which might be similar among men and women. Secondly, the research focuses on the specific challenges that particularly affect women in Upper Egypt. Challenges include medical, social and psychological problems.

Finally, the research provides recommendations for different stakeholders to improve women living with HIV situation in Upper Egypt. The recommendations will help policy makers to design gender sensitive programs that bridge the gap between men and women affected by HIV.

2.3. Research questions

In order to achieve the mentioned objectives, research attempts to answer this main question.

- What are the particular challenges that women living with HIV face in Upper Egypt and how it affects their life?

  The answer of this question involves examining the different areas of potential challenges that could face WLHIV in Upper Egypt. Some of these challenges face both men and women. Other challenges are related to women position and gender disparities.

Under this question there are sub questions which are;

- What is the current situation of services provided to women living with HIV in Upper Egypt?

- What are the needs of women living with HIV in Upper Egypt and how to move forward to improve their quality of life?

Answering those questions involve mapping of the current services provided for WLHIV from government and NGOs. The answer also involves giving recommendations to improve the situation of WLHIV in Upper Egypt.

2.4. Research outline

This research consists of six chapters. The first chapter is the introduction which gives the fundamental orientation about HIV in Egypt and around the world. The introduction gives the context about types of challenges that face PLHIV in Egypt generally and WLHIV in Upper Egypt particularly. This chapter is followed by the second chapter which is on research approach. It includes identifying the problem statement, research objectives, research questions and ended with research outline.

The third chapter covers the literature review. The literature part gives the necessary background about similar studies. The literatures include studies related to different factors like poverty, gender equality and reproductive health. The purpose of the literatures is to examine the possible relations between HIV and other social problems. Chapter four describes the research methodology including ethical consideration of the research. Chapter five includes analysis of the collected data. Finally, chapter six concludes the main points from the analysis and gives the recommendations.

2.5. Research design

The qualitative methods are helpful to understand the roots and the implications of social behaviors (King et al, 1994). The research was designed to identify the challenges that WLHIV

face in Upper Egypt. It was important to have a better understanding of the problem by listening to different stakeholders. The research used qualitative tools for collecting data including interviews and focus group discussions.

Firstly, Interviews with WLHIV were conducted to understand their prospective about their own challenges. The access to the WLHIV was challenging but "friend of PLHIV NGO" helped to invite them from different governorates in Upper Egypt (ElMnia, Assiut and Fayom). "Friends of PLHIV NGO" is the main NGO that works with PLHIV in Upper Egypt. The interviews with WLHIV covered the different aspects of their needs including medical and social challenges. In addition, questions about services provided to them were important to determine the efforts from governmental and nongovernmental stakeholders.

Secondly, focus group discussion was conducted with WLHIV to discuss with them the common problems they face. The FGD was important to understand the personal differences among women and to identify the general patterns in their needs.

Thirdly, key informant interviews were conducted with the staff of "friend of PLHIV NGO". The interview with the NGO founder was informative as he was involved in HIV field from twenty years. He was NAP coordinator in Mnia before his retirement so he has both governmental and NGO experience. Another group of interviews were conducted with the staff and social workers to explore the different aspects of their work.

The interviews also included men living with HIV from the same governorates to understand the differences between men and women needs. The last interview was conducted with MoH official. It was very informative and helped to understand the governmental prospective and efforts to help WLHIV in Upper Egypt.

2.6. Ethical consideration and privacy

Consent formswere used before each interview. The consent was in Arabic and the researcher read it to ensure that they understand it.All ethical considerations and precautions were taken into consideration during conducting the research. The interview was documented by taking notes (No recording). The researcher used codes instead of names to guaranteethe privacy. The interviews were conducted in the NGO premises to ensure privacy. The researcher explained clearly the research objectives to avoid any vague expectations about research outcomes.

2.7. Sample

Five interviews with WLHIV were conducted. The interviewed women came from three different NGOs in Upper Egypt (Fayom, Mnia and Assiut). In addition, other five interviews were conducted with men from the same governorates.

Interviews with NGOs included founder, program director and social workers from“Friends of PLHIV” in Mnia. FPLHIV is a leading NGO in the field of HIV in Upper Egypt. It was established as early as discovering cases of HIV in Mnia with an initiative from a former national AIDS program coordinator in Mnia. It provides support group services for PLHIV in Mnia and Upper Egypt. Finally, an interview with a representative for ministry of health was conducted.

Women living with HIV	5 IDIs
Men living with HIV	5 IDIs
NGOs representatives	3 IDIs

Ministry of health and population	1 IDIs
FGD with WLHIV	1 FGD

Purposive sample was used to reflect the condition of women living with HIV in the selected governorates. The selected governorates are (Fayom, Mnia and Assiut) used to represent a sample of the other governorates in Upper Egypt. Upper Egypt has specific characteristics related to the social structure and gender roles. Moreover, rural Upper Egypt is the poorest region all over Egypt. The vulnerability of women living with HIV in a poor conservative society highlighted many dimensions of HIV situation in Egypt. Deprivation from services can increase the burden of poverty in Upper Egypt. In addition, many places in Upper Egypt put different obstacles on women rights which might be much more aggressive in the case of women living with HIV. Exploring the effect of these challenges provides policy makers and researcher with vital information about this topic. Upper Egypt includes 941 of the poorest villages in Egypt. This poverty affects different aspects of life.

Chapter Three: Literature Review

The first reported cases of HIV were diagnosed in 1981 in Los Angeles, United states. Five young homosexuals were infected by a specific type of pneumonia which is very uncommon. Other cases with similar immune deficiency problems were reported over this year and the term AIDS was used to describe the new disease in 1982. After four years, the virus that causes the disease was isolated and identified as (HIV). Accordingly, the people who are infected with the virus are called people living with HIV as they can live with it for many years without symptoms. Those who reach to end stage and their immunity become very weak are called AIDS patients.

There are many researches tackled the problem of HIV from different prospective. Yet, many of these researches focused on the scientific aspect of the disease and its epidemiological spread. Other researches tackled the social and cultural challenges related to the disease. This research belongs to social part of literature. As a result, the literature review chapter covers the relations between HIV/AIDS and other social problems like gender inequality and poverty. Previous researches highlight that there is a strong relation between HIV and many of those problems.

The study investigates challenges related to daily life. Access to health services, dealing with family members, right to move and travel, access to ARVs and the other aspects of challenges were researched to provide a comprehensive picture of the problem.

3.1. Poverty and HIV/AIDS

"AIDS is primarily a disease of poor, be they poor nations or poor people in rich nations". (Whiteside, 2008)

This statement highlights one of the most important aspects of HIV. Burden of the disease is much harder on poor and lead to increasing their challenges. There are many researchers investigated the relation between HIV and poverty. Multi-dimensional poverty determines the poverty levels by portraying multiple deprivations for example (life standards, child mortality, and educational level). Alkire (2010) utilizes micro data from household surveys and can be collected and used as indicator of poverty assessed in line with the standard UNDP definition, looking at indicators of health (nutrition and child mortality), education (child enrollment and years of schooling,) and living standards (measure of assets in a household), access to hard flooring, water, electricity, a toilet and cooking fuel).

On The IMF working paper titled "HIV/AIDS: the impact on poverty and inequality" It was highlighted that HIV problem has a lot to do with poverty. It is not only the direct effect on life expectancy, HIV affects people life in many ways. For example, HIV is responsible for increasing child mortality rates in many sub-Saharan African countries. HIV claims life of many youth who represent the effective power in the developing community. Accordingly, it contributes to increasing poverty in the developing nations. If we take MDGs as a universal development agenda, we will find HIV as a major challenge. MDGs mention HIV explicitly in goal number six "Reverse the spread of HIV/AIDS". But HIV has a lot to do with the other goals. Goal number one is to eradicate extreme poverty. HIV causes poverty in many countries by killing the people who can make money. Moreover, HIV pushes many students to leave their school as it claims life of their parents. Goal number two aims to achieve universal access to primary education. This will not happen without decreasing the new infected cases with HIV in the developing countries.

Figure 1 Millennium Development Goals (Source: UNDP.org)

Previous researches highlighted that many places in Upper Egypt face pressing life conditions. There are unequal resources distribution in Upper Egypt comparing to Cairo and Delta. The poverty rate is the highest in Upper Egypt and specifically rural Upper Egypt (51.5 %), followed by urban Upper Egypt (29.4 %) and it is the least prevalent in Urban Governorates (9.6 %); the same applies to the poverty gap and the squared poverty gap(CAPMAS 2011).

Table 1: Poverty in Egypt, 2011

Table 1: Poverty in Egypt, 2011 (% of total population)			
	People Living Under Extreme Poverty Line	People Living Under Lower Poverty Line	People Living Under Upper Poverty Line
Urban	2.6	10.6	24.6
Rural	9.6	30.0	52.7
Total	6.7	22.0	41.2

Source: World Bank (2011)

Table 2: Regional distribution of poverty in Egypt

Table 2: Regional Distribution of Poverty in Egypt, 2012 (%)				
	Extreme poverty	**Poor**	**Near poor**	**Share of population**
Metropolitan	2.8	4.6	9.1	17.0
Lower Egypt	13.7	27.6	44.7	31.1
Upper Egypt	83.1	67.1	45.0	50.3
Borders	0.4	0.7	1.3	1.5
Total	100.0	100.0	100.0	100.0

Source: World Bank (2012)

Tabletwo shows that Upper Egypt includes the majority of poor in Egypt. This poverty affects different aspects of life.

Figure 2: Percent of poverty by district

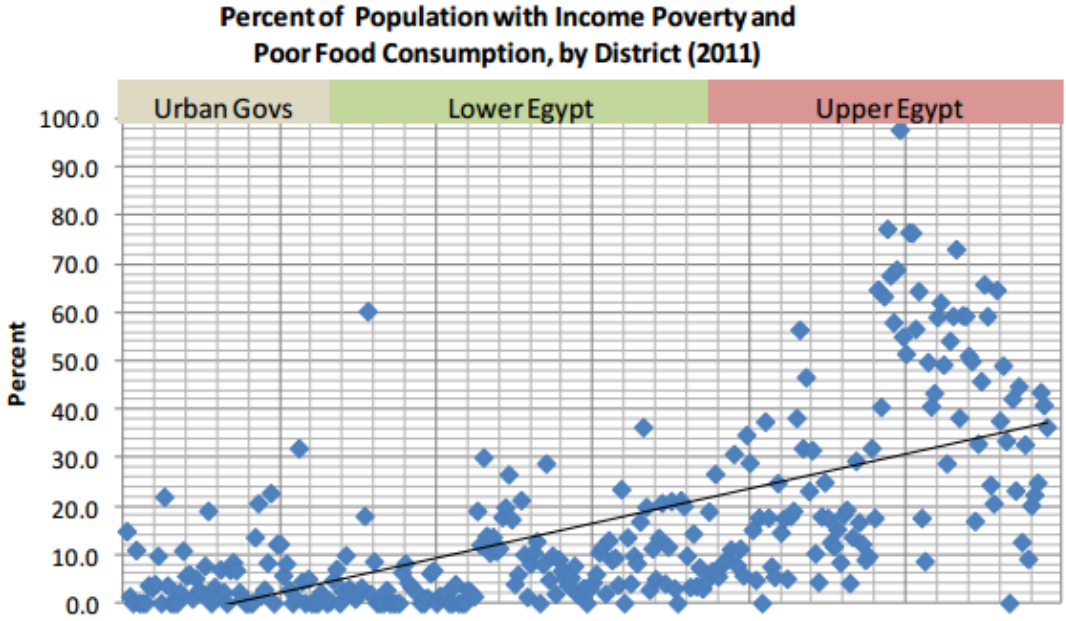

Figure 2(WFP, 2013)

Figure two shows the disparities in poverty level between different regions in Egypt. It is clear that Upper Egypt continued to have the majority of poor comparing to Delta and Cairo. This poverty level affects all aspects of life.

Deprivation from services can increase the burden of poverty in Upper Egypt. For example, there are only three distributing centers for ARVs in all Upper Egypt while there are eight in the rest. This put extra load on PLHIV to travel to the nearest center every month to get the medication. In addition, many places in Upper Egypt put different obstacles on women rights which might be much more aggressive in the case of women living with HIV. Exploring the effect of these challenges can provide policy makers and researcher with vital information about this topic.

3.2. Women and HIV

In Africa, more women are being infected from men through unprotected sex. Many countries in Sub-Saharan Africa have girls living with HIV five times more than boys (UNAIDS, 2000). This is due to biological and social factors. The biological factors are that women are more exposed to infection due to large surface area of genitalia. In addition, seminal fluid contains more viral load than vaginal fluid. On the other hand, men have power over relations and sexual practices in many developing countries. Accordingly, women face more difficulties to express their opinion or to protect herself by requesting using condom.

Although the issue of women and HIV is an important subject in development reports more than in academia, there are some studies tackled the issue in some communities around the world. Suzanne Mulligan (2006) examined social and economic determinants that affect women's infection with HIV. In her paper, Mulligan listed factors that enhance women exposure to HIV/AIDs. The list included Double standard morality, sexual violence and inferior status of women as social determinants make women more exposed to HIV/AIDS.

In many countries, gender roles enable men to have authority over women. Rights are not equal between men and women especially in developing countries where women fight to have fair opportunities (Baksh-Soodeen and Johnson, 2002). Scientists have discovered that survival rates for ladies are lower than survival rates of men tainted with HIV/AIDs; also, the mortality rate is higher among ladies of shading than European ladies (DeMarcoand Johnsen, 2003). Contrasts in survival and mortality may be because of the numerous obligations of ladies as responsible for family and children (DeMarcoand Johnsen, 2003).

The recent Population Council study entitled "Sexual and reproductive health for women living with HIV" addressed an important aspect of the problem which is the reproductive health

needs in terms of having safe sex, giving birth and using contraception. The study opens a door for further investigations about more aspects of challenges.

Regarding risky behaviors, Krai, Bluthenthal, Lorvick, Bacchetti, and Edlin (2001) stated that commercial sex workers are in a high risk to be infected with HIV. The study concluded that having sex for money is a major source of HIV infection. This study shed light on a hidden risk in Egypt. The sex workers in Egypt are not legalized and there is no official access for them. There is no regular checkup for sex worker in Egypt. There is shortage in data regarding their behaviors and numbers. Previous studies in Egypt (like BBSS) used snow ball sampling to access them. BBSS highlighted the limitation of access to illegal workers in sex due to social and legal barriers.

3.2.1 Gender inequality

Gender can be defined as social roles and expectations related to being a woman or man (World Bank, 2011). The issue of gender equality is a hotly debated topic and it is one of the development priorities. World leaders gathered in September 2000 to declare Millennium Development Goals (MDGs) and committed to meet those goals by 2015. MDG goal number three is promoting gender equality and empower women. Governments and NGOs have made remarkable efforts through different interventions to achieve this goal.

Tanenberg (2003) portrayed the requirement for gender based research and states that HIV avoidance methodologies ought to consider the different parts of women encounters, particularly those identified with power inequality. Women who are recently living with HIV have accentuated that social powerlessness and the unequal power connection between men and

women are deterrents to having safe sex and that these force aberrations added to their defenselessness to contamination.

There is a debate in the literature about the way to assess gender equality (World Bank 2011). The first prospective is to measure equality in opportunities. The second is to measure equality in outcomes. The individuals who see equality as fairness of chance contend that it permits one to recognize imbalances that emerge from circumstances outside the ability to control of people and those that originate from contrasts in inclination and decisions. A considerable assemblage of examination records such male-female contrasts in hazard avoidance, social inclination, and disposition about rivalry. It takes after that if men and ladies contrast, by and large, in disposition, inclination, and decisions, then not all watched contrasts in results can be ascribed to contrasts in circumstances. The individuals who contend for fairness of results contend that distinctions in inclination and demeanor are to a great extent "learned" and not intrinsic that is, they are the aftereffect of society and environment that lead men and ladies to disguise social standards and desires. Constant contrasts in force and status in the middle of men and ladies can get to be disguised in desires, practices, and inclination that propagate the disparities.

Studies show that Egypt takes steps to improve gender equality status in Egypt. Gender mainstreaming in socioeconomic national plan and development of national strategic framework are among best practices adopted by Egypt (MDGs Progress Report, 2010).

3.2.2 Gender inequality implications on health

A gender implication on health is a controversial issue as it is linked to many taboos in different communities. Starting in the mid-1990s, various worldwide gatherings were held and women reproductive health rights and wellbeing issues especially in developing nations turned into the central plan. The 1994 united countries International Conference on Population and Development (ICPD), known as the Cairo meeting, declared action plan for moving forward to enhance women reproductive rights. The issue of gender inequality and its consequences is hotly debated all over the world. Discrimination against women takes many forms including depriving them from access to health care. This can be life threatening in case of women living with HIV.

There is shortage in studies addressing health implications of gender inequality in Egypt. The following data shows reproductive health indicators that can be used to understand women needs in Egypt. It is remarkable that the disparity between poorest and richest among women is very high in indicators such skilled attendant at birth 97(richest 20%) and 55 (poorest 20%).

Economic vulnerability of women leads to many health complications. Women dependence on men weakens her situation in negotiation about using condoms or not to have sex. Different studies highlight those issues in African countries. The paper “How men's power over women fuels the HIV epidemic” by Gupta (2002), argues that to protect women from HIV we need to empower them. The paper stressed on the importance of the economic empowerment to give women a chance to decide about her sexuality. It concludes “If we are to contain the HIV epidemic we must tackle its root cause—gender inequality. It is this that is compromising the ability of women to protect themselves and promoting a cycle of illness and death that is threatening the future of households, communities, and entire nations”.

Table 3: Indicators on the situation of girls and women

MATERNAL AND NEWBORN HEALTH	YEAR	TOTAL	URBAN	RURAL	POOREST 20%	RICHEST 20%	SOURCE
Contraceptive prevalence (%)	2008	60	64	58	55	65	DHS 2008
Antenatal care coverage at least once by skilled personnel (%)	2008	74	85	67	54	92	UNICEF global database/ DHS 2008
Skilled attendant at birth (doctor, nurse or midwife) (%)	2008	79	90	72	55	97	UNICEF global database/ DHS 2008
Adolescent birth rate (number of births per 1,000 girls aged 15–19)	2006	50					UNFPA, UNPD, MDG database http://unstats.un.org [accessed in May 2011]
Maternal Mortality Ratio (adjusted) (maternal deaths per 100,000 live births)	2008	82					WHO, UNICEF, UNFPA, World Bank, Maternal Mortality Estimation Inter-agency Group (MMEIG) / UNICEF global database
Lifetime risk of maternal death, 1 in:	2008	380					

(UNICEF, Gender equality profile2011, p. 6)

Moreover, the economic situation can enhance women vulnerability in the marginalized communities. The synergy between many risk factors like poverty, discrimination against women, discrimination against PLHIV, conservative cultural habits and poor health services can lead together to an extremely stressful situation for women living with HIV in Upper Egypt.

Researchers stated that poverty can increase risk for infection with HIV/AIDS and that living with HIV/AIDs then lead to a remarkable decrease in individual and overall income and productivity (Amaratunga and Gahagan, 2002). Poor girls and women can take more risks to secure their basic needs even if they know the effect of risky behaviors on their health (Baksh-Soodeen and Johnson, 2002). These risky behaviors vary from a community to another. In many countries working as a commercial sex workers can be the only option for a needy girl. Klien,

Williams and Witbrodt (1999) portrayed the situation of poor women and the impact of low self-esteem on her ability to take right decisions and to protect her health.

The State of World Population (UNFPA 2009) report indicators highlight shocking facts of the situation of countless ladies living in developing nations. More than 585,000 ladies die every year in poor countries because of pregnancy related problems, around 1,600 passing away everyday for reasons identified with pregnancy and labor and at rates 200 times higher than those in rich nations. There is no prepared birth attendant accessible to support at 60 million births every year, and less than 30 percent of the moms in poor nations all in all get post-partum care, contrasted and a normal of 90 percent in rich nations. Nearly 50% of the 175 million pregnancies that happen every year in developing nations are undesirable or not well timed, and the number is most likely higher, given the frequently lacking information on immature female pregnancies (UNFPA, 2009).

3.3. Role of government and NGOs in HIV problem

There are many researches on a global level addressing roles of different stakeholders in facing HIV problem in different countries. Some of these researches focusing on highlighting the role of NGOs and others pay more attention to the governmental role. For example, a study titled "The role of non-governmental organizations (NGOs) in HIV/ AIDS prevention and care" analyzed two examples from Germany and Namibia to show the vital role that NGOs can play in developing a prevention model and achieving national goals. The study gives insights on the difference between developed and developing countries in terms of roles. There are many services that can be provided by both governmental and nongovernmental organizations. The role that NGOs play is affected by many factors. One of the most important factors is the political will to cooperate with NGOs. There is a shortage on the researches about role of NGOs

in Egypt in combating HIV. Accordingly, it was important to compare between the roles that NGOs play in Egypt and other countries in the discussion.

3.4. HIV in Egypt

Although many studies tackled HIV problem in Egypt from different prospective, there is a dearth on women related studies on this topic. The main study that provides basic information about HIV in Egypt is the BBSS. The study is a result of collaborative efforts from Ministry of health and population, FHI 360 and center for development services. BBSS provides information about behaviors among most at risk populations (MARPS) in Egypt. The study selected four risk populations and measured the prevalence of HIV among them. The study took sample from men who have sex with men (MSM), injecting drug users (IDUs), female sex workers (FSW) and street children. BBSS highlighted that Egypt faces concentrated epidemic among two of the MARPs.

In the study "HIV/AIDS Surveillance Systems: A Case Study of Egypt", research highlighted the pressing need to improve the surveillance system in Egypt in order to have reliable results. The research also stressed on the importance of raising awareness about HIV in Egypt as a prerequisite for a good surveillance system.

"A qualitative study of antiretroviral therapy adherence among HIV-positive women in Egypt" the researcher examined the factors that affect adherence to Anti Retro Viral (ARVs) which are the medications required to reduce viral load for PLHIV. The study used thematic analysis and proposed five factors contributing to adherence: fear of stigma, financial constraints, characteristics of ART, social support, and reliance on faith.

3.5. Lessons from the world

There are many lessons that Egypt can learn from the other countries. One of the successful models in combating HIV is Senegal. Senegal discovered the first infected cases as early as 1986 which is the same year that HIV was discovered in Egypt. Senegal was very successful in admitting the problem from the first year. Community leaders played a very positive role in fighting stigma and discrimination against PLHIV in Senegal. (Pisani, 1999; Putzel, 2006). As an Islamic majority country (69% are Muslims), it was crucial for HIV campaigners to secure support of religious leaders. Many community based awareness activities were conducted to provide different influential players with information about HIV.One of the lessons learned from Senegal is integrating community and religious leaders in HIV programs.

The other lesson from Senegal experience is controlling MARPS. Senegal faced a concentrated epidemic like Egypt among sex workers and MSM. The effective strategy that they face was to provide medications and testing services for MARPS to decrease the infection rate among them. According to this successful policy Senegal kept the infection rate below 0.1% among general population(Foley and Nguer, R., 2010).In Egypt, sex working is illegal action. There are no statistics about sex workers numbers or places and there is no supervision for their health. It is risky that Egypt does not know enough information about this risky group which might lead to high infection rate among them

Another successful model that Egypt can learn from is South Africa experience in fighting HIV related stigma. South Africa faced serious problems due to stigma and its implications on the society. HIV activists found that stigma weaken the community response towards HIV. One important step was when a women declared on a local radio that she is living with HIV and explained types of stigma that she face. After this, many cases recorded more

testimonials and talked loudly about their problems. Local communities did not accept this attitude in the beginning. Later, a public figure and judge Edwin Cameron declared in (2005) that he is living with HIV.

Chapter Four: Discussion and analysis

4.1. Challenges related to medical services

Many WLIHIV face challenges related to medical examinations and other medical services. One of the most important challenges is the reaction of service providers upon knowing that a woman is HIV positive. There are many cases of violations from the medical team against WLHIV in hospitals and private clinics. Some physicians refuse to examine WLHIV and ask them to leave the clinic immediately. Moreover, some doctors and nurses may insult WLHIV and discriminate against them by pointing out that HIV come to those who have multiple sexual relations.In other cases, doctor asked for extra money to make a surgery for WLHIV and he said that the money is needed for using more effective autoclaves (sterilizing machine). Another kind of violation is to change the intervention strategy from surgery to medication in order to avoid making a surgery for an infected woman.

It is important to know that those physicians who refuse to deal with WLHIV may deal normally with Hepatitis B or C patients. Hepatitis B has the same ways of transmissions of HIV and Hepatitis C is also a blood borne disease. Because of large numbers of Egyptian who are infected with Hepatitis B or C viruses there is much more acceptance to deal with them. As a result, many WLHIV tell physicians that they are Hepatitis patients to avoid discrimination. This differentiation in dealing with patients is not based on any scientific background. HIV is a very weak virus that cannot live outside body for more than few seconds. HIV is very easy to eliminate comparing to HCVwhich is high resistant virus and can survive for days and weeks outside body. While HIV dies at 70 degree C or with alcohol 70% concentration, HCV needs an autoclave that use very high temperature combined with high pressure to kill it. It is clear that

discrimination against HIV is not due to the scientific facts about the virus. The stigma and discrimination is mainly due to misconceptions and believes around ways of transmissions.

4.1.1 Why WLHIV need to disclose their status to physicians?

WLHIV prefer to tell physicians about their status. Some of them hide their status due to fear from stigma but they wish to be able to disclose. There are reasons behind their need to disclose. First of all, it is part of the medical background that will help physician to properly diagnose their problems. WLHIV indicated that they do not feel that they have proper diagnosis because their physicians did not know that they are immune compromised. Some physicians require more laboratory tests to understand the case because of hiding their HIV status. This can lead to more time and money which represent a burden on women especially in Upper Egypt where resources are limited and mobility is challenging.

Secondly, WLHIV need to tell their physicians about HIV status to avoid any contradictions between the prescribed medications and ARV medications. There are classes of medications that can lead to many side effects for PLHIV. Some WLHIV suffered from different side effects from antibiotics varied from skin rash to diarrhea. Other medications should not be taken with ARVs which is obligatory for WLHIV and they cannot stop it. Medications which affect the immunity system can lead to serious problems if physician does not know that patient is immune compromised. In addition, doses can vary from case to case according to immunity status. As a result, WLHIV need to tell her physicians that they are living with HIV to avoid any contradictions between medications.

Thirdly, WLHIV want to tell their physician to avoid any harm for other patients. In other words, infection control procedures are not strong in many health facilities in Egypt. WLHIV

want to avoid transmitting the virus to any other patients through not sterilized equipment. Consequently, WLHIV need to ask physicians to pay attention to infection control measures to avoid any risk of transmitting infections during or after surgeries. Many PLHIV do not tell to avoid the previously mentioned reactions and others disclosed as they could not be in position of infecting another person.

Fourthly, WLHIV need to tell their physician to avoid being infected with other viruses. WLHIV know that their immunity is weak and they might not be able to resist any new infection. Infection with any other viruses is a risk for any patient who has surgery but it is a major threat for immune compromised patients as it may kill a person. Due to mistrust of infection control measures in many places in Upper Egypt, WLHIV are threatened by being infected with any virus during surgery.

Finally, WLHIV need to tell physicians in case of delivery to have caesarian section. It is required that any pregnant WLHIV to have CS to avoid transmitting of HIV to her baby during delivery. A woman stated that she had a normal labor and she took the risk of infecting her baby as she was not able to tell her physician that she is living with HIV. In high socio economic classes a woman can decide that she will have SC regardless she needs it or not. But is poor communities women might give birth in home and they have no power to ask for CS unless they tell about their status.

4.1.2 Access to reproductive health services

Reproductive health services include different kinds of medical services that are related to reproductive system. WLHIV require special attention in terms of reproductive health services as they have further needs. For example, opportunistic infections are group of infections that

attack people when their immunity is weak. There are many kinds of infections that attack WLHIV and it is one of their most common medical complaints among them. Those infections are repetitive and may last for a long time as WLHIV have weak immunity. Some of those infections are vaginal infections. It is challenges for WLHIV to access a female physician to have gynecology medical examination. This burden of going to female physician is common in many places particularly in Upper Egypt due to cultural and religious beliefs. Women usually go to primary health care units for seeking medical advice in regular cases. Moreover, there is the challenge of disclosure that a woman is HIV positive which add more difficulty in diagnosis and treatment.

WLHIV need reproductive health counseling to understand the healthier life choices. To explain, many PLHIV do not know the risk of having unprotected sex. They have misconception that they can have sex with their husbands as long as both of them are infected. This is dangerous practice as it can lead to increasing the viral load in their bodies and it can also lead to transmitting other serious sexually transmitted infections. In addition, WLHIV need to learn about hygienic behaviors that they need to protect themselves. Many WLHIV do not have proper knowledge about using condoms and do not know how to negotiate it with their husbands. It is crucial for WLHIV to have access to safe and stigma free reproductive health service centers where they access to proper services and counseling. It is challenging to find this kind of place in Egypt generally and in Upper Egypt particularly. Because there is low numbers of WLHIV known cases it is not efficient to establish a specific place in each governorate. Moreover, even if a place was established for WLHIV they might not go to it to avoid community stigma for this place. Online and phone counseling could be an effective solution. There is a hotline number for

HIV which is a service from MoH. Mistrust is privacy and technology illiteracy are main challenges for effective distance counseling.

Pregnancy and birth giving are major concerns for WLHIV in Upper Egypt. WLHIV can safely have babies if they follow the medical guidelines. The first important requirement for WLHIV is to know her status. A woman has to know that she is infected with HIV to protect her child. She should have a specific dose of ARVs during the first three months to decrease the viral load in her body. In addition, she should have SC to avoid any blood contact between mother and child during labor. Finally, WLHIV should not use breast feeding to avoid transmitting the virus through breast milk. WLHIV in Upper Egypt face different obstacles to have a healthy child. Many of them do not know their status or they are ignorant about its consequences. Sometimes they discover their pregnancy late and do not have the required ARV dosage in the proper time. Many of WLHIV do not disclose their status during labor which leads to a major risk of infecting their children. Some WLHIV used breast feeding as they were not able to buy milk due to their poverty.

Social norms and living in extended families put more pressure on WLHIV who seek for reproductive health services. One of the challenging social norms is restricted mobility. A woman cannot go to different places without her husband with her. Accordingly, many women have no access to medical health services as men are always busy outside home. In the cases where husband died it is more complicated. Community expect from women to move less when their husband die. Norms of seeking reproductive health services disabled women to go alone to physicians. A woman should be accompanied with another woman to the physician if her husband is unavailable.Based on the fact that most of WLHIV do not disclose to their relatives, they cannot go with any of them to the physician and discuss their disease with him.

4.1.3 Access to laboratory tests and ARVs

There are some laboratory tests required to monitor PLHIV status. Those tests include CD4 test which give an indicator about immunity level. There is also the viral load test which monitors the quantity of virus inside the blood. WLHIV should do those tests on regular basis every three months. WLHIV can do those tests for free in MoH laboratories in Cairo. The problem is the centralization of these services. A woman from Upper may not be able to afford going to Cairo to do those tests. Moreover, travel cost is considered a barrier for many poor women. Accordingly, many of WLHIV indicated that they have not made the test for two years. This problem is mainly due to governmental routine and in appropriate dissemination of laboratory equipment. NAP argued that the numbers of cases in Upper Egypt are small so they cannot afford those test in Upper Egypt as it will be very costly.

Similarly, ARVs which are the required medications for PLHIV are not equally distributed. There are eleven distributing centers all over Egypt. Only two out of them are located in Upper Egypt. WLHIV need to visit the distribution center every month to collect the medication. This visit represents a burden on women in terms of time and money. Moreover, many of WLHIV may be physically unable to travel. As a result, many WLHIV may not collect their medication in the proper time which can lead to serious implications on their health.

Above all mentioned obstacles, women in Upper Egypt have further limitations. WLHIV cannot travel alone. They cannot also justify why they should travel every month. They cannotleave their children alone. Accordingly, many WLHIV face serious problems to be committed to the medications which leads to developing resistance to the line of treatment and jeopardize her health status.

4.2. Stigma and Discrimination

WLHIV suffer from stigma and discrimination among their families and communities. There are many reported cases of women who were insulted by their family or husband's family. People always relate HIV to illegal sexual relations. In other words, family members and surrounding community tend to accuse WLHIV with unethical behavior which is a big issue in a conservative society like Upper Egypt. This misconception can lead to different violations against women. Some WLHIV reported that her husband family deprived her from heritage. Other WLHIV were not allowed to raise their children. As a result, many women prefer not to say that she is living with HIV and do not take the medications in order to keep her secret.

Another kind of violation is discriminating against all family members. Community may discriminate against daughters of WLHIV by not marry them. This is very harmful kind of discrimination in a small society like village in Upper Egypt where families know each other. Moreover, some people insult sons of WLLHIV by mentioning that this virus comes only for the sex workers.

Stigma is a major concern for WLHIV. Without stigma, HIV can be a normal disease that people can live decades with it. Because of stigma, WLHIV may prefer to die in silence to avoid bringing shame to their families. The effect of stigma is clearer in case of women and particularly in Upper Egypt due to gender gap. One can safely make the claim that stigma is the root of most of the problems related to HIV. Accordingly, it is important to investigate on the root causes of stigma in Egypt.

4.2.1 Root causes of stigma in the community

Stigma seems to be the major challenge that faces WLHIV in Upper Egypt. It is important to understand where stigma comes from to be able to deal with it. As a social attitude, it has many factors that contributed to it. Based on this research the media and religious misconceptions were crucial in building stereotype about PLHIV.

A) Role of media

Media is a very influential tool in building conceptions and transferring knowledge. On one hand, media tools can disseminate health messages and play a great role in educating people. On the other hand, media can manipulate people's minds and spread wrong ideas and misconceptions. In Egypt, television played a vital role in combating different diseases like Bilharzias and children Dehydration. Television campaigns that tackled the importance of rehydration in treatment of children diarrhea were very successful and led to decrease child mortality in Egypt. Unfortunately, the opposite happened with the HIV. Televisioncampaigns that tackled HIV contributed to stigma against the virus. To clarify, Egyptian television campaigns stressed on the link between HIV and unethical sexual relations. It was a good intention to encourage youth to avoid having unprotected sex but it led to harmful effect on PLHIV. For example, one of the shows on the early stage of introducing the disease to the Egyptian community quoted an order from the Holy Quran that warning males from having sex outside marriage. This was a very strong message that this disease is a kind of punishment from God to those who do not obey his order. In another message during the same campaign, the message focused on the danger of having sex while being abroad. The message was meant to stress on the importance of being faithful. The hidden message that was delivered is that this disease comes from outside and it infects people who have sexual relations with foreigners. This

is not true and history of statistics in Egypt shows that most of the cases came from governorates that have no tourists.

Unfortunately, Egyptian drama took the wrong message about the disease and focused on it. During the period from 1990-2000, Egyptian movies covered HIV issues. All of those movies gave a very negative image of the virus and people who live with it. To clarify, movies at that time linked the virus to immediate death and to illegal behaviors like drugs and sex. For example, one of the movies portrayed the virus as a type of conspiracy. It showed that the virus came from Israel through girls who come to south Sinai to infect the Egyptian men. This was inaccurate and wrong message. This message led to many misconceptions about the disease. Firstly, it put stigma on those who were infected that they did something wrong so the community should not sympathize with them. Secondly, the movies focused on only one way of transmission and exclude the others which led to false security sensations for those who do not have sex with foreigners. Thirdly, it linked the disease to tourism which may affect people's attitude towards tourists. Another movie at the same period portrayed PLHIV as an addict people who will die very soon and they should be in prison to avoid spreading the disease. The movie was so tragedy to the extent that it showed a father killed his son at the end of the movie to protect the community from his infected son. These kinds of ideas led to serious repercussions on the community. It led to an internal stigma and feel of shame inside PLHIV. Many PLHIV think about death when they know for the first time that they were infected. Moreover, many people including health providers expect that people cannot live with HIV for more than few years. In fact, the situation in the real life is much better as PLHIV can live for decades providing that they have proper care.

On the better side, the Egyptian movie "Asmaa" was produced few years ago. It talks about a woman who is living with HIV and suffers because of misconceptions about the disease. The movie gives a proper knowledge about the disease and put in a real life story. Asmaa, the woman name, was infected from her husband and she did not leave him until he died. The movie focused on the daily challenges that face Asmma in family and work place due to stigma. Asmaa suffered to have access to health care because physician refused to deal with her or were curious to know how she was infected. Asmaa stated in the movie that when she dies, she will die because people are sick (she means with stigma) not because she is sick. Asmaa movie helped a lot to provide a different view of WLHIV. It was effective tool for behavior change and many HIV activists use it in their trainings.

To conclude, media plays a crucial role in shaping public opinion. Egyptian media contributed to stigmatizing PLHIV by linking them to drugs and sex. The message that was meant to be delivered to encourage people to abstain or to be faithful ended up to labeling PLHIV. In the first few years after discovering the disease, Egyptian dramaportrayed the virus as a conspiracy and linked it to death. In the last few years, the movie Asmaa gave a humanitarian aspect of WLHIV and helped to improve the public attitude towards PLHIV.

B) Role of religious leaders

Religion plays an important role in people's life. Conservative and rural communities pay more attention to religious concepts. In Egypt, the first religion is Islam and the second is Christianity. Both religions are strongly affecting their fellows and shaping their attitudes. In Upper Egypt, religion and culture are merged together and resulting in a conservative community with specific characters. For example, gender roles in rural Upper Egypt are more similar

between Muslims and Christians from the same village than between Muslims from Upper Egypt and Muslims from Cairo or Alexandria.

Religious leaders in Upper Egypt are considered community leaders. People follow religious leaders not only in the spiritual aspects but also in general life attitudes. On one hand, religious leaders usually spread the messages of peace and cooperation. On the other hand, religious leaders might interpret holy texts according to their culture and understanding. Some religious leaders link between HIV and forbidden practices like Homosexuality and drugs. Moreover, some of them consider HIV as a punishment from God to those who did not obey the religious orders. According to this understanding, some religious leaders contribute to stigma against PLHIV and particularly WLHIV. There are many religious leaders who understand the reality of HIV and help people to accept it as a normal disease. Different trainings and workshops tackled the issue of religious point of view from PLHIV.

C) Culture and misconceptions

Misconceptions are the main underline cause of stigma against WLHIV. There are many misconceptions that people believe to be true. First of all, there are the misconceptions about ways of transmissions. Many people do not know that HIV is transmitted by blood in addition to sexual relation. People think that HIV is transmitted only by sexual relation outside marriage. This is not true. The virus could be transferred by sexual relation inside or outside marriage. Another misconception regarding ways of transmission is that it comes from homosexuality. This misconception has a historical background. The first reported cases of AIDS were found in gay community in the United States. This fact does not mean that HIV infects gays only.

Secondly, there are misconceptions about the start of the disease. Some people tend to think that HIV started as a biological weapon. Others believe that HIV came from abnormal sexual practices with animals. Those misconceptions strongly contribute to stigma and discrimination. Moreover, it helps to put HIV in the image of a curse. Those ideas are reflected in the messages that community carry about HIV. Some WLHIV was thinking in the same way when they told about their infections at the first time.

Thirdly, there are misconceptions related to the life expectancy of people PLHIV. Many people think that HIV kills people in a short period of time. The fact is people can live a long time with proper care. This misconception leads to very harmful effect on PLHIV psychology. Many WLHIV thought that they will not be able to raise their children because they will die. Some WLHIV did not want to take the medications as they thought they have no chance to survive.

Finally, there are misconceptions related to most at risk populations. Some people think that HIV comes only for people who are injecting drug users, sex workers or men having sex with men. This misconception comes from the numbers of MARPs who are infected with HIV. The fact is HIV can come to anybody by who was exposed to one of the ways of transmission. As a result, many people do not accept to be tested as they think they are totally safe as long as they are not one of the MARPs.

Those misconceptions affect people's point of view towards PLHIV. Women in particular are more affected by this misconception due to gender disparities. Education among women in Upper Egypt is less that among men. As a result, women are more affected by those misconceptions.

4.2.2 Causes of stigma in health care setting

Stigma in health care setting is one of the most dangerous forms of stigma. Health providers are the most influential people in WLHIV health. WLHIV have to disclose about their cases in different situations to health providers. Discrimination against WLHIV can vary from violating privacy to complete denial of health service. There are many factors contribute to stigma in health care setting. Literatures highlighted different causes of stigma among health providers. One of the factors is fear of infection. It is common factor if the medical intervention requires direct contact with blood. For example, during surgeries many physician and nurses refuse to deal with PLHIV.

Another factor is the misconception about the disease. Many health care providers did not have proper knowledge about social aspects of HIV. Faculty of medicine teaches a very short part about HIV. Students pay less attention to HIV as they think they might not face PLHIV in the real life. There is a shortage on the epidemiological facts about HIV. Many physician do not know the procedures of preventing mother to child transmission. There is misconceptions about the life expectancy of PLHIV. All of these factors portray a dark image of PLHIV which is reflected in dealing with PLHIV.

As community members, health providers may have their own judgments. Unfortunately, they might not be able to separate their personal judgment from their professional role. Medical ethics including patients' privacy and dealing with any patient are not strongly monitored in many health facilities in Egypt. There is no punishment that can be applied for a physician who refuses to deal with PLHIV.

4.3. The importance of counseling

Counseling is an important part of services provided to PLHIV. NAP requires that each person who wants to be tested for HIV should attend a counseling session. There are governmental counseling services all over Egypt named voluntary counseling and testing (VCT). Counselors play a vital role in providing tested people with the needed information. Many WLHIV discovered their cases due to proper counseling. To explain, when a case of HIV discovered, counselor request from him or her to talk to his partner and encourage him for testing. This is very important and helps in early diagnosis of HIV. In addition, counseling help in changing people's attitude towards HIV. It helps people to understand their situation without being panic. Counseling gives important information about how to protect your partner and how to continue you life normally. Counseling helped WLHIV who needed to know information about reproductive health. It helped them to discover that they can have normal life with the virus. Counseling is a key in PLHIV life. If it is conducted properly, people will have proper information and support that enables them to continue their life.

4.3.1 Having Children living with HIV

HIV can be transmitted from mother to child. The virus can infect the child during pregnancy, delivery or lactation. It is a major concern for WLHIV to protect her child from virus. There are medical guidelines for WLHIV to avoid mother to child transmission. There are two types of procedures. The first case is when father is infected and the mother is not. It is easy to handle as long as they are both aware. Father has to use ARVs to reduce the viral load to the minimal line. They have sexual relation at the time of high potential for pregnancy. Mother takes a prophylactic (Protective) dose of ARVs. In this case there is minimal risk for transmitting to mother.

The second case is when both father and mother are living with HIV. In this case mother takes a special dose of ARVs in the first four months. Moreover, mother has to follow up with a physician to have a CS instead of normal birth delivery. Mother should not breast feed her baby to avoid transmitting virus through lactation.

The mentioned guidelines for preventing mother to child transmission can lead to prevention of new born babies with HIV. This goal is a universal goal and it was declared by many international organizations working on HIV field. Preventing mother to child transmission goal has been achieved in many developed countries as it can be controlled.

The problem is that many WLHIV in Upper Egypt do not know that they are infected. The official statistics estimate that we might have few thousands of people who living with HIV and they do not know all over Egypt. There are different indicators that the number of WLHIV who do not know may be larger. One of the indicators is the gender disparities that affect women ability to travel and to have test. Another indicator is stigma that discourages women to have the test and can push herprefer to die in silence to avoid shame. The third indicator is the gap between numbers of discovered cases in men and women. The global ratio says that women represent almost half of PLHIV. Egyptian statistic shows much less.

Another aspect of the problem is the stigma that might affect women ability to follow the guide lines to protect her child. Some WLHIV had no choicebefore delivery to have SC and they were forced to deliver normally. Poverty contributes to the limitation of choices. Many WLHIV in Upper Egypt gave birth in home or in public hospitals where they have less power to negotiate with physicians.

4.3.2 Relationship with husband

There are two main points in WLHIV relationship with husbands. Firstly, using of condoms. There arereported cases where men transmitted the virus to their wives because they did not want to use condoms. Some men do not use it because they found it irritating and others do not know how to use it. In addition, there is a misconception that condoms are used only when men have multiple relations. This led to negative point of view towards condom. In a closed society like a village in Upper Egypt, men might feel shy to go to pharmacy and ask for condom. On the other side of coin, gender roles disables women to negotiate using of condom. A woman may be forced to have unprotected relation with her husband even if she knows about his status. There are many WLHIV who were infected by this way of transmission.

The second point is disclosure between the partners. Gender roles play an important role in determining who should tell and who can keep it secret. In the majority of reported caseswomen were infected through their husbands. A couple may know at the same time if they were both tested together. In other cases which is common, men know first as they have more access to testing services. When the results come the counselor tells a man that he should tell her wife to protect her. Some men discuss it openly with her wives and others do not.

On the other side, women have less power to know or to choose to tell. Because of different social barriers, women would not access the testing service without their husbands' approval. Social norms give men power over women in different aspects of social life. The effect of gender discrimination on women health is life threatening in case of HIV. Men may misuse their power over women to hide essential information about their status. In addition, men can infect women by reject using condoms.

4.4. Role of government and NGOs

Government plays the vital role in services provided for WLHIV in Upper Egypt. There is NAP coordinator in each governorate. Services are not equally distributed among governorates. There are many concerns about the efficiency and quality of the services provided for WLHIV.

HIV related services provided by NAP started with VCT and confirmatory test. The confirmatory HIV test is available only through ministry of health in central laboratories in Cairo. Those who were exposed to any way of transmission are encouraged to visit VCT center in any governorate. Moreover, VCT services areprovided for free by both government and NGOs. There is one NGO in Upper Egypt who provides the service (Friends of PLHIV). After the counseling and the primary test there are two options. The first option is positive result. In this case, the counselor request from a person to go and visit the central labs for confirmatory test which is also anonymous and for free. In addition, counselor gives detailed information about the HIV and explains what will happen if the test results were positive. The other option is the results are negative. In this case, the counselor advice the person to have another test after three months to avoid false negative results due to being in the window period and the viral load is undetectable.

In addition to VCT services, NAP provides the required ARVs for free to all patients after the confirmatory test. The Egyptian guide lines state that ARVs should be started if the CD4 cells count was under 500. PLHIV should visit the assigned medical center on a monthly basis to have regular checkup and to collect the medicine. Those who do not want to deal with NAP can buy the medications from the private pharmacies.

There are some concerns regarding the medications. Firstly, some PLHIV stated that there was a shortage in some medications in previous years. This instability in the medication supplies causes a great worry for PLHIV. Secondly, there are only eleven centers for medications distribution. Two only are located in Upper Egypt. This geographical challenge represents a significant barrier for PLLHIV in Upper Egypt and particularly for women. Thirdly, NAP requires that PLHIV to visit the distribution center in person. A family with parents and children living with HIV will pay the cost of three persons travel every month.

Chapter Five: Conclusion and Recommendations

HIV is one of the most serious illnesses in today's world. It is responsible for millions of death all over the world in the past few years. The burden of the disease is more influential in developing countries. Developed countries aim to achieve Zero new cases and Zero AIDS related death. Poverty, weak health care services and stigma are major challenges in the developing countries.Egypt has low prevalence of HIV among general population. There are less than half of the infected people who are aware of their status. The numbers of new cases in Egypt is alarming. There are many risk factors that should be addressed in the Egyptian case. Egypt has a concentrated epidemic which basically means that there is above 5 % of people are infected in the high risk groups. In addition, the number of reported cases is remarkably increasing each year. Numbers of women who accept to take the test are very limited. The ratio of women to men in the infected cases is 1:1 globally but it is 1:4 in Egypt. The low numbers of the discovered cases are mainly due to stigma against HIV.

5.1. Conclusion

PLHIV face many challenges. Stigma and discrimination is a great part of the problem and leads to serious implications including denial of health services. There are additional challenges on WLHIV due to gender disparities. Gender roles sometimes disable women from travel and seek help which can be life threatening in the case of HIV/AIDS.

The cases of WLHIV in Upper Egypt are examples of the interactions between many factors of social determinants of heath. To explain, Upper Egypt has a combination of high levels of poverty and conservative environment. The burden of HIV on WLHIV in Upper Egypt is

extremely high because of the synergy between the disabling factors including poverty, ignorance and gender disparities.

5.1.1 Medical challenges

The first group of problems that face WLHIV in Upper Egypt is related to medical services. WLHIV needs a special medical attention due to their weak immunity. Moreover, there are many obstacles in access to proper health care services for WLHIV in Upper Egypt. For example, there are no suitable places that can provide reproductive health services for WLHIV. Many WLHIV need female physicians and accessible place to be able to visit clinic regularly. In addition, WLHIV need a trained medical team to deal with their cases which is not available in most of the cases in Upper Egypt. WLHIV have to go to fever hospitals to seek medical help from trained personnel. Unfortunately, fever hospitals do not have specialties that WLHIV need like Gynecology.

The major problem with the medical services is the stigma and discrimination against PLHIV generally and WLHIV in particular. Most of WLHIV do not tell their physicians about their HIV status to avoid stigma. The implications of not telling the status might be very dangerous. In some cases WLHIV had to give birth in the normal way although she knows this might transfer the virus to her child. Many women do not have a say in the way that they will give birth with. The only way to have CS in many cases is to disclose.

5.1.2 Access to services challenges

The second group of the challenges is related to access to services. There is unequal distribution of services among country regions. For example,there are limited distributing centers for ARVs in Upper Egypt. Women need to travel every month to collect their medications which

represent a considerable burden on their health and budget. In addition, there are regular tests that WLHIV should do and those tests are available only in Cairo. Taken into consideration many social constrains on women travel in Upper Egypt, some women do not regularly take their medications. In other cases, women do not even make the test to know her status even if she knows that her husband is infected.

5.1.3 Social challenges

Stigma against WLHIV is a major problem. There are many factors contribute to the stigma against PLHIV. One of those factors is media. Media is a very effective tool of spreading ideas. Egyptian media introduced HIV in a negative way many times. In the awareness campaigns, Egyptian media stressed on the multiple sexual relations as the main tool of transmission. On the Egyptian drama, HIV was represented as conspiracy from the other countries. Many Egyptian movies linked it to foreigners and to criminal behaviors like injecting drugs. As a result, many people believe that WLHIV did something wrong to be infected with this virus which is not accurate assumption.

Misconceptions and misunderstood religious ideas played an important role in spreading stigma. Some people see HIV as a punishment from God. This misconception was developed based on shortage knowledge about ways of transmissions. The effect of this wrong idea is extremely harmful on women. Many women prefer to risk her life on being accused with unethical behavior. In addition, there are additional factors that contribute to the stigma in health care setting. Fear of infection is one of the most important factors. There is limited information about HIV in the medical curricula and it has less attention from both professors and students.

5.2. Recommendations

5.2.1 Counseling

Counseling is an important part of the services provided for PLHIV. NAP provides counseling through it centers in many governorates. In addition, some NGOs have trained counselors and provide the service. Counseling have a crucial role in educating people about the information that they need to know about HIV. Counseling also gives a lifesaving psychological support in the early stage of discovery.

There are two critical points that counseling can help with. The first point is the sexual relation with partner. In many cases men know their status first. It is challenge for the counselor to convince a man to talk to his wife and bring her for the counseling and testing center. It is very important that man start using condom to avoid infecting his wife. Some men do not tell their wives. In one case a man continued to have unprotected sex with his wife and he did not tell her about his infection. It is highly recommended to develop guidelines fro dealing with married partners and to help them to protect each other. The recommended guidelines should be generalized and used in the counseling centers across Egypt.

The second important part of the counseling is explaining the procedures of safe pregnancy and delivery. It is possible for a couple who live with HIV to have children. Counselor should make sure that parents know how to live a normal life including their right to have children. It is highly recommended to integrate procedures of WLHIV child birth in the gynecology curricula. A WLHIV should be able to give birth in any hospital and to be able to inform about her status to the physician to protect her child. This is crucial to protect the future generation and to reach to Zero new cases.

5.2.2 Public awareness

It is recommended to increase public awareness of the disease and encourage people to take the test. Special programs should focus on women and educate them about protection methods. Female rural health worker can play an important role in outreaching women in the remote areas. One of the important indicators of public awareness success is the increase in numbers of women who accept to take the test. Increasing numbers of test takers is vital to protect their family from being infected.

In addition, PLHIV should be addressed by strategic programs to empower them to speak up and express about their problems. It is an important step to change the stereotyping of HIVas a foreigner disease. Media has to play a leading role in portraying the positive image of PLHIV. Awareness messages should be carefully designed to help people to understand the disease without labeling the patients.

5.2.3 Medical services

Government should pay more attention to provide accessible services in Upper Egypt. Referral system should be developed to allow primary health care centers to refer WLHIV to a trained skillful health provider. To be efficient, one center in each governorate could be enough in this stage. In addition, centers for medications distributions and testing services have to be available in each and every governorate. A system of follow up should be developed to monitor the adherence level to the medications. Free medicine and testing services is a very important aspect of services that should continue.

Medical services should be free from stigma. Activation of medical code of ethics is a must. A health provider who violates patients' right in terms of privacy should be punished

according to law. Any hospital reject to deal with PLHIV should be investigated. A proper education should be provided to physicians and nurses in their faculties. In addition, continuing education should be tackled the new lines of treatment for HIV and the global guidelines in dealing with the blood borne diseases.

5.2.4 Coordination between government and NGOs

A further coordination should take place among different stakeholders in the field of HIV. Civil society organizations should be more transparent about their programs. In other words, programs that address MARPS or any sensitive issues should be coordinated with NAP to avoid any social objections. Government should play a leading role in connecting PLHIV to the NGOs that can help them.Support group services should be launched in each governorate by coordination between civil society and NAP. NGOs have more flexibility and can provide different services for WLHIV including support groups, financial help and stigma free medical services.

Specific indicators should be developed to monitor the improvement on the national level. Civil society can do more efforts to outreach people for testing and in raising public awareness.HIV should be on the public health agenda. More attention should be given to educating decision makers about the magnitude of the problem.

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Annexes

Annex 1 (Interview Guide)

Questions:

How do you evaluate the current situation of WLHIV in Upper Egypt?

What are the main challenges that face WLHIV in Upper Egypt in terms of :

- Medical challenges
- Social challenges
- Services related challenges

What are the differences between men and women regarding HIV?

How culture and social norms affect WLHIV?

What are the causes of stigma that face WLHIV?

What are the services provided for WLHIV in Upper Egypt?

Annex 2 (The IRB Approval)

CASE #2014-2015-133

THE AMERICAN UNIVERSITY IN CAIRO
INSTITUTIONAL REVIEW BOARD

To: Ahmed Abdeldaim

Cc: Mariez Wasfi

From: Atta Gebril, Chair of the IRB

Date: May 7, 2015

Re: Approval of study

This is to inform you that I reviewed your revised research proposal entitled "Challenges facing women living with HIV in Upper Egypt" and determined that it required consultation with the IRB under the "expedited" heading. As you are aware, the members of the IRB suggested certain revisions to the original proposal, but your new version addresses these concerns successfully. The revised proposal used appropriate procedures to minimize risks to human subjects and that adequate provision was made for confidentiality and data anonymity of participants in any published record. I believe you will also make adequate provision for obtaining informed consent of the participants.

This approval letter was issued under the assumption that you have not started data collection for your research project. Any data collected before receiving this letter could not be used since this is a violation of the IRB policy.

Please note that IRB approval does not automatically ensure approval by CAPMAS, an Egyptian government agency responsible for approving some types of off-campus research. CAPMAS issues are handled at AUC by the office of the University Counsellor, Dr. Amr Salama. The IRB is not in a position to offer any opinion on CAPMAS issues, and takes no responsibility for obtaining CAPMAS approval.

This approval is valid for only one year. In case you have not finished data collection within a year, you need to apply for an extension.

Thank you and good luck.

Atta Gebril

Dr. Atta Gebril
IRB chair, The American University in Cairo
2046 HUSS Building
T: 02-26151919
Email: agebril@aucegypt.edu

Annex 3 (Informed Consent Form)

الجـامـعـة الأمـريكيـة بالقـاهـرة

استمارة موافقة مسبقة للمشاركة في دراسة بحثية

عنوان البحث : التحديات التى تقابل السيدات المتعايشات مع فيروس نقص المناعة البشرى فى صعيد مصر

الباحث الرئيسي: أحمد حسين على عبد الدايم – طالب ماجستير-الجامعة الأمريكية بالقاهرة
البريد الالكتروني: ahussein2012@aucegypt.edu
الهاتف: 01008024596

انت مدعو للمشاركة فى دراسة بحثية عن (التحديات التى تقابل السيدات المتعايشات مع فيروس نقص المناعة البشرى فى صعيد مصر).

هدف الدراسة هو (معرفة التحديات التى تقابل السيدات المتعايشان فى الصعيد-معرفة الخدمات المقدمة من الجمعيات المختلفة للسيدات المتعايشات)

نتائج البحث ستنشر فى (دوريات علمية ومؤتمرات علمية).

المدة المتوقعة للمشاركة فى هذا البحث (ساعتين لمقابلة شخصية أو جلسة نقاشية)

اجراءات الدراسة تشتمل على (مقابلات شخصية مع السيدات المتعايشات والمسئولين بالجمعيات والبرنامج الوطنى لمكافحة الايدز)

المخاطر المتوقعة من المشاركة فى هذه الدراسة (الحديث عن المشكلات قد يسبب مضايقة نفسية)

الاستفادة المتوقعة من المشاركة في البحث**:** (المساعدة فى رسم السياسات التى تساعد السيدات المتعايشات على حل مشكلاتهم).

السرية واحترام الخصوصية: المعلومات التى ستدلى بها فى هذا البحث سوف تكون (سرية). لا أحد سيعرف هوية الأشخاص الذين اشتركو فى البحث.

أذكر الافراد الذين يمكن الاتصال بهم عند الرغبة فى الحصول على مزيد من المعلومات عن الدراسة وحقوق المشاركين وكذلك فى حالة حدوث أي اصابة أثناء المشاركة فى هذا البحث. على سبيل المثال يمكنك كتابة

التالى: " أي أسئلة متعلقة بهذه الدراسة أو حقوق المشاركين فيها أوعند حدوث أى اصابات ناتجة عن هذه المشاركة يجب ان توجه الى (أحمد حسين على 01008024596)".

ان المشاركة فى هذه الدراسة ماهى الا عمل تطوعى, حيث أن الامتناع عن المشاركة لايتضمن أى عقوبات أو فقدان أى مزايا تحق لك. ويمكنك أيضا التوقف عن المشاركة فى أى وقت من دون عقوبة أو فقدان لهذه المزايا.

الامضاء: .....

اسم المشارك : .....

التاريخ : ...../...../.....