HIV/AIDS STIGMA: AN INVESTIGATION INTO THE PERSPECTIVES AND EXPERIENCES OF PEOPLE LIVING WITH HIV/AIDS

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Abstract

People’s attitudes towards people living with HIV/AIDS remain a major community challenge. There is a need to generate a climate of understanding, compassion and dignity in which people living with HIV/AIDS (PLWHA) will be able to voluntarily disclose their status and receive the support and respect all people deserve. However, many people experience discrimination because they have HIV/AIDS. In a certain area in Khayelitsha, a township in Cape Town, a young woman was killed after disclosing the HIV status after being raped by five men. This has become a barrier to testing, treatment, on quality of life and social responses to HIV/AIDS. While many previous studies have focused on the external stigma in the general population, there is a dearth of studies on stigma among PLWHA themselves and hence the aim of the present study was to investigate stigma attached to HIV/AIDS from the perspective of PLWHA. The focus group research method was used to collect the data. Six focus groups consisting of 8-10 people in each group were held in Khayelitsha drawn from organizations working with PLWHA and Treatment Action Campaign (TAC). Data was analyzed using discourse analysis and the PEN-3 Model was used to explain the themes that emerged from the data. Results showed that PLWHA are affected by both enacted and internal stigma related to HIV/AIDS. It was found that the experiences of discrimination and stigma often originate from the fear and perceptions of PLWHA as immoral or living dead. They suffer rejection at home, work, school and in the health care centres. Results also showed that PLWHA felt shame, guilt, hopelessness and useless. This internalized stigma leads to withdrawal, depression, not to disclose the HIV status and prevent people for testing for HIV and also affect health-seeking behaviour. However, participants who were well informed and those who were members of the support groups reported that they are coping with the illness and they are open about their HIV-status. This suggests that education efforts have been remarkably successful in changing attitudes. It is recommended that stigma reduction programmes should involve PLWHA, community leaders and the community members to be part of the planning and implementation. It is also important to look at the successful programmes already existing in the area and adapt them and also to evaluate the effectiveness.

Declaration

The author hereby declares that this whole thesis, unless specifically indicated to the contrary in the text, is her original work.

R Mlobeli (Dlakhulu)

Dedication

To My Father

It was sad to lose you before this mission was accomplished, but thank you for believing in me and being always there for me during the process. I also dedicate this work to the participants we have lost during this process.

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Chapter 1

Introduction

1.1 Background of the study

The tragedy of HIV/AIDS is not only the problem of HIV/AIDS-infected people themselves, but also the problem of their families and their communities. Their families are responsible for much of their nursing and care, both in and out of the hospital. HIV-positive people do get pre-test and post-test counselling in hospitals or in clinics to assist them with their test results and to handle the difficulties which they will face in living with HIV/AIDS. However, after being diagnosed HIV/AIDS positive, they go back to their families who did not get any form of information of counseling to prepare them for the news. This impact negatively on the ability of the family to adapt to having a person living with HIV/AIDS in the household.

Several researchers have argued that the lack of support from friends, family and the community decreases disclosure and generates rejection and discrimination which increases emotional distress experienced by those who are HIV positive (Bond, Chase & Aggleton, 2002; Brown, Macintyre & Trujillo, 2003; Niang et al., 2003). As the family is often the only source of care giving for HIV positive individuals, it is very important to reduce stigmatization in this sphere (Herek & Glunt, 1988). HIV/AIDS-related stigma within the family has also been described as the most subtle and insidious form of stigma and the hardest to address effectively. In addition, Malcolm et al. (1998, in Brown, Macintyre and Trujillo, 2003) further argued that by inhibiting open communication in the family stigma makes disclosure in the family difficult and without disclosure prevention and care become impossible.

Many people who are diagnosed as HIV-positive feel completely hopeless as they think that they are going to die right away. HIV diagnosis can be seen as a change in a way a person sees herself or himself from being successful or starting to do so to being doomed in life. Their feelings of despair are doubled by the stigma, ignorance and often violence that continue to underpin the epidemic in South Africa. In Khayelitsha one of the Townships in Cape Town, reports from Radio Zibonele, a local Radio station, have shown how people living with HIV/AIDS (PLWHA) have had to face being cast out of their families and communities. It is important to understand the fear that underlies the rejection and stigmatization experienced by PLWHA. According to Goffman (1963, in Parker & Aggleton, 2002), stigma is a discrediting attribute and at some level culturally constructed. He further argues that stigma can be seen as a negative attribute mapped onto people, who in turn by virtue of their difference, are understood to be negatively valued in society. This is supported by Parker and Aggleton’s (2002) acknowledgement that stigma operates in relation to difference, and by making social inequalities reasonable it creates and reinforces social exclusion. Similarly, some researchers have reported that social exclusion of PLWHA that begins in the family and extends into the community has been linked with poor self-esteem of PLWHA (Fieldblum, & Fortney, 1988; Herek & Glunt, 1988; UNAIDS, 2002a). It is further argued that PLWHA with poor self-esteem are more likely to engage in high-risk sexual behaviour, hence perpetuating the spread of the pandemic (Duh, 1991; Fieldblum, & Fortney, 1988; Preston-Whyte & Brown, 2003; UNAIDS, 2002a).

People’s negative attitudes towards PLWHA remain a major community challenge in the fight against HIV/AIDS. It is further mentioned that families and friends of PLWHA also experience stigmatization. In South Africa this process has exacerbated the erosion of communal values among Africans including the support provided by the extended family. For example, Bond, Chase & Aggleton (2002) acknowledged that the care of orphans has become a major challenge to communities. By 2010, in countries most affected by AIDS, at least 44 million children will have lost one or both of their parents to all causes of these 44 million orphans 66% of parents will have died of AIDS

(Orphan and Vulnerable Children in the Region, undated fact sheet). In South Africa apart from orphaning, the direct impact of the HIV/AIDS epidemic on children can already be seen. This is the time to develop closer community relations rather than generating rejection and harm.

Recently in Khayelitsha four men raped a 21-year-old female and after she disclosed her HIV/AIDS status they killed her. There is a need to generate a climate of understanding, compassion and dignity in which PLWHA will be able to voluntarily disclose their status and receive both social support and respect that all people deserve. However, many people experience discrimination because they are infected with HIV and/or living with AIDS. Both HIV and AIDS have been given a negative and a frightening face that makes infected people afraid to be open about their HIV/AIDS status. This stigmatization continues to happen in the health care centre. Ms Y (a member of a support group in Khayelitsha) indicated that one of the health workers at the clinic looked at her file and before calling her name shouted in front of other patients that she is tired of these AIDS people. After calling her name, she said “What do you want us to do because you know that you’ve got AIDS so you are sick” (Ms Y, verbal communication, 2003). Furthermore, HIV-positive people get stigmatized as morally corrupt, and irresponsible and sinners. Evian (1991) supported this point indicating that others think that AIDS is a plague sent by God to destroy the sexual immorality that has overcome people.

As shown in the case of the woman raped and killed after disclosing her status in Khayelitsha, discrimination and violence against those with HIV/AIDS is prevalent in this township. Stigma attached to HIV/AIDS makes people reluctant to come for treatment or disclose their illness. Such reluctance is influenced by feelings of shame, guilty, embarrassment, fear, sadness, and anger associated with the condition. UNAIDS (2002) have reported that health workers fear of infection has jeopardized the quality of the services and social support rendered to PLWHA (Lee, Kochman & Sikkema, 2002). It is further argued that this has made PLWHA to be reluctant to access available health services (Brown, Macintyre & Trujillo, 2003; Kalichman & Simbayi, 2003). It has become clear that we cannot move forward in a significant way to responding to the HIV/AIDS epidemic until we address the issue of stigma against PLWHA as we have been doing for all persons with other diseases. Moreover, discrimination, denial, exclusion and poverty have been a major obstacle in efforts to control the spread of the epidemic.

Numerous studies have focused primarily on examining the attitudes of the non-infected about those who are infected and on understanding why HIV is so stigmatized. Although much work has been done there is a need to do more looking directly on stigma related to HIV/AIDS from PLWHA's own perspectives. This study looked at the perceptions and experiences of PLWHA about the stigma related to HIV/AIDS. The qualitative method was employed to achieve this aim.

1.2 Purpose and aim of the study

The main goal of this study was to identify the nature of HIV/AIDS-related stigma felt by PLWHA in Khayelitsha and the impact this has on them. This information will help in developing intervention programmes that will help to reduce these socially established attitudes in their context using the language understood by the community.

1.3 Aim of the study

The main aim of this study is to investigate both the nature and the impact of stigma against HIV/AIDS experienced by PLWHA in Khayelitsha Township in Cape Town.

1.4 Specific objectives of the study

The objectives of the study are:

a) To identify the nature of stigma against HIV/AIDS in Khayelitsha.

b) To determine whether such stigma affects PLWHA in Khayelitsha.

c) To determine how it affects PLWHA in Khayelitsha.

d) To identify possible ways of countering the stigma from PLWHA, using information and insights from PLWHA themselves.

1.5 Relevance Of The Study

Khayelitsha residents have been reluctant to acknowledge the epidemic. The impulse to distance themselves from the epidemic is less a response to HIV/AIDS than a reaction to social issues that surround the disease and give it meaning. More fundamentally, it is the predictable outgrowth of the problematic relationship between those infected and the larger society, a relationship characterised by domination and subordination, mutual fear and mutual disrespect, a sense of otherness and a pervasive neglect that rarely feels benign.

Using both a social construction and activist approach, this study wants to provide information that will enable people to acknowledge the devastating toll that stigma attached to HIV/AIDS is taking on our communities so that community can have some understanding of the epidemic and the ways in which they can implement programmes of education, information, counselling and support services for everyone. This knowledge will help to empower the community with skills on how they may interact with HIV-infected people and promote a climate of tolerance and empathy within the community members regardless of their health status.

1.6 Lay Out Of The Rest Of The Thesis

Chapter 2 reviews literature that is relevant to this study. It looks at the nature of the AIDS epidemic, the spread of HIV/AIDS, the HIV/AIDS epidemic in South Africa, sources of stigma related to HIV/AIDS as well as psychosocial impact of stigma attached to HIV/AIDS.

Chapter 3 looks at the theoretical frameworks pertinent to this study.

Chapter 4 presents methodological issues for the study. Objectives and the rationale behind the employed approach is provided, including discussion of participants, the research method, research instrument, and the procedure. The chapter also looks at data analysis, ethical consideration as well as reflexity.

Chapter 5 offers a thematic content analysis of perceptions and experiences of PLWHA about both external and internal stigma they experience. Themes emanating from these findings are comprehensively discussed linking them with the literature reviewed and using PEN-3 model for identification and discussion of discourses found in the study.

Finally chapter 6 provides the summary of the findings of the study and discusses about the study limitations. It also highlights meanings postulated by PLWHA attached to these findings and their implications for HIV/AIDS stigma reduction interventions and recommendations.

Chapter 2

Litarature Review

2.1 Introduction

Many studies have demonstrated that anybody can acquire HIV and die from AIDS (Duh, 1991). Yet a large portion of society still views HIV/AIDS as someone else's disease.

Duh (1991) argues that the end result of this view is that people with AIDS have suffered from lack of sympathy, lack of support, and, in many cases, discrimination. Therefore, destigmatising HIV/AIDS remains a major challenge.

The AIDS epidemic has been accompanied by intensely negative public reactions to persons presumed to be infected by HIV (Herek & Glunt, 1988). Several studies have shown that the HIV pandemic has evoked a wide range of reactions from individuals, communities, and even nations, from sympathy and caring to silence, denial, fear, anger and violence (Brandt, 1988; Brown, Macintyre & Trujillo, 2003; Herek & Glunt, 1988). Malcolm et al. (1998, in Brown, Macintyre & Trujillo, 2003) suggest that stigma is an important factor in the type and magnitude of the reactions to this epidemic. It is hypothesized that HIV/AIDS stigma can have a variety of negative effects on HIV test seeking behavior, willingness to disclose HIV status, health-seeking behavior, and quality of health care received, as well as and social support solicited and received (Herek & Glunt, 1988; Jemmott & Lockes, 1984; Parker & Aggleton, 2003).

2.2 The nature of the AIDS epidemic

According to Evian (1991), for one to understand the nature of the HIV/AIDS disease, it is firstly vital to distinguish between two important concepts, namely, HIV and AIDS. HIV is the retrovirus virus that causes AIDS (Kalichman, 2003, p.17). Several researchers mentioned that HIV belongs to a group of retroviruses called lent viruses (lenti means “slow” in Latin) because it progresses slowly as it takes years before symptoms appear. HIV virus directly infects the immune system the very system that the body uses to fend off infections (Doka, 1997; Duh, 1991; Kalichman, 2003). The target of HIV is a specific type of white blood cells called T- helper lymphocyte cells or T-helper cells (Doka, 1997). The T-helper cells control several branches of the immune system, they are like the body's army because they command other immune cells to destroy possible causes of infection and disease (Doka, 1997; Kalichman, 2003). Overtime HIV impairs the body's ability to fight off many by diseases destroying T-helper cells. The immune system attempts to control HIV by producing antibodies against the virus. However, the efforts are only partly effective because HIV hides inside of T- helper cells, slowly infecting more and more cells until the entire immune system can longer function (Doka, 1997; Kalichman, 2003). A person who is infected with HIV does not necessarily feel sick if they do not yet have AIDS and they can feel healthy for years (Berer, 1993; Schneider, 1994; Squire, 1993).

AIDS is the later stage of HIV infection. The progression from HIV infection to AIDS depends upon how fast the body's immune system is destroyed (Duh 1991). The rate of destruction depends upon the number of viruses versus the number and quality of T-cells in the body. A person is diagnosed with AIDS after the immune system becomes HIV disabled or when the person becomes seriously ill from diseases that take advantage of the broken-down immune system (Doka, 1997; Duh, 1991; Evian, 1991; Kalichman, 2003). In effect, AIDS is the terminal phase of infection with the HIV.

According to Parker and Aggleton (2002), there are three phases of the AIDS illness. The first phase one has the HIV infection and often it is unnoticed and silent. The second phase of AIDS the disease becoming more visible with a range of infectious diseases. The third phase is potentially the most damaging of all as it involves an illness of social, cultural and political dimensions, including stigma, discrimination and denial (Parker & Aggleton, 2002).

Duh (1991) acknowledges that at the turn of the century infectious diseases such as tuberculosis and pneumonia caused most of deaths worldwide. Not only did the powerful antibiotics and vaccines afford the control of these killers but also environmental improvement (Duh, 1991). Furthermore, infectious diseases of civilization like heart disease, and cancer replaced other fatal diseases. As a result of the successes, the scientists turned their research focus on these non-infectious diseases and put to rest the infectious diseases. In the 1980's a new fatal infectious disease, AIDS, awakened them (Evian, 1991; Fieldblum and Fortney, 1988; Squire, 1993). Since then HIV/AIDS has become the object of extensive medical and social research as well as policymaking, widespread media attention, and policy discussion.

Although only discovered in the early 1980s AIDS has become the world's greatest threat to health and communities, as it has killed millions of people of all ages and ethnicities (Duh, 1997; Kalichman, 2003; Lachman, Lachman, & Butterfield, 1988). Several researchers state that due to its exponential spread, HIV will have devastating problems for every facet of society in years to come (Aggleton & Homans, 1988; Collier, 1987; Doka, 1997; Evian, 1991; Jacoby, 1994; Squire, 1993)

2.3 The spread of HIV/AIDS

Perkel (1992) mentioned that from the time AIDS was first recognised as a distinct syndrome, it became increasingly evident that it was spreading at an alarming rate. Similarly, Duh (1997) postulated that AIDS is a new disease but it has become part of our lives because our immediate family, friends and people in our communities get positively diagnosed on a daily basis. The first case was identified in 1981 in the United States and within eight years, 167 373 cases had been identified around the world. In 1982 the first cases of AIDS were reported in Africa (Duh, 1997)

Doka (1997) postulated that the HIV virus likely existed for a period of time prior to the 1970s and it probably did so by only infecting isolated groups of people. In addition, researchers argue that significant social changes in the 1970s made changes in patterns of mobility as well as in sexual behaviours, drug use, and blood use and collection also created a context in which a viral disease such as HIV/AIDS could rapidly spread. According to Doka (1997), when it emerged in the 1970s in Western Europe, North America, Australia, New Zealand, and urban areas of Latin America, the disease primarily infected gay men, drug users, and persons infected through blood products. He also mentions that heterosexual and prenatal transmission represented a small but increasing proportion of those infected. In Sub-Saharan Africa, parts of Latin America, and the Caribbean, HIV was recognised about the same time, but it primarily spread through heterosexual intercourse, use of blood, and unsterile needles (Doka, 1997). Prenatal transmission is more common in Sub-Saharan Africa, Latin America, and the Caribbean because both genders are affected equally. In Eastern Europe, the Middle East, North Africa, Asia, and the Pacific the disease is beginning to emerge among those engaged in high-risk behaviours (Doka, 1997). Based on the studies conducted by Bond, Ndubani and Nyblade 2000 (in Bond, Chase & Aggleton, 2002), in Zambia they estimated that 30-40% of infants born to women infected with HIV become infected constituting around 21,000 infant infections each year.

In South Africa, the statistics indicate that HIV infections and deaths associated with AIDS have rapidly increased in the past 15 years. According to UNAIDS (2004), that it is estimated that up to 1500 new HIV infections occur in South Africa each day and it is believed that as many 600 people die of an AIDS-related illness each day. According to a 2002 national seroprevalence study, the overall HIV prevalence in the South African population was 11%, with the highest rate (21%) occurring among people living in townships and informal settlements (Shisana & Simbayi, 2002). This clearly shows the seriousness of the burden of disease in South Africa. This has recently been confirmed in a follow-up national survey by Shisana et al. (2005) reporting that HIV prevalence amongst persons aged two and older is estimated to be 10.8%, with the highest rate (17.6%) occurring in urban informal settlements followed by second highest (11.6%) in rural informal settlements.

2.4 HIV/AIDS epidemic in South Africa

According to Dorrington, Bradshaw and Budlender (2004) and Rehle and Shisana, (2003) nationally, the epidemic can be considered to be entering the mature phase. The Actuarial Society Africa (ASSA) model estimates that 6.5 million people were infected with HIV in the year 2002. According to the Shisana et al. (2005) household survey results this number has now come down to 4.8 million persons aged two years and older living with HIV/AIDS who are found in South African homes._It is argued that number of people who are newly infected peaked in about 1998 and has begun to decrease. However, the number of people dying from AIDS each year has only now started to increase.

Preston-Whyte & Brown (2003) highlighted that about 1800 new infections are diagnosed on daily basis and by 2010 it is predicted that the mortality will result in increasing numbers of children who are orphaned (report profile). This is supported by the rapid mortality surveillance system established by the Burden of Disease Unit of the Medical Research Council (MRC) and ASSA at the University of Cape Town (UCT) which has shown that there has been an increase in young adult mortality and that by year 2000, AIDS had become the biggest single cause of death.

The Department of Health (2004) report of the national HIV and Syphilis Sero-prevalence Survey of Women attending Public Antenatal Clinics in South Africa- 2003 estimated that in South Africa at the end of 2003 4.7 million people were living with HIV, of whom 189,000 were babies. Nationally there has been an increase in HIV prevalence as compared to 2002.The figures were as follows: national 2002 prevalence was 26.5%

and during 2003 the prevalence was 27.9%. From the findings made by the South Africa Department of Health using a model developed making sure that at antenatal sites across the country all woman coming for the first time are tested estimated that 34.5% of women aged from 25-29 are infected with HIV, making this the age group with the highest prevalence. It is further indicated that 29.5% of women aged 30-34and 29.1% women aged 20-24 are HIV-infected (UNAIDS, 2004).

The Nelson Mandela/HSRC Study of HIV/AIDS (Shisana & Simbayi, 2002) which was a household study looking at a proportional cross-section of society stipulated that from 8428 people tested nationally, 11.4% were found to be HIV positive (also see Rehle & Shisana, 2003). It was found that South Africans aged 2 years and older were living with HIV/AIDS in 2002. It was found that the HIV prevalence was highest in Africans at 12.9%, followed by Whites at 6.2%, Coloureds at 6.1% and Indians with the lowest prevalence of 1.6%. It was also found that females had a much higher HIV prevalence (12%) than males (9.5%). These results also showed that HIV prevalence among adults aged 15-49 years was 15, 6%, with 17.7% in women and 12.8% in men in this age group. Rehle and Shisana (2003) pointed out that among Africans aged 15-49 years a prevalence of 18.4% was found. It is further acknowledged that the epidemic was highest in people living in urban informal settlements (21.3%) compared to those living in urban formal settlements (12.1%) or those in rural areas (8.7%).

The follow up study by Shisana et al. (2005) shows a notable difference from the previous survey in 2002. They found that the survey of 2005 found higher HIV prevalence among youth 15-24 years (10.3% vs. 9.3%) and a similar prevalence in adults 25 years and older (15.6% vs. 15.5%). HIV prevalence in the 15-49 age group was 16.2% in 2005 and 15.6% in 2002. Results show that the prevalence in children aged 2-9 years is high. Boys aged 2-4 years had a prevalence of 4.9% and 5.3% among female children. Among boys aged 5-9 years the prevalence is 4.2% and 4.8% among girls.

Shisana et al. (2005) argue that the observed high prevalence in South African children in this age group is similar to that observed in Botswana and Zimbabwe. They postulated that in Botswana the 2004 national HIV prevalence among boys aged 5-9 years were 5.9% and for girls it was 6.2%. According to Central Statistical Office (2005, in Shisana et al., 2005) for older children aged 10-14 in Botswana, it was 3.6% among boys and 3.9% among girls. These results suggest that HIV prevalence among children is a major problem in South Africa.

As in 2002, females are more likely to be living with HIV, and this proportion has increased over time (Shisana et al. (2005). The largest increase in prevalence is found among females aged 15-24 – 12% in 2002 compared to 16.9% in 2005. Furthermore, the female to male ratio for HIV infection in 2005 is also highest among youth aged 15-24 years, while the prevalence in females is almost four times that of males – 16.9% vs. 4.4%. In addition, the findings of the RHRU Youth Survey conducted in 2003 (in Shisana et al., 2005) found the similar HIV prevalence in males and females (4.8% and 15.5%). These results suggest that South African youth are vulnerable to HIV infection. The HIV pandemic is spreading most rapidly amongst young women. To address this problem it is important to focus at the socio-environmental models which take account of issues such as gender and power, and which recognise that intervention programmes need to be culturally sensitive and tailored to local contexts.

2.5 Stigma and discrimination

According to Herek and Glunt (1988), stigma is defined as a mark of shame or being discriminated against for any particular reason. They acknowledged that: “the focus of social psychological research is not on the stigma itself but on the social relationships in which a particular mark is seen as shameful or discrediting" (p. 886). Shisana (2004) has said that stigma can be defined as consigning someone to a category that attaches on him/her a label of being an undesirable. She further argues that the resulting shame leaves the individual with a feeling of being personally responsible for their consigned undesirable status. Goffman (1963, in Brown et al., 2003) postulated that stigma is an undesirable attribute or quality that significantly discredits an individual in the eyes of others. Moreover, stigmatisation is a dynamic process that arises from the perception that there has been a violation of a set of shared attitudes, beliefs and values. Society thus labels an individual or group as different or deviant. According to the Population Council (2002) the concept of stigma is often used interchangeably with that of discrimination (Population Council, 2002). Manser and Thomson (1999 in Policy project, 2003) further argued that even though the word stigma and discrimination are often used interchangeably their meanings do differ. Discrimination focuses on observable behaviour, which means the unjustifiably different treatment given to different people or groups (Bond, Chase & Aggleton, 2002; Brown, Macintyre and Trujillo, 2003).

Stigma depends upon the social representations or the dominant discourse concerning the HIV illness. These are the ideas that are widely shared in ones community in association with certain groups. The same idea is supported by Parker and Aggleton (2002) who also indicates that other authors have defined stigma as social processes that are linked to societal power structures.

There are two main different types of stigma, namely, the internal and external stigma (Bond, Chase & Aggleton, 2002; Brown, Macintyre & Trujillo, 2003; Policy Project, 2003). According to Bond, Chase & Aggleton (2002), internal or self-stigma is manifested in self-blame and self-depreciation. It can also be viewed as perceived stigma that is manifested in the fears that people have around being stigmatised if they are HIV-positive and choose to disclose their status to others. In addition, felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, or disease such as HIV or association with a particular group or behaviour (e.g., homosexuality and promiscuity) and this kind of stigma is internal stigma (Brown, Macintyre & Trujillo, 2003; Policy Project, 2003).

Enacted or external stigma is when people are actually discriminated against because they have or are thought to have HIV (Bond, Chase & Aggleton, 2002; Parker & Aggleton, 2002). Jacoby (1994, in Brown, Macintyre & Trujillo, 2003) argues that enacted stigma refers to the real experience of discrimination. It is further argued that the disclosure of an individual's HIV-positive status could lead to loss of a job, health benefits, or social ostracism. According to Herek and Capitanio (1998, in Brown, Macintyre & Trujillo, 2003), individuals who hold negative attitudes or who enact stigmatising or discriminatory behaviour have been referred to as the perpetrators of stigma and discrimination. In contrast, those with or associated with the condition (e.g., HIV) or the behaviour (promiscuous sex) are considered the targets of stigma. Case studies and testimonies from Uganda, Malawi, Zambia, Zimbabwe and India support this argument by describing HIV/AIDS-related stigma and its consequences for women as particularly severe. Due to gender inequalities there are huge levels of violence against women. Women are multiply disadvantaged by HIV/AIDS with their gender, familial and economic positioning rendering them especially vulnerable. They are kicked out of houses, blamed to be carriers and so on. It was found in the studies done in Uganda Malawi, Zambia, Zimbabwe and India that infected people are forced to leave their marital home after the death of husband from AIDS and that is probably one of the reasons for taking time to be recognised (Bond, Chase & Aggleton, 2002)

2.6 Sources of stigma related to HIV/AIDS

AIDS has been identified as the deadly disease. For example, in Xhosa its name is "*Gawulayo*", which means killer. Van Vuuren (1997) indicates that AIDS is seen as a disease far more contagious than it really is because it is regarded as a divine retribution for certain aberrant lifestyles. People associate HIV/AIDS with people who lead a promiscuous life and think that they are the only ones who are at risk of being infected by HIV/AIDS.

According to Treichler (in Policy report, 2003), language is crucial to stigma. Since the beginning of the pandemic, a series of powerful metaphors have been mobilised around HIV/AIDS, which have served to reinforce and legitimise stigmatisation. These have included describing HIV/AIDS as death, horror, shame, punishment, crime, war and otherness.

According to Perkel (1992), because in the early days of the AIDS epidemic the disease was associated with the male gay community in United States, stereotyped attributions of blame and guilt for the disease were placed on their shoulders. Herek and Glunt (1988**)** argued that HIV/AIDS is highly stigmatised because it is a disease that is perceived as the bearer's responsibility because the primary modes of transmission of the infection are behaviours that are considered to be of choice. The antithesis to this symbolisation is that of the innocent person with HIV/AIDS, infants and young children, who are commonly positioned as devoid of any blame shame or guilt with respect to their infection. The distinction between innocent and guilty PLWHA is underpinned by the strong emphasis upon the association between lifestyle choices and health states that has emerged in medical and public health discourses over the past few decades. It is further argued that in the Third World trends are different especially in Africa where homosexual transmission is believed minimal. Consequently, it was estimated that by 1987 that the heterosexual spread accounted for about 75% of HIV infections among African adults (Doka, 1997; Duh, 1997).

As noted earlier, AIDS-related stigma is complicated by the epidemic′s association with already marginalised groups. Consequently, most individuals do not respond to AIDS as a transmissible disease rather they respond to it as transmissible disease of gay men and other minorities. Weeks (1977, in Aggleton & Homans, 1988) argues that AIDS is not a disease of a particular type of person and it has affected and killed heterosexuals and homosexuals, women and men, black and white, young and old, rich and poor, the promiscuous and the inexperienced. One can further argue that the sources of stigma attached to HIV/AIDS come from identification of AIDS with persons and groups like homosexuals and Blacks already stigmatised prior to the epidemic. AIDS thus provides many people with a metaphor for prejudice and it is a convenient hook on which to hang people′s hostility toward out-groups. It is misleading to talk about risk categories as it leads to a belief that it is always someone else's disease. It is further claimed that identification of AIDS as a gay plague has potentially disastrous effects. It does not only lead to the stigmatisation of the disease itself, but it also encourages those who do not see themselves as gay to believe that they will not get it.

Gevisser (1996) made an attempt to understand the process involved in the media constructs of public consciousness about AIDS by analysing a decade of AIDS clippings. In his analysis of the language used in the headline GAY PLAGUE, Gevisser found that by using the word "plague" the media was either consciously or subconsciously defining a public consciousness of the epidemic that of retribution and punishment for sin. Busse (1996) supported this further arguing that the representation of AIDS as a gay disease had further problems for PLWHA. His findings noted that AIDS reporting retained its gay focus long after HIV was identified as a heterosexual issue. According to him, blame became a major feature of the epidemic. Busse explored the understanding that people have of AIDS, where it comes from, and how it impacts PLWHA and informs their self-image. Moreover, it has been suggested that stigma is applied with varying degrees of force, depending on local moral judgements about how a PLWHA contracted HIV (Population Council, 1999). For example, Ms A in Khayelitsha mentioned that she was admitted at Jooste Hospital for HIV illness after she delivered an HIV-positive baby boy and the people from her area sent messages that she deserved to be there but they only felt pity for the baby as no one came to visit her until she was discharged (Ms A, Personal communication, 2003). She further argues that the father of the child threatened to kill her if she mentioned that the child is his. “I am scared to go for the AIDS grant because people shout at me telling me that I misuse the tax payers money but they feel pity for my friend who is getting money for TB illness” (Mr. R, verbal communication, Khayelitsha). The above story illustrates the apprehension many people still have about HIV/AIDS, despite the information and educational programmes about the disease. Results of a recent study also show that people endorsed the statement that people who got AIDS through sexual intercourse or drug use have gotten what they deserve (Lee, Kalichman & Sikkema, 2002). Moreover, other studies have shown that the stigma associated with HIV is greater than that of other stigmatised illnesses. People have approached HIV and AIDS emotionally because of the perception that the main means of transmission (homosexuality and injected drug use) involve immoral and criminal activity. Similarly, HIV/AIDS is a disease that is perceived as the bearer’s responsibility because the primary modes of transmission of the infection are behaviours that are considered voluntary and avoidable (Lee, Kalichman & Sikkema, 2002). Some people end up dying silently of HIV and AIDS while they have chance to seek help. In many countries, people infected with or affected by HIV/AIDS belong to groups vulnerable to racism; racial discrimination, xenophobia and related intolerance and that this has a negative impact and impede their access to health care and medication. The condition that HIV and AIDS are contagious always has greater stigma attached to them (Lee, Kalichman & Sikkema, 2002; Policy Report, 2003).

Herek and Glunt (1991) pointed out that the stigma attached to HIV/AIDS as an illness is layered upon pre-existing stigma. Kelly and Wood (1990, in Herek and Glunt, 1991) stated that stigma is not unique to the HIV/AIDS pandemic. It has been well documented with other infectious diseases such as tuberculosis (TB), syphilis and leprosy. In addition, it is a fatal disease and this causes fear of infection. Secondly, it is perceived as a condition that is unalterable although the effectiveness of highly active antiretroviral therapy (HAART) has begun to change the perception of HIV to one of a chronic illness. Stigma is most common with diseases that are seen as incurable, disfiguring or severe. It is also seen in diseases associated with transgression of social norms such as socially unsanctioned sexual activity. Both these sets of criteria fit HIV/AIDS (Herek & Glunt, 1988, in Population Council, 2002). Bond, Chase & Aggleton's (2002) study results from Zambia indicated that in the community people frequently reported putting physical distance between themselves and persons suspected of having HIV/AIDS. Similarly, Van Dyk (1991**,** in Kalichman & Simbayi, 2003) in a South African national survey reported that 26 % of respondents would not be willing to share a meal with PLWHA, 18% were unwilling to sleep in the same room with someone with AIDS, and 6% would not talk to a person they knew to have AIDS.

Duh (1991) argues that regarding AIDS education, the public is given facts instead of understandable and useful information. Moreover, he postulated that lack of understanding is the reason for the hysteria about AIDS.

2.7 Psychosocial impact of stigma attached to HIV/AIDS

The high rate of HIV/AIDS transmission is a major problem in our communities. There is no cure for AIDS but people continue to engage in risky behaviors as there are still large numbers of people with repeat infections of sexual transmitted diseases (STDs) attending clinics and lot of people dying of HIV/AIDS-correlated illnesses as well as an increasing rate of AIDS orphans. The question is what prevents people from getting tested for HIV, engaging in healthy behaviors, disclosing their HIV status and not to adhere with treatment?

There are many educational programmes offered by health sectors and different organizations to empower people with knowledge about HIV/AIDS. However, such initiatives have failed to change risky behaviours. Researchers indicate that knowledge of risk is not enough to change behavior since other external factors (like gender, power, politics, culture, economic, religion, etc.) might influence it (Bandura, 1989; Perkel, 1992).

According to Bond, Chase and Aggleton (2002), their research conducted in Zambia showed that in the household and family setting stigma was manifested in the forms of verbal abuse, rejection, eviction and imposed restrictions on the person. In addition, people with AIDS were subjected to blame, bitterness, anger, denial and the withdrawal of treatment and care, sometimes leading to blatant neglect.

It is further argued that in Southeast Asia the AIDS discourse comprises a clear continuum of guilt and innocence with sex workers or intravenous drug users seen as most guilty, followed by clients of sex workers, and monogamous wives infected by their partners seen as most innocent, followed by HIV-positive children infected during pregnancy, childbirth or breastfeeding.

According to the report of the Department of Health in South Africa, it appears that women who are infected are stigmatized more that men (2000, in Policy Report, 2003). Ms N, a facilitator of a HIV/AIDS support group in Khayelitsha, reported that they encounter problems where women are violated or rejected by husbands, family members and friends after disclosing their HIV/AIDS status (Ms N, Personal communication, 2001). She mentioned that it might seem wise not to confide in anyone rather than risk a fearful or hostile reaction. This is supported by Evian (1991) who reports PLWHA are often rejected by their family and friends and lose the very people whom they need most. One can imagine people dying in hospital beds, knowing there are many people who think they have got what they deserve. The Bond, Chase & Aggleton (2002) mother–to-child study done in Zambia shows that participants felt that men were likely to share their status with their wives in the expectation of a supportive response, while women were much less likely to disclose their HIV status to husbands for fear that it might precipitate divorce, violence or prohibit disclosure.

According to research conducted by McGrath, Ankrah, Schumann, Lubega and Nkumbi (1989) on the psychosocial impact of HIV/AIDS-related stigma, it was discovered that subjects often do not tell their families that they have AIDS because they perceive that stigma will result. Ms. N reports ‘When I was diagnosed positive I was shocked, feeling guilty, hating myself, frustrated and having a fear of how my mother will react when I tell her about my condition” (Ms N, Personal communication, Khayelitsha). According to Lee, Kalichman & Sikkema, (2003), stigmatised individuals are vulnerable to feelings of self-hatred which can result when they internalise society’s negative views of them. Moreover, internalised stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatisation by others, which negatively affects disclosure. Marshal (2002, in Policy Report, 2003) describes enacted stigma and discrimination as a collective dislike of what is unlike. It is further postulated that enacted stigma is usually intentional, although people are not always aware that their attitudes and actions are stigmatizing. For a disease like AIDS, stigma is felt not only by the patient themselves but also by the family.

UNAIDS (2002) echoed that another effect of stigmatisation is that regardless of HIV status, employees working in HIV/AIDS programmes may be seen by community as HIV positive, and discriminated against. It is further agued that in the research literature report, a woman was denied blessing of her marriage ceremony by a pastor because of her involvement in HIV/AIDS work. According to people working in the field of HIV/AIDS, it is said that the biggest hurdle to treatment of PLWHA in South Africa is not lack of expensive medication, but fear and denial. Ms L, co-ordinator of the HIV/AIDS Campaign in Khayelitsha living with HIV says that fear of being stigmatised, fear of rejection by the family and friends, and fear of discrimination from communities is an enormous problem (Personal communication, 2003). She claims that she does not feel any physical pain but the most pain she feels is rejection, which is going to accelerate her condition because she is lonely and empty inside. According to Osborne (1997), PLWHA need to reclaim their dignity that has slowly been eroded by discrimination, stigmatisation and the lack of an acceptable positive role model, information support and psychosocial support.

There is a belief that knowledge of one's own HIV infection status is an important intervention in controlling HIV infection. Most of the clinics have free Voluntary Counseling and Testing (VCT) but rate of people accessing these services is still very low. It is has been shown that the denial, stigma and discrimination play an important role in preventing people from testing (Aids Bulletin, 2000). According to Kalichman and Simbayi (2003) AIDS-related stigmas are another factor that probably influences seeking

VCT in South Africa. In addition, they argued that stigmatising beliefs about AIDS and their associated fears of discrimination could influence decisions to seek HIV testing and HIV treatment services. Similarly, Chesney and Smith (1999, in Lee, Kalichman & Sikkema, 2002) postulated that the stigma associated with HIV/AIDS negatively impacts people's decisions regarding whether and when to be tested for the virus. Furthermore, HIV-related stigma deters many HIV–positive people from seeking medical care and from disclosing their serostatus to others because doing so can lead to rejection, discrimination, hostility, and physical violence (Bond, Chase & Aggleton, 2002; Herek & Grunt, 1988; Niang et al., 2003).

Most of the PLWHA in Khayelitsha battle with the issue of how to handle and control the process of disclosure (Ms. L, personal communication, 2003). She claims that if there is nothing done to encourage disclosure, the rejection and discrimination will be generated and people will continue practising unsafe sex. Lee, Kalichman & Sikkema, (2002) echoed that the choice to not disclose one's serostatus can lead to an increased sense of isolation and psychological distress among HIV-positive people and an increased likelihood of engaging in unsafe sexual practices.

Lee, Kochman and Sikkema (2002) conducted a study looking at the internalised stigma among PLWHA in Milwaukee and Madison, Wisconsin and New York City. They found out that the majority of the sample experienced internalised stigma related their HIV status. They mentioned that individuals who experienced high internalised HIV stigma had been diagnosed with HIV more recently, their families were less accepting of their illness, they were less likely to ever have attended an HIV support group, and they knew fewer people with HIV. Furthermore, individuals with high internalised HIV stigma also worried more about spreading their infection to others. Lee, Kochman and Sikkema after controlling for the effects of key behavioural and psychosocial variables, mentioned that the hierarchical regression analyses showed that internalised HIV stigma contributed significantly to levels of depression, anxiety, and hopelessness.

Bourdieu, (1977, 1984) and Bourdieu and Passeron, 1977 (both in Parker and Aggleton, 2003 argue that all cultural meanings and practices embody interests and signal social distinctions among individuals, groups and institutions, then few meanings and practices do so as clearly and as profoundly as stigma, stigmatisation and discrimination. They further postulate that stigma and discrimination therefore operate not merely in relation to difference but even more clearly in relation to social and structural inequalities. Second, and even more importantly, stigmatisation does not simply happen in some abstract manner. On the contrary, it is part of complex struggles for power that lie at the heart of social life (Parker & Aggleton, 2003). The next chapter will discuss the theoretical framework pertinent to this study.

Chapter 3

Theoretical Framework

3.1 Background

Various theories have been developed to understand, predict and promote behavior change. This study will draw on some models, which have either been developed specifically to predict and explain the health behavior practices.

According to Schlebusch (1990), in scientific discourse a ‘model’ is a set of assumptions one makes about any particular phenomenon in order to describe and explain the structure and operations one observes. When information about a subject is scant there are likely to be several models attempting to explain it, but as knowledge accumulates some of the models turn out to be inadequate and drop out until finally only one is generally accepted. Deacon, Stephney and Prosalendis, (2005) postulated that theoretical approaches to stigma remain problematic. They acknowledged that in order to be able to explain the functions or effects of stigmatization one has to resort to functionalism (defining stigma in terms of discrimination), and to be able to understand the role of the individual in stigmatization we should resort to individualism (defining stigma as a problem of individual ignorance). Philan and Phelan (2001 in Deacon, Stephney and Prosalendis, 2005) explains HIV stigma as a process and they came with these four processes;

1. People distinguish and label human differences.

2. Dominant cultural beliefs link labeled persons to undesirable characteristics like negative stereotypes.
3. Labeled persons are placed in distinct categories so as to accomplish some degree of separation of ‘us’ from them.
4. Labeled persons experience status loss and discrimination that lead to unequal outcomes.

This suggest that stigma should be understood as a problem of fear and blame, rather than as a problem of ignorance or a mechanism of social control, this helps to understand the stigmatization process without resorting to individualism or functionalism (Deacon, Stephney and Prosalendis, 2005). Theoretical models that take into account the interplay of individual and environmental factors are therefore considered since the study of HIV/AIDS-related stigma is a social phenomenon. Social Identity Theory, Social Action, Self-empowerment Model, PEN- 3 and the Instrumental Symbolic HIV stigma model are described and their understanding of behavior change is indicated. Therefore, the study focused on social theories of stigma.

3.2 Social Theories of stigma

According to Kunkel (1975), one cannot study societal structures and processes social problems and their causes and solutions, or be interested in grounding social change, without models of man and of society. Airhihenbuwa and Obregon (2000) postulate that the true experts in the methods of the production and acquisition of knowledge in a culture are the people themselves. Schlebusch (1990) argues that people’s behavior can be anticipated by understanding their social and cultural background since many concepts are acquired by incorporating attitudes and beliefs from social and cultural references. He further argues that reality is often defined by the concepts of people hold and by their perceptions of the world, and people are frequently unaware of the effect of concepts usually functioning at an unconscious level can be considered to be a normal way of perceiving things. Therefore, it becomes clear that terms such as normality, abnormality, illness, disease and health are difficult to define because they present complex concepts which change and vary with time according to people’s viewpoints and value systems (Schlebusch, 1990). For him, people act in accordance with a world-view (e.g., views about child-rearing practices, education, nutrition, health, etc.), which becomes important in determining an individual’s behavior in such matters. It means that if one understands such views one can anticipate how people will behave when faced with these issues.

3.3 Social Identity Theory

According to Tajfel (1959, 1978, 1981, in Foster & Potgieter, 1995), social identity theory (SIT) proposed that intergroup bias might be the direct result of the perception by individuals that they belong to a common social category. Social categorization does not divide according to locations but it defines one’s place in society. The perception of people in terms of categories or groups on the basis of criteria has relevance to the classifier. For example, people who use ways of transmission as a classifying criterion will have strong argument that those who lead a promiscuous life deserve to be HIV- positive but feel pity for those who are infected through blood transfusion. Tajfel, 1959; Bruner 1957 and Wilder 1981 (in Foster & Potgieter, 1995) indicate that social categorization forms part of a fundamental cognitive process known as categorical differentiation. They further argue that because we cannot process the infinite array of information present in our environment, people develop short cuts by categorizing objects and people into groups. The complexity of the environment is reduced through the operation of the principle of accentuation. This describes the phenomenon whereby the similarities within a group and the differences between groups are exaggerated or accentuated. This is accompanied by the differences between groups: we are HIV-negative and they are positive, we are not like them, they are very different. Furthermore, Foster and Potgieter (1995) argued that the perception of social group is characterized by an evaluative (positive or negative) and an emotional (feeling of like, hate) component.

It is through the process of social comparison that the evaluative dimension of group membership is determined (Foster and Potgieter, 1995). Therefore, one’s own group is compared to specific out groups using some dimension of comparison. Furthermore, the outcome of this social comparison process is a graduation differences, termed a status hierarchy. In addition, if a group is perceived to be superior to another on some relative dimension it has high status; if it is perceived as inferior, it will have low status. In other words, the more positive the characteristics attributed to the group, the higher that group’s status will be. A central tenet of SIT is that individuals have a need for, and thus motivated to strive for, appositive self-concept. It follows that if the outcome social comparison bestows a negative social identity on in-group members, these individuals will try to achieve some type of change so as to gain a positive social identity (Foster and Potgieter, 1995).

Parker and Aggleton (2003) claim that stigma plays a key role in producing and reproducing relations of power and control. Furthermore, it causes some groups to be devalued and others to feel that they are superior in some way. Therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings.

3.4 Social Action Theory

Foster and Potgieter (1995) indicate that the acceptance that the structure of social relationships between groups is neither fixed nor unchanging incorporates the possibility of social change. Social change is the collective attempt to change the social position of the in-groups. This means that if the community perceives HIV-positive people as an out-group, models like social creativity should be applied, as they are essentially an attempt to redefine some existing group characteristics in positive terms. Positive ones should replace negative labels and attitudes towards HIV/AIDS.

Foster and Potgieter mentioned another model which is radical, as political protest, strikes and revolution to restructure society, that is, social action. They also suggested the social mobility model in social change where people perceived to be at low status group (like PLWHA in this study) will be motivated to higher status focusing on values and standards.

3.5 Self-Empowerment

According to Airhihenbuwa (1995), among approaches to health education / promotion and disease preventions, the self-empowerment method is believed to be more encompassing and more effective than preventive-medical or radical-political approach. It is further agued that the preventive-medical approach focuses on influencing individual decisions leading to the adoption of positive health behaviours, whereas the radical-political-approach focuses on manipulating the social and political environment so as to tackle ill health at its foundation (Tones, Tilford & Robinson, 1991, in Airhihenbuwa, 1995). Airhihenbuwa (1995) further argues that the self-empowerment approach facilitates choices for individuals and communities within the context of the socio-cultural and political environment. Social norms created within certain culture could influence the thinking or judgement of what constitutes risky or health behaviours (Preston-Whyte & Brown, 2003). At the same time some people use cultural explanations as an excuse when they are asked to change life threatening behaviours.

3.6 Instrumental and Symbolic Stigma Model

Herek and Capitanio (1998 in Deacon, Stephney and Prosalendis, 2005) use the term “instrumental stigma” to describe intended discrimination based on an inflated fear of contracting HIV, as well as intended discrimination based on resource concerns due to judgements about the likely social contribution of PLWHA. For them “symbolic stigma” described the kinds of moral judgements that may cause a third kind of discrimination, such as refusing to provide the same treatment for intravenous drug users and innocent victims of HIV/AIDS because the former are judged to be more blameworthy for contracting the disease or not allowing PLWHA to serve on a school board because they are judged as immoral (Deacon, Stephney and Prosalendis, 2004).

In Herek and Capitanio’s Instrumental Symbolic stigma theory (1998 in Deacon, Stephney and Prosalendis, 2004) it is argued that it is not all the discriminating factors that would result in stigma. Herek and Capitanio further argue that although both instrumental stigma and symbolic stigma are socially constructed and may lead to discrimination against PLWHA, it is not really useful to try and define them both as stigma as they do not originate from the same social cognitive or emotional processes or respond to the same kinds of interventions. This discussion on instrumental and symbolic stigma has key implications for how one designs interventions. It is further argued that there is a need to address discrimination based on moral judgements, risk and resource concerns in different ways (Deacon, Stephney and Prosalendis, 2004). One way of looking at stigma is through a cultural point of view.

3.7 PEN-3 Model

I think when implementing education programmes one has to look at cultural dimension and evaluate the relationship between education and power or cultural issues. According to Parker and Aggleton (2003) sociological emphasis on the structural dimensions of discrimination is particularly useful in helping us think more sensibly about HIV and AIDS-related stigmatization and discrimination. It is acknowledged that there is a need to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination.

Airhihenbuwa (1995) developed the PEN-3 model which allows the kind of flexibility that encourages intra-cultural diversity such that the process should be engaged each time a programme is conceived. In some environments the role of experts such as traditional healers, religious practice, and of interpersonal communication are also born in mind. One has to look at the ideas that circulate in a society and constitute common sense and also focus on the specific processes by which these contents are shaped. The PEN-3 model challenges health and cultural workers to address health issues at the macro level as well as the traditional micro level of health programme interventions (Airhihenbuwa, 1995). He further argues that this method incorporates existing models/theories and frameworks in health education while drawing on theory and application in cultural studies.

The PEN-3 model has three categories (listed according to the acronym PEN) within each of three dimensions (Airhihenbuwa, 1995). The first dimension is health education with three categories the person, extended family and neighbourhood. HIV/AIDS is not only the problem of the infected person it also affect the family and the neighbours should also be part of the health education programmes that will be developed to decrease the stigma related to HIV/AIDS. They are the ones who know the stigmas. The second dimension of PEN-3 according to Airhihenbuwa is the educational diagnosis of health behavior. Moreover, he mentioned that this dimension evolved from the confluence of the three health-related models the health belief model (HBM), theory of reasoned action (TRA) and other frameworks that came before. However, these theories have no central role in culture. He postulates that the PEN-3 extends the possibilities of this dimension by placing culture at the core of health promotion and disease prevention programmes. The factors in this dimension are perceptions, enablers, and nurturers (Airhihenbuwa, 1995). It is argued that perceptions comprise the knowledge, attitudes, values and beliefs, within a cultural context, that may facilitate or hinder personal, family and community motivation to change. For example, the understanding and morals at Khayelitsha about stigma related to HIV/AIDS could differ from the understanding and morals at Gugulethu although it might be the people of the same culture. Values and morals differ from community to community. Other dimensions are enablers and nurturers. Availability of resources is not the same in all the communities especially in the disadvantaged communities like Khayelitsha whereby they have limited resources and also the degree to which health beliefs, attitudes and actions are nurture, by family, friends and community differs (Airhihenbuwa, 1995).

The third dimension of Airhihenbuwa’s PEN-3 model is the cultural appropriateness of health behaviour. This is the critical dimension as it situates culture in dynamic and interacting forces that manifest themselves in individual, family and community behaviour. This dimension consists of the categories of positive, existential, and negative behaviours (Airhihenbuwa, 1995). For example, a disease like cancer was stigmatized and people were not open about it and ended up being silent and die alone while they could have gone for help. Today they are open because it is less stigmatized so it would be wise to encourage the programmes that managed to come with positive behaviour. The other dimension is existential behaviour. One can say in the case of mass media that plays a leading role in transforming expert knowledge into lay knowledge and its influence on people's social psychological constructions of phenomena is powerful. If the message has no harmful health consequences we should not blame it for failure because it is misunderstood. According to Airhihenbuwa (1995), the last dimension is negative behaviour. Furthermore, these are the beliefs that are based on the health beliefs and actions that are known to be harmful to health. For example, in the case of people who believe that AIDS is the gay plague and continue practicing unsafe sex since they think it is not their problem. These beliefs should be examined and be understood on their cultural context before attempting to change them. According to Airhihenbuwa (1995), the process of culturalizing health knowledge, attitudes and practice does not assume that people are powerless or ignorant. He further argues that the process affirms diversity in the way people construct their locations. Moreover, what is positive or negative cannot be based on a universal notion promoted in economic development.

THE THEORETICAL MODEL: PEN-3

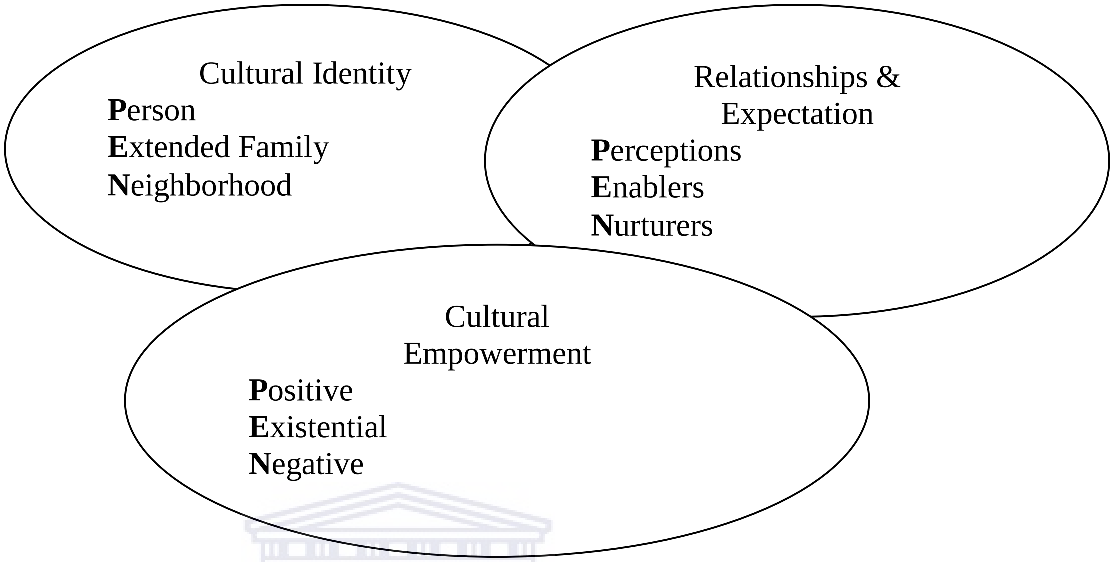

Figure 1

One can assume that social behaviour in association with various social factors plays a definite role in health care and disease. Poor and underdeveloped communities like Khayelitsha have less access to health care and are associated with shorter life expectancy, increased risk for HIV/AIDS, substance abuse, higher crime rate, unemployment and poverty. Large numbers of people every year are affected by STDs which exerts an enormous cost in terms of suffering, lost jobs, medical care, rejection by family and community members and infants born with infections. To combat this pandemic sexual activity constituting health-risk behaviours such as AIDS should be approached from a psychological point of view applicable for that community. The PEN-3 model helps us to identify the kinds of stigmas that will come up when we analyze our data so that we could come up with relevant programmes to reduce stigma. It is also important to follow the PEN-3 model because it looks at the programmes that worked well in the area and also involve the people in that area when planning intervention. This will help not to repeat the intervention programmes that already exist and also makes possible for the evaluation of existing programmes.

Chapter 4

Methodology

4.1 Methodological framework

The qualitative method was used to allow the complexity of issues, depth of understanding and flexibility of exploration around touchy subjects since the study is interested in the feelings and perceptions and experiences of HIV/AIDS-positive people (Schroepf, 1991). According to Denzin and Lincoln (1994), it is difficult to give a clear definition of qualitative research since it involves a multiple set of overlapping interpretative practices by individuals to their actions, which are located within a particular social context, without dehumanising them. Often it is defined as a multi-method paradigm that attempts to make sense of subjective meanings. Thus, this study seeks to validate HIV-positive people's subjective perceptions and experiences of stigma exerted against them.

It is the socially constructed positions that influence the way in which HIV/AIDS-positive people respond to and experience the dynamics of being stigmatised and rejected. However, not all HIV/AIDS positive people go through the same experiences. Most of quantitative research of perceptions and experience about stigma related to HIV/AIDS largely concentrated on people′s experiences from which they made inferences about infected people′s social reality. Quantitative research has undermined HIV-positive people′s ability to construct their own social reality. Qualitative methodology is therefore an effective alternative approach in addressing these biases. However, it is also criticized for being biased because of lack of accurately defined procedures for ensuring objectivity. Neither of these approaches is right or wrong but they complement each other in a constructive manner (Banister et al., 1994; Patton, 1990). Huysamen (1997) supports this by pointing out that the labels quantitative and qualitative are misnomers as the two approaches complement each other rather well.

4.2 Participants

The sample was composed of six groups of 57 Xhosa-speaking PLWHA ranging from 6 to 10 per group as shown in Table 1. The participants were drawn from two organisations working with HIV/AIDS positive people in Khayelitsha, namely, Treatment Action Campaign (TAC) and other HIV/AIDS Support Groups in the area. These organisations were chosen due to the fact that we were looking for people who have disclosed their status and in who were in terms with the illness even if they have not yet disclosed in their families. This worked because 30% of the participants were people who have disclosed their status in the support group but not yet disclosed in their families due to some problems with disclosure. About 98% of the participants were unemployed and 60% were living in informal settlements with no formal services like water, toilets and electricity. The subject's ages were from 15 to 49 years old. As nearly all of the participants were unemployed, it allowed the researcher to do the groups during the week from Friday and during weekend.

In terms of sex, Table 1 shows that two groups were composed predominantly of females with one or two males in each group. The other two groups had equal numbers of males and females. Finally, the last two groups had only females. Four groups were gender mixed with two female groups although the idea was to try also have one male group and one female group; According to Banister et al. (1994), giving gender groups a space within which they can vocalise their accounts is a way of empowering them because they can connect with sensitive issues in their lives. Participants told us that they feel free to share ideas in a gender mixed group because most of the time when they meet they are used to being together. It was indicated that many support groups did not have many male participants although now they have formed an organisation or a support group for males which was busy campaigning during the data collection time.

Characteristics of participants in each focus group		
Group	**Male**	**Female**
One	2	8
Two	5	5
Three	0	10
Four	4	6
Five	0	9
Six	0	8
Total	**11**	**46**

Table 1: Summary of sex composition of focus groups in the present study

4.3 Research method

Focus groups were an appropriate and potential tool to be used for this study. According to Patton (1990), a focus group interview is an interview with a small group of people on a specific topic. Groups are typically eight to 12 people who participate in the interview for 1 to 2 hours. This qualitative research method originated in market research but has been used increasingly in social research generally because within a limited period of time real-life data can be captured from more than one person in a social context where people can consider their own views in the context of the views of others.

Patton (1990) further argues that facilitating and conducting a focus group interview requires considerable group process skills. It is important to know how to manage the interview so that one or two people do not dominate it, and so that those participants who tend not to be highly verbal are able to share their views. In this respect, the facilitator and co-facilitator were both trained on how to conduct focus groups prior to data collection as part of the Penn State University (PSU); Human Science Research Council (HSRC) and the University of the Western Cape (UWC) Research Capacity Development Research Project on Stigma and also had previous experience in this field from the studies they have participated in before this one.

4.4 Research instrument

A focus group guide was used (see Appendix A). The research questions were formulated with the help of the project research team mentioned above and were also taken to the PSU's Institutional Review Board (IRB, i.e.) Ethics Committee for approval before use. There were five open-ended questions each with four to five probes. Open-ended questions were chosen so that people could explore their feelings.

4.5 Procedure

The permission was first asked from the co-ordinators of both TAC and other NGOs working with PLWHA in Khayelitsha to conduct the study. Permission of the participants was then also sough individually. Due to the sensitivity surrounding the acknowledgement of one′s HIV/AIDS status, the focus groups were conducted at TAC and other community settings like houses and churches places where they were used to and felt comfortable to meet at with the permission of the people in-charge. Furthermore, the permission of participants to audiotape the session was sought.

No one refused to take part in the study and all participants gave us permission to audiotape them during the sessions. Both the facilitator and co-facilitator managed to create a non-threatening climate enabling participants to express their views freely. Each focus group lasted approximately 1-2 hours and was conducted in Xhosa the language used by all participants. Each group was audio taped with consent of the participants. The cassette tapes were transcribed in Xhosa after transcriptions back-to-back translation was done changing from Xhosa to English and back from English to Xhosa and independently ensuring that there was no change in meaning and interpretation. Written notes were also taken during interviews.

4.6 Data Analysis

To analyse data, the discourse analysis approach was employed since concentration was on the way language produces and constrains meaning as spoken by individuals. According to Foucault (1980), language permits us to go beyond the linguistically reflected power exchanges between persons and groups to an analysis of the structures within they are deployed. This is done by coding as much of the recurring discourse as possible in order to make sense of it. The purpose of coding the data is to achieve overall interpretation of cumulative meaning. This is supported by Fairclough (1992) indicating that force of utterance, that is, what sorts of speech acts (promises, requests, threats) they constitute, the coherence of text and the intertextuality of texts constitute the framework for analysis. Thus, analysis of discourses involves sifting out repeating themes.

According to Foucault (1980), discourse can be defined as an assemblage of statements occurring in an ongoing conversation. Furthermore, Henriques (cited in Fairlough, 1992) indicated that in the perpetuation of, and the appropriation of the individual as he/she is positioned by particular discourse forms the social framework of meanings into which we are inserted, the ways we make sense of, and regulate, our experiences. It is rooted in our everyday knowledge and shapes and perpetuates concerns and beliefs that people hold. Thus, a person who is living with HIV/AIDS may talk about labels attached to HIV/AIDS. The statement or talk would be seen as the discourse. The frequency of the text of the talk will position an individual stigmatised into a social framework and will indicate how he is affected.

Fairlough (1992) also acknowledged limitations of the approach mentioning that in discourse each statement can be placed in more than one category because the meanings conveyed in one statement often relate to a range of discourses, some of which are contradictory. The strength of the interpretative picture of the analysis is developed through the repetition rather than through microanalysis of every word. Furthermore, to show how analysing daily language usage reveals slippages of understanding and of subjectivity. It also aims to deconstruct the assumptions which underline the apparent simple ideas expressed through a statement

4.7 Reflexivity

According to Banister et al. (1994), reflexivity is one of the important characteristics of qualitative research through which knowledge is produced and constructed. It lies on the basis of continuous critical evaluations of personal experiences about the research encounter. The researcher had a co-facilitator who observed the researcher's characteristics that might have had some influence in the findings. This helped with the objectivity of the study. The fact that the researcher was involved in a study looking at the protocol used in clinics for STDs where the researcher was a simulated client for a year has exposed her to the problems PLWHA encounter. Through exposure in these conditions motivated the researcher to be more involved in programmes related to HIV/AIDS. The researcher became a TAC volunteer and HIV counsellor in the community. My social identity as researcher was located in relation to participants. This helped the researcher in terms of recruiting participants in this study. Having someone they trust and could identify themselves with as their facilitator made them comfortable to be open during discussions. Hollway (1984) supports this idea, arguing that researcher's own positioning in social context and the significance of reflexivity in the research are important in discourse analytic research. Potter & Wetherewell (1987) acknowledged that sensitivity to power relations embedded in research practice and an imperative to locate one's own subjectivity as researcher is central. In this study the researcher was concerned about power relations emerging in the discourses of participants as well as those evident in the research process itself. In this respect, the researcher was aware of the power inequalities between the researcher and participants and amongst PLWHA themselves. Secondly the training in Psychotherapy and Counselling Psychology the researcher obtained at UWC and HIV-Lay Counselling received at Aids Training and Information centre (ATIC) helped the researcher to be neutral during the group sessions so that her personal views and experiences about HIV/AIDS-related stigma did not influence the outcomes of the study in any major way. The co-facilitator was also observing, taking notes and taking care of the recording machine. This was done in order to increase the validity of the study.

4.8 Ethical Considerations

Permission to conduct the study was sought from the Post Graduate Studies Committee in the Faculty of Community and Health Sciences and Senate. Participants were informed about the present study from the beginning and their permission to participate was asked. So the researcher read through and explained the informed consent to the clients. Confidentiality was assured to protect the identity and to respect privacy of the participants. Participants were informed that they have the right to withdraw at any time when they do not feel comfortable to continue with the process. They were asked if they are comfortable to be given numbers during discussion so there would be nowhere in the study where their names will be mentioned. They agreed and this worked very well although two participants mentioned their names during discussion and claimed that they were okay with that. They were told that the information gathered in this study would be made available to TAC and other NGO's in the community so as to inform their future intervention

Chapter 5

Results And Discussion

Introduction

The data provide information about the perceptions and experiences of PLWHA about the stigma related to HIV/AIDS experienced from the community members and also health providers. The analysis draws out central themes related to the key questions asked about HIV-related stigma. Eight themes were identified with each theme having various having various sub-themes. The main themes are listed below:

1. Perceptions and beliefs about HIV and death
2. Negative community responses
3. Social exclusion, discrimination, and HIV-stigma from the family members
4. Othering of female PLWHA
5. HIV and promiscuity
6. Context of care in clinics
7. Disclosure of HIV client’s status by health care providers
8. Challenges faced by PLWHA about staff shortage in clinics.

In each theme discourses about the beliefs and practices related to perceptions, enablers and nurturers (educational diagnosis of health behaviour) will be explored. According to Airhihenbuwa’s (1995) PEN-3 model, this examination will relate to a particular health problem in different segments of the family or community. On the basis of the information generated the researcher will categorize the different beliefs and practices found into positive, existential and negative beliefs (cultural appropriateness of health behaviour). This framework will be applied using some information from the literature reviewed in this study. Then a short summary of the results will also be presented in this chapter.

Theme 1: Perceptions and beliefs about HIV/AIDS and death

When they were asked their views about HIV/AIDS the most pervasive perception was the view that HIV/AIDS is seen as a death sentence. Their knowledge and belief about having HIV was akin to death. *"Having HIV/AIDS" led* to fear of overwhelming negative consequences.

Firstly, participants from the six groups indicated that being HIV-positive your life has came to an end with death a likely outcome. This negative perception of viewing HIV as death sentence has nurtured fear and negative behaviors as illustrated below:

"*To me having HIV/AIDS is synonymous with death although there is medication to lower its impact" (Participant 5, Group 4)*

"For me to be HIV- positive is to face a death sentence that is why most people decide not to know their status because after you are diagnosed positive you will know that your life is finished unlike the time you were not aware of your status".(Participant 4, Group5)

Furthermore, it was mentioned that from the moment HIV/AIDS was identified messages of death accompanied the epidemic. These messages have spread rapidly fuelling anxiety, and fear of death against PLWHA as well as those who are most affected. Participants mentioned that the fact that HIV/AIDS was "advertised" in their community at the beginning as a killer and that it affects those who live promiscuous lives has made people to be afraid to be open about the illness and have made them to become hopeless since they know that they are going to die anyway. The existential belief nurtured this negative perception and a barrier is postulated in the following message displayed by the participant from the groups:

"The first time you discover your status you think you are going to die. You worry about dying. I think the reason is because of the messages that HIV/AIDS is incurable." (Participant 9, Group 2)

Treichler (1999 in Policy Project, 2003) pointed out that since the beginning of the pandemic a series of powerful metaphors were used around HIV/AIDS that have reinforced and legitimized stigmatization. These existential included HIV/AIDS as death, horror, shame, punishment, crime, war and otherness. Various perceptions were expressed about PLWHA and death. It was noticed that the environment became tense and the voices were softer when they responded to this question. Some voices were also expressed like feeling hopeless, will live short lives and will not be accepted by community members. It is also possible that the death of young people in the community might have reinforced this perception. The existential nurtured these negative perceptions are illustrated by the following enablers:

“To see young people dying everyday worries me and think that I will also die soon” (Participant 4, Group 6)

“When you go to funerals you often see young people been buried. It’s often young people who are involved.” (Participant 4, Group 1)

It is evident that the messages that were brought in the beginning about HIV/AIDS as a killer has instilled the same extent of fear for those who are HIV terminal ill and of those who have not yet in that level. From the above examples, it seems as if this existential is also motivated by different processes such as seeing someone dying of HIV, seeing someone suffering from AIDS, experience it personally or the fact that you know that it is a killer.

1.1 Association of HIV with other stigmatized diseases

Stigma is most common with diseases which are seen as incurable or severe. It was mentioned that people respond negatively to PLWHA because of the life threatening nature of the disease and its association with death. This negative perception includes association of HIV with other historically stigmatized diseases, as Syphilis, Leprosy and Tuberculosis (TB). Herek and Glunt (1988) argue that the stigma attached to AIDS as an illness is layered upon pre-existing stigmas.

“When your blood is weak and may be you did not tell them that you are sick again, even if you were sick from fever they will say that you are lying you know what is wrong. They will say that AIDS has got you. They think they know the symptoms whereas they do not. A person with TB is associated with HIV/AIDS these days; if you are a HIV-positive person they say you also have TB these days. So this means that we need education” (Participant 6, Group 6)

“If you have TB, it is assumed that you are positive” (Participant 9, Group 3)

It was reported that if you were HIV-positive, people would not want to share the resources with you. Participants in this study also mentioned that in Khayelitsha some people believe that if you have HIV you are going to die and it will be a waste to invest resources in dying people. According to Patient and Orr (2003 in Deacon, Stephney and Prosalendis, 2005) in certain resource-poor contexts where there is little state support, some beliefs about PLWHA will have greater impact (e.g., “they will be a drain on resources”) and create more of focus for stigmatizing ideology. The negative existential and barrier that HIV-positive person is wasting resources is the societal force that might be used to prevent them to use the resources that they are entitled to.

“Once your health deteriorates it always looks like you are dying. There is nothing that you will be able to do ever again. The people will look at you in a funny way like when I went for a grant people becomes angry that we are paid as compared to

people who are not paid for TB and other illness. They said the government is wasting money which could be used for better things." (Participant 4, Group 5)

However, some participants argue that the people who did not want to share resources with them are those who lack information about the disease. It was postulated that community does not differentiate between HIV-positive people and those people who are living with AIDS as people see both of them as non-productive community members who are going to die anytime. The existential behaviour and barrier that nurtured this perception is shown in the following negative behaviour:

"Many people need education because they still don't know the difference between HIV and AIDS. If you are HIV-positive in our area it is the same as if you are already at a later stage of HIV (i.e., AIDS). It seems as if you are useless and hopeless, you cannot do anything. They do not want us to use government resources because they think that we are going to die anyway." (Participant 6, Group 2)

Another striking aspect was the fact that HIV/AIDS is worse than other terminal disease. It was reported that HIV is perceived as a serious infectious, incurable and fatal disease which could not be cured. The severity of the disease has made HIV/AIDS more stigmatized than other chronic disease like cancer hither to. The existential belief and barrier that there is no cure has nurtured the negative perception that it could not be cured and this is reflected by reports of hopeless feelings:

"I think HIV/AIDS has been known for a long time and I think there should be cure by now but there is no hope." (Participant1, Group 4)

"There is no hope for the cure of AIDS. It is better for other terminal illnesses because you can get treatment from sangomas ad witch doctors not like AIDS. AIDS is a worse fatal disease than all the diseases that have been in the world"
(Participant 4, Group 4)

The medical paradigm in this instance appeared to be accompanied by strong images of disease which drew on comparisons with other epidemics and illnesses (Brandt, 1988). Significant on this medical discourse of AIDS is the absence of a discourse on traditional African medicine that is used for treating AIDS. This perspective distances AIDS from other terminal illnesses which further emphasizes people's helplessness regarding the problem. Perceiving AIDS as something totally different from other disease this would increase denial and not accepting the illness.

1.2 HIV as any other illness

The alternative positive perception suggested that HIV/AIDS should be viewed and responded to in the same way as other terminal illnesses.

"Although it is incurable, I think a cure will be found like the cure of other illnesses"
(Participant 3, Group 3)

“I think HIV/AIDS is like cancer, although it is terminal it can be treated” (Participant 8, Group 3)

Some participants reported a positive perception that they have hope and have accepted their HIV status. Mostly these were people who were well informed about HIV. They also mentioned that they have accepted the illness and have disclosed their status although it was also difficult for them at the beginning. They have accepted their condition through education about the disease and this existential belief has empowered them on what they should do to live longer lives. The existential behaviour that has nurtured and enabled this positive perception is illustrated bellow:

“I didn’t think that I will die and had hoped that I will live longer. I have not given up hope and have been infected for 10 years” (Participant 1, Group 3)

“I agree; those who are HIV-positive and have accepted their status should help those who are still struggling to accept their status because if I don’t accept my positive status, stress may kill me. It is useful helping people to come to terms with their status to reduce stress” (Participant 2, Group 4)

“People who are less informed think that you will die” (Participant 1, Group 3)

Some people indicated that they are not discouraged by the negative and discriminating remarks of the community members and are encouraging those who are HIV-positive and who are offended by those remarks to be open about their status. They encouraged PLWHA to disclose the HIV status. They believe that if they disclose their positive status to the community and educate them about the illness most people will accept them. It was reported that education about illness is the existential behaviour that should be encouraged because it has nurtured positive behaviour disclosing and acceptance of the status regardless of the negative perceptions that would nurture negative behaviour to be silent and not accept their HIV status:

"I think we HIV-positive people should be open about our HIV-status and educate people at churches and in the community and tell them that it does not kill so that we could live normal lives and accept our status. By doing so the community will also accept us" (Participant 4, Group 4)

It is noteworthy that the increased access of antiretroviral therapy was also mentioned which could be one of the reasons for them to be positive about their health condition.

"Now there is antiretroviral treatment that helps us to decrease the viral load and increase our cd-4 counts" (Participant 5, Group 6)

"It is better now because there is antiretroviral treatment" (Participant 4, Group 2)

"I am also on antiretroviral and not scared to disclose my status because if I do not disclose I will die of stress and find it difficult to go for treatment" (Participant 4, Group 3)

For the participants whose views were dominated by HIV/AIDS as an incurable disease, the moderating impact of antiretroviral therapy seems to have been undermined by the negative perception that was nurtured by negative behaviour of stigma experienced within the family members and the community.

"I do not think the more availability of antiretrovirals will make a change because it does not cure the disease it only delays the progression of the illness, so the people will continue stigmatizing us." (Participant 3, Group 1)

"People will not change their thinking because they will look at you in the same negative way while you were not on antiretroviral, their attitude will not change" (Participant 4, Group1)

"Community members are not accepting and that makes you loose hope even if you know that there is something that can help their negative attitude overwhelm you and you become confused" (Participant 6, Group 5)

The absence of a vaccine or cure for the virus was also strongly reported in this discussion.

Theme 2: Negative community responses

When they were asked if the community thinks in similar way participants described positive as well as negative responses from the community members. Several negative perceptions were strongly reported that shows that the community discriminates and stigmatizes them. It was further mentioned that stigma and discrimination further drive the epidemic and prevent those who are already infected from seeking treatment or assistance. Participants reported that negative perceptions nurtured those who think that they are not at risk to engage on risky behaviours or not to respond to the disease.

"Community members do discriminate us for example church members think that we are sinners and HIV/AIDS is seen as a punishment from God" (Participant 7, Group 5)

"Most people think that HIV is for people who have multiple partners" (Participant 3, Group 6)

It was reported that in Khayelitsha there is a tendency of diagnosing people if they see any symptoms especial rash and fever. Some of the existential behaviours that nurtured these negative perceptions are reported as follows:

"HIV-positive people are looked down upon. If you have a small rash on your face or you have flu, it is often assumed that you are HIV-positive. One of the distressing

incidents in the community was when members of the community refused to hold a baby who was suspected to be positive, when you see such practices you feel hurt" (Participant 3, Group4)

"Members of the community often like to behave as if they are doctors. The community needs to be educated because they also think you will die. I often go to X area to receive my grant and I met someone there who thought that I was dead" (Participant 8, Group 3)

"There is often assumption that you are positive on the basis of few symptoms. You are often assumed to be positive without a diagnosis been made" (Participant 10, Group 3)

Participants reported that most people are not knowledgeable about the disease and even those who have medical knowledge are uncertain and become frustrated as the illness progresses. These reactions induced anxiety, distress and anger. Brashers et al. (1998 in Deacon, Stephney and Prosalendis, 2005) argue that lack of biomedical knowledge shows uncertainty about the impact of the disease changes in the different phases of the HIV illness. It is further postulated that medical and social assumptions about people's biological incapacity through the effects of disease could be natured by the fact that biological knowledge of HIV/AIDS is socially constructed. According to Epstein (1996, in Deacon, Stephney and Prosalendis, 2004) it is indicated that on the study about social construction of medical knowledge of HIV/AIDS there is a huge literature on the social construction of science in general. The negative behaviours nurtured by this existential belief are illustrated in the following remarks:

“If you get easily sick, it is also concluded that you are HIV-positive. They say that you have AIDS. When there is conflict your neighbours often use this as a weapon in the conflict. When you are with your friends you also realize that they often talk about HIV. The topic suddenly changes because they also don’t directly talk about HIV and you sense that they are talking about you” (Participant 3, Group 5)

“Another thing is that when we speak about this thing, you think that there are people you have seen where the HIV condition is bad and you think that you also will be in that position. The people will say I am the one who is cheap while busy sick. You realize now that when you get this thing people will say you had no morals” (Participant 2, Group 6)

The above discussion is on line with other researcher’s argument that numerous sources of heightened uncertainty, including complex changing treatment, ambiguous symptom pattern, and fear of ostracizing social response, play a critical role in the experience of PLWHA and are linked with negative perceptions of quality of life and poor psychological adjustment” (Deacon, Stephney and Prosalendis, 2005). It is further argued that uncertainties in medical knowledge of a disease, and in the lack of a cure, could thus both increase stigmas by others and independently increase anxiety and fear among PLWHA in the different phases of the disease.

2.1 Positive community responses

The HIV pandemic has elicited both negative and positive responses from the community members. There were indications from participants that community has made a positive impact in their lives. The people and institutions who have nurtured their positive behaviour are mentioned below:

"I would say my neighbours, even though I never could hide it, I was able to disclose it to them so that they could know what it is. They were able to support me" (Participant 4, group 6)

"Some churches are accepting of PLWHA; there are also projects or structures to educate the community about HIV/AIDS" (Participant 7, Group 1)

There was also evidence about education that has positive impact on encouraging community members to accept PLWHA. Education is reported as the existential that has nurtured the positive perceptions about their acceptance. Some participants mentioned that if people should be educated about the illness at least they could accept PLWHA. This view came from the belief that most community members who lack information about HIV and AIDS associate HIV with death.

"People often think about death when they think about HIV. This is due to misinformation or lack of information" (participant 3, Group 5)

It was further argued that prevention strategies played a major role to avoiding further spread of the epidemic. Health education is therefore reported as urgently required to bring about the necessary behaviour change:

"The community should be educated. People who are stigmatizing others lack knowledge" (Participant 7, Group 5)

"It's lack of knowledge. Many people need education because they still don't know the difference between HIV and AIDS. Some do want to disclose but are afraid of being stigmatized" (Participant 6, Group 2)

"Some parents, older family members often think that you will die because of lack of information" (Participant 5, Group 3)

2.2 Food as a measure of acceptance or rejection

In many societies PLWHA are seen as shameful, the epidemic has shown itself capable of triggering responses of compassion, solidarity and support, bringing the best in people, their families and communities, but the disease is also associated with stigma, repression and discrimination as individuals affected by HIV have been rejected by their families, their loved ones and the communities. The participants in this study expressed different experiences regarding acceptance of persons living with HIV/AIDS. There were participants who shared positive experience of being embraced and supported by various sections of the community. It was also indicated that some community members do care especially after you have disclosed your status they will make you have enough food so that you could adhere with the treatment and also advised you about other places where you could go for help. Below is the example of the positive behaviour that has nurtured and enabled medical adherence:

"I spoke to community leader who promised me confidentiality and told me about support groups. I often ask food from the neighbours during the day in order to take medication" (Participant 3, Group 3)

"Some community members were respectful, others brought food for us. Workers at a factory X area involved us in work on HIV/AIDS. They supply us with food and this helps us to take our treatment because we should have something before we take the pills." (Participant 2, Group 5)

Theme 3: Social exclusion, discrimination and HIV-stigma from family members

Participants reported negative perceptions and enablers from the family as they mentioned that the families that were supposed to take care of them when they are sick were the ones who were discriminating and rejecting them.

“It’s not only in the community but also at home. My mother said I must tell my sister about my status. After I told her I noticed that she changed. She became moody towards me and looked at me as if I am a living grave” (Participant 6, Group 2)

“My sister also wanted to leave me” (Participant 2, Group 2)

“After I disclosed my status at home I was undermined by my parents and siblings and I was not accepted at home at all” (Participant 2, Group 1)

3.1 Parents involvement

On the negative perception of the family, most youth experienced difficulty to be accepted by parents when they have disclosed their status. Dominant voices from the youth were of the parents not accepting their HIV status associating their HIV with promiscuous lives and also PLWHA mentioned that parents are claiming that they are an embarrassment in the community. These youth faces a major problem regarding disclosure. The existential belief of embarrassment that has nurtured and a barrier of disclosure are shown by these remarks:

“Our parents attend church and they do not want us to disclose our status and do not accept us saying that we are an embarrassment. You become stressed and do not know what to do.” (Participant 4, Group 3)

"Our parents force us to hide our status because of embarrassment. My mother wanted to hide my status from my dad" (Participant 5, Group 3)

Some of the participants further remarked that rejection suffered at home could launch an individual on a path on instability, insecurity, immense distress and some instances suicide.

"Some parents become angry at you because they think you were promiscuous that is why most people think of suicide when they find out their status" (Participant 2, Group 3)

"I was rejected and sworn at by my aunt when she discovered that I was positive. I was hurt but later accepted the rejection" (Participant 9, Group 1)

"I feel that I can't tell my parents about my status, and that my life will be shortened and that I will not be able to reach my goals because they will reject me" (Participant 7, Group 5)

An alternative voice that some parents are accepting and supporting their children when they discover that they are HIV-positive was expressed in the following statements:

"There are other parents whose behaviour towards us is sympathetic. For example, the mother of one of our members was understanding about the HIV and she educated some of us" (Participant 6, Group 4)

"I spoke to a community leader who promised confidentiality and told me about support groups. At least he was supportive" (Participant 4, Group 3)

It was also mentioned that the existential behaviour of "othering" PLWHA within a family has nurtured the negative behaviour of rejection. Some participants reported that HIV-positive people are not welcomed in the community and this has been further reinforced by various distressing experiences of rejection at home, not being treated well at work as well as in the churches and schools. In one group a middle age male appeared to express shame and guilt and felt that they were seen as "others" for being HIV positive. He mentioned that every time when they watch TV and something in HIV came up the brother would say there is your "thing" and switch off the TV. The following statement echoed the existential behaviour of "othering" of HIV person within the family:

"If there is a TV programme on HIV they will often call me and ask me if I have seen my thing" (Participant 3, Group 2)

"They talk about it as if it's something out there and is for certain group of people not them" (Participant 10, Group 1)

One participant indicated that in the clinics there are some health care providers especially those who are the age of their parents who treat them as they own the disease. The following message illustrates the existential behaviour and nurturing of “othering” of HIV youth within the clinic:

“At one clinic the sister in charge mentioned that this is our AIDS. You can see that she is fed up when she saw us and want to behave like our parents since she is old” (Participant 9, Group 2)

3.2 Stigma and discrimination at school and work

Few people mentioned that they felt bad and being dehumanized when they were rejected and discriminated at school as well as in the work place. This negative behaviour of discrimination and its nurturer and barrier at school is shown below:

“At school some of the teachers say we will pass the disease over to others or we will infect other students. They show negative attitudes and this force us to live school if you are known or to be silent if you are not known” (Participant 1, Group 1)

There were also participants who mentioned that they have experienced discrimination at work. Most of the voices reflected that they have lost work because of the unfair treatment from the management due to the fact that they were HIV-positive. This negative behaviour has nurtured a barrier of unemployed to PLWHA:

"I was injured and when I went back they wanted me to start working. I disclosed to the sister in charge and shop steward. They accepted me, especially the shop steward. Given my condition, I have to attend treatment and they said it was okay, In December, the supervisor started making some comments. In January, the management said I didn't have work anymore; there is no more work for me. I noted that the attitude of the sister has also changed. The management said I was always absent when I went away to get treatment. This was obviously not true as I only went for treatment once a month. They thought I wouldn't be productive. I instituted legal action and I am still waiting for that process" (Participant 7, Group3)

"Even the police [she was a police officer] manifest stigma. The treatment I received suggested that they forgot that I am a human. I became fearful and avoided work because of stigma and I was unhappy for being stigmatized and belittled. People can die in the police because of fear and hiding. When medical aid was depleted, I had to leave work because of stigma" (Participant 7, Group 2)

"I would like HIV/AIDS to be openly discussed. My boss said I couldn't work anymore because of my positive status" (Participant 9, Group 3)

"I was asked to go to the clinic and later was asked what my status was. The company management discovered my status and denied me promotion. I was asked to take

leave by management. When I committed one mistake I was fired and I think the reason for being fired was not strong" (Participant 8, Group 2)

3.3 Perceived modes of transmission

Although the mention of HIV transmission was infrequent participants indicated that some people are still ignorant about HIV/AIDS, particularly about modes of transmission. It was postulated that numerous community members have used the supposed risk of transmission to avoid PLWHA. The existential that has nurtured these negative perceptions was shared in the following comments:

"At home there is also a stigmatization because they don't want to share utensils with me. I think in the community there is a fear that a positive person will infect them. Fear and anger are sometimes the problems. Even my friend was scared that I was going to die. Other community members stigmatize positive people because of fear and ignorance" (Participant 2, Group 2)

"*Some people still don't want to share utensils with us for the fear that we will infect them." (Participant 2, Group 4)*

"I had a similar problem when I could not share utensils with my family for fear of infection" (Participant 1, Group 3)

It was further reported that although the majority recognized that the virus was transmitted sexually, they also expressed confusion about modes of infection and echoed many misperceptions about how HIV is contracted.

“They think if you stay in the say room and share blankets and clothes you will infect them. Other friend of mine was moved to stay in a horrible old outside room which was not in good condition for her health using her own things that are not used by other family members scared of being infected” (Participant 1, Group 4)

This negative perception also included the belief that the disease was easily caught by coming to close contact with some one who is infected:

“I found that if you are HIV-positive they do not accept you, it is like you will bring something to them or would infect them” (Participant 3, Group 4)

“Yes a person would not sit with me like this (showing the way we were sitting in a group) due to lack of knowledge because I have this thing” (Participant 6, Group 6)

3.4 Food contamination stigma

There were voices where women mentioned that they felt shame and guilt when they are not allowed to cook or take care of children because of their health status. The existential behaviour that nurtured this negative behaviour and a barrier is illustrated below:

"I found it difficult to disclose my status to my family and friends. When I prepare and dish food my family does not accept the food for the fear that they might be infected" (Participant 3, Group 4)

"I think we are not accepted, for example at home I didn't cook because my family is scared that I will infect them" (Participant 5, Group 3)

Theme 4: Othering of female PLWHA

Culture or tradition, especially African tradition, is seen as another aspect which reinforces inequality of gender relations by justifying male superiority and the subordination of women. Men are assigned by culture to be in control of the sexual aspect of the relationship. They also decide on what would be regarded as normal or deviant behaviour. Female participants reported that they are seen as loose and blamed for spreading illness to their male partners. HIV stigma-related stereotypes add on the pre-existing stigmas in the community and the marginalized group like women in the family and society experience multiple stigmas when they are HIV-positive. The participants mentioned that most of the time women are accused of infecting their male partners. This negative existential behaviour is exemplified below:

"With couples it is often assumed that it's the woman who infected the man" (Participant 8, Group 1)

“Sometimes it happened that the in-laws often think it is the daughter in-law who infected their son” (Participant 2, Group 1)

“One thing I hate is that the person who is visible for being without morals is the woman. With women it would be found to be the one who brings it (HIV), it will not come with the man in the house” (Participant 7, Group 6)

It was reported that most people who go to the clinic for help are women and even if they go together with their partners treatment is administered separately and this could contributes to making the infection appear as if it is a woman’s problem. Furthermore, by women going for treatment, it would be an admission of moral infraction that implies that they contracted the disease through sleeping with somebody other than their partners. Sentiments that express the existential belief of blaming women for infecting men follow:

“So many times I find that most of the people who disclose their status are women. Once a woman has disclosed that she is positive, if it was up to the community, no one should go nearer her ever again. Let us say, that you are positive and you have a boyfriend, it is possible for the people to say to him “do you know that the girl you are in love with is positive”. That is why I say it is so dominant in the community, because once you as a woman have a boyfriend they would want to know if your

boyfriend is aware that you were sleeping around although it is not like that and is not their concern" (Participant 1, Group 4)

Unmarried women also indicated that it is worse when you are young women having children outside marriage or engaged in sex before marriage they associate the illness with promiscuity, careless and materialized lives that result in HIV. This existential belief of blaming women has nurtured more stigmas on women living with HIV/AIDS as compared to men living with HIV/AIDS:

"They often think women are more promiscuous and not men" (Participant 5, Group 6)

"Yes women are treated differently. There is a perception that we are promiscuous, that we infect men. Women are seen on the same way foreigners are seen – as the ones who infect others" (Participant 8, Group 5)

"Women are more stigmatized and insulted more than men" (Participant 1, Group 2)

4.1 Stigma visited upon children of PLWHA

For the participants who were parents, anxiety was expressed about the fate of their children once they are dead. There was also fear that these children may not necessarily be accepted. The enabler nurtures this negative behaviour of not accepting the children of HIV-positive people that there will be no support when they are no longer alive is illustrated below:

“I worry about my child because I ask my self who will support them” (Participant 10, Group 3)

“I thought my family would not accept me. I was surprised when they accepted me. My child died and I am worried who will look after the other one” (Participant 4, Group 3)

They will be also be stigmatized because of the fact that their parents were HIV-infected.

Some PLWHA mentioned that their neighbours do not allow their children to play with their kids.

“The community needs to be educated because even your neighbour chases away your child just because of their positive status, while the child was there to play with the other children, it seems as if the child will infect the other children” (Participant 1, Group 6)

“I worry about what people will think and mostly about my children” (Participant 4, Group 6)

4.2 Labeling PLWHA

It was reported that in Khayelitsha if one is suspected of being HIV-positive or is HIV-positive people give the person names such as Z3, prostitute, won lotto and other negative names. This existential behaviour accounted for most of the stigmatizing behaviours from the community. This prevents people from disclosing, seeking help and going for free HIV testing. Participants mentioned that it is better not know or disclose your status if you know that you are going to be labeled and treated inferior if you are aware of your positive health status. Stigmatizing behaviours reported in this study took various forms include negative and derogatory labeling. This makes the people to be afraid of knowing or disclosing their status others end up not going to seek help from the clinics. The negative behaviour of labeling PLWHA has nurtured silence about the status and barrier to free testing and seeking healthy sexual behaviour.

“ When the community members know your status they are very stigmatizing because you are no longer called by your name but by names such as lotto or 4X4”
(Participant 4, Group 5)

Sometimes they say that you called a thing, they will say “this thing with AIDS” as if you are nothing” (Participant 3, Group 5)

Participants further mentioned that the community devalues them and are given names especially those linked with taboos and they are discriminated because of their

HIV status. Goffman (1963) suggest that a person who possesses characteristics defined as socially undesirable like HIV/AIDS acquire a spoiled identity that then leads to social devaluation and discrimination. These pre-existing negative existential beliefs from community members has nurtured negative family and community beliefs. Negative labeling HIV people exacerbate social division by stereotyping the marginalized group in this study that is PLWHA, as responsible for the illness and its spread.

"Sometimes they say that you called a thing, they will say "this thing with AIDS" as if you are nothing" (Participant 3, Group 5)

"You are called bitch, won lotto or Z4" (Participant 6, Group 5)

Theme 5: HIV and promiscuity

Participants mentioned that other community members felt pity for children who have contracted the disease from their parents and people who got it through helping injured people or being involved in an accident as compared to one who have contracted the disease through sexual intercourse. It was further reported that others do not even think that it could be contracted in other ways than sex because when they see HIV-positive person they conclude that the person was non-normative. By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This existential behaviour nurtures the barrier as such groups are denied access to the services and treatment they need as if they have invited the disease.

"I became worried about community views. Apart from that you are nothing just because to them you were sleeping around that is how people think about you. They start giving you terrible names. You end up not asking help from them because they think you are punished for immoral sexual behaviour practices" (Participant 1, Group 5)

"Where the HIV is bad is when they treat you as if you are nothing and you are the person who sleeps around and now you deserve to be sick. "(Participant 2, Group 6)

Association of HIV with promiscuous behaviour came from the messages that were used in the early 80's as HIV was introduced as the disease of gay men. Some who have very high levels of knowledge about the disease decide not to be identified with HIV people not that they do not know how it is transmitted but do not want to be identified with people are considered to be immoral by the society. They are not willing to give support to people who are infected through sexual behaviour claiming that they deserve to be sick because they believe that God punishes them or have sinned. Participants reflected that this negative existential behaviour is considered the main nurturer of the negative perception of the community that PLWHA are promiscuous and morally deficient.

"I was hurt because it was concluded that I was HIV-positive as a result of being promiscuous. In fact I was infected by my partner who was promiscuous"
(Participant 3, Group 5)

"It is distressing because they think you are promiscuous" (Participant 8, Group 5)

"People think that if you are HIV-positive you are promiscuous and you and your family are then stigmatized" (Participant 2, Group 5)

"People know how infection happens from the radios but they like promiscuity theory that is why they do not talk about other ways a person could get it" (Participant 6, Group 6)

Theme 6: Context of care in clinics

According to Goffman (1963) stigmatized people may suffer disadvantage without experiencing any direct discrimination by avoiding situations that they think will be discriminatory (self-stigmatizing). Santana and Dancy (2002 in Deacon, Stephney and Prosalendis, 2005) acknowledge that stigma can also be internalized leading to self-doubt, lower self-esteem, depression, immuno-suppression and even premature death. These feelings can then be intensified if an individual is subjected to secondary rejection in various social settings such as health care centers. In this study it was mentioned that in clinic M some health workers shouted them in front of other patients or sent them back without any reason. This negative perception has nurtured negative behaviour of negative attitude and barrier of denying access to the services and treatment they need as illustrated below:

“Nurses often displace their anger on us. They lose temper and are very rude to us and others shout at us”. (Participant 1, Group 3)

“We are sometimes abused at clinics because they say that we are demanding” (Participant 9, Group 3)

“There is a problem at clinics. In one of the clinics, the sister- in-charge did not like people who are HIV/AIDS-positive. If there were no counsellors at that clinic, we would struggle. She often sent us back” (Participant 6, Group 2)

“I have not had a bad experience but I have observed the reactions of the medical staff when someone misses hi/her date. That person is sent back without medication and given a new date and this hurts”. (Participant 5, Group 4)

6.1 Formula feeding and HIV-stigma

Secondary stigmatization has occurred in both community and health care settings with the use of formula feeding as the positive people are advised not to breastfeed and are given formula to feed their infants. Participants reported that they were not treated well when they go to fetch the formula that they are entitled to or end up not getting it at all. Some women expressed that they were chased away when they went to collect formula for their children. It was also mentioned that there are health care providers who sell the formula to community members. This negative behaviour of mishandling formula feeding that is supposed to be given to children of PLWHA is indicated by these remarks:

"The government gives milk to children but nurses don't give milk. After one month they say there is no milk and I have discovered that this milk is sold to the community for R12" (Participant 3, Group 3)

"If you got it this month you do not get it next month. You will see them at the townships selling this milk for R12 (participants are all surprised). The government must see to this problem because this milk does not go to people entitled to, they sell it for their own gain not for the benefit of positive children. We buy it from them, in the clinics when you ask for the milk they shout us about our virus". (Participant 4, Group 3)

"The nurses have a problem of not giving people milk" (Participant 5, Group 6)

Participants mentioned that the community members when they see them at the clinic fetching milk associate formula given to them with HIV. It was mentioned that negative perception from community members in the clinic made it difficult for PLWHA to go collect formula especially those who have not yet disclosed their HIV-status. The existential belief which has nurtured this negative behaviour is shown below:

“When community members attending the clinic see you taking the formula they conclude that you are HIV-positive. This is not good especially if you did not disclose your status to them” (Participant 5, Group2)

“Most of the people in the clinics they discriminate you when you receive formula and distance themselves from you because they think that everyone who receive a free formula is positive and they also think that your child is also positive” (Participant 3, Group 4)

6.2 Challenges faced by PLWHA about different colours of stickers on the clinic folders

In some societies laws, rules and policies can increase the stigmatization of PLWHA. Discriminatory practices such as notification of ‘HIV patients” by using different colour of the folder or putting a sticker on the folder furthers the stigmatization of such group as well as creating a false security among individuals who are not considered at high-risk.

It was mentioned that in some clinics patient’s folders had different colours. This enabler exposes their medical condition. They indicated that it is possible for other patients to establish the medical condition of their fellow patients based on the colour of the folder.

“HIV-positive people sit in their own section and this is not acceptable. The colour of our folders is different from other folders. This enables other patients to know our status” (Participant 4, Group 5)

Participants reported negative behaviour of confidentiality bridging by community members within the clinic setting that is a barrier for them to go for help in the clinics. The existential behaviour about boundaries in the clinic has nurtured negative behaviour the restriction of PLWHA’s right to anonymity and confidentiality. Participants acknowledged that if they are seen at certain sides of the clinic/hospital with certain people then the community starts to label them and even spread the gossip in the township that they are positive without proof.

“In Khayelitsha *the X clinic is inside the hospital. Other patients at the clinic can deduce that you are HIV-positive if you sit in certain sections of the clinic. This often leads to such patients telling others in the community that you are HIV-positive based on where they saw you” (Participant 1, Group 1)*

“The issue of different colours for folders is disturbing” (Participant 8, Group 5)

“The other problem in the community is that if your neighbour sees you at X clinic, she tells other neighbours that you are receiving treatment for HIV” (Participant 5, Group 4)

Most of the participants mentioned that they are not treated like other patients because whenever they visit the clinic doctors do not physically examine them whereas other patients are physically examined. According to Herek and Capitanio (1998 in Deacon, Stephney and Prosalendis, 2005) not giving people treatment or physical examination they suppose to get because of their status is stigmatizing them. They felt physically excluded as they were not examined and this enabler discouraged them from seeking help. They mentioned that they feel bad and hurt if they are not offered the resources as if they are going to infect them or drain the resources while others benefit from those resources. It was strongly indicated that this negative behaviour depriving physical examination has nurtured a barrier of not going to seek help from the health care facilities.

"The other problem is that some of the doctors don't do a medical examination if they know that you are HIV-positive. They just give you medication" (Participant 6, Group 4)

"When I went to the clinic I wish the doctor could conduct a physical examination. However, I was given medication on the basis of what I told the doctor, there was no physical examination" (Participant 10, Group 3)

"At X clinic you are seen by the nurses and not doctors. They said I am not too sick and could not give me a nearer follow-up date". (Participant 1, Group 3)

Some participants further argue that it is not all the clinics that are not good. They find some clinics to be good but only the certain sections of the clinic that are not good. Participants highlighted that the problems of being not examined are experienced when they are in the general section of the clinic but the HIV section of the clinic and other integrated sections are taking good care of them. In this sense they prefer the HIV clinic but they mentioned that when their CD-4 counts improves the doctors refer them to the general section.

"At X and M clinics it is okay but the general side is not okay. There are no medical check ups in this section and we are just told that our condition is normal"
(Participant 4, Group 4)
"Sometimes when our CD-4 counts improve we are changed and referred to general clinic side and the treatment there is not nice. At one of the clinics the nurse told me that I have 4 days left. How are you going to feel if someone says this to you".
(Participant 1, Group 1)

"Sometimes you are told that you won't live. Obviously this affects you mentally"
(Participant 9, Group 1)

In some clinics they found the health workers helpless as some PLWHA view the nurses as incompetent. Some participants spoke of being given wrong treatment or incorrect explanations for use. The participants who reported this enabler are those who attend workshops about the treatment and are also members of the organizations that teach the community about HIV treatment so they are well informed. They even request that in future they are willing to have workshops where they could educate both health workers and community members. The negative perception about health care workers competence is explored in the following statements:

“We are given medication without any proper diagnosis. The treatment that we receive for STIs is not good. Nurses and doctors don’t want to attend workshops. My neighbour who is a nurse says that she is not interested in attending those workshops”. (Participant 7, Group 5)

“I agree because I was given wrong treatment” (Participant 5, Group 3)

“Some of the medical team draws your blood without your consent” (Participant 6, Group 5)

Theme 7: Disclosure of HIV client’s status by health care providers

When they were asked about the feeling of the health care workers towards PLWHA and the concern about confidentiality came up. It was indicated that they used to disclose their status on the friends who visit them while they are on duty. Some participants mentioned that they also talk about their status with other clients in the clinic. Lack of confidentiality existential within the clinic is illustrated by the following remarks:

“The other thing that is not good is that the nurses chat about our status to their friends who come to visit them in the clinic.”(Participant 1, Group 1)

“He is right, that happened to me. The counsellor talks to clients about me and I left that area. Another practice that is not good is that after hours she talks about clients’ (Participant 8, Group 1)

Some participants also mentioned that health care workers spread the news about their status even within their neighborhoods. Lack of confidentiality makes it difficult to come for help when it is needed and also discourage testing for HIV if you are not ready to be known by public. Those who mentioned that health care workers gossip about their status also strongly pointed out negative perceptions, and the enabler that the VCT counsellors are also sharing confidential information in places where they socialize and with their colleagues.

“Some counsellors behave unprofessionally. When they see you in the community they show their friends that you are one of their HIV clients”. (Participant 10, Group 1)

7.1 Impact of confidentiality breach by health workers on PLWHA seeking help

It was further postulated that participants tend to be very distressed when these negative labels were used in conflict situations between HIV-positive and HIV-negative community members. For participants who had not yet disclosed their status before these conflicts, it was very distressing for them to learn that community members know their status. Although they were not entirely clear how this happened, one of their possible explanations was the breach of confidentiality by medical personnel. This negative behaviour is a barrier to free VCT and has also nurtured silence about the illness instant of disclosing and going for necessary help in the clinics.

"A community member claimed to know my status and she said a health worker informed her. There are nearly 10 nurses who behave in this way in the neighbourhood that is why people do not trust them and don't test". (Participant 8, Group 2)

"A friend of mine was in conflict with her neighbour and she shouted her about her HIV status and we discovered sometimelater that the information was heard from the counsellor who stays nearby and this hurts and makes you regret knowing your status". (Participant 4, Group 3)

This perception is indeed worrisome. This is particularly disconcerting because of some of the negative experiences some participants had with some medical personnel. PLWHA encounter problems when they go to educate and disclose their status as part of the health education section in the clinics where they volunteer because the health care workers are also stigmatizing and do not take HIV as their own problem. Some participants who volunteer in clinics felt that they were rejected, isolated and discriminated at some of the health care services in such a way that they end up not disclosing HIV status when they educate other patients. The participant remarks one of the enabler:

"In one of the clinics we did volunteer work; nurses did not like to share their tea cups with us" (Participant 3, Group 4)

Theme 8: Challenges faced by PLWHA about staff shortage in clinics

There are clinics which were perceived as best clinics in treating PLWHA it was also indicated that since the number of infected people increase it is difficult for the staff working there to deal with everyone. The shortage of doctors was a pervasive voice as this enabler was reported in all the six groups and participants mentioned that they had to wake up at four in the morning for the facilities that opens at 19h00 and sometimes they were sent back home without being attended because of the large numbers of people in that facility.

"We go to the clinics at four in the morning and are seen at about three in the afternoon and sometimes sent back home not seen at all". (Participant 1, Group 3)

"Both HIV section and other sections need more doctors because they are all under staffed there are lot of people with one or two doctors only".(Participant 7, Group 3)

It was also mentioned that in some clinics nurses will have long conversations on phones or with their friends during working hours and this negative behaviour nurtured exasperation from the clients. It was mentioned that this makes them to wait long before they could be seen. This existential behaviour also nurtured a barrier on treatment adherence because they claim that they have to stay in the clinics the whole day with empty stomachs and could not follow the pattern of taking their pills.

"The nurses at X clinic have private conversations that are too long during working hours" (Participant 1, Group 3)

"I think it will be better if we are seen by positive staff in the clinics because the staff does not care about us. We wait for ever to be seen with empty stomach and end up not taking treatment for the day and it is worse when you are chased away because the next day you have to come and stay the day without treatment so how are you going to adhere with your treatment" (Participant 6, Group 4)

"Some nurses arrive at 07:00 and the gates are still closed they go and chat not considering that we were there from 04:00 in the morning and when we ask them to open the gates they often display their anger on us. They loose temper and are very rude and we know that they work under pressure" (Participant 1, Group 3)

8.1 Positive perceptions about health care workers

Alternative views expressed positive perceptions that some health care workers are helpful and they keep confidentiality. The clinics that were reported as good clinics are those who have support groups and other programmes for LWHA. There were also few clinics inside and outside the area which were mentioned as having care of PLWHA.

“Our counsellor was very helpful and supportive. We did some training and she is helpful” (Participant 6, Group 2)
“The people from clinic X were also very helpful and supportive” (Participant 10, Group 2)

“We did never have any problems at the clinics” (Participant 5, Group 6)

It was also mentioned that information and support groups are the existential which have nurtured this positive behaviour within the clinics. In this regard the clinics with support were indicated to be more supportive and support groups per se were perceived welcoming, informative and supportive to PLWHA.

“We feel happy when we attend the support group. This is because we get food and are not afraid to share cups. It is okay because we get support. In some hospitals you are treated well and some health personnel offer good treatment” (Participant 7, Group 4)

"The support group is helpful. The leader of the groups also visits us at home" (Participant 3, Group 4)

"Some people still don't want to share utensils with us for fear that we will infect them. We are able to deal with some of these issues in support groups and receive counselling" (Participant 2, Group 3)

8.2 Brief summary of the results

HIV-related stigma and discrimination remains an enormous barrier to effectively fighting the HIV and AIDS epidemic. PLWHA in Khayelitsha perceived and experienced stigma related to HIV differently. Fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status publicly. Some are coping with the illness and are open about their status. In this case education and information from support groups has been found as an existential behaviour and enabler which need to be encouraged.

It is clearly elaborated that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. The diseases is associated with repression, discrimination, as well as individual's living with HIV has been rejected by their families and by the community as whole. The families, friends, loved ones and the community as a whole evict some PLWHA from their homes. In some cases, they are turned away from health care services, not given formula feeding, suffer from breach of confidentiality about their HIV status, and health care providers who are in short supply often hold negative attitudes, and are at times seen as incompetent.

There is also evidence that women and youth are more likely to be badly treated and rejected within a family. Some PLWHA find their families, health care services and neighbours to be supportive. It is also explored in this study that in Khayelitsha people still believe that casual contact, sharing utensils or being in the same room with a person living with HIV could put you at risk for HIV infection. Although there is not much reported on HIV transmission in the workplace the supposed risk of transmission has been used by numerous employers to terminate or refuse employment. It was also evidence that if PLWHA are open about their HIV status at work or at school they may well experience stigmatization and discrimination by others.

The different beliefs and practices related to perceptions, enablers, and nurturers are explored and have been categorized into positive, existential and negative beliefs. Stigma is found to be a powerful tool to social exclusion. We need programmes that will confront the fear based messages and negative social attitudes in order to reduce the discrimination and stigma of PLWHA in Khayelitsha. The PEN-3 model will be used to determine whether the emphasis will be on the person, the extended family, or the neighborhood when planning intervention to decrease HIV stigma. The following chapter provides recommendations and conclusion.

Chapter 6

Conclussion

This chapter provides a summary of the major findings of this study discussed in the previous chapters explores the study's limitations and offers recommendations for future research.

6.1 Summary Of Research Findings

The purpose of the study was to investigate both the nature and the impact of the stigma surrounding HIV/AIDS that is experienced by PLWHA in Khayelitsha Township in Cape Town, South Africa. Six focus groups were conducted with PLWHA of whom three were mixed gender groups and three were composed of only women. The findings indicated that PLWHA are affected by the stigma attached to HIV/AIDS in various ways.

Firstly, most of the participants perceived HIV as akin to death due to the large exposure to funerals related to HIV/AIDS. What is worrisome here is that the people who have died are mostly of their age group and this negative perception has provoked the idea that they are also going to die soon. STDs are well known for triggering negative responses and reactions. According to Evian (1991), it is acknowledged that others think that AIDS is a plague sent by God to destroy the sexual immorality that has overcome people. Together with a series of messages that were used at the beginning of the pandemic that HIV/AIDS is a killer, punishment for immoral behaviors and belief that HIV/AIDS is shameful there is enough evidence that these existential beliefs have nurtured this negative behavior of associating HIV with death.

On the other hand, some participants perceive HIV similarly to other stigmatized diseases. Those who see it in this way tend to be well informed about HIV and its progression in different stages. It was found that this view helped PLWHA's to cope with the illness as compared to those who lack the bio-medical knowledge about HIV and AIDS. Evian (1991) mentioned that for one to understand the nature of the HIV/AIDS disease, it is vital to distinguish between two important concepts, namely, HIV and AIDS.

Some PLWHA in the focus groups participants indicated that AIDS is perceived to be more immoral unlike other terminal illnesses due to the way it is contracted through sex. It was indicated that although there are other ways of contracting HIV sex is the most commonly mentioned mode of transmission, especially when people want to excuse themselves from taking care of HIV-positive people. Van Vuuren (1997) indicated that AIDS is seen as a disease far more contagious than it really is because it is regarded as a divine retribution for certain aberrant lifestyles. It is found that this has a negative impact on PLWHA as it prohibit health status disclosure, prevent seeking healthy health behaviours and free HIV testing, makes PLWHA to feel guilty, angry and hopeless.

In addition, Herek and Glunt (1988) argued that HIV/AIDS is highly stigmatized because it is a disease that is perceived as the bearer's responsibility because the primary modes of transmission of the infection are behaviours that are considered to be of choice. The distinction between innocent and guilty PLWHA is underpinned by strong emphasis upon the association between lifestyle choices and health states that has emerged in medical and public health discourses over the past few decades.

Some participants reported a positive perception that they have accepted their HIV status. In this case education is found to be the enabler that has nurtured the positive process of accepting their HIV status and has encouraged them to disclose their status.

Generally it was found that people are aware of HIV/AIDS but may lack completely accurate knowledge of HIV/AIDS.

Several negative perceptions were strongly reported in the focus group discussions. These show that the community rejects, discriminates and stigmatizes PLWHA. Furthermore, some PLWHA were physically abused after they disclosed their HIV status. Lack of medical knowledge about HIV is considered to be what has nurtured this negative behaviour. Herek & Glunt (1988) postulated that the AIDS epidemic has been accompanied by intensively public reactions to persons presumed to be infected by HIV. Several studies echoed that the HIV pandemic has evoked a wide range of reactions from individuals, communities and even nations, from sympathy and caring to silence, denial, fear, anger and violence (Brandt, 1988; Brown, Chase & Aggleton, 2003).

Importantly, some participants have said that the community had made a positive impact in their lives. Participants mentioned that people who are members of support groups and other organizations dealing with HIV are very supportive to PLWHA and that they refer them to places where they could be attended if they are not able to help them themselves. It was also found that most of the PLWHA who are members of support groups are coping with HIV status and are open about their HIV status.

Furthermore, it came up in these results that food was used as measure of acceptance or rejection as members of the community who accept PLWHA were mentioned to be those who were offering food to PLWHA so that they could adhere with their treatment and also remain healthy. This motivates PLWHA to be open about their status and to adhere to their treatment.

Many youth spoke about their parents not accepting their HIV status, as well as associating their HIV status with promiscuity, claiming that they are an embarrassment, and chasing them away from their homes. Ignoring the existence of HIV/AIDS and neglecting to respond to the needs of those living with HIV infection are some of the forms of denial. This has nurtured negative behaviour of not disclosing their HIV status at all. According to Lee, Macintyre and Sikkema (2003) stigmatized individuals are vulnerable to feelings of self-hatred which can result when they internalize society's negative views of them. Moreover, internalized stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others which negatively affect disclosure.

An alternative experience among youth was that some parents are accepting and supportive to their children when they discover that they are HIV-positive.

PLWHA in Khayelitsha find themselves stigmatized and discriminated against within the home. Some people mentioned that they felt bad and dehumanized when they were rejected and discriminated against at school as well as in the work place.

Participants mentioned that they had lost their jobs because of discrimination at work and others were denied promotion because of their HIV status.

Some participants reported that numerous community members have used the supposed risk of transmission to avoid PLWHA. It was found that people who express stigmatizing attitudes about HIV often have retained misinformation about the transmission of HIV. It was reported that in Khayelitsha there are people who still believe that HIV can be transmitted by casual contact. This belief has enabled a negative behaviour of isolating PLWHA.

Women also mentioned that they are treated as “others” and not allowed to cook or take care of children because of their health status. It was also reported that HIV-infected women are treated differently from HIV-infected men. The participants mentioned that most of the time women are accused of infecting their male partners. Men are likely to be excused for their behaviour that resulted in their infection, whereas women are not. In this regard, culture, especially that based on African tradition enables inequality of genders and justifies male superiority over and the subordination of women. According to the report of the Department of Health (2002) in South Africa, it appears that women who are infected are stigmatized more than men (in Policy Report, 2003a).

In addition, unmarried women indicate that the stigma is worse when you are young women having children outside marriage or engaged in sex before marriage, as people associate the illness with promiscuity. These women also showed concern about their children as they mentioned that their children will be stigmatized because of the fact that their parents were HIV-infected.

It was reported that in Khayelitsha if one is suspected of being HIV-positive people in the community will give that person names such as Z3, prostitute, lotto winner and other “negative” labels. Some participants mentioned that community members associate HIV with promiscuous behaviours and do not even think that it could be contracted in other ways than sex because when they see HIV-positive person they conclude that the person was non-normative. This negative behaviour is nurtured by existential belief that HIV is a gay plague, punishment from God and these inaccurate explanations has provided a powerful basis for both stigma and discrimination. These stereotypes enable some people to deny that they personally are likely to be infected or affected.

Various perceptions of the attitudes that health care providers have towards PLWHA were reported. Some people reported that PLWHA are stigmatized and discriminated against by health care providers. Some say that they were shouted in front of other patients and sometimes sent home without reasons. Marshall (2002, in Policy Report, 2003a) describes enacted stigma and discrimination as a collective dislike of what is unlike. It is further postulated that enacted stigma is usually intentional, although people are not always aware that their attitudes and actions are stigmatizing.

Others reported that the formula feeding which is entitled to them was not easily accessed because there are health care providers that are selling it in the community to get money.

It was also indicated that in some clinics their folders are having stickers on them that expose their medical condition.

They also indicated that some doctors do not physically examine them on visits whereas they examine other patients. These negative behaviours prevent them from wanting to seek help in clinics.

There were also remarks about the incompetence of health care providers as PLWHA were reporting that they were given wrong medications or wrong instructions to follow when they were given treatment.

Furthermore, it was mentioned that some health care providers and counselors disclosed their HIV status in the community and with their friends without their consent. This negative behaviour is a barrier preventing people from coming to the clinics for free HIV testing.

It was further indicated that there is staff shortage in most of the clinics. This enabler is reported as the nurturer of negative behaviour sending them back home without being seen and also the fact that they have to be in the clinics early in the mornings and come back late.

Alternative views expressed positive perceptions that some health care workers are helpful and that they keep patient confidentiality. Clinics with support groups were mentioned to be more supportive and welcoming to PLWHA than those without. Education and support groups were reported as the existential behaviours which have nurtured this positive behaviour.

6.2 Limitations Of The Study

A major limitation of this study is that we did not manage to get male-only groups of PLWHA where they could explore their feelings. While the male participants reported that they were comfortable to be in mixed groups, the researcher felt that it would have been much better if they were given their space as in Xhosa culture since there are issues, including sexual ones that males do not share easily with women. Secondly, looking at the area a big as Khayelitsha it will be impossible to say that our sample represents PLWHA in the whole of Khayelitsha although the researcher attempted to get people from different areas within Khayelitsha. Therefore, the findings are not be generalizable to all PLWHA in Khayelitsha.

6.3 Recommendations For Future Research And Intervention

Several findings in this study have indicated that HIV is akin to death, incurable, and could lead to discrimination. People who are well informed about HIV respond differently to HIV than those who are not well-informed. An educational programme could be effective in changing negative behaviour about the illness. Airhihenbuwa (1995) argue that people who are empowered about their health through knowledge are more likely to make appropriate decisions about their health. He further argues that health education is committed to health of all. In this sense the individual should be empowered to make informed health decisions appropriate to their roles in their families. PLWHA in this regard need to be empowered by health education so that they are able to challenge the perceived association of HIV with death. Programmes that were used to decrease stigma associated with other terminal illnesses like TB and Leprosy should be revisited and be re-evaluated so that they could be used to target this problem. According to Airhihenbuwa (1995), evaluating existing intervention programmes would help not to repeat the same projects. This would also help to identify the projects that work in the area.

There was evidence that fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status in public. Messages which were used to introduce this pandemic at the beginning are reported to be the factor that fuelled existential beliefs which are now a barrier to HIV prevention. These are introduction of HIV and AIDS as the gay plague, association of HIV/AIDS with promiscuity and also by perceiving HIV and AIDS as a punishment for immoral behaviours. This is placing an emotional burden on PLWHA and those affected by the HIV/AIDS. Support groups would be appropriate and effective channel for changing these perceptions and behaviours. Since these are long-term cultural beliefs home visits and one-to one contacts in the community can address this problem. Arhihenbuwa (1995) argues that involvement of community members and their leaders becomes critical in the provision of culturally appropriate health programmes. It is further postulated that it is important for them to define what constitutes their community or neighbourhood at the beginning of a project.

Lack of medical knowledge about the progression of HIV in different stages and misinformation about HIV contraction were also indicated in this study. Perceiving HIV as AIDS and assuming that HIV could be contracted through casual contact could hinder personal, family and community motivation to change. The mass media, posters, flyers, radio and television messages would be the effective channels for increasing knowledge, reinforcing previous held attitudes and changing behaviours that were recently established because they are not tied to cultural beliefs.

The results also indicate health service problems with respect to adequately supporting PLWHAs including: incompetence of health care workers, staff shortage, the withholding of formula feeding, and HIV testing without consent. These enablers could be a barrier to change and has impact on non-compliance with treatment or coming for testing in the clinics. PLWHA need to be educated so that they are able to challenge the availability of services, accessibility, assert their rights as patients and government officials and skills and types of services they are entitled to. Institutions and other monitoring mechanisms can enforce the rights of PLWHA and provide powerful means of mitigating the effects of discrimination and stigma. These institutions need to include the community members when combating HIV/AIDS-related stigma and discrimination because the rationale behind stated beliefs and practices should be well understood.

People also reported that health care workers shout at them in front of other patients, they are not physically examined and they are treated as others in “others” within the clinics. These enablers have nurtured PLWHA not to seek help in the clinics and have prevented people from coming for free HIV testing. It will be important to increase the number health workers that are trained to understand and respect PLWHA. According to airhihenbuwa (1995) PEN-3 model, it will also be important to have workshops that will empower with knowledge those who are not trained at this area. There were alternative voices that some health care workers are helpful and they keep confidentiality. It will be more important to look at what worked and did not work in the clinics that are mentioned to be treating PLWHA with dignity. Airhihenbuwa (1995) acknowledged that health education programmes involve health beliefs and behaviours. Therefore, these programmes must reflect the cultural perspectives of the people for who they are designed.

6.4 Future Research

Although the explorative nature of the research does not allow findings to be generalized, it would be interesting to find out about the experiences of families having HIV-positive members and also the experiences of health care workers dealing with HIV-positive people about the stigma related to HIV/AIDS. This will give us broader knowledge on experiences of people about stigma related to HIV/AIDS so as to inform the development of intervention programmes.

6.5 Conclusion

It is evident from these findings that stigma impacts PLWHA and prevents them from seeking preventive and treatment services. Stigma enables people to believe that they are not at risk for HIV "HIV/AIDS is someone else's problem". Some cultures have value systems that may conflict with some components of HIV prevention. Stigma needs to be addressed at the community level in order to minimize its impact on HIV prevention services. Rejecting cultural values will not solve the problem there is a need to challenge cultural norms by encouraging positive culturally-appropriate messages about HIV. The development of stigma reduction programmes will promote non-stigmatizing responses to PLWHA.

PLWHA who internalize community negative views about what is moral and immoral become vulnerable to feelings of self hatred, guilt and distress. Similarly, PLWHA who internalize stigma associated with their disease and associate HIV with death hold negative view of HIV disease and themselves. This is likely to negatively affect their mental health and their ability to effectively manage their HIV disease. There is a need to decrease the stigma related to HIV/AIDS and promote a climate of tolerance and empathy within community members regardless of their health status. This is even more essential to ameliorate internalized among PLWHA themselves.

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Appendix A

Interview Guide

1. What are your views about HIV/AIDS?

    a. What do you think influenced you to hold these views?
    b. Is your views shared by others in the community?
    c. What are some positive things in your community that is supportive of PLWHA?
    d. What are some negative things in your community that is against PLWHA?
    e. How about at Health care facilities?

2. What are specific behaviours by Nurses, Physicians, and other Health Care Providers?

    a. Are woman LWHA treated differently?
    b. How about men LWHA? Are they different?

3. To what extent would you say Health Care Personnel have considered factors like gender when treating or advising you?

    a. Are there other factors – other than gender?
    b. Is there a health care facility that you would consider to be more friendly and humane toward PLWHA in this community?
    c. Outside the community?

4. How do you think health care providers feel toward PLWHA?

    a. What are some positive or negative feelings?
    b. What should be done to remove the negative discrimination against PLWHA?
    c. What should the community do to remove discrimination against PLWHA?

5. Are there any additional comments that you wish to make before we complete the discussion?