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International Masters Programme in Social Work and Human Rights

**The obstacle of HIV/AIDS related stigma and discrimination
in HIV prevention, care and treatment in Sweden; *a study of
People Living with HIV/AIDS and service providers.***

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Gothenburg, May 16th, 2010

Peninah Kansiime

Errors and omissions in this paper are entirely mine.

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Abstract

HIV/AIDS related stigma and discrimination are probably as old as the disease itself. Despite the fact that Sweden is one of the countries providing top quality medical care to people living with HIV/AIDS, the epidemic of HIV related stigma and discrimination looms large at different levels in the Swedish society. This paper sets out to discover how stigma and discrimination are obstacles to HIV prevention, care and treatment. The paper also seeks to find out the level of disclosure among people living with HIV/AIDS, their social networks and also offers ways of combating stigma and discrimination in Sweden.

The study employed a qualitative, individual interview method. A total of twenty respondents were interviewed, some are people living with HIV/AIDS and the others, service providers with different professional backgrounds in the HIV field. Data analysis integrates previous research and chosen theoretical framework to provide a better understanding of the issue at hand.

The main findings of this study include among others: that HIV/AIDS related stigma and discrimination exists in Sweden and it is a big obstacle to HIV/AIDS prevention, care and treatment. Forms of stigma include self stigma, which is the most common form of stigma in Sweden plus stigma from society. Discrimination is seen in the healthcare system, the media, migrations board and the justice system. The Swedish Communicable Diseases Act also seems to be enhancing stigma and discrimination. The negative treatment in society and various institutions, plus the harassment of People Living with HIV/AIDS by the media prevents people from testing for HIV/AIDS and also from seeking care and treatment. As a way of combating this epidemic, respondents suggested that dissemination of HIV/AIDS information, knowledge and education at all levels in society is the key to abetting the epidemic. There is need to strengthen people living with HIV/AIDS, deal with clinics, hospitals and also make HIV prevention a responsibility for everyone.

Key Words: HIV/AIDS, stigma and discrimination, Sweden, PLWHA, Communicable Diseases Act, Human Rights

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ACRONYMS

AIDS – Acquired Immune Deficiency Syndrome

ART – Anti Retroviral Therapy

HIV – Human Immunodeficiency Virus

IDU – Injecting Drug Users

MARP – Most At Risk Populations.

NGO – Non-governmental Organization

PLWHA – People Living With HIV/AIDS

STI – Sexually Transmitted Infection

UNAIDS – United Nations Joint Programme on HIV/AIDS

USA – United states of America.

WHO – World Health Organization

CHAPTER ONE: INTRODUCTION

1.1 Background on HIV/AIDS

With over a twenty five years appearance on the global scene, the HIV pandemic remains the most serious of infectious disease challenges to Public health. Efforts have been geared towards understanding the natural history of the HIV infection and efforts have also been made to treat it (Persson et al. 1992). It has spread over the world since the beginning of the 1980s. The first recognized cases were among homosexual men, mainly in New York and California. As a result, the disease was first called Gay-Related Immune Deficiency Syndrome (GRID). Slowly it was realized that it was not “specially” a gay disease. Other groups that were detected early in the spread of the epidemic were the hemophiliacs and recipients of blood transfusions. Subsequently, AIDS was identified among injecting drug users, their sexual partners and infants born to sick mothers. The epidemic was simultaneously spread in a number of geographical locations around the world. The current picture of the HIV/AIDS panorama is that over 90 percent of the HIV-infected live in Asia, Africa and Latin America, the part of the world called the South, and the majority of the infected are women (Foller & Thorn 2005).

Sweden’s first HIV clinical case was detected in the early 1980s, specifically 1982 and it has, slowly increased over the last decade (UNGASS 2010). The report also notes most of the new cases are found in immigrants who were infected, mostly heterosexually prior to their arrival in Sweden. Foller and Thorn (2005) note that in comparison to other countries, the numerical impact of HIV/AIDS in Sweden has been moderate, but at the same time, the political, social and cultural impacts of the disease have been massive. The shock caused by HIV/AIDS was naturally heightened by the massive attention given to the disease in the media. They also note that the medical and political silence in the early stages of the epidemic is most likely due to the fact that AIDS in the beginning was perceived as a disease exclusively affecting the socially marginalized. Globally, there have been efforts geared towards the prevention and treatment of HIV/AIDS. Despite the fact that many measures, policies and strategies have been put up by international bodies and individual countries world over to combat the disease, infection rates worldwide continue to rise. UNAIDS epidemic update (2009) shows that the number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million. The total number of people living with the virus in 2008 was more than 20 percent higher than the number in 2000, and the prevalence was roughly threefold higher than in 1990 worldwide.

The global rise in HIV infections mirrors the HIV growth trend in Sweden. The UNGASS country report (2010) notes that by the end of 2009, a total of 8 935 HIV positive cases had been detected in Sweden of which 6206, or 70 percent, are men. The number of new cases detected has been relatively stable over time with a slowly increasing trend since 2002. Since the late 1980s up to 2002, approximately 300 new cases have been detected annually; while after this date the annual number of new cases has been approximately 400. As a country, Sweden is one of the countries in the world

with the best medical care towards PLWHA. Questions are being asked as to what is causing the rise in HIV infections worldwide, and specifically Sweden. As a country, Sweden went ahead to include HIV in the contagious diseases section under the communicable act by setting tough laws on the spread of the virus. This has and still draws a lot of international criticism towards Sweden. Among the reasons brought up as being responsible for the rise in prevalence is HIV related stigma and discrimination.

The UNGASS (2010) report lists Men who have sex with men (MSM), Injecting drug users (IDU), Youth and Young Adults, Migrants to Sweden, People travelling abroad, People who buy and sell sex and Pregnant women as the most at risk persons (MARP). According to the 2009 Euro Index carried out in twenty nine European countries, Sweden ranked twenty fourth with 624 points compared to the winning country, Luxembourg with 857 points. Among the areas in which Sweden ranked lowest and had gaps is discrimination of people with HIV, school attendance for children with HIV, equal care for marginalized and migrant population, among others (Cebolla & Bjornberg 2009).

1.2 Definition of the Problem

HIV/AIDS has been found to be the most stigmatized medical condition in the world (Simbayi et al. 2007). They add that research carried out across all continents has found people to hold adverse views about HIV. HIV/AIDS stigma has been defined by (UNAIDS 2003) as a process of devaluation of people either living with or associated with HIV and AIDS. To Goffman (1963:13) refers to stigma as “an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself.” HIV/AIDS stigma can be classified as a disease stigma. Disease stigma is a theory or set of beliefs that claims that people with a specific disease are different from the “normal” people in society because they are infected with a disease agent. Such thinking creates a relationship between biological diseases and negatively defined behavior or groups in society. Discrimination refers to action based on stigma. HIV-related discrimination follows stigma, and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV Status (UNAIDS 2008).

Scambler (1998:1054) identifies to types of stigma; enacted and felt stigma where by “enacted stigma refers to actual discrimination or unacceptability, whereas felt stigma refers to the fear of such discrimination.” HIV/AIDS related stigma and discrimination has been fronted by experts on HIV as an obstacle to care, prevention and treatment. HIV has been the world over, accompanied by another epidemic of fear, stigmatization and discrimination. This has posed a challenge to those who are concerned about providing not only an effective response to HIV/AIDS but also a humane one based on a concern for human rights and the principles of social justice. This epidemic has severely constrained the abilities of individuals, families, communities and governments to respond effectively, and continues to undermine the efforts to prevent HIV transmission at the community and global level (Malcolm et al. 1998).

Jonathan Mann, (the founding Director of the World Health Organization's former Global Programme on AIDS), addressed the 1987 United Nations General Assembly and in what would soon become a widely accepted conceptualization, he distinguished between three phases of the AIDS epidemic in any community. The first of these phases was the epidemic of HIV infection – an epidemic that typically enters every community silently and unnoticed, and often develops over many years without being widely perceived or understood. The second phase was the epidemic of AIDS itself – the syndrome of infectious diseases that can occur because of HIV infection, but typically only after a delay of a number of years. Finally he described the third epidemic, potentially the most explosive – the epidemic of social cultural, economic and political responses to AIDS. This was characterized above all, by exceptionally high levels of stigma and discrimination and, at times collective denial that, to use Mann's words, "are as central to the global AIDS challenge as the disease itself" (Mann in Parker and Aggleton 2003: 443).

Moges (2007) notes that although they have reached normalization in many countries, stigma and discrimination have been identified as one of the major impediments in HIV prevention efforts in Sweden. From his research findings, he writes that some people living with HIV/AIDS started to disclose themselves and tried to participate in the prevention of HIV/AIDS. However, they were subjected to stigma and discrimination and this forced them into hiding and concealing their HIV status from the rest. The stigma and discrimination was fueled by negative reports by the media about PLWHA, especially those in court for violating of the communicable diseases act that will be describe later on. This act has been criticized to be in violation of fundamental human rights because it includes things like detaining a virus carrier in hospital, even if he or she did not show any AIDS related symptoms. This Act also stipulated compulsory partner tracing of people diagnosed with HIV/AIDS. This does not only undermine confidentiality of the person with HIV but also the act of isolation is criminalization of HIV which is a human rights abuse.

The criminalization of HIV has been under intense debate in the past years with a number of countries having to amend their laws and do away with what activists refer to as human rights violations. This has left many people wondering, both in Sweden and internationally why Sweden, a country that even funds human rights programmes can enact laws that promote stigma and discrimination towards PLWHA. Over the world, doctors, nurses, social workers, lawyers, human rights advocates and other service providers working with PLWHA have felt the adverse effects that this has, and is still having on their efforts to prevent, care, and treat HIV. Stigma and discrimination brought about by state laws, plus stigma from elsewhere, have contributed to the rise of HIV infection rates in Sweden by mainly discouraging HIV testing. Basing on the above reasons, this study sets out to find out, how stigma and discrimination affect HIV care, prevention and treatment by targeting PLWHA and service providers in Sweden.

1.3 Aims and Objectives

The overall aim of this study is to explore the obstacle of HIV related stigma and discrimination to HIV prevention, care, and treatment. In so doing, the study seeks to find out the contexts in which it exists, its causes, and effects on status disclosure. The social networks that offer support to PLWHA are also studied and their various roles highlighted. The study is carried out among PLWHA, plus professionals or service providers in the HIV/AIDS field because they are a very important aspect in the fight against HIV/AIDS. The study also aims to provide respondent driven views on how stigma and discrimination can be combated.

In order to achieve the aims and objectives of this study as highlighted above, the research questions include:

- What are the contexts of HIV/AIDS related stigma and discrimination that exist in Sweden?
- What are the underlying causes, of HIV/AIDS related stigma and discrimination in Sweden?
- What are the effects of HIV related Stigma and Discrimination on prevention, care and treatment?
- What kind of support do PLWHA receive from their social networks?
- How can HIV related Stigma and discrimination be addressed in Social Work and health service provision?

1.4 Significance of the Study in Social Work and Human Rights

In general, this study is aims at creating awareness about the kind of stigma and discrimination that exists against PLWHAs in Sweden and how it has proved to be an obstacle to HIV prevention, care and treatment. It also gives the parties concerned in the fight against HIV a platform to air out their views and find ways on how this problem may be stamped out of society. To social work, this study highlights another problem associated in the struggle against the HIV pandemic to which social workers are a key player. In this struggle, social workers are working hand in hand with other professions like the medical personnel, media, courts of justice, politicians, among others. Some professions that social workers work with contribute to the problem. Lack of co-operation from any of the other professions may be detrimental to the efforts of social workers and a solution has to be found.

As regards human rights, stigma and discrimination is a human rights violation and, instead of being swept under the carpet, it should be brought to the table and a solution found. In this case, social workers also play the role of advocating for the rights of PLWHA. It brings out the need for social workers to fight for the rights of the marginalized in society and promote social justice. This study will not only increase on the practice knowledge of Social Work but also Psychology, medicine, journalists, judges

and many others because many people in those professions are key service providers to people living with HIV.

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview

Literature reviewed here was as a result of database searches from. Selection of literature used for this paper was based on the different themes and research questions. Many researchers from various professional fields have over the years spent various resources on unraveling the mysteries of HIV and its complexities. Gilbert and Walker (2009) note that most literature on HIV/AIDS reflects research done mostly at the micro or individual level and there is a need therefore to focus on the macro level as well. As regards HIV/AIDS stigma and discrimination, Herek and Capitanio (1998) note that stigma serves different purposes for different persons. For some, it is for religious, political, or even for purposes of personal safety. Lee, Kochman and Sikkema (2002) discovered that PLWHA experience different levels of stigma with some experiencing no stigma at all.

2.2 Causes of HIV Related Stigma and Discrimination

As a first step towards mitigating HIV related stigma and discrimination, researchers sought to find out what its underlying causes were. As a result, a number of reasons, explanations and theories have been generated to explain what really causes negative attitudes and reactions towards PLWHA. Some researchers point out fear as a driving force in HIV/AIDS stigma and discrimination. Clements (1989) asserts that policies of segregation by individuals and states against PLWHA suggest that fear is the biggest response to HIV. Maman et al. (2009) also noted that fear was a driving factor of stigma against PLWHA in Tanzania and Zimbabwe. Fear resulted into the isolation and neglect of PLWHA especially in the last stages of the diseases. Accounts of the experiences of PLWHA created a fear of HIV in them. Stigma is also founded on the fears that HIV is both a dangerous and contagious disease (Crandall 1991). One can say that this same fear has a counter productive end to it. People stigmatize those with HIV because of fear and PLWHA refuse to reveal their status because of the fear of stigma as Gilbert and Walker (2009) note.

Foller and Thorn (2005) point out individual and public denial as another cause of stigma and discrimination. Denial may even be both a cause and effect of HIV related stigma and discrimination. To illustrate this, self denial by a PLWHA will cause self stigma while public denial will trigger stigmatizing attitudes to those tested positive for HIV that in turn cause PLWHA to stigmatize themselves. States and leaders that deny the existence of the epidemic only serve to exacerbate the problem. Michael Blackwell in Foller and Thorn (2005) cites an example of Romania under the dictatorial regime of President Nicolae Ceausescu. Another such example is South Africa's former president Thabo Mbeki who publicly denied that AIDS was not caused by a virus, an action that was estimated to lead to about 300,000 deaths (Bosely 2008). Malcolm et al (1998) found out that denial, which has also been an individual response in some cases results from a combination of socio-cultural and psychological factors of HIV/AIDS. They note that it

often occurs by distancing the problem from the individual or society by placing it elsewhere.

Stigma and discrimination against PLWHA is also due to social judgment orchestrated by religious, moral and cultural beliefs held by society. Stigma does not come naturally, neither does it spring from people's minds rather, it builds and reinforces on earlier prejudices (Maluwa, Aggleton and Parker 2002). HIV is viewed by many as a punishment from God for someone's wicked lifestyle. It is not uncommon to find people who say that people with HIV deserve it because they were homosexuals, IDUs or prostitutes, in other words. Balabanova et al. (2006) noted such thinking in Russia where people were unforgiving to those who had become infected through sex or drugs. Mawar et al. (2005) note that people with stigmatized diseases are blamed for having violated social values and taboos and so they deserve the diseases they carry.

Crandall (1991) found similar results in his research on HIV stigma in the USA. He found that most respondents felt the least pity for homosexual and IV drug users as compared to a doctor who got infected while at work. Carr and Gramling (2004) note that stigma in the USA was predominant in church, among other places like family, friends, employers and coworkers. Vorster (2003) notes that in such cases, the church has a role to play in dispelling such prejudices and preaching love and acceptance for all. Babalola, Fatusi and Anyanti (2009) found similar prejudices in their study on stigma in Nigeria where by the Muslim respondents were found to be less accommodating towards PLWHAs as compared to Christians.

Previous research also attributes HIV/AIDS stigma and discrimination to ignorance and lack of knowledge. The abuse of human rights through various forms of stigma and discrimination, towards PLWHA, results from the lack of a culture of human rights knowledge and education at the grassroots of some societies (Kohi et al. 2006).

2.3 Contexts of HIV/AIDS Related Stigma and Discrimination

In their research about the different forms of HIV related stigma and discrimination, Malcolm et al. (2008) come up with contexts such as the individual, society, employment, health care systems, travel and migration.

People within society, family, friends and institutions often pin point, stigmatize and discriminate PLWHA. Some of them isolate PLWHA and even forbid the sharing of common household utensils by the other members of society or family. At times, relatives having PLWHA in their home are stigmatized as well and considered to be vectors of HIV. States also promote HIV stigma and discrimination through various policies and regulations they put in place. Malcolm et al. (1998) note that it often takes the form of coercive government procedures which may include compulsory tracing for MARPs, prohibition of PLWHA from certain professions, isolation and detention, compulsory treatment and medication, travel restrictions, classifications of HIV as a dangerous disease among others.

Such rules whose intention is to protect society are a violation of human rights and they only increase stigma and discrimination. Society's actions or lack of action contribute to different forms of stigma and discrimination. By covering up HIV cases, and failing to act promptly, they promote stigma and discrimination as this gives rise to new infections and also denies medical access to PLWHA according to Malcolm et al. (1998). Clements (1989) conducted a study on isolation of HIV positive prisoners in the United States of America and notes that even if such measures are justified as a means of protecting them from exposure to risks, they are counteractive. He noted that HIV positive prisoners were accorded fewer privileges and had garbage collected in brightly colored for easy identification among other things. Such acts only caused stress and they were found to be depressed and feelings of helplessness. It also greatly reduced the self esteem of the prisoners.

Self stigma, another form of stigma is in most cases as a result of the stigma in the society. Goffman (1963) elaborates that stigma can be both visible and invisible. A person living with visible stigma has to learn to live with encountering prejudices every day while a person who lives with an invisible stigma has to live with the fear of being exposed. Malcolm et al. (1998: 355) point out that "how people perceive HIV as stigmatizing appears to be anchored in what they understand to be the commonly held beliefs in their society, and perceptions of stigma may differ depending on the actual experiences of stigma and discrimination". They note that people who belong to the already marginalized groups will be more afraid of revealing their status. In his study among HIV positive homosexual men in Sweden, Mansson (1992) notes that on the one hand, they have to deal with the anxiety of stigmatization and becoming an outcast and on the other, the anxiety of disease and death. He says that the sources of this anxiety are within society, the individual himself, plus the combination of these two factors.

Herek et al. (1996) cites the mass media as both creating and combating stigma. Personal exposure to media information influences knowledge about HIV according to Babalola, Fatusi and Anyanti (2009). Researchers note that negative media reports contribute to the development of stigma in society. Visser et al. (2006) cite an example of a South African boy, Nkosi Johnson who was barred from attending school because he publicly declared his HIV positive status. "Gays, junkies and whores... soon you'll be in danger too" and AIDS – a threat to us all" are two examples of contemporary Swedish headlines cited in Bredstrom (2008:312). Thi et al (2008) noted that the Vietnamese government media campaign of linking HIV to IDUs and sex workers created stigma against PLWHA. On the other hand, proper use of the media by relaying positive HIV messages reduces societal stigma against PLWHA (O'Leary et al. 2007). In their research carried out in Botswana, they found that the HIV message that was included in the popular USA soap, *The Bold and the Beautiful* made people more accepting towards PLWHA. Maman et al. (2009) note that in Thailand and South Africa, anti stigma media campaigns solicited respect and compassion for PLWHA in society.

HIV stigma and discrimination in employment has been characterized by ostracism and harassment from fellow colleagues and even pre-employment HIV testing that results

into unemployment if found to be HIV positive. The Human Rights Watch (2004) documented several such examples among women living with HIV in the Dominican Republic. What was worse is that such tests were never voluntary and any slight rumor about someone being HIV positive resulted into an impromptu and involuntary HIV test there and then. Health facilities contracted to carry out HIV tests forwarded their results straight to their employers without letting them know. This is however not the case in all countries. In most countries there are anti discriminatory laws on employment against PLWHAs for example in Sweden according to the UNGASS (2010). In most cases however, PLWHA never make use of these laws because they are laden with confidentiality loopholes and leave them exposed in case of a law suit.

In the health care system, reports about HIV/AIDS related stigma and discrimination trickle in from both developed and developing countries (Malcolm et al. 1998). They note that high levels of information and knowledge among health care workers about HIV do not necessarily alter negative attitudes towards PLWHA. In some countries, HIV positive healthcare workers have been laid off from work and their right to work violated. A survey conducted among health care personnel in Puerto Rico by Varas-Diaz and Neilands (2009) shows that some of them advocated for laws that oblige PLWHA to reveal their status to them so that they take proper caution and also that PLWHA should not work in health services. In Ethiopia, health workers admitted to having gossiped about PLWHA verbally and non-verbally with their colleagues, and there were also accounts of them verbally abusing PLWHA (Banteyerga et al. 2005). On being asked what influenced such behavior towards PLWHA, they mentioned community or societal actions and a lack of training and refresher courses on HIV among others.

A similar pattern was noted in Ho Chi Minh City, Vietnam by Thi et al. (2008) where labor rooms for women with HIV were separated and a poster reading HIV Positive plastered on the door. As a result, many nurses shunned the ward and some patients even had to see themselves through abortions without any help from midwives. Some doctors however recognize the need to protect, provide and support within their means to PLWHA. In Uganda recently, health officials shocked members of parliament on the HIV/AIDS committee when they asked them to withdraw the criminalization of intentional transmission of HIV/AIDS clause from HIV/AIDS Prevention and Control Bill 2009 (Karugaba 2010). Their argument was that it will only serve to increase discrimination against PLWHA and also undermine their human rights. They urged government to expand programmes to reduce the spread of HIV while protecting the rights of PLWHA instead of applying criminal law to it. This was a good move among representatives of Ugandan health care personnel, however, the politicians refused to back down despite being warned that it would hamper Uganda's HIV prevention efforts.

In the context of travel and migration, some countries have imposed travel bans on PLWHA to their countries. Just recently, the United States of America, China and South Korea lifted their countries' ban on PLWHA after a period of over twenty years. South Korea however still maintains compulsory HIV testing for foreigners after three months despite lifting the ban and also deports any foreigner with HIV if considered a threat to public health (The Global Database on HIV Travel 2010). Some students have been

subjected to such outrageous policies especially students from Africa (Malcolm et al. 1998). Maluwa, Aggleton and Parker (2002) note that some countries require its returning citizens to submit to an HIV test and as a result, some have been denied entry back to their countries.

2.4 HIV Related Stigma, Discrimination and Power Relations

As a central discussion in their paper, Parker and Aggleton (2003) assert that stigma is partly responsible for producing and reproducing relations of power and control. It leads to the devaluation of some groups while it elevates others. Stigma therefore is tied to forces of social inequality. Bredstrom (2008:26) notes that “critical HIV/AIDS researchers agree with AIDS activists in arguing that HIV/AIDS is much a political as it is a medical issue. These researchers reveal that HIV/AIDS discourses not only relate to existing power relations, ‘already inscribed relations of power’ but also play a role in the continuing reconstruction, deployment and challenge of such relations.” Looking at the populations considered most at risk in Sweden, they include men who have sex with men, drug abusers, and immigrants. Previous research proves that people in such groups have always been stigmatized and discriminated against by other members of society. The above emphasis on stigmatization as a process linked to competition for power and the legitimization of social hierarchy and inequality highlights what is often at stake in challenging HIV and AIDS related stigmatization and discrimination. By examining the relationships between inequality and stigma it may be possible to find solutions for the power struggles in HIV related stigma and discrimination Parker and Aggleton (2003).

2.5 HIV/AIDS Stigma, Discrimination and Human Rights Violations.

When it comes to HIV, prejudice, thoughts and attitudes lead to actions or lack of actions that have negative consequences to a person or deny them what is due to them (Maluwa, Aggleton & Parker 2002). Examples include being denied health care and being laid off from a job because of one’s HIV status. These are human rights violations that are not objectively justified. Such rights violations can originate from government, family, friends, communities, private organizations, institutions among others. Human rights in HIV enforce responsibility and accountability and therefore it is the duty to ensure against discriminatory tendencies towards PLWHA directly or indirectly through their policies and also making the instruments of justice available to them. In their study, Kohi et al. (2006) were told accounts of respondents being denied food, and even doctors denying oxygen and blood transfusions to PLWHA arguing that it was of no use as they would die soon. They noted that such acts of discrimination are rooted in the lack of a human rights culture in African communities. Klitzman et al. (2004) undertook a study on policies of name based HIV reporting, partner notification and criminalization of non-disclosure of HIV positive status. They discovered that although there are potential public health benefits, they created threats to confidentiality, civil rights and created government mistrust.

2.6 Consequences of HIV Related Stigma and Discrimination

Stigma, discrimination and social marginalization are the consequences of being HIV positive and they cause HIV risk and vulnerability today. By nature of humanity, people's physical and psychological health may be adversely affected when cut off from their social group. This is because man is a social animal (UNAIDS 2008). Clements (1989) notes that isolated prisoners in the USA were found to be highly stressed and depressed with no feelings of self worth. Stigma is very much a concern for those having HIV because it does not only start from the knowledge of one's HIV positive status, but right before a decision to take the test is even made. It is common for people taking HIV tests to weigh the risk of being discriminated if the results turn out positive.

HIV stigma causes a double and sometimes multiple stigmas among the already marginalized groups in society. Such groups include homosexuals, poor people, IDUs, sex workers, immigrants among others, as revealed by several research findings. Foller and Thorn (2005:27) note, "as HIV/AIDS in the beginning was primarily associated with homosexuality it became part of a double stigma that did not only fall upon individuals that were actually infected or diseased – it made the stigma of homosexuality a heavier burden than before. If stigma, through its reductive mechanisms, always dehumanizes individuals and groups, it can also have the function of demonizing through blaming the stigmatized groups for being the cause of "societal ills" that is perceived to threaten the whole society. From the perspective of social psychology, demonization connects stigma with the emotions of fear and denial." This causes PLWHA to conceal their HIV status from others in society.

There are however, costs attached to concealing a stigma. Concealing a stigma may lead to an inner turmoil that can later have negative effects on a person's mental life. It affects long-term social relationships more than the short-term relationships because people choose who they want to associate with, and then they will opt for shallow relationships because then they do not have to reveal their stigmas. This will allow them to assimilate into the main stream community, but at the same time, they will avoid associating with other similarly stigmatized people thus denying themselves of many benefits like social support, social services and social relationships that come with being open about a stigma. Some PLWHA withdraw from social life as a result of this by reducing or cutting off sexual contact according to Persson et al. (1992). Simbayi et al. (2007) report of men who resort to vices such as excessive alcoholism or cigarette smoking as a way of coping with this. All this can take a toll on their physical health (Heatherton et al. 2005). Various studies reveal that HIV positive people who keep their status hidden from their close relatives or allies eventually become isolated, depressed and always looking over their shoulders when compared to those who confide in people they trust.

Previous research shows stigma and discrimination to be an obstacle to care, prevention and treatment of HIV/AIDS. Research carried out in most countries has reported different forms of HIV related stigma and discrimination. The forms of stigma and discrimination faced by PLWHA in Uganda may not necessary be the same faced in Sweden or China. The forms existent in the different countries are dependant on a number of factors like

culture and prevalence rate, among others, but stigma and discrimination exist almost everywhere. Among some forms of discrimination and stigma reported is the one instigated by medical personnel. In a study conducted among women living with HIV in the Dominican Republic, the Human Rights Watch (2004) reports cases of doctors telling patients in front of their children that they have HIV because they were irresponsible. For the case pregnant women diagnosed with HIV, things just got worse. They were told that they had to give birth by caesarean section and when the time for birth came, they were unattended to and some eventually forced to deliver the natural way. Women were also sterilized thereafter basing on inadequate or misguided information about its benefits by doctors as a means of stopping them from giving birth. Most medical procedures on these women were delayed, withheld, or administered under pressure. They also treated these women as incapable of handling results of their tests and told them to other people thus breaching confidentiality.

In their comparative study about HIV related stigma and discrimination in Thailand, Tanzania, Zimbabwe and South Africa, Genberg et al. (2009) discovered that it is a barrier to HIV testing and access to ARVs. Some PLWHA defaulted on their medicine doses because they would not risk being seen taking ARVs in public. HIV related stigma and discrimination also affects the disclosure of one's HIV status. Gilbert and Walker (2009) note that public health guidelines encourage disclosure in order to create an environment of acceptance and therefore reduce all forms of stigma. However, disclosure is a complex process accompanied by stigma. PLWHA in Hong Kong decided not to reveal their positive HIV status to health practitioners after realizing that they were treated differently when they said they were HIV positive according to Wong and Wong (2006). Gilbert and Walker (2009) outline moral judgment and blame, ostracism, relationship termination, verbal or physical abuse and discrimination as the factors discouraging disclosure among PLWHA.

2.7 HIV/AIDS related Stigma and Discrimination in Sweden

UNGASS (2010) reports that in 2009, a total of 486 new cases were reported, up from 442 new cases in 2008. Hundreds of newly diagnosed HIV positive people out in society but stigma and discrimination remain high in Sweden; without doubt, HIV related stigma and discrimination plays a big role in obstructing prevention efforts. The report says that Sweden's National strategy on HIV emphasizes the need to reduce stigma and discrimination among PLWHA and affected groups if HIV prevention measures are to be successful. It points to the anti-discrimination law that was put in place to handle related cases but only a few HIV cases have been reported so far and out of those few, only one had a guilty verdict attached to it. The report further highlights measures taken to combat stigma and discrimination but what is missing on this list is the provision of medication to undocumented migrants plus the decriminalization of HIV infections (UNGASS 2010). When critically analyzed, the above blind spots that appear to be conspicuously absent on that list are state driven through the various regulations in place.

In a letter supplementing the 5th periodic report of Sweden to the committee on Economic, Social and Cultural Rights that was scheduled to be reviewed by the committee in 2008, Medicines Du Monde (MDM) and HIV-Sweden, two organizations that support people living with HIV/AIDS in Sweden with various services asked the committee's review to cover several areas of concern related to the health and status of the health and rights of undocumented migrants and persons with HIV in Sweden. In this report, it was noted that there are several problems regarding access to HIV treatment and prevention programs in Sweden. One is discriminatory treatment of persons living with HIV in the health care system, secondly, undocumented migrants lack of access to treatment, thirdly, deportation of persons living with HIV back to countries where HIV treatment is not accessible and lastly state failure to ensure availability of needle exchange programs Cronberg et al. (2007). The report further states that "undocumented migrants with HIV face even double discrimination; discrimination based on their legal status and discrimination based on HIV status. A third form of discrimination they face is because of their ethnicity or race. HIV-Sweden reports on an African woman who was recently denied care at the antenatal clinic after she informed them she was HIV positive. It is not uncommon for people living with HIV in Sweden to be afraid of going to primary healthcare because of stigma and discrimination" Cronberg et al. (2007: 8).

Walden Laing (2001:110) notes that 'the gay community and spokesmen for human and civil rights opposed the fact that detention could be enforced without regular court proceedings. However, equally strong was the opposition from within the medical profession, where some doctors working with AIDS patients referred to the council of Europe recommendation R89 on ethical issue.' It was reported by Cronberg et al. (2007) that the UN Special Rapporteur on the Right to Health found some worrying trends in Sweden. That when viewed in line with the right to health, some health policies fall short of the standard. UGASS (2010:24) reports that "any person who is legally present in Sweden and needs anti retroviral therapy (ART) has access to treatment. Although undocumented persons can obtain emergency care they have no direct access to prevention, treatment, counseling and support for HIV and STI. Solutions are sought locally."

The above accusations of discrimination against HIV positive people are not without evidence because in the same letter. Cronberg et al. (2007) provides an example of discrimination of an HIV person; at Karolinska Sjukhuset, a director of the hospital decided to give free HIV treatment to undocumented migrants. The decision was a result of a young man who died of AIDS at the infection clinic in April 2001 because he was denied adequate antiretroviral treatment. As an undocumented migrant from Chile, he was not covered by the national health insurance scheme. The Swedish state, however, has not explicitly supported this nor have there been government attempts to fund such urgent medical care through national Health insurance. An analysis of literature confirms that the area of HIV related stigma and discrimination is a ripe area for research in Sweden mainly because it exists but it is swept under the carpet, also, solutions to this problem have to be found if the fight against HIV/AIDS is to be effective in Sweden.

However, HIV related stigma and discrimination in Sweden does not only occur in the above settings. A lack of knowledge about how to treat PLWHAs in society seems to be apparent. In her research about resisting stigma among caregivers of PLWHAs, Poindexter (2005) narrates a story of a US based social worker whose son was rejected by his uncle because he had HIV. She says that in Lars' last days, his desire was to pay a final visit to his cousins in Sweden but he was rejected by his uncle (a medical doctor by profession) and barred from visiting his home and his cousins.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 Rationale for Using Theory

People may argue that theories of stigma are not needed to evaluate what works or does not, to reduce stigma and discrimination (Deacon et al. 2005). This is based on the argument that there is simply no time to do that. It is however quickly pointed out, that the few evaluations carried out on anti-stigma interventions suggest an ineffectiveness of the most common interventions (e.g. mass media education campaigns). This is because interventions are not holistic and integrated because they miss out on a number of issues such as advocacy, legal rights protection, and general poverty relief in association with education programmes. Deacon et al. (2005) also note that our definition of stigma determines our understanding of its operations and how to address it. Therefore, there is need to understand the stigmatization process, its specific context, effects and variations in order to formulate effective interventions. It is on this basis that this research study has used the social networks theory, the systems and ecological theory and the theory of symbolic interactionism by G. H. Mead, to understand the HIV related stigma and discrimination in the Swedish context so that all stake holders can come up with meaningful and effective interventions.

3.2 Social Networks Theory

According to the University of Twente (n.d) on social networks and analysis, the idea of social networks has been in existence for over 50 years. The core of network analysis (social network theory) is the study of how the social structure of relationships around a person, group, or organization affects beliefs or behaviors. Causal pressures are inherent in social structure. The axiom of every network approach is that reality should be primarily conceived and investigated from the view of the properties of relations between and within units instead of the properties of these units themselves. It is a relational approach. In social and communication science these units are social units: individuals, groups/organizations and societies. In general, network analysis focuses on the relationships between people, instead of on characteristics of people. These relationships may comprise the feelings people have for each other, the exchange of information, or more tangible exchanges such as goods and money (University of Twente).

Kadushin (2004) notes that this theory is perhaps the only one in social sciences that is not reductionist, and, can be applied to a variety of levels from small groups to global systems. He defines a network as a set of relationships. More formally, a network contains a set of objects (in mathematical terms, nodes) and a mapping or description of relations between the objects or nodes. Wade (2005) elaborates that in this theory, social relationships are viewed in terms of nodes and ties, the nodes being the individual actors and the ties being the relationships between the actors. The kinds of ties between nodes are not limited and simply, a social network shows all relevant ties between the nodes under study. The network can also be used to determine the social capital of individual

actors. He notes that the social network theory's power stems from its difference from traditional sociological studies, which assume that it is the attributes of individual actor that are important. Its alternate view is that, the attributes of individuals are less important than their relationships and ties with other actors within the network. This approach has been used to explain many world phenomena successfully. However, little room is left for individuals as agencies as well as a limited ability to influence their success, because it is mainly based on the structure of their network.

Social network theory focuses on identifying conditions in society that influence the social network and the way it functions. Social networks exist in almost all groups and communities, even those in which residents experience chronic stressors as well as positive and negative life events. Residents of most communities demonstrate a tremendous amount of resilience, coping skills, and the capacity to help others in times of need (Asander et al. 2004). According to according to Hepworth et al. (2010) they also serve as community-level protective factors. Community-level care may be inspired when people became aware of a particular situation, for which a resource response is needed. Relatives, friends and neighbors are support systems that when activated, provide support in times of need or adversity. Professionals and organizations can, and do provide support, in response to a variety of situations. But neither the professional nor the organization can or should replace natural support and resource systems. This theory was chosen because it helps us understand the relationships between PWLHA and the different people in their environments. It also brings to light what kind of help and support that they receive from other people.

3.3 Systems and ecological theory

The systems and ecological theory deals with the environment. It emphasizes the social focus rather than the individual or client. According to Payne (2005), the systems theory integrates the atomistic-holistic continuum. It requires us to think about social and personal elements in any social situation while at the same time, seeing how those elements interact with each other to become holistic. In line with this theory, (Paquette & Ryan, n.d) note that the environment has four structures which include the micro, meso, exo and macro systems which all impact an individual. Because of its broad focus of incorporating many other aspects of other theories, it integrates elements of traditional psychodynamic practice and psychological theories permitting their incorporation in its wider framework. Systems theory has a circular effect where all elements of a system influence, and are influenced by each other. The basic principles of systems theory are rather simple, one of these is connectedness, the principle that all parts of the system are interconnected, and change in one part will influence the functioning of all other parts. A second principle is wholeness, the idea that any phenomenon can be understood only by viewing the entire system. Finally, the feedback principle which states that a system's behavior affects its external environment and that environment affects the system (Walsh 2010).

Allan (2006) notes that there are four qualities of a system. He says that first, a system is made up of interrelated parts, it exists in an environment, in which systems can be open or closed but a system cannot be completely closed or open. Basing on Luhmann's systems theory, he says that systems are formed by their boundaries with the environment, and, we need to think about the relationships between systems and their environments as running on a continuum. The other quality is that systems are dynamic, and therefore they involve processes. He further adds that dynamic systems have feed-forward and feedback dynamics. The fourth defining character of a system is that systems can be smart or dumb and that feedback systems are smart, but not always. A system must have a goal and there must be mechanisms in place to make changes basing on new information and the system's goal. He argues that function then belongs to the relationship between systems and their environment rather than the systems alone. There exist boundaries between systems and their environments and these boundaries are reduced through communication and language. According to Allan (2006: 225) "Luhmann asks us to look at systems and their environments. Part of what this means is that every differentiated subsystem has three references: [1] the external environment common to all subsystems, [2] its relation to other subsystems within the larger system, and [3] its relationship to itself." He also points out that society and people are independent so they need each other, because at times, the one is a necessary environment of the other." This theory therefore explains how systems in the environment of PLWHA are interrelated and how they affect each other. In the context of this paper, it also helps come up with solutions within society as a means of putting and end to injustice.

3.4 Theory of symbolic interactionism

Symbolic interactionism emerged as a distinctive theoretical perspective in American sociology around the turn of the Century (Herman & Reynolds 1994). The theory of symbolic interactionism by G. H. Mead suggests that interaction between human beings occurs through symbols and the interpretation of meanings (Giddens 1991). It explains how the social becomes self. The term "symbolic interactionism" was invented by Blumer to describe sociological and social psychological ideas he presented as emanating directly from Mead, especially but not exclusively in his book *Mind, Self, and Society*, according to book rags (n.d). "Symbolic interaction theory" is a term that is related to those ideas, though not necessarily in the specific forms presented by Blumer or Mead. Joas and Knobl (2009) note that Blumer's definition of symbolic interactionism is based on three simple premises: The first premise is that human beings act towards things on the basis of the meanings that the things have for them. The second premise is that the meaning of such things is derived from interaction with one's fellows, and the third premise is that these meanings are handled and modified through, an interpretative process used by the person in dealing with his or her encounters. Giddens (1991) points out that, symbols are the key to this view and simply, a symbol is something which stands for something else. Human beings respond to one another on the basis of the intentions or meanings of gestures. So gestures are symbols to be interpreted. In the imaginations of

participants, this is the basis of the entire act because people respond to one another on the basis of imaginative activity (Herman & Reynolds 1994)

According to Comp (n.d) this theory's assumptions are that people live in a symbolic world as well as a physical world. Individuals learn about themselves through interactions with others, and develop feelings about ourselves basing on how people react to our own behavior. Also, individuals have minds that are capable of processing, obtaining information and developing processes which increase one's development. Its concepts include the self; which connotes that people learn about themselves through interaction with others. That we learn about ourselves and develop self-worth according to how people react to our behaviors or to what people tell us about our selves. The other concept is society, where by socialization is a method by which human beings obtain symbols and apply meanings to them. Socialization is part of our culture and we not only learn various meanings for the symbols of our society but we also learn about our own roles within society. Role, the third concept asserts that our roles in society are learned through interaction with others. The theory proposes that the greater the person's clarity of role expectations, the greater the person's ability to perform that role to their greatest potential. The second proposition is that the greater the agreement an individual perceives about their role, the less strain they will experience. Role strain decreases one's self worth. This theory explains the concept of self stigma.

Mead's insights on development have influenced, particularly, researchers studying the child's self-consciousness and the acquisition of cultural values (Giddens 1991). This theory, is one of the theories used to explain child development but can be used in understating stigma and discrimination also when it comes to people living with HIV/AIDS. Referring to Mead, Giddens (1991) explains that by imitating actions of people in their environment, infants and young children develop as social beings. Children achieve an understanding of themselves as separate agents-as a "me" by seeing themselves through the eyes of others. People achieve self-awareness, when they learn to distinguish the 'me' from the "i". The "i" is the unsocialized infant, a bundle of spontaneous wants and desires. The 'me' is the social self. Therefore, individuals develop self-consciousness, by coming to see themselves as others see them. He further explains that to symbolic interactionists, there is an exchange of symbols in all human interactions. During interactions, people always look for clues to appropriate behavior, depending on the context, and also to interpret other people's actions.

In summary of Mead's theory, man is born into societies with symbolic interactions. Herman and Reynolds (1994: 49) note that as a result, "the use of significant symbols by those around him enables him to pass from the conversation of gestures-which involves direct, unmeaningful response to the overt acts of others-to the occasional taking of the roles of others. This role-taking enables him to share the perspectives of others. Concurrent with role-taking, the self develops, i.e. the capacity to act toward oneself. Action toward oneself comes to take the form of viewing oneself from the standpoint, or perspective, of the generalized other (the composite representative of others, of society, within the individual), which implies defining one's behavior in terms of the expectation of others"

CHAPTER FOUR: RESEARCH METHODS

4.1 Qualitative Research Method: Justification

Gilbert (2008: 22) writes that “there are three major ingredients in social research: the construction of theory, the collection of data, and no less important, the design of methods for gathering data. All of them have to be right if the research is to yield interesting results.” Qualitative and quantitative methods are the most commonly used methods in research. They can be used independently, or they can be combined to give what is known in social research as mixed methods. Quantitative research aims to measure using numbers while qualitative research usually describes scenes, gathers data through interviews or analyses the meaning of documents. In practice however, the distinction between the two is not absolute (Gilbert 2008). Although they have been viewed to be contrary to each other, the two methods are complementary and can yield very good results if appropriately combined together in researching social phenomena.

Taking into consideration the purpose of this research, i embraced the qualitative descriptive approach because the goal is to understand and describe the kind of stigma and discrimination people living with HIV in Sweden face, it’s obstacle to prevention, care and treatment. I use this method because I agree with Kvale (1996) when he says that it is sensitive and powerful in capturing people’s experiences and lived meanings. It also allows them to share their experiences with others from their own perspectives. The study follows an exploratory descriptive design I need to describe in detail the context and experiences of study participants. As Crang and Cook (2007, p.1) put it, “ the basic purpose in using these methods is to understand parts of the world more or less as they are experienced and understood in the everyday lives of people who lives of people ‘who live them out’.” The subtle and polite nature of qualitative research makes it the best method for examining sensitive HIV related issues. It is complementary to quantitative studies and it aims to fill the gaps left by quantitative studies (Power 1998).

This study used the semi-structured interview to collect primary data. It was the intention of this study form the very beginning to use two methods, semi-structured interviews and Focus group discussions, but given the sensitivity of the HIV topic in Sweden, it proved to be impossible to gather respondents in a group. Never the less, given the outcome of all the interviews, i am convinced that everything this study intended to find out was captured in the lone method used. Empirical focus is on the analysis of all interviews and snowball sampling was used in order to obtain information from PLWHA and service providers that are relevant and convenient for this specific research.

The method used for interviewing is semi-structured interviews. Most of the questions on the interview guide are open-ended. The aim of having those types of questions is to give the respondent to answer impulsively and spontaneously, about the questions asked without withholding back. I also followed up the questions with probing and prompting during the interviews as a means of acquiring more information on the subjects. All interviews were tape recorded and transcribed as verbatim and word by word as possible. The aim of this was to capture the feeling and the emotions behind the statements of the

respondents and convey them as well to the reader. This may help in soliciting an appropriate response from those who are in position to make a positive change about the situation.

4.2 Research Design

It is important that researchers always ask themselves about the most appropriate research design to their problem (Gilbert 2008). In order to undertake this study, advance decisions, making up the master plan had to be made specifying the methods and procedures for collecting and analyzing the information needed. Each step of the research process was carefully considered taking into account that a wrong step at one stage may ruin the entire research procedure. This thesis follows the seven stages of interview investigation namely thematizing, designing, interviewing, transcribing, analyzing, verifying and reporting as noted by Kvale and Brinkman (2009). The theme of this research was determined for the very beginning and all the other stages have appropriately been followed as described by Kvale and Brinkman (2009). All interviews were conducted using a semi-structured interview guide.

In order to capture a wide range of views, both PLWHA and service providers, drawn from Sweden's largest three cities of Stockholm, Malmo and Gothenburg were interviewed. Also, the study was not limited to only ethnic Swedish respondents but all nationalities were welcome to take part in this study given the global nature of the HIV pandemic. So we had respondents from all over Europe, Africa, and South America. Interviews took a time range of twenty five minutes to an hour and twenty minutes, all depending on how open the respondent was even when probing and prompting was appropriately used. The interviews were also tape recorded and transcribed verbatim for analysis.

4.3 The Respondents

In total, twenty respondents took part in this study to generate the empirical data but nineteen interviews were carried out. Only one interview had two respondents at the same time, while the rest were individual interviews. Out of the twenty respondents, six were PLWHA (two females and four males) while the rest were service providers (all of them female). Only four of the twenty respondents (two PLWHA and two service providers) are not originally Swedish, however, three of them acquired Swedish citizenship and the other one is from another Nordic country (see table 1 below). These four respondents have been living in Sweden for years ranging from twelve to thirty six years.

Table 1. Respondent Disaggregated Data.

	Total number of respondents	Number of female Respondents	Number of male respondents	Originally Swedish	Not originally Swedish
PLWHA	6	2	4	4	2
Service Providers	14	14	0	12	2
Total	20	16	4	16	4

PLWHA interviewed have known about their status for a period ranging between two to twenty five years. Two of them are married and the rest are not. Specific details about their countries of origin are not mentioned in respect of their privacy.

Service providers interviewed are those providing HIV related services and they include social workers both at the hospitals and in NGOs, a lawyer, a body therapist, a graduate in migration and ethnic studies plus nurses at two infection clinics. Apart from two, all the others are still in active service. Their period of service in the HIV field ranges from a period of two and a half to twenty five years. All service providers are professionals in their fields of expertise, or have been trained in health related issues. No matter the time spent serving in the HIV field, all respondents seemed to have gained a lot of experience and knowledge while working with PLWHA.

For a smooth flow of the analysis and an easier understanding for the reader, i have given my informant Pseudonyms and their position as PLWHA or service providers will be mentioned as i extract quotes from the interviews. This is done to protect their confidentiality. These names bear no resemblance whatsoever to the respondents' real names.

4.4 Interview Procedures and Situations

Initially, my interviewees were got through my supervisor, who proved to be a valuable resource given the fact that he is a well known researcher in the HIV field, especially in Sweden. He gave me a list of HIV service provision organizations i could contact, plus specific individuals at the infection clinics in Gothenburg that i could contact. In turn these interviewees connected me to other service providers that could get time to talk to me, and most especially also to PLWHA. All interviews, except three were carried out in the respondent's offices, or for the PLWHA, at the premises of the contact NGOs. As regards the other three interviews, two of them were carried out in the respondents' homes and one interview was carried out on telephone.

In all these interviews, informed consent was ensured in advance the interviewees' voluntary participation the initial time i contacted them. Also, at the start of every interview, informed consent was asked and also permission to record the interviews was

sought. Luckily, no request was turned down by the respondents. I also made it very clear to respondents that they were free to terminate the interview if they felt that could not go on but luckily, all respondents stayed on till the end of each interview. The organizations contacted tried their best to get me a focus group consisting of PLWHA but it turned out to be a very difficult task.

4.5 Transcription

Kvale and Brinkman (2009) note that audio recording, video recording, note taking and remembering, are the methods used for recording interviews. They are then documented and analyzed. They further note that audio recording has been the most common way of recording interviews. This helps the researcher concentrate on the topic at hand and the dynamics of the interview. In this research, the use of the audio recorder was engaged to help me concentrate on the topic and the dynamics of the interview. After the interview, I transcribed the data myself knowing that this will help me listen to the interview again, more attentively and also note if there are some issues that need to be followed up. This is in line with Kvale and Brinkmann (2009) assertion that transcription is an interpretive process where the differences between oral speech and written texts give rise to a series of practical and principal issues.'

Transcribing data can be done selectively or verbatim depending on what method the researcher deems appropriate for the type of study. My interviews were transcribed mainly verbatim and in line with Gilbert (2008), this guides my analysis and reveals themes i had not thought of earlier on. It also helps me to capture the emotions behind the responses and also capture the linguistic descriptions.

4.6 Methods of Analysis

This section seeks to explain how data in this research paper is analyzed.

4.6.1 Interview Data Analysis

All nineteen interviews were audio recorded, transcribed and qualitatively analyzed. Kvale and Brinkmann (2009) identify three modes used in interview analysis and they include analyses focusing on meanings, under which is meaning coding, meaning condensation, and meaning interpretation. The second mode is analyses focusing on language which include linguistic analysis, conversation analysis, narrative analysis, discourse analysis and deconstruction. The third mode is general analysis which includes bricolage and theoretical reading. I do not define all the different types but I will briefly point out and explain the method of analysis used in this study. I used meaning categorization where data was categorized to match previously selected themes. Meaning interpretation was also used where new ideas related my research questions were discovered in the data.

4.6.2 Introducing Approach of Analysis in Relation to Theory, Previous Research and Data

The approach used in this data analysis in relation to theory is that no particular theory or theories are used to analyze data, rather what i have done is to employ the help of theory in understanding certain phenomena better, by explaining why things are the way they are. This is done as a means of avoiding a situation where some important data will be missed and also avoiding a biased interpretation of only selecting the parts that can be viewed in relation to theory as Kvale and Brinkmann (2009) point out.

Gilbert (2008) notes that theory highlights things that we would not see or things that we find puzzling i.e. providing explanations but it also provides predictions as this study discovers by the use of different theories. Given this background, i put together the different concepts important to my research theme gathered from my data, in relation to HIV/AIDS, stigma and discrimination in relation to previous research and the research questions of this study. So, basically, i try to explain and analyze some data from the interviews in relation to theory, concepts and previous research.

4.7 Limitations of the Research Method Employed

Data collection by semi-structured interviews used in this study as the sole method has some limitations. In as much as a healthy number of twenty interviewees responded to this study, a small number of six PLWHA were interviewed. It is important to note that it is not easy to get such respondents here in Sweden despite the fact that there are over 8500 PLWHA in Sweden. I believe that a bigger number of PLWHA interviewed would bring about a wider knowledge of experiences they go through. They would also provide a deeper understanding of the HIV related stigma and discrimination as an obstacle in prevention, care and treatment. So the views and reflections of PLWHA may be limited and less representative to the other 8500 plus. However, the vast number of service providers shared views and opinions that corresponded with those of the six interviewed PLWHA. Power (2008) notes that attitudes and knowledge among people in caring professions are important points of inquiry in fathoming and enhancing service delivery. They also shared the true life stories about their own experiences with HIV related stigma and discrimination because they work with PLWHA. The above, coupled with the encounters that their clients have narrated to them close the gap and this qualifies it to be a qualitative study.

4.8 Ethical Considerations

Ethics is a matter of respect and sensitivity to other people's rights (Gilbert 2008). Ethics say that while truth is good, respect for human dignity is better regardless of whether it leaves one ignorant or not. As researchers, he also notes that we need to take into account the consequences of our actions upon our respondents and act in a way that their human rights and integrity are not violated. To him, this is what is known as ethical behavior. In

this study, the author has taken ethical issues seriously throughout the entire study. Kvale and Brinkmann (2009) note that ethical issues in interviews arise mainly because of the complexities of studying private lives and going public with the results. They also add that ethical issues go thorough the entire research process and ethical concerns should be considered from the start of the investigation to the final report. This is very true for this study given the sensitive nature of the HIV/AIDS topic not only in Sweden, but on a global scale. Kvale and Brinkmann (2009) emphasize three ethical guidelines of consent, confidentiality and consequences.

As regards to this study, a consent form was formulated and permission to conduct an interview was asked before the interview started. Also, the audio recording of interviews was done with permission from respondents. I made it very clear to the respondents at the start of the interviews that they were free to terminate the interview if they felt they could not go on. They were also free not to answer any question they deemed to be too private or personal. In this research therefore, no respondent is mentioned by name as all names used are pseudo names. In writing this report, i have taken responsibility to reflect on the possible consequences not only for the persons taking part in this study, but for the larger group they represent as Kvale and Brinkmann (2009) advise.

4.9 Validity, Reliability and Generalizability

From the very start of this research project, i took into account the three concepts of validity, reliability and generalizability as they are of importance to social research. Kvale and Brinkmann (2009) explain that validity refers in ordinary language to the truth, the correctness and strength of a statement. Reliability pertains to consistency and trustworthiness of research findings; it is often treated in relation to the issue of whether if other researchers carried out the same study they would get similar findings. Thirdly, generalizability has to do with whether the findings of study are transferable to other subjects and situations. These concepts are put into consideration because most researchers aim to have good indicators.

As a strategy to make my research findings from the qualitative interviews carried out reliable, i tried as much as possible to avoid leading and ambiguous questions. Also to note, major concepts were measured in relation to literature on previous research. Validity was ensured by conforming to the seven stages of validation identified by Kvale and Brinkmann (2009) namely; thematizing, designing, interviewing, transcribing, analyzing and reporting as discussed in the various sections of methods employed in this research.

Kvale and Brinkmann (2009) highlight three forms of generalization that include naturalistic, statistical and analytical generalization. Considering the qualitative interview method used in this study, the generalizations i make in this study are as a result of naturalistic and analytical generalizability. It is naturalistic because i used my experience of coming from Uganda. As a country that has been so adversely affected by HIV/AIDS, it fought a lot to reduce stigma and discrimination against PLWHA having seen the

obstacle they have on prevention, care and treatment of HIV. Also i used my experiences gained while working with HIV prevention, care and treatment in Uganda. As regards analytical generalizability, i used reasoned judgment from findings and data gathered from the interviews. Kvale and Brinkmann (2009) also note that the validity of generalization hinges on an analysis of the similarities and the similarities between the original and the present case, and to the extent to which the attributes compared are relevant. Analyses of both similarities and differences from the data obtained in the interviews have all been taken into account in this study.

CHAPTER FIVE: RESULTS AND ANALYSIS

5.1 Presentation of Data and Analysis

Data from the interviews is presented in this section in relation to the theories discussed above and previous research. I analyze data from all interviews, dividing them into themes that are similar to my research questions and also those that came up during the interviews process.

5.2 Stigma

All informants offered their opinions about HIV related stigma and discrimination and both groups agreed on one thing; that HIV related stigma and discrimination is very real and does exist here in Sweden. For the PLWHA, they have lived the experience, and so they shared with me some, out of their many true stories. Some of the service providers also had their own stories to tell. For some, having to work with people living with HIV has subjected them to some form of stigmatization and discrimination, although worth noting is that most of the service providers are never stigmatized or discriminated. However, they too shared with me some of the experiences, some so absurd and bizarre, that most of their clients have shared with them as regards to stigma and discrimination.

There are some major contexts of stigma in Sweden identified and experienced by the informants and they are scrutinized below.

Self Stigma

A key form of stigma identified by both groups of informants but mainly the people living with HIV is self stigma. This self stigma is caused by a combination of issues, that will be discussed later on but one source is the fear of reactions that PLWHA get from the society when they reveal their status. Another reason is the reports and experiences they get from their fellow PLWHA who have revealed their status. Adam, living with HIV and also an immigrant from a European country, notes that:

...so, stigma makes that...that I feel like outside. Outside from this so called healthy part of society and i think that, sometimes I think that may be I over dramatize the situation here so we start to talk about self stigma, that I feel more badly as a person because I am only, only this possibility that I have inside of my character that how will people react if I tell them that I am HIV positive. They will surely think in their mind that I am a bad person, my way of living was very bad, that I was promiscuous, that all, all those things so I feel, I feel ashamed of it...

Adam's feelings are very much in agreement with what authors like (Mawar et al. 2005; Crandall 1991) noted in their studies that stigmatized people are blamed for having violated social values and taboos and thus they deserve to be like that. The informants note that living in such fear and shame makes them feel like they are not living their own lives and they are subjected to a life of secrecy and shame that they do not deserve.

Isabel, an HIV positive immigrant from South America shares her feelings on this when asked how stigma makes her feel:

Yes, yes... and this stigma make like you...eeeh...most of the time you feel you are living in secret, and you shame a lot. And now I am suffering this, I am so tired [with a pained expression on her face] of this kind of life that I don't want and I don't deserve, why do I have to shame?!

Isabel's sentiments were shared by many other respondents living with HIV. Such sentiments were also found in a study by Simbayi et al. (2007) that internalized stigma was linked with signs of cognitive-affective depression and is a cause of suffering to most PLWHA. G. H. Mead's theory of symbolic interactionism provides a clear understanding of the concept of self stigma in Giddens (1991). This is because according to him, by living in a symbolic world, we learn about ourselves and our worth through interaction with others and what they tell us about ourselves. In this case where people living with HIV have been morally ostracized and judged by society, it is only normal that they live in fear, shame, and guilt because of their condition.

On the other hand service providers also unanimously agree that self stigma is the biggest problem and it comes with negative effects in service provision to the people living with HIV. Hannah, a lawyer working with an HIV organization points it out clearly when she says that:

...I think the biggest problem is the self stigma, the fear is much larger than the real threat, and the fear is a real barrier for support. Since people don't tell about their being HIV positive, they are afraid to go to support organizations for instance, and it's also necessary to work with support, to prevent that people are really getting depressed and isolating themselves, for that you need to give support quickly and the information about being HIV positive.

As regards to Hannah's view, Maman et al. (2009), also discuss that the fear of being stigmatized causes PLWHA to isolate themselves and feel neglected. Gilbert and Walker (2009) also agree with this when they write that fear is the number one reason as to why PLWHA do not disclose their status.

Service providers however, are humble to confess that they are part of the cause of not only self stigma, but also stigma from society and discrimination in some cases. This is because when someone is diagnosed with HIV, they tell them not to tell anybody unless it is a doctor, or they meet a sexual partner, which conditions are stipulated in the law. Those that work at the infection clinics ask them to get most of the treatment they need from there, instead of the local hospitals or other departments that can handle their cases.

...but I think we, at the hospital, we also...is a part of what do you say? Yes, contribute to the stigma because in some way you can say it is a good thing because the patients can come here for every medical problem, not only things that are related to HIV, so if you have a cold, or have an abscess, whatever, you can come here and see a doctor here, and for one thing it's a good thing, but its also...because you are safe here you know, you know all the people who works here and...but on the other hand, it also contributes to the

stigma because you don't have to see another doctor or tell any one else that you have HIV and its...its...if you...its with the medication, if you don't want to go to the pharmacy, then you can come here to the clinic and the nurses we go to the pharmacy and we collect it for you and then you can come here and get that and of course its good for the patient and it's a service, but on the other hand, i think it contributes because you don't have to do it yourself and...and so in some ways i think we are helping to keep the stigma and... (Says Anna, a social worker at one of the infection clinics)

Carr and Gramling (2004) heard the same thing from some of their respondents who said their doctors had told them to keep their mouths shut about their HIV positive status. Their intention for doing this is good; to protect people living with HIV from stigma in society, but this stigma instead may reflect back to their clients. Service providers are part of the larger society of PLWHA and in order to understand the whole stigma and discrimination problem, society has to be viewed in its totality. The systems and ecological theory explains this because it argues for a causality effect in which all elements of a system are influenced by and influence each other (Walsh 2010). The stigma faced by PLWHA influences service providers to come up with protective measures. These measures however, have both positive and negative effects on PLWHA, and one of the negative effects is the same stigma that they are trying to guard them against.

Stigma from Society

Prejudices and biases about people living with HIV from the society are a very common occurrence and they set the stage for silence and self stigma among PLWHA. Respondents noted that most of the time, the reaction from society is negative and at times, disclosure of their HIV positive status leads to a complete destruction of relationship and a severance of friendship ties. Some members of society do not even keep it to themselves, but they go on telling whoever cares to listen about people's HIV statuses. Adam narrated an incident along that line:

I had such a personal experience which was very, very bad, because somebody, who didn't like me sent anonymous letters to all neighbors in the house where I live, and there was written that 'do you know that my neighbor and my name, that he is gay, and he has Aids, and he is ...it was well written and that he is pedophile, because he transmits his education to the children?' and I live in a house, where on the ground floor, there is kindergarten and it was something terrible because I was like naked in the house, my neighbor said [Words inaudible]...and I was...I thought, my first thought was that I have to move because I was so ashamed, and then, the first week, so I was inside, all the time, I didn't want to go outside, but then I thought, I cant hide myself from other people, so I made an advertisement, which I put up 'dear neighbors, I know that you have got this kind of letter, if you still have this kind of letter, so please give it to me because I want to go to the police.' Because I knew who made it, and I wrote that if you have any questions please come to me and I will answer all your questions. So I went, some people they heard, they came to me, they had those letters, and they had those prints...

When such information lands in the ears of some people in society, they use it to further create stigma towards the people living with HIV by bringing the 'reality' closer to the

people and triggering off alarm buttons in society. This however takes a toll on PLWHA socially, health wise and in many other aspects. Weitz in Henslin (1996) refers to stigma as a sociological term used to mean negative effects that evoke a 'halo effect' that sends up a red flag and negatively influence all aspects of a person's reputation. In the above narrative we see Adam's neighbor capitalizing on that for his own selfish gain without giving thought to the implications of his action on Adam.

Some HIV positive respondents noted that the stigmatization becomes worse when a person is homosexual, an immigrant or belonging to any of the identified MARP. The Swedish society has been over the years told that it is mainly immigrants from African and Asian countries and homosexuals, and to an extent injecting drug users that carry the HIV virus. So the HIV positive people in those categories face double, or even multiple stigmas. Even if one is heterosexual, chances are high that when society gets to know that they are HIV positive, they are placed in such categories and if they are Swedish, then the first questions that pop up have to do with the fact if they had sex with any person that falls in those groups:

Although I think that people were...they could hear that I was HIV positive, so the first thought that came was oh, he must be a gay. It is so connected, connected to each other and since I was...I was not married, I was living alone, single man, I had no children, so for them, they tell people he is HIV positive so automatically he is gay...so I had to tell them that I was gay, another sexual orientation and it felt very, very, very badly because I felt like I just had to be open and to take off my clothes and just, I felt like to stay naked in front of many people...many persons, that if I hadn't been HIV positive then I wouldn't have to talk about my sexual orientation (Adam recalls).

Disease stigma is negative social "baggage" affiliated to disease. It associates what society refers to as negative behaviors like prostitution, homosexuality among others, with people suffering from a particular disease. By so doing, it stacks meanings and values onto a biological phenomenon like disease (Deacon et al. 2005). Maluwa, Aggleton and Parker (2002) noted that HIV stigma just builds and reinforces on already existing prejudices. Bredstrom (2008) says that members of such risk groups have been singled out particularly as prone to risk and have been stigmatized as dangerous and culpable to spreading the virus. Even today, looking at UNGASS country report (2010) by Sweden, you see that stereotypes have been created as to who is most at risk of getting HIV and this leads to other forms of stigma and discrimination.

This takes a negative toll on people living with HIV and it seems harder for one to reveal their sexual orientation, especially if it is considered a deviation by society than to reveal that one is HIV positive. Respondents also noted that it is widely believed in Swedish society that ethnic Swedes do not have HIV. They believe HIV is something down in Africa or Asia and this belief fans the flames of unprotected sex, especially among the youth as long as sex is not with a foreigner and also gives some a real shock when they are diagnosed with HIV. Madeleine, a nurse at one of Gothenburg's infection clinics narrates one such account and shares her observations:

...I have a Swedish girl, she got infected when she was twenty, and she had a Swedish boyfriend, and he had HIV and transmitted it to her because he couldn't suspect, he couldn't suspect that he had the disease. And when she came here sick with a primary infection, she couldn't believe that she had HIV because she was Swedish and had a Swedish boyfriend, all he got were various infections and she got healthy, and then he got sick and then they discovered that, because we don't believe that a young Swedish girl has HIV...because I have two women in the late I think '87 and '88, they came with severe AIDS to the clinic, because they had been out to the VD at vard centrale [local hospital], so they were not feeling well, losing weight, diarrhea, they have a lot of problems, but the doctors couldn't see because they are Swedish and one was thirty and the other almost fifty and they didn't believe that they could have AIDS, Swedish partners, the young girl had been in America, got infected in the USA and the other woman was middle age and her husband I think for ten or eleven years and both were infected so... but it takes some time because we think it's a black skin or coming from Asia then you take the test because we believe that they could be positive, but Swedish, white skin, young girl, it is just not possible

Such stereotypes created about who has or does not have HIV gives self confidence to people in the larger society by making them believe that if they and their partners do not fall among the categories mentioned, they are safe and they should do as they please. This serves to show that there is stigma attached to being an immigrant because it is one category considered to constitute the largest percentage of people living with HIV in Sweden according to the UNGASS report 2010 by Sweden. These kinds of fears are also indicated by some other countries like Hong Kong that demand HIV tests for all foreigners staying in the country for more than three months according to (HIV Travel 2010). Once diagnosed HIV positive, they are put on a flight back to their countries.

At times, some service providers reported, it becomes hard to tell whether the stigma then faced by such people is because they are HIV positive, or because they are immigrant, homosexual or drug users. The lines become hard to draw because being an immigrant, homosexual or a drug user alone subjects people to stigma from society:

If I have to relate it to my work and migrants with HIV, it is more complicated because you cannot see clearly whether the stigma is about people being migrants, or whether it is about the HIV, that is even an issue when we talk about the group homosexual, you don't know whether the stigma is about homosexuality or the stigma is about HIV. So, the stigma can be self stigma, where people think...they think and they assume, they go into this self discrimination and isolate themselves and it can also be there, like they go to the hospital, they don't even have HIV but they assume, those who are working there assume that they are HIV just because they are from Africa or...so it's, it's not clear, it is not so easy to draw the line like this, it's HIV stigma. (Says Linda, a service provider in one of the HIV NGOs)

Deacon et al. (2005:2) expound on this issue when they say that "although some stigmatizing ideas lead directly to discrimination, there is no one-to-one relationship between stigmatizing ideas (ideology) and discriminatory actions. Not all discrimination arises from stigma and not all stigmatizing ideas lead to, or can be used to justify discrimination." They note that people who stigmatize PLWHA may never act on these beliefs. A PLWHA may be denied a job because he is an immigrant and not because he

has HIV. Further still combining discrimination with stigma may block research and action against its other causes like gender or class and possibly other ideas for intervention against discrimination.

Stigma Faced by Service Providers

Although some of the service providers interviewed reported that they have never faced stigma as a result of working with people living with HIV, there are also some that confessed to have been subjected to stigmatization when they revealed that they work with people living with HIV. When asked whether as a service provider, she is stigmatized and discriminated because she works with people living with HIV, Cecilia, a social worker with an NGO notes that:

Probably it has happened but maybe I haven't noticed that...that much. So, it I have not had big issues but I notice that when people asks what I work with, they have sometimes very strange reactions, and they doesn't want to talk to me anymore. If we are like in a meeting somewhere or ...yeah, not people I work with here, but in another kind of meetings when people ask what I work with and they get very quiet and start to talk someone else. That I have noticed, several times.

As a result of their work with people living with HIV, some service providers have had ties severed by friends in the past that adamantly refused to understand the kind of work they do as Gloria a service provider in an NGO explains below:

I for myself, I have friends who don't want to...in the beginning, I have finished friendship, because I work here. They have been afraid for the children, when they have been pregnant, and they know that I work here, so some have a fantasy that I can spread, I don't know how but they were so scared I think, but they don't want to say that, so I feel it and we talk about it and it was tough because I felt...otherwise I don't how explain because I work here, and after that we have had no contact. At first I was...it should help...how should I help and get information and so on and then suddenly I start, what's happened? I know, my logic says that you can't. you can't, and when I ask, when I felt that I said...I was very angry, I react in a way that I will leave it, because I cant change their behavior or their reaction because they don't want to have information and they don't want to have the right information and I cant force that to them. Just leave it... *[Words inaudible]* or otherwise, we have lost the contact. Because you can't force people to take part in...because they have...they are very scared, and they don't allow that information

To others, the stigma is not directed towards them, but instead, it is directed to the people seen walking with them in society.

... no I have not, but what happens is that the rumor, among Africans because I work with HIV positive people, when they see me in town, two, three four times with one guy, or with one girl, they go around saying yeah, he is often with [she mentions her name], because he is sick, he might be HIV positive because I work with HIV... so when I go around in Malmo you find that, even with my other colleagues working with support, when they are moving with somebody in town, the rumor, those who know those people

suspect she is going with that girl because she is...because they are supporting him [recounts Linda].

Such reaction from society has an effect on the way service providers interact with their clients outside the service provision setting:

It is okay once, but not four times. It has happened, it has happened, not that it happens everyday but it has happened. That is why we are even afraid ourselves when we are in town, how we meet people, especially those who are HIV positive. We can go by them without reacting like we know them and that is bad. If somebody is very afraid, of being disclosed, so we are very careful when...like I am going and I meet one HIV person I have contact with regularly and he is or she is standing there with a friend, I just have to walk by. You understand? Because I don't know what the friend knows about him. When i say hi, I don't know how the friend is going to take it. So HIV is still like sexually transmitted infection that is very, very like feared [Linda Continues]

This stigmatization of service providers shows how deep rooted stigma and discrimination are among some people in society and how they serve to deny people living with HIV proper social interactions that are very much needed by any person.

It is interesting to note though, that some people living with HIV believe they have never been stigmatized but they are quick to add that it is because they have accepted who they are and do not disclose their status unless it is really necessary. So those who know have accepted them as well, and if they get to reveal and they are stigmatized or discriminated, they care less because one either accepts who they are or just let them live their lives. One school of thought projected during the interview is that stigma is mainly faced by unmarried people living with HIV, seeking for sexual partners and also the newly diagnosed people who are yet to come to terms with their positive HIV status like Adam notes below:

So frankly speaking, not any longer, not any longer because I think, stigma and discrimination is more connected to the new diagnosed people, not to those people that have got used to life with Aids...with infection, because as I told you so, we could learn a lot of strategies how to avoid situations where...in which we can be discriminated and stigmatized.

In line with this observation Persson et al. (1992) wrote that as a way of avoiding stigma, many PLWHA reduce or cut off sexual contacts in order to avoid stigma because then, they will not have to reveal their status. This is one of the many strategies that they use however; they don't seem to hold for a very long time given the fact that HIV destroys the immune system. This leaves the nature of their disease exposed sooner or later depending on the availability of ART and the ability of their body to contain the virus. Unmarried people get anxious and stressed because they have a desire for sexual relations that now seem to be limited given their conditions.

5.3 Discrimination

Most respondents noted that there is less of discrimination than stigma for people living with HIV mainly because there is a law against discrimination in Sweden. However, discrimination exists and where it is found it is just too much and perplexing at the same time.

I don't think we have much of discrimination. It's the middle part; it's the stigma that is the problem. We don't have much bad treatment but we have a lot of fear for bad treatment. That's what we have [says Hannah]

A reason for this according to previous research may be due to a lack of clear distinction between stigma and discrimination noted by previous researchers (UNAIDS 2003). Such a response was received from some respondents during the interviews because they would not clearly draw a line between the two concepts stigma and discrimination. Parker and Aggleton (2003) note the meaning of discrimination is normally taken almost for granted, as though it were given or obvious on the basis of simple common usage. This concept, which in common usage means simply "treating unfairly", occurs most commonly in sociology in the context of theories of ethnic and race relations. Early sociologists viewed discrimination as an expression of ethnocentrism.

Respondents however gave different explanations why discrimination seems to be a less common occurrence and one of them is the rate at which people disclose their HIV status as one respondent notes below:

But my theory is also that less people tell about their status because they don't have to, so that is why discrimination has been insignificant, they don't have to tell about their status. If more people told, if those seven hundred living here in Skane told about their status, I think we would have lots of discrimination because suddenly work places would have problems like [words inaudible] I think it would be more of a problem [Says Viveka, a service provider based in Malmo]

The fact that discrimination of PLWHA in Sweden is less visible than stigma does not mean that it does not exist. It seems to be invisible because of many factors. Most accounts told by respondents however seem to be cases of discrimination, resulting from the stigma.

Discrimination in the Health Care System

Respondents raised complaints about the discrimination by health workers towards people living with HIV/AIDS. The only health care workers that were an exception in this category are those working at the infection clinics. Respondents bemoaned the treatment people living with HIV are subjected to by the other workers in the health care system as Hannah explains below that:

The discrimination we see is because of fear from the health care, they tell people that they can't give them health care, that they need to go somewhere else, that they don't have knowledge about HIV, and that they are scared of transmission. That is the discrimination we have, there is discrimination but the largest problem is the fear of not having good support in the primary health care, so the self stigma and the fear are the big

problem, and that people in the infection clinic have very good knowledge and they give good support, but if you go to vard centaralen [local health center] and primary health care, they don't have much knowledge about HIV and if someone comes and tells them they have HIV, they usually don't get good health care and good support.

Banteyerga et al. (2005) also noted this lack of HIV knowledge among health workers in their research. Some health workers try to hide their discrimination by carrying out unnecessary tests, but some are blunt in assuring the clients that they are dangerous are recounted by Madeleine:

yeah, mostly in hospitals. It is so sad that people working in hospitals are still so uneducated but...I have one patient she was called to make a surgery on the hand, and she was talking to the doctor and the doctor said, you have to know, that you are dangerous, you have a dangerous disease, so you have to be...you know the nurse that will take your test will use double gloves and my patient said, 'okay, give me the paper, what test I should take and I will take it to my nurse at the infection clinic, because she will use only one pair of gloves and that will save money for the hospital.'

The idea of using double gloves when handling PLWHA was also encountered in Puerto Rico by Varas-Diaz and Neilands (2009) and it also happens in many other countries only that it goes undocumented. Some PLWHA like in the story above stand up for their rights, but unfortunately, this is probably not the case for many others. The dentists come out as the most mentioned category of healthcare workers that discriminate against people living with HIV. There are only a few specific dentists around Sweden that can handle cases of people infected with HIV, and this mainly because all the other dentists claim not treat people with HIV. This at times leads to a heavy work load for those few dentists and at the same time, a delay in service for the clients as they wait in long ques as reported by Christina, a nurse:

It's a...any case that I have...for example if they go to the dentist, when the dentist wants you to come at the last time...last time of the day so he can clean up after you have left or he can just come in dressed like an astronaut [both laugh] you know what i mean?...yeah, so...that i have some patients that have reacted because maybe they have...there is no need to have all this protective clothes on. So, some of our patients choose to go to the dentist at a special place here in...at Sahlgrenska...because...they are good to take care of these patients and its no big deal about it, so some of our patients are...

In the operating theaters, some respondents reported that their surgeries become surgery of the day meaning that no one comes in before or after and HIV positive patient is operated upon because the theater is then strongly disinfected! Lise, a former service provider recalls one particularly interesting story:

...there was one time me and a colleague went to an eye doctor with a client, just at the doctor here, one is sitting outside waiting, and the other go with the person into the doctor, so the doctor starts examining the eye, and then after twenty minuets he is reading the papers about the person, and stood up screaming, running and was jumping on us why we didn't tell him the person had an HIV diagnosis and we told him but you are supposed to read the papers before you treat him. She was so upset, and the guy was just looking on, he didn't know how to react to this very, very...didn't have the energy to reach on

that so we had to react. You are a doctor, you are supposed to read before you start your treatment or examination and she went out and was washing her hands for five minutes, and she came out with double gloves, and...so actually, social care at the hospital, or the dentists, psychologists, nurses, gynecologists...the funniest thing, actually, is working with people that is not manifested is that you should work with everybody like they have an infection, but it is not like that in real life and it means, that even if you are educated, stigma goes, it hits double up somehow, no matter how educated one is, one can have reactions like that. It hits the individual double up...

This is just one out of the many examples of what PLWHA are subjected to in the health care system. For some, they are subjected to so many questions, and many cases, these questions don't have anything to do with the treatment they seek for:

And that I have been meeting in other parts also when I went to see...I went to the doctor, then I had...then you have to tell in Sweden, I had problem with my sinuses, and the doctor said, yeah do you have any other disease, I said yeah that is what I have and am on medication. He said 'oh, is that really true?' yes, that is true. 'Oh, how did you get that?' then I said to him the HIV is transmitted through blood or body liquid, so sex and blood transfusion. 'yes, that I know' he said, but 'how did you get it?' so he didn't catch it up that I didn't want to give him back that it was a stupid questions. So...yeah so, and I think that it is very strange that it is okay to ask that [reports Malin a respondent living with HIV]

However, cases of discrimination of PLWHA in the healthcare system are not new as noted by Cronberg et al. (2007) regarding the Chilean immigrant who died due to inadequate ART because he was not covered by the Swedish national health insurance scheme. What is baffling is that years have passed after this incident but the Swedish government seems not to be bothered about providing illegal immigrants with ART.

The Courts and the Justice System

Some respondents raised concern about the way cases involving people with HIV are handled by the courts of law. It was noted by respondents that the judges were harsh when delivering sentences to PLWHA involved in HIV related crimes, and many a time, they are not given a fair hearing. They noted that it gets worse when the person being prosecuted is a foreigner because then, they are handed higher sentences and condemned to be deported after serving their time in detention. This is done without regard as to whether the countries they are being deported to have medication or not. Eriksson, a PLWHA notes that:

HIV men as they are being called in the media, they have been given lot, harsher punishment than Swedish citizens, so...well these HIV men that has been you know been of a foreign background, there sentences have been quite as hard in many cases as Swedes doing the same thing, and they are being expelled from the country and quite often to the country where they have medical facilities for them, so, they have been both in jail, expelled and then slow death in their country of origin. It's not nice.

As Jurgens et al. (2008) point out; there is risk for selective or arbitrary prosecution. Because of the stigma that still surrounds HIV and the persistence of HIV- related

discrimination; criminal sanctions are often directed disproportionately at those who are socially and, or economically marginalized. There is also a risk for lack of conviction without sufficient evidence and also an invasion of privacy by digging into the patient's medical record. Some respondents interpreted this as an act of racism and discrimination. A particularly very disturbing story about this was shared by Hannah from her legal work with HIV issues:

...and I have another really terrible example; it is a woman living in Smaland, close to Vaxjo, she was living in a refuge camp, and she went to a party with two men and she was raped, the next day she told the nurse at the asylum clinic, and the nurse told her to go to the place where women get support for this kind of violence, and they asked her to go to the police because in Sweden it's a serious crime to rape someone or have sex against their will, and she also went to Noah's Ark in Vaxjo where they also told her to go to the police and she did, and a woman from Noah's Ark in Vaxjo went with her, and she told the police about the rape, that there were two men I don't from Iran or Iraq, something like that country, but she was the one put in custody. Because the men said that she didn't say that she was HIV positive...yes, in Sweden, she is a woman, she is black, and she is HIV positive. And in the court, the men still said no, we didn't force her to have sex, she wanted to have sex with us, but she didn't say that she was HIV positive. She was convicted, and sent to prison. So that's discrimination.

Such trends of instigating that foreigners are responsible for the spread of HIV is noted in many countries especially those that hold travel bans for PLWHA to their country. HIV Travel (2010) cites Hong Kong as one country that tests and deports any foreigner discovered to be HIV positive. Jurgens et al. (2008) note that applying criminal law to HIV exposure or transmission endangers and further oppresses women instead of providing justice. This is partly because women are more likely to be blamed for the infection by their partners and subjected to violence. The racism and prejudice about the kind of people having HIV is also present in the medical system. Some respondents noted that when one goes to have an HIV test so many questions are asked and they are given one straight away if they are of immigrant origin but if one is Swedish, you can only be guaranteed a test if you had a sexual intercourse with a foreigner as Viveka explains below:

Well that is also a problem here, when...when you say you want to do a test, they have questions they ask to people why they want to have sex, and some of the questions are did you have sex with a foreigner, was he black or was he white, which country was he from and depending on the answers, they get the test or not...

Respondents backed up this racism belief with various accounts that point in that direction as Viveka recounts a story about her friend who was dating an African man

...my friend who had a relationship with a man...he was from Nigeria and he was unfaithful and she wanted to make tests so they asked where he was from so she had to take nine tests in every hole she has [laughs] so they took her case serious, but I think if she had told them that I had sex with a Svensk normal guy, I think they would only have taken the Chlamydia test or something like that and not HIV, but that is what Swedish policies and politics are resulting in if you are moving towards groups like immigrants or you [refers to the Interviewee, an Africa], then if you are also treated like that when you

want to make a test, the result is that next time when you want to have sex, you decide whether to use a condom or not depending on what the person looks like, and maybe you don't even want to have sex with a person who looks like those people who are supposed to carry HIV. So that is my interpretation in my struggle towards equality, that it's crazy with the interrogation in Sweden, we can never be equal, people with immigrant background and the native Swedish, we can never be equal if this continues!

Some respondents brought the issue of racism up several times when it comes to dealing with people living with HIV and this issue has also been highlighted in previous research on a number of occasions. The Human Rights Watch (2004) found out that PLWHA of Haitian origin in the Dominican Republic were denied health care and also blamed for importing HIV to the Dominican Republic. Lennarth Hjelmaker (2008) notes that HIV/AIDS is a rights issue. People's rights should be respected and they should not to be subjected to stigma and discrimination. All vulnerable groups should be made identified and provided with support. Reports from different countries however, show that most of these people face extreme discrimination and lack of meaningful access to HIV prevention services.

Migrations Board

Respondents brought up the notion that the migration board is very discriminative towards asylum seekers that are living with HIV. One cannot use their HIV positive status to strengthen their asylum seeking reasons, and some respondents think that such people should be empathically considered given the fact that Sweden is one of the very few countries that provide top quality medical care and treatment to people living with HIV. Conberg et al. (2007) write that an area of troubling concern is the failure of the Swedish Migration Board to look effectively at access to anti-retroviral treatment when determining whether to deport an HIV-Positive asylum seeker. The report notes that the government relies heavily on their embassies' general reports on availability of HIV treatment, but does not consider accessibility, including the financial accessibility of treatment. It fails to look into the particular circumstances of each case and makes very broad and harmful decisions based on very general and for the most part, non-informative reports. Hannah attests to this observation when she notes that:

... for instance the migration board, stigma is important because it is a barrier for understanding the real situation for HIV positive migrants, asylum seekers; it's a barrier for emotionally understanding. It's like; they say you can go to Eritrea because there is now treatment in Eritrea, but emotionally, they don't have any empathy, and I think the stigma is the barrier for empathy. It's a kind of blame yourself if you have HIV, that is your own fault, you had sex, so we can't take responsibility for your life, and that your dying, it's not my responsibility, so if we are looking at the group of refugees, you know when you are coming from a country that there is a risk that you will be tortured and sent to prison with a death sentence, in that case, you have a right to get residence in Sweden but if you will die from HIV, you don't get a residence and so i think that stigma is an important part of this. It blocks the empathy.

Countries named by HIV Travel (2010) as banning travel to their countries for PLWHA are most likely to subscribe to similar policies exhibited by the Swedish migration board.

The discrimination faced by PLWHA from the healthcare system, justice system, and migrations board can be best understood in the framework of the ecological and systems theory. These three areas are part of a wider system, and as Allan (2006) notes, a system is made up of interrelated parts and none of them can be completely open or closed. Walsh (2010) puts it even clearer when he says that the basic principle of this theory is that all parts of the system are interconnected and a change in one part will influence the functioning of all other parts. The way health workers treat people with HIV influences the way the Court handles cases involving PLWHA and it in turn also has an impact on the migrations board when it comes to deciding whether PLWHA can be granted asylum and the cycle continues.

5.4 Causes of HIV Related stigma and discrimination

Respondents came up with a numbers of reasons they believe are responsible for fuelling HIV related stigma and discrimination.

5.4.1 The Lack of Knowledge and Information

This study also found out from the respondents why all these prejudices, stigma and discrimination are directed towards people living with HIV. Respondents noted various reasons and among them include lack of knowledge and information about HIV, the media and the Swedish law on infectious diseases.

Some respondents believe that people living with HIV are subjected to stigma and discrimination mainly because there is a general lack of knowledge and information about HIV in the general Swedish population regardless of one's level of education. Sarah, another social worker in one of the infection clinics in Gothenburg notes that:

...I think that it is connected with knowledge, because we don't know a lot about HIV, so we think we know who gets the HIV; it's poor people in other countries, and in our countries it is the gay people, the prostitutes, the drug users, I think so...the people still think in that way...so it wont happen to me. And then I think most of our patients they come from outside Europe...

Others differ from that school of thought; they believe that there is at least enough basic information about HIV disseminated in schools and at the youth clinics as Madeleine points out that:

...here in Sweden we have a lot of information, young people can get condoms for free at the youth clinics, we have information in schools, education in school for young people, and we can read it all over papers, everyone knows that there is HIV/AIDS in society...

However, most service providers always tell people with HIV especially the newly diagnosed, that people in society do not know much about HIV.

...I have to make it clear for the patient, that society doesn't have the knowledge you know because it is very much fear from them, they don't have the knowledge and they don't know how to handle it... [Says Hellena, a social worker]

Kohi et al. (2006) and Banteyerga et al. 2005 got a similar response on this issue in their research in two different countries. Their respondents noted a lack of knowledge and education as a cause of stigma and discrimination towards PLWHA. To some of the respondents in this study, the problem seems to be that society does not connect the information they have about HIV to PLWHA because most people confess that they have never seen or interacted with any HIV positive person as noted by Lise:

... they don't know about it themselves; maybe they have never been in a situation where they meet, stand and spend sometime with and HIV positive. But when the HIV positive say they are HIV positive, people sometimes just walk away, they don't know how to react.

Respondents noted the stigma and discrimination PLWHA are subjected to forces them into secrecy about their HIV status so most people in society only hear that HIV exists but they think it is a distance phenomena that is not anywhere near them, so when exposed to reality, their initial response is fear. So, fear is mentioned by respondents of this study as a cause of stigma. Maman et al. (2009) and Crandall (1991) mention that fear is the underlying cause of stigma and discrimination towards PLWHA.

5.4.2 The Media

The media was largely apportioned blame by the respondents for stigmatizing and discriminating people with HIV and at the same time influencing the court, migrations and society's reaction towards people living with HIV. Jurgens et al. (2008) argue that the media's emotional campaigns about HIV results into the invocation of criminal laws against the most marginalized in society. In such cases, power relations come into play as the strong try to dominate the weak. As Parker and Aggleton (2003) assert, stigma is partly responsible for producing and reproducing relations of power and control. It devalues other groups while it elevates the others. Hannah says that:

One important issue is the media, when the media writes HIV man, that is an indication for stigma and it leads to a kind of discrimination in the court system because people who are convicted for HIV crimes, if they are migrants, they get long sentences, they are very hard punished and after being in prison they have to leave the country, and that is sometimes a death sentence because they don't get treatment in their country. But that's a very big problem because it's a stigma, a race stigma when they write HIV man in the whole society, and it is fordormor [Prejudices]...

Respondents noted that the media rarely writes anything constructive about HIV, apart from the first of December, the worlds' AIDS day, that is when the media tries to remind people about the HIV pandemic, but for the rest of the three hundred and sixty four days in the year, it is either silence about the issue or a scandal involving someone with HIV whom they always refer to as the HIV man or the HIV woman.

...even here in Skane, we had a case that a married woman, that was infected when she was seventeen, eighteen in France on the holidays, she wanted to forget about it, she was on treatment and so on but she had gotten married and she born and had two children and

she was living ten...almost ten years with a the man without telling him that she was HIV positive...and she knew, and then she was sentenced to prison, but now she is free and this is a famous case because newspapers and mass media in Sweden they just love these horrible stories... [Notes Adam]

The fact that the media according to some respondents only gets to say something constructive about HIV on the first of December, which is the international World Aids Day has as echoed by Isabel:

...then here you see, you hear about HIV or AIDS just the... the first...the um 1st December... And the rest of 364 days you never hear about AIDS or HIV and it's... I am so angry

The media in Sweden according to some respondents, fans the flames of fear and hatred against PLWHA as it seems to be one sided when it comes to the issue of HIV/AIDS. Herek et al. (1996) discuss the media as both creating and combating stigma. In the Swedish context, given the accounts of the respondents, it seems to be the playing the role of creating stigma. Some respondents like Malin below, throw the responsibility back to the law:

I don't think it is the media, I think it is the law, because if it is something against the law, we put words on it, and then they are called the HIV man because they have given it to someone, but if somebody is hitting someone with a knife, they call him the knife man in the newspaper for people to know, so I think it is more...of course maybe that is the way the media is...they pick it and make it a little more than it is, always, but I don't think that this is only when it comes to HIV, but I think it's...the, main thing is the law itself

Respondents shared their various opinions about the law as discussed below. Some shared Malin's opinion but others partially agreed with what the law has to say about HIV transmission.

5.4.3 The Swedish Law on Infectious Diseases

Respondents had mixed reactions about this law. For some, it has both a positive and negative aspect; to others it is entirely good, while to others, it is horrible. Citing personal communication (2010) between me and a legal representative in one of the HIV organizations in Sweden, chapter four of the communicable disease act includes the treating doctor deciding on behavioral rules to stop further transmission. The behavioural rules must only include the below mentioned rules: restrictions applying to work, education or other activities, ban on donating blood and organs ,ban on lending or by some other means permitting others to use used hypodermic needles, obligation to inform care providers and other personnel who carry out non-medical intervention about infection carrier status, obligation to inform sexual partners about infection carrier status, obligation to practice behaviours during sexual relations that reduce the risk of spreading infection, obligation to observe stricter hygiene procedures, obligation to visit the treating physician regularly. Chapter five provides for compulsory isolation if a person who is carrying a disease that is included in the Swedish Communicable Disease Act is not

following the guidelines. There is no maximum limit to how long such cumulative isolation may continue.

Those in support of the law, whether entirely or partially say that it makes free treatment a right for everyone living with HIV. Anna, one of the respondents in support of this law says that:

On one side I think it's...it's because of this law that we have care for these patients, and its free, they have free medicine, so in...that's a good thing...

The respondents in support of the law also noted that it serves to protect the public from communicable diseases and also reduce public expenditure on health, and maybe that is why Sweden is one of the countries with the lowest HIV prevalence in the world like Linda explains below:

...So at one time they have to take measures so that instead of having ten HIV positive people they have five, because they are paying for that. One HIV positive person is costing the society over 100,000kr a year and they don't pay a penny. So, you cannot just say go and when you...I just studied a course, not a program but a course in public health, and when you want to protect the population, there are certain measure you have to take. It regards the question of public health, as I see it...

But those against the law say that it is a very horrible law, especially to those living with HIV. Respondents argue that it puts the burden of protection against HIV on those living with HIV while the 'others' do as they wish:

...It's a...I think it's a very hard law because it puts all responsibility to the HIV positive person. They say responsibility? Yeah. Its...yeah, all responsibility on the HIV positive person and if something happens, if they have sex, and some things happen, the condom can break, but its then, the HIV positive person who is responsible according to the law...and I don't think it is fair. I think it makes it very hard, for people to live with HIV, so it's harder... [Says Cecilia]

The law hits hard on HIV positive people looking for sexual partners and as a result, some opt to give up on sexual relationships and live a single life:

...but for patients it is very difficult, I think this is the most difficult with this illness, with HIV, the social thing, I don't think it's the HIV infection, because there is medicine, the most difficult for the patients is the social part of it and I have many patients who live alone, and don't want to meet someone because they must tell them that they have HIV and how I can help them...it is very difficult but if you meet a person, and this person has to know who you are before you go to bed, they can't see anything else apart from HIV, they can't see that you are a person I want to know, and after, the people can tell the partner that I have HIV and maybe this person can take it, maybe, but I can say that is very, very difficult especially with young people who have HIV who don't have any partner, they are going to be alone for the rest of their lives... [Notes Maria, a nurse]

With such kind of policies in place, it seems like government has taken over the role of regulating adult sexual behavior. Malcolm et al. (1998) notes that states also promote

HIV stigma and discrimination through various policies and regulations they put in place. Some respondents, however, argue that this law is of a very big disadvantage to those that are HIV negative because what it has done in society is to give people a false sense of security. Viveka says that:

...I think it's related to the false interpretations that people get that they have false safety, the public, they think they are protected, that the government are protecting them with the laws, but they are not because the laws are not working I think. Some people do not know about their status and they are positive, and some people know and they are still having unprotected sex or they don't have sex at all because they feel they can't tell anyone because they are afraid how they will react...

Previous research carried out in this area is in support of the respondents' views that argue along this line. In their ten reasons opposing the criminalization of HIV, Jurgens et al. (2008) note that placing the responsibility for transmitting the virus exclusively on PLWHA gives society a false sense of security and undermines the public health message to practice safe sex. Respondents noted that it is this false sense of security that people keep on having unprotected sex, getting infected with other sexually transmitted diseases, and even HIV because some people don't know that they have HIV and such people can't be prosecuted. Some respondents are actually convinced that it is not the people who know that they have HIV that are the problem, but it is the people who don't know that they have HIV that are the real problem because they keep on unknowingly spreading the virus by having unprotected sex. In her opinion, echoed by some respondents, Linda thinks that:

...the problem on the side of society is not those who know. Those who know that they are HIV positive, they know what to do, the problem we have in society, is those who don't know, because you cannot hold them responsible for anything they have done. If I am HIV positive and I have unprotected sex, and somebody else is infected, you can't punish me, because I didn't know...

Those entirely in support of the law say it is good that there is free treatment and also there are mechanisms put in place to punish those who maliciously spread the virus to others. Other respondents however point out that at times, this is abused when innocent HIV people are falsely accused by people who want to get back at them for their own selfish reason. A true story supporting this view was narrated by Adam:

...there was a famous case that the...in Stockholm, that the boy...one young boy was from a rich community in Sweden and he went to Stockholm, and he was very popular, and he had sexual relations with many persons and first, when he had succeed a lot of money from his grandpa, more than one million, so those persons that he had sex...they accuse him because they wanted to have money for a bad feeling although no one of them was infected, but they said he had sex with them, safe sex, but without informing them about it. So I think, I think it is terrible...

Jurgens et al. (2008) discussed some of these very issues that come as result of having such a law in place. They note that enactment of HIV-specific criminal offenses, as well as individual criminal prosecutions against people living with HIV for conduct that

transmits or risks transmitting HIV, has often been accompanied by inflammatory and ill-informed media coverage or commentary by high-profile figures such as prosecutors, government officials, or legislators. This study has discovered cases related to that in Sweden. This rhetoric can only discourage people from coming forward to seek HIV testing and counseling and from talking openly and honestly about AIDS.

This also points to power relations in society as Parker and Aggleton (2003). They explain by saying that ultimately, therefore, stigma is linked to the workings of social inequality. To properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings. They note that it is important to better understand how stigma is used by individuals, communities and the state to produce and reproduce social inequality.

Some respondents think that it is a ridiculous law and it is surprising that some offences that seem to be more serious have softer punishment as compared to transmission of HIV. As Malin notes:

... yeah, I think it is...I don't know I have been thinking back and forth but I think it's extremely, it is extremely big...punishment if you have infected someone else, that I think it is strange, that it is so criminalized, much more criminalized than other things, and that it is regarded as...a great...I don't know, and when it comes to women or men...women who are hit by their husbands and not treated well by their husbands, these cases where they can...where it goes further and the punishment is so low, that I think is so strange because I think this thing this is something that you can point on

This law has drawn criticism both locally and internationally towards Sweden, Adam reported that:

when I move in international conferences when I declare that I am from Sweden so they say 'how can Sweden this country that is talking so much about human rights issues, can have this kind of...where I noted that I can be put in prison if I had sex with some one and I didn't tell whether I transmitted or not?

This law is a human rights issue and as noted by Cronberg et al. (2007), the UN Special Rapporteur on the Rights to Health has noted that there are some worrying trends in Sweden. If examined through the prism of right to health, some health policies are a cause for genuine concern and for this, Bredstrom (2008) Sweden has been also found guilty by the council of Europe of violating international law. Discrimination is a human rights violation and is prohibited by international Human Rights law. The International Covenant on Economic, Social and Cultural Rights (1966) Article 12 (1) states "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." Simply put, every human being has a right to enjoy the highest attainable standard of health conducive to living a life in dignity. Edwin Cameron, Justice of the supreme court of appeal of South Africa said in Jurgens et al (2008) that it is stigma that lies primarily behind the drive to criminalization and it is rooted in the moralism that

arises from sexual transmission of HIV that too often provides the main impulse behind the enactment of these laws. He says that such laws and prosecutions in turn only add fuel to the fires of stigma. Prosecutions for HIV transmission and exposure, and the chilling content of the enactments themselves, reinforce the idea of HIV as a shameful, disgraceful, unworthy condition.

In a theoretical context, the effect that the law on HIV plus the media have on stigma towards PLWHAs can be understood when viewed in the lenses of the ecological and systems theory. The interconnectedness of different systems in society affects each other and causes an individual to react in a certain way.

If the law is revisited and made friendlier towards PLWHA, it will trigger off a chain of positive changes in the media, healthcare and society in general towards PLWHA.

5.5 Effects of HIV Related Stigma and Discrimination

Respondents noted that the stigma and discrimination PLWHA in Sweden are subjected to forces them into silence about their status and it affects when and to whom they disclose their HIV status.

5.5.1 Level of Disclosure

It was noted among respondents living with HIV that their level of disclosure is very low due to the stigma and discrimination they are subjected to. Gilbert and Walker (2009) cite moral judgment and blame, ostracism, relationship termination, verbal or physical abuse and discrimination as the factors discouraging disclosure among PLWHA. Others explain that they only tell a few people, close family and friends because they are told at the infection clinics not to tell. This is because the service providers at the infection clinics are aware that people out there in public seem to know so little about HIV. Emilie, a social worker at an infection clinic says that:

...I have to make it clear for the patient, that society doesn't have the knowledge you know because it is very much fear from them, they don't have the knowledge and they don't know how to handle it, it's not open everywhere...

They are however told to reveal to close family and friends and they are prepared for the kind of reactions to expect. In as much as most of them stick to only that pattern of a few family and friends, respondents noted that it is always painful when revealed. As Greene and Serovich (1996) note, most respondents prefer to disclose their status mostly to their close family members. They are accepted eventually after the initial shock has worn off and the reality of the unchangeable situation weighs in on them. Gustav, like other respondents, shared with me how his parents reacted when he told them about his HIV results:

My father cried and was very sad it was the first time I saw him cry in front of me, and he had a very special [*word inaudible*] being a father, and a father you don't cry before your children, so...yeah he was very sad. My mum went mad, she was angry more, and frustrated that I could die and she didn't have grandchildren and...and...and yeah, she felt shame and that they failed as parents

Respondents noted that they are given so much care and attention initially but with time, people get used to their situation and treat them normally. Eriksson who is living openly about his HIV status shared that

...I remember the first years after I told at work, they asked me quite often how I was, and if I was doing well or I was sick, etc and I liked that, and that is one of the things I miss nowadays. Very few people ask me nowadays how I am doing and nowadays when people are asking I get kind of surprised and I am like; why are they asking me that? Things are changing.

Respondents also shared that they lost some friends when they revealed their status to them, but with time, they learnt to socialize with only those who accept them and when they meet new people, they are very careful about revealing their status and do it only if they have to like when they meet a new sexual partner like the state laws require.

5.5.2 Effect of Stigma and Discrimination towards Prevention, Care and treatment of HIV

Respondents noted that stigma and discrimination is a very big obstacle in the prevention, care and treatment of HIV. They believe there are so many people out there in society living with HIV but they are very scared to come and get tested because if results turn out positive, then their social relationships will be ruined. Some respondents noted that there are PLWHA that are even scared of coming to the infection clinics because they fear being seen by anyone who knows because they will automatically conclude that they have HIV. Emilie cited an example of one of her clients who feared coming to the hospital:

I have a person I talk to, she is a woman, she is twenty five, and she got the disease when she was twenty and she is an ordinary Swedish girl from an ordinary Swedish family and she's got several sisters and brothers, and she couldn't imagine she got it so she went to this testing because she wanted some pills, she took this blood test and was positive for HIV, and she really had this self stigma. She found it very difficult to talk about it, that she was infected; she didn't want to come to the hospital, sometimes we talk to each other outside the hospital because she couldn't come here

Respondents also reported that some clients cannot even go to the pharmacy to buy medicine and so the nurses and social workers at the infection clinics have to help them with that. Some even ask for appointments that do not coincide with others from the same country, if they are of a foreign background and they usually check the infection clinic corridors to see if there is any familiar face that might pose a threat to their secret. Their fears are not unfounded however because some PLWHA reported cases of very strange

reactions from staff in the pharmacies when they presented them with their prescriptions. Gustav is one of PLWHA that has experienced such a scenario and he narrates that

...at the pharmacy when you get treatment, or when you get your medication, and so you give your receipts and...and then they fill in the forms on the computer and then they 'oh my God, he has AIDS!' [*Both laugh*]...and you see the way they look at you and they get quiet, and then they leave, and then they are talking to the boss, and yeah...and its...its small moments you see them do things they normally don't and you have to tell them that oh my treatment is in that fridge over there because they get hysterical about it.

Respondents working as service providers in NGOs noted that stigma and discrimination bars PLWHA to come to organizations and seek help and in so doing, they miss out on these very vital services offered. As Hannah says below:

...it's a barrier for support, I think the biggest problem is the self stigma, the fear is much larger than the real threat, and the fear is a real barrier for support. Since people don't tell about their being HIV positive, they are afraid to go to support organizations for instance, and it's also necessary to work with support, to prevent that people are really getting depressed and isolating themselves, for that you need to give support quickly and the information about being HIV positive.

Jurgens et al. (2008) echo this when they say that it challenges HIV prevention and treatment and also acts as a barrier for seeking support by PLWHA. They also note that it discourages people from coming forward to seek HIV testing and counseling and from talking openly and honestly about AIDS. Genberg et al. (2009) plus many others researchers have over the years proved with their study findings that stigma and discrimination are a barrier to HIV testing and access to ARVs.

5.6 Social Networks

Respondents living with HIV seemed to be doing very well on their own without the need of a vast social network. The reasons for this are that there is very good treatment and care for people living with HIV, they don't often fall sick and when they do, they are very well taken care of by staff at the infection clinics. Some respondents said that apart from the naturally ordained love and care from family members, they were not really dependant on family. Interesting to note however is the fact that infection clinics are a second home to many respondents because the personnel there understands them most and what they are going through. Isabel, in response to which people make up her social network says:

I feel safe, this is like my second home, and during these 21 years I have been seriously sick before. So, for me, the hospital is not so strange [laughs]...and I feel like my second home, and I go there, and I feel safe there. And I can talk to my social worker or my nurse anytime, I can talk to them, even when I just want to cry!

However, this applies mostly to the immigrants who have no family here in Sweden, and also those who have not revealed their status to most of their family and friends. Other

respondents resort to organizations for people living with HIV, and also to friends in the same situation as them:

...I get...my first support is from my closet friends, and then this kind of organizations, with also from Noah's ark because they have social support practical, impractical issues I don't need so much support because I manage everything in my life myself, psychological help, if I feel bad so I just call... [Says Adam]

All in all, respondents seemed to be self reliant on most issues as expressed by Gustav:

Well, the first few years it was a lot of social things. I mean we had...you know...we had dinners quite often, cafes, we had some parties but that's not nowadays like in the '90s. I believe that there are no people going to need our organization as much as before I guess.

UNAIDS (2008) note that human beings are inherently social animals. They do not fare well in isolation and this can be greatly affected if they are cut of from their social groups. This study wanted to find out how PLWHA are supported or survive in the face of the ugly experiences of stigma and discrimination they are subjected to. It was found out that in Sweden PLWHA mainly rely on the medical staff at the infection clinics, their fellow PLWHA and friends who accept them as they are, and to a lesser extent, family.

The social network theory was used to study the how the social structures of relationships around PLWHA affects belief and behaviors. Kadushin (2004) defines a network as a set of relationships. More formally, a network contains a set of objects and a mapping or description of relations between the objects or nodes. Wade (2005) elaborates that Social network theory views social relationships in terms of nodes and ties. Nodes are the individual actors within the networks, and ties are the relationships between the actors. There can be many kinds of ties between the nodes. In its most simple form, a social network is a map of all of the relevant ties between the nodes being studied. In this case, PLWHA, infection clinics, HIV service NGOs, friends and family are the nodes and the ties are the relationships that exist between them. For example, the kind of ties between a PLWHA and the staff at the infection clinics is a medical tie, for the family, it is a family tie, for friends, social ties and for the NGOs it can be social, medical, legal ties depending on the kind of services that the NGOs provide. In this theory, attributes of individuals are less important than their relationships and ties with other actors within the network.

5.7 Ways of Combating Stigma and Discrimination

This study purposed to give people living with HIV and service providers, a chance to share their views about what they feel can be done to combat HIV related stigma and discrimination in Sweden.

5.7.1 Information, Education and Knowledge

Most respondents rotated around the notions of information, education and knowledge. It is only the ideas on how to do it that differed but the concepts are still the same. Linda echoed this opinion by some of the respondents by saying that:

The stigma, is information, we have many...we know that we have many people even in the health centers, they don't have enough information about HIV, they don't have it, especially the health centers. So that is why we always tell the HIV positive people to go to the infectious clinic because they have more experience. So it is information, education, information, education, knowledge, receive the knowledge. And then, some people they have the knowledge and they just don't want to be nice, or they still...the knowledge is there, but they don't put it together with their feelings.

Some respondents go on to add that this knowledge information and education should be spread vigorously in school. They suggested that ways of making them interested in the topic should be devised because they seem not to be interested in the topic. HIV is something that seems so far from the societies in which they live. Education in schools should be tailored to suit all cultures if the message is to be effectively spread across. This should be done skillfully as well because some parents are not comfortable with their children receiving sex education and yet in this era of HIV/AIDS, they can't be left out in ignorance as Viveka says below:

I think they...improve sexual education, and include to everyone that some people who are from other cultures [*words inaudible*] other parents so that they can allow them to attend class, and they can discuss. Some schools are doing it, they call it...they don't call it sex in the heading, they call it education about life, life education or something like that, so, the parents can't tell when the class is coming

According to respondents, many youth do not seem to be interested in the topic about HIV mainly because they feel it is something far away from them and that government has put up measures to protect them. When asked how to get the youth interested in talking about HIV, Eriksson suggests it can be done by:

Being more fun [*respondent laugh*] make them these exercises, you can stand in four corners and in a line, you know all those exercises you can do.

Some respondents noted that the media should help out and play the positive role expected of them in this issue by helping spread information, knowledge and education in a positive way. Isabel notes that:

Yeah, media is a gold mine of information...we, people attack...eh constantly of rubbish on TV [laughs]...yeah? And...mmm...why not...aaah spend time...it cost...eehh I think, it cannot cost so much to do some commercial and get some sponsor to get commercial everyday to show how to use condom, for example in [mentions her country of origin], for...some years ago was not possible to show a penis on TV and show it how to, but now they do it, but here, you cannot do it. It's just so simple!

O'Leary et al (2007) agree with Isabel that the media can help mitigate societal stigma if they relay positive messages about HIV. They cited an example of Botswana where the

popular American television soap Opera called “The Bold and the Beautiful” helped change people’s opinions on how to treat people with HIV. Respondents also suggested information should be given appropriately according to age if the message is to be effectively delivered and not to use a ‘one size fits all’ approach because different age groups process information differently.

5.7.2 Openness

According to respondents, one way of achieving the above, respondents suggested, is by putting a human face to HIV and encouraging people with HIV to be open about their HIV status. Anna says that:

I think we have to open up...and talk more about it...We have to work with them, we have to put the patients to sometimes be more open as well...because, not telling anyone that’s...I think we have to start talking about it in society...

Gloria, a service provider says that this can be achieved faster if we:

Talk about it. And for everyone, and to have it on a daily basis, to normalize it, and to talk about it, and not take it at...it’s you, not me...it’s in the society and we must live with it altogether.

It is common knowledge as discussed in previous research and in the findings of this study that secrecy about one’s HIV status is a big burden. It is like a hard dark shadow, a heavy weight on one’s shoulders that if not lifted, weighs PLWHA emotionally, mentally, psychologically and health wise. Some respondents reported that at times they just want to let it all go, publish it in the news or find a way of letting the while world know so that they can get peace of mind and not have to live a such a huge secret that does not even deserve to be a secret. Isabel let me in on her emotions about this and she told me:

Yeah, it doesn’t feel so good. But I am feeling, right now, I am feeling tired of...of why I have to hide me [with a sad helpless look on her face]? Why? Sometimes I, I, I, want to go out, run and I scream I have HIV...So what? [Both laugh] yeah, I am feeling like this right now, so what? Because I am tired. Because that make me...eh feel so bad person and I am not a bad person, and I am not HIV, I am not AIDS, I am a woman, and a person, a human being...do you understand? Why? Because...why do the people who have cancer, diabetic can talk free about it...

There are benefits in being open about one’s HIV status as noted by respondents because it lifts off the burden of secrecy and there is no more fear of having someone discover that you are HIV positive. Anna adds that:

...because you can see a difference between those who don’t tell anyone about it and *[next words inaudible]*...the patients that tell one, two or three persons...yeah and it’s a difference in a way how they feel or...yeah I think it is difficult, and those patients that take their steps and tell to someone, often they are pleased afterwards that they have done

it because it is really different to share with someone else, so...often, it is something positive because I think because often the people they tell it to take it in a good way.

Previous research by Heatherton et al. (2005) shows that HIV-positive people who do not disclose their status to significant others are likely to become more isolated, more depressed, and more anxious than those who selectively confide in people whom they feel they can trust. So it is to the benefit of PLWHA that they open up about their HIV status but they need to be strengthened in order to open up.

5.7.3 Strengthening People Living with HIV/AIDS

Respondents noted that there is need to strengthen people with HIV to talk more about their status. On this issue, Adam thinks that:

...first we have to strengthen HIV positive people and make them stronger so that they don't have to hide themselves, or to be ashamed of having HIV infection. We have to give more faces to the infection, because we talk about oh HIV, there is HIV, there is a danger of HIV, but how many people, how many of those persons know, or have met HIV persons and know who...what...how to connect HIV....

The WHO (2009) priority interventions note on this issue that PLHIV are a vital resource in the fight against the epidemic and they should be included in advocacy efforts, policy dialogue, and service delivery and in the effort to reduce stigma and discrimination. They can serve as expert patients and trainers as well. The report however notes that in order to do this, they require training, supervision, remuneration and also a removal of policy constraints that prevent them from taking on these roles.

5.7.4 Make HIV Prevention a Responsibility for all

A general consensus among respondents is that every member of society should take responsibility for their own health and lives and stop letting government and just a few people who are already burdened with disease, to look out for their safety. Some respondents go as far as calling for a change in the law, removing the burden of responsibility from people living with HIV to everyone. Gustav said that:

I think the responsibility should lie on everyone in Sweden and not only on people who know that they are living with HIV and that we continue to focus on the campaigns against stigma and discrimination, like the campaigns for World Aids day and...people are discriminated or they have had bad meetings in the hospital or somewhere else...it needs campaigns and also...one of the things is that if they want me to talk about my status to someone before I have sex, I think it should be more easier if I don't have the law but they force me to talk about. I think it's easier, then it's my choice and it's your choice to take your responsibility if we want to have sex.

Some respondents feel that this is a breakdown in values, an ethical and moral issue that society has accepted but it needs to be talked about and worked upon as it's not a

desirable value. It has been accepted by society because the state laws maintain it as a status quo. Like Parker and Aggleton (2003) note, a new emphasis on community mobilization aimed at unleashing resistance to stigmatization and discrimination, structural interventions aimed at developing a rights-based approach to reducing HIV- and AIDS-related stigmatization and discrimination should be a high priority. This will create a transformed social climate in which stigmatization and discrimination themselves will no longer be tolerated. This will concretize HIV related stigma and discrimination as a rights issue and will deal greatly with people who stigmatize PLWHA. A change of the laws calls for effective leadership. The WHO (2009) says that leaders with consistent messages are needed to help people envision a better future and these calls for leadership often seem to be aimed at politicians and others in positions of great power who put these kinds of laws into operation.

5.7.5 Deal with Clinics and Hospitals

Having been identified by respondents as a major institution that stigmatizes and discriminates people living with HIV, some respondents feel that something needs to be done in the health care to change practitioners' attitudes and beliefs about people living with HIV. Anna's advice to her colleagues in the medical profession in Sweden is that:

... we here in the health sector have to open up as well...not...it's not easy, I think it has to be done on many different levels.

The WHO (2009) document on policy interventions says on this issue that health workers at all levels have opportunities to play leadership roles and use their professional and personal connections to advance the cause of scaling up the response to HIV. The struggle should not be left only to those that work at the infection clinics and the few kind dentists who are let PLWHA onto their duty rosters.

Chesney and Smith (1999) agree with this by saying that political leaders and health care personnel should take the lead in combating this third epidemic. An analytical look at the suggestions by respondents in the battle against HIV related stigma and discrimination in Sweden, using theory reveals an overhaul of all units, or systems in society. The ecological and systems theory breaks it down very well and the above suggestions serve to reveal that positive and effective changes in the wider environment of PLWHA will eventually reflect back on them and ensure a reduction of stigma and discrimination directed towards them.

As Adam (2006) notes, people and society need one another; society is impossible without people and people are impossible without society. At anyone point, the one is the necessary environment of the other. The WHO (2009) on policy interventions sums up the interventions in relation to theory by suggesting that accelerating the response to HIV requires leadership from business, industry, trade unions, and academic and research institutions. And it will require leadership within neighborhoods and communities, from community councils, faith-based and other community-based organizations, formal and informal groups, networks of people living with HIV, people vulnerable or at high-risk of

infection, youth, and so on. This is in line with the writing of Maluwa, Aggleton and Parker (2002) who suggest that there should be a multifaceted response of combining community intervention with legal and structural intervention whose combination support a rights based approach

5.8 Summary of Findings

A major finding of this study is that HIV related stigma and discrimination exists in Sweden. One of the major forms of stigma is self stigma and there is also stigma from other people in society. Health service providers working out of the infection clinics have been singled out as the most common category of people that discriminate against PLWHA. The dentists, save for the very few that can take on PLWHA have been accused of being the number one discriminators in healthcare. The people providing services to PLWHA have also faced some stigma and discrimination, although this is at a very minimal level.

The laws put in place by the state regarding HIV have proved to be very oppressive towards PLWHA. They have been burdened with the responsibility to prevent further HIV infection while at the same time providing a false sense of security to the 'normal' members of society. This has been proved by the rising number of HIV infections in Sweden statistically over the years. Some even think it worse that the statistics reveal given the high numbers of Chlamydia cases in Sweden.

The media is cited as a cause of stigma and discrimination towards PLWHA. Together with the law on infectious diseases, it has influenced sentences handed down to PLWHA in the justice system. The justice system has been discovered to be unfair, and biased against PLWHA especially those of foreign background. The migrations board has also been found to be very inconsiderate and not empathetic towards asylum seekers living with HIV.

The study also revealed, that despite the tough laws and overwhelming stigma and discrimination, PLWHA are accorded the best free medical care and treatment at the infection clinics, thanks to the laws put in place to ensure that. But on the other hand, illegal migrants have been excluded from this service to the detriment of their health. The infection clinics have been found to be a very important node in the social networks of PLWHA as they seem to rely on them almost for everything

The stigma and discrimination has been attributed to a general lack of knowledge about HIV/AIDS in the population, fear, the media and the law on infectious diseases. Stigma and discrimination have led to the low levels of status disclosure among PLWHA, forcing them into living in secret and is also acting as a huge obstacle towards HIV/AIDS prevention, care and treatment.

Ways suggested by respondents to eliminate HIV related stigma and discrimination in Sweden include openness about the epidemic at all levels, strengthening PLWHA,

changing the law to be fair to all, having corporate responsibility in the fight against HIV, and providing knowledge and information to health service providers in all medical units outside the infection clinics.

In general, all the above results or findings were put across by both PLWHA and service providers interviewed.

CHAPTER SIX: CONCLUSION AND DISCUSSION

6.1 Discussion: Revisiting Research Questions

This section discusses the significance of the results presented under analysis with reference to the research questions. Previous research and theory are not used in this section because they have already been referred to in the preceding chapter.

6.1.1 What are the contexts of HIV/AIDS related stigma and discrimination that exist in Sweden?

HIV related stigma does indeed exist in Sweden. Self stigma was projected as the main context of stigma followed by stigma from society. Self stigma is caused by a combination of many issues and respondents noted that chief among them is the stigma PLWHAs are subjected to at the different structural levels in society. Since HIV was originally considered a gay disease in Sweden, respondents noted that PLWHA are often judged about their sexual lifestyles by society. This also includes immigrants and anyone belonging to the MARPs category thus being subjected to double, or even multiple stigmas. This has left them with feelings of shame, neglect and embarrassment about who they are and has taken an emotional and psychological toll on some of them. They noted that Stigma in society has destroyed relationships and caused previous social ties to be severed. Respondents also believe that stigma, whether self stigma or from society is experienced mainly by the newly diagnosed PLWHA and those that are not married or without sexual partners. This is because with time, PLWHA have learnt to avoid stigmatizing situations. They have slowly learned how to cope with stigma.

Respondents noted that there is less discrimination of PLWHA in Sweden however, most of the situations narrated in this study by respondents are cases of discrimination. Some respondents argued that little discrimination is noticed because not so many people make their HIV positive status known publicly. Apart from the infection clinics, the health care system, mainly the dental clinics were singled out as the places where PLWHA face the most discrimination. Respondents noted an overwhelming lack of HIV/AIDS knowledge among health workers in Sweden. Discrimination was also cited in courts of law where PLWHA in HIV related cases are not given fair hearing and judges are harsh when delivering sentences. Respondents agree that foreigners are given harsher punishment and afterwards, they are deported back to their countries regardless of ART accessibility in their home countries. The Migrations board was found to be non-empathetic towards HIV positive asylum seekers.

6.1.2 What are the underlying causes, of HIV/AIDS related stigma and discrimination in Sweden?

Service providers admitted to contributing towards stigma and discrimination by telling their clients not to reveal their status but to a few close people. Even if it has counteractive effects, it seems to be the best solution at the moment. To a small extent, some service providers are also stigmatized because they work with PLWHA. The Swedish law on infectious disease was also projected as discriminatory towards PLWHA thereby triggering discrimination in other levels of society. Although it provides free medical care it has loopholes that place the burden of HIV prevention on PLWHA and gives people in society a false sense of security. Another cause noted is the lack of HIV knowledge in society with the most educated stigmatizing and discriminating against PLWHA the most. Respondents also noted a general lack of interest in HIV/AIDS information especially among the youth. For all the negative stories and images about HIV that they display, the media is causing stigma and discrimination towards PLWHA. Respondents noted that media portray as negative and condemning towards PLWHA. This has affected the treatment accorded to them in society.

6.1.3 What are the effects of HIV related Stigma and Discrimination?

Respondents noted that disclosure level is limited to only a few close family members and trusted friends, for the sake of accountability. Exceptions here are those living openly about their HIV status that needed to release the secrecy burden, and also move around in different institutions sharing knowledge and information about HIV. This has come at a social cost of losing some friends and relatives that cannot accept their HIV positive status. Respondents also noted that they reveal their status to new partners and health workers as required by the law. On a worrying note, respondents unanimously agreed that HIV related stigma and discrimination is very much an obstacle to prevention, care and treatment efforts in Sweden. This makes some respondents to believe that HIV figures in Sweden may be higher than statistically portrayed by government and thus action is needed to avert what seems to be like a time bomb in Sweden. As regards care, stigma and discrimination cuts out the social care that PLWHA might have been able to receive from family and friends.

6.1.4 What kind of support do they receive from their social networks?

PLWHA interviewed were found to be very self reliant in most aspects without having to depend on family and friends for almost anything. Respondents noted that this is due to the fact that they receive proper medication and they adhere to it. They also noted that in case of any medical problem, staffs at the infection clinics are always at hand to help them in any way that they can. The help is not only limited at medication but they can go or call to talk, cry, or shout any time they feel they want to vent out their emotions. This also contributes to low levels of disclosure according to respondents. This may also be as a result of Sweden being a social welfare state that basically takes care of its citizens that fall short in some aspects. The few friends and family that stick with them plus the staff at the infection clinics give them the strength to accept their situation and go on with their

lives normally. The various NGOs also step in where the state and society fail to provide help needed at that particular time.

6.1.5 How can HIV related Stigma and discrimination be addressed in Social Work and health service provision?

The need to scale up information, education and knowledge about HIV/AIDS at all levels in society especially in schools was put across by respondents. Respondents consider the young population to be mostly at risk given the high levels of Chlamydia. Respondents also noted that now is the time for the media to put aside their old prejudices about HIV and act as a channel of spreading information about the diseases and how it can be avoided. Respondents suggested that PLWHA should be strengthened in all aspects so that they can come out and speak boldly about HIV dispel all rumors and myths surrounding the disease in the Swedish society. Also, HIV prevention should be made a responsibility of everyone by removal of laws that make it a one sided effort legally. They called for a change in the infectious disease law as one of the first steps to combat stigma and discrimination in Sweden. Because PLWHA have a right to medical care even outside the infection clinics, respondents suggested that staffs at the clinics and hospitals should be handled in ways that can change their negative attitudes towards PLWHA. Respondents noted that health care workers need to open up and accommodate them.

6.2 Reflections

Given the above views and reflections from PLWHA and service providers, the author's reflections are presented below. They can either complement the above views or be included with the others.

The media in Sweden should change its approach to how it portrays HIV/AIDS to the society. The media is a powerful tool that can make or break a person, an institution, or anything that it sets out to put in the spotlight. It would be of great advantage if the media made an effort to work with everybody involved in the fight against HIV by dismantling the negative images they have built about PLWHA in Society. This calls for vigilant campaigns in both digital and print media to allocate time and space for HIV/AIDS issues that educate and inform the masses. The media can also help in exposing people and institutions that stigmatize and discriminate against PLWHA, not as a way of shaming them but passing on a message that PLWHA human rights need to be respected as well. This, if done correctly will help mitigate HIV/AIDS related stigma and discrimination as exemplified by the case of Botswana in O'Leary et al (2007).

PLWHA should be encouraged to be open about their HIV status. The earlier people put a face to HIV, the earlier they will accept that it is a reality just within the neighborhood and can be mitigated if people are careful enough to heed to public health campaigns. This does not mean that stigma and discrimination will go out completely rather, HIV will reach a level where it is considered normal in society and PLWHA accepted as

normal people, because they actually are. In order to back up PLWHA efforts, high profile figures in the Swedish society like the royal family, celebrity musicians, sports personnel, academicians among others should play the role of HIV good will ambassadors. They do not have to be HIV positive; rather they should serve as instruments of HIV information and knowledge. Musicians from different genres can also compose songs laden with information about HIV in a bid to sensitize the society.

My other reflection is that the Swedish law should be revised as a way of respecting the human rights of PLWHA. Criminalization of HIV is a misguided strategy that institutionalizes stigma and discrimination otherwise if it was that effective, we would not see the number of people diagnosed with HIV rise in Sweden every year. The silence about this topic in the judicial system should be broken; otherwise this gives society the impression that PLWHA should be blamed for their condition. This study does not seek to exonerate those that intentionally transmit HIV they should still face the law but not under 'special' sections in the law. "Instead of applying criminal law to HIV transmission, governments should expand programmes which have been proven to reduce HIV transmission while protecting the human rights both of people living with HIV and those who are HIV negative" UNAIDS (2008:2). Sweden as a human rights advocate, needs to look into its own house and cover all loop holes in the law that are contradictory to the human rights values that it stands for internationally. It does not seem fair that a small percentage of the population has to ensure that nine million people do not contract the HIV virus. Let the fight against HIV be a battle for everyone. Like the old adage goes, there is strength in numbers, the more individuals or organizations rallied to the HIV cause, the better for everyone.

As a matter of urgency, dentists and other health workers outside the infection clinics should be accorded special training on HIV facts and how to handle PLWHA like Banteyerga et al (2005) recommend. My reflection on this is that health personnel may have been pointed out because they are among the few people that PLWHA disclose their HIV status to as dictated by the law. The reactions and attitudes of health workers towards PLWHA mirror the reactions in society. HIV information, education and knowledge should also be streamlined to people in the courts and justice system plus the migrations board as a way of combating their prejudices.

On the above note, there is need to scale up HIV/AIDS education and dissemination of information in the general populations. There is need to do away with the classification of MARPs like immigrants, homosexuals, IDUs among others because this only serves to mislead the public about who can have HIV. It makes them believe that if one does not fall into the above category, then they are free from HIV and so all caution is thrown to the wind.

Finally, like Aggleton and Parker (2002) advise, there should be two strategies in mind to combat this; one is towards prevention of prejudicial thoughts formed by individuals, and then those who address or redress cases of persistent or occurring stigma through discrimination. There should be a multifaceted response of combining community intervention with legal and structural intervention whose combination support a rights

based approach. Emphatic action should be grounded on the experience of individuals and communities.

6.3 Concluding remarks

From the analysis, it is clear that stigma and discrimination against PLWHA is found at many levels in society and it has proved to be a barrier to HIV prevention, care and treatment. In order to mitigate the impact of HIV related stigma and discrimination, effective strategies that encompass and involve all structures or levels of society, right from the political leadership to the common man in society should be implemented.

This study also found out that lack of adequate HIV knowledge and information in the Swedish society is the root cause of HIV related stigma. There is also need to integrate HIV information with human rights. In order to scale up this, PLWHA should be adequately involved in HIV Prevention, care and treatment efforts because they have the experience of living with HIV and knowledge to inform others. They are a vital resource that should be adequately facilitated and supported by the government and people in society.

6.4 Suggestions for further research

This study did not have the opportunity to talk to health service providers outside the health clinics like the dentists. It would be great to sit down and talk to them in order to hear their side of the story and also brain storm with them on how they think they can be helped in order to be more accepting towards PLWHA in Sweden.

The effect of the media on HIV perceptions in society would also be another interesting area to study in detail.

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Interview guide for PLWHAs.

Introduction

The overall aim of the thesis is to study the obstacle of HIV/AIDS related stigma and discrimination in HIV prevention, care and treatment. It also sets out to study People living with HIV/AIDS in Sweden, their level of disclosure, social networks and ways of addressing HIV/AIDS related stigma and discrimination.

The data collected from this discussion will be primarily used for research purposes as part of a partial fulfillment of the International Master in Social Work and Human Rights at Gothenburg University with the hope that it will also be a reference for policy makers, social workers, doctors and other service providers to combat HIV/AIDS related stigma and discrimination.

The data from this interview is confidential and so is your name, personality and any other thing particular to you.

I- Bio Data

Sex: _____

Marital Status: _____

Nationality: _____

II- General Questions

1. When did you discover that you are HIV Positive?
2. How did you feel when you found out that you are HIV positive?
3. Did you reveal your status to anyone?
4. To who?
5. Why that particular person or people?
6. How did that person(s) react to the news?
7. What do you understand by HIV/AIDS related stigma and discrimination? (after the respondent's answer to this question, I give the definition of the two concepts as used in this study)
8. Can you recall any incident(s) where you have felt stigmatized and discriminated because of your HIV status?
9. How did you respond in that situation?
10. How do handle HIV related stigma and discrimination when it happens to you?
11. How does HIV/AIDS related stigma and discrimination affect you?
12. How has it affected the disclosure of your HIV status?

13. Where do you get support from?
14. Have you ever felt stigmatized or discriminated by any service provider e.g social workers, nurses, doctors etc?
15. What do you think about the state laws regarding a person who has tested HIV positive e.g. tracing all your previous sexual partners?
16. How do you think HIV related Stigma and discrimination can be addressed?

Thank you very much for your time.

NB: All questions shall be asked in a flexible manner, coupled with probing and prompting depending of the answers provided by the interviews.

Interview guide for Individual Interviews of service providers.

Introduction

The overall aim of the thesis is to study the obstacle of HIV/AIDS related stigma and discrimination in HIV prevention, care and treatment. It also sets out to study People living with HIV/AIDS in Sweden, their level of disclosure, social networks and ways of addressing HIV/AIDS related stigma and discrimination.

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The data from this interview is confidential and so is your name, personality and any other thing particular to you.

II- Bio Data

Sex: _____

Education Level: _____

Nationality: _____

III- General Questions

1. For how long have you worked with people living with HIV/AIDS?
2. What do you understand by HIV/AIDS related stigma and discrimination?
3. Does HIV related stigma and discrimination exist in Sweden?
4. In what contexts does it exist?
5. How do you think it affects service provision?
6. Have you come across cases in Sweden where the service providers stigmatize and discriminate people living with HIV?
7. Have any of your clients reported cases where they have been stigmatized and discriminated against because of their HIV status?
8. What kind of help do you offer clients with such cases?
9. Have you ever been stigmatized or discriminated by people you know or don't because you work with people living with HIV/AIDS?
10. What do you think about the Swedish Communicable Disease Act?
11. What do you think can be done to combat HIV/AIDS related stigma and discrimination?

Thank you very much for your time.

NB: All questions shall be asked in a flexible manner, coupled with probing and prompting depending of the answers provided by the interviews.

