

### Department of Social Work

International Master of Science in Social Work

Insiders' Views and Reflections on HIV/AIDS Prevention Targeting Immigrants with Multicultural Background in Sweden, Gothenburg

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Gothenburg, June 1, 2008 Kassaye Tekola Moges

All errors and omissions in this paper are entirely mine.

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#### **Abstract**

This research sets out from two global phenomena: HIV/AIDS and Migration. HIV/AIDS is perhaps one of the most distressing human suffering globally. Migration is also global phenomena accompanied by rapid human movement in the contemporary world. These two phenomena are deduced to be associated together in "immigrants as risk category for HIV/AIDS" especially in developed countries like Sweden, where HIV prevalence among the native population is low.

This research project explores the views and reflections of insiders', who are drawn from large group "immigrants", and are also educators of HIV/AIDS prevention to same group in Gothenburg city of Sweden.

The research employed individual interview and small group discussion research methods and integrates the analysis and discussion with prior research and theoretical considerations from structural to individual level integrating cultural concerns in multilevel framework in the context of HIV prevention targeting immigrants with multicultural background in Gothenburg city of Sweden.

The main findings of the research based on the insiders' views and reflections include among others: lack of clearly tailored methods of HIV prevention which are culturally sensitive and specific to multicultural immigrant groups, low participation of immigrants and absence of People Living with HIV/AIDS (PLWHAs) participation in the HIV /AIDS prevention. Furthermore, stigma and discrimination appear still in the making; HIV/AIDS and Chlamydia are growing up. On contrary, people especially youngsters in Sweden consider HIV as a "distant disease or problem". This has been contributing towards Knowledge, Attitude and Practice (KAP) gap for safer sex to prevent from HIV/AIDS pandemic.

Key Words: HIV/AIDS, Sweden, Immigrants, Multiculturalism, Culture

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#### List of Abbreviations

**AIDS** -Acquired Immune Deficiency Syndrome

**HIV** -Human Immunodeficiency Virus

IEC- Information, Education and Communication

**IDUs** -Injecting Drug Users

IPPF EN- International Planned Parenthood Federation European Network

KAP-Knowledge, Attitude, Practice/Behavior

MSM- Men who have Sex with Men

NGO -Non-governmental Organization

PLWHAs-People Living with HIV/AIDS

**SAFE**- Sexual Awareness for Europe

**SFI-** Swedish for Immigrants

SMI- Swedish Institute for Infectious Disease Control (Smittskyddsinstitutet)

**STD-** Sexually Transmitted Disease

**ToTs-** Trainers of Trainees

**UNAIDS** -United Nations Programme on HIV/AIDS

**UNESCO**-United Nations Educational, Scientific, and Cultural Organization

WHO -World Health Organization

#### CHAPTER ONE: INTRODUCTION

#### 1.1- Background

In the globalizing world, the movement of people crossing the national boundary is so common and on the increase. The underlying causes might differ from place to place, from time to time, bringing in many explanations intersecting the causes and reasons. Recently people are displaying on a daily basis their willingness to risk everything for a job or refugee in Europe, feeling strife and economic stagnation in the south (Ireland, 2004). It is among many contemporary explanations. Meanwhile it looks from the history of human beings that the movement of people is inevitable.

The increase in movement of people has been facilitated by the advancement of transportation and many other accompanying factors. And the movement is so rapid in the present era of globalization. Consequently, the transnational movement of people is largely contributing towards the making of multiculturalism. And this in essence is making the concept of multiculturalism a prominent concept in the globalizing world. That could be why some writers are preaching this concept more than before in recent times. For instance, MacLachlan (2006:1) notes that 'multiculturalism is the only way in which the whole of humanity can be greater than the sum of its parts'. After I adopt Sue's(2006) explanation about multiculturalism, I use it to mean that the combined existence of life experiences and cultural values that include individual, group and universal dimensions in the context of differences in identity, cultural background, language religion etc.

The movement of people from place to place, from nation to nation, from developed to developing countries and vise versa, etc is not a problem by itself. It becomes a concern when it dresses problem with it. Increasing mobility has consequences for the transmission of HIV and many researchers have indicated that people from regions with low prevalence are moving to countries with high HIV prevalence, and vice versa (Duifhuizen, 1996). In line with this fact, movement of people from high to low HIV pandemic countries, concerns the 'host' country with the presupposition that the immigrants come with the virus and endanger their society.

In recent years, HIV/AIDS is regaining concern in Sweden as the HIV/AIDS infection is rising. Now and then literatures in the area are pointing out specific risk groups for HIV/AIDS infection. Whenever the risk groups of HIV in Sweden are identified, immigrants come at forefront. In the recent strategic document of the Swedish government it has been explicitly indicated that an important starting point for preventive and supportive efforts of HIV is to make those groups that are most at risk from HIV/AIDS visible. The document states that the groups considered most in need of targeted measures are: men who have sex with men(MSMs), injecting drug users (IDUs) young people and adults, people from foreign backgrounds, people traveling abroad, pregnant women, people who are the victims of prostitution (Swedish Ministry of Health and Social Affairs, 2007).

As a matter of interest taking people from foreign background who are stated as one of the risk group, this paper focuses on exploring the views and reflections of those who are parts of this group in the context of HIV prevention with particular emphasis to the multicultural dimension such as the context of cultural and linguistic differences of the targets. This leads us to the concept of immigrant. There are various ways of defining immigrant referring to complex phenomena. Immigrant usually refers to "foreign-born persons who have left their nation of birth to dwell in another country" (Fong, 2004:8). In this paper, for the sake of clarity and convenience, I adopt the more straight forward category 'country of birth' used by Hedlund (2007:10). Here, persons who

are born in one country and at some point in time have moved to Sweden and have lived for an extended period of time and associate themselves as largely belong to 'home' cultural background are denoted as 'immigrants'. In this definition I exclude those who are foreign born adoptees with the assumption that the cultural diversity and linguistic differences do not apply to them.

In this research project the Swedish context of sexuality is taken into account while looking at the HIV Prevention efforts. 'Scandinavia is known for its liberal attitude towards sexuality' (Christianson, et al, 2003: 44). However in many societies, attitudes towards sexuality are conservative. There is probability of coming across with immigrants from conservative attitudes. It is also interesting to look at how immigrants who come from such conservative society are being dealt within the HIV/AIDS information, education and communication (IEC) for prevention in the middle of Swedish liberal society.

#### 1.2-Problem /Question at Issue

There have been various efforts by concerned governmental, non-governmental and international agencies in order to combat the HIV/AIDS pandemic, globally, nationally and locally. However, the prevention efforts have been challenged by various factors. Amongst many factors culture usually comes as important factor. Broadly, culture refers to "shared customs of communication and common experiences of living in the world" (Maclachlan, 2006:36). With context of HIV prevention taking cultural approach means considering a population's characteristics including lifestyles and beliefs (UNESCO, 2001). So, I use culture in this context.

According to UNESCO (2008) the challenges associated with HIV and AIDS have proven to be especially difficult because they differ from culture to culture. The ways in which the pandemic is regarded as well as the ways in which responses are conceived and implemented are intimately linked to factors such as traditional practices, gender issues and beliefs (UNESCO, 2008). The importance of culture in understanding the HIV pandemic has been emphasized by so many authors as well. For instance Feldman (1990) has noted that 'it is impossible to truly understand the role of AIDS in our lives unless we consider the social and cultural contexts of AIDS-related behavior'.

There is an assumption that programs are not as effective as they are planned to be. Especially programmes such as HIV/AIDS prevention with immigrants who are culturally heterogeneous needs cultural competence of personalities involved. I borrowed the concept of cultural competence from Sue (2006) and here cultural competence in specific context of HIV prevention is to mean the ability to communicate, interact, negotiate and intervene having the awareness, knowledge, and skills needed to function effectively with groups from diverse cultural backgrounds.

When we come to Sweden, there are evidences that HIV/AIDS infection is increasing in Sweden in recent times. For instance, Bredström (2005) has stated that Swedish media reported in January 2004 that the number of persons infected with HIV continues to rise in Sweden and at the same time it was described as the global situation. Referring to the Swedish Institute for Infectious Disease Control (SMI), the rising numbers were explained by the fact that more and more people from HIV-affected regions are coming to Sweden (Bredström, 2005). This is the basic reason why this research emphasizes on immigrants as its targeted subjects among others.

In line with the above justifications, this particular study tries to assess and analyze the aforementioned puzzling issues in the context of HIV/AIDS prevention targeting immigrants who are supposed to be with multicultural background and highly heterogeneous groups taking the

views and reflections of those immigrants, who are at the same time HIV prevention education providers for their fellow immigrants. For the purpose of this research project the informants are referred as Trainers of Trainees (ToTs) of immigrants. ToTs are understood as elements of immigrants, who are also agents to transfer knowledge and information about HIV/AIDS, and also taken as facilitators to change attitudes and help to bring behavioral change of their fellow immigrants so as to prevent them from any risks of HIV/AIDS pandemic. In this paper ToTs can interchangeably used as health educators, 'informätors', HIV/AIDS practitioners or sometimes as social workers depending on the context used.

#### 1.3- Aims and Objectives

The overall aim of the thesis is to explore insiders' views and to get reflections on HIV/AIDS prevention activities and /or works targeting immigrants. Meanwhile, it aims at finding out how the notion of multiculturalism affects the HIV/AIDS prevention efforts targeting immigrants in Sweden with particular reference to Gothenburg city. The special interest is exploring the views and reflections of HIV/AIDS practitioners' specifically ToTs. Furthermore, this thesis aims to capture the views of professionals in the area of HIV/AIDS prevention targeting immigrants with special emphasis of addressing culturally diverse groups towards the common objective of HIV/AIDS prevention. All these subjects belong to people with immigrant background and that is why taken as insiders of big group 'immigrant'.

In order to explore the insiders' views and reflections on the HIV/AIDS prevention targeting immigrants with multicultural background, my research questions are as follows:

- What are the predicaments and/or impeding factors that can be identified by HIV/AIDS prevention practitioners in relation to HIV prevention in Swedish society in general and immigrants in particular?
- How the interplay between culture and HIV/AIDS influences HIV/AIDS prevention targeting immigrants?
- How multiculturalism affects the HIV/AIDS prevention targeting immigrants?
- What explanations can be drawn from the accounts of practitioners for the gaps in Knowledge, Attitude and Behavior/Practice (KAP) in relation to HIV/AIDS pandemic?

#### 1.4 Significance of the Study in Social Work

This study has significance for social work in that it tries to point out multiculturalism which is one of the central social work principles. This study is in concurrent with the perspective of Sue (2006) who views that multicultural understanding to be at the absolute core of social work activity to clients, who come from different cultural contexts and against mono-cultural ways that do not enhance cultural competence in dealing with diverse groups. Multicultural social work practice which is viewed as "both a helping role and a process that uses modalities and defines goals consistent with the life experiences and cultural values of clients; recognizes client identities to include individual, group, and universal dimensions; advocates the use of universal and cultures specific strategies..." (Sue: 2006:20). Therefore, this thesis is supposed to have relevance as it tries to bring the notion of multiculturalism in dealing with social problems such as HIV/AIDS pandemic.

The other significance of this research is that it tries to identify multilevel problems associated with the fight against the global epidemic HIV/AIDS which is one of the concerns in social work by

bringing in the context of migration which is another global phenomenon on which social work has stake. Specifically, this research paper has significance as it attempts to explore the links between migration and HIV by presenting framework of analysis for development of migration related HIV prevention programs in areas where migrant population has largest HIV infection.

#### 1.5 -Structure of the Paper

In the preceding sections, first chapter, I have already provided with a brief introduction of the paper under which, the background information of the research area, the problem statement, the aim of the research and research questions and also the significance of the research to social work have been introduced.

In the second chapter of the research project earlier research materials are reviewed. This chapter consists six sections which emphasize on HIV/AIDS and migration from international perspective to national level. This chapter, after discussing migration and HIV/AIDS from transnational perspectives, goes down to Sweden's specific information.

In the third chapter, theoretical framework of the paper has been included. Under this chapter, theoretical considerations from structural level to individual level have been introduced by taking multilevel framework that links between and among migration; HIV/AIDS and culture with the very purpose of understanding migration and HIV/AIDS, in which culture also come as third component. With respect to understanding HIV education and information for prevention two specific theoretical perspectives (communication theory and KAP model) are also introduced.

The fourth chapter presents the research methods employed and also describes the whole research process from methodological orientation and awareness discussing relevant concepts with respect to their handling in the research process.

The fifth chapter presents the data and analysis through dividing in to parts and themes. Prior research and theoretical perspectives are integrated in the analysis of the data with close link with research questions. And also the main results are summarized after the analysis at the very end of this chapter.

In the sixth chapter, discussion by revisiting research questions and theoretical considerations and/or perspectives is made. At the end of this section some reflections of the author are also included.

Finally, the paper puts concluding remarks and also leaves out some loosely discussed issues that came out interesting with the eyes of the author for further future research.

#### CHAPTER TWO: LITERATURE REVIEW

#### 2-Earlier Research in the Area

#### 2.1- Transnational Perspective on Migration

Migration is an international phenomenon that can be looked from broader perspective. International migration refers to persons moving across boundaries of nation states and historically as well as currently mankind is on the move (Hedlund, 2007). It is a general fact that sizable number of people especially the younger generation from different countries with different background travel outside their countries for various reasons. At global level it is believed that very significant number of people migrate. International migrants are usually categorized according to the motives for moving to another place, with labor migrants and refugees as main categories, although migration due to family ties is also common (Hedlund, 2007).

The migration movement of people across the world is significant. For instance, the UN estimates that perhaps some 150 million people (or 2.5 percent of the world's population) today live outside their country of birth (Moses, 2006). The issue of migration stretches from international to national and local concerns. Despite the significance of migration, the current global movement of people and its impact both on sending (home country) and receiving (host country) remains unclear (Carballo and Siem, 1996). However, immigration and immigrant health policies reflect prevailing public fears and attitudes by which immigrants have been perceived as culturally and economically threatening (Carballo and Siem, 1996).

Migration represents one of the most common vehicles of cross-cultural encounters (Maclachlan, 2006). Various socio-economic factors mediate as pulling and pushing factors for migration. In recent times, rapid developments in communication and transportation systems have enabled people to move further and quicker than before in resulting in mass migration and coupled with these changes and/or developments, the movement of individuals and populations has become an important factor in shaping the global spread of HIV/AIDS (Carballo, and Siem, 1996). In line with this, there is a growing volume of literatures relating migration with the spread of HIV/AIDS especially tracing on the movement of people from high HIV hit countries to low ones.

#### 2.2-Quick look of Immigration in Sweden

In the current global movement of people, developed countries seem to take more and more people. Sweden is not an exception. Along with other countries in Europe, Sweden has experienced increases in immigration over the last several decades and it can be viewed as an example of immigrant inclusion within the broader comparative framework of immigration and social change in Europe (Bernhardt, et al., 2007).

As indicated by Hedlund (2007), at present times about 13% of the Swedish population or just over 1 million individuals born in another country live in Sweden. As a result Sweden is today considered as a multicultural society (Akhavan, 2006).

#### 2.3-HIV AIDS as Global Social Problem

HIV/AIDS is a global epidemic threatening the wellbeing of society. Almost over the last three decades HIV/AIDS has grown from a localized health concern to a global issue that comes out at large in national and international agendas. Though AIDS is a global problem, it has been more associated with structural patterns in society. Boloor (1995, cited in Lichtenstein, 2004) notes that HIV/AIDS is socially patterned in terms of who is most at risk of HIV/AIDS transmission, both locally and on a global scale (i.e., some societies or groups are more vulnerable than others).

Current estimates show that worldwide a total of 33.2 million people now live with HIV/AIDS; in 2007 alone, an estimated 2.5 million people were infected with HIV; everyday 6,800 people (i.e 283 every hour) contract HIV; and 2.1 million people died from AIDS in 2007 alone (amfar AIDS Research, 2007; UNADIDS/WHO, 2007).

Now it is about three decades that HIV/AIDS has still threatening the lives of human beings. Three decades ago there was optimism that health for all will be achieved globally. World Health Organization (WHO) was the front runner to set this very social objective. In 1977, the World Health Assembly, the Central Authority of WHO stated that "the main social target of WHO in the coming decades should be the attainment by all citizens of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life" (Health for all, 1977, cited in Walden Laing, 2001). However, this very blessing optimism has been hindered by the emergence of HIV/AIDS. In concurrent with this Walden Laing(2001) explicitly indicated how one tiny virus let down the global optimism and altered the prospects of a healthier world and healthier communities in the foreseeable future as well.

As MacLachlan(2006) clearly indicated for over a decade governments, international agencies and non-governmental organizations (NGOs) have put great efforts into changing people's high risk behavior regarding HIV/AIDS and despite these, the pandemic has continued to spread and serious questions begun to be asked about the methods of prevention used. As indicated by MacLanchlan (2006) high risk behavior for HIV/AIDS transmission varies in different places and among different groups, but includes sexual relations (particularly through multiple partners, causal relations, violent intercourse and prostitution), mother-to-child transmission(during pregnancy, at birth or through breast-feeding), intravenous drug use(through infected needles) and contaminated blood (encountered during sexual intercourse, in certain initiation ceremonies, unhygienic removal or circumcision, tattooing and skin piercing).

#### 2.4 HIV/AIDS: International Comparative Perspective

From an international comparative perspective, the prevalence of HIV in Sweden is low. At the end of 2002, the proportion of the population aged 15–49 years living with HIV/AIDS was 0.08% (Hertz and Ramsstedt, 2005). UNAIDS (2003, Cited in Hertz and Ramsstedt, 2005) estimated that the corresponding adult prevalence was 0.3% in Western Europe, 0.5–0.9% in Eastern Europe and Central Asia, 0.5–0.7% North America, and 7.5–8.5% in Sub-Saharan Africa.

According to EuroHIV (2002) although the number of newly diagnosed HIV infections remains globally stable, data shows a continuous increase among persons infected through heterosexual contact (+64% between 1997 and 2001), primarily among immigrants from countries where HIV is widespread (mainly sub-Saharan Africa). This shows that in many areas, one of the biggest changes in recent years has been the emergence of unprotected heterosexual intercourse as a

cause of new HIV infections (IPPF European Network, 2007). The major challenges currently facing Western Europe are to prevent a slackening of safer sex practices and to improve access to screening and treatment for all infected persons, especially immigrants from sub-Saharan Africa (EuroHiv, 2002).

Looking at more recent data, it shows that heterosexually acquired HIV infections, most of which were among immigrants and migrants, which accounted for the largest proportion (42%) of new HIV diagnoses in Western Europe in 2006(UNAIDS/WHO, 2007). About 29% of newly diagnosed HIV infections in this region were attributable to unsafe sex between MSMs, and only 6% to IDUs (EuroHIV, 2007). IPPF European Network (2007) in it recent publication emphasized that policy makers need to address these issues urgently and sensitively by addressing the needs of risk groups especially that of migrants as a key vulnerable group when formulating HIV prevention Policy.

#### 2.5- General Overview of HIV /AIDS in Sweden

According to the National Swedish Board of Health and Welfare (1992), the spread of HIV-infection in Sweden began in 1979 among homosexual men living in Stockholm. The earliest known case of infection via blood transfusion occurred in 1980 and also infection among IDUs became more wide spread in Sweden during 1983-84 (The National Swedish Board of Health and Welfare (1992).

In recent time in Sweden, according to UNAIDS/WHO (2006) by the end of 2004, a cumulative total of 6704 HIV cases have been reported; 1981 of the infected individuals had developed AIDS, including 1283 who had died. UNAIDS/WHO (2006) further indicated that in the year 2004, Sweden reported 426 new HIV cases, 67 new AIDS cases and 21 AIDS deaths. In the same document it has been indicated that of the new HIV cases, 59 % were transmitted heterosexually, 18% by MSMs, 6% by IDUs, 3% vertically (mother-to-child), 1% by blood and blood products and 12% by other or unknown causes.

The current overall Sweden's HIV prevalence rate for adults aged 15 to 49 is estimated to be 0.2 %( UNAIDS, 2006). However, It has been indicated that the number of people in Sweden becoming infected with STDs including HIV/AIDS have grown drastically over the past five-year period (Swedish Ministry of health and Social Affairs, 2007). Because of this, HIV/AIDS has regained growing concern by concerned pertinent authorities in Sweden.

As Bredström(2005) notes although not as prevalence as it was in the case of gay men, refugees and immigrants have recurrently appeared as a 'risk category' in the Swedish HIV/AIDS policy discourse. Migrants and refugees are singled out as some of the most potent disease carriers in Sweden (Bredström, 2005). According to UNAIDS/WHO (2006) most cases of heterosexual transmission are found among non-Swedish migrants, mainly those who come from sub-Saharan Africa. It has been further pointed out by UNAIDS/WHO that people who have been infected outside Sweden constitute two thirds of the reported cases in recent years. Most of this cohort acquired HIV prior to their immigration to Sweden (UNAIDS/WHO, 2006).

#### 2.6- HIV/AIDS Prevention in Sweden

As I indicated earlier referring to literatures, the prevalence of HIV/AIDS in Sweden is very low from an international comparative perspective. The explanations for the low prevalence have been usually associated with the prevention measures Sweden has adopted since the emergence of the epidemic. During the late 1980s, a number of nationwide campaigns were undertaken to prevent the spread of HIV/AIDS in the general population of Sweden (Herlitz and Steel, 2000). In those early times of HIV/AIDS prevention in Sweden, every household was sent written information explaining ways in which HIV is transmitted, ways to prevent HIV, and information dispelling myths associated with HIV transmission and also groups considered to be at particular risk of contracting HIV such as customers of sex workers, MSMs, young single persons, and those who are likely to have causal sexual contacts, partners of IDUs, and persons traveling abroad, were provided with additional, target specific information via various media (Herlitz and Ramstedt, 2005).

The HIV/AIDS prevention in Sweden hasn't been static. The focus and targeting has been characterized by a sort of dynamism. As noted by Herlitz and Ramstedt(2005), the frequency of targeting of HIV/AIDS prevention campaigns have been modified since 1980s towards focusing on four identified groups: adolescents, immigrants and refugees from endemic countries, homosexual men, and HIV-infected persons and their relatives. Although the prevention efforts began in the early 1980s, it was not until 1987 that the AIDS commission initiated a nationwide campaign to prevent HIV in the general public; at the time approximately 100 cases of AIDS and 1500 cases of HIV had been documented in Sweden (Herlitz and Steel, 2000). On top of these, when we look from geographical dimension, the major HIV prevention measures by the public authorities of Sweden have focused on large cities. It is because of the fact that 78% of the HIV cases have been identified in the largest cities (Stockholm, Gothenburg, and Malmö) (Herlitz and Ramstedt, 2005).

Focusing on the explanations given for low HIV prevalence in Sweden many authors cited the efforts that Swedish government implemented sex education in schools apart from the pubic HIV/AIDS campaigns. It is apparent in the profile of Sweden that it has a long history of sexuality education that goes way back in late 1800s and early 1900s (IPPF EN, 2007). To highlight some on the progressive trend of sexuality education in Sweden, it introduced voluntary sexual education in 1942, aired the first sexuality education on radio in 1954, and it became the first European country to establish compulsory sexuality education in all schools in 1955(IPPF EN, 2007). IPPF EN(2007) further outlined that sexuality education in Sweden is known as 'sex och samlevnadsundervisning' (sex and relationship education) and the age at which provision begins generally not latter than 12 or 13, which means before puberty and generally before first intercourse by which it tries to answer any questions about sexuality in open and honest way. Even though, relationship and sexual education has been part of the national curriculum in schools in Sweden since 1956, unfortunately it is less taught these days in many schools especially in many multiethnic schools setting (Edgardh, 2002).

In general, school based age appropriate information concerning contraception; sexually transmitted diseases (STDs) including HIV and the various public HIV prevention campaigns might have contributed to the low prevalence of HIV in Sweden. As complementary explanation, HIV testing has also played central role to Sweden's programme of preventing the spread of HIV epidemic. Dzigner(1998) notes that HIV testing has been widely promoted and encouraged on the basis that once HIV infected people aware of their sero-status and receive the counseling needed, they will take the necessary steps to protect their partner.

Among the general population Sweden has tried to prevent STDs in general and HIV in particular through engaging county councils, communities and voluntary organizations. This is also true, in Gothenburg city where this research has been conducted. Knowledge, information and education are important channels which have been used by these concerned bodies. It is obvious that such methods have worked for the native Swedish population as evident in many literatures, though clear measures and indicators as to the extent of the effectiveness are lacking in many instances. But what about the immigrants who haven't received sex education at schools as they were at their home country where in most cases such methods are lacking and also because of their disadvantageous position to benefit from the HIV campaigns due to language and cultural barriers. I will include in the analysis part of this report by bringing in the views and reflections of professionals working with these groups.

#### CHAPTER THREE: THEORETICAL FRAMEWORK

#### 3. Theoretical Considerations: links from Structural to Individual Level

#### 3.1 Multilevel Framework: AIDS, Migration and Culture

Much of the social science research actively emerged in response to AIDS from earlier times up to the present, focuses on surveys of risk related sexual behavior, and on the knowledge, attitudes and beliefs about sexuality that might be associated with the risk of HIV infection and therefore most of these studies have aimed to collect quantifiable data on numbers of sexual partners, the frequency of different sexual practices, previous experience with other sexually transmitted diseases, and any number of other similar issues that were understood to contribute to the spread of HIV infection(Parker, 2001). On the other hand, there was a growing focus on the interpretation of cultural meanings (as opposed to the calculus of behavioral frequencies) in relation to finding the most important alternative approaches to research on sexuality and AIDS (Treicher, 1999).But when the component of migration is included some elements that are associated with migration are left out without being explained. So when groups such as immigrants are taken the consideration of multilevel framework sounds reasonable (Soskolne and Shtarkshall, 2002).

According to Soskolne and Shtarkshall ( 2002) the multilevel framework can be adopted as follows.: a multi-level framework for analysis of the links between migration and HIV can be taken by including the association of migration with structural macro factors—such as lower socioeconomic status and limited power in the new society; intermediate structural factors such as limited social capital and interaction of cultural norms; and individual-level factors such as depleted psychosocial resources and loss of cultural beliefs and low use of health services. Finally all these factors affect risky sexual behaviors and transmission of HIV (Soskolne and Shtarkshall, 2002). So this paper adopts this frame work and tries to explain part of the impeding factors in HIV/AIDS prevention in the context of immigrant population of Sweden, Gothenburg.

Both migration and HIV/AIDS are not new phenomena. Migration has existed through out human history and HIV/AIDS has prolonged its history to about three decades. However, when we look these two phenomena, it is in the era of the latter that many of the political and social problems surrounding migration have become the most evident and concerning. Carballo & Siem (1996) noted that, the AIDS pandemic has prompted a complex relationship between social and economic conditions on the one hand, and individual and public health on the other. It would be important to indicate that in the case of HIV/AIDS, the tragedy is that social marginalization on the basis of personal behavior has often coincided and exacerbated the societal marginalization of immigrants, of the poor, and of those whose cultures and sexual preferences are considered 'different' (Carballo, and Siem, 1996:40). These show that understanding HIV prevention targeting immigrants needs the consideration of migration in the structural context and relate to explanations with respect to culture.

Within the aforementioned framework if we focus on the cultural element, there are authors that have emphasized the importance of culture in relation to HIV/AIDS. For instance, MacLachlan (2006:280) noted that 'the tragedy of AIDS illustrates the often complex interplay between culture and disease'. Cultural attitudes have had an impact on the accumulation and dissemination of information regarding transmission of HIV (McCombie, 1990). Although the effectiveness of interventions varies by type, length and other characteristics of the intervention, the most

efficacious HIV prevention programs have specifically been directed at groups at risk of infection, focused on relationship and negotiation skills, involved multiple sustained contacts and used a combination of culturally appropriate media of delivery (MacLachlan and Mulatu, 2004, cited in MacLachlan, 2006). According to some studies, despite the fact that most intervention studies have not explicitly studied the roles that cultural variables play within cross cultural factors into their HIV prevention themes and contents have confirmed the all-encompassing influence of culture in risk perception, risk-taking behaviors and adoption of protective behaviors (Wilson and Miller, 2003).

As Knipe and Arber (1993) have pointed out linguistic, cultural and social differences may cause problems in HIV/AIDS prevention. Referring to immigrants having multicultural background, the interplay between culture and AIDS can be a point of interest as immigrants are so heterogeneous to fit into specific HIV prevention programs. It looks important how intervention programmes deal with cross-cultural differences, cultural barriers to communication, etc. Meanwhile, HIV prevention at its very end is determined through behavioral change at individual level and therefore, those theories explaining behavior and behavioral change are also important in HIV/AIDS prevention discourse.

#### 3.2 Specific Theoretical Perspectives

Many theories particularly psychosocial models and communication theories such as the theory of reasoned action, social learning theory and health belief models explain HIV/AIDS prevention programs from behavioral perspectives. Recently, Social Cognition Models and Social Cognitive Theory are widely used in research on health related behaviors and particularly these theoretical frameworks are useful for planning and conducting interventions and in many instance educational approaches to the prevention of HIV/AIDS have also come at forefront (Aaro, Schaalma and Ästrom, 2008). However, as this thesis by large considers the multicultural awareness, knowledge and practice at its center stage of HIV/AIDS prevention targeting immigrants taking the views and reflections of ToTs and professionals working with immigrants, individual level analysis in the context of behavioral change would be out of scope of this paper. Rather, I bring in two important theories to explain the HIV prevention in context of information provision and knowledge transfer. One theory is from communication dimension largely from educators, the other is from explaining the gaps after the information and knowledge is channeled. Meanwhile, I use them mostly limiting my self up to the views and reflections health educators in the context of these theories and/or models. These are communication theory and the KAP (Knowledge, Attitude and Practice) Model.

#### 3.2.1-Communication Theory

The communication theory is credited back to Yale, who was a prominent communication theorist (Bennett and Hodgson, 1992). These authors noted that a number of prominent workers have extended the original work of Yale communication theory to develop more sophisticated models of influence through mass communication. While presenting the communication theory Macdonald (1992) explicitly indicated that communication at its very simplest involves a communicator or communication event, a massage and a recipient. Macdonald (1992) notes that this communication act is the basic building block for all social relationships as it is a means by which all information and knowledge is transmitted. That is why I consider this theory as important in the HIV prevention in which information provision and knowledge transfer are important.

According to Macdonald (1992) in communication theory the communicator uses a series of signs or symbols which he or she encodes in a message. The same author noted that the recipient, once his or her attention is aroused, decodes the message and if motivated, acts on the information received. In essence the communication event is to do with confirming and therefore this communication theory is more akin to training (as an education and training) since it attempts to develop certain attitudes and forms of behavior (Macdonald, 1992).

The communication theory can be contextualized in HIV/AIDS prevention works, by taking the elements of the theory in its simplest from. In the context of HIV prevention, the communicator or communication event could be health educators, mass media, workshops, seminars, etc; a message could be how to prevent from HIV, knowledge about the means of transmission, deconstructing cultural taboos, misconceptions and myths associated with HIV/AIDS, etc; and the recipients are targets and /or subjects of communication and in my case immigrants.

By adopting this theory, I use it in the context of UNAIDS communication framework adopted in 2001. The UNAIDS communication framework urges HIV/AIDS programme implementers to reorient their approach ascertaining the role of socio-cultural influences (socio-economic status, gender relations, cultural norms, and spirituality) and environmental influences (government policy, access to services) in shaping individual behavior. The UNAIDS framework calls for refocusing communication interventions on the basis of five key contextual domains: government policy, socio-economic status, culture, gender relations, and spirituality. These contextual domains, while they lie outside the control of individuals, have a significant influence on their HIV/AIDS-related health behaviors (UNESCO, 2001).

According to Payne (2005) communication theory and its understanding can be used for: analyzing and developing practice by improving communication skills, working on communication problems, and analyzing problems in team work.

#### 3.3. 2- The KAP Model

The KAP model postulates that education is carried out in order to increase knowledge regarding the health consequences of certain behaviors and this model takes that increased knowledge is expected to lead to a change in attitudes towards health compromising behaviors as well as health enhancing or risk reducing behaviors(Aaro, Schaalma and Ästrom ,2008). The same authors indicated that in this model, attitude change is assumed to lead to change in practice (behavior). Behavior change (in the direction advocated) is assumed to lead to an improvement in health or reduction in risk of disease, injuries or death. (Aaro, Schaalma and Ästrom, 2008:38). As AIDS is considered as disease, this model has been used in the context of HIV prevention programmes.

Aaro and et al(2008) note that providing information and increasing knowledge of health consequences of a specific behavior will in short term most likely lead only to marginal if any changes in behavior. The long term behavioral effects within a culture of a high level awareness and knowledge of health consequences of the actual behavior may still prove to be considerable according to them. More recent research on the relationship between attitudes and behavior has revealed that rather substantial correlation between attitudes and behavior may exist, provided that relevant attitudes are in focus and properly measured and therefore, the attitude concept still deserves to be included in theories and conceptual models on health behavior, though they are not the only predictors (Aarø, Schaalma and Ästrøm, 2008).

As I indicated earlier, I use the KAP model in the analysis of my data only in the context of views and reflections I got from my informants about the people they are working with and try to intermingle explanations through bringing in from earlier research.

#### **CHAPTER FOUR: RESEARCH METHODS**

#### 4-Qalitative Research Method: Justification

Quantitative and qualitative research methods are two broad tools in research methods. Although quantitative methods are regarded as more exact and measurable and qualitative methods are seen as more subjective, the choice of methods depends on the purpose of research. Traditionally, though these methods have seemed to be in contrast, practically they can be taken as complementary and interactive to each other. Kvale (1996) notes that in the practice of social research qualitative and quantitative approaches interact and if we take in more open approaches to interview texts qualitative and quantitative analysis intermingle and so the relative emphasis and choice of methods depends on the type of phenomena investigated and the purpose of investigation and therefore their utility depends upon their power to bear upon the research questions.

As this paper tries to explore the views and reflections of ToTs, taking their experiences in HIV/AIDS prevention, I have chosen the qualitative interview method. The choice of this method could be justifiable as it is in line with Kvale's (1996:70) assertion that this method is uniquely sensitive and powerful method for capturing the experiences and lived meanings of the subjects everyday world which allows them to convey to others from their own perspectives. By transitivity, the qualitative interview method is good method to explore about HIV/AIDS prevention from the experiences of personalities who actively involve in the work

This study employs two methods among others to obtain primary data. These are semi-structured interview and small group discussion. The empirical focus is made on the analysis of individual interviews made on immigrants receiving HIV/AIDS prevention training as Trainers of Trainees (ToTs) to channel same HIV education to the respective fellow immigrants and also based on data from the small group discussion. In doing so, purposive/convenient sampling(sampling strategy that selects participants according to the goal of this particular research) has been employed with the objective of gaining relevant information from ToTs, and representatives of professionals working in HIV/AIDS prevention, who are convenient for the this specific research.

For individual interview, the method of interview used is semi-standardized interview. The questions in the interview guide are made as open-ended as possible in order to gain impulsive and spontaneous information about the issue at hand. During the interview, probing (follow up questioning) and prompting have been used in order to generate more information on the subject. After tape-recording all the interviews, one-to-one selective transcription was made.

The methods of maintaining and generating conversations with people on a specific topic or range of topics and the interpretations which social researchers make of the resultant data, constitute the fundamentals of interviews and interviewing (May, 2001). In qualitative research, lack of standard techniques invites researchers to multitude of techniques and it is partly due to the richness and the complexity of the subject matter (Kvale, 1996). As the intention of the author is to obtain the views and reflections of the insiders, who are parts of immigrants and at the same time active in the endorsement on the HIV/AIDS prevention education targeting immigrants, the semi structured interview is convenient. As May (2001) indicated, flexibility and the discovery of the meaning are characterize such methods.

#### 4.1 Research Design

While discussing the ingredients of social research Gilbert (2001) indicated that design of methods of data collection is one of the important ingredients. And also, as Kvale (1996) indicated the very virtue of qualitative interview is their openness. However, there are standard choices of methods at the different stages of the interview investigation. In order to have good research, the overall design of an interview should be considered. For instance, it has been claimed that things can go wrong when the overall design of an interview investigation is not considered. Kvale(1996) identified seven steps of interview investigation: thematizing, designing, interviewing, transcribing, analyzing, verifying and reporting. In this thesis, these stages of interview investigation are followed. The author has them in relation to their very purpose which they stand for as indicated by Kvale. The theme of the research was identified on the onset of this research. I have chosen the design that most fit to the research theme as I indicated earlier. Then, I conducted the interview with ToTs, having semi structured interview guide.

The empirical data from the interview with ToTs has been complemented with information from two interviews with professionals and small group discussion involving concerned personalities from agencies working on HIV/AIDS prevention with immigrants. The small group discussion has consisted three individuals who have been working in HIV prevention targeting immigrants. In order to capture diverse views the persons are drawn from different background (originally an Eritrean, Iranian and Jordan but currently all are Swedish by citizenship). This method is used to assess the common and varying views and elicit the range of views of personalities involved in one way or another on HIV prevention. The author involved as a facilitator/moderator in leading the group discussion. The level of involvement was kept medium in order to maintain some control over the direction of the discussion towards the specific research questions. The group discussion took about one and half hour. The discussion was tape recoded and selectively transcribed for analysis.

In including the small group discussion method, the interest of the author has been to point out consensus and disagreements on the issues, to draw points of agreements and disagreements relevant to the study from the interactive discussion within the group which has paramount importance to complement on the data from the individual interview. And also, the data from the small group discussion are used to triangulate the data with individual interview.

#### 4.2 Interview Procedures and Situation

I have got the interviewees though an organization, with which I was placed for my field work earlier in March, 2008. After I discussed my research topic with my field host organization, I got the list of six health educators who are all belong to immigrants. There are a total of 60 who have gone through similar training for the last six years. But all are not active practitioners in the current HIV prevention works. All I met are said to be those immigrants who are currently actively involve in the HIV prevention works as health educators or ToTs for fellow immigrants.

I ensured the issue of informed consent by asking all my interviewees' voluntary participation on the outset of contacting them. One interviewee out of six couldn't come on the day of interview due to personal reasons, though volunteered to be interviewed at the beginning. I gave them all an informed consent form before starting the interview. I conducted three interviews in my respective respondents' office after we reached an agreement that office is quiet place to make the interview. I did one interview in café and one interview in an open public park which was very silent, enjoying

nice summer weather near to the central Library of Gothenburg University. The interview with individuals (ToTs) took about an hour in average.

The interview with the two professional followed the same procedure in terms of informed consent and voluntary participation. I did the interview in their respective offices. The interview took about one and half hour for each.

With regard to the small group discussion, I contacted six professionals based on the recommendation of an organization who directly works on HIV/AIDS and sexual relation issues. These professionals represent different national backgrounds and are working directly with immigrants in STI and HIV/AIDS related issues. It was very hard to bring all together to a session for the focus group discussion due to office duties and personal schedules. After I realized that it is difficult to get them all for the focus group discussion, I decided to make a small group discussion with three professionals who could come on the scheduled day and time of group discussion session. I conducted the discussion in one of the organization who volunteered for the session. The session took about one and half hour.

#### 4.3 Transcription

Transcribing has been one of the processes of producing this report. I used the procedures and methods of transcription identified by Kvale(1996). Methods of recording interviews include audiotape recording, videotape recording, note taking and remembering (Kvale, 1996). Out of these, I used audiotape recording and note taking (especially for probing and follow up questions). Using the tape recorder has helped me to concentrate on the topic and dynamics of interview. After all the interviews completed, I did the transcription my self with the awareness that transcription itself is an interpretative process as mentioned by Kvale (1996).

I did selective transcription rather than verbatim. It is in line with the assertion of Kvale's (1996) note on the question as to what is the correct transcription. Kvale (1996) noted that a more constructive question is "what is a useful transcription for my research purpose?" So, I didn't make verbatim transcriptions as my research purpose doesn't take into account the linguistic descriptions for analysis. So I made selective transcription in relation to my research purpose and questions. I have included most of the conversations in the analysis but with little emphasis on verbatim descriptions.

#### 4.4 Methods of Analysis

#### 4.4.1 Interview Data Analysis

In the method of analysis, the five interviews were tape recorded, transcribed, and subjected to a qualitative analysis. In similar manner the interview data from two professionals and data from a small group discussion was transcribed and subjected to analysis.

The approaches to interview analysis identified by Kvale (1996) like meaning condensation, meaning categorization, narrative structuring, meaning interpretation and generating meaning through ad hoc methods have been considered. I don't discuss them here one by one; rather I highlight how I used them as approaches of the analysis for my interview data. I used the meaning condensation in a way that very long statements of the interview were reduced to shorter and brief

ones without affecting the meaning what was said by my interviewees. I made the meaning categorization through bringing together issues and occurrences indicated by the interviewees. And also, I tried to generate meanings from the texts of interviewees, eclectically by bringing the common sense approach of meaning generation in words and numbers by taking different parts of the material as proposed by Kvale(1996).

As a method of analysis, I didn't make use of narrative structuring since there is no story telling during the interview. Partly, I used meaning interpretation in that I expanded some texts from the interview data that I found very strong and related to the research questions I posed earlier.

#### 4.4.2 Introducing Approach of Analysis in Relation to Theory and Data

At this juncture, I want to make clear the approach I use in making analysis of data in relation to theory. I don't use specific theory to analyze and explain my data from individual interview and focus group discussion through out. Rather, I opt for the abduction method. In the literature there is more or less agreement about the general nature of abduction. Following Aliseda (1997), abductive approach relates to the search for of an acceptable explanation for a surprising or anomalous (individual or general) observational fact. Abduction approach goes back and forth with a mix of inductive and deductive approaches to analyze data and to relate to contexts. Furthermore, I want the readers of this work to understand my way of handling theories in the context of relating concepts with respect to relationships rather than taking grand theory or very specific theory which will miss sizable part of data unexplained and/or unanalyzed in relation to the research questions I posed earlier. By doing so, I could say it is appropriate to use such method as far as it explains the issue at hand.

The above way of handling abductive approach is appropriate because it is in line with the recent and modern research application and using theories to explain data. As Gilbert (2001) clearly indicated "theories are composed of concepts linked by relationships". My theoretical consideration is also in concurrent with the very idea of theoretical framework which lies on an explanation which takes the form of an assertion that can be explained. As indicated in Gilbert (2001) this can also denote a perspective on the social world that is too general, too broad and all-encompassing to be confirmed or refuted by empirical research. These kinds of broad and radically different perspectives are referred to as theoretical frameworks (Gilbert, 2001). So within this understanding, I try to connect to range of concepts that are important for the research theme that I have got from my data in relation to the subject migration, HIV/AIDS and culture by referring earlier research in general and research questions I posed, in particular. In general, based on the aforementioned assertions, I try to explain some important patterns from the interview in relation to theories, concepts and prime research that analyze and interpret them in the analysis section using predominantly abductive approach.

#### 4.5 Limitations of the Research Method Employed

The method employed for empirical data collection through interviews has some limitations. The author has taken only five subjects for individual interview due to shortage of time and difficulty to find more persons who can be representative of the immigrant population. Though there were about 60 ToTs who have been trained as health educators of immigrants, I have been informed that they are not currently active so it is quite difficult to access them. So, the views and reflections obtained from these interviewees might be limited and result in less representative and contribute towards a source of error and bias. It would have been much better if I could access more TOTs and able to improve representative ness of all health educators working with immigrants.

Therefore, in order to minimize the limitation it would have been better if the study employed quantitative methods as well to complement the results from interview. In order to thoroughly understand how the HIV/AIDS prevention programs are organized and implemented in general and focus on immigrants in particular, it might be also useful to make evaluative studies on the organizations working with this group.

I admit that the number of cases from which I got first hand accounts through interviews was very limited and indeed the paper is rather empirically informed reaction and focuses on views and reflections from the parts to the whole.

The other limitation could be taking immigrants as a whole might weaken the notion of specificity which is one of the aspects of qualitative research interviews (Kvale, 1996:30). However, I believe that since my focus is on the views and reflections of my interviewees, who are part of immigrants as well as closely know their respective immigrants, and not on the immigrants as a whole, it is suitable for qualitative study as well.

#### 4.6 Ethical Considerations

The author has taken the ethical issues in the process of this work. Ethics is concerned with the attempt to formulate codes and principles of moral behavior (May, 2001). In this particular thesis, the method of study is interviewing and accordingly, ethics in relation of the method which are indicated by Kvale (1996) are taken into account. Kvale (1996) notes that ethical decisions do not belong to separate stages of interview investigations but arise through out the entire research process. In most text books, for example in Kvale(1996,) three ethical guidelines (informed consent, confidentiality and consequences) are emphasized.

After giving them the consent from to the individual interviewees, I reached to agreement with them to keep their confidentiality. So in this research I don't mention the subjects of this research by name or recognizable entities. And also I don't disclose any information that potentially violates the confidentiality of the interviewees. But they agreed with me to mention about the countries where they came from, if necessary.

It may be difficult to anticipate the potential consequences of an interview report (Kvale, 1996:260). However as I am aware of the ethical issues in relation to the consequences; I don't reveal the interview report as identifiable or specifically recognizable terms in consideration of any possible consequences.

#### 4.7 - Validity, Reliability and Generalizability

Validity, reliability and generalizability are important concepts in social science research methods. In this presumption, I took into account these concepts while doing this research project. In general terms, these concepts are used by researchers to make their indicators to be as good as possible. Gilbert (2001) indicated that validity is used to measure the concepts as accurate as to be measured; reliability is to denote whether the measure used is consistent from one measurement to the next; and generalisability is used as to know whether results are generalizable. This is the general understanding in research arena on these very concepts. Since I use the qualitative interview approach, I adopt the validity, reliability and generalisability used by Kvale(1996).

In order to make my research finding reliable, I followed some procedures required in the research process. I tried to avoid leading and ambiguous questions while conducting the interview even though it is difficult in most cases. I tried to triangulate the major concepts consulting related literature etc. In order to maximize validity, I followed the seven stages of validation (thematizing, designing, interviewing, transcribing, analyzing, and reporting) identified by Kvale (1996). I have discussed them in various sections of methods I employed in this research project.

With regard to generalization, I have made a close look as to how to generalize using the qualitative interview method. As Kvale (1996) notes a persistent question posed to interview studies as to whether results are generalizable. According to Kvale (1996) the issue of qualitative generalization has been treated particularly in relation to case studies and usually three forms of generalization-naturalistic, statistical, and analytic are identified. The generalizations I make in this research project are cumulative results of largely from naturalistic and analytic generalization. It is naturalistic in that I used my previous personal experience in HIV/AIDS prevention and it is analytic in that I based the generalization from reasoned judgment about the extent of findings and data from individuals interviewed and group discussion made. I made analysis of differences and similarities from the data obtained in the interview contexts and the seemingly related and different views and reflections are taken. This is in concurrent with generalization in qualitative studies indicated by Kvale (1996) in claiming generalizability in qualitative research using interview method.

#### **CHAPTER FIVE: RESULTS AND ANALYSIS**

#### 5-Presetation of Data and Analysis

In this section, I present the data from the individual interviews and small group discussion in relation to theories and prime research. First, I present overall about my interviewees and small group participants. Then, I analyze data from the accounts of both individual interviews and small group discussion having themes that reflect my research questions.

#### 5.1-The Respondents

A total of 10 informants participated to generate the empirical data. The data was generated from five interviews with health educators/ToTs (two females and three males), from a group discussion participants with three professionals (two females and one male) and from interview with two professionals in the field of HIV/AIDS and STDs.

As I indicated earlier, the ToTs interviewed are those who are said to be currently active as HIV/AIDS prevention practitioners targeting immigrants. Due to ethical considerations, the presentation of data doesn't include individual details. However, I can present the general information about the participants. In terms of nationality, two of them are originally from Eritrea, one from South Africa, one from Iran and the other from Uganda. They have stayed in Sweden with a minimum of 12 years and a maximum of 29 years. All of them are with immigrant background but now possess Swedish nationality. They have involved in HIV/AIDS prevention and related works ranging from 2 to 14 years of service. When we look at their educational level, two of them have a college diploma, two with BA level degree, and one master's level degree. In terms of marital status, only one is single while others have got married.

The other two informants are professionals, with educational background of Masters Level, one in public health and one with social work. The focus group participants are three of whom one possesses MA while the other two are with BA level degree. All respondents were originally from foreign background but by now all possess Swedish citizenship.

All ToTs indicated that they are working in HIV/AIDS prevention related works because of the fact that they have educational background in health training and/or social work profession. Three ToTs out of five were trained in health related disciplines before they came to Sweden and get involved in HIV prevention and related works. The remaining two have undergone either short term training or university level education in related field. Since they started working with immigrants in relation to HIV/AIDS they have gained a lot of experiences. This has been reflected in the interviews as the explanations they gave tend to be more of professional.

For the sake of convenience and analysis, I give to my informants differentiating code as follows. I tag "informant A to E" for ToTs, "Informant F" and "Informant G" for the professionals and "Informants H" for the focus group participants. Whenever I extract direct quote from the data obtained from my informants, the respective code for a given informant appears with text.

#### 5.2 Analyzing the Data: Dividing into Parts and Themes

In this section I analyze the data in relation to themes that relate to my research questions. In the analysis theories, concepts, and data from prior research are inculcated in the context of HIV prevention.

## 5.2.1 HIV/AIDS Prevention Experiences with Immigrants: Surrounding Challenges, Impeding Factors, Predicaments and/or Dilemmas

The informants shared their experiences in the area of HIV/AIDS in general and prevention component in particular with reference to immigrant groups in Gothenburg city. There are diverse experiences in context of HIV prevention to take into account in the analysis. However, the seemingly common and persuasive ones in terms of relevance for the subject under scrutiny are presented here under.

There are range of difficulties and /or challenges identified by informants in the effort of HIV prevention targeting immigrants in Sweden in general and Gothenburg area in particular.

**Segregation as More of Structural Problem:** One of the points identified by informants as structural problem is segregation. Most immigrants in Gothenburg live in some parts of the city like in *Agered, Kortedala, Bergsjön.* The informants identified that segregation could be source of inequality and poverty. Even though poverty is generally low in Sweden in general, due to the universal welfare system, relative poverty could exist in segregated areas of Sweden.

The professionals (informants F & G) pointed out that even though, buying sex is illegal in Swedish law, there is no evidence as to covert prostitution is there or not. To support this presupposition, I tried to check for some literature. However, I couldn't find any study in support or against this presumption during this research project. This might be one area of future research in the area. The lack of research and sufficient data in this regard limits this study from going further to relate with prostitution which is one of the contextual factors considered in HIV/AIDS problematic.

However, the small group participants identified marginalization of immigrants as the overriding reason for the need to provide HIV/AIDS information. Immigrants' access to HIV information is limited due to language barrier and limited social capital especially for new comer immigrants. This is in line with the structural factors I identified under the framework analysis.

*Lack of clear Methods:* All informants pointed out that their job is based on short term projects. Continuity is in question though some have worked for long years. All indicated that There is no strategy which is goal oriented and with specific methods as to deal with immigrants.

As one of the informants explained:

There is no improved methodology as to how to specifically deal with diverse immigrant groups ...still sexuality is a taboo among many immigrants I have worked with. I got always confused as to what method should I use (Informant B).

A professional interviewed (informant F) related lack of methodology due to less emphasis on public health issues in Sweden in recent past. There was little emphasis in public health in Sweden as per the professional interviewed. Public health is very important in HIV/AIDS prevention as it

meets different methodologies from social science to medicine integrating various scientific methodologies in combination (informant F). The same informant added that in Sweden public health is a recent development; it is not more than six years that public health has been given emphasis in Sweden and now it is in transitional phase.

Lack of Specific Strategies and/or Methodologies: Lack of strategies and specific methodologies are one of the important requirements lacking in HIV prevention targeting immigrants in Sweden as per most informants. These have been identified by the two professionals and four health educators. The informants are aware of the current Swedish government national strategy to combat HIV/AIDS and other certain communicable diseases which has been adopted in 2007, which I mentioned in the earlier sections. They question the availability of specific methods and strategy in use for immigrants as top down approach without to let participate the immigrants themselves. Especially the professional informants indicated that the national strategy has not being tailored specific to immigrants even though they are targeted in the strategy in general terms.

With regard to filling the gaps identified, a professional informant explained that in terms of developing strategy and adopting specific methodology to work with immigrants, Sweden is now in transitional period (Informant F). I have cross checked as to whether there is a strategy to deal with this group, and I have found that there is newly developed strategy in 2007 at national level. But the strategy is not specific rather it considers immigrants as one group. It is like 'one size fits all approach', though these group are diverse and heterogeneous.

However, it is obvious in the document that the process is in transition. In the national Strategy to Combat HIV/AIDS and certain other communicable diseases, Sweden's Ministry of Health and Social Affairs(2007) states that 'an increasing number of people are living with HIV infection or AIDS and the number of those being infected by HIV every year is growing'. It also asserted that at the same time sexually-transmitted diseases are also increasing in Sweden for which the adoption of a strategy is needed to prevent the spread of HIV infection and certain other communicable diseases and reduce their consequences.

Immigrants and AIDS together: Sensitive Issues: In most cases the informants associated challenges largely in dealing with two sensitive issues: immigrants and HIV/AIDS. This is apparent in the following, which one of the informants said:

My experience is that... when I approach people...I mean immigrants to inform them about HIV/AIDS, they tend to keep distant, I don't know why? But I think it is probably they feel that they are being associated with a deadly disease...." (Informant E).

From the above it is clear that this health educator and/or social worker has difficulties and challenges in handling immigrants and AIDS together as these are very sensitive subjects in combination to deal with. Harour- Knipe and Rector (1996) indicated that it is very difficult to discuss of a stigmatized disease, AIDS, and an often stigmatized group, migrants together.

The informants view that targeting immigrants all together in relation to HIV/AIDS problematic in most cases have negative connotation. This was especially noticeable in the interview data with ToTs with African background. For example one of the informants said that:

...at the beginning it was as difficult as you feel that you have been targeted and labeled, because as it also related with racial difference in association with HIV/AIDS...Here people and also the mass media used to relate HIV/AIDS with immigrants and homosexuals, not

only as risk group but also, if you are a black, you considered to have caught HIV/AIDS, in addition if you are homosexual, if and so that has devastating feeling on you (informant D).

Here, it might be interesting to have an insight on the role of the media as a means of communication. In communication theory, information received from the environment is processed through language then organized by an individual (Payne, 2005). In UNAIDS communication framework on HIV/AIDS, the environmental influence is within one of the explaining contexts of the HIV/AIDS problem.

Lack of Participation of People Living With HIV/AIDS (PLWHAs): Lack of PLWHAs, who disclose themselves to the public, is one of the bottlenecks for those HIV/AIDS educators in the HIV/AIDS prevention education and communication. Out of five interviews with ToTs only two of them knew PLWHAs. It was indicated by the informants it is due to the fact that most people don't want to reveal themselves to the public. In order to have effective HIV prevention the participation of PLWHAs has paramount importance. The involvement of people living with HIV/AIDS at every stage is one of the criteria in order to have effective HIV prevention (UNESCO, 2005). All the informants associated lack of PLWHAs with stigma and discrimination.

Sigma and Discrimination: How and on Whom? All informants from individual interview pointed out that there is high stigma and discrimination towards PLWHAs. To validate this information, the issue was also raised to professionals interviewed and also discussed among participants in the small group. The result appeared all the same. Let me put what was said by a professional informant:

Stigma and discrimination is as much as in Africa or elsewhere, if not less here in Sweden, some PLWHAs started to disclose themselves and tried to participate in prevention of HIV/AIDS. However, due to much discrimination and stigma they faced, they refrained and get back to hide themselves. Currently, even though there is an organization of HIV positive group here in Gothenburg, I know two persons who revealed their HIV status publicly (Informant F).

The implication of stigma and discrimination is apparent in the HIV prevention experiences of informants. One informant indicated that "we tell them (participants of education/training)...we don't show cases to them about the HIV/AIDS. They (participants) consider that it is not here, rather in Africa, Thailand or other countries...they consider it as distant disease rather than belongs here...nobody care about it"(informant C). The other informants also have similar view in many regards with regard to how immigrants are associated with HIV discourse. For instance, homosexuals and immigrants do not want to be identified in relation and context of HI/AIDS. For example, ToTs indicated that they limit themselves in general aspects such as telling facts about: what HIV/AIDS means, how it is transmitted and how to protect. They refrain from going beyond that limit in fear of reactions from discriminated groups especially immigrants and MSMs.

The professional informants (informants F and G) blamed the media in Sweden for presenting sensational news without taking into account constructing the meaning of HIV/AIDS towards specific groups especially immigrants and MSMs in stigmatizing and discriminating ways.

#### 5.2.2 HIV/AIDS and Culture in IEC for Immigrants

The cultural setting in shaping and reshaping ways of HIV/AIDS education provision to immigrants has been reflected by the informants. As identified by the ToTs the practical methods of HIV IEC are using workshops, seminars, small group discussions, going out to SFI (Swedish for Immigrants) classes, reaching immigrants through associations, on HIV/AIDS day etc. The health educators indicated that they also give education if they are invited by associations. They answer questions raised about sexuality in general and HIV/AIDS in particular. As the small group participants emphasized they take into account gender issues, religious issues, and cultural issues and so on but they lack specific method for specific group.

In the context of UNAIDS communication framework (adopted in 2001), UNAIDS urges HIV/AIDS programme implementers to reorient their approach ascertaining the role of socio-cultural influences (socio-economic status, gender relations, cultural norms, and spirituality) and environmental influences (government policy, access to services) in shaping individual behavior, but this have been difficult to identify from discussion with the participants.

Among the informants there is a common agreement with regard to having knowledge and communicative skills that takes into account the cultural background and at the same time having knowledge about AIDS being sensitive to culture specificity of the respective groups to be dealt with. There is no disagreement as to whether there is need to have the cultural competence too. One of the Informants summarized this notion in the following way.

It is a must to understand the cultural background. ...you have to give information in language they [immigrants] know, context they would understand, and terms with which they are familiar with. Otherwise, you miss your audience and your effort will be irrelevant (informant A).

The other information from the accounts of the informants is that they looked confused as to whether they are appropriately addressing the HIV prevention education to the targets. It looks stacking in the middle and demeaning their confidence in their effectiveness of education to the groups they give education of HIV/AIDS prevention. The common question appeared as: "Do I really understand them?" The following are some of the data from the informants.

When I raise the issue of religion, they react to me as I have disrespected their religion, so try to avoid talking about religion and focus on general information about HIV/AIDS" (Informant B).

Here, it looks from the informants' view that they have difficulties in dealing with their respective immigrant groups in the HIV prevention education. As one informant pointed out whenever one talks of culture and AIDS, religion comes as third part(Informant B). As per the information from professional informant, it looks that even though dealing specifically to a group taking into account the cultural background, they are not confident enough as to they have the cultural competence or not.

We have new comer immigrants with differing knowledge and educational background, they have so many supercilious things with them, with most immigrants we find cultural taboos about sexuality. we are always confused how to reach them, some don't want us at all, some need the information very badly...I can say we are working with issue in dilemma...we have a long term problem-AIDS, but a short term solution(Informant G).

Mahalingam (2006) places immigrants on a continuum between participants in their 'home' culture and their 'host' culture. If we see what the informants said with reference to their targets, it dictates some major gaps as to how culture has influence on HIV prevention targeting immigrants.

#### 5.2.3 Multiculturalism in HIV Prevention: Opportunities and Limitations

The small group discussion participants pointed out that multiculturalism can be taken as opportunity for HIV prevention works. They indicated that varying groups having diverse background gives opportunity to learn from each other. They said that you find these groups in the same place as they are mostly segregated. This makes the HIV prevention work simple in terms of accessing the groups.

However, the informants also viewed multiculturalism as limitation in HIV prevention in most cases. They pointed out that having multicultural group all together makes difficult to come up with IEC materials that are sensitive to every culture represented within this multicultural group.

Multiculturalism is viewed by most informants as having a problem as it has been indicated and discussed with the context of immigrants living in Sweden, Gothenburg. I want to bring in an explanation by one of the group participants who indicated it as a problem.

...multiculturalism is like a glass wall. You see each other; you don't talk to each other... HIV/AIDS education by its very nature needs interaction and communication. But how you communicate and interact if you don't understand each other in terms of language, culture, and other factors (Informant H).

All the group participants seemed to agree on this notion. The other interesting intersection with this notion obtained from a professional (informant F), who explained the problem of multiculturalism in context of segregated part of Gothenburg city. The informant said:

Multiculturalism looks very nice from the outside surface...But I view it as a problem...it is a source of confusion...it doesn't help to build good citizens. For instance crime is over represented among the immigrant youngsters... because they are confused...their neighbors are not alike, you find an African, an Asian, an Arab, a Christian, what is not..., who have different cultures in the same neighborhood ...Children and youngsters from immigrant families don't get answers for the question who I am? . In similar way we are confused what methodology to use for HIV prevention towards such groups" (Informant F).

From the above it is obvious that there is problem associated with having multicultural society together as indicated by the informants. However it is important to note that how the HIV/AIDS practitioners could be culturally competent to work with the immigrants with multicultural background.

When we relate to the theoretical explanations, Soskolne and Shtarkshall (2002) noted that immigrants may be at greater risk because they continue to retain their cultural norms or experience cultural losses without acquiring the cultural values of the new society

#### 5.2.4 Views and Reflections on Knowledge, Attitudes and Practices

All informants emphasized that most immigrants have the knowledge on how to prevent themselves from HIV, and also have positive attitude towards using prevention methods such as condoms and also tell that they practice safe sex. The informants indicated that they focus on those who are supposed to have low level of knowledge especially new comer immigrants (both youngsters and adults) and women who have low educational background in the country of origin. As per all informants even these groups have basic knowledge and information about HIV and how to protect themselves. The need for providing information and education is to keep them curious about HIV and STDs all the time.

However, according to all the informants Chlamydia is increasing alarmingly especially among the youth population including immigrants. The professional informant (informant F and G) indicated that in 2006 alone a total of more than 32,000 people get infected with Chlamydia out of which more than 6,000 are in west Sweden especially in Gothenburg and 87% of them get infected in Sweden. They noted that this shows there is unsafe sex which means that there is gap between knowledge, attitude and actual practice.

As most informants identified, most people in Sweden consider HIV/AIDS as 'distant disease' that belong to 'others': As one of the informants said and others agreed:

Here we lack how to scare people about HIV/AIDS, because we don't have that evidence that tells HIV is also here. We usually tell them figures... They say 'wow' but relate it to 'others'. There are only very few that we count with fingers that disclose themselves as HIV positive in front the public...we don't use PLWHAs to scare them (Informant H)

The KAP model claims that, although knowledge about HIV/AIDS, for instance, routes of transmission is important, attitudes are changed by two-way communication. Here the explanation of communication theory can be intermingled. There is a need of communicator from trust source. PLWHAs could be taken as trust source. From information or education receivers' side, the communication theory claims that in order to achieve behavioral changes, the receiver needs to fully incorporate the message with a positive attitude (Payne, 2005). Confidence and trust, the model suggested, will lead people to act in line with their knowledge. According to the communication theory, if people in a critical situation are told what they ought to do by someone they trust, they will frequently act rationally and correspondingly, lack of change in behavior or attitudes was explained by reference to individual fears and blockage (Macdonald, 1992).

But in context of Sweden, the KAP gap is apparent as the trust source of information from HIV positive people is lacking in most cases. Here one sees relationship with having testimonial account from PLWHAs that disclose themselves in front of the public. Lack of PLWHAs, who reveal themselves, has contributed towards believing by most people in Sweden to consider HIV problem as 'it doesn't belong to them' but 'to others'. This consequently has created the KAP gap.

#### 5.3 Summary of Results/Findings

-One of the main findings of the research is that there are no clearly tailored strategies and methods of HIV prevention, which are culturally sensitive and specific to multicultural immigrant groups in Sweden, Gothenburg. There is a clue from professionals interviewed that Sweden is in

transitional period in the formulation of strategies and culturally specific methods to address the problem of HIV/AIDS among immigrant groups.

- -The provision of HIV prevention education and production of IEC materials targeting immigrants are limited due to language barriers and cultural diversity. Information and education about HIV is limited to general information than specific information in fear of cultural insensitivity and difficulty due to diversity and /or heterogeneity of the immigrant population living in Gothenburg. This is apparently come out as the influence of culture in HIV/AIDS prevention as viewed by most of the informants.
- -The participation of immigrants in HIV education programs is limited. ToTs have difficulty to access immigrant groups, as they also distant themselves due to the discomforts with being targeted as immigrant group in association with HIV risk group.
- -There is lack of PLWHAs who disclose themselves in front of the public in fear of stigma and discrimination. Stigma and discrimination are still in the making and it has been indicated as too much to the extent of limiting the number of PLWHAs, who have disclosed to the public to only two persons though there are PLWHAs in hundreds in Gothenburg City alone. There has no any single person living with HIV who has disclosed himself/herself from the immigrant group, as far as the informants of this research know.
- -Most informants of this research pointed out that many people especially the youngsters consider HIV/AIDS as a distant disease that present in Africa and other underdeveloped countries and not in Sweden. This has an implication to risk unsafe sexual practice. The implication has been already implied by high rate of Chlamydia in Sweden in recent years which shows high risk for the increase in the HIV cases too.

In general, all the aforementioned results that came out from the views and reflections from the immigrant themselves, among whom most of them have been working for relatively long time in HIV/AIDS prevention and related issues have been informative for possible corrective measures by concerned bodies in the area.

#### CHAPTER SIX: DISCUSSIONS AND REFLECTIONS

#### 6.1- Discussion: Revisiting Research Questions

In this section the overall repercussions of the results presented under analysis are discussed with making reference to the research questions, theories and prime research indicated earlier

What are the predicaments and/or impeding factors that can be identified by HIV/AIDS prevention practitioners in relation to HIV prevention in Swedish society in general and immigrants in particular?

Here the interest is not to identify the conventionally understood factors impeding HIV prevention, rather predicaments identified by the informants in the context of their work on HIV prevention in Sweden in general and Gothenburg in particular are emphasized.

Language Barrier, Diversity of Cultural Background and Marginality as Impediments for HIV Prevention: There are a lot of difficulties identified as predicaments of HIV/AIDS prevention targeting immigrants in Gothenburg city. The differences in language, the diversity in terms of cultural background, and marginalization are some of them that most of the informants identified. The language barrier is apparent as impeding factor in HIV prevention because it has limited the provision of information to be mostly only through ToTs who know the language of specific immigrant group. And also the language barrier limited immigrants access to information available in Swedish in the internet and plenty materials (leaflets, brochures, fliers etc) available in Swedish language. With regard to diversity in terms of cultural background, it has been impeding factor in that, it make difficult the production of IEC materials cheaply because of the need for producing materials in different languages which are specific and culturally sensitive. With regard to marginalization, the reasons identified include limiting factor of interaction of these groups with the larger society. By its very nature, to internalize HIV education it requires interactive ways of learning. The other point related to marginalization is that, in these marginalized groups; IDUs are increasing with whom HIV prevalence is also growing.

As Soskolne and Shtarkshall (2002) identified migrants are usually not exposed to HIV prevention message that target the general population in the host country due to language and cultural barriers that also exist when they need for HIV/AIDS care. These problems are more of structural problems, which call for macro level intervention. These problems in context of immigrants have been discussed in some literatures in the area. For instance, Kipe and Arber (1993) discussed that in most cases immigrants are among the least privileged members of the societies in the 'host' country in which they are living and migrant health often falls between gaps of the country's programs, particularly where prevention is concerned. And also, migrants are at potential exposure to risk due to lack of access to information and to health care; difficulties in comprehending prevention messages; because of language difficulties, but more importantly because of profoundly different understandings and approaches to sexuality or to relationships between sexes; particularities in living situations; social and economic difficulties which could lead to such risk behaviors as covert prostitution or injecting drug use(Soskolne and Shtarkshall, 2002).

The strategy in question: As indicated earlier, even though there is national strategy to combat HIV/AIDS and other STDs in Sweden. In indicating the challenge and the importance of the national strategy the following statement has been included in the strategic document.

The number of HIV-infected people who have migrated to Sweden from areas of the world where HIV infection is more widespread among the population is substantially increasing. Identifying infected individuals and assisting them by providing treatment and psychosocial support is a challenge for society and essential to prevent the further spread of infection (Sweden Ministry of Health and Social Affairs, 2007)

Three informants highly criticized some of the current actions taken by authorities in sending back some immigrants after get tested HIV-positive. To triangulate this information from individual interview, I asked the group participants about this issue and its implication on HIV prevention. One of the participant indicated that she knew some HIV positive immigrants whose case for asylum seeking was rejected and sent back home, though the reason told to them was not explicitly associated with being HIV positive. The informants explained the implication of such measures in HIV prevention by indicating that immigrants do not want to go for HIV test and those already did will not be encouraged to reveal themselves in public and consequently, it makes talking about AIDS just in the surface as it doesn't exist. This will undermine the role of immigrants living with HIV/AIDS to actively participate in prevention of HIV. But it is difficult whether the action of sending back HIV positive immigrants, emanate from the strategic document, since such methods have not been explicitly included in the strategic document. This needs further scrutiny in the future. Here I have presented only the views and reflections of the informants.

In the context of HIV prevention targeting immigrants the necessity of two-sided approach have been emphasized by professionals in the area. Both 'top down' and 'bottom up' approaches should be implemented so that they can reinforce and complement each other (Duifhuizen, 1996). AIDS programmes should involve and consult migrant communities, and at the same time, they should stimulate and support initiatives within these communities so as to improve the effectiveness of programmes developed. Research and experience indicate that it is extremely important to include those who are most affected such as immigrants and ethnic minorities living with HIV/AIDS as well as their families, partners and friends so as to make HIV prevention effective (Duifguizen, 1996). This leads to the discussion of stigma and discrimination.

Stigma and Discrimination is still in the Making: Even though they reached normalization in many countries, stigma and discrimination have been identified as one of the major impediments in HIV prevention efforts in Sweden, Gothenburg. As indicated by the informants even though 61% of HIV/AIDS cases are immigrants, a single person hasn't disclosed himself/herself to the public in fear of stigma and discrimination. Only two Swedes from an association of PLWHAs in Gothenburg go out to the public breaking stigma and discrimination. It is quite very low compared to the number of people living with HIV.

It is clear that lack of PLWHAs is one of the impeding factors in HIV/AIDS prevention. In communication theory, the effectiveness of any given message influences the degree to which it is decoded (made sense of) and acted upon (Macdonald, 2001). And also, the effectiveness of communication depends on who the source is as well (Payne, 2005). If the information and education is given only by those who are not get infected, it has implication on the trustworthiness of the information.

If we refer literature about stigma and discrimination, we find similar notions that support the views obtained from the informants. Deacon (2005) noted that in Europe HIV/AIDS was not initially perceived as a threat to the general population because of its association with stigmatized groups (gay men, IDUs, commercial sex workers and members of immigrant communities from Haiti and Africa). Mann (1996) notes that Stigma and discrimination in HIV/AIDS is a threat to public health

as the HIV 'knows no boundaries' it has no use than damage if we stigmatize a group and it largely influences their participation in prevention

The stigma and discrimination could be seen from the following perspectives as well. As Lichtenstein (2004) has noted AIDS as a social problem center on the understanding of the disease as a socially constructed phenomenon. Lichtenstein (2004) has stated that 'AIDS is not just a virus that afflicts hopeless individuals at random but is a product of social and economic factors that help determine how, when, and where particular persons are infected. It has been indicated by many writers that HIV/AIDS is not an equal opportunity disease and it affects certain people more than others. For instance as stated by Lichtenstein (2004) around the globe, HIV/AIDS affects those who are poor or disenfranchised. AIDS has been considered as a disease of socially deviant risk groups or AIDS as an equal opportunity disease has explicitly acknowledged the structural factors underlying the HIV risk for disadvantaged or marginalized members of society (Lichtenstein, 2004). Such kinds of notions easily constructs stigma and discrimination to groups who are already get infected and also to a group who are at risk.

## How the Interplay between Culture and HIV/AIDS Influences HIV/AIDS Prevention Targeting Immigrants?

One of the interesting points in the HIV/AIDS prevention to immigrants in Gothenburg is that, most educators emphasize on giving general facts rather than focusing very specific issues about HIV/AIDS. This has been largely due to the various influences of cultural background of immigrants. It appeared difficult for most ToTs to educate and inform citing examples specific to cultural and religious issues as they face a lot of resistance from the group. The ToTs worry most of the time to find way of education that doesn't scare or doesn't have disrespectful connotation from the immigrants' perspective. This has a lot of implication on the effectiveness of information and education for HIV/AIDS prevention.

Despite relentless struggles against HIV/AIDS, the infection has continued to spread and serious questions began to be asked about the method of prevention used (Maclachlan, 2006). From the above it is questionable as to whether the methods of prevention are effective .Data show that HIV is increasing in Sweden among immigrants. Maclachlan (2006) has noted that IEC strategies focused too strongly on imparting knowledge and not enough on bringing about behavior change; they were too general and not specific enough to people's lived contexts and were to individualistic, rather than taking into account broader community issues.

The cultural approaches in HIV prevention have got emphasis in recent times by governments, concerned international agencies and NGOs in many countries (UNESCO, 2005). Sweden also looks aware of this. However based on the information obtained from the informants of this research project the notion of cultural approach in the context of immigrants has been largely taken by assigning educators from the same country background. There is no evidence from the informants as to whether specific methods of cultural approach in HIV/AIDS prevention are used or not. It is important to refer here what UNESCO (2005) recommended as to how culture should be taken into account in HIV/AIDS projects.

UNESCO (2005) recommends that culture should be taken into account in three respects. These are: firstly, context (i.e. the environment in which HIV/AIDS communication takes place); secondly, content( i.e. local cultural values and resources that can influence prevention education, whereby culturally appropriate content of sensitization messages is crucial for them to be well understood and received ) and lastly method(i. e enabling people's participation , which helps to ensure that

HIV/AIDS prevention and care are embedded in local cultural contexts in a stimulating and accessible way.

However, the representation of culture is also ambiguous for immigrants. There are people within immigrants who get confused as to which culture they belong. There are immigrants who oscillate between home culture and host culture. Bahatia and Ram (2001) notes that there is insufficient theorization of how immigrants represent their culture, and there is inadequate exploration of how power and marginality shape immigrants representations of culture.

#### How Multiculturalism Affects the HIV/AIDS Prevention?

The concept of multiculturalism is understood very loosely in its common sense by the informants as I indicated under the analysis. The understanding of multiculturalism needs a close look to individual, professional, organizational levels (Sue, 2006). According to Sue(2006) at individual level to have effective communication, helping professionals(in this case HIV/AIDS prevention practitioners) must deal with their own biases, prejudices, and misinformation /lack of information regarding culturally diverse groups such as immigrants; at professional level cultural orientations must reflect multicultural world view; at organizational level institutional practices, policies, programs and structures must be reflective of equity and equality; at societal level the overall broad frameworks for example policies and large scale change strategies should be reflective of multiculturalism with equality and equity

The immigrants are heterogeneous in many respects. There are differences between nations in terms of cultural orientations. Even, within immigrants from the same nation there are immense differences of cultural values. As indicated by most informants multiculturalism has various effects when come to HIV/AIDS prevention. The heterogeneity of immigrants in terms of the cultural, religious and language differences have huge effects on the HIV/AIDS prevention as evidenced by the community workers and/ health educators especially in bringing difficulties to produce IEC materials for these group.

From the interview data it is possible to infer that it is very sensitive to work with groups like immigrants who have already labeled as 'HIV/AIDS risk groups' and also HIV/AIDS by itself is deadly disease nobody wants to be associated with. Such sensitivity calls for multicultural sensitivity. Otherwise, the HIV prevention work remains insensitive to them and leads to unintended consequences. As (Sue, 2006) noted insensitive social work practice can result in cultural oppression rather than liberation'. So, here it might be important to consider improving cultural sensitivity and competence of workers in educating and informing these groups about HIV being sensitive to respective cultural values of the immigrants.

From the informants it has been indicated that in order to improve their practical work with immigrants of multicultural background there are networks within and among various organizations working with similar groups. The networking has paramount importance to improve the competence of workers and improve the communication skills as well. According to Payne (2005) communication theory can be used to develop practice by improving communication skills, working on communication problems, and analyzing problems in team work. The health educators indicated that the networking they have with different working groups has improved the communication skills and competence towards working with immigrant groups in HIV/AIDS prevention and related works. But they believe that it is inadequate to increase their cultural competence up to the need to fully understand the diverse groups they are working with.

# What Explanations for the KAP Gap in Relation to HIV/AIDS Pandemic?

Knowledge and attitude are believed to be fundamental to change behaviors. The informants of this research project indicated that the persons whom they targeted fulfills most of the time these two behavior predictors and fails on actual practice. A number of studies have demonstrated that the association between knowledge about health consequences of a particular behavior and the behavior itself is usually low and often even close to zero (Aarø etal., 1986; Osler & Kirchoff, 1995 cited in Aarø, et al., 2008). Within the KAP model the correlation between attitudes and behavior is assumed to be substantial, and the model focuses uni-directionally on how attitudes are supposed to influence behavior but researchers have found that their relationship is weak (Aarø, et al., 2008). Here however, the intention is not to look for measures in knowledge, attitude and behavior that are usually used to measure trends in program evaluations of health related education, rather it is to bring in possible explanations that may explain from practical point of view from the professionals and health educators participated in this research.

Most of the informants reflected that people in Sweden in general including immigrants who have stayed long in Sweden in most cases have adequate knowledge and also have positive attitude towards not to practice unsafe sex. However, generally this has not stopped most people especially youngsters from practicing unsafe sex. This has been manifested by high Chlamydia rate in recent years which shows unsafe sexual practice and huge chance for the spread of HIV. Here it might be important to bring in partial explanation from communication theory. The communication theory as put by Macdonald (1992) indicated, if the recipient is aroused and motivated, the recipient acts upon the information received. As it was apparent from the experiences of the interviewees, many people are not motivated to listen about the information especially if it is full of facts. This calls for innovative and entertaining culture specific methods and strategies in order to make HIV prevention activities more effective.

The informants reflected on the reasons for less interest of the education recipients, indicating that they believe that the disease is "not close to them", rather it is a disease "out there in Africa, Russia, or outside Sweden". This might have a lot of implications on the attitude building and behavioral change. This shows there is a lot to work towards awaking people that, HIV should not be considered as a "distant disease" it could also be "close to here". This could be explained in relation to the high movement of people facilitated by transportation and technology. People could be well informed that they can be infected unless they practice safe sex. This calls for a working approach that should adopt practical methods in the context of specific group by taking cultural, social and related factors into account.

In many instances, the informants pointed out the role of media in relating the HIV/AIDS to others especially immigrants. From the side of most immigrants, as indicated by small group discussion participants, they are developing the conception of HIV transmission among MSMs to others (Swedes). From either side there is throwing away blames to others is getting constructed. In effect, it has significant influence on HIV prevention education and information by considering it as the concern of others than them. When such perceptions intersect with culturally determined barriers of communication it would be easy to get oneself in risky behavior. Worth (1990) has noted that culturally determined values influence how individual perceptions of AIDS are selected, how attitudes towards high risk behavior are formed, how habits that characterize high risk behavior are developed, and how risk reduction information will be processed.

#### 6.2. Reflections

Having all the views and reflections from the practitioners' of HIV/AIDS prevention with immigrant groups, the author's reflections, that can either be complementary or can be included with others' views and reflections are presented here below.

There should be a way of deconstructing the prevailing view among many people that reached normality to associate HIV/AIDS with groups like MSMs, immigrants and IDUs. It has been apparent from the views of participants of this research project that associating HIV/AIDS with these groups couldn't help much than harm towards the HIV prevention efforts. Indeed, it has made reaching and accessing these people difficult as they keep distant themselves when HIV/AIDS prevention workers try to approach them. The HIV prevention practitioners seemed aware of the reasons and pointed out that it is because of the negative connotation with AIDS and these groups that have been developed in the HIV/AIDS discourse particularly in relation to whose problem it has been.

From the side of the groups to whom HIV usually has been associated, it might be the psychological and social harm that have contributed towards alienating them. These have a lot of implications on HIV prevention efforts for the larger population and needs some attention by authorities who are working on the issue of HIV prevention and related works.

It might be easy to throw away blames to others for sensitive issues. For example, blaming the media for aggravating alienation and labeling towards certain groups looks easy as most of the informants in this research project did. However, blaming each other might construct towards non-serving and negatively impacting the HIV prevention efforts in the globalizing world, where any body could be anywhere in any country within minutes, hours, at most in days. Flipping the other side of the coin, the media has also very significant role in deconstructing the association of AIDS and labeling towards certain specific groups. The point I want to make here is that the role of the media should be in the context of preventing from further problems associated with AIDS, by reconstructing the direction of knowledge about AIDS towards the conception that HIV/AIDS can be "every ones" problem and not "only others" problem. It should be considered as a disease that could belong to everyone who lacks the knowledge about AIDS and who practice unsafe sex. Otherwise, it doesn't help than harm in the efforts towards HIV/AIDS prevention.

My other reflection is that HIV prevention should not be seen only from the dimension of protection such as safe sex using condoms and working towards this behavior/practice by impacting knowledge and attitude change. Rather it also has to do with the cultural, social, environmental, political and by large beyond individual behavioral change. The HIV prevention should be considered in the context that ranges from individual up to structural levels. So the importance of considering all levels from macro to micro levels rather than focusing on specific levels. There have been oscillating explanations and emphasis by theoreticians. Early psychosocial theories emphasized the individual behavior; anthropologists and sociologists mostly emphasized the socioeconomic and cultural dimension and others with respect to their specific discipline, and so on. As a result, explanations have remained mostly discipline specific leaving out important dimensions. But practically specific disciplines do not work independently on the problems such as HIV/AIDS which virtually touches every thing from individual to societal level. Swinging approaches have been adopted following timely waves by countries, politicians, academicians, local and international organizations and so forth. However more recent approaches try to integrate all individual, cultural and structural concerns. I am in favor of such approaches. I am against approaches that leave out the individual approach and focus only on structural ones and vise versa. For instance, approaches

put in the context of: 'focus on the forest not on the trees' tend to leave out the importance of particulars. I argue for "the trees are also important, not only the forests". For example PLWHAs are important to target them in HIV prevention education as they are valuable to educate others from life experience of their own than facts about HIV/AIDS by others.

In my opinion the 'one size fits all' conception and approach which has been reflected on grouping of immigrants all together seems erroneous and needs further research. In such approach I see the implication on HIV/AIDS prevention in that it downsizes the content of HIV/AIDS prevention education to focus on the general facts than tailoring to specific information in fear of misunderstanding other cultures and take care of not to disrespect others' culture and religion. This has been consistently observed from the views of the informants as to how they try to provide education and information to a group with multicultural background.

# **Concluding Remarks**

In order to have effective HIV prevention programs for immigrants, long term strategies and clearly identified methods should be tailored to fit the needs and contexts of immigrants. The participants of this research project are of the opinion that more specific methodologies and culturally specific and sensitive methodologies are highly required to make the HIV prevention much more effective in multicultural society in general and immigrants in Gothenburg in particular.

From the analysis it came out clear that there is lack of involvement and participation of immigrants in the designing and planning of projects that targets them. The methods and strategies are more of top down than bottom up approaches. Both top down and bottom up approaches might be considered so that they can reinforce and complement each other.

The participation of PLWHAs from both immigrants and Swedes irrespective of race and ethnic background is very important in HIV/AIDS prevention. Their participations at every stage are important elements to be considered in order to have effective HIV prevention.

Culture has very important role in HIV prevention. Therefore, there is need for improving the cultural competence of health educators and personnel involved so as to improve their roles in HIV prevention in multicultural group of immigrants.

To result with effective IEC, which are valuable for HIV/AIDS prevention homogeneity looks potentially important as a means, though might not be an end in itself. But immigrants are diverse, heterogeneous and have multicultural background. There is a need to closely examine the views and reflections of immigrants themselves, who closely work with these groups for improved intervention of HIV prevention.

The concept of multiculturalism can be contextualized in HIV prevention targeting immigrants with multicultural background. To wok towards the framework of multiculturalism, which runs from individual level up to societal level there should be understanding of its pros and cons especially for effective communication at various levels.

# Some Suggestions for Future Research

This research project didn't explore on how best HIV prevention can be organized targeting immigrants who are multicultural group. This might be potential area to explore in the future.

The low socio economic status and relative poverty especially for new comer immigrants has been raised by informants of this research several times. Some connected to "probable covert prostitution". Since prostitution might also have implication on HIV/AIDS prevention efforts, it might need further study. The probability of having hidden prostitution might be seen in relation to the law that prohibits buying sex but not selling, here in Sweden for having probably "unintended consequences".

The effect of segregation in Gothenburg is another dimension to be looked at. During this research process there are some research areas in relation to segregation came out that might be interesting for future researchers. To mention some, the emergence of sub-cultures especially among the youth groups from immigrant family background living in multicultural neighborhoods.

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# **Annex I**

# **Interview guide for Individual Interviews (ToTs)**

### Introduction

The overall aim of the thesis is to explore the views and reflections of ToTs on HIV prevention targeting Immigrants with multicultural background. Meanwhile, the special interest is to find out how the notion of multiculturalism and/or heterogeneity in terms of cultural, religious and linguistic background affects the HIV/AIDS prevention efforts targeting immigrants in Sweden with particular reference to Gothenburg city.

The data collected from this discussion will be used for the research purpose as part of partial fulfillment of International Master of Science in Social Work in Gothenburg University.

I assure you that the data from this interview will be confidential. Your name and other particularities to recognize you will not be disclosed to anybody.

## **I-Basic information**

bex	
Age	
Marital status	
Educational Level	
Occupation	
Vationality	
Religion	
Country of Birth	
Year of Arrival to Sweden	
Your role in HIV/AIDS prevention	

## **II-General Questions for Views and Reflections**

- 1- Would you tell me your overall experience in HIV/AIDS prevention with immigrants?
- 2- What are challenges you face in HIV/AIDS prevention work with immigrants?
- 3- Can you identify major predicaments (impeding factors) in relation to HIV/AIDS prevention with immigrants?
- 4- How do you think the interplay between culture and HIV/AIDS influences HIV/AIDS prevention targeting immigrants?

- 5- How do you understand Multiculturalism?
- 6- How do you think multiculturalism affects the HIV/AIDS prevention targeting immigrants?
- 7- What is your view on immigrants' knowledge on HIV prevention?
- 8- What is your view on immigrants' attitude on HIV prevention?
- 9- What is your view on immigrants' behavior on HIV prevention practice?
- 10- Do you observe any gap on knowledge, attitude and practicing safe sex among your targets?
- 11- What explanations do you offer for the gaps in Knowledge, Attitude and Behavior/Practice (KAP) in relation to HIV/AIDS pandemic?

# **III- Refining Questions**

(Questions to be raised in between or after the above questions based on the answers from the respondents).

- 12- How do you describe immigrants?
- 13-Do you think immigrants belong to HIV/AIDS risk group?
- 14- What is your opinion on the statement "immigrants are one of the risk groups of HIV/AIDS transmission".
- 15- Can you explain the composition of immigrants HIV/AIDS prevention program has targeted?
- 16-What is your view on the relation between culture and HIV/AIDS?
- 17-To what extent the relationship between culture and HIV/AIDS has been dealt within the HIV/AIDS prevention programs targeting immigrants?
- 18- How cultural background affects HIV intervention?
- 19- Do you think the immigrants' background has influenced HIV/AIDS prevention programmes? How?
- 20- Are the HIV/AIDS prevention strategies targeting immigrants culture specific?
- 21-Do you think that staffs working with immigrants on HIV/AIDS are culturally competent?
- 22-Do you tell me the information needs of immigrant on HIV Prevention?
- 23- Why it is important to deliver HIV/AIDS information to migrants?
- 24- What is your view on the effectiveness of information, education and communication about HIV/AIDS for immigrants?

- 25- To what extent the IEC materials on HIV/AIDS targeting immigrants cover the needs of immigrants?
- 26-What is your view on the specific strategies/methods of HIV/AIDS prevention for immigrants?
- 27- What specific methods do you use to promote immigrants' knowledge, attitude and behavior in relation to HIV/AIDS pandemic?
- 28-Do you have any thing important to raise here in relation to HIV prevention that we haven't covered in this interview?

Remark: All questions are used flexibly and with probing and prompting following the replies from the interviewees as necessary.

# Annex II Guide for Small Group Discussion

## Introduction

The overall aim of the thesis is to explore the views and reflections of personnel on HIV /AIDS prevention targeting immigrants with multicultural background. Meanwhile, the special interest is to find out how the notion of multiculturalism and/or heterogeneity in terms of cultural, religious and linguistic background affects the HIV/AIDS prevention efforts targeting immigrants in Sweden with particular reference to Gothenburg city.

The data collected from this focus group discussion will be used for the research purpose as part of partial fulfillment of International Master of Science in Social Work in Gothenburg University.

In my part, I assure you that the confidentiality of all members will be kept and in similar manner, I remind all of you to respect the confidentiality of all members of this focus group.

# **Opening Circle:**

Introducing personal information

#### **Ground Rules**

- -Don't hold private conversations with the person next to you but direct all comments to the group.
- -Don't interrupt while other speaks (let other finish).
- -Switch off mobiles

## **Discussion Questions**

(N.B- Questions were used flexibly)

- 29- What does HIV/AIDS means to you?
- 30- What does Culture means to you?
- 31- How do you understand multiculturalism?

- 32-Would you tell me your overall experience in HIV/AIDS prevention with immigrants?
- 33- What are the challenges you face in HIV/AIDS prevention work with immigrants?
- 34-Can you identify major predicaments (impeding factors) in relation to HIV/AIDS prevention with immigrants?
- 35-How do you think the interplay between culture and HIV/AIDS influences HIV/AIDS prevention targeting immigrants?
- 36- How you relate culture with HIV/AIDS?
- 37-How do you think multiculturalism affects the HIV/AIDS prevention targeting immigrants?
- 38- Can you tell me about the knowledge, attitude and practice of safe sex of your targets for preventing themselves from HIV/AIDS?
- 39-What is your view on immigrants' knowledge on HIV prevention?
- 40-, What is your view on immigrants' attitude on HIV prevention?
- 41- What is your view on immigrants' behavior on HIV prevention practice?
- 42-Do you observe any gap between HIV/AIDS knowledge, attitude and actual practice of risk behavior among immigrants?
- 43- What explanations do you offer for the gaps in Knowledge, Attitude and Behavior/Practice (KAP) in relation to HIV/AIDS pandemic?
- 44-What are the specific methods you use in HIV prevention targeting immigrants?
- 45- What gaps do you see on strategies of HIV/AIDS prevention for immigrants?
- 46-Do you have any suggestions to improve the HIV/AIDS prevention methods targeting immigrants?
- 47- What other ideas do you think have left without being discussed regarding HIV/AIDS in relation to immigrants?

# Thank you very much!!!

#### Annex III

# **Informed Consent Form**

The following is a presentation of how we will use the data collected in the interview.

The research project is a part of our education in the International Masters program in Social Work at the University of Gothenburg, Sweden. In order to insure that our project meets the ethical requirements for good research we promise to adhere to the following principles:

- Interviewees in the project will be given information about the purpose of the project.
- Interviewees have the right to decide whether he or she will participate in the project, even after the interview has been concluded.
- The collected data will be handled confidentially and will be kept in such a way that no unauthorized person can view or access it.

The interview will be recorded as this makes it easier for us to document what is said during the interview and also helps us in the continuing work with the project. In our analyze some data may be changed so that no interviewee will be recognized. After finishing the project the data will be destroyed. The data we collect will only be used in this project.

You have the right to decline answering any questions, or terminate the interview without giving an explanation.

You are welcome to contact us or our supervisor in case you have any questions (e-mail addresses below).

# Student name & e-mail Supervisor name & e-mail

Kassaye Tekola Kristian Daneback