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Exploring psychologists' perceptions of the relationship between HIV-related stigma and the self-esteem.

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2010-06-21T09:33:18Z
http://hdl.handle.net/10539/8182

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CHAPTER 1: INTRODUCTION

BRIEF OVERVIEW AND RATIONALLE

Stigmatisation of people with HIV and AIDS has been investigated in numerous studies. However, little research has been done to explore the impact of these individuals' experience of HIV-related stigma on their self-esteem. The aim of this study therefore was to do a qualitative investigation on psychologists' views on the self-esteem of people living with HIV and AIDS exposed to HIV-related stigma.

UNAIDS in their 2007 report indicated that Southern Africa is the country most seriously affected by HIV and AIDS in the world (UNAIDS & WHO, 2007). Thirty-five percent of people infected globally with HIV and AIDS are in South Africa. South Africa also accounts for 32% of all new infections. HIV is therefore an issue that cannot be ignored in South Africa. These statistics provide an indication of the number of people infected with HIV and AIDS that may be in need of care. The HIV pandemic in South Africa cannot be separated from contextual factors that enable the pandemic to grow. Conversely it also significantly influences the psychosocial circumstances within the South African context (van der Walt, Bowman, Frank & Langa, 2007). One of the factors associated with HIV and AIDS that has a negative impact on the psychosocial circumstances of South Africa is HIV-related stigma (Campbell, 2004).

The severity of stigma that people with HIV and AIDS encounter is profound and is evident in several research reports (Herek & Capitanio, 1993; Herek, Capitanio & Widaman, 2002; Deacon, Stephney & Prosalendis, 2005; Kalichman et al., 2005; UNAIDS, 2007). People respond differently to these stigmatising experiences which creates a challenge for managing its effects on society (Green & Sobo, 2000). Stigma therefore continues to play an important role in the management of the AIDS pandemic, not only because of its effect on the prevention of HIV but also because of the manner it impacts already infected individuals (AIDS Action, 2001; Kalichman et al., 2005) Studies on HIV report that stigmatisation may threaten the identity of individuals or groups and lead to loss of self-esteem of those infected (Visser, Kershaw, Makin, Forsyth, 2008). Existing interventions and research, however, seems to be more focused on the stigmatiser than the stigmatised (Deacon et al., 2005). In other words too much attention is being directed at causes of HIV-related stigma, resulting in the effect it may have on aspects such as the self-esteem of the victim being neglected (Deacon et al., 2005).

The general importance of self-esteem has been recognised through the works of leading authors and academics such as Rogers, Rosenberg and James (Katz, 1998). A review of literature shows studies in which measures of the impact of HIV-related stigma revealed an impact on the self-esteem (Deacon et al., 2005; UNAIDS, 2007). However all the studies mentioned used quantitative research as a method, highlighting the need for qualitative inquiry into the impact HIV-related stigma may have on the self-esteem of people living with HIV and AIDS.

Rogers (1950 & 1961) conducted extensive studies on self-esteem with clients he consulted with over a number of sessions. He found that the self esteem is best understood through a collective view of clients' reflections over time. Based on these postulations the researcher believed that psychologists who have had numerous consultations with clients that have been diagnosed HIV positive would provide a detailed account of the self esteem of people living with HIV and AIDS.

STRUCTURE OF THE RESEARCH REPORT

Chapter 2 is a review of the literature that informed this study. Here the alarming nature and impact of HIV and AIDS on a global level but more specifically on a national level (either or) is provided. The literature review also gives an indication of what the concept stigma entails and how it impacts on the self-esteem. A description of stigma in relation to Goffman (1963) is provided alongside the notion of stigma as a social process postulated by Parker and Aggleton (2003) and Deacon et al. (2005). This is followed by a description of the self-esteem. The self-esteem is depicted by providing accounts of what is perceived as personal identity as well as self-esteem and the collective identity. Self-esteem as a personal identity is primarily informed by Albert Bandura's (1986 & 1989) concept of social cognition; whereas self-esteem as a collective identity is primarily informed by Luhtanen and Crocker's (1992) proposed four-dimensional model of collective identity, referred to as collective self-esteem (CSE). These provided insight to the explanation of the impact of stigma on the self-esteem.

Chapter 3 provides a synopsis of the methods employed to conduct this research by providing an account for the research design. A description of the participants interviewed is also given, followed by an account of the procedure for data collection. The steps employed for the data analysis is also outlined and finally a reflection on the ethical procedures accounted for during the research process is discussed.

Chapter 4 provides the major findings of this research. Three major themes supported by sub and sub-sub themes are presented in this chapter.

Chapter 5 provides a discussion of the most salient themes in the findings. A reflection of the strengths and limitations of the study is also provided in this chapter. This is followed by a discussion of the areas highlighted for future research and finally some closing comments are presented.

CONCLUSION

The above chapter introduced this research paper by outlining the underlying principles that informed this study. This was done by providing a brief statistical overview of HIV and AIDS both globally and in South Africa. Furthermore it was highlighted that not only do these statistics create concern with regards to the HIV infection and mortality rates in South Africa, but that the contextual factors that enable the growth of this pandemic associated with these statistics cannot be viewed separately from this. One of these factors, which has negatively influenced the psychosocial circumstances of those living with HIV and AIDS in South Africa, is HIV-related stigma. It has been proven that HIV-related stigma can have detrimental effects on the self evaluation of those who are infected with HIV. This study therefore focused on the manner in which HIV-related stigma may influence the self esteem of stigmatised individuals who is infected with HIV. Finally an overview was provided of the structure of this research report.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

This chapter is a presentation of previous research that was explored to inform this study. A profile of HIV and AIDS sets stage in illustrating the number of people infected with HIV and AIDS. It particularly illustrates the number of people that could be subjected to the sufferings of an HIV diagnosis, particularly suffering brought about through HIV-related stigma. This profile is representative of the global, African and national infection rates. Next, important aspects around the concept of stigma are discussed as it is important to understand stigma in relation to its broader social, political and cultural context (Deacon et al., 2005). However, it is essential to first clarify how stigma can be defined, how it arises and its operating mechanisms. As a point of departure a discussion of the definition of stigma is provided in order to structure the conceptualisation of this phenomenon. This discussion has been initiated by the work of Ervin Goffman (1963). Early studies in this area drawing on stigma from this perspective have encouraged individualised analyses of this concept (Deacon et al., 2005; Herek, Capitanio, & Widaman, 2002 and Parker & Aggleton, 2003). Drawing on research from Parker and Aggleton (2003), a more detailed understanding of stigmatization as it functions in the context of HIV and AIDS indicates the need to also understand stigma as a social process, specifically in relation to social inequality. Deacon et al., (2005) agrees with this notion of stigma as a social process, but further adds that although the process of stigmatisation facilitates the process of social inequality, social inequality too contributes to the spread of stigmatisation, especially against those who are HIV positive.

Following the definition of stigma, the different manifestations of HIV-related stigma within a social context, the family, the workplace and the health sector have been outlined. The outline of the manifestations of HIV-related stigma provides an indication of sectors within society where HIV-related stigma is most prevalent. Similar to the process of defining and explaining stigma an understanding of the self-esteem has been provided. This understanding has been presented from the perspectives of self-esteem as a personal identity as well as a collective identity. This follows a reflection on the impact stigma may have on the self-esteem of individuals who are HIV positive which was informed by the conceptualisation of stigma and the development and role of the self-esteem previously explained. The chapter will be summarised in the conclusion paragraph.

PROFILING HIV AND AIDS

Southern Africa is the country most seriously affected by HIV and AIDS in the world (UNAIDS & WHO, 2007). According the December 2007 global AIDS epidemic update, South Africa accounts for 35% of all people living with HIV and almost one third (32%) of all new HIV infections and AIDS deaths in the world (UNAIDS & WHO, 2007). Reports from the Department of Health National HIV and Syphilis Sero-Prevalence Survey in South Africa revealed that 29, 1% of pregnant women were living with HIV in 2006 (Department of Health, 2006). Furthermore, the report of the South African National HIV Prevalence HIV Incidence, Behaviour and Communication Survey estimate that 10,8% of all South African's over the age of two years were living with HIV in 2005 (Shisana, et al., 2005). The highest prevalence rates were in the 20 to 35 year age group and among those aged 15 to 49 years old. (Department of Health, 2006). Provincially, the estimates indicate that in KwaZulu-Natal (40%), Gauteng (35%) and the Free State (33%), approximately one in every three pregnant women are HIV-positive. Comparatively, the Western Cape (15%) and Limpopo (19%) provinces have low HIV-prevalence rates among pregnant women (Department of Health, 2006).

Comparing these statistics to statistics provided by the UNAIDS (1998), South Arica ranked fifth in the adult prevalence rate, with Botswana comprising the highest HIV prevalence rate at the time. Over the 16 years since the introduction of this survey in 1990, the prevalence amongst antenatal attendees has increased from less than 1% in 1990 to about 30% in 2005, showing a very rapid rise of the HIV-infection rate amongst women of child-bearing age.

HIV is a medical condition as well as a psychosocial issue. In order to conceptualise the demographical and psychosocial progression of the disease it is therefore important to understand how the disease progresses medically as will be outlined below.

HIV (Human Immunodeficiency Virus) is a 'Retrovirus', which consists of, amongst others, retroviruses consisting of Ribonucleic Acid (RNA). These contain a special viral enzyme called Reverse Transcriptase, which allows the virus to convert its RNA to DNA and then integrate, and take over a cell's own genetic material. HIV replicates in and kills the helper T cells, which are the body's main defences against illness (Van Dyk, 2001). Infection occurs when the virus particles enter the body and attaches itself to the CD4 cells and microphages which are immune cells. Once the virus has attached itself to the cells surface it penetrates the wall, which protects it from the body's immune system and therefore cannot be destroyed by the body's defence mechanisms (Whiteside & Sunter, 2000). Following the

window period, when the virus cannot be detected due to the HIV antibodies (what is tested for when testing for HIV) being unidentifiable the body goes into an incubation period. During this period a battle commences between the virus and the body's immune system whereby the virus and cells from the immune system destroy each other. Eventually, the virus is able to destroy the immune system more quickly than it can be replaced, which causes the CD4 count to fall. With the decline of CD4 cells, opportunistic infections begin to occur (Whiteside & Sunter, 2000). The HIV therefore reaches an advanced stage often referred to as Acquired Immune Deficiency Syndrome (AIDS). AIDS is characterised by the appearance of the opportunistic infections. These are infections that take advantage of a weakened immune system (Van Dyk, 2001).

The above provides a statistical as well as a medical account of the severity of the HIV and AIDS pandemic. The statistical analysis is based on global research as well as research conducted within South Africa. Due to the prevalence of HIV, it is important that stigma not be underestimated. The change in statistics indicate there is no generic solution because of the diversity in cultures or social and political context, which is what will be explored in chapters below. The next section looks particularly at the concept of stigma and the impact it has on people and their social settings.

CONCEPTUALISING HIV-RELATED STIGMA

A lack of common ground has been identified in the literature when defining stigma (Deacon et al., 2005). Disputes have been around focusing on stigma from an individual level in relation to the social dimension of stigma (Deacon et al., 2005 & Parker and Aggleton, 2003). Furthermore, the notion of stigma is often used synonymously with that of discrimination (POLICY Project, Centre for the Study of AIDS, USAID & Department of Health, 2003b). Discrimination, however, refers to behaviour, whereas stigma is defined as an attribute or quality. In other words, when people act on their prejudice, stigma turns into discrimination. Discrimination can be defined as any action or measure that results in someone being treated unfairly because they belong or are perceived to belong, to a particular group, for e.g. a gay man being discriminated against because of his sexual orientation (UNAIDS, 2002).

The attachment of discrimination to illness has a long history, impacting on people with mental illness and physical disorders such as cancer, Tuberculosis (TB), Sexually Transmitted Diseases (STD's) and leprosy (Skinner & Mfecane, 2004). According to Deacon et al. (2005) biology is an important aspect in understanding variations in the strength and

content of stigma towards a disease. In the same way as the pandemic or disease changes through the various biological stages, so too can stigmatisation as a result of the pandemic or disease change. This is particularly true for a condition such as HIV and AIDS (Alonzo and Reynolds, 1995) as it progresses through different phases, which can evoke different levels of stigma at each phase. These changes can affect how stigma is experienced by individuals living with HIV and AIDS. Considering the four stages of HIV, Alonzo and Reynolds (1995) splits the variation in the experience of stigmatisation into four phases. The first phase is the phase of being at risk: pre-stigma and the worried well. Phase two relates to the diagnosis: confronting an altered identity. Phase three is described as the latent phase: living between illness and health and phase four is the manifest phase: passage to social and physical death.

Literature contending around the nature of stigma, particularly HIV-related stigma has predominantly been informed by the work by Ervin Goffman (1963) and therefore contributes to the theoretical underpinnings for much of the literature on stigma (Parker & Aggleton, 2003). Goffman (1963), described stigma as a significantly discrediting attribute, which reduces the person who possesses the attribute in the eyes of society. He categorised stigma into three significant themes. The first categorisation is termed “Abominations of the body” which relate to various physical deformities. The second theme is called “Blemishes of individual character” which relates to people with a weak will, to have unnatural passions or to be dishonest. Lastly Goffman (1963) refers to “Tribal stigma of race, nation, and religion” or stigma relating to race, nation or religion or membership of a discredited social group.

Goffman’s (1963) definition of stigma as a “discrediting attribute” has provided focus and insight to stigma as an individual attribute, in other words, a relatively static characteristic. However, there is another angle from which Goffman’s concept of stigma can be understood. Link and Phellan (2001) and Parker and Aggleton (2003) postulate that Goffman’s work also involves social aspects of stigmatisation, which can be devaluing to relationships rather than being a fixed attribute. For example, Goffman (1963) pointed out that individual attributes can be stigmatising to the associates of such an individual, a process referred to as secondary stigmatisation (Angermeyer , Schulze and Dietrich, 2003).

According to Link and Phelan (2001) stigma can be separated into three mechanisms. Firstly stigma can occur at a person-to-person level, referred to as direct discrimination. This includes activities that devalue, reject, exclude or blame the other person. Structural discrimination is a second mechanism whereby social contexts enforce stigma without person-to-person actions. An example would be a place of social interaction where the occupants are believed to be HIV positive, which enforce stigma without person-to-person

actions. The third mechanism is self-stigmatisation, a process that operates through the stigmatised person. This mechanism indicates that stigmatised persons apply labels to themselves, that they believe in these labels, and therefore live accordingly. This kind of stigma people apply to themselves is also known as internal stigma (POLICY Project et al., 2003b).

Internal stigma is distinguished from external stigma, otherwise referred to as enacted stigma. External stigma (enacted stigma) refers to the actual experience of discrimination. This may include, amongst others, experiencing social isolation, social inequality, oppression, categorising, anger, and exclusion. Internal stigma relates to the felt or imagined stigma. This is the shame linked with a discredible phenomenon, such as HIV and AIDS, and the fear of being discriminated against. The latter often causes reluctance to disclose. Activities associated with external stigma as identified by POLICY Project et al. (2003b) include: avoidance, rejection, moral judgment, unwillingness to invest in persons living with HIV and AIDS and abuse. Internal stigma may be chosen as a coping mechanism to protect oneself from enacted stigma (POLICY Project et al., 2003b). Distinguishing between internal and external stigma is necessary as it allows us to refrain from merely defining stigma in terms of discrimination. In other words, according to Deacon et al. (2005) it is important to be mindful that stigma may occur without the presence of discrimination. This occurs through the process of internalised stigma, whereby the person may experience stigma based on his or her personal beliefs about a specific attribute they may possess, whether enacted upon by society or not.

Herek et al. (1998) defines HIV-related stigma as discounting and discrediting behaviour directed at people perceived to have HIV or AIDS and the individuals, groups, and communities with which they are associated. This definition has been selected as it incorporates the multiple stigma expressions from an individual as well as a social perspective. On a social or community level stigma and discrimination are processes that can be reinforcing of power relations, devaluing the victimised individual or group (Holzemer & Uys, 2004). This is because stigma creates difference and social hierarchy which in turn legitimizes and perpetuates social inequality (Parker &Aggleton, 2003). Some groups therefore feel devalued whereas others feel superior through the acts of discrimination. According to Parker and Aggleton (2003) stigma is therefore ultimately linked to the workings of social inequality. Link and Phellan's (2001) model is in agreement to this as it describes stigma in terms of status loss.

Deacon et al. (2005), however, is of the view that Link and Phellan's (2001) model fails to illustrate the similarities of disease stigma in relation to other forms of prejudice. Describing stigma as a multi-dimensional concept perceived differently from different contexts, cultures and individuals, Deacon et al. (2005) is of the opinion that it cannot be assumed that one definition represents stigma in a particular community or context. It is therefore necessary to seek a broader explanation of how stigma is brought about, why stigmatisation is a practice for some and not for others, and how the same social context can be characterised by different forms of stigma for different diseases (Deacon et al., 2005). Similar to Parker and Aggleton (2003) it is suggested that stigma is instead a complex social process linked to competition for power and tied into existing social mechanisms of exclusion and dominance. However, according to Deacon et al. (2005), the functions and effects of stigmatisation need to be explained without only defining stigmatisation in terms of discrimination. In conjunction with this there is a need to understand the role of the individual in stigmatisation without resorting to defining stigma as a problem of individual ignorance. An informed understanding of issues relating to stigmatisation and discrimination, in relation to HIV and AIDS therefore requires the incorporation of social exclusion as well as the individual processes of these individuals or groups. The social understanding of stigmatisation can particularly be helpful when understanding stigma within the context of the developing world. Throughout much of the developing world, for example, bonds and allegiances to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they appear, are social and cultural phenomena linked to the actions of whole groups of people, and are not only the consequences of individual behaviour (UNAIDS, 2000). According to Parker and Aggleton (2003) and Deacon et al. (2005), understanding the social context of stigmatisation and its likely consequences for affected individuals and communities can help develop better measures for combating and reducing the effects of stigmatisation in relation to disease.

Factors contributing to HIV-related stigma

Considerable research has been contributed to the concept of HIV-related stigma (Holzemer & Uys, 2004; Visser et al., 2008), for example research conducted by Herek et al. (2002) whereby the prevalence of HIV-related stigma was monitored in the United States from 1991 to 1999. At the time of this research HIV remained a significantly stigmatised condition despite measures to decrease this phenomenon.

The International Centre for Research on Women (ICRW) (2005) identified various factors contributing to HIV-related stigma. This include the fact that HIV and AIDS is life-threatening and therefore people have a fear for it. Two of the primary modes of HIV infection are through unprotected sexual activities and intravenous drug use, behaviours which are already stigmatised by many societies. These behaviours are viewed as the responsibility of the individual and therefore people with HIV and AIDS are perceived to be responsible for contracting the condition. People infected with HIV are therefore often blamed for their condition and many people believe that better moral decisions are associated with staying HIV negative (ICRW, 2005). In some societies the infection is associated with minority groups or group behaviour, for example, homosexuality (Deacon, et al., 2005). HIV is a progressive, incurable, degenerative, and often disfiguring condition. It is also thought to be highly contagious and a threat to the community at large. The former two manifestations relate stigma as an exercise of power, but stigma can also be a response to fear or risk of a disease that is incurable and potentially fatal. In other words, people with HIV are perceived to be a danger to society (ICRW, 2005). The above manifestations of HIV correspond with Goffman's categorisations of stigma types.

HIV-related stigma has its own unique qualities, (Skinner and Mfecane, 2004), but possess a "double deviance", Green and Sobo (2000) as it frequently goes together with other stigmas associated with race, gender, homosexuality, drug use, promiscuity etc. This relates to a previous discussion regarding the social process of stigmatisation. Due to its social nature stigma not only affects the individual who is carrying the virus but also increases the exclusion of already stigmatised groups (Holzemer & Uys, 2004). Consequently certain communities or cultural groups perceived to be more affected by HIV experiences more discriminatory acts (Skinner & Mfecane, 2004). Examples would be of a black gay HIV-positive man, or a physically handicapped HIV-positive woman. Each of these would feel stigma in all areas of difference from the norm, with each point of stigma isolating them from different sectors of their community.

The social nature of stigma can also create a differentiation by which stigma is experienced. In other words, the manifestation and experience of stigma may vary from different cultures, race groups or between genders (Holzemer & Uys, 2004). The degree to which a person with HIV or AIDS actually feels stigmatised may also depend on individual differences. This means that members from the same group, that is people from the same race or culture, may experience certain discriminatory acts as more derogatory than others. For example, research has demonstrated that women often feel more stigmatised than men as they

experience more isolation from their communities and rejection from their families. It has also been found that persons with HIV experience more stigma than individuals with cancer (Fife and Wright, 2000). The following section is an exploration of the manifestations of HIV-related stigma in different contexts.

Manifestations of HIV-related stigma

Research has proven that an HIV infection, of which the acquisition is prominently associated with sexual and drug-using behaviours, is capable of provoking intense, value-laden reactions from society (Centre for Disease Control [CDC], 2000; [ICRW], 2005). According to a 2000 study conducted among 5641 respondents in the United States, 40.2% of participants responded that HIV transmission could occur through sharing a glass, and 41.1% responded that it could occur from being coughed or sneezed on by an HIV-infected person. Other responses included that persons who acquired AIDS through sex or drug use have gotten what they deserve (18,7 %). Approximately 25% of those who were misinformed gave stigmatising responses, compared with approximately 14% who were informed (CDC, 2000). Evidence from a multi-country study by the ICRW (2005) conducted from 2001-2004 in Ethiopia, Tanzania, Vietnam and Zambia shows that HIV-related stigma is still a great concern in African countries. In Ethiopia, Tanzania, Vietnam and Zambia, people commonly expressed the fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV or AIDS, and that no exchange of body fluids was needed for transmission to occur (ICRW, 2005).

According to Deacon et al. (2005) in many South African societies people living with HIV and AIDS are seen as shameful. In some cases HIV and AIDS may be linked to 'perversion' and those infected will be punished (Deacon et al., 2005). Sometimes, HIV and AIDS are believed to bring shame upon the family or community, and whilst negative responses to HIV and AIDS unfortunately widely exist, they often feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and proper and improper behaviour. Six factors as features of stigma have been identified according this study by Holzemer, et al. (2007) conducted over three phases from 2003-2006. Data were collected from five African countries namely Lesotho, Malawi, South Africa, Swaziland and Tanzania. The six factors include verbal abuse, negative self-perceptions, healthcare neglect, social isolation, and fear of contagion and workplace stigma. Levels of negative self-perception proved to be the highest of all factors.

The manifestation of stigma has left visible tracks in the history of HIV and AIDS in South Africa. A well known case is the case of Gugu Dlamini who was murdered in 1998 for disclosing her HIV positive status in public (Nicodemus, 1999 in Skinner and Mfecane, 2004). The Treatment Action Campaign (2000) also documented the murder of Mpho Mtloung together with her mother by her husband, who then also committed suicide after he learned about his wife's HIV positive status. Furthermore Sapa (2002) in Skinner and Mfecane (2004) also reported cases whereby HIV-positive children could not register into schools. In addition to the above many other well known cases have been covered by the mass media.

POLICY Project et al. (2003a) conducted a fieldwork study to obtain a wide range of experiences of HIV- related stigma. The study involved 182 participants who participated in 23 focus groups and 11 in-depth interviews across nine provinces of South Africa. This study revealed that HIV positive people experience the most stigmas at the workplace, with their families and from the health services. They also found that the stigma is highly differentiated by gender. The following paragraph will be an exploration of these HIV-related manifestations.

HIV-related stigma and the workplace

HIV and AIDS is a workplace issue because it affects workers and the families, enterprises and communities which depend on the workplace. In conjunction with the dependence of HIV positive people on their employer, the workplace has a vital role to play in the wider struggle to control the epidemic. (International Labour Organisation [ILO], 2005). However, workplace HIV and AIDS prevention and treatment initiatives are more welcomed by employers in developed countries. More focus have been directed at HIV prevention, education and condom promotion, some have even expanded to include care and treatment. (Pulerwitz, 2004). HIV and AIDS stigma, however, presents major challenges to the successful implementation of workplace HIV and AIDS programmes (Pulerwitz, 2004). Employees may experience HIV-related stigma from colleagues and supervisors. Almost a quarter of employees reported a fear of being fired if they had AIDS (Pulewitz, 2004).

HIV-related stigma and the family

The HIV and AIDS pandemic have elicited both negative and positive responses from families and communities (POLICY Project et al., 2003a). HIV positive disclosure has caused some families to get together with other support structures (for e.g., employers) to

offer support and care and sometimes to find a means for the access of Antiretroviral (ARV) drugs (Brown, MacIntyre and Tuljillo, 2002). However, according to Policy Project et al. (2003a) disclosure evokes stigma, which results in a reluctance to seek such support from family members.

The family system is a very important source of support and care giving for HIV positive people (POLICY Project et al., 2003b). It is therefore important to enquire into social exclusion beginning in the family as often it extends to the community. This often results in inhabited communication in the family, hence the stigma interfered with possibilities of disclosure which in turn inhabits possible care and support from family members (POLICY Project et al., 2003a).

HIV-related stigma, gender differentiation and sexual orientation

Gender is a major mediating factor toward the impact of HIV-related stigma, and its impacts is experienced more by women than by men (POLICY Project et al., 2003a). Social constructions of sexuality and sexual promiscuity (UNAIDS, 2002) is a major influence on the impact of gender discrimination on HIV-related stigma. International researchers have proven that females and homosexual males are more likely to experience discriminatory treatment in comparison to heterosexual males (Katz, 1998). The attachment of gender discrimination to HIV stigma has led to women being blamed for spreading the epidemic (Skinner & Mfecane, 2004).

The prevalence of sexual behaviour among homosexual men in South Africa is currently unknown due to the focus on heterosexual behaviour as it is the primary mode of HIV infection. Consequently there is also little awareness of formal documentation regarding the stigmatisation and discrimination of homosexual males in South Africa (Cloete, Simbayi, Kalichman, Strebel & Henda, 2008). A study was therefore conducted by Cloete et al., (2008) to examine the stigma and discrimination experiences of men who have sex with men (MSM) living with HIV and AIDS in South Africa. This was done by collecting anonymous venue-based surveys from 92 HIV-positive men who have sex with men and 330 HIV positive men who only reported sex with women (MSW). The results revealed a high level of internalised stigma among all HIV positive men who took part in the survey, with 56% of men reporting that they concealed their HIV status from others. Furthermore HIV-positive MSM reported experiencing greater social isolation and discrimination resulting from being HIV-positive, including loss of housing or employment due to their HIV status. However these differences were not significant.

HIV-related stigma and the health sector

Research have revealed the extent to which people are stigmatised and discriminated against by health care systems. Some studies have revealed the reality of non-attendance of hospital staff to patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines (Duffy, 2005; Madru 2003).

Holzemer and Uys (2004) indicate that research reporting on the conditions of the health care workers who have to care for HIV positive individuals can be a contributing factor to stigma among doctors and nurses. Working conditions and the lack of protective equipment results in a fear of exposure to HIV. Another frustrating factor is the lack of medicine for treating HIV and AIDS patients. A study conducted by Unger,Welz and Haran (2002) as cited in Holzemer and Uys (2004) studied the workload and job satisfaction of 200 nurses working in a rural KwaZulu-Natal hospital. It was reported that between 1995 and 2000, nursing staff increased by 10% (from 620 to 683). However the annual absenteeism of staff increased by 310%. Working conditions around HIV and AIDS therefore had a major impact on nurses' job satisfaction and absenteeism.

The effects of HIV-related stigma

The extraction of the above-mentioned literature indicates the extensive nature of stigma against people with HIV and AIDS. From this it can be seen that HIV-related stigma can significantly impact on those infected as well as those affected by an HIV positive diagnosis. Research conducted regarding the relationship between HIV-related stigma and the health care sector for example, also reveal the impact HIV related stigma may have on the pandemic itself. The acknowledgment of these manifestations of HIV-related stigma is important for the eradication of the stigma. One such strategy would be the visibility of the pandemic as one of the major impacts of discrimination against people infected with HIV is the suppression of the pandemic, forcing individuals who are infected or have anything associated with the virus into hiding. (Skinner & Mfecane, 2004).

It has been reported that the fear of discrimination often overpowers the fear for the disease itself (Lie & Biswalo, 1994). Hence the fear of discrimination also impacts on the diagnosis and treatment as due to such fear people delay diagnosis, which in turn also delays treatment and exposure to guidance regarding a healthier lifestyle (Lie & Biswalo, 1994). The stigma associated with an HIV diagnosis perpetuates the association of HIV to death, hence members of society perceives avoidance of a possible positive diagnosis as a more

comforting option. As previously indicated in this chapter fear of discrimination results in reluctance of disclosure to friends and family, therefore the fear of discrimination also restricts access to care and treatment to those who are aware of their HIV positive status (Brown, MacIntyre and Tuljillo, 2002).

As previously indicated stigma can get internalised to the self-perception and sense of identity of an individual, referred to as internal stigma. Internalised stigma can impact on the individual's perceptions of him or herself and can influence interaction with society. Examples of the impact of internalised stigma on the self evaluation have particularly been identified among the homosexual population and in gender differentiation. For example, research among homosexual men found that the rejection experienced by homosexual men due to an HIV-positive diagnosis fed into their sense of self, causing them to feel compromised and to blame themselves for their situation (Isaacs, 1993). Similar results were found with a sample of HIV positive women. The impact of HIV-related stigma on self evaluation, incorporating identity formation of individuals who are HIV positive is the primary focus of this research paper and will therefore be discussed in more detail in the following section.

CONCEPTUALISING SELF-ESTEEM

William James played an influential role in the development of self-esteem, although he often did not refer to self-esteem but rather "to his own regard" (Katz, 1998). He described self-esteem as a judgmental rating of the self, self-worth when one has high self-esteem and self-degrading or self-hate when one has low self-esteem. It is a ratio—the James equation—success divided by pretensions (Mruk, 2006, p. 11). Another influential figure to the notion of self-esteem is Morris Rosenberg (1965). Self-esteem has been described by Rosenberg as the favourable or unfavourable attitude toward the self (Rosenberg, 1965). He contends that every individual has attitudes towards a multitude of objects in the world, and one of these objects, probably the most important, is the attitude toward the self. It involves the extent to which a person values, approves of or likes him or herself. This favourable or unfavourable attitude toward oneself has been termed the self-esteem. According to Mruk (2006) self-esteem encompasses both beliefs and emotion and can apply specifically to a particular dimension, for example the belief that you are a good person or feeling proud of yourself (Mruk, 2006). Furthermore it can be related to personality constructs (e.g., shyness), behavioural (e.g., task performance), cognitive (e.g., attributional bias), and clinical concepts (e.g., anxiety and depression).

Often an association is made between the self-esteem and the self-concept. However, clear distinctions can be drawn between self-conception and self-esteem (Bhatti, Derzotes, Kim and Specht, 1989, Roland & Foxx, 2003). Langer (1999) contends that to esteem is to evaluate and therefore self-esteem relates to the value an individual places in him or herself. According to Bhatti et al., (1989) the latter relates to the concept individuals hold of themselves as physical, social and spiritual beings. In other words, the self-concept relates to the way in which individuals define themselves. In essence one can say that the way in which an individual evaluates him or herself (which refers to the individual's self-esteem) is typically based on certain aspects of the self-concept (Roland and Foxx, 2003). In this formulation, self-esteem is the dimension of self-concept, which addresses whether one accepts, respects, and considers oneself worthwhile (Roland and Foxx, 2003). An individual with clear, definite and consistent ideas about him or herself will therefore possess of a high self-concept and low self-esteem will be the result of a confused self-concept (Baumeister, 1999).

Self-esteem is believed to play an integral role in the understanding of normal and abnormal behaviour (Roland and Foxx, 2003; Van Zyl, Cronje & Payze, 2006). This association of self-esteem to mental health asserts that self-esteem is related to positive mental health. It is believed that higher levels of self-esteem can be associated with variables such as internal control, autonomy and high ego function. Conversely, it is suggested that lower levels of self-esteem can be associated with negative outcomes, including certain mental disorders (Roland and Foxx, 2003). In addition to mental illness, low self esteem is a vulnerability that has also been linked to physical illness (Jonsson, 2006). Jones et al. (1984) draws a distinction between physical conditions that are known and those that are unknown to the possessor. They refer to these as 'marks' of the individual. Examples such as skin disorders can leave a person confused resulting in them seeking professional assistance in trying to alleviate themselves of these symptoms. Information regarding this condition therefore becomes known to the person. However there are some conditions people find too degrading to talk about to others. One such condition is HIV and AIDS. Information regarding such conditions therefore remains unknown. HIV can therefore be considered as an unknown condition. The presence of the 'marks' brought about by the condition can result in the person paying particular attention to the mark over a period of time resulting in an integrated network of thoughts, feelings and expectations with respect to the mark. As individuals accumulate self knowledge pertaining to their 'mark' they can develop feelings of personal responsibility and may begin to attach more value to their own perceptions of the

'mark' when constructing the self concept. In this process they may value their own perceptions more than that of others (Jones et al., 1984) as they do not feel free to seek guidance regarding their condition. With regards to HIV and AIDS, research (POLICY Project, 2003a) have shown that people who are HIV positive often develop internalised stigma due to personal beliefs around the diagnosis. People who are HIV positive may therefore base their self concept on the internal stigma of being HIV positive. On the contrary, individuals who can turn the experience of HIV-related stigma into a positive experience may be able to build their self concept in relation to their physical well-being based on these positive evaluations.

Roberts et al., (2001) contend that low self-esteem can be a risk factor for conditions such as depression and the possibility of suicide. Improvement of self-esteem can therefore be a valuable tool in addressing problems such as depression and suicide brought about by the daily demands society brings (Van Zyl, et al., 2006). Van Zyl et al. (2006) reflect on the contributing factors to the development of a low self-esteem. One of the factors highlighted by them is family background. Labelling can also serve as a contributing factor to a low self-esteem, examples include being named in derogatory ways or being referred to as not good enough. They have found that contributing factors to the development of low self-esteem (discrimination) tend to form the core of the negative labels people tend to associate with their diminished self-esteem. People who experience the above-mentioned factors tend to linger on these negative labels and associate these with their self-esteem.

Types of self esteem

Exploration of the literature indicated that distinctions can be made between global and specific, personal and social, and trait and state self esteem (Jonsson, 2006; Luhtanen & Crocker, 1992; Rubin & Hewstone, 1998). Trait and state self esteem will be discussed briefly. Personal and social self esteem can be linked with the individual and social process of stigma and will therefore comprise a more detailed elaboration.

Trait and state self esteem

Self esteem can be divided into two separate components: trait and state self esteem (Jonsson, 2006; Rubin and Hewstone, 1998). Traits are perceived to be dispositional forces that cause individuals to have consistent experiences resulting in them carrying the past into the present and across the diverse circumstances (Jonsson, 2006). Trait self esteem can therefore be described as "the product of self-evaluations made over a relatively long period of time"

(Rubin & Hewstone, 1998, pp 42). State self esteem is described as a temporary psychological condition and the product of self analysis taking place in the here-and-now (Jonsson, 2006 & Rubin and Hewstone, 1998). The self esteem may therefore be a stable trait or brought about as a result of a process of self analysis that is continuously updating self-perceptions based on recent experiences.

Drawing a distinction between trait and state self esteem when attempting to understand the self esteem of people living with HIV and AIDS can be important for various reasons. State self esteem can be important in understanding brief experiences of discrimination as a result of different stages of the HIV condition the person may go through. In other words, a person's experience of HIV-related stigma may be different when he or she is in stage one of the condition in relation to when he or she is in stage four, which can result in such person changing previous self attitudes based on more recent experiences of HIV-related stigma. Understanding the concept of trait self esteem can be important for being mindful of traits an individual may have acquired through his or her upbringing. These traits may influence his or her resiliency when analysing the self. By being mindful of such traits one would be reminded that different individuals can experience similar HIV-related experiences differently, which in turn can mean that peoples self esteem can be affected differently by these experiences as well.

Personal and social self esteem

Traditionally issues of self and identity have been conceptualized at the level of the personal self. The personal self is mainly concerned with processes among individuals, in terms of how reflected appraisals from others contribute to the manner in which a person defines the self (Ellemers, Spears & Doosje, 2002). Social self esteem on the other hand refers to the shared image a person holds of him or herself in relation to the social group he or she associates him or herself with (Rubin & Hewstone, 1998). These concepts will now be discussed in more detail referring to examples as it relates to HIV-related stigma. Personal self esteem will particularly be discussed in relation to social cognitive theory as postulated by Bandura (1986 & 1989). Social self esteem or collective self esteem will be based on Luhtanen and Crocker's (1992) proposed four-dimensional model of collective identity.

Self-esteem as a personal identity

Bandura (1986, 1989) believes that the capability of reflective-self consciousness is a unique human trait that enables people to analyse their experiences. People however do not

only gain knowledge themselves through reflection but also through self-evaluation. People monitor their ideas through this self evaluation, act on them, judge the results and change them accordingly. Bandura refers to this process "Self reflective capability". Self reflective capability operates similar to Rogers' (1951) notion of self-esteem which argues that acting on misjudgments of personal evaluation can produce adverse consequences or inaccurate evaluation of one's functional value.

Social Cognitive theory is considered appropriate for understanding the impact of HIV-related stigma on the self-esteem because of its belief that the manner in which people interpret the result of their behaviour informs and modifies their environments and the personal factors they possess, which in turn inform and alter subsequent behaviour (Bandura, 1989). The notion of reciprocal causation as well as self reflection in relation to the influence it might have on a person's life path form part of the social cognitive theory and will be discussed in following paragraphs of this section.

Social Cognitive theory challenges the notions that human behaviour is based on one-sided determinism, whereby behaviour is depicted as being shaped and controlled either by environmental influences or by internal dispositions (Bandura, 1986 & 1989). According to Social Cognitive Theory behaviour, cognition and other personal factors as well as environmental influences all operate as interacting determinants that influence each other concurrently. Bandura (1989) refers to this process as reciprocal causation. Reciprocal causation of personality factors and behaviour is an indicator of the relationship between thought, affect and action. (Bandura , 1986 & 1989). People's thoughts, beliefs and feelings affect their behaviour. These behaviours will have certain external effects which then get reciprocated and partly determine thought and emotional reactions (Bandura, 1989). If the notion of reciprocal causation is to be applied to HIV positive people's experience of HIV-related stigma it would mean that the thoughts and feelings evoked from stigmatic experiences may have an impact on these people's behaviour. The external effects brought about by this behaviour can in turn impact on their thoughts and feelings. In other words, the person has a part in the reactions received from society as external effects can be traced back to his or her own interpretations and feelings of the discrimination experienced.

The relation between environmental influences and personal factors express social influences that activate emotional reactions through modelling, instruction and social persuasion. Physical characteristics for example age, size, race, sex and physical attractiveness also evoke different reactions from society in comparison to what is said and done. Similarly, socially conferred roles and status also generate different social reactions. A

person's social environment can therefore be predetermined by his or her social status and observable characteristics before they even have to say or do anything (Bandura, 1986 & 1989). For example, the status assigned to HIV positive people by a particular community can determine their social status and based on the theory of reciprocal causation may in turn influence his or her thoughts and feelings. The collective identity (which will be discussed in the following section of this chapter) of people living with HIV and AIDS can therefore impact on their thoughts and behaviours. A holistic reflection of the social cognitive theory as postulated by Bandura in relation to the stigmatic experiences and discrimination experienced by people living with HIV and AIDS demonstrates that people living with HIV and AIDS can be directly involved in the behaviour received from society. However society's preconceived ideas about them equally impact their status.

Accurate appraisal of one's own capabilities is very important for effective functioning. Bandura (1989) refers to this process as self reflection. Accurate information regarding a person's own capabilities provides the foundation for human motivation and personal wellbeing. In other words people need to believe in themselves in order to persevere in the face of difficulties (Pajares, 2002). Adults who have to deal with many demands such as marital relationships, careers and parenthood, for example may find many aspects of life stressful and depressing (Bandura, 1986 & 1989). As discussed in the previous section of this chapter people living with HIV and AIDS experience problems such as these referred to above due to the stigma associated with their condition and are therefore likely to experience life stressful and depressing as indicated above. According to Bandura (1989) people who do not believe in their personal abilities undermine their ability in the efforts they take up to deal with these challenges.

Variation of life events that occur progressively impacts on the course of a person's life (Bandura 1986 & 1989). These life events can include social experiences determined by age, occurrences in the physical environment or biological occurrences. Other life events such as illness, divorce and career changes etc. too can influence the direction an individual's life takes. Bandura (1986 & 1989) postulates that the ability to alternate course of life is dependant on self beliefs of efficacy. According to Greenwald and Banaji (1995), theories regarding social behaviour such as what has been discussed above describe social behaviour as being under conscious control. However, considerable recent literature suggest that the influence of past experience on a person's judgement of the self can also operate in a fashion that the individual does not have introspective awareness of (Greenwald and Banaji, 1995).

Thus, the effect of internal evaluation on a person's social behaviour may not always be based on conscious thought, but can rather be operating on an implicit, unconscious fashion. This phenomenon is referred to as implicit social cognition. Taking this into consideration it would therefore be difficult for a person to exert control over his or her course of life as he or she would not be aware of the operating mechanism that influences the self's beliefs of efficacy.

Self belief is therefore dependent on a considerable level of social support. In order for a person to overcome the stresses his or her life path takes, he or she requires social support to give meaning and worth to what they do **(**Bandura , 1986 & 1989). According to Bandura (1986 & 1989) the cognitive process by which people decide how to interpret phenomena, is determined by symbols (verbal/ non-verbal). Cognitive factors greatly influence the observations of environmental events, the manner in which they are interpreted, their effects, the emotional impact it might have and how this information will be organised for future use (Bandura 1986 & 1989).

The above illustration of Bandura's social cognitive theory is a depiction of the autonomy that is associated with the self. In Western cultures, the values of independence and autonomy are undeniable. The following will provide an illustration of people's evaluation with regards to their identification with the social groups to which they belong, which may be more applicable to less Western cultures in South Africa.

Self-esteem as a collective/social identity

Collective identities refer to people's evaluations of and identification with the various social groups to which they belong. The collective identities are grounded on aspects such as demographic factors and personal social networks. For example, most people identify themselves as members of a certain nationality, race, gender, religion, social class, marital status, sexual orientation, and occupation (Katz, Joiner & Kwon, 2002). However although membership to a social group is necessary, it is not sufficient to hold a collective identity. According to Katz, et al., (2002) there is a wide variation in terms of the manner in which members of a social group identify with the group. The diversity in culture as well as the socio political history of South Africa is a clear example of this. One cannot assume that all South Africans hold similar norms and beliefs about being South African. At the same time, it is unclear precisely what types of thoughts, experiences, and behaviours constitute collective identification with a group, for example, one woman who is HIV positive may

experience the HIV diagnosis differently to another based on her experiences. Based on the above, the social identity of people who are HIV positive can be influenced by their socially constructed identities, for example their identity as a woman or a man or their identity as a homosexual or heterosexual man or woman. As described in the previous section of this chapter the stigma associated with HIV often results in people who are HIV positive to isolate themselves from society and therefore base their social identity on their HIV status.

Luhtanen and Crocker (1992) proposed a four-dimensional model of collective identity referred to as collective self-esteem (CSE). Examples utilised to better explain each dimension will be based on the belief of people who are HIV positive that their social identity and therefore CSE is based on their HIV status. The first dimension of their model refers to a person's perception regarding how he or she functions as a member of his or her social group. This type is called Membership CSE. An example would be a student's perception regarding his or her function within that social group, for example the belief of the person who is HIV positive that his or her status can impact his or her potential to pass a degree. The second is private CSE, which involves a person's private evaluation of the social group. For example, the belief of the person who is HIV positive about what it means to be HIV positive. The third involves the extent to which a person's believes that the social group is valued by others, referred to as Public CSE. For example, the belief of the person who is HIV positive about society's perception of people with this diagnosis. The fourth is identity CSE, which involves the extent to which group membership is important to a person's individual self-concept. This would involve the extent to which the individual with HIV will allow the diagnosis to determine his or her value in the self. Here it is important to be cautious in conveying that people who are HIV positive should demonstrate pride in their diagnosis, but rather that he or she should not devalue their general CSE or the CSE they possessed prior to their HIV diagnosis.

The notion of a collective self-esteem can be incorporated with Bandura's Social Cognitive Theory. The two-way influence between behaviour and environment indicates behaviour modifies environmental conditions through daily interactions and is in turn altered by the very condition it creates. The involvement of the environment can serve as social or collective influence. Social cognitive theory assumes that values and behaviour patterns arise from diverse sources of influence, as Bandura (1989) believes, in an interactional theory that treats human development and human evaluation as a product of both internal and social influences. According to Pajares (2002) natural activities that people engage in with success or failure influence future decisions. Bandura (1997) hypothesize that behaviour can be

predicted by beliefs of capabilities rather than the actual capabilities. This provides an explanation for why people's behaviours are sometimes not similar to their actual capabilities and the behaviour for one person may be different for another though they possess the same potential (Pajares, 2002). For example, two graduates whose capabilities are the same but the one is HIV positive and the other HIV negative. The one who is HIV positive often evaluates himself as less worthy and therefore avoids interaction with society and therefore does not attend class. The HIV negative person who has been attending class regularly is therefore more likely achieve to higher grades than the HIV positive person though their capabilities are similar. Similarly, someone with a more confident self evaluative nature, but with less skill may achieve better than the person with less self belief. The evaluative strengths an individual possesses influence the courses of action they pursue. Thus, unless someone feels confident about the outcome of a particular activity, such activity will be avoided (Pajares, 2002).

HIV-RELATED STIGMA AND SELF-ESTEEM

According to Goffman (1963), when individuals become stigmatised later in life they have been socialised regarding what it means to be normal and what it means to be stigmatised long before seeing themselves as deficient. As these individuals have developed a specific social identity, it is therefore possible that individuals with HIV have internalised the stereotypes associated with their illness through socialisation prior to contracting HIV themselves.

A response to stigmatisation involves the need to modify the self-esteem. For stigmatised individuals, the reactions and evaluations received from others may have very negative effects, which may lead to difficulty in constructing and maintaining a stable self-concept and consequently the self-esteem (Jones et al., 1984). These negative evaluations may cause the stigmatised individual to evaluate him/herself as different from others and therefore perceive interaction with others as a humiliation (Jones et al., 1984).

Research suggest that females are more vulnerable to the construction of a negative self-esteem (Jones et al., 1984). This might be the result of girls being under more scrutiny from a very young age in comparison to young boys. For example, girls may have greater concerns about their weight (Jones et al., 1984) and complying with gender specific roles (Stangor, 2000). What can be deduced from this is that the age at which stigmatising was first experienced has an impact on the severity of self-evaluation. The earlier in development an

individual has been faced with reactions from others due to certain deficiencies; the more self-conscious that individual will be during later stages in life (Ramsden, 2001).

Emotions can have detrimental effects on the development of an individual's self-esteem. Low self-esteem is self-reinforcing (Langer, 1999) and negative behaviour generates negative responses, which in turn may create reluctance within an individual to approach others. The lack of this experience may interfere with the development of interpersonal skills (Jones et al., 1984). The inability to interact with others will consequently be prevalent and rejection will continue. This conception relates to the Rogerian notion of conditional positive regard (Rogers, 1951). 'Conditional positive regard' holds that an individuals' acceptance is dependant on appropriate behaviour by that individual. Rogers describes fulfilment of prescribed conditions as conditions of worth (Rogers, 1951).

Previous sections of this literature review provide support for the significance of the role stigma potentially plays in the quality of health care and the quality of life of people living with and affected by HIV and AIDS. A central argument regarding the impact of stigma has been formulated around the perceptions of individuals and the consequences of these perceptions on social interactions (Link and Phelan, 2001). However, it is important when understanding the notion of HIV-related stigma within a context such as South Africa influenced by social interaction (UNAIDS, 2000) to also integrate HIV-related stigma as a social experience with the individual experience as postulated by Parker and Aggleton (2003).

An HIV or AIDS diagnosis to a group membership may impact personal evaluations of the self due to the devalued nature of being HIV positive. This also applies to people affected by an HIV diagnosis such as the family members of the HIV positive person. Individuals who are HIV positive's vulnerability to personal devaluation is due the possibility of members of devalued groups internalising negative stereotypes about themselves on the basis of their group membership, for example HIV diagnosis (Katz et al., 2002). Being devalued simply on the basis of being HIV positive, regardless of personal self evaluation, could impact emotional well-being. Members of devalued groups are treated differently by others on the basis of their group membership, and therefore may be socialised to develop attitudes and behaviours that are of a devaluing nature.

CONCLUSION

A review of the literature demonstrated the alarming impact HIV and AIDS has on the world, but in particular South Africa. This indicates the need for intervention against the

spread of HIV and AIDS as well as alleviating the suffering of those who are already infected. Particular reference has been made to the suffering due to HIV-related stigma by providing an understanding of what HIV-related stigma entails and the manner in which it manifests itself in the South African context. Exploration of the literature has shown that stigma negatively affects self-perception, emotional well-being, social interaction and life chances. It is also assumed that individuals who feel stigmatised will also experience low self-esteem and limited personal control. Goffman's (1963) work has been acknowledged in terms of providing an understanding of stigma. The need for acknowledging the social nature of stigma as postulated by Parker and Aggleton (2003) has also been reflected upon.

One way in which stigma impacts on individuals within society is by affecting the self-esteem. The self-esteem was depicted by providing an account of what is perceived as personal identity as well as self-esteem and the collective identity. This is in keeping with the acknowledgment of stigma as a social process. Self-esteem as a personal identity was primarily informed by Albert Bandura's concept of social cognition, whereas self-esteem as a collective identity was primarily informed by Luhtanen and Crocker's (1992) proposed four-dimensional model of collective identity referred to as collective self-esteem (CSE). These provided insight to the explanation of the impact of stigma on the self-esteem.

CHAPTER 3: METHODOLOGY

The aim of the research is to investigate the relationship between HIV-related stigma and the self-esteem of individuals who are HIV positive as perceived by psychologists in their work in the field of HIV and AIDS. This understanding was sought by means of an explorative approach, using semi-structured interviews and an analysis of the themes emerging from these interviews. A primary goal of this study is to provide direction for future research as well as providing new insights to a topic relatively under researched within the South African context. The creativity and flexibility accommodated for within the exploratory research approach allows for investigations into relatively unknown areas of research (Durrheim, 2006) and was therefore considered the most appropriate approach for this study.

RESEARCH QUESTIONS

One primary question gave direction to the investigation: "What are psychologists' perceptions of the self-esteem of clients who are HIV positive that have been exposed to HIV-related stigma?" From this question , as the research progressed three supplementary questions emerged from exploration of participants' most salient arguments. The first question was: What are psychologists' perceptions of the construction of the self-esteem of the individual with HIV? From this the question "How do you think the self-esteem of HIV positive individuals can be impacted by HIV-related stigma?" emerged. The third and final question was: "What were psychologists' recommendations for the improvement or preservation of the self-esteem of people who are HIV positive".

RESEARCH DESIGN

This research employed an open, flexible and inductive approach in an attempt to look for new insights into the self-esteem of individuals who are HIV positive. The proposed study can therefore be classified as a qualitative, exploratory design (Durrheim, 2006). The primary focus of this research was to explore each participant's individual perceptions and experiences with individuals who are HIV positive in relation to the topic being researched, which is further suited to the qualitative design (Neuman, 1997).

These methods are in keeping with exploratory data analysis as creativity and flexibility is an advantage of this type of research design (Neuman, 1997). The researcher viewed data through the eyes of the interviewee, thereby guarding against interpreting data in

a biased manner. In so doing the researcher kept an open mind to information that might be contradictory to the research topic.

RESEARCHER REFLEXITIVITY

Researcher reflexivity is a process whereby the researcher actively acknowledges that his or her actions and decisions are likely to impact the meaning and context of the data under investigation (Horsburgh, 2003 as in Lietz, Langer and Furman, 2006 & Kleinsasser, 2000). The researcher has a particular interest to the field of HIV and AIDS which has been informed by various professional and personal experiences. Researcher reflexivity enabled the researcher to be cogniscant of the ways in which her beliefs, experiences and identity intersected with or differed from that of the participant. As a beginning researcher this was a challenging task and therefore required from her to remain mindful of such distinctions or similarities. Therefore instead of claiming complete objectivity the researcher made her own personal and professional positions explicit. This reflection occurred through individual thought as well as dialogue with her supervisor that acknowledged the researcher's own experience and perspectives.

Through reflection on her exposure to HIV and AIDS the researcher realises that over the years it has become easier to engage with the topic. The researcher's first encounter with the challenges and discourses around HIV and AIDS was five years ago when she volunteered at the Love Life Call Centre as a telephonic counselor or "Helping Buddy". This was followed by training in HIV and AIDS prevention for the purpose of training first year students during their orientation programme. The researcher then also majored in HIV and AIDS counselling during her Honours training in 2004, whereby she needed to complete a six month practicum component at a HIV and AIDS couples counselling clinic. This experience further provided her the opportunity to work as an HIV and AIDS Coordinator at the Department of Correctional Services for six months. Informing students and clients about the concerns of HIV infection has helped the researcher to better understand facts about the HI virus. This has also guided the researcher to develop a philosophy that an HIV diagnosis is not a death sentence. This knowledge in turn influenced the manner in which the researcher could understand certain terminologies used by the participants. It also influenced the researcher's attitude toward an HIV diagnosis as she believes that such a diagnosis should not allow the infected or affected to give up on the potential to life. This attitude could have come across in the manner questions were asked of the participants.

The researcher brought to the interview basic counselling skills acquired through her experience as a Masters' counselling psychology student. This allowed the researcher to engage with participants' on a one-to-one basis which could facilitate the exploration of participants' authentic experiences and feelings pertaining a very sensitive topic. Furthermore the experience as a Masters' Psychology student allowed participants comfort regarding speech pertaining to confidential information as they were assured of the researcher's commitment to keeping their details as well as the details of their clients confidential.

The above process of researcher reflexivity creates physical evidence of the researcher's personal and theoretical tracks, evidencing the researchers learning process.

SELECTION OF PARTICIPANTS

Participants were recruited by means of non-probability, purposive sampling.

The sampling procedure was guided by specific conditions or selection eligibility. The sample was selected from a specialised target population as informed by the purposive sampling procedure (Neuman, 1997). Selection eligibility was based on two fundamental selection criteria. The first requirement was that participants needed to be qualified psychologists as per the requirements of the Health Professions Council of South Africa (HPCSA). Secondly, these participants were required to have at least two years experience within the field of HIV and AIDS. Purposive sampling therefore ensures that selected participants are particularly informative and can provide meaningful information with which to address the research questions (Richie & Lewis, 2003). The sample represented varied ethnic backgrounds from the Johannesburg region. Participants consisted of eight psychologists working in private practice with a current or previous client base of individuals who are HIV positive. These included 5 females and 3 males. Participants were interviewed based on knowledge obtained from HIV positive clients within their private practices as well as other HIV and AIDS endeavours. In order to ensure the plausibility of qualitative research, participants descriptions are provided below.

Participant 1 is an African female university lecturer of two years standing, lecturing in the department of psychology of a leading Johannesburg university. Her focus is on health psychology in general, but she has worked on developing HIV and AIDS material, such as training manuals, training of trainers on HIV and AIDS, and she has done in-depth research in the field of HIV and AIDS. She has approximately ten years experience in the field of HIV and AIDS.

Participant 2 also is an African female psychologist in private practice, consulting with clients on a broad range of issues, including HIV. Her clients include individuals, groups, families etc. She has been in private practice for approximately 10 years. Prior to that she worked for the

Department of Health and did a period in the corporate sector as well. Specifically to HIV she worked with HIV pregnant mothers in the maternal ward of one of the hospitals in the Gauteng region and now consults with individuals who are infected and affected by HIV in her private practice.

Participant 3 is a Caucasian male psychologist who has been in private practice for approximately six years. He primarily specialises in addictions, but also consults with HIV infected or affected individuals in his private practice. With regards to HIV he was previously involved in working with HIV infected children in a children's home in one of Johannesburg's townships , and also spent a year working on an HIV based programme which also primarily involved working with individuals who were HIV positive, specifically focusing on issues of bereavement.

Participant 4 is a Caucasian female psychologist who has been in private practice for approximately eight years. She specialises in employee wellbeing work as well as psychometric assessments. She consults with people who are HIV positive in her capacity as psychologist and her clientele primarily comprises of Afrikaner, homosexual males. She has, however, also consulted with females who are affected by HIV.

Participant 5 is an Afrikaner female psychologist who has been in private practice for approximately six years. Previously she lectured at a university for approximately thirteen years. She consulted with individuals infected and affected by HIV in her private practice. These particularly involved clients who consulted for couples counselling.

Participant 6 at time of the interview was a psychology lecturer, but also runs a private practice. She is an African female psychologist. With regards to HIV and AIDS she was running a Home Based Care project two years ago whereby she consulted with individuals who are HIV positive as well conducted HIV-related training. In addition she was also involved in Home based visits for individuals infected or affected by HIV and the coordination of HIV-related support groups.

Participant 7 was an African male lecturer at one of the Johannesburg universities. In addition he also worked for a non-profit organisation providing HIV-related counselling for individuals infected or affected by HIV. The scope of his practice particularly involved children who have been orphaned by HIV and AIDS, domestic workers who are referred by their employers and Human Resource Managers who seek guidance regarding their employees who are HIV positive. In addition he has also conducted extensive research in the field of HIV and AIDS.

Participant 8 was an African male psychologist in private practice consulting for various organisations offering psychological services ranging from individual counselling, trauma debriefing, HIV and AIDS counselling and Employee Wellbeing Programme Services.

THE SEMI-STRUCTURED INTERVIEW

As discussed in previous chapters, the concept of self-esteem is well researched as this constitutes an important factor to the mental health and behaviour of any individual (Jonsson, 2006). This has however not been the case for individuals who are infected with HIV (Friedman, 1993). Research focusing on the self-esteem of people predominantly revolves around the self-esteem of homosexuals, the impact of gender differentiation and the self-esteem (Katz, 2002), the relationship between occupational dynamics and the self-esteem, but very little about the relationship between HIV and the self-esteem of people living with HIV and AIDS. Furthermore literature that do mention the relationship between an HIV diagnosis and the self-esteem implement quantitative investigations. A qualitative investigation into the relationship between HIV-related stigma and the self-esteem of individuals who are HIV positive is therefore a relatively unknown area of research. The employment of an exploratory, semi structured interview allows for investigation in unknown areas of research and was therefore regarded as most applicable as the researcher attempts to search for new insights into this phenomenon (Durrheim, 2006 & Terre Blanche, Durrheim & Kelly, 2006).

In-depth, semi-structured interviews were used to gain an understanding of the self-esteem of individuals who are HIV positive in relation to the HIV-related stigma they experience which allowed for the spontaneous interaction between the researcher and participants. The flexibility afforded by exploratory and open ended interviews allowed for the structure of the interviews to change as the interviews progressed, which resulted in high quality responses, characterised by depth of perceptions elicited from the interviewees (Neuman, 1997).

HIV-related stigma elicits different responses from those who engage with it. Similar to the literature, participants of this study too expressed various opinions regarding the impact of such stigma to the self-esteem of individuals who are HIV positive. The flexibility of the semi-structured interview allowed the researcher to probe for more specific answers in order to obtain a deeper understanding of participants' perceptions of HIV-related stigma to the lives of individuals who are HIV positive. The interviews therefore often were explorations in

which the participant and the researcher were jointly engaged, which resembled conversations rather than standardised interviews.

THE PROCEDURE

Potential participants were contacted telephonically. The researcher informed participants of the research to be conducted as well as the requirements for participation to the study. After the participants indicated an interest to participate in the study as well as meeting the study requirements, an appointment for further discussion between the participant and the researcher was set up. At the onset of the meeting the participant was provided with an information sheet (Participant Information Sheet, Appendix II), providing the participant with the rationale and aims of the research. After the researcher ensured that the participant thoroughly understood the objective of the research and his or her ethical rights pertaining to the research, the participant was presented with the Participant Consent Form (Appendix III). Only once the participant agreed to participate in the study by signing the Participant Consent Form was the interview conducted.

The participant was also informed that the interview would be audio recorded, for which a Participant Consent for Audio Recording Form (Appendix IV) was required to be signed. Following the participant signing consent for audio recording, interviews were audio recorded. The researcher administered the interview herself. Discussions were guided by thirteen open ended questions and interviews lasted approximately 40 to 50 minutes. The interview schedule has been attached as Appendix V.

The first interview was transcribed and sent for review by the researcher's supervisor. This was done in order for the researcher's supervisor to identify potential problems with the research procedure. The researcher therefore initiated the research process with a pilot study. Through the review of this pilot study the researcher's supervisor alluded her to the utilisation of her counselling skills during the interview process, which allowed for the establishment of better rapport with future participants.

DATA ANALYSIS

Thematic content analysis was employed to analyse the data. This method was considered most appropriate to the nature of this study as it allowed the researcher to interpret the social reality of HIV-related stigma from participants personal and individual perspectives but still being mindful of the explicit rules and procedures of thematic content analysis. As previously indicated the researcher has found that the concept of self-esteem in relation to HIV and AIDS has not been

explored in great depth, specifically within the South African context. The expansive view provided by thematic content analysis (Braun & Clarke, 2006) allowed for the detailed extraction of information provided from the interviews with the psychologists.

The interviewer elicited data from the tape recordings through the transcriptions of the one-to-one interviews. Transcriptions were transcribed *verbatim* (word for word) which guarded against losing information that may later become significant. One participant preferred communicating in Afrikaans. This interview was transcribed directly from Afrikaans to English. The allowance of the participant to communicate in her mother tongue allowed for the free expression of information which in turn contributed to the richness of the data obtained.

Analysing the data by means of thematic content analysis guided the researcher to condense raw data (such as beliefs regarding HIV-related stigma, the development of the self-esteem, attitudes regarding social status and the development of the self-esteem of the individual who is HIV positive) into categories or themes based on valid inferences and interpretation (Golding, 1999). The analysing process was initiated by identifying different units of analysis and allocating it into different categories, otherwise referred to as the coding process (Golding, 1999 & Titscher, et al., 2000). These codes were regulated and matched by the researcher's supervisor, hereby ensuring inter-coder reliability (Titscher et al., 2000). Following this coding process the researcher progressed by condensing the general codes into overall applicable themes. Themes identified were strongly linked to the data. A quantitative representation of the data in relation to the specific theme is therefore provided as a means of providing for the precise and parsimonious summary of the findings as well as to ensure the quality of interpretation and inference (De Sola Pool, 1959 & Holsti, 1969). The allowance of themes to be primarily informed by the data resulted in certain themes having little relation to the questions asked and also did not always relate to the researcher's theoretical interests. Themes were therefore identified by means of an inductive thematic approach (Braun & Clarke, 2006).

Although the research originally sought to explore psychologists' perceptions regarding the relationship between HIV-related stigma and self-esteem, data analysis identified two additional themes namely; constructing self-esteem in the individual with HIV, as well as recommendations for the preservation and improvement of the self-esteem of someone who is HIV positive. As indicated in the Researcher reflexivity section of this chapter, Holsti (1969) stipulates objectivity as a requirement to effective content analysis. This means that although the researcher allowed flexibility and exploration during the process of analysing the data she had to keep in mind the explicit rules and procedures of content analysis. This process guards against the possibility of formulating themes based on her personal subjective reflections as indicated described and

outlined in the Researcher Reflexivity section. Themes and sub-themes of the findings were substantiated by research previously conducted as well as the relevant theory pertaining to the specific theme. Holsti (1969) refers to this as the "generality" of thematic content analysis. Researcher reflexivity also contributed to the trustworthiness of this project. Once the initial analysis was completed the researcher sent her analysis to another researcher, her supervisor to engage in further dialogue regarding the trustworthiness of the analysis. The observation of two analysers within a qualitative research project also relates to triangulation by observation (Lietz et al., , 2006). Triangulation was an important strategy for establishing the rigor of this qualitative work as the opposing perspectives allowed for increased understanding of the data.

ETHICAL CONSIDERATIONS

Conducting research in the field of HIV and AIDS can elicit sensitive information as well as implicate the participants of the study in numerous ways. This is especially true for the participants of this study as talking about the experiences of their clients required from them to discuss highly confidential information. These raised various ethical issues which needed to be addressed before the interviews could be conducted and remained a constant concern throughout the interviews. The ethical issues that were taken into account during this research process are set out below.

Application for ethical clearance from the University of the Witwatersrand was the initial step in obtaining permission in order to progress with the proposed research. A clearance certificate was received from the Graduate Studies Committee (non-medical) of the University of the Witwatersrand, (Appendix I) as permission to progress with this research. This ensured that research procedures were in keeping with the research requirements of the university.

Contact with potential participants could only be commenced once the aforementioned consent had been approved. As soon as the above-mentioned clearance certificate was received potential participants were contacted telephonically to invite them to participate in the study and to provide them with details concerning the nature, objectives and process of the research. For those who agreed to participate, an interview time and venue was agreed upon at the convenience of the agreed participants.

Before the start of the interview participants were provided with a Participant Information Sheet (Appendix II) outlining the purpose, procedure and duration of the study. After the participants indicated a thorough understanding of what the study entails they were

provided with the participant consent form (Appendix III), which they were requested to sign. All forms outlined all ethical considerations and procedures.

All but one of the participants was comfortable with conversing in English. The one participant who was not entirely comfortable with her English proficiency preferred communicating in Afrikaans. The researcher allowed for this. The researcher therefore ensured that she used accessible language for all participants.

While participants were asked to speak in detail about their confidential case material, the researcher ensured the participants of the anonymity of their clients' details by omitting any identifying details from the transcripts and in the final report. The original list of participants would only be available between the researcher and her supervisor. Participants have also been informed that the public will have access to analysed data by means of the university library.

Participants were informed of the right to refuse participation or to withdraw agreement to participate at any time without any implications to this decision. In addition, the participants could also make any enquiries regarding the study at any time during the course of the interview.

Participants were informed that no negative implications have been envisioned as a result of participation to this study. The participants were also informed that there are no incentives for participating in this study.

Separate consent for audio recording was requested (Appendix IV). Upon agreement to have sessions recorded it was requested from participants to provide their signatures on these forms. Tapes and transcriptions were stored in a safe and secure place at the home of the researcher and will be destroyed on successful completion of the research report. This was verbally explained to the participants and included in the Participant Information Sheet.

CONCLUSION

The overall aim of this research was to establish psychologists' perceptions on the self esteem of HIV positive clients who have been exposed to HIV-related stigma. This was done by means of a qualitative exploratory research design. Data was collected through interviewing eight psychologists who have a minimum of two years experience in working with individuals who are HIV positive. Interviews were semi-structured and conducted with the use of open-ended questions. The interviews were transcribed and then coded and analysed according to the methodology of thematic content analysis. Ethical considerations were taken into account at all levels of the research process and were discussed with all participants.

CHAPTER 4: PRESENTATION OF FINDINGS

This chapter provides an analysis of the data collected from participants. Three main themes have been identified from these findings. These include participants' construction of the self-esteem of people living with HIV and AIDS; HIV-related factors that contribute to the self-esteem of people living with HIV and AIDS and recommendations for the development and preservation of the self-esteem of people living with HIV and AIDS. Participants' construction of the self-esteem of people living with HIV is discussed first. This theme relays the variation in understanding the manner in which HIV-related stigma impacts on the self-esteem of people living with HIV and AIDS. Different factors relating to HIV-related stigma that may impact the construct of the self-esteem have been identified and will be the focus of discussion in the next theme. Recommendations regarding the preservation and development of the self-esteem of individuals affected by HIV-related stigma have been elicited from discussion in the above-mentioned themes. This will be the third theme of discussion.

CONSTRUCTING THE SELF-ESTEEM OF THE INDIVIDUAL WITH HIV

Participants of this study provided a variation in perspectives to the manner in which the self-esteem of individuals who are HIV positive is constructed. This theme involves an exploration of these accounts in order to construct the self-esteem of people living with HIV. In achievement of this understanding two sub-themes have been identified namely: understanding the relationship between HIV-related stigma and self-esteem, and the evolving nature of the self-esteem of people who are HIV positive.

Understanding the relationship between HIV-related stigma and the self-esteem of individuals who are HIV positive

Exploration of participant responses illustrate that, in keeping with the literature (Roberts, Ciesla, Direnfeld and Hewitt, 2001 & Van Zyl, Cronje & Payze, 2006), stigma does have an effect on the self-esteem of people living with HIV, as it is internalised into these individual's evaluation of themselves and thus impacting on such person's self perceptions and how they interact in the world. Six participants acknowledged that HIV- related stigma affect the development of the self-esteem of the individual with HIV. The following two accounts best describes this:

> Oh yes, there is, I think so. We could say that at this stage, HIV is normalised, it is like a normal condition that people know about

> but it still carries a lot of stigma and it is that particular stigma that makes people feel that I am not good enough and if the society thinks that HIV happens to certain people who were not good enough in terms of their behaviour, then it does definitely effect the way one evaluates oneself so the blame issue effects the peoples self-esteem. **(Participant 1)**

> I think there is, because people will tell you that, people who have been HIV positive for quite some time. Even though they are seeming to be coping with it, they get moments when they forget about it, and some clients will say they get sensitive, as some of them are teachers and some at working, when people start discussing HIV, they do not know how to get into conservation, as they feel that people can see that if I keep quiet, then people also suspect if I talk too much, they do not know how to react, so they become withdrawn in a way, because that withdrawal, you still trying to make sense of how should be, so your self-esteem drops and I have situations where when they start having opportunistic infections, like shingles or anything that can be seen by other people, you will find that those people will make comments relating to HIV, "okay, you got this, I hope it is not something like …, so they find it difficult to defend at that particular moment but it stays with them and they feel oh my goodness, maybe people are looking at me and thinking this, and actually I know it's this so their self-esteem does get affected.
> **(Participant 2)**

The above responses reflect the perception HIV positive people have of society's views of a person who is HIV positive or what people with HIV can expect when their HIV positive diagnosis is made public. The perception is that people perceive them as "not good enough" and/or "that an HIV positive diagnosis is the result of irresponsible behaviour"**.** These negative perceptions and experiences from society due to the HIV positive diagnosis result in the person who is HIV positive to question his or her self worth. This is in accordance with Goffman's (1963) view that both the negative reactions anticipated or experienced by stigmatised people and their own awareness of their violation of social norms by possessing a stigmatising attribute that contribute to negative evaluations of self and a loss of self-esteem.

Although most participants believed that HIV-related stigma does impact the self-esteem of individuals who are HIV positive, dissimilarities to the manner in which HIV-related stigma is experienced by these individuals have been identified. In other words, for some HIV-related stigma is experienced and perceived in a manner that results in a decrease in self-esteem, whereas others use the experience to positively re-evaluate themselves. The following account by participant 2 demonstrates this:

> Yes, there is a sense of reflecting, a lot of reflecting on your life and where you find yourself and it can go two ways, self reflection, and some become a positive thing, for others not so positive, it takes them to a dip, they feel they cannot handle life, they become suicidal, but for others it becomes a sense of oh my goodness, I am lucky I know now I can take care of my life differently. **(Participant 2)**

Variation in the experience of HIV-related stigma is a phenomenon often neglected in the literature (Deacon et al., 2005; Visser, Kershaw, Makin, & Forsyth, 2008). Research conducted by Visser et al., (2008) is in accordance with the phenomenon that stigma is not one all encompassing entity, but depends on the perspective of the infected individual as well as the non-infected people around them.

The variation in the experience of HIV-related stigma results in a variation to the relationship between HIV-related stigma and the self-esteem of individuals who are HIV positive. It is argued that experiences resulting in stigma due to an individual's HIV positive status causes the development of a negative self-esteem, evident in the following statements by participants 4 and 7.

> Really low, because of the stigma attached. The white Afrikaans homosexual men, it is virtually nothing.
> I think they struggle with that. I think they see themselves as quite different. Some of them see themselves as victims others have recognised that this is because of their own behaviour. But I think that they see themselves as quite different leading very different lives and then also quite abnormal within what is suppose to be normal in society. Within their own homosexual community they're fine, they're very supportive of each other, there is lots of social support there. But compared to the larger population of the so called normal behaviour, there is just no comparison at all. **(Participant 4)**

> There are people especially in the initial stages, when I say the initial stages, just after they have found out that they are HIV positive, after they have received results that they are HIV positive. The self-esteem tends to plummet just a little bit. The person feels terrible about themselves. **(Participant 7)**

However participants 2 and 3 found that some of their HIV positive clients demonstrated an increased self-esteem.

> I am just thinking of a young lady that I am seeing, she discovered that she is HIV positive about two weeks ago, she came here and told me that she has made a decision to re-evaluate her life now and made a decision, that one: she is going to change her home, she went shopping and changed the colours of her bedroom and all of that, and she bought a bigger fridge as she has decided to eat healthy and needs to store all the stuff in the fridge and in that case it is a positive way of re-evaluating one's life, take care of one's self and be positive about life.

(Participant 2)

> There are lots of things that influence disclosure. And it was very interesting that he found himself at the point where he wished to disclose to his family that he is HIV positive. And that in fact that it had become a matter of pride, so there was an interesting twist to watch something that can get someone down by to become something that he really wanted to do. And then funny enough it drove him to go publicly, and I mean publicly in the bigger scheme of things and do something quite overt about the HIV. It lingers to the positive living kinda stuff. (**Participant 3)**

Participants arguing that HIV-related stigma results in the decrease of self-esteem of individuals with HIV attribute the decrease directly to the feeling of diminished self worth as a result of prejudice following on the stigma associated with HIV. However, some participants reflected on the turning point the experiences associated with their HIV diagnosis has brought in the lives of some of their clients. Such turning points include engaging in activities such as making alterations to their immediate environment or the need to share their life experiences with other people.

It appears that individuals who are HIV positive are affected by the stigma associated with HIV, but on variant levels based on aspects such as personal experiences or achievements over time. While the literature supports the assertion that success in relation to individual capability and social status accounts for self-esteem (Buckley & Carter, 2005; Greenwald & Banaji, 1995 & Katz, Joiner & Kwon, 2002), participants' accounts indicate that it is important to keep in mind that for some the stigma associated with an HIV diagnosis is likely to cause a decrease in self evaluation, but others do experience the diagnosis as a revelation in their lives and therefore present more valuable self evaluating characteristics.

The above accounts of the variations in the impact of HIV-related stigma to the self-esteem of individuals who are HIV positive highlights the importance of the cognitive processes to the perception of HIV-related stigma in different individuals (Bandura, 1997). The importance of cognition to the development of self-esteem among individuals affected or infected by the stigma associated with HIV is highlighted. As Bandura (1986 and 1989) postulate that through self evaluation a person determines his or her circumstances and thoughts determines self evaluation. In other words, through cognitive restructuring individuals' interpretation of their circumstances can change when their thoughts change. According to Bandura (1986 & 1989) the cognitive process by which people decide how to interpret phenomena, is determined by symbols (verbal / non-verbal). Cognitive factors greatly influence the observations of environmental events, the manner in which they are

interpreted, their effects, the emotional impact and motivation power it might have and how this information will be organised for future use (Bandura 1986 & 1989).

Throughout this theme it has been highlighted that the stigmatic experience of people living with HIV can be influenced by multiple contexts and multiple processes. Certain individuals or groups therefore experience HIV-related stigma different from others. These individuals or groups can also experience individual as well as contextual changes within themselves, for example, a change in environment, relationships, as well as age. Such changes in turn can result in a change in how people with HIV experience HIV-related stigma. These individual changes can lead to a fluctuation in the construct of self-esteem. The following sub-theme provides a more detailed account of participants' construct of the self-esteem of individuals who are HIV positive, particulary the evolving nature of these constructs.

The evolving nature of the self-esteem of the individual with HIV

As noted in the previous paragraph, according to the extracted data HIV-related stigma does impact the self-esteem of individuals with HIV. However, personal or contextual factors may cause certain forms of stigma to be perceived differently at different times. From the analysis it is understood that a description of the self-esteem of the individual with HIV has an evolving nature depending on contextual circumstances, individual characteristics, environmental influences and social circumstances. Participants' views regarding the manner in which the self-esteem of the individual with HIV changes will be highlighted in this sub-theme. Five of the participants shared this view. According the following two quotes extracted from interviews with participants 2, and 8, even though HIV-related stigma is likely to have a negative effect on the self-esteem of those infected, perceptions of the discrimination experienced may be influenced by factors such as personal development, levels of support or stage of the disease.

> I would not say there is a specific profile because it depends on the individual and depends on how, where the person is at in their lives at that particular time when they get the news and most of the time, you find the self-esteem will naturally take a dip, because the person feels a sense of loss, they feel that people can see that they are HIV positive, there is a sense of feeling uncomfortable with oneself and a sense of wanting to give up on one's dreams, what one believes in and how one defines themselves ... **(Participant 2)**

> Varied depending on factors such as stage of the disease, levels of support etc. Generally low, especially for those who experiences rejection after disclosure. **(Participant 8)**

Factors such as personal development, levels of support or stage of the disease that may have an influence on the perceived discrimination as expressed above may also impact on the development of the self-esteem (Katz, 1998). Personal factors impacting on the manner in which HIV-related stigma is experienced may therefore result in changes to the self-esteem. The self-esteem of individuals with HIV can therefore be characterised as evolving in nature. This was supported by participant 1, who highlighted that in addition to the phase or context in a person's life factors such as age, the social environment and relationships with peers too may play an integral role to the development of the self-esteem of individuals who are HIV positive. Participant 1 further added that this is the case because these factors impacts on the self-esteem of most people whether the person has been diagnosed with HIV or not.

> I am trying to say there is no way I can say that people with HIV have a negative self-esteem or people with HIV have a positive self-esteem, it depends on a number of things,
> Well, I guess it depends because of self-esteem, self-esteem is not static, it changes, it changes depending on your age, it changes depending on your environment, it changes, you've got your kind of self-esteem when you with peers, you've got your self-esteem when you are with your friends and I would imagine that this would be the same for HIV positive people, you would have your self-esteem with HIV positive people, so that could influence your self-esteem and it depends on how you felt about yourself before you knew about your HIV status **(Participant 1).**

This was supported by participant 3 and 7. Participant 3 found that the manner in which one of his clients related to his HIV diagnosis was consistent with his phase of life. According participant 7 the initial diagnosis of HIV is most likely to result in feelings of diminished pride. Adjustment to the diagnosis, however, can result in a change in the individual's functioning at a later stage. In other words he agreed with participant 8 that the stage of the HIV condition the person is in influences his or her evaluation of the self. The differentiation in effect of being in stage one in relation to stage four may have on the self-esteem can be due to the level of stigma being different at different stages of the disease as contended by Alonzo & Reynolds (1995).

> I am thinking of somebody who I saw for three years. He acquired the HIV, just going into the midlife crisis. So it sparked of this really horrendous midlife crisis and he'd been diagnosed about a year before I started seeing him. And what it really had done for him was that it really brought to the fore the sense of "what am I worth?" It drenched up something rather than bringing it about. Where it kind of curled up all the stuff of changed careers around twenty times, came out of the closet sort of mid thirties, so a lot of

> that stuff around self worth, but in that case it was also linked to the emotional midlife crisis, which automatically involves the self-esteem **(Participant 3)**.
>
> I think that when you are in that crisis that you just found out that you are HIV positive, pride would be the last thing on your mind. But I think pride that can be observed in people who are HIV positive is at a later stage, after they have adjusted **(Participant 7)**.

The self-esteem of all people with HIV therefore cannot be placed in one specific category that is, a category of low or high self-esteem. It is important to take individual characteristics as well as contextual factors into consideration when attempting to establish the relationship between the self-esteem and HIV-related stigma. Examples of contextual factors that may be different for different people with HIV are women who experience different responses regarding their HIV status or HIV positive individuals who have different experiences regarding their HIV positive status at the workplace (which will be discussed in more detail in following themes). The person who experiences more support at home from her spouse or the person who works in a supporting work environment is more likely to have a more positive self-evaluation due to his or her supportive context. However, the individual who experiences the opposite may feel disempowered and consequently extend this sense of disempowerment to his or her self evaluation to a devalued internal concept. Beliefs regarding the ever changing nature of the self-esteem are in keeping with literature that describes self-esteem as a temporary psychological condition otherwise referred to as state self-esteem (Rubin & Hewstone, 1998; Jonsson, 2006). This position holds that an individual's self construct is primarily influenced by the situation at hand.

FACTORS ASSOCIATED WITH HIV-RELATED STIGMA THAT IMPACT ON THE SELF-ESTEEM OF PEOPLE WHO ARE HIV POSITIVE

In the previous theme it was concluded that HIV-related stigma does impact on the self-esteem of individuals who are HIV positive. In this theme the researcher will elicit the factors associated with HIV-related stigma highlighted by the participants that impact on the self-esteem of individuals who are HIV positive.

Personality Organisation

The sub-theme personality organisation was used to classify personal characteristics that contribute to the response individuals who are HIV positive have toward stigmatising

experiences from society. Participants considered personality characteristics an important factor to understanding the self-esteem of people who are HIV positive. Personality organisation encompass internal resources that contribute to a person's level of resiliency against internally threatening facets of life. In other words, participants described an individual's personality organisation as a predetermining factor to the manner in which the person who is HIV positive will respond to the stigmatising reactions in their surroundings. McWilliams (1994) postulates that personality organisation comprises of two dimensions. The first involves a person's individuation or extent of pathology and the second relates to his or her type of character. The participants' discussions around personality however involved internal resources contributing to personal resiliency. It should therefore be noted that this factor therefore does not relate to the theoretical meaning of personality organisation, but rather participants account of the personality of their clients who are HIV positive.

Participants highlighted personality organisation as an important factor to personal well-being in any person's life. The importance of this understanding when investigating the self-esteem of individuals who are HIV positive was expressed by four of the research participants, the following two participants' best described this:

> No, no, as I said it depends on the person's personality, where the person finds themselves at that particular moment and what is going on in their lives, so if the person has been in a situation where things are not going okay, it becomes more difficult to be positive about being HIV positive, so if there is something a person is holding on to, so they are able to use that as an operating basis, for instance for her things are going well at work, she is where she wants to be in her career, so I think that is her operating base **(Participant 1).**

> And like any other trauma then, depends on your personal resources. What kind of person are you. Are you the type of person whose resiliency is low or are you the kind of person that can withstand certain things. So personal resources would be quite critical **(Participant 2):**

According the above accounts extracted from the data an individual's personality organisation serve as a platform to challenging circumstances, such as social isolation. In other words an understanding of the personality organisation of people living with HIV can inform how stigmatising reactions from society may impact the person's self evaluation. The person who has a strong personality organisation, or put differently, has a strong resiliency level, as quoted by participant 2, might react better to isolation from society and in turn not allow these situations to result in negative self evaluation. Conversely, the individual who has

a weak personality organisation may experience the same isolation, but due to a weak resiliency level, would allow the stigma to create negative self evaluation.

The above is in accordance with the literature that finds it is important to have an understanding of personality as it can be useful to the understanding of the psychological welfare of human beings (Lanyon and Goodstein, 1982). Jonsson (2006) postulates that an individual's personality organisation can serve as a disposition that can impact on individual experiences and actions. In other words the self esteem of individuals who are HIV can be predisposed by personality constructs. From this account it can be deduced that the manner by which an individual evaluates diverse situations such as the stigmatising effects of an HIV diagnosis can be informed by pre-existing traits such as his or her personality organisation.

The above is in agreement with research by Roberts et al., (2001) who found no significant relationship between acute life events experienced by HIV positive individuals and aspects of neuroticism such as low self-esteem, if the person has a stable personality organisation, rather the long term effects of their circumstances impact more on the feelings of worth. Longstanding life events, such as unequal power relations amongst those infected with HIV in relation to the HIV negative segment of the population, however, may impact on this internal resource base. The vulnerability of these internal resources may in turn influence the self evaluating abilities of those who are HIV positve.

Levels of accessed social support as a determinant of changes in the self-esteem

Self belief is therefore dependant on a considerable level of social support. In order for a person to overcome the stresses his or her life path takes, he or she requires social support to give meaning and worth to what they do **(**Bandura , 1986 & 1989).

Participants have identified that an HIV positive individual's reactions to stigma are not only pre-determined by a specific personality organisation but that adequate social support serves as a strong sustaining factor as to how a person's personality organisation can uphold an individual who is HIV positive's self evaluation. This sub theme therefore serves as a description of the acceptance and support or rejection (overt or subtle) the person with HIV experiences and how this relates to the formation of their self-esteem. The importance of social support to the formation or maintenance of the self-esteem was expressed by two of the respondents that is, participants 1 and 2 as indicated below:

> ... the kind of social support that they have, what is happening in their lives at that particular moment, so if a person still has a good relationship, things are looking well at work, that type of things, if

> they still feel a sense of worthiness, a sense of belonging, a sense of being functional **(Participant 2)** .

> if a person has pride in themselves, they will still have pride in themselves even after they test positive and also with a good support system, with knowing other people who are living with HIV and knowing that there are living their lives to the fullest, it sort of changes one and that is why HIV positive people encouraged to join support groups – helps work with that internalised stigma because in support groups, that is where you are speak and meet other people who are living with HIV and they share and you realise that you are not alone. **(Participant 1)**

The afore-mentioned accounts demonstrate good social support as an important contributing factor to the individual with HIV feeling worthy of him or herself. Lack of social support may contribute to the individual feeling isolated and distant from his or her particular community be that the community at church or at work, for example. This is in agreement with the literature that has found that HIV-related stigma directly hurts people who lose community support due to their HIV infection (Skinner & Mfecane, 2004). Furthermore, Chu (1969) indicate that interaction with significant others is an important factor to the development of peoples' self evaluation as the sense of self is developed based on the treatment of these significant others. From this it shows that the widespread isolation people who are HIV positive experience from significant others in their communities, can result in the development of a devalued sense of self, based on the devalued responses received from people perceived to be important to them (Rankin, Brennan, Schell, Laviva and Rankin, 2005).

Research by Cloete, Simbayia, Kalichmanb, Strebel and Henda (2008) regarding stigma and discrimination experienced by homosexual males in South Africa have found that HIV positive homosexual males reported considerable levels of support from their family and friends. Participants of this study made specific reference to homosexual males being among those that experience the most discrimination from family and friends, which will be discussed in more detail later in this paper. The contradiction between these findings highlights the importance of being mindful of the possibility that stigmatic experiences may be different for different individuals or groups, as highlighted in theme one of this study. Hence, it would also be important to be mindful of differentiating concerns when considering the factors associated with HIV-related stigma that may impact on the self-esteem of people who are HIV positive.

The fact that data of this study was obtained from psychologists can be seen as an influencing factor to the differentiation of these results to that of Cloete et al., (2008). The

clients that these psychologists reflected on are most likely to be those members of society who have been experiencing diminished social support, hence their decision to seek counselling. Social isolation may therefore not be the experience of all homosexual men who are HIV positive. Furthermore, as will be indicated in one of the following themes, participants indicated their clients to have high levels of internalised stigma. According to Goffman (1963) internalised stigma symbols contribute to identity degrading, resulting in subsequent devaluing of individuals, thus affecting their social interactions. Limited social interaction results in these individuals being exposed to a great deal of social isolation and alienation. Internalised stigma should therefore be considered as an influencing factor to the experience of social isolation and therefore the reduction of self-esteem and self efficacy of individuals living with HIV and AIDS.

The quality of the relationship with family members

A further sub-theme within this theme is the quality of relationships with family members. This sub-theme relates to the impact a lack of family support brought about by HIV-related stigma may have on the self-esteem of people living with HIV. There is clear evidence from participants' responses that families play an important role in providing support and care for people living with HIV and AIDS. This is in keeping with research that has found that in the majority of developing countries families are the major source of support when somebody falls ill (Rankin et al., 2005). Clients from five of the interviewed participants have, however, indicated that family responses are not positive and that HIV-infected members of the family find themselves stigmatised and discriminated against within the home. The following accounts from participants 6 and 4 best describe this:

> Those who are open about their status they complain that they don't find support. You can imagine some of the partners, who should really be the one who should be supportive, but if that person that you feel safe with, in terms of that person not being supportive that creates problems **(Participant 6).**

> As I have said the majority of clients who I have seen have not disclosed to their family. They suspect that it is a no go area, it's not to be discussed. In fact the one chap got extremely sick. I actually said, "don't you think that it's time the family should know". He said "the family can find out at the funeral." **(Participant 4).**

The above account demonstrates that fear of discrimination limits the possibility of disclosure to family even if they can serve as potential sources of support, which can also be observed from the response from participant 5 below:

> Most of them want to hide it from the family. But once they tell the family they are actually surprised by the support that they get from the family.
> But most of the time they are hiding it from the family so if they are taking medication they do not take it regularly, because they are scared. But once they tell the family it is almost like now I can just be myself and I can share my worries **(Participant 5)**.

The above account suggests that often HIV positive individuals' fear of isolation creates a reluctance to disclose their status which, in turn, denies them the possibility of comfort a family can provide in times of being ostracised by society. This is in keeping with the literature which shows that the fear of discrimination has been shown to create problems for disclosure, since disclosure has the common reaction of rejection, leaving the person living with HIV alone (Skinner & Mfecane, 2004). Participant 1 is in agreement with this but adds that 'family stigma', that is stigma family members of the individual who is HIV positive experience, is often the cause to stigmatisation experienced by the HIV positive family member.

> Due to the "family stigma" A family member being diagnosed associated with disappointment. One family member would be disappointed in another family member for being diagnosed HIV positive. This in turn results in the HIV positive member with HIV developing disappointment within the self. **(Participant 1)**

The above account by participant 1 demonstrated that the experience of disappointment from the family by people living with HIV and creates internal disappointment for that person. Such disappointment experienced in the form of discrimination at home can cause the individual with HIV to develop a negative self evaluation. Excerpts from participants 4, 7 and 8 were in agreement to this:

> Then I think support would be one of the most crucial things when it comes to someone who is HIV positive self-esteem survives that initial experience of finding out. If there are people who are interested in you, people who you can talk to, to provide some kind of support by just being there helps a lot. **(Participant 4)**

> My sense is always, rightly or wrongly so family is a place that you can expect love and protection or so when a negative response comes from someone who is in the family it tends to be more painful.
> It can be more devastating than from a stranger. So if you are stigmatised by family it is almost will I go to them if the negative

> response comes from the people whom I have considered to be a sanctuary **(Participant 7).**
>
> The impact of stigma from the home and workplace may be similar. The stigmatised are often depressed which then lowers their esteem **(Participant 8)**.

In response to the prompt: "how does not having the closeness of the family or that feeling of there is no way that my family will understand me makes them (individuals who are HIV positive) feel about themselves, this participant continued by stating:

> Oh, dreadful. You get so much in terms of self-esteem within the family that it is a huge loss the fact that they can't disclose. At the moment there is a level of acceptance within the family of them. But if they disclose they would lose the little bit that they've got and they are not prepared to do that **(Participant 4)**.

The above accounts are in keeping with literature which states that family has a fundamental impact on self-esteem. The perceived value of the approval of the family can be so powerful that it allows issues such as social success to lose value (Mruk, 2006). In other words, vulnerability due to stigma the individual with HIV experiences within the family can result in the magnitude of lack of support from the family to have a stronger weighting than the perceived stigmatisation from society. Likewise the weighting of support from the family can have a stronger influence on the individual with HIV's sense of self worth, despite stigmatisation experienced from society. Below are the accounts by participants 1 and 2:

> I think a lot can be attributed to the husband support, you understand, so the way she is, the way she carries herself, only the husband who knows, nobody else knows, you can see that she is being positive about it, she has that sense of pride of herself because she is still, even though the diagnosis is there, nothing has changed in her life, the kind of social support that they have, what is happening in their lives at that particular moment, so if a person still has a good relationship, things are looking well at work, that type of things, if they still feel a sense of worthiness, a sense of belonging, a sense of being functional **(Participant 2)**.
>
> Sometimes it does bring families together. It brings people closer and people feel that we've got to support this member of the family **(Participant 1)**.

From the above discussion it can be said that family support plays an integral role in the development and perseverance of self-esteem among individuals who are HIV positive. The lack of support from family due to HIV-related stigma and discrimination can therefore cause the individual with HIV to negatively evaluate him or herself.

Appraisal of capabilities from society

Appraisal of capabilities is a second sub-theme within the sub-theme "Levels of accessed social support as a determinant of changes in the self-esteem". Discussion around this sub-theme relates to peoples beliefs about the manner in which their capabilities affect what they choose to do, how much effort they mobilise, how long they will persevere in the face of difficulties, whether they engage in self debilitating or self encouraging thought patterns, and the amount of pressure they experience in taxing situations. For the purpose of this study this discussion will primarily focus on the relationship between belief in capabilities and engaging in self debilitating or self encouraging thought patterns. Three participants' responses indicated that HIV positive people's evaluations of their capabilities are dependent on the perceived evaluation of others and the self's comparison with others.

> Within in my experience with clients that I have dealt with, there is a sense that they have lost something, most of all they have lost a sense that they are going to live for a very long time. That is the major one, but over and above that they have lost control over a number of issues. Their choices have become a bit limited. So compared to people who are HIV negative, people who are HIV positive they feel that they have lost certain things that are quite substantial in their lives. But then from time to time in the work place, it becomes a part of your reality, that you are overlooked for a promotion, you are overlooked for some training and so on. But that comparison comes in when the person asks "Was I not chosen for this course or this just because I am HIV positive **(Participant 7)**.

> Everybody thinks, I still want to register for that degree, because you know I have always wanted to have that. But for people who are HIV positive, its like, why should I register for that, I might at the time that I graduate be sick and dying, so it takes an extra effort to encourage them to do things that they always wanted to do, otherwise they think there is no point, it is not going to benefit me in life, I will die so people with HIV and especially in terms of relationships again compared to people who do not have relationships **(Participant 1)**

From the above it can be deduced that the nature of the HI virus, that is, it being an incurable condition, cause individuals who are HIV positive to believe that they cannot make long term investments. The fate of their physical well-being excludes them from engaging in long term investments. This is partly due to society's perception that people living with HIV and AIDS possess fewer abilities due to the fact that HIV is a degenerative condition. Beliefs around HIV being degenerative or incurable contribute to HIV-related stigma (ICRW, 2005). The stigma associated with HIV being an incurable condition cause people who are HIV positive to believe that they cannot exert control over their personal motivation, thought processes, emotional states and patterns of behaviour.

Participant 8 agreed with the views of participant 1 and 7 but added that the physical weakening of the individual with HIV further adds to the diminished evaluation they have of their own capabilities as well as the views that society has.

> Given the negative connotations associated with the disease, the general view they have of themselves is that they are different to others. This is especially true for those who have begun wasting physically as their disease stage deteriorate **(Participant 8)**.

What can be understood from the above is that individuals who are HIV positive may experience less stigma when people cannot physically identify their condition. Hence, the more visible the signs and symptoms of the virus, the more likely the person is to experience negative evaluations from society which consequently allows them to feel that society thinks less of them which in turn results in HIV positive individuals thinking less of themselves.

Individuals' comparisons of themselves with other members of society otherwise referred to as interpersonal comparisons are reflected appraisals, and social comparisons (Staples, Shwalbe and Gecas, 1984). The driving force of these formulations is that, since human beings' self-evaluations are dependent in part upon the perceived evaluations of others, and upon comparisons with others, high social regard should engender positive appraisals and in turn correlate positively with self-esteem. In other words, the more people think that others think highly of them, the more highly they are likely to think of themselves and vice versa. People living with HIV and AIDS receive devalued evaluations from the people around them due to the stigma associated with being HIV positive. Hence society entitles people living with HIV and AIDS with a diminished social regard due to negative appraisals they encounter.

Social Identity

Social identity is that part of an individual's self-concept which derives from his or her knowledge of his or her membership in a social group, together with the value and emotional significance attached to that group membership (Tajfel, 1981, p 255 in Katz et al., 2002). Data collected from two participants suggest that identification with a specific social group such as being gay and ones gender association predisposes a person who is HIV positive to an increased risk to distress associated with a devalued self evaluation. This can be identified from the following response of participant 4:

> Really low, because of the stigma attached. The white Afrikaans homosexual men, it is virtually nothing. I am not sure if they have pride at all. They have reconciled to the fact that they are gay. A

> lot of people know that they are gay. So their social groups and some people in the work situation would be aware that they are gay, but none of them have told their family of their status **(Participant 4)**.

These accounts are in keeping with research conducted with homosexual men suggesting that sexual orientation link membership in these devalued social groups to emotional well-being (Katz et al, 2002). They postulate that sexual minority status can have profound effects on the ways in which homosexual individuals feel about themselves. Results of one study with homosexual HIV positive men suggested that the societal stigma against homosexual men was associated with lower self evaluation (Frable, Wortman, & Joseph, 1997). According to participant 4 the diminished self-worth homosexual men who are HIV positive possess is exacerbated by HIV-related stigma.

Another group of people who are exposed to a higher level of HIV-related stigma experience due to their social identity are women. Participant responses suggest that women are subjected to more stigmatisation than men due to the fact that women hold less ascribed status, power, and access to resources than men do. This can be identified in the following account:

> Yes women and men do experience stigma of HIV differently. Firstly, because men and women experience almost everything differently in society. Men have a privilege that when bad things happen to them, because we think that they are strong they should manage with that. And they grow up with that attitude that I can handle anything. I can handle situations like HIV/AIDS. And they do, believe you me. I have a feeling that men are better able to handle HIV compared to women. It does not destroy them psychologically the way it destroys women. It does not affect their self-esteem the way it affects women's self-esteem. Because they have other areas in their lives where they can be successful and compensate for this particular self-esteem. They have access to better opportunities **(Participant 1)**.

From the above accounts HIV can be described as a social condition. In other words, whatever has already been constructed in society will overlap with what is happening with individuals who are HIV positive and consequently their self-esteem. Although significant progress toward gender equality have been made over the past few decades, women continue to hold less ascribed status, power, and access to resources than men do (Katz et al., 2002). In other words, the gender inequality and the prejudice expressed against homosexuals makes individuals with these social identities as well as an HIV positive status doubly impacted by the pressures of society which in turn mean that their self-esteem can be doubly impacted upon as well.

The inability to comply with believed social standards

The inability to comply with believed social standards is a further sub-theme to the sub-theme social identity. The term social standards have been used to describe social challenges or expectations such as the ability to buy a house, the ideals of obtaining tertiary qualifications or the prospects of bearing a child as extracted from the data. According to the data people living with HIV believe that they are unable to meet these standards. According participants verbalisations people who are HIV positive's belief in their inability to meet these social expectations influence the manner in which they compare themselves to those members of society that are not HIV positive. They contend that aspects such as the incurability of the HIV condition creates the belief that long term ideals such as those mentioned above infringes on their prospects to attain these goals. These beliefs affect the manner in which people who live with HIV evaluate themselves. This is in agreement to Katz's (1998) belief that success at meeting life's challenges, high esteem related to achievement, significance in the eyes of others, virtue (adhering to moral standards), and competence are important contributes to self esteem. The following three accounts from the data are in accordance with this:

> I am thinking of somebody who I saw for three years. He acquired the HIV, just going into the midlife crisis. So it sparked of this really horrendous midlife crisis and he'd been diagnosed about a year before I started seeing him. And what it really had done for him was that it really brought to the fore the sense of "what am I worth?" It drenched up something rather than bringing it about. Where it kind of curled up all the stuff of changed careers around twenty times, came out of the closet sort of mid thirties, so a lot of that stuff around self worth, but in that case it was also linked to the emotional midlife crisis, which automatically involves the self-esteem **(Participant 3)**

> Because you can never be HIV negative again, so it takes away something, with a whole lot of associated realities. Practically, it is about can you have kids, can you get married. Your relationships, private life, how is it going to be affected. So it affects a person in a big way. **(Participant 7)**
> Given the negative connotations associated with the disease, the general view they have of themselves is that they are different to others (**Participant 08)**

According the above people who are HIV positive believe that they do not have the ability to meet the demands of society due to their HIV status and therefore evaluate themselves as less worthy to individuals who do not have a life threatening diagnosis such as HIV. This is in agreement with Katz' (1998) argument that success as perceived by society is

one of the most important aspects to an individual's self-esteem. The belief of people who are HIV positive regarding their inability to meet society's standards stems from the stigma associated with HIV being an incurable condition, which in turn results in a negative self evaluation.

The individuals sense of mortality

Participants' verbalised that the self-esteem or pride of an individual who is HIV positive is strongly related to risk factors, in this case the risk of dying. HIV-related stigma therefore causes people who are HIV positive to believe that they identify with the terminally ill. Data from two participants' accounts revealed this association between self-esteem and the fear of mortality. This is in accordance with the literature which reveals that mortality had become a key factor in the development of HIV- related stigma (ICRW, 2005). The following accounts are indicative of this:

> The ones I have seen, self-esteem is low. Whatever information you give them, there is that thing where they feel they are going to die **(Participant 6)**.

> It's about survival, but you get to that point after you have fought to be able to survive. It is difficult to have a sense of pride while you are struggling to have a sense of being alive. As we said the news that one is HIV positive almost invariably confronts one with mortality **(Participant 7)**.

It can therefore be deduced that the feeling of hopelessness in relation to the fear of death should be taken into consideration when attempting to establish the relationship between the self-esteem and negative external influences such as stigma for individuals who are HIV positive. This can be substantiated by Stamatakis, Lynch, Everson, Raghunathan, Salonen & Kaplan (2003), who contend that self-esteem is considered to be importantly associated with both psychosocial states as well as physical health. Others have suggested that low self-esteem is a core feature of health inequalities (Stamatakis et al., 2003).

Diminished Status

Two additional sub-themes have been identified in this sub-theme namely; diminished social status and diminished occupational status.

Diminished social status

The above sub-theme relates to participants' accounts indicating that individuals with HIV take up the role of appraisals assigned to them as indicated in the previous theme.

According to Buckley and Carter (2005) a person's positive or negative self-evaluation occur either through taking up the role of appraisals reflected upon them or more directly through comparison with others. In either case, self-esteem is based upon an interpersonal process that utilises hierarchically organised and socially recognisable positions as the frame of reference (Staples et al, 1984). Through the stigma associated with individuals who are HIV positive society places them at the bottom of these social hierarchies despite any personal achievements.

> I think the prejudices of society. This one particular chap is quite a senior guy in one of the audit firms. There are a lot of people who are very supportive of him. He is very gay, very feminine. He has openly admitted that he is gay. He dresses like a gay man. He is extremely well groomed. He drives a beautiful car and yet he gets huge, huge prejudices from other people within the company, the touch guys. They don't want him there. And when his HIV status was confirmed he actually felt it necessary to tell management. He felt that he should actually be upfront about it. And the response was pathetic. They didn't want him there, but they could not get rid of him because he is too damn good. Very intelligent, pleasant guy. In fact one of the nicest, most interesting clients I have ever worked with. My sessions with him used to be one of the highlights of my week, just because he such an incredible human being **(Participant 4)**.

> You know for some people it kinda means nothing because I am going to die. Or I have heard some people say that it will all amount to nothing. Or I remember one client say to me, that when I die people will say I was HIV positive, that it will sort of undo the sense of achievement **(Participant 3)**.

Participants indicated that diminishing reactions from society such as indicated in the above excerpts gets internalised by these individuals resulting in them evaluating themselves similar to how society does. This is evident in the reluctance to engage with the general public due to the belief of a negative self worth. This is in accordance with the literature which states that there is no doubt that interpersonal processes form an important base for the self-esteem, and that they are reflected (to some extent) in the relationship between social prestige and self-esteem (Staples et al., 1984).

Occupational status

The sub-theme occupational status refers to participant's beliefs that individuals' self-evaluations arise within such contexts as the workplace therefore the character of occupational conditions should have predictable consequences for individuals' self-esteem. This has been identified in the accounts of three of the interviewed participants, namely participant 1, 4 and 7.

> Because your workplace self-esteem is based on your performance and your relationship with your colleagues. So if you're doing work to the best of your ability and your boss is impressed with you, you will feel good about yourself. If there are colleagues that you feel comfortable with, the environment is homely you will feel good.
> But we know that this is not always the case. Because we know even those people who work in the health sector, they themselves carry a lot of stigma. They will stigmatise against their colleagues and you will be surprised. I thought they were nurses so they should understand or I thought they were doctors, so they should understand how they can discriminate against their colleagues. Now this becomes even more problematic for people who have nothing to do at all with HIV and health and then you go and disclose your status to your colleagues and you work at Edgars and people do not really have the privilege that we have of reading about the stuff. So because we are dealing with people who do not know about the stuff will not be that supportive. Unless in their own personal lives they have come in contact with HIV positive people **(Participant 1)**.

According the above, treatment at the workplace gets affected by an HIV positive diagnosis. Participants highlighted experiences such as colleagues conversing about the individual who is HIV positive behind their back, non-recognition of such an individual's performance by his superiors and being excluded from certain benefits. Due the impact of factors such as performance at work and relationships with colleagues on the development of an individual's self-esteem, the experience of the above-mentioned factors due to an HIV positive diagnosis can have a negative effect on such individual's evaluation of the self (Bagozzi, 1980 & Ardt & Greenberg, 1999). Participant 4 agrees with this:

> I think all of them have been stigmatised within the workplace, which is why they have not disclosed their status. They might be known to be gay. It's just by virtue of the fact they are gay, there is an assumption that they might be HIV positive, so the stigma is high. I would say that they have few relationships that are healthy, positive and supportive and just accepting of who they are. **(Participant 4)**

Participant 7 indicated that due to frequent contact over extended periods of time people develop close relational ties with fellow colleagues. Social exclusion from superiors can therefore have a different effect than the social exclusion experienced from an authoritative figure. A reaction of social isolation due to a colleague's disclosure of HIV status can therefore have a similar disappointing effect as it will have within the family setting.

> There are certain workplaces that try to treat their employees as family. Which has it's own advantages, but also it has it's disadvantages. Because in the same way these are people that are

> close to you, these are people that interact with you on an ongoing basis, these are people that will know when you are not at work. These are people that if you are to get sick at work, which is to raise alarm to the help that you need. So it is almost like there is certain closeness that develops between colleagues. The clearly if you are to experience stigma at the workplace it will impact negatively. Also depending on whether the stigma comes from your seniors or your peers **(Participant 7)**

According the above statements from psychologists regarding the experiences of clients, the hierarchy a person occupies at his or her workplace does not necessarily determine the frame upon which interpersonal relations at the workplace are based. In other words, the social status is not the sole influence of an individual's self-esteem, equally so for individuals who are HIV positive. On the contrary, personal groups rather than status groups appear to be more important at times. According the experiences of the clients of participant 3 and 4 this is however, the area where people who are HIV positive suffer mostly at the workplace. In other words, workplace relations can have a detrimental effect upon the self-esteem of someone who is HIV positive.

Internalised stigma

Internal stigma refers to someone with HIV's thoughts about themselves and how they believe the public perceives someone with HIV. Similar to research by POLICY Project et al., (2003a) two participants stated that people living with HIV and AIDS may impose stigmatising beliefs and actions on themselves. Internal stigma, otherwise referred to as personal stigma, relating to experiences of rejection or fears of rejection are commonly reported in the literature (e.g., Campbell, 2004; Deacon et al., 2005 & POLICY Project et al., 2003a).

According to participants of this study the impact of HIV-related stigma is often associated with victims' internalised notions of HIV. The impact of HIV-related stigma on the self-esteem of individuals who are HIV positive due to individual's internalised notions of HIV and AIDS can be observed in the following two accounts:

> Some of them see themselves as victims others have recognised that this is because of their own behaviour. But I think that they see themselves as quite different leading very different lives and then also quite abnormal within what is suppose to be normal in society **(Participant 4)**.

> And yes there is internal stigma as well. Stigma that people subject themselves to, not knowing whether people would support you or not. People feel bad about having HIV and have this internal stigma. They feel bad about having a deadly virus, they feel bad

> about having had sex, they feel bad about a number of things associated with HIV.
> But there are people who feel guilty once they have HIV because they feel I could of done things differently, I should not of had the number of partners that I had, I should not of slept with that person when I was drunk because that is probably the time when I ended up, not using condoms, I ended up getting HIV, so it is a matter of my status plus a number of things I am now feeling, I am not a good person, otherwise I could of done things differently if I was a good person so that effects your self-esteem and that may feel negative about it **(Participant 1)**.

According to the above two accounts from participants 1 and 4, individuals who are HIV positive often devalue themselves when comparing themselves to members of society in general. This is as a result of their internal beliefs around HIV. These beliefs frequently revolve around these individuals understanding of the contraction of HIV which gets associated with individual life style practices. Individuals who are HIV positive who believe that an HIV positive diagnosis is associated with irresponsible behaviour are therefore more likely to develop negative self-evaluations due to the guilt associated with their HIV infection.

RECOMMENDATIONS FOR INTERVENTIONS AIMED AT REDUCING HIV-RELATED STIGMA INFLUENCING THE SELF-ESTEEM OF PEOPLE WHO ARE HIV POSITIVE

Participants expressed that HIV-related stigma remains a concerning factor to addressing the impacts of HIV and AIDS in the South African society. Furthermore six of the eight participants felt that there is a relationship between HIV-related stigma and the self-esteem of the individual who is HIV positive. It therefore seems obvious that intervention strategies aimed at addressing the self-esteem of the individual with HIV should involve the empowerment of individuals who are HIV positive in an attempt to eliminate HIV-related stigma and discrimination. Data elicited from participants' expressions regarding the link between stigmatising factors and the self-esteem of individuals who are HIV positive also indicate that it is important for interventions to address stigma in order to deal with the self-esteem of individuals who are HIV positive. The difficulty of the task should not be underestimated, as has been shown by the persistence of discrimination based on factors such as gender and sexual orientation, which also adds to the discrimination experienced by HIV positive individuals.

Participants' recommendations regarding important future aspects to be addressed regarding the self-esteem of individuals who are HIV positive are highlighted in this section. Direct suggestions arising from the interviews with the psychologists and recommendations drawn from the influence of HIV-related stigma on the self-esteem of people who are HIV positive will be discussed interchangeably.

Public investment in individuals who are HIV positive

This theme relates to society's investment in people who are HIV positive as this might have an impact on the stigma associated with an HIV diagnosis. Likewise individuals who are HIV positive's observation of such an investment may have a positive effect on negative self evaluations as the investment from society may create a desire for internal investment.

One way of ensuring positive social exposure of individuals living with HIV can be to empower HIV positive individuals with the ability to conduct workshops regarding HIV and AIDS themselves. This was a strategy emphasised by participant 6. According participant 6 providing HIV positive individuals the opportunity to be accountable for their own projects create an internal feeling of self worth which, in turn, can influence the individual's self-esteem. A similar project was successfully conducted in Cambodia under national strategies and in coordination with local partners, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR, 2006) Training was conducted by professionals which illustrated to the HIV positive individual's an investment in their professional development. Furthermore the HIV positive individuals would also be provided with an opportunity to deal with their altruistic needs whereby they would be provided an opportunity to make a difference in other HIV positive people's lives by sharing their personal experiences with challenges such as the stigma associated with this condition. Participants would be provided the opportunity to explore with activities such as poetry, short story telling, conducting interviews etc. This would provide them an opportunity to explore and find recognition for their own capabilities. Public investment in individuals with HIV does not only have to involve literal public speaking. It may also involve government's investment in individuals who are HIV positive. Research regarding Uganda's success story revealed one of the strategies was the government's investment in people living with AIDS to have a place in parliament. It was HIV positive women's inclusion in parliament that made a significant impact as it consequently also dealt with the gender differentiation (Green et al., 2006).

Participant 1 reflected on a Miss HIV beauty contest that was held in Botswana, which is an illustration of such public investment in individuals who are HIV positive.

> In Botswana they have a beauty contest, they call the miss positive, miss HIV positive, and people who are HIV positive enter that beauty contest and there have been a lot of criticisms in the field of HIV, about whether we should be doing that, should we have a beauty contest at a national level that says HIV positive Miss Botswana, somewhere else I am trying to think, but there are pockets in the society, we need to do positive things to bring the pride back in HIV positive women and men of course but I mainly work with women most of the time and the argument for these initiatives like Miss HIV Botswana, and in
> there are messages that these activities are sending to the society and is it a good thing, is it a positive thing, will it bring you pride, yes, it will make you feel good about yourself, that you still beautiful and pretty and you can win a contest and win a prize **(Participant 1)**,

A beauty contest is connotated as a positive event by the people of the public. Furthermore contestants of a beauty contest are frequently observed in a positive light. In other words, exposure to the public through an event normally perceived positively by society can draw attention away from the negative connotations associated with an HIV diagnosis and refer HIV positive women to positive associations in society. According to participant 1 an event of such nature will instil feelings of pride within HIV positive women.

However, caution should be drawn to challenges faced by such an intervention. One of these would be the issue of disclosure as well as the exposure these individuals would be subjected to. Another important aspect of consideration is that ladies who are willing to expose their status in public in this fashion most likely already have a positive self evaluation. This intervention therefore might not be the most effective strategy for ladies who do not have a positive self evaluation.

Another aspect to consider with respect to this strategy is that such an event might send out a message that there is pride associated with an HIV diagnosis, which can be a contradiction to interventions emphasising HIV prevention. The idea therefore serves as a foundation to the value of public investment in individuals with HIV, but rather than displaying such an intervention by means of a beauty contest, public investment can be demonstrated through the funding of public speaking or motivational speaking events involving individuals who are HIV positive. This would also allow the investment to involve both males and females. Such interventions are most likely to send a message to society that can serve as a mediating factor to stigma associated with HIV positive people. The HIV

positive individuals would have had personal investment to such strategies which can in turn create a sense of pride regarding their own achievements.

Exploration of the existential issues associated with HIV and AIDS

The above-mentioned theme relates to the relationship between mortality and the stigma associated with HIV and AIDS. The relationship between stigma associated with the mortality of an individual who is HIV positive and the self-esteem was a prominent factor expressed by participants of this study. The manner in which HIV positive individuals devalue themselves due to feeling different from the rest of society in relation to their beliefs regarding their prospects of death was strongly emphasised by participants 3 and 4 who expressed the need for further research regarding the existential meaning associated with an HIV positive diagnosis:

> Someone I know did research regarding the meaning of HIV. Meaning in the existential sense. I think in the sense of what am I going to do with this. I suppose in therapy I have seen people get to the point where, I know I am HIV positive. I know I am not going to die tomorrow. Now what? And that is a good place to be. The sense of I am not going to die, now I actually need to get a life. And in some way I think that is kind of work around self-esteem stuff. I suppose it would be valuable to think about building a life or continuing to build a life. What to do with our world. Should I change careers or whatever it is that would valuable? Perhaps it would be important to speak about courage, that this takes courage. of HIV **(Participant 3)**.

> I think the problem lies in the fact that all of them are expecting them to die and they are at various levels of coming to grips with that. If you think in terms of Kuebler-Rosses' bereavement theory. The young good looking male model guys are in the anger stage. The successful guy was doing the kind of bargaining depression stage, where it was "What do I need to do to make myself well, What do I have to learn to make myself not die alone. He was organising himself to make his life lasts for as long as possible. He knows what his CD4 count is at what stage of the virus he is and he does not expect to live beyond forty. And what was interesting was he was struggling with whether he should get a dog. What age should the dog be? Should it be an old dog from the SPCSA, because he is going to die quite soon or should it be a puppy? And he has actually negotiated with his peer group that someone who he trusts would take care of the dog. The dog was a huge dilemma in his life **(Participant 4)**.

The above accounts emphasises the need for research regarding HIV positive individual's understanding to their condition. Results from such research projects can help inform information delivery to individuals who are HIV positive. Providing them with

information regarding the prospects of their future can in turn provide individuals with HIV motivations for long term endeavours. Success in life creates internal value and therefore insight into the possibilities of such success will impact on individuals with HIV feelings of self worth.

Emphasis of treatment strategies

The above mentioned theme has been elicited as participants indicated that emphasis on treatment strategies may have an indirect positive effect on the self-esteem of individuals who are HIV positive. Participants indicated that there is a positive relationship between physical wellness and mental wellness. In other words participant transcriptions have shown a positive association between health behaviours and a positive self evaluation. Two accounts are indicative of this as highlighted below:

> I think definitely there is a positive association there. The higher your self-esteem it would also be associated with a sense of value for yourself, self worth you know. You feel that you are worthy of being taken care of, taking care of yourself. Chances are that it would have a positive effect on your commitment to taking your treatment **(Participant 7)**.

A deduction to be drawn from the above is that emphasis on health behaviours (for example condom use, support group attendance, taking the necessary medication and possibly receiving counselling) would result in an increase in physical health and contribute to an increase in mental health, which could in turn result in a positive self evaluation. The impact of physical deterioration on the manner in which individuals who are HIV positive compare themselves to other members of society was expressed in the following account by participant 8:

> Given the negative connotations associated with the disease, the general view they have of themselves is that they are different to others. This is especially true for those who have began wasting physically as their disease stage deteriorate. **(Participant 8)**

It is well documented that the stigma associated with people living with HIV and AIDS are both disrupting the functioning of communities and complicating prevention and treatment of HIV (Skinner and Mfecane, 2004). The following account from participant 1 is in agreement with this:

> And they don't want to take drugs, because it identifies them as having HIV, even though they have HIV. So there is definitely stigma to taking medication. **(Participant 1)**

Therefore encouraging treatment strategies can contribute to the elevation of the stigma associated with HIV which can in turn impact on the elevation of a negative self view. It is however important to be aware of discriminating against individuals who present physical symptoms of HIV. The emphasis should therefore only be on the positive relation between adhering to HIV medication regimes. The effectiveness of such interventions is most likely to have a positive impact on mental wellbeing as indicated through the research of Skinner and Mfecane (2004) which in turn might impact on components of self evaluation.

Educate and counsel the family as well as the infected individual

The above-mentioned theme serves as a sub-theme to the Emphasis on treatment strategies but particularly focuses on treatment by means of counselling for families in conjunction with the infected individual. This is in agreement with research by Mathithi et al., (2005) indicating a need for alteration in HIV counselling strategies. Participant 1 suggested that the families of individuals who are HIV positive should attend counselling similar to the person who is infected with HIV. This is because frequently the family members do not know what an HIV diagnosis entails and merely act on the information gathered from other stigmatising sources in society. Such family members then in turn practice these stigmatising behaviours in their homes against family members who are HIV positive due to a lack of knowledge.

> Most of the time when the people go and tell their families, they face discrimination and stigma I personally say I cannot blame those families because all that they know is what is being talked about in the society about HIV. They did not get a chance to sit in that consultation and hear from a well informed perspective like you did as the person who is disclosing the status, you go to tell your 55 year old parents who at the time when they grew up, there was no HIV, the only time they hear about HIV is when they hear other young people dying in the community and they hear that they are dying because they have been having lots of sex with lots of different men and women. How to you expect to your parents to respond to your own HIV, so we missing the link because we are not counselling the family, we are not preparing them for the news, they do not know much and their reaction usually immediately is like where did you get from, what did do to get that and those kind of questions are the ones that come from a perspective that is not informed and people will start worrying about you getting sick and again it is real. **(Participant 1)**

Participant 1 bases the emphasis of the importance of counselling for family members on evidence from families who have been for counselling. These families are less stigmatising toward their family members which in turn has a positive impact on the self-

esteem of individuals who are HIV positive belonging to these families. Participant 1 makes the example of individuals who have received counselling from church organisations. These families appear to be less stigmatising to family members who are HIV positive.

> Now with families who then go on and attend counselling and be open and educated, sometimes in churches they speak about it, so sometimes families will say, I got support from the church because I told my pastor about my child and then my pastor explained and gave me some counselling, so those families will okay and they will not judge because they are not prejudice but families will be hands-off, now the other twist to it is I say sometimes to people that we should again look at what was the relationship between this person and their family before the HIV. **(Participant 1)**

Accounts from participant 6 is in agreement to this as she stated that family members who have requested from nurses to do home visits experience less stigma from other family members which in turn influences the family relations.

> And if it is possible we would try and see this person. Those would be the ones we would try and encourage to come forward. We try and see these family members together to try and talk about this.
> Yes they would come out and say that they have problems and we would ask them if they want to have counselling. The problems would be around bereavement and their relationships. So they would ask if you could come and talk to this person. **(Participant 6)**

Stronger emphasis on the importance of support from the workplace

Participant's voiced the importance of HIV programmes at the workplace as a means of addressing HIV-related stigma at the workplace as well as in society at large. Although this has received strong attention, participants indicated that such programmes are often not adequately implemented in reality. Adequate implementation of workplace programmes to address HIV-related stigma at the workplace would make a phenomenal contribution to combating HIV-related stigma at the workplace. This in turn would influence the individual with HIV's evaluation of him or herself as positive evaluation at the workplace plays an important role in the development of a healthy self-esteem. Inadequate implementation of programmes reducing HIV-related stigma at the workplace as expressed by two participants of this study is in keeping with a study conducted by Dickinson and Stevens (2005) which concluded that external drivers – legal requirements, economic performance, and social pressures – have framed corporate responses to HIV and AIDS to a degree, but have generally been weak. Moreover, they have also found that there has been relatively little

synergy between these external drivers and the internal drivers – voluntary regulation, visibility, and company HIV and AIDS 'champions' – that could propel companies into pro-active, bold responses to HIV and AIDS.

The following account by participant 1 and 6 illustrate the belief regarding the inadequate implementation of HIV programmes at the workplace and its impact on the self-esteem of HIV positive employees:

> I think that the workplace should be open about that. They should teach each other how to handle other people. I don't think that the workplace is very open to each other's struggles. Still they need to maintain the high levels of standards. But I think that there are some workplaces where they teach each other how to handle it. It affects how people relate to each other and then it affects how people feel about themselves. **(Participant 6)**

> Because your workplace self-esteem is based on your performance and your relationship with your colleagues. So if you're doing work to the best of your ability and your boss is impressed with you, you will feel good about yourself. If there are colleagues that you feel comfortable with, the environment is homely you will feel good.
> Now disclose your status. If that is an environment where people are sensitised to dealing with people who are HIV positive, because not everybody already knows. I work in this field so most people in my office would know for example what are the facts and myths around HIV positive people. So if I had to go to my boss, "I've always wanted to tell you something and I wanted to tell you that I tested HIV positive and this is the story". Chances are in this department I'll get support. Because this is a psychology department, we read about it, we teach about it, we know.
> But that is not always the case. Because we know even those people who work in the health sector, they themselves carry a lot of stigma. They will stigmatise against their colleagues and you will be surprised. I thought they were nurses so they should understand or I thought they were doctors, so they should understand, how can they discriminate against their colleagues. Now this becomes even more problematic for people who have nothing to do at all with HIV and health and then you go and disclose your status to your colleagues and you work at Edgars and people do not really have the privilege that we have of reading about the stuff. So because we are dealing with people who do not know about the stuff will not be that supportive. Unless in their own personal lives they have come in contact with HIV positive people. **(Participant 1)**

Exploring the social constructions of gender roles

Different responses were elicited from participants regarding gender differences associated to stigmatising experiences. Two participants' responses regarding the difference

between HIV-related stigma experienced by men and women and how this may cause a difference in the impact stigma has on the self-esteem of men and women indicated a variation in the standards for masculinity and femininity roles allocated to women and men.

> I think society construct men in certain ways so their self-esteem is likely to take more of a knock if they are being stigmatised or if it is found that they are HIV positive and they have not adjusted properly. Because that affects their standing in society in some way or their ability to continue performing masculinity in certain ways. Society constructs women in certain ways, that makes it easier for women to disclose **(Participant 7).**

According to participant 7 the stigma associated with HIV and AIDS are better dealt with by women as women do not have the same social expectations from society as men do. In other words, according to participant 7 the stigma associated with HIV is exacerbated for men due to their inability to conform to societies' expectations. This is in agreement to a study conducted by Cloete, et al., (2008) that all HIV-positive men in South Africa, irrespective of sexual orientation, experienced considerable internalised AIDS stigma, emotional distress and discrimination. The internalisation of society's expectations from males may result in a reluctance to disclose feelings about the self, which in turn excludes these males from the possibility of social intimacy (Polce-Lynch et al., 1998). Such disclosure patterns can inflate men's self-esteem presentations in that an individual who wishes to present himself in socially desirable ways may be less expressive when disclosing negative feelings about himself. (Polce-Lynch et al., 1998)

> I have a feeling that men are better able to handle HIV compared to women. It does not destroy them psychologically the way it destroys women. It does not affect their self-esteem the way it affects women's self-esteem. Because they have other areas in their lives where they can be successful and compensate for this particular self-esteem. They have access to better opportunities. **(Participant 1)**

According the above account from participant 1 women's self-esteem are more likely to be affected by the social constructions of gender roles associated with an HIV positive diagnosis. This is because women who are HIV positive have the added burden of society's constructions of their gender. In other words, women have to bear the social construction associated with their gender as well as their health status.

These variations in opinion regarding the impact of the social construction of gender roles to the self-esteem of individuals who are HIV positive is in keeping with research conducted by Strebel, et al., (2006) stating that social constructionist theory recognises that norms for masculinity, femininity and sexual scripts vary widely across communities.

Addressing the divergent constructions of gender would therefore have to be an integrate part of effective HIV and AIDS interventions addressing the difference in self-esteem constructions among men and women. This is in keeping with results obtained from the study conducted by Strebel, et al., (2006) stating that HIV and AIDS interventions need to highlight social constructions of both gender and masculinities.

Acknowledgement of individual differences in synergy in HIV and AIDS programmes

The acknowledgement of individual differences in synergy with HIV and AIDS programmes addressing the impact of HIV-related stigma on the self-esteem of individuals who are HIV positive relate to programmes that seek to extend beyond merely distributing messages but instead focusing on engaging with various meanings of events and circumstances in the lives of people who are HIV. This would mean interaction with the values, beliefs, traditions and social structures in which people live. The acknowledgment of various aspects to a person's life in the construction of HIV and AIDS programmes addressing the self-esteem of individuals who are HIV positive have been extracted from the following account:

> We need to look at it differently for people from different socio-economic backgrounds, because it will never be the same. I feel that stigma and self-esteem in relation to HIV happens in the context of your broader self-esteem in relation to other things that are happening in your life. Your family, your peers, your work self-esteem and that they all work together to compose the overall self-esteem. If only one of those are being affected we cannot in total say that people with HIV have a negative self-esteem. **(Participant 1)**

The acknowledgment of a person's knowledge of him or herself to the effectiveness of an HIV and AIDS programme that attempts in dealing with factors such as HIV-related stigma which threatens that sense of self is in keeping with the literature. According to Duer (1998) as identified in Healthlink (2007), the President of the World Bank, Wolfensohon postulates that in relation to the lifestyles and realities of local people has long been the argument of anthropologists and participatory development theorists. "We are realising that building development solutions on local forms of social interchange, values, traditions, and knowledge reinforces the social fabric. We are starting to understand, that development effectiveness depends in part, on 'solutions' that resonate with a community's sense of who it is," wrote former World Bank President, James Wolfensohn (Duer, 1998, p 6).

Facilitation of open communication skills

Extracts from participant 6's accounts indicate that open lines of communication facilitate patients' acceptance of the condition as well as coping skills with the stigma of being HIV-positive.

> I think they have a low self-esteem. Also it's like a dilemma when they get this information they do not know what to do. They've got to be encouraged that they should share and talk to people.
> All of the nurses might help you, but you also need to help yourself. But if you are sort of closing yourself, people won't want to talk to you. But like I have said, you find those who have overcome. And then the medical part would be sorted by the nurses. But then we also felt that they need counselling, so that they can get into the culture of talking. **(Participant 6)**

In addition this also facilitates adherence to treatment which, as noted in a previous sub-theme, influences an individual's physical well-being and in turn can have a positive effect on his or her emotional self evaluation.

Summary of recommendations

The following recommendations for interventions against HIV-related stigma influencing the self-esteem of individuals who are HIV positive were made:

Society needs to illustrate more public investment in the wellbeing of people who are HIV positive. Such public investment might have an impact on the stigma associated with an HIV diagnosis as this may positively affect the opinion of other members in society toward individuals who are HIV positive. Similarly, HIV positive individual's observation of public investment in their wellbeing may impact on the manner in which they value themselves. Participant 1 reflected on a Miss HIV beauty contest that was held in Botswana, which is an example of such positive public investment in individuals who are HIV positive. This study however recommends public investment in the form of funding of public speaking of individuals who are HIV positive. The reason for moving away from the beauty contest is that such an intervention may be in disagreement with prevention strategies as this demonstrates pride associated with an HIV diagnosis.

A need for exploring the existential meaning associated with an HIV positive diagnosis was strongly voiced by participants of this study. Findings from this research suggest that the provision of information regarding the prospects of future endeavours such as future investments may create internal value and in turn feelings of self worth for individuals who are HIV positive.

Emphasis on treatment strategies can create a positive association between the manner in which these individuals compare themselves to other members of society. Positive physical wellbeing may be positively associated with positive self evaluation. Interventions directed at the physical wellbeing of individuals who are HIV positive (through emphasis on condom usage and adherence to medication) may therefore also be a vehicle for addressing emotional and mental wellbeing of individuals who are HIV positive. It is however important to guard against the discrimination of those who possess physical symptoms associated with an HIV diagnosis.

A sub-theme to the emphasis on treatment strategies is the emphasis on providing HIV counseling for family members who are affected by HIV and AIDS as a means of mediating HIV-related stigma from family members. Family members exerting less stigma onto HIV positive family members may result in these family members rendering more support to their infected family members. Such support would in turn result in the development of a more favourable self evaluation among individuals who are HIV positive.

Addressing HIV-related stigma at the workplace may also be a vehicle for addressing HIV-related stigma in society. Although such programmes have been emphasised in the labour sector, practical implementations have not been satisfactory. This is in keeping with research conducted by Dickonson and Stevens (2005) indicating that external drivers to the implementation to HIV workplace programmes have generally been weak, resulting in unsatisfactory results in certain HIV and AIDS workplace programmes. A person's workplace self evaluation is a major contributing factor to his or her overall self appraisal (Stapples et al., 1984). Improvement in interventions addressing HIV-related stigma at the workplace aimed at the individual's vocational self evaluation may therefore have a valuable impact on such a person's overall self appraisal.

Interventions addressing the difference in self-esteem constructions among men and women resulting from different opinions regarding the difference of HIV-related stigma among women and men need to consider the divergent constructions of gender as an integrate part of effective intervention implementation. This is in keeping with results obtained from the study conducted by Strebel, et al., (2006) stating that HIV and AIDS interventions need to highlight social constructions of both gender and masculinities.

Interventions aimed at addressing the self-esteem of individuals who are HIV positive need to extend beyond distributing generic messages but need to attempt engaging with various meanings of events and circumstances in individual's lives. These events however

need to be looked at in synergy to that person rather than merely addressing one aspect of that individual's life.

Open lines of communication facilitate patients' acceptance of their HIV condition, adherence to medication, as well as coping skills toward the stigma of being HIV positive. These contribute to the development of a positive self-esteem.

CHAPTER 5: DISCUSSION AND CONCLUSIONS

The following chapter provides a summary of the findings of this study with specific reference to the research question. Important observations made from the participant interviews that could not be incorporated into the three themes discussed in chapter four, but that need to be highlighted in this research report, will also be incorporated into this discussion. Furthermore the researcher will discuss the conclusions that were deducted from this study. Strengths and limitations of the study will also be looked at in this chapter, where after recommendations for future research will be provided.

DISCUSSION OF THE FINDINGS

The main aim of this study is to determine psychologists' views on the relationship between HIV-related stigma and the self-esteem of individuals who are HIV positive. A review of studies done in the field of HIV and AIDS, specifically HIV-related stigma, indicate that room exists for qualitative enquiry into the manner peoples' evaluation of themselves in relation to HIV-related stigma experienced could be examined.

All participants indicated that a relationship between HIV- related stigma and the self-esteem of people living with HIV and AIDS does exist. However, the relationship between stigma and self-esteem does not manifest the same in all HIV positive people. What was apparent from the interviews was that clients expressed differing impacts of the disease on their self-esteem. Psychologists' accounts indicated that certain people with HIV and AIDS evaluate themselves negatively, which is indicative of a low self-esteem, while others identified positive characteristics within themselves, which can be interpreted as a sign of positive self-esteem. The reason for the differential experiences of HIV-related stigma among people who are HIV positive is indicative to HIV-related stigma being a concept that needs to be understood primarily from an individual as well as a social perspective. Concentrating on understanding HIV-related stigma from the perspective of the infected individual allows one to understand this phenomenon from the perspective of the stigmatised rather than the stigmatiser. Individual attributes such as the age of the person or the stage of the disease can be used as a means of understanding the meaning of HIV-related stigma for different HIV positive individuals. These individual factors (a person's age or stage of the disease) are changing attributes, hence the person may experience HIV-related stigma in a different manner at one time of his or her life than at another time.

Stigma as a socially evolving entity involves the interplay of power relations, which in turn can result in status loss or status gain for the stigmatised or the stigmatiser. The stigmatised person evaluates him or herself negatively as the disempowering experience from stigmatisation gets internalised into these individual's evaluation of themselves. Although power relations operate on a social level, the data revealed that a stigmatised individual may also experience the intended act of status loss by the stigmatiser as an opportunity for status gain. It therefore becomes an individual process whereby the person at which stigmatising acts have been directed at experiences the discrimination differently than intended by the stigmatiser. Certain socially determined factors, such as level of support may allow the stigmatised person to have a different experience than intended by the stigmatiser. It is therefore necessary to note that status loss in respect of the stigmatised person only occurs automatically in the view of the stigmatiser, which is in accordance with the literature. Status loss as intended by the stigmatiser results when discriminatory experiences are internalised by the individual. A related aim of this study therefore was to explore how HIV-related stigma as an individual as well as socially constructed concept relates to the self-esteem of HIV positive people. The findings indicate that factors such as personal development, levels of support or stage of the disease that may have an influence on the perceived discrimination may have an impact on the development of the self-esteem. In other words, personal factors impacting on the manner in which HIV-related stigma is experienced may result in changes to the self-esteem. The self-esteem of individuals with HIV can therefore be characterised as evolving in nature and the changing nature of the self-esteem of these people can be due to a change in the experience of HIV-related stigma.

From the discussion regarding the relationship between HIV-related stigma and the self-esteem of people living with HIV and AIDS it is important to recognise that the intricate nature of individual perceptions may have an important influence on stigma and that these can be internalised by individuals who are HIV positive. It may therefore be important to not only think about individual differences but to incorporate the frameworks within which these individuals exist when thinking about interventions in response to HIV-related stigma.

Various factors associated with HIV-related stigma have been identified as contributing to the self-esteem of people living with HIV and AIDS. These factors incorporate individual as well as social features. Personal characteristics such as an individual's personality organisation have been identified as a factor in how people living with HIV and AIDS get affected by the experience of HIV-related stigma. Participants indicated personality organisation as the internal resource base by which people that are

living with HIV and AIDS have to fight off the effects of the challenges brought about by HIV-related stigma. It was said that the person with a strong personality organisation is most likely to react better to such challenges by not allowing it to affect his or her evaluation of the self. The person with a weak personality organisation may experience the same challenges more intensely and therefore allow the experience to negatively affect his or her evaluation of the self. It should, however, be noted that although participants verbalised a person with HIV and AIDS' internal resource base as personality, the descriptions provided did not relate to the theoretical description of personality. Rather participants' descriptions alluded more to personal resiliency as a contributing factor to the manner in which people who are living with HIV and AIDS allow stigmatising experiences to affect their self evaluation.

Participants have identified that individuals who are HIV positive reactions to stigma is not only pre-determined by a specific personality organisation, but that adequate social support serves as a strong sustaining factor to how a person's personality organisation can uphold an HIV positive person's self evaluation. An example of such social support would be support received from the family. Family is a particularly impactful source of self-esteem.

Participants' emphasis on the manner in which discrimination from the family impacts on the individual's self evaluatory abilities is but one example of the importance of social support as a mediating factor to the experiences of HIV-related stigma. The family is a very important social construct and an important base for social relations. What the findings have revealed was that individuals who are HIV positive often experience change in these relations due to HIV-related stigma. Individuals who are HIV positive therefore experience a change in their social relations which in turn may result in a change in the manner they evaluate themselves. The data indicates that such change could be attributed to HIV-related stigma.

The level of social support can also be determined by the level of appraisal people living with HIV and AIDS receive from society or from their immediate environment. The perception that people believe in their abilities can allow a person who is HIV positive to have a feeling of internal worth. However, messages conveyed from society or communities to which these people belong such as peers, the workplace or the family often echo the belief that because HIV is a degenerative condition or a condition for which there is no cure, people infected with this condition do not have the ability to meet society's demands. People who are living with HIV and AIDS therefore believe that society does not find value in the contribution they can make and these beliefs affect whether they engage in self debilitating or self encouraging thought.

People living with HIV and AIDS therefore perceive their membership to social groups to be affected by their HIV status. The perception that society evaluates them based on their HIV status affects their social identity. The extent to which this identity is affected is influenced by the emotional significance the HIV positive person attaches to that group. When viewed from this perspective, HIV can therefore also be described as a social condition. In other words, whatever has already been constructed in society will overlap with what is happening with individuals who are HIV positive and consequently their self-esteem will also be affected. Although significant progress have been made toward gender equality, women continue to hold less ascribed status, power, and access to resources than men do. Similarly, homosexual men continue to be faced with social prejudice. Discrimination on the basis of gender and sexual orientation result in individuals with these social identities to be doubly impacted by the pressures of society when HIV positive. This in turn mean that their self-esteem is doubly impacted upon as well.

The approach to conceptualising and investigating HIV-related stigma in relation to the self-esteem of people living with HIV and AIDS can have important consequences for developing methods of intervention against HIV-related stigma and can therefore be one way of caring for people living with HIV and AIDS. Findings regarding HIV-related stigma as an individual and socially constructed phenomenon and self-esteem as a personal as well as a social identity have been incorporated into the recommendations for the preservation and improvement of self-esteem of people living with HIV and AIDS. This understanding informed recommendations to be the mission of both those infected and those affected.

The recommendation for investing publicly in individuals who are HIV positive creates an opportunity for both HIV positive and HIV negative people to work together for a common cause. Interventions of such nature can illustrate to individuals who are HIV positive that the public finds value in their well-being, which in turn may create urgency for HIV positive people to find value in themselves. This allows for the development of a public collective self-esteem whereby the person infected with HIV is provided with an opportunity to find value in the group he or she belongs to. As indicated in the presentation of the findings, caution has to be given to such strategies interfering with prevention strategies as the intention is not to create the idea that one should find pride in one's HIV status, but rather that one should not devalue yourself because of this status. The nature of such interventions would also allow for the alleviation of power differentials as HIV positive individuals would be afforded a chance to work alongside individuals who are HIV negative, who they often perceive as their counterparts.

Participant responses emphasised the need for some level of general acceptance and support for the person who is HIV-positive as this can result in an increase in the manner by which they evaluate themselves. However, this should be a reciprocal process. Individuals who are HIV positive can equally contribute to the improvement of their self-esteem, by frequently taking their medication and staying healthy. However, the constant taking of high doses of medication can also generate stigma from society. It is therefore necessary to instil the importance of adhering to HIV medication among those who are infected or affected by HIV. Through educating HIV positive people about the importance of taking medication and staying healthy the stigma against HIV that gets passed through to individuals who are HIV positive can be mediated and reduced. Frequent and regular use of taking medication can improve these individuals' physical health, which can in turn facilitate or improve mental health. This relates to membership collective self-esteem. Regular use of medication is most likely to generate good results which in turn would improve his or her collective self-esteem.

Participants' accounts regarding HIV positive people's reluctance to disclose to family members due to fear of discrimination relates to the level of trust these individuals have in their family and society at large. In all relationships discrimination counteracts trust. This often leaves those infected alone and distanced from the rest of their families as well as their communities and colleagues. The fear of discrimination has been shown to create problems for disclosure, since disclosure has the common reaction of rejection, leaving the person living with HIV alone. This also decreases his or her chances for social support. Data from this study confirms a well known belief that social support is crucial for the maintenance of mental health. Individuals' reluctance to disclose therefore deprive them of the possibility of such support from those who they care about and who care about them. However, social contacts and family members may also resist being informed of a family member who is HIV positive. Such resistance to being informed about a family member's status can be due to the fear of stigmatisation and discrimination to themselves. They too may then become vulnerable to exclusion by being associated with a person with HIV. One of the participants therefore emphasised the need to inform family members of the implications and information around HIV and AIDS together with the infected individual. By providing the entire family with guidance regarding the technicalities of an HIV diagnosis all parties will be empowered by disclosure of their status. This empowerment relates to gaining information regarding the HI virus which would in turn provide such individuals with the relevant knowledge to fight against discriminatory acts. Here it is referred to the mental power to alleviate the effects of possible discrimatory acts from society.

Too much investment in people who are HIV positive can relay a message that is contradictory to campaigns emphasising the importance of protection against contracting HIV. Interventions regarding the importance of care for people living with HIV and AIDS should therefore be done in conjunction with HIV prevention campaigns. Addressing issues around HIV-related stigma could be an effective way of doing this, because HIV-related stigma interferes with the success of prevention programmes as well as the care of people living with HIV and AIDS.

STRENGHTS AND LIMIATIONS OF THE STUDY

An essential strength of this research is the qualitative nature of the research analysis. As indicated in the literature review, previous researchers typically used quantitative methods to do enquiries into how HIV positive people think and feel about themselves. This study extends deeper expansive knowledge into the field through obtaining data in a qualitative manner. In other words, this research went beyond describing 'how much' of something there is, to reveal more about the essential qualities of what was being studied. The researcher believed that examining psychologists' perceptions of HIV positive individual's thoughts and feelings by means of open-ended questions allowed information to be examined that otherwise could go unreported. All participants have a minimum of 5 years experience in the field of HIV and 2 years in private practice, which allowed for the data to be supplemented with rich information regarding a very sensitive topic.

Results of this study should also be interpreted in the light of its methodological limitations. The purposive sampling method is subject to selection biases. In order to obtain informed information regarding the self-esteem of people living with HIV and AIDS specific psychologists were targeted and thus the sample of psychologists could have been bias against conducting interviews with other psychologists from the same region. Sampling bias may also have created a limitation to the actual reporting of the experience of HIV related stigma. People who feel most stigmatized by their diagnosis may be reluctant to attend counseling, hence psychologists accounts of people living with HIV and AIDS may be limited to people living with HIV who had the freedom to speak about their experiences and not those who have a fear for expressing such feelings.

However individuals who are part of a therapeutic intervention are also the ones who have received guidance regarding their vulnerabilities hence they may be stronger and more open to receiving help regarding the challenges of their HIV status, which may have

influenced the fact that participants perceived certain HIV positive individuals stronger than others. Those who do not feel impacted upon may be less likely to seek help.

Another potential weakness of this research is the small sample size as only eight participants were interviewed. The lack of ethnic and gender diversity can also be viewed as a weakness. However qualitative research does accommodate for a sample size of this volume due to the wealth of information that this method of research can yield from its participants. In addition the eight psychologists interviewed provided the accounts of at least four clients who are HIV positive each. These clients also may have been from different ethnic backgrounds and gender. Therefore though eight psychologists were interviewed the data was informed by the experiences of many more people from different backgrounds infected with HIV.

Despite the above limitations, the researcher believes that the current findings contribute to new knowledge that could be useful in intervention planning for people living with HIV and AIDS. Interventions that can assist people living with HIV and AIDS to better adjust to their condition and the social environment are needed. In particular, coping efficacy to address managing social stigma and reducing internalised stigma. The recommendations for such coping efficacy may help people living with HIV and AIDS to find more value in the self, in other words the self-esteem. A more favourable self-esteem may result in better mental health and the alleviation of conditions such as depression and anxiety related disorders.

RECOMMENDATIONS FOR FUTURE RESEARCH

Stigma continues to have an extremely important role in the AIDS epidemic, not only because of its effects on HIV infected individuals, but also because of the ways in which stigma might be contributing to the spread of the epidemic. There is, an important and very powerful need for research to provide a greater understanding of stigma and how best to ameliorate its effects on both HIV-infected individuals and society as a whole. Specific suggestions regarding the alleviation of HIV-related stigma have been outlined below.

Although this is a well researched area it is important to identify the causes of stigma as well as its potent effects. Data from this study revealed that stigma against people who are HIV positive are still highly prevalent in the South African communities and therefore require additional research into this domain. Future studies should focus on identifying these cause-effect relationships in culturally-specific contexts, concentrating on their impact on illness progression and quality of life. Additional studies regarding the alleviation of stigma

in the South African communities would facilitate the mediation of impact on the self-esteem of individuals who are HIV positive.

More specifically relating to the impact of the stigma on the self-esteem of individuals who are HIV positive, data from this study also indicate a need for gaining a clearer understanding of the existential factors associated with an HIV diagnosis. The issue of mortality is a strong influencing factor toward the stigma (internal and enacted) experienced by individuals who are HIV positive. Results from this study also indicate that this concern regarding "how long am I going to live" affects the manner in which these individuals invest in themselves which in turn allows for a deterioration in the manner in which they evaluate themselves.

Variation in participants' responses regarding the stigma associated with certain social construction regarding gender and sexuality also created a need for further research into people's beliefs regarding the manner in which male and female perceptions of stigma differ, as well as the variation regarding how this may influence the self-esteem of males and females respectively.

Although support groups is an existing popular means of supporting those who are affected by HIV-related stigma, coping strategies and support groups for HIV and AIDS should be assessed to establish whether social integration and support are consistent, and whether they enhance the quality of life and wellbeing of persons living with HIV and AIDS.

The results suggest opportunities for addressing both the internalised stigma felt by those living with HIV, as well as possibilities for decreasing stigmatising attitudes within communities. While it is true that HIV-infected individuals suffer adverse societal consequences because of their disease, helping individuals recognise the extent to which stigma has been internalised and addressing this, could help them cope better with their HIV status.

Finally recommendations for future research on HIV-related stigma and self-esteem should also be directed at increasing the sample size as well as expanding the cultural group. This may aid in identifying the reasoning behind individual specific stigma.

CONCLUSION

Overall results from this study indicates that, although highly researched and implemented in HIV-related interventions, HIV-related stigma continues to be a problem for the living standards of individuals who are HIV positive as well as those they are associated with. HIV-related stigma results in the individual infected with HIV to devalue him or herself

due to feelings and internal beliefs around HIV and AIDS, as well as disempowerment in relation to those who act in discriminatory ways against them. The impact of HIV-related stigma on the self-esteem is therefore influenced by internal convictions or a personal identity, as well as beliefs around his or her place within society otherwise phrased as collective identity.

Addressing the self-esteem of individuals infected with HIV and AIDS relates to the improvement of the lives of those living with HIV and AIDS. Interventions with this objective in mind should therefore incorporate strategies of addressing both personal identities in relation to self-esteem as well as collective identities to this diagnosis.

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APPENDIX I: ETHICS CLEARANCE FORM

APPENDIX II: PARTICIPANT INFORMATION SHEET

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Ms. L. Primo
Supervisor: Ms. J.N. Frank

Good Day

My Name is Lynn Primo and I am a Psychology Masters student at the University of the Witwatersrand. I am required to do a research report to fulfill in the requirements for my degree. The focus of my research is the relationship between HIV-related stigma and self-esteem of people infected with HIV and AIDS. This study aims at addressing the challenge to understanding, alleviating and preventing an inhibited self-esteem as a result of HIV-related stigma. I hope that this study will contribute to further research in understanding the impact of HIV-related stigma on the personal development of people living with HIV and AIDS.

As someone who works in the field of HIV and AIDS, I would like to invite you to participate in my study. Should you wish to participate in this study please note that anonymity and confidentiality cannot be assured. Considerable consideration is given to the fact that HIV is a sensitive subject; therefore all identifying information would remain between myself and my research supervisor. The researcher will respect anonymity as best possible by using pseudonyms in the research report. You have the right to refuse participation and agreement to participate may be withdrawn at any time. No negative implications will result from a decision to withdraw. You can feel free to make any inquiries regarding the study at any point during or after the interview.

Interviews will be conducted with several experts who have worked for more than two years with people infected by HIV and AIDS. Data will be collected by means of semi-structured interviews and you will be able to interact spontaneously in relation to questions asked. I will administer the interview myself. The interview consists of approximately 13 questions, therefore the interview will take approximately 1 hour.

For the purpose of transcribing and analysis, an audio tape recording will be made of the interview for which separate consent is requested. Only my supervisor and I will have access to the interview tapes and transcriptions. These tapes and transcriptions will be destroyed upon completion of the research. The results of this research will be presented in the form of a research report in keeping with the requirements of the School of Psychology. This study has been given clearance by the Human Research Ethics Committee of the University of the Witwatersrand.

Should you be interested in seeing the results of the study, a summary of the results will be made available after completion of the study?
Thank you for taking this time to consider participating in my study. Should you have any further enquiries, please do not hesitate to contact me or my supervisor.

Please complete the attached consent form if you wish to participate in this study.

Ms. Lynn Primo
Cell: 082 777 4204

Janice Frank
Tel: 011 717 4518

APPENDIX III : PARTICIPANT CONSENT FORM

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Ms. L. Primo
Supervisor: Ms. J.N. Frank

Good Day

Please read the following section before signing consent below:

The researcher would like to assure the participant that confidentiality will be guaranteed as no names or identifying information will be used. In addition to the participants confidentiality there is no question around the confidentiality of the individuals' information you may provide. You have the right to refuse participation and agreement to participate may be withdrawn at any time. No negative implications will result from a decision to withdraw. You can feel free to make any inquiries regarding the study at any point during or after the interview. Should you not feel comfortable with a specific question you have the right not to answer?

I …….. have read the above as well as the attached letter and understand the nature, purpose and procedure of this research. I hereby choose to be a participant in this study and hence be interviewed.

Participant's signature	**Research Signature**
……..	……..
Date: …….	Date: ……
Time: ……	Time: ……..

APPENDIX IV : PARTICIPANT CONSENT FOR AUDIO RECORDING

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Ms. L. Primo
Supervisor: Ms. J.N. Frank

The researcher will have to audio tape the interview in order to ensure that the data recorded during the interview is of good quality as well as quantity for the purpose of later reference. In order to protect the identity of the participant no personal details will be indicated on the tapes. The tapes will also be stored in a safe place where only the researcher will have access to it. Only the researcher and her supervisor will have access to the interview tapes and transcriptions. These tapes and transcriptions will be destroyed upon completion of the research.

I …….. hereby provide permission for the tape recording of the interview that I will be participating in.

Subject's signature **Research Signature**

…….. ……..

Date: ……. Date: ……

APPENDIX V: INTERVIEW SCHEDULE

Introduction

1. Please describe the work that you do. *Please describe the relationship between stigma a person who is HIV positive may experience from family and his or her self esteem.*

2. How long have you been working in this field?

Questions

3. *Please describe the self esteem of someone who is HIV positive*. / Do you think that people who are HIV positive see good in themselves? Please elaborate on your answer.

4. Please describe the pride of someone who is HIV positive.

5. How do people who are HIV positive compare themselves to other people? What influences the self esteem of someone who is HIV positive?

6. *What/ Who influences the self esteem of someone who is HIV positive?*

7. Do think there is a relationship between the stigma and self esteem of someone who is HIV positive? Please elaborate on your answer./ *Do you think there is a relationship between the stigma experienced by someone who is HIV positive and his or her self esteem? Please elaborate on your answer.*

8. Do you think there is a relationship between stigma from family members and the self esteem of someone who is HIV positive? *Please describe the relationship between stigma a person who is HIV positive may experience from family and his or her self esteem.*

9. Do you think there is a relationship between stigma experienced from the workplace and the self esteem of someone who is HIV positive? *Please describe the relationship between stigma a person who is HIV positive may experience from the workplace and his or her self esteem.*

10. Do you think that there is a difference in the relationship between gender specific HIV-related stigma and the individual's self-esteem? *Do you think that women and men experience HIV-related stigma differently? Please elaborate.*

11. *If yes, do you think that there is a difference in the self esteem of women and men who are HIV positive?*
12. Do you think the stigma attached to taking medication affects HIV positive peoples self esteem?

13. Please provide suggestions for future research regarding self-esteem of people living with HIV.

APPENDIX VI: PARTICIPANT TRANSCRIPTS

Participant 1

Researcher: Can you please describe the work that you do

Participant 1: Well, I teach so I am lecturing on health psychology and social psychology, so I think you approached me because of my health psychology teaching and I teach on practitioners health behaviour and practitioners behaviours towards patients and how to do improve the relationship between health practitioners and patients and sometimes I focus on specific topics like HIV, smoking, diet, mainly on lifestyle conditions

Researcher And then how long have you been doing this?

Participant 1: I joined the varsity two years, and doing research on HIV for ten years, so.

Researcher: So that is vast amount of knowledge, other than research on HIV, have you done specific work relating to HIV

Participant 1: Yes, I have worked as a programs person in HIV and AIDS, I have development HIV and AIDS materials, training materials, adaptations of training manuals for South Africa, a lot of training of trainers on HIV AIDS

Researcher In terms of the self-esteem of someone, how would you describe the self-esteem of someone who is HIV positive?

Participant 1: Well, I guess it depends because of self-esteem, self-esteem is not static, it changes, it changes on your depending on your age, it changes depending on your environment, it changes, you've got your kind of self-esteem when you with peers, you've your self-esteem when you with your friends and I would imagine the HIV positive people, your self-esteem with HIV positive people and know you know about them, so that could influence your self-esteem and it depends on how felt about yourself before you knew about your HIV status and also how much do you know about HIV that influences how you feel about yourself, so with that response, I am trying to say there is no way I can say that people with HIV have a negative self-esteem or people with HIV have a positive self-esteem, it depends on a number of things, there are people with HIV who because society sees HIV

mainly as a condition that you get because you have been sleeping around, now you have people who are born with HIV, they are virgins, they adolescents, they never slept around, so how do we expect that statement to cover them. They may feel that because they did not bring it upon themselves, they should not feel guilty about it so it may not effect their self-esteem, there are people who are HIV positive because they were sexually active, and they had a number of partners so that might feel that they are actually responsible for it and when the society then backs that up by saying, HIV is a condition that you get by sleeping around, because it then impact on your guilt, it might influence your self-esteem and you might really feel not good about yourself because you have been participating in sexual active things that resulted in this HIV and society then amplifies that by the messages and there are people who been married with this one partner all their lives and they never slept with anyone else but this one partner and when he gets HIV and brings it to the home and then how do you feel about yourself when you have HIV. So it depends on your personality, on your psychological make up, on your self-esteem at that exact point in time. If you did not feel good about yourself, we don't hope that HIV will change the way you feel about yourself. You know there are messages about being positive with HIV and living positively and there are positive roles models, they speak about their status on tv or on radio and everywhere and they are living life to the fullest if you want to put it that way. They start new relationship that have children, new relationships even when they HIV positive so you could say for those people it probably has not negatively effected how they feel about themselves, if that is what you are asking about self-esteem, Is that what you were asking? Yes

Researcher: The way the person evaluates him or herself.

Participant 1: Yes, so for those people it has not really changed the fact that I am a good person, I am going to get a good husband, I will have a good home, I will have children and I will rise, educate and do the things normal people, I am using the word "normal" here as in people who do not have HIV.,

Researcher: Mhmm (yes)

Participant 1: But there are people who feel guilty once they have HIV because they feel I could of done things differently, I should not of had the number of partners that I had, I should not of slept when I was drunk because that is probably the time when I ended up, not using condoms, I ended up getting HIV, so it is a matter of my status plus a number of things I am now feeling, I am not a good person, otherwise I could of done things differently if I

was a good person so that effects your self-esteem and that may feel negative about it. And if you are in an environment, like your peers, your friends, your family, who are not supporting you who is living with HIV, who think that you who have HIV are spreading the virus, then it might effect how you feel about yourself, you don't feel good. Because HIV mainly effects young people, we would expect that it would have a negative impact on them because usually when young people discover that they have HIV, they already have their lives planned to do things, to go to varsity, to work for my parents, to do things, the minute you hear this, they think I will not be able to go to varsity, I will not be able to finish my degree, if I will finish and get employment, I will not be able do the things I wanted to do for my parents because I will die and it effects how you feel. When you are still young, everybody around gets pregnant, and you are not sure if you should get pregnant with HIV, you will host all the baby showers for your friends but there will never be a baby shower for yourself, it will effect how you feel, in an environment where fertility is valued. Women are expected to find husbands, men are expected to find wives, and you not sure, I have spoken to people in my work who say when I discovered I had HIV I got into relationships and I disclose my status, I would tell my partner until I realised I tell my partner and then three months down the line he disappears. I meet another person, I want to come clean, let me tell my partner about my status, three months down the line, he disappears. So this woman told me something that I thought was powerful she said: In life, I'm being punished, one, I was punished for getting the virus, secondly, I am being punished by being innocent by the partners that I get and I have decided that I am not going to disclose it anymore, so let live my life, if it ever happens that I get pregnant, its fine I will get pregnant, I will have children. So for people like us who work in this field, we raise eye-brows and how on earth are you going to do that and continue to sleep with people and you don't tell them your status. So on the other side, she feels it actually impacts on her self-esteem, on the way that she evaluates herself because now she thinks that they disappear because they know that she is HIV positive where in actual fact men disappear all the time, they ran away from their partners without even knowing about their HIV status. It depends on what is happening in the environment.

Researcher: How would you describe the pride of someone who is HIV positive?

Participant 1: How would I describe their pride? (laughter). I am not sure what there is to be proud of when you are HIV positive because it is a illness and it is not like any other illness because you cannot cure it and not only because it is not incurable but also because

even with treatment it is not easy to access treatment, so you have nothing to show, it is not an achievement with HIV, in Botswana they have a beauty contest, they call the miss positive, miss HIV positive, and people who are HIV positive enter that beauty contest and there have been a lot of criticisms in the field of HIV, about whether we should be doing that, should we have a beauty contest at a national level that says HIV positive Miss Botswana, somewhere else I am trying to think, but there are pockets in the society, we need to do positive things to bring the pride back in HIV positive women and men of course but I mainly work with women most of the time and the argument for these initiatives like Miss HIV Botswana, and in Nigeria University students are encouraged to test, and if you test negative, you get a scholarship, you know those things, so there are something that, there are messages that these activities are sending to the society and is it a good thing, is it a positive thing, will it bring you pride, yes, it will make you feel good about yourself, that you still beautiful and pretty and you can win a contest and win a prize, but at the end of the day, a disease like any other disease is not something that you can be proud of, you would feel sorry for yourself, you would wish that you did not have it, nobody wishes to have a disease and especially a disease that kills like HIV and a disease that carries some much stigma around it, one it means that like activities that like those, only people who have a high self-esteem will get into that contest, so there will be a lot of women who will have HIV that will never get into that contest because they do not want to be identified as being HIV positive, so we already dealing with a group of people who feel good about themselves, that is publicly talking about, that have excepted their status, who are like, we can even have a contest around it, it leaves a majority of people who still face a stigma in their communities, who feel like there is no ways I can do this otherwise my parents will kick me out of the house and it happens or husband will kick me out of the house and it happens. So what is the pride of a HIV positive person? It think it has nothing to do with it with their disease, if a person has pride in themselves, they will still have pride in themselves even after they test positive and also with a good support system, with knowing other people who are living with HIV and knowing that there are living their lives to the fullest, it sort of changes one and that is why HIV people are encouraged to join HIV supports groups because in support groups, that is where you are speak and meet other people who are living with HIV and they share and you realise that you are not alone, it brings back your pride, you realise you can still do the things that you wanted to do, you still have a partner, you still start a family, you can still get that big business that you always wanted to start

Researcher: So it depends on what your level of pride was before and the also the current circumstances that you

Participant 1: Yes, what messages you are getting from the society

Researcher: Some of the questions overlap from what you are saying, so you can feel free to say that it relates to the previous point that you have mentioned or maybe if specifically subject you mentioned..

Participant 1 : Okay.

Researcher: How to do people who are HIV positive, compare themselves with other people, what influences the self-esteem of someone who is HIV positive

Participant 1: I would say the comparison are in terms of long terms plans, people who are HIV, some that I speak to, find that they cannot make long-term plans in their lives and everybody else makes long term plans. Everybody thinks, I still want to register for that degree, because you know I have always wanted to have that and for people who have HIV positive, its like, why should I register for that, I might at the time that I graduate be sick and dying, so it takes an extra afford to encourage them to do things that they always wanted to do, otherwise they think there is no point, it is not going to benefit me in life, I will die so people with HIV and especially in terms of relationships again compared to people who do not have relationships, they get really worried about whether they will be able to get partners and whether when the get in those partnerships, will they be effected if they disclose their status and for everybody else that will not is not issue and whether they should or should not have children especially because they get mixed messages from the health professionals as well, health professionals are also human, so they do the inclination of sometimes saying what if you die and leave orphans, don't pregnant, etc., and when they do hear those messages, then compared to be people who are not battling with the decisions around fertility on the basis of their HIV status, then of course they would wish that of course, I wish I did not have HIV and otherwise people are okay, people are living their lives, they might feel that they don't broaden their horizon, they don't want to meet new people and have new friends because they will have to deal with the fact that one day or another these new people will know about their status

Researcher: Do you think there is a relationship between the stigma experienced by someone who is HIV positive and his/her self-esteem

Participant 1: Oh yes, there is, I think so. We could say that at this stage, HIV is normalised, it is like a normal condition that people know about but it still carries a lot of stigma and it is that particular stigma that makes people feel that I am not good enough and if the society thinks that HIV happens to certain people who were not good enough in terms of their behaviour, then it does definitely effect the way one evaluates oneself so the blame issue effects the peoples self-esteem. Women are proportionally affected by HIV and so to some people, women are the ones who perpetrate HIV. Families who think that their child was the best one and that there partner was the one who actually brought the HIV to their child and this is very interesting when I speak to people, especially families who live with HIV, I get that, to my surprise, it is invariable, people think that their person was not on the wrong, it was the other person who brought HIV to my sister, to my brother, or to my child and therefore the kind of stigma that society has on who brought the HIV makes the party who is blamed to feel that they were not good enough and is it usually in marriages something has happened, maybe it is the man who has brought HIV to the house whereas it is because we know generally it is the man who has extramarital relationships, but it is not always the case that it is the man who brought HIV to the house but it is like society immediately thinks that , oh if the disease is HIV positive, it should be the husband and therefore it effects the way people deal with HIV and the way they evaluate themselves. The stigma around death as well, so it does not only affect the self-esteem of the person who has HIV, it affects the families self-esteem, if there is anything called the family self-esteem. If your child died from HIV, it is like the family was loose, the family could not control, the morals of the family are brought into question because how can your children go on and die and it brings a lot of stigma to that particular family and families are finding it difficult to battle with this. We have been encouraging people to talk about the cause of death and to mention during burials that, like we mention with anybody else, that this person had a accident between that road from whatever to whatever and this how it happened and they go to hospital and etc., or this person had high blood pressure from this particular year and had diabetes from this particular year and they passed on but with the problem with HIV, you do not mention it most of the time, its like this person got sick in the toilet and so and so and had this pain this in the head and that pain here and then they passed away, there is no mention that they were diagnosed with HIV or AIDS and that's because of the stigma that it carries for the families that is left behind now not even for the particular person and they do not feel good about it, they feel that one, their child has done has let them down and two they have let down the bigger community, so it does carry a lot of stigma.

Researcher Yes, it I think it goes hand in hand to what you were talking about… Please describe the relationship between stigma of a person who is HIV positive they experience from their families

Participant 1: Yes, with HIV, we encourage the people to come and test and disclose the status with their family members, but the person who gets the counselling and information on HIV, is the one who tests, so you come for a pre-test counselling and they tell you everything about HIV, you get tested , you come for your post test counselling, you are told everything, you attend support groups and we expect you to go and tell people who have no clue what this condition is about. Most of the time when the people go and tell their families, they face discrimination and stigma and I personally say, I cannot blame those families because all that they know is what is being talked about in the society about HIV. They did not get a chance to sit in that consultation and hear from a well informed perspective like you did as the person who is disclosing the status, so if you have already been told everything about HIV, you've dealt with a personal level, you know you cannot blame yourself, you know you could not of done something in this situation to prevent and I am making an example, you come to terms and it does not dent your self-esteem and you feel good, well it is not a death sentence, I will be legitimate**,** I will be okay and I will still do the things I wanted to do and actually I want to tell my parents, and there you go to tell your 55 year old parents who at the time when they grew up, there was no HIV, the only time they hear about HIV is when they hear other young people dying in the community and they hear that they are dying because they have been having lots of sex with lots of different men and women. How to you expect to your parents to respond to your own HIV, so we missing the link because we are not counselling the family, we are not preparing them for the news, they do not know much and their reaction usually immediately is like where did you get from, what did do to get that and those kind of questions are the ones that come from a perspective that is not informed and people will start worrying about you getting sick and again it is real, the way people with AIDS present themselves when they are sick it's scary, no body wants to be close to that kind of situation, but they have to because they are your parents, now they start imaging and think about so and so's child who was so sick and bedridden and she could not even get herself to got to the toilet and she was missing on herself and is that what you are going to put us through and they always think you are almost get to that condition in the next six months because they do not know what it means, because of all those implications and what is running around in their thoughts, and now you are going to die, stigma comes

from that, and they do face a lot of stigma. Now with families who then go on and attend counselling and be open and educated, sometimes in churches they speak about it, so sometimes families will say, I got support from the church because I told my pastor about my child and then my pastor explained and gave me some counselling, so those families will okay and they will not judge because they are not prejudice but families will be hands-off, now the other twist to it is I say sometimes to people that we should again look at what was the relationship between this person and their family before the HIV, strained family relationships have always been there, so if you have never had a good relationship with your family, conflicts, staying away from your family for a long time, and then you come and tell them you are HIV positive. You don't really expect that to improve your situation, do you? The worst that will happen, they will use that against you, the next time there is that other family conflict that normally happens, they will use that against you, so I always say to people be careful when you encourage, I will call them patients, to go and disclose their status to people because it depends on the situation, if they know that my family is the kind of family that if I had a problem, I would run to and they would support me and then this would be the time you should tell them because they will support you. But if you know that you've always been on your own in life, you don't have that kind of a family where you can turn to for support. Your family is each man for himself and God for all kind of arrangement, then don't go and tell them. Then they won't change. Sometimes it does bring families together. It brings people closer and people feel that we've got to support this member of the family. So we might say it's stigma, when it's just people not knowing how to support.

Researcher: So it is very much based on what people know, how informed they are.

Participant 1: Yes what people know? How informed they are, and also what was the typical family relationship before the HIV. Because if it wasn't good, then don't hope that it will change. It may change because people might then sympathise with you. But you don't want people to sympathise with you. Each time you go home they ask you the same questions around, How are you feeling, How is your HIV. You don't want that in life.

Researcher: Please describe the relationship between stigma experienced at the workplace and his or her self esteem

Participant 1: Well it depends on whether you have disclosed. So if your colleagues don't know and your boss does not know it does not affect your self esteem. Because your workplace self esteem is based on your performance and your relationship with your

colleagues. So if your doing work to the best of your ability and your boss is impressed with you, you will feel good about yourself. If there are colleagues that you feel comfortable with, the environment is homely you will feel good.

Researcher: So it still boils down to what was there before.

Participant 1: Exactly. So if you had a good relationship with them, that's good. Now disclose your status. If that is an environment where people are sensitised to dealing with people who are HIV positive, because not everybody already knows. I work in this fields so most people in my office would know for example what are the facts and myths around HIV positive people. So if I had to go to my boss, " I've always wanted to tell you something and I wanted to tell you that I tested HIV positive and this is the story". Chances are in this department I'll get support. Because this is a psychology department, we read about it, we teach about it, we know.

But that is not always the case. Because we know even those people who work in the health sector, they themselves carry a lot of stigma. They will stigmatise against their colleagues and you will be surprised. I thought they were nurses so they should understand or I thought they were doctors, so they should understand, how can they discriminate against their colleagues. Now this becomes even more problematic for people who have nothing to do at all with HIV and health and then you go and disclose your status to your colleagues and you work at Edgars and people do not really have the priveledge that we have of reading about the stuff. So because we are dealing with people who do not know about the stuff will not be that supportive. Unless in their own personal lives they have come in contact with HIV positive people.

Now in the workplace, there is something called the Workplace Framework Policy for dealing with HIV. Most companies or institutions have that. And this tells managers and employers how to deal with people who are HIV positive. It is a legal document, it's a framework. Most people follow it and it talks about discrimination and that we should not discriminate against others. The challenge with implementing that framework in most workplaces is; 1) who else should be told about an employees status at a workplace; 2) should we then when we have a staff meeting feel free to talk about it?; or should it be this person and their supervisor, if this person is sick their supervisor has an understanding of what is happening with them. So it becomes an issue of now that you have disclosed your status I am making it known to the boss of the company. Who else should know? Should it be your

immediate supervisor or should it be the person you are supervising, because if you are supervising other people in the environment they would need to know if you are working irregular hours what is happening with you. And then that could create a dilemma. If you don't disclose people will start speaking behind your back because once you get sick it discloses itself. So it is a condition that discloses itself anyway the problem is that people talk behind your back. "You know there is something. Where there is smoke there is fire. This person cannot be missing so many working days and getting this and it is been happening for six months or so." So sometimes you do not know whether you should just be upfront and let the staff know that this is the situation and let them deal with that. Or you should keep it between yourself and the employee, but should they pick up there is something happening, they will speak about it anyway.

And once people speak behind your back that is when self esteem is affected.
So sometimes people are trying to spite you. Sometimes they were trying to handle another situation, but they just misreferenced it or mishandled it by making reference to you. And yes you definitely do not feel good when people start speaking about you behind your back.

Researcher: So the devaluation is not always something intentional. Society does not always want people to feel bad about themselves it's just sometimes how we communicate about it.

Researcher: Do you think that women and men experience HIV related stigma differently

Participant 1: Yes they do. Firstly because men and women experience almost everything differently in society. Men have a priveledge that when bad things happen to them, because we think that they are strong they should manage with that. And they grow up with that attitude that I can handle anything. I can handle situations like HIV/AIDS. And they do, believe you me. I have a feeling that men are better able to handle HIV compared to women. It does not destroy them psychologically the way it destroys women. It does not affect their self esteem the way it affects women's self esteem. Because they have other areas in their lives where they can be successful and compensate for this particular self esteem. They have access to better opportunities. They have access to self esteem opportunities and other stuff. And your self esteem is comprised of a number of things happening in your life. So if you got HIV and you spend lots of time reminiscing over your status it will definitely

affect your self esteem. But if you have other distractions and you do not have time to reminisce over your health issues because you have work to do and projects to complete, your life is happening, you're getting promotions and earning more money and you buying a car and a house. The chances are that the fact you are HIV positive will bother you are different from the person who is not making it in life. Generally women have fewer opportunities to make it in life. And even fewer when they have HIV.

And also because of certain decisions. Women are the ones who carry the pregnancy. And most of the problems around HIV are around carrying the pregnancy and delivering the baby. Men are not subjected to that kind of stigma "You will bring a child to this earth and die." Because its like it's the woman who brings the child. So if a couple has a baby and they are both HIV positive, the person who faces a lot of stigma is the woman. The woman is considered to be irresponsible. How can you get pregnant when you are HIV positive. It will affect your health, it will do so much and you will give birth to a child that's got HIV and you will get sick and die. And nothing on the man, because the man does not have to face those decisions whether I should breastfeed or give normal birth or caesarean which is decisions to be made around your HIV status. But with men, it is a one minute sexual encounter and the pregnancy happen. And that's it, no reference to the man about this thing. And as a woman you spend the rest of your life that your child at the end of the day was positive or if your child manages to go through the PMTCT (prevention of mother to child transmission) and your child is negative and you are positive you still think about "Am I going to be able to raise my child, take my child to school you know, see to it that my child grows before I die. Because with men there is less emphasis on that. So the do face stigma completely differently.

So in terms of care, women are caregivers in the society. So when women have HIV they become strained and sick and you find that they themselves are struggling to care for them and because people expect that they are the ones who care and people expect of them to care. And most of the time men have people to care for them because are there, whether they are your sisters, your mother your wife anything, women in the society are always there to care for them, but there are no one there for women when they get sick. So that is one of the things that makes completely different for men and women.

Researcher: Do you think the stigma attached to taking medication affects peoples self esteem?

Participant 1: Well I know some HIV positive people who are taking medication who immediately when they come back to their homes they take their medication from the bottle who identifies the HIV treatment to another neutral bottle. And people do that they do not want to be identified with having HIV. Because the minute you start taking treatment, it's like your CD4 count is low, your viral load is high and you will soon die. So it is frightening and it makes them feel that they need to compensate. So the fact that people transfer their medication to a neutral bottle means that people are worried about what people would think about them.

And yes there is internal stigma as well. Stigma that people subject themselves to, not knowing whether people would support you or not. People feel bad about having HIV and have this internal stigma. They feel bad about having a deadly virus, they feel bad about having had sex, they feel bad about a number of things associated with HIV. And they don't want to take drugs, because it identifies them as having HIV, even though they have HIV. So there is definitely stigma to taking medication.

Researcher: And in relation to how you feel about yourself?

Participant 1: Once you take medication, you think that you are close to being terminal, you think that you are going to get sick, you think that you are soon going to die.

Researcher: And yes, once you think that you are going to die, it changes your outlook to life. You do not make long term plans, everything is about the here and now.

Researcher: Can you please provide any suggestions in terms of future research around the self esteem of people who are HIV positive

Participant 1: I just think we need to look at it differently for men and women. It will never be the same. We need to look at it differently for people from different socio-economic backgrounds, because it will never be the same. I feel that stigma and self esteem in relation to HIV happens in the context of your broader self esteem in relation to other things that are happening in your life. Your family, your peers, your work self esteem and that they all work together to compose the overall self esteem. If only one of those are being affected we cannot in total say that people with HIV have a negative self esteem. Because women have other areas in their life to compensate for the negative health wise self esteem. So there could be

other things that are happening in their lives that could make them feel really good about themselves and it could compensate.

But again we should not your health related, especially because it is a deadly condition would again affect your other self esteems. So even though you feel good about yourself family wise, friends, work and then you get HIV it might actually reverse the gains you've made in the other areas. You might then feel that because I have HIV, my friends are getting married and I am not, maybe I should not go out with them, maybe I should just stick around my house. So it is now starting to affect your relationships. They have not done anything, remember it is the internal stigma. It is that thing that says I feel angry when I am with them, because they are doing things. Imagine they would come and say I was so stressed because I had to take an HIV test and guess what I am negative. And maybe you think "Oh my God what should I say" So you decide to spend less time with them. At work you decide to spend more time by yourself because you don't think that people would understand. Or maybe you heard someone speaking about somebody else, they don't know that you are positive and you hear the negative things that they say and you realise there is no way that I can tell here. And you decide to withdraw. And because we talk about long term plans, people with HIV feel there is no place for me. Why should I go further and study. Imagine, if you don't that affects your chances of getting promotion. Your self esteem will then go down, because if you don't advance yourself you will not get promoted. And you not being promoted has nothing to do with your status, because they don't even know, they just assume that you are not competent, you are not making an effort and you are not because you are thinking "Why should I" So this all influence each other.

Participant 2

Researcher: Work that you do, please. How long have you been doing it?

Participant 2: At the moment, I am seeing clients in a very broad spectrum, I see from depression, bi-polar, HIV, I see individuals, families, couples …..

Researcher: How long have you been in private practice?

Participant 2: I have been in private practice part time for 10 years and then full time for 2 years, used to work for the hospitals, government institutions and did a bit of consulting and I discovered that when you consult, you go in and leave recommendations and then they call you in two weeks time for the exactly same things and it has not been implemented, so I went into the corporate world for 6 years and then I got what I wanted from the corporate.

Researcher: In terms of working in HIV related cases?

Participant 2 I worked in HIV since 1996, how I started was they wanted a psychologist in Pretoria. In the maternal ward which was basically concentrated on HIV positive pregnant mothers and then I lost a friend of mine that was in 1996, I did not cope well at well and when my supervisor saw I will be the best person to work there, and I thought that this guy was really insensitive but thought about it and it was the best thing I have ever done for my myself, and actually it was a healing process for me, one and two and helped me to understand more about HIV and under the normal circumstances

Researcher: Can you describe the self-esteem of someone who is HIV Positive?

Participant 2: I would not say there is a specific profile because it depends on the individual and depends on how, where the person is at in their lives at that particular time when they get the news and most of the time, you find the self esteem will naturally take a dip, because the person feels a sense of loss, they feel that people can see that they are HIV positive, there is a sense of feeling uncomfortable with oneself and a sense of wanting to give up on one's dreams, what one believes in and how one defines themselves, so if a person is a wife for example[le, they feel how am I going to do this, there is intimacy issues, and if someone is single, it is even more challenging, it's like oh my goodness how am I going to get into relationships because I have to explain my situation , so I would say the common thing is feeling unsure, feeling low and feeling incompetent in many ways, because it is emotionally, socially, it is in the world of work as well, because one will feel there will be

issues around being absent from work and people are going to start questioning it, I am going to start his and then be tracked

Researcher: So the challenges that come around this will cause people to evaluate/reflect on themselves?

Participant 2: Yes, there is a sense of reflecting, a lot of reflecting on your life and where you find yourself and it can go two ways, self reflection, and some become a positive thing, for others not so positive, it takes them to a dip, they feel they cannot handle life, they become suicidal, but for others it becomes a sense of oh my goodness, I am lucky I know now I can take care of my life differently. I am just thinking of a young lady that I am seeing, she discovered that she is HIV positive about two weeks ago, she came here and told me that she has made a decision to re-evaluated her life now and made a decision, that one: she is going to change her home, she went shopping and changed the colours of her bedroom and all of that, and she bought a bigger fridge as she has decided to eat healthy and needs to store all the stuff in the fridge and in that case it is a positive way of re-evaluating one's life, take care of one's self and be positive about life

Researcher: So it does not necessarily have to be a negative evaluation

Participant 2 No, no, as I said it depends on the person's personality, where the person finds themselves at that particular moment and what is going on in their lives, so if the person has been in a situation where things are not going okay, it becomes more difficult to be positive about being HIV positive, so if there is something a person is holding on to, so they are able to use that as an operating basis, for instance for her things are going well at work, she is where she wants to be in her career, so I think that is her operating base

Researcher: How would you describe the pride of someone?

Participant 2 The pride? It depends on what you mean by the word pride

Researcher: I mean how proud they are are of them, "how proud I am of myself"?

Participant 2: I think that is tied in with the self esteem, it is tied in with how you see yourself, and it is also tied in with the people around you and it is not necessarily about what they know or do not know about your status, it is just a matter of where you are in your family or social circle, I will call it that, for example, there is a women that I am seeing who is HIV positive, who has been married for eight years, there relationship is relatively good,

and they went for a test, she was positive and he was negative, and they she took it, much as she is a strong personality, but I think a lot can be attributed to the husband support, you understand, so the way she is, the way she carries herself, only the husband who knows, nobody else knows, you can see that she is being positive about it, she has that sense of pride of herself because she is still, even though the diagnosis is there, nothing has changed in her life, I will say the pride of a person who has HIV, is influenced on how the person feels about themselves even before the diagnosis and then secondly, the kind of social support that they have and thirdly, what is happening in their lives at that particular moment, so if a person still has a good relationship, things are looking well at work, that type of things, if they still feel a sense of worthiness, a sense of belonging, a sense of being functional. There was one guy that I saw a few weeks back, he said to me, he has been HIV positive for 18 years but by the way that is not why he is here, but he laughed about it and said HIV for me is not a issue, I managed it, I have been living with it for 18 years, so in her situation she has good support, very good support and two she has schooled herself on HIV and AIDS, she understands the pro's and cons and she is comfortable

Researcher: So definitely, your own knowledge and where you come from and this is based on what you have seen that it does not have to be negative, virus does not necessarily have a negative impact on someone. And then how do people who have HIV positive compare themselves with other people, what influences the self esteem of some of the people, you will see that some of the questions will link to the answers you have given

Participant 2 I think that the comparisons around people are relationships, the comparison becomes, oh my goodness, will the other person stay with me or are they going to leave me now that I am HIV positive, secondly, if not in a relationship, how will it be to get into a relationship with someone and then there are issues around discrimination, if I disclose, how will my friends treat me? And how will people at work treat me if I disclose, I think those are the issues that come up, those questions crop up, you think, if you were not HIV positive, you will not be asking yourself those questions, but it brings in a sense of being different, and a sense of worry around, I might keep quiet about it now, but what if something happens which is going to force me to declare my main difference

Researcher: Do you think there is a relationship between stigma of someone who is HIV Positive?

Participant 2: I think there is, because people will tell you that, people who have been HIV positive for quite some time , even though they are seeming coping with it, they gets moments when they forget about it, and some clients will say they get sensitive, as some of them are teachers and some at working, when people start discussing HIV, they do not know how to get into conservation, as they feels that people can see that if I keep quiet, then people suspect if I talk too much, they do not know how to react, so they become withdrawn in a way, because that withdrawal, you still trying to make sense of how should come, how you should be, so your self-esteem drops and I have situations where when they start having opportunistic infections, like shingles or anything that can be seen by other people, you will find that those people will make comments relating to HIV, "okay, you got this, I hope it is not something like …, so they find it difficult to defend at that particular moment but it stays with them and they feel oh my goodness, maybe people are looking at me and thinking this, and actually I know its this so their self esteem goes down a bit

Researcher: It is almost like it has a ripple effect

Participant 2: Yes, it does, the more you feel less of yourself, you feel people know, the more withdrawn you become, the more depressed you get and it impacts on your health as well because it will get to a point where people will get concerned about you, you are not yourself, you still cannot say what you are not yourself, why, what is the problem?

Researcher: Please describe the stigma of a person who is HIV positive and the experience from the family?

Participant 2: The stigma?

Researcher: Yes, the relationship and the stigma from the family, the stigma from the family per say, and how it can influence his/her self esteem?

Participant 2: This morning I had a client, she is HIV positive and the sister is HIV positive, so they are three sisters, the third sister was not aware of the status of the other two, the first sister is critically ill, she is in hospital as we speak, now they had to disclose to the sister, so they kept the disclosure from her particularly because of how they perceive her personality, they perceive her as someone who is very judgmental, so they had a sense of, we cannot talk about it to her but when they disclose it to her now as of the sickness they had response that actually surprised them because she was very supportive one, two, she said this must not be spoken about to any other person outside the family, so you can see that it is not

only about the HIV positive person but it is also the self esteem of the affected, which is the family, because for the family, it is a matter of, this is one of us, so there is a correlation, as said before, if the family is supportive, it enhances the HIV positive person's self esteem but if the family is negative and not supportive, then the HIV positive's person's self esteem will be low because of the stigma

Researcher: Also the stigma towards that family, and please describe the relationship of the stigma of a person who is HIV positive and the experience at the workplace and how the stigma in the workplace may influence the evaluating of his/herself

Participant 2: Most of the time, that I have been in the corporate world, people don't talk about the HIV status at all, you got all these wellness progammes and testing and all of that, but still it does not make way for people to disclose, reason being once the person discloses, they will definitely be different to the next, it takes very strong personality to be able to make the decision that you are going to disclose not matter what, and you do get cases where people have done that and because of how they conduct themselves, I will say they get some kind of respect, when they have that kind of attitude, I have HIV and then what? So people can receive them but in other cases people don't disclose because they are scared of the stigma and if for whatever reason people know who has HIV positive then they start to tip toe around the person, we have found that there are situations when the person starts to loose weight or their absenteeism rate increases or something leaks that they are HIV positive and then people will move away from that person and whatever responsibilities the person had before they become reducing but all of this is very informal because it is not legal, as we know every business is shouting and supporting HIV and AIDS but the stigma issue is a very critical issue, you will be surprised how senior people, how little they know about HIV and AIDS, but they have to talk about HIV and AIDS because it is starting to effect the business financially and that is what I was interested in how they handle or manage the financial impact. So there is definitely a relationship, people don't disclose because once they do they are stigmatized

Researcher: They are stigmatized in terms of their functions at work

Participant 2: Yes, their functions at work, their promotions and how other people will relate to that and will think I do not want to be associated with you because you are like this and if I associate with you, I will also like that and will try to distance themselves from you if you are known to be HIV positive

Researcher: And whether there is an HIV status or not, then the person gets treated like that, like in the workplace, you not given the jobs, as they feel you are not capable of it

Participant 2: Yes, and that is why most of the time people will not disclose because, I had a situation where in the stores, one of the front ladies was on and off work, she was diagnosed with TB, and she did not have a choice, she had to talk about it and went on treatment and her state of health, really deteriorated and everybody suspected her of being HIV positive but from a work point of view, it was very difficult to deal with as she did not disclosed, and it was very clear that she could not cope with her functions and when I had a discussion with her, she told me she was scared because if she discloses, she is scared she might loose her job, so it is also helping people to understand what the company policy says with regards to what happens to you as an employee if you disclose one, and what happens to you as employee if your health has deteriorated so all of these things will effect a person self esteem, if you come in every day you not feeling good about yourself, you looking over your shoulder thinking I wander if they are seeing or not seeing and wander whether I am going to be given a dismissal letter, or I wander whether they are going to make a case against me so they can rid of me, so these things will weigh down any reasonable individual

Researcher: Do you think that men and women experience HIV related stigma differently?

Participant 2: (Laughter), I am going to be biased but I do not think there is a biased as such, but in my experience, I will say yes, firstly I find that it is very difficult for men to go for a HIV test, they find it very difficult, but for women, I do not want to say it is easy but for women are more able to take that risk and when women know they are HIV positive, they are also more able to surround themselves with people who will support them, they become very proactive, in terms of finding out how do I live positively and most of all it would require some sort of emotional support by themselves but would not say the same for the men, but men do but the percentage would be will be very low, in my experience, so I would say their experience is totally different

Researcher: And how would you say those different experiences impact on their self-esteem?

Participant 2: For women for most the case that I heard of people that are HIV positive and who have been HIV positive for years do not allow the HIV to depress them as a woman, most of the examples I am giving are people who are coming and saying hey by the way I am HIV positive but that is that the reason, I have had quite a few cases of those but it is women In most cases, so you find that most women in my experience, even though they are HIV positive, they still mothers, still have roles to play in that community, one, and two, they still relatively jolly people, you understand, such that sometimes when see they HIV positive person, you think how did this happened, as this person, how do they manage to stay above this, but for men in most cases, who are diagnosed with HIV, it takes a lot of support, but even before it gets to the support part of it, it takes a long time for the people to even source out for that couple, because they will be depressed, they will not know who to talk to, not knowing what to do, not knowing how to access support and that type of thing, until they reach a dead-end, which then forces them to see a therapist, so the self-esteem, I would say, they are able to work with their self-esteem and keep positive and stay positive even though they will have their ups and downs, they stay more positive and maintain a better self-esteem in my experience.

Researcher: And then do think the stigma attached with certain medication, HIV medication, effects someone self-esteem?

Participant 2: It would naturally, one, there are side effects attached to taking this, and the breasts coming out, for women I don't think that those effects will impact negatively because they will have a very nice image/cleavage, for men, there is a various serious issue, remember there was an article from the papers, there was a guy who grew breasts, and if you are schooled in HIV AIDS, you will know that the person is on treatment and that is one of the side effects, so obviously something like that will work on a person's self-esteem so even before they contemplate taking the ARV's, issue like these will pop up that if I take ARV's, I will have to take the ARV's I will have to take it for the rest of my life and what if I get that side effects, so it impacts on their self-esteem, cause they are still contemplating taking their ARV's, and for women, not specially for women but for HIV positive people, generally it is also about, think the person has to take the medication at certain times, it is a matter of there is no way you can do that with people you staying with you knowing, because if you taking medication eight in the morning, eight in the evening, it takes a very clever person not to slip as in other people finding out that he is HIV positive, we need to do something? You can't be ducking for the rest of your life, so that also impacts on one's self-esteem because that the

person will feel I have this cross that I have to bear, and everybody now knows about it. I have one prostitute that I have been seeing for quite some time and she refused to take medication, she can't take medication because she is back home, she is from the Cape, there is no way she can take the medication, she is going to take the medication when she comes back from home, so you cam imagine, weighing saving your life now, could end up being critical, and postponing taking the medication, because people are going to judge you, so self-esteem is not about the way you define yourself because you thinking just people are starting to see me taking mediation, even though they don't know which medication it is, I will have to explain.

Researcher: So it makes sense, the family, because it is mostly the family who will note these things

Participant 2: Yes

Researcher: And then lastly, can you provide any suggestions for future research regarding self esteem and people who are HIV positive?

Participant 2: It is a bit of a tricky area because you cannot touch it and I think that talking to people who are HIV positive, can actually help or who can contribute more because there is the perception of the psychologist which is what we are working with now.

Participant 3

Researcher: Please describe the work that you do?

Participant 3: I've been working for approximately six years after my internship. I run a specialised practice generally. I specialise specifically in addictions.

Researcher: What type of work have you done with HIV specifically?

Participant 3: My work in HIV started in a previous profession where I worked in an HIV children's home. When I started training as a psychologist I also worked in a children's home in Soweto, which also focused on HIV. Then I spent a year working on HIV based programmes in Alex. Most of the work that we did was either with HIV positive people or with bereavement. I then also specifically worked on an orphan's project. And then when I went into private practice it was like a marketable skill, as people knew that I was willing to work with it. It then actually took me into addiction, more than addiction taking me into HIV work. Because most of the people that I worked with, with HIV acquired the HIV in the throws of addiction, it was mostly drug related. The other sort of HIV work I do or have done is with HIV mothers. I have worked in children's hospitals

Researcher: Please describe the self esteem of someone who is HIV positive?

Participant 3: It's difficult, it's difficult. I think sometimes the self-esteem stuff around HIV is more related to other pathologies that plays out. If I can think of somebody particular who I saw who was quite obvious narcissistic, you know where the self-esteem was quite inflated. I suppose because I work clinically, it is more about the other pathologies attached to it. In fact in my experience it was actually quite rare where I have seen people coming in specifically because of, its like they've sort of just accidentally contracted the HIV. I think also by the time people come the depression has set in. They usually come if something else plays out ... as a result of. I think it is a difficult thing to answer, because it plays out with other stuff so you can't really say it is one or the other, the HIV or the pathology.

Researcher: How would you say these pathologies play out with someone who is HIV positive in relation to someone who is not?

Participant 3: I think sometimes when people are diagnosed with HIV there comes a point say in long term therapy, if they want to do that kind of work where the stuff around future starts to play out. Where there's a kinda sense of survival, will I be sick soon. Then the

issue of ambition starts to play out. Where people are faced with a situation where if I should go back to university to finish let's say my master's degree. Will I finish it? Where that ambition gets kind of constrained, by the sense of dying. People are not conscious of the fact that they are not going to die and not going to die in the short term. And it does knock the self esteem. It does affect the sense of efficacy. Will they be able to do, will they be able to achieve? I suppose then yea, there is a strong knock on effect on "Can I, Will I be able to get there?"Because that existential crisis of dying and death which you don't know when it will happen, but you know it will happen is very different to the sense of knowing that "I will die" which other people have. The rest of us have some existential sense of I will die.

Researcher: And that in a sense will affect "my worth"?

Participant 3: Yes, for sure, for sure. And I am now thinking of somebody in particular (this information is confidential hey, if do mention any names just change them, because I do think of my clients in terms of names) I am thinking of somebody who I saw for three years. He acquired the HIV, just going into the midlife crisis. So it sparked of this really horrendous midlife crisis and he'd been diagnosed about a year before I started seeing him. And what it really had done for him was that it really brought to the fore the sense of "what am I worth?" It drenched up something rather than bringing it about. Where it kind of curled up all the stuff of changed careers around twenty times, came out of the closet sort of mid thirtees, so a lot of that stuff around self worth, but in that case it was also linked to the emotional midlife crisis, which automatically involves the self-esteem.

Researcher: How would you describe the pride of somebody who is HIV positive?

Participant 3: You know this very same person I am thinking of, the issues he was going through was very difficult for therapy, because it holds so much stuff, you know who's going to think what. And I think in my experience there is a difference in gender, there is definitely gender differences, age differences, racial and cultural differences. There are lots of things that influence disclosure. And it was very interesting that he found himself at the point where he wished to disclose to his family that he is HIV positive. And that in fact that it had become a matter of pride, so there was an interesting twist to watch something that can get someone down by to become something that he really wanted to do. And then funny enough it drove him to go publicly, and I mean publicly in the bigger scheme of things and do something quite overt about the HIV. It lingers to the positive living kinda stuff. Whereas if I think of somebody else who really kinda struggled to ... he couldn't intellectually bring

himself to the point or at no point could harness some sense of positive living. He could not harness some sense of what can I take out of this or what does it mean. He was very bright very successful.

Researcher: Did his status affect how he felt about his achievements?

Participant 3: You know for some people it kinda means nothing because I am going to die. Or I have heards some people say that it will all amount to nothing. Or I remember one client say to me, that when I die people will say I was HIV positive, that it will sort of undo the sense of achievement.

Researcher: It's like it would not be Doctor X who died, but this person who died of HIV.

Participant 3: Correct, correct

Researcher: How do people who are HIV positive compare themselves to other people?

Participant: I am now thinking of a specific situation and again I am thinking about my long term client where he was in a relationship with a man who was not HIV positive and they met and he told the man that he was HIV positive. And the relationship developed, so it was really it was really done in a kind of open kind of way. The two of them subsequently started a business, which failed, for all kinds of reasons. But he struggled to keep up with the partner, also because of his own kind of stuff. The partner then went on to be quite successful and he didn't. And could have then helped to end the relationship. When I think of that, it was kind of a power thing, but I also think that it is a dynamic in the relationship.

But then if a think about a young woman I saw in the hospital who had a colleague she kept comparing herself to, but then again that comes back to what it will all amount to, in a sense at the end it will all mean nothing. But if you died of some cancer it would not necessarily affect your achievements.

You know another thing I found quite interesting was when I ran groups, for people who are HIV positive and one of the comparisons that came up was whether I was HIV positive and therapeutically that is quite interesting to deal with. And don't think just for the client, but also for myself, in the sense of why is that important for the client and does it kind of change what you think I feel for you. It then kind of took the comparison the other way around in the sense of my sense of not being HIV positive.

Researcher: What would you say, who and what influences the self esteem of someone who is HIV positive?

Participant 3: I think often it is the voices that they themselves have. I think they hold of a voice of prejudice themselves. Because people don't find out that they are HIV positive and then they say this is the works of God. They've already heard some of the stuff somewhere and somehow these things have been internalised and they then in turn own the prejudice, it then gets internalised. And think they are very often not undoing those voices. So many people just don't disclose. They hold strong internalised views of it, but I think that when people do wish to disclose their biggest fear is that of rejection and rejection and self-esteem is linked and that is when they then come up against am I worthy of being loved. Why don't you love me? Why did you reject me?

Researcher: Do you think that there is a relationship between the stigma experienced by someone who is HIV positive and his or self esteem?

Participant 3: Ja, ja. I suppose I am now also thinking of a woman I saw who came to see me. She had gone to the doctor for a pregnancy test and the doctor had routinely done an HIV test. She in the process also lost the baby, but while she was pregnant she had found a reason not to tell her partner that she was HIV positive. She then lost the baby and then lost the reason for not telling her partner that she was HIV positive. This then just spiralled into this huge compensation. She would work long hours. She really did all the kind of stuff that made look like she was getting stronger, where really what was underneath was just fragile person

Researcher: Would you say that those were almost like her defense mechanisms?

Participant 3: Exactly. So I think that there is a relationship. And again the issue for me is it also depends on the persons resources. People whose resources are higher will have better ways than people whose resources are lower and I do think that that connection is clear. I think sometimes it would be irrelevant whether it is HIV or cancer. You would hook to the stuff that you would hook to. I also think that the age of diagnoses is also different toward self esteem. I would think about the person I spoke of earlier who was going through a midlife crisis and for him it was very different to the other man I spoke of who was in his early thirtees. And of course with kids it is different. So I really think that the stage of life depends. So for a woman who is young diagnosed with HIV and has not had kids yet it is

very different to a woman has kids and is about 45 or is diagnosed at fourty and has a five year old who is not positive.

Researcher: So how would you say they experience that difference?

Participant 3: I think that different stages of life affect who we are in the world, how we see ourselves in the world, how we see others in the world, how we see the world in general. And I think all of those situations. Also people in their twenty's make more friends that people in their fourty's. So the sense of isolation is very different around the fourty's around HIV, but the sense of disclosure around twenty can be more stressful because then more people can find out. There definitely is a thing around phase of life and personality

Researcher: So someone who has had a more social life style, even prior to being HIV positive is most likely to experience the HIV differently to someone who was not.

Researcher: Can you please describe how the stigma someone who is HIV positive may experience from their family may affect that person's self esteem

Participant 3: You know one of the stories that sticks out for me is an indirect story about HIV. A patient I saw was in a family where people were dying. You know where once a week she'd been to funeral or even twice a week. Where literally there was an exterminating influence. And nobody ever spoke about it. Nobody ever said that somebody is dying from this or this. And one of her cousins whom she was really close to became very ill and she was in and out of hospital. So she was kind of deteriorating and they would think that she was going to die, but then she would get out and get better and so on. Nobody would say that she has HIV. She could speak about it to me, but she wouldn't speak to her mother about it. Her mother interestingly enough is a nurse. Her mother also would not say anything. But then again the woman who I spoke of earlier who was pregnant. Alot of her stuff was around how things seem, she was very narcissistic. So she couldn't tell because she couldn't feel lessened. She thought it would diminish her to her family, because she was the one who made lots of money. So she was the one who help support this one and that one. So was that figure in the family. So she could not conceive the possibility of being lessened in the eyes of her family.

Researcher: Do you think that her status had an influence on her narcissistic personality?

Participant 3: I think it just shot it through the roof. It heightened a lot of stuff. It heightened the perfectionism, the driveness, her sense of ambition. She struggled to read literature around people who are HIV positive. She struggled to read anything around people who got sick, you know most of those stories people tell about how they got ill and so on. She struggled to deal with her mortality

Researcher: Did she ever disclose to her family

Participant 3: She had been very careful. She never gave me any way of contact with anyone outside. She knew that there was a duty to disclose on the part of the clinician. She was very very careful to never give her partner a name. He was a prominent figure, she never identified him, she never gave me any other number than her cell phone number or a next of kin's. I did not know who she worked for. She vaguely gave me an idea of what she did, I knew more or less where it was. She was very careful not to disclose too much, because she knew that there was a duty to disclose on my part and the doctor I sent her to who was an HIV specialist.

Researcher: Can you please describe how the stigma someone who is HIV positive may experience from their workplace may affect that person's self esteem

Participant 3: You know I don't really have experience in terms of the workplace because my clients don't really disclose at work. One person I saw, he actually passed away recently. He got very ill, but never disclosed at work. The partner had also gone all out to hide the fact that he was HIV positive. In fact to this day, I continued to see the partner because I saw them as a couple. He had only disclosed to his (HIV positive persons) mother after he had gotten so ill that they could not hide it anymore. The mother also kind of found out by accident. The mother saw a bed file or something, but he was the one who confirmed it to her.

This is also because he is ashamed of his partner. His partner contracted it in the context of the relationship, he was involved with someone else and he had the highest sense of shame.

Researcher: Do you think that the stigma experienced by someone who is HIV positive due to the medication that they are taking affects their self-esteem

Participant: As I have mentioned before the people who I see have not disclosed their status to the people who they live with or to family members. I therefore do not think that I am able to answer that question.

Researcher: What would you suggest for future research regarding the self-esteem of someone who is HIV positive?

Participant 3: Someone I know did research regarding the meaning of HIV. Meaning in the sense of the existential sense. I think in the sense of what am I going to do with this. I suppose in therapy I have seen people get to the point where, I know I am HIV positive. I know I am not going to die tomorrow. Now what? And that is a good place to be. The sense of I am not going to die, now I actually need to get a life. And in some way I think that is kind of work around self esteem stuff. I suppose it would be valuable to think about building a life or continuing to build a life. What to do with our world. Should I change careers or whatever it is that would valuable? Perhaps it would be important to speak about courage, that this takes courage.

Researcher: Just to understand what you are saying. We should explore the meaning of HIV for someone and how that can be valuable for the person?

Participant 3: Absolutely. Furthermore regarding the research we should also explore the resources of someone who is HIV positive. The self esteem is a resource. How much of it is due to personality and to pre existing trauma. So is the HIV diagnosis just part of that trauma in life. Because some people are not as traumatised by their diagnosis and sometimes it is just a complete projection on our part thinking that this is such a train smash. But it isn't for everyone.

Researcher: Thank you for your time and input.

Participant 4

Researcher: Please describe the work that you do?

Participant 4: I've been private practice since 2000. I've been doing employee wellbeing within the private practice, doing onsite work and so on. I run my assessment centre. I am a senior assessment consultant. I do neurotherapy, hypnotherapy.

Researcher: In relation to HIV?

Participant 4: In relation to HIV it is private practice work. Often the people come through the call centre. They will call in for something and then it will come up during treatment. I have had a couple of private referrals from people I have seen before. I have specifically done a lot of work with white Afrikaans gay men who are HIV positive.

Researcher: Can you please describe the self esteem of someone who is HIV positive?

Participant 4: Really low, because of the stigma attached. The white Afrikaans homosexual men, it is virtually nothing.

Researcher: How would you describe the pride of someone who is HIV positive?

Participant 4: I am not sure if they have pride at all. They have reconciled to the fact that they are gay. A lot of people know that they are gay. So their social groups and some people in the work situation would be aware that they are gay, but none of them have told their family of their status.

Researcher: So, most of the people whom you have seen have not disclosed their HIV status, neither their sexuality to their family members.

Participant 4: In fact most of them are very distant from their family, they have minimal contact and minimal interaction. And I think part of that is that some of them are on antiretrovirals and they have to take their medication in private because they don't want people to know that they are suffering from HIV.

Researcher: How do people who are HIV positive compare themselves to other people?

Participant 4: I think they struggle with that. I think they see themselves as quite different. Some of them see themselves as victims others have recognised that this is because

of their own behaviour. But I think that they see themselves as quite different leading very different lives and then also quite abnormal within what is suppose to be normal in society. Within their own homosexual community they're fine, they're very supportive of each other, there is lots of social support there. But compared to the larger population of the so called normal behaviour, there is just no comparison at all.

Researcher: What would you say influences the self esteem of someone who is HIV positive?

Participant 4: I think still the stigma. I think they're also struggling with the socio-political change now. Because of what is happening in South Africa and the political change, they're the white Afrikaans male. Which is kind of this endangered species now? In the work situation for example, with promotions, BEE and stuff like that. They see themselves as very isolated, very much a group on their own, differentiated by all of us.

Researcher: So there are other external factors which contribute to how they evaluate themselves.

Participant 4: Yes of course there are. I think the prejudices of society. This one particular chap is quite a senior guy in one of the audit firms. There are a lot of people who are very supportive of him. He is very gay, very feminine. He has openly admitted that he is gay. He dresses like a gay man. He is extremely well groomed. He drives a beautiful car and yet he gets huge prejudices from other people within the company, the touch guys. They don't want him there. And when his HIV status was confirmed he actually felt it necessary to tell management. He felt that he should actually be upfront about it. And the response was pathetic. They didn't want him there, but they could not get rid of him because he is too damn good. He is a very intelligent and pleasant guy. In fact one of the nicest, most interesting clients I have ever worked with. My sessions with him used to be one of the highlights of my week, just because he such an incredible human being.

Researcher: Would you say there is a relationship between the stigma experienced by someone who is HIV positive and his or her self esteem?

Participant 4: Without a doubt. You know they may have accepted themselves but in relation to what they experience it does affect them. It's almost though his intelligence and abilities is imaged by the fact that he is gay and HIV positive.

Researcher: How does it influence the value that they place in themselves

Participant 4: I think it makes them very sad, because his abilities are not being recognised for what it is. It is overshadowed by the HIV and his homosexuality. It is not separated, valued and praised and considered worthy in its own right. It is always the yes but. He is brilliant, yes but.

Researcher: Can you please describe the relationship between stigma someone who is HIV positive experience from family and his or her self esteem

Participant 4: As I have said the majority of who I have seen have not disclosed to their family. They suspect that it is a no go area, it's not to be discussed. In fact the one chap got extremely sick. I actually said, "don't you think that it's time the family should know". He said "the family can find out at the funeral."

Researcher: So how would you say not having the closeness of the family or that feeling of there is no way that my family will understand me makes them feel about themselves?

Participant 4: Oh, dreadful. You get so much in terms of self esteem within the family that it is a huge loss the fact that they can't disclose. At the moment there is a level of acceptance within the family of them. But if they disclose they would lose the little bit that they've got and they are not prepared to do that.

Researcher: Can you please describe the relationship between stigma someone who is HIV positive experience at the workplace and his or her self esteem?

Participant 4: I think all of them have been stigmatised within the workplace, which is why they have not disclosed their status. They might be known to be gay. It's just by virtue of the fact they are gay, there is an assumption that they might be HIV positive, so the stigma is high. I would say that they have few relationships that are healthy, positive and supportive and just accepting of who they are.

Researcher: Do you think that women and men experience HIV related stigma differently?

Participant 4: That is difficult for me to answer as I have not had many HIV positive ladies in the practice. They are not heterosexual men with HIV, which I think that they would be treated in the same way as women with HIV. I really don't know. But I have recently had

a client come to me who was gang raped. Immediately we had to send her for tests and one of risk factors was that she might be HIV positive. And she said to me that her life is basically over. If it comes out that her life would be over, because no man would not want to have sex with her and she would never get married etc. Their view of her would be to kind of use her like a prostitute which would mean that they would not want to have a relationship with her.

Researcher: Can you please describe the relationship between stigma someone who is HIV positive experience as a result of the use of medication and his or her self esteem?

Participant 4: Yes and no. There are quite a few people who refuse to take medication. They prefer to adopt the holistic health, exercise, diet just to look after themselves, because they have heard of such horror stories in terms of the side effects of the antiretrovirals. There were two particular men who were lovers. They were terrified of dying the HIV death. That was more a motivation for taking antiretrovirals. They were extremely good looking. They're very vain, very aware of their very good looks; they've made a lot of money out of modelling. They were very afraid of what the HIV symptoms would do to their looks. They went through hell because of the side effects, but they were determined to make sure that the antiretrovirals work

Researcher: Because of their good looks they get good responses from society, which influences how one evaluates yourself. How would you say that pre-determined evaluation of themselves may be influenced by the stigma they may experience from society?

Participant 4: Neither of them have disclosed openly that they're gay. They were fine with each other. They were fine with their immediate group of homosexual friends. They played a heterosexual role. They dated women. So he disclosed to his homosexual peer group, but certainly not to the open public. Amongst the homosexual group they get a lot of support. Many of them are HIV positive so they really support each other in terms of the antiretrovirals. Do this, do that etc.

Researcher: How would compare someone who has that support to someone that does not?

Participant 4: I think that they cope a lot better. I think it gives them more motivation, to try and live a normal life, to what is normal for them. So it does make quite a difference.

Researcher: Can you provide some suggestions for future research regarding the self esteem of people who are HIV positive?

Participant 4: To find out what personality characteristics could be nursed. I've never really thought about it. I think the problem lies in the fact that all of them are expecting them to die and they are at various levels of coming to grips with that. If you think in terms of Kuebler-Rosses' bereavement theory. The young good looking male model guys are in the anger stage. The successful guy was doing the kind of bargaining depression stage, where it was "What do I need to do to make myself well, What do I have to learn to make myself not die alone. He was organising himself to make his life lasts for as long as possible. He knows what his CD4 count is at what stage of the virus he is and he does not expect to live beyond forty. And what was interesting was he was struggling with whether he should get a dog. What age should the dog be? Should it be an old dog from the SPCSA, because he is going to die quite soon or should it be a puppy? And he has actually negotiated with his peer group that someone who he trusts would take care of the dog. The dog was a huge dilemma in his life.

Researcher: So all of these things influenced his motivation

Participant 4: Absolutely. There is an issue regarding taking medication. You know what is good and not good for your body. My attitude is to just take everything, at least you have tried.

Researcher: Thank you for your time and input to my research.

Participant 5

Researcher: Please describe the work that you do.

Participant 5: I was lecturing at Vista University for about thirteen years. I now have a private practice for about six years. I also work at a school, West Rand primary. I did my masters in Educational psychology, then did my doctorate in educational. Then I realised that a lot of the problems is not always the kids then I went back and did what they call a PSYD. It is an integrated clinical, counselling and educational programme. I did it at the University of the Free State. I am also part of a post graduate programme at Potchefstroom University.

Researcher: In terms of HIV?

Participant 5: Clients in my private practice. Quite a fair part of my counselling is couples counselling.

Researcher: How would you describe the self esteem of someone who is HIV positive?

Participant 5: It's different. I had a guy who had a very high self esteem. Then I also have some clients with a very low self esteem.

Researcher: What would you say influences that self esteem?

Participant 5: They have a good self esteem all the time or a low self esteem all the time. Afterwards maybe it will affect them, after they get sick. They become worried about what people may think and how people would evaluate them, if they look at them differently.

Researcher: Would you please describe the pride of someone who is HIV positive.

Participant 5: They are not very proud of themselves. They thought that it is not going to happen to them, it's always something that happens to other people.

Researcher: How do people who are HIV positive compare themselves to other people? What influences the self esteem of people who are HIV positive?

Participant 5: I would say they negatively compare themselves. Other people have an advantage over them. Other people also have a quality life ahead of them. At the beginning they think that life is coming to an end for them. Like a cancer patient, they think that they have been issued a death sentence. They think that others have an advantage in terms of time

over them. When they hear that they are HIV positive, they have a very negative perception of the future. At the beginning they think that there is nothing more to life, I have the death sentence. But as they continue and realise that today is still the same as yesterday, so they realise but this is a long term thing. If I get the right treatment and if I look after myself I can live as long as the next person. They see people dying in motor car accident or so, so other people who are not HIV positive suddenly die and me who has the virus is still alive.

Researcher: So the initial perceptions are that my life is going to come to an end, I can't make long term goals. And is life prolongs, they experience life, they realise that they can continue living. Do you think that there is a relationship between the stigma experienced by someone who is HIV positive and his or her self esteem?

Participant 5: Yes, I think so. From past experiences with self esteem, I would say that it is influenced by what other people think of you. Especially if you have a low self esteem, you always think of or make decisions based on what others think.

Researcher: Can you please describe the relationship between stigma a person who is HIV positive may experience from the family and his or her self esteem?

Participant 5: Most of them want to hide it from the family. But once they tell the family they are actually surprised by the support that they get from the family. But most of the time they are hiding it from the family so if they are taking medication they do not take it regularly, because they are scared. But once they tell the family it is almost like now I can just be myself and I can share my worries.

Researcher: Can you please describe the relationship between stigma a person who is HIV positive may experience from the workplace and his or her self esteem?

Participant 5: In the cases I have they all did not want the work to know. All of them, the first time they see me want to make sure that this information will not be given through to the workplace, so I cannot really say. But the one guy I am seeing is really sick. So he needs to take of so every now and then. At some time they might ask him to get himself tested.

Researcher: Do they explain to you, why they do not feel comfortable with people knowing?

Participant 5: It is almost as if it is going to influence their daily performance. That it would have an impact on their prospects at the workplace.

Researcher: Do you think that women and men experience HIV related stigma differently?

Participant 5: I think that women are more accepting. They have to go on with life. They are a bit stronger. Men just seem to be very difficult. From a couple that I am seeing. The guy has HIV as a result of having more than one relationship and the woman did not have. Afterwards they blame their partners for it. They're not accepting responsibility. They want to blame and say it is other people. Whereas the woman would say, I have to do something about it because I still want children.

Researcher: How would you say these different perceptions influence their self esteem? What is the difference between men and women?

Participant 5: I would say women have a lower self esteem. Men make practical plans, while women are more emotional about it.

Researcher: Can you please describe the relationship between stigma a person who is HIV positive may experience from taking medication and his or her self esteem?

Participant 5: It also depends on the situation. There are some clients I have who do not have any problem with taking the medication. When they live with others they actually hide the medication.

Researcher: Can you provide any suggestions in terms of future research regarding the self esteem of people who are HIV positive?

Participant 5: I think research done over time. So at the beginning when they find out that they are HIV positive. Do a self esteem inventory. And then just compare it to six to eight months from there. Just to see if there is a difference. You have to see what the self esteem was like before they got the disease. And then six months later see if there is any change. There is one story of a couple that is very significant for me. This gentleman is young, very successful, many degrees, in a management position. His wife also has a few degrees so he could not marry her because he could not afford the lobolla. Then she fell pregnant. He then became ill, had stomach problems and so on. This affected his work, could not attend his management meetings and so discovered that he is HIV positive. He then got so cross with the world. Then he started to blame his past. During their relationship he had another relationship as well. He did not want to take responsibility for that affair that he had.

Eventually the two of them just drove away from one another. Although she was pregnant she just lost her sense of life. She was actually at a stage of committing suicide. They just did not want to know anything. They are so highly educated. One would think that they would make use of the sources that they have, but they were just not interested. She did not want to come back for therapy. She saw no use in counselling because she does not have a life anymore. She just says that I am going to die and my child is going to live without a parent. They are so highly educated, they just think that it is not going to happen to them. All the booklets I had the man just wanted, it was like "Can I have it, can I have it" It is as if he did not have the knowledge before the time.

Researcher: It makes you wonder, whether they actually did get exposure or education at work or if its just that they did not listen. This stuff does not apply to me. It is an interesting aspect to research, whether despite all the programmes out there can it be that we still have such high rates because people do not pay attention. Then what is it that we have to do to draw people's attention?

Participant 5: You know at the one school where I work there is a lot of information that they have to give through to the children. The teachers' response is not HIV again. The other thing is that you find that there are more and more teenage pregnancies, which tells you that kids are more and more sexually active at a younger age.

Participant 6

Researcher: Please describe the work that you do?

Participant 6: At the moment I am lecturing. I have been doing that since February this year. But before that I was involved in home based care projects in the West. That was a church project. The pastor there actually felt that he could help the community. He felt the church could help people involved in training of people in home based care. There were about eight of them. So I was managing or actually supervising them, because they had a scope of practice. There were some very complicated situations where they needed some professional assistance. So that is how I came to work with cases of HIV.

Researcher: How long have you been working in this field?

Participant 6: Two years, since 2006.

Researcher: Have you done any other type of HIV work?

Participant 6: This is basically what I have done. But as a manager you are exposed to training. They train everybody, whether you are a home based care worker or whether you are a manager as long as you are involved in the projects. Let me say they train all the stakeholders about HIV or whatever area it is that you are working in. They would train you about what it is to manage, how to go about a business plan, how to collaborate with the other stakeholders. So I have had a lot of training in HIV and the specific area involves that I was working in, which was home based care for HIV positive people. So they train you throughout so you know what is happening.

Researcher: Have you done counseling with people who are HIV positive?

Participant 6: Yes. Like with this home based care, they would do the medical part, the nurses. They were also trained to do counseling, but I also helped them as clinical supervisor. How to handle people. How to intervene. How to deal with sensitive issues because at the end of the day they would come to report to me how they were doing, the work they were doing, and the area they covered. Those specific patients. They would experience problems sometimes. Either from the family or from the patient, I would then assist with that. They would also report practical logistical things that they managed for each person to go for treatment, things like that. Sometimes they would

struggle with issues around the grant and I would say to them go to a social worker. And we would work around the counseling procedures, also their own roles in terms of who should do what. So you would encourage people to do counseling. Cause now family issues to come up. So that is how I got involved, also talking to the family , so now they come because now they know, they are now prepared to cooperate. We also had an office at the church. So they would come to know that there is somebody there who they could go to, so we were sort of the point of contact for the community.

Researcher: Please describe the self esteem of someone who is HIV positive?

Participant 6: I think they have a low self esteem. Also it's like a dilemma, when they get this information they do not know what to do. They've got to be encouraged that they should share and talk to other people. So it is difficult. They are also faced with the issue of dying. They also experience from friends some form of rejection. So it is quite difficult. There were a few of them who came to the point where they felt, Okay this is me and them they would come forth and share. But the majority struggled to accept. So our counseling would be that I have got this and it can be treated just like other diseases there is no cure. Like diabetes for example. And to get information. And we should help other people while helping ourselves. All the nurses might help you, but you also need to help yourself. But if you close yourself, people won't want to talk to you. But like I said you do find those who also felt that they need counseling so that you can get a culture of talking. So the social worker would come together with some other people. So she said to me let's start a group, so I had to go twice a month, fortnightly. So the caregivers would encourage them to come out. So there would be group counseling where they would get to talk and also share information. And then we also as their facilitators we would share with them our progress to keep them motivated or whatever it was just to keep that culture of talking. There was the one she was very much in the programme and she was in the advantage stage. But that's the way she would talk about it that she was in the advance stage. But she was making progress.

Researcher: Please describe the pride of someone who is HIV positive?

Participant 6: The ones I have seen, it is low. Whatever information you give them, there is that great thing, where they feel they are going to die.

Researcher: How do people who are HIV positive compare themselves to other people? What influences the self esteem of someone who is HIV positive?

Participant 6: They regard themselves as different. You know they have those symptoms and despite that they know how to get pass those symptoms. And they avoid other people. So it rests really on the other people.

Researcher: So they restrict themselves from other people. What or who would you says influences the self esteem of someone who is HIV positive?

Participant 6: I think the way they perceive themselves. And at the moment they know it is not curable. I think if you about that, you don't know how long you are going to live. You can't really plan other things because there is this thing. "But, what if". I think they sort of feel that they are out of control. Whatever they start, it will always be no HIV. I will do this and do this, but I am HIV positive. For others they are sort of locked up. Some differ. There were quite a few cases. I remember this guy who refused to be seen at home, who refused to accept treatment, who refused when they encouraged him go forward. And I was going with tit, I had to manage it. Because the church had said these people have been going there and they have been giving reports. And they wanted to know are those people there? Are they dealing with the cases or are they just writing numbers so that they qualify to be funded. So they said just help us, so you can go there and see how these patients are coping. Help them to be discharged. They must not just be kept on the role for numbers sake. So the whole thing self esteem, some of them would come to a point where they would just don't cooperate. There was also one lady who refused to take treatment, where she would say this one she wants me to do these things. Although one year where the church was giving blankets she did come. But I could see the problem could be his interaction with other people. Regarding the issue of pride, that one is interesting. There was a lady that came that was HIV positive. She was one of the clinic's aids. She would talk about it and she was out there. And she was fine, she was taking her treatment. To the extent where she was so positive, I remember the very last group that I had she was there. And she was encouraging these other people that the best way to cope with it, is to come out and disclose. And even the way she was pushing I felt that it was too much. No being able to accept the fact that, the people they have come here let them works it out amongst themselves. You don't want to push people and them they can't handle it. It must come from within. So she was pushing, pushing. But she was fine and they could understand why she was fine, because she was taking her medication,

she had nothing to hide. She was looking so fine that even the caregivers were querying whether she HIV positive.

Researcher: Do you think there is a relationship between the stigma experienced by someone who is HIV positive and his or her self esteem? Please elaborate on your answer?

Participant 6: Yes. The workshops that I experienced these people would be exposed to HIV and what it is about. And then there would come a point where these people would so positive, some people would come up and say how they feel.

Researcher: Please describe the relationship between stigma a person who is HIV positive may experience from family and his or her self esteem?

Participant 6: Those who are open about status they complain they don't find support. You can imagine some of the partners. That should really be the one that should be supportive, but if that person you don't feel safe with in terms of that person not being supportive that creates problems. And if it is possible we try and see this person. Those would be the ones we would try and encourage to come forward. We try and see them together, to try and talk about this.

Researcher: Would this be in the group as well?

Participant 6: No just two of them. In the group, those are the people who feel that they can attend a group.

Researcher: Individuals who experience problems with their family?

Participant 6: Yes, they would come out and say that they have problems and we would ask them if they want to have counseling. The problems would be around bereavement and their relationships. So they would ask if you could come and talk to this person.

Researcher: So some of them were capable of standing up for their families?

Participant 6: Yes, some of them were. But a few they wanted to get help with that. There was just lady that was having a problem. So whatever it is he would be encouraged to find out what is going on. She knew that she was HIV positive, but when it

came to telling the partner. When we would say let's go talk she would wait for days and then there were cultural issues. She would them let you come, but when the husband comes she would them say she did not want him to know, because what she said was the husband would quarrel where did she get it? Meanwhile it was possible that she was infected by him. So it was obvious that the husband had an attitude about these things. I would say just go together, just go for testing.

Researcher: How would you say the manner in which she tried to hide things from her husband affected how she felt about herself?

Participant 6: I think she got a sense of needing to dodge us. Dodge saying this and saying that. That's why this caregiver referred her, because he could not deal with her in terms of where they stand. It was like hide and seek.

Researcher: Please describe the relationship between stigma a person who is HIV positive may experience from the workplace and his or her self esteem?

Participant 6: I think the workplace should be open about that. So they could teach each other how to handle other people. I don't think the workplace is very open to people's struggles. Still they need to maintain the high levels of standards. But I think that there are some work places, I can't say exactly which ones where they teach their people how to handle it. It affects how people relate to each other and then it affects how people feel about themselves.

Researcher: Do you think that women and men experience HIV-related stigma differently? Please elaborate.

Participant 6: My experience with HIV people is ja, they experience it differently I think. We as women are different in that men are more closed and difficult to get through or interact with. Women are too expensive. I don't know whether are more exposed to the dangers of the virus when it comes to sexual activity. There was one group where it came up. That if men came out like women there would be more affected, if you think about stigma especially. Then some men would come up with these traditional explanations. We would then say let's stick to the medical side of things. Some of them would then say that traditionally it is right for me to have more than one woman. So what I was saying as a traditional person, I do not recall things being done in this manner. It is now a mixture of cultures, the traditional and the so called modern ways of doing things.

Because what we know is that if the man was married and he wanted a second wife it was actually with agreement from first one. And you would find that they would live together in harmony, in terms of sharing the resources, bringing up the children.

So what we try to do is to encourage more men to come to our group so that they can also learn to think about these things. So men were also encouraged to do activities and to explore their abilities. They were encouraged with sport and agriculture and so.

Researcher: So if men and women experience stigma differently, would you say there is a difference in self esteem of men and women?

Participant 6: Yes, it they have disclosed I think they do. Mind you, I once went to this area where there was a natural disaster. There they would do counseling. I noticed how men would handle things differently. There was one lady who was sobbing, and she was carrying this picture of a child that dies and the man would say don't cry it is going to be okay. So what he was saying is: don't cry like this because it is not so bad. He also did not want to grief, so men do not handle things.

They also suggested to the person who must give the report about the group that they should train more men counselors.

Researcher: So what you are saying is that men do not allow themselves to experience their feelings?

Participant 6: Yes. I think that if they are men in the group they might express themselves. I think for me it would help if there were a male group. I think it would be interesting to see how this group would do.

Researcher: Do you think the stigma attached to taking medication affects HIV positive peoples self esteem?

Participant 6: It does. I mean whatever you take medication for; from my experience it is not nice. I know at the clinic the doctor or whatever you would question properly stick to the medication. So how much more for HIV mediation and then people don't take them properly, which is unfortunate, because it takes time for the regime to work so if you don't take it on time it is going to be less effective. So that one, people see it as a life sentence, people question the end result, am I going to be well? So in the group people would be encouraged to take their medication. But in some cases there would be a

good reason like I can't take medication on an empty stomach. Then we would have to intervene with that first.

Researcher: Please provide suggestions fro future research regarding self-esteem of people living with HIV.

Participant 6: I think it would be good thing to intervene on a one basis as well. To ask these questions and see what explanation the people themselves would give. Is everybody's opinion going to be similar or is there going to be differences in terms of gender, socio-economic differences etc. I think if you touch on things like background and tradition then you get to know why people are doing what they are doing. Like one book that I was reading they talk about upbringing and attitude toward AIDS, the use of condoms. You know they've got this reasons and stereotypes, that they feel they should stick to. Then you can know how to come around that. How to reframe that positively? I think that when you interview them individually and you also sit in a group, then they learn, they also learn from each other.

Participant 7

Researcher: Can you please describe the work that you do?

Participant 7: Generally I am a lecturer at the university. I teach undergrad and I also teach honours. And I am also a transformation lecturer, which deals with equity. In terms of HIV/AIDS in particular, what I am doing currently is to see patients who are readers of the Sunday Times. The Sunday Times runs a service where they offer the infrastructure for offices, administrative kind of work in terms of the booking of appointments, making sure that there is room to see these patients, providing reception for these patients. So it is me and a colleague of mine. That is something that we do every Saturday. The patients that we see range from children who have been orphaned because of HIV/AIDS – to domestic workers whose employers read the Sunday Times, domestic workers who are either infected or affected by HIV and sometimes HR Managers who are grappling with handling being told that a staff member is HIV positive. So it is a whole range of people, infected and affected.

Researcher: How long have you been doing this for?

Participant 7: The Sunday Times thing, specifically has been more than a year now on a weekly basis, but other than that. I don't know if you know about Centre for the Study of AIDS, they tasked someone to write a review on an annual basis so I was tasked to write the 2004 one which dealt with a whole range of issues, specifically issues dealing with masculinity and HIV/ AIDS. It was quite a thorough kind of project.

Researcher: Are you seeing any clients relating to HIV in your private practice?

Participant 7: So far I have not. Not because I do not want to but lets just say that within the clientele that I am carrying at the moment there have not been any HIV related matters that I have had to deal with.

Researcher: Can you please describe the self esteem of someone who is HIV positive?

Participant 7: Look it depends. There are people Especially in the initial stages. When I say the initial stages, just after they have found out that they are HIV positive, the after they have received results that they are HIV positive. The self esteem tends to plummet just a little bit. The person feels terrible about themselves. Regardless of how educated that person is, regardless of how much information they have of HIV and AIDS. It is only an

issue that they deal with, the issue of mortality, which they are going to be dying, how they are going to be dying and so on. So finding out throws people in some kind of a crisis, included in that, the lowered kind of self esteem. If I can give you an example, one of my clients that I saw following finding out that they were HIV positive. What they did was to start what they did was to start generate some you could say some form of self medication. They started drinking a little bit more and started becoming a little bit more indiscrete when it came to intimate partners. To a point where they actually got referred by their parents because their parents thought that they were endangering themselves. They were not accepting that they were HIV positive and that they were going the wrong way around dealing with finding out that they were HIV positive. So as I am saying it throws people in all kinds of crisis initially, part of it being a lowered self esteem. But as people get used to the idea as they adjust a little bit to the news that they are HIV positive it gets better. There are some people in fact who are HIV positive that has some indications that their self esteems are even better than those who are not HIV positive. Because some how it feels that being HIV positive throws in something that brings about some meaning in their lives. That they have something to live for by being an activist and spreading the word and making sure that other people do not get infected and so on. So it differs, but mainly at the beginning, the self esteem is a bit lowered.

Researcher: How would you describe someone who is HIV positive's sense of pride?

Participant 7: Shoo. There again, I think pride is, I do not know if one should call it a human emotion. It is one of those that can be associated with levels of self actualisation. Where there has been some kind of transients of certain basis needs that one should adjust to somehow. I think that when you are in that crisis that you just found out that you are HIV positive, pride would be the last thing on your mind. But I think pride that can be observed in people who are HIV positive is at a later stage, after they have adjusted. It can be pride that is associated with activism. It can also be pride that they have managed to pull themselves back together, let's call it the burden of being HIV positive with integrity. That they have managed to not fall apart, to pull themselves together and to keep on living for their kids or looking after themselves. There again I would say, pride is hardly observable at just finding out that one is HIV positive, but there are a whole variety of associated things, like activism and feeling good about yourself, managed to pull yourself together, managing to look after yourself later on after you have adjusted.

Researcher: So the way that you take charge of yourself will influence your pride as well as your self esteem?

Participant 7: Yes. I also wonder to what extend feelings of pride become employed as part of the general defence mechanism, because being HIV positive is one of the things that you can't remove. If you are HIV positive, you are HIV positive you know. And it does affect a sense of being, how you feel about yourself, how you view yourself and so on and at some point you need to wean yourself to feel a sense of pride in an attempt to come out of sometimes the depressed stage/ reality of being HIV positive. Because you can never be HIV negative again, so it takes away something, with a whole lot of associated realities. Practically, it is about can you have kids, can you get married. Your relationships, private life, how is it going to be affected. So it affects a person in a big way. So a sense of pride I would say ameliorates the depressive reality, for some people that are HIV positive, because it differs from person to person.

Researcher: So like you said, it becomes a defence mechanism, it becomes a means of standing up against the reality?

Participant 7: Also engaging in self medicating behaviour is an indication of giving up on yourself. If you endanger yourself it is almost like you are deliberately trying to destroy yourself. You don't care about yourself anymore. A high self esteem would be associated with a higher sense of value for yourself. That you are valuable, you matter, that you are worth looking after. Pride you know is a bit problematic when it comes to being HIV positive. A sense of pride is a string of emotions that are extraneous. You first need to feel like you are alive; you are safe and so on, before you can even start feeling a sense of pride. A sense of pride in my understanding in a context of HIV is difficult to associate it very clearly with HIV and AIDS, not only with HIV and AIDS, with any other illness for that matter. So going back to it being employed as a defence of the depressive reality, so calling upon your sense of pride somehow enables you to stand up, pull yourself out of that low sense and in that sense it would be associated with a higher sense of self esteem. When you say pride, you need to ask yourself pride of what. And I have given two indications where there could be some kind of a link.

- Pride in the sense that you are able to look after yourself, to survive.
- Or you are able to continue shouldering your responsibilities, if you are a parent look after your kids, if you are an employee doing your job properly and even getting

promotions. It's about survival, but you get to that point after you have fought to be able to survive. It is difficult to have a sense of pride while you are struggling to have a sense of being alive. As we said the news that one is HIV positive almost invariably confronts one with mortality.

Researcher: How do people who are HIV positive compare themselves to other people?

Participant 7: There is a sense that they have lost something. Within in my experience with clients that I have dealt with, there is a sense that they have lost something, most of all they have lost a sense that they are going to live for a very long time. That is the major one, but over and above that they have lost control over a number of issues. Their choices have become a bit limited. So compared to people who are HIV negative, people who are HIV positive they feel that they have lost certain things that are quite substantial in their lives. But then from time to time in the work place, it becomes a part of your reality, that you are overlooked for a promotion, you are overlooked for some training and so on. But that comparison comes in was I not chosen for this course or this positive just because I am HIV positive. Those feelings of self comparison also brought about when you see someone sexually or when you hear about another person's plans or even the general plans of society. You know such and such is going to happen. In 2010 there's going to be world cup, people who are HIV might feel that I will not be alive by then. So there is that foreshortened sense of future basically. There is this book titled, Bounds of possibilities for people who are HIV positive, while they are still adjusting to being HIV positive. For them there is a sense of it is not bounds of possibilities, it's like limits of possibilities. Possibilities are limited. In a real sense of things, you can't choose a life cover, or insurance that you want there is a lot of things that exclude people who are HIV positive. In terms of investment, can you buy a house that requires being paid of over twenty years, you feel like you are not going to be able to live until then. So there is a real sense of what is possible or let me rather say what is perceived to be possible for HIV positive people as compared to HIV negative people. I am saying perceived because being HIV positive is something that is treatable at the moment. It cannot be cured, but it has come to a similar level as any other chronic illness, but then one is to check if they are on treatment, in terms of changing their lifestyles and so on. So one cannot be reckless anymore, because the more reckless you get the more you limit the positive effect the treatment may have or your ability to withstand the effects of being HIV positive.

Researcher: How would you say your self esteem influences your commitment to treatment?

Participant 7: I think definitely there is a positive association there. The higher your self esteem it would also be associated with a sense of value for yourself, self worth you know. You feel that you are worthy of being taken care of, taking care of yourself. Chances are that it would have a positive effect on your commitment to taking your treatment.

Researcher: What would you say influences the self esteem of someone who is HIV positive?

Participant 7: Look definitely, in a certain sense finding out that you are HIV positive, for a lot of people is a traumatic experience. And like any other trauma then, depends on your personal resources. What kind of person are you. Are you the type of person whose resiliency is low or are you the kind of person that can withstand certain things. So personal resources would be quite critical. Then I think support would be one of the most crucial things when it comes to someone who is HIV positive self esteem survives that initial experience of finding out. If there are people who are interested in you, people who you can talk to, to provide some kind of support by just being there helps a lot. As well as personal counselling, which is really, really important in the initial stages. And later on, one of the challenges of being HIV positive is that the traditional ways of doing therapy (I'm saying traditional, because there is just no way or any where that it is written that you need to commit yourself to so therapy for so many months or years then your done). People who enter therapy do so for a number of different issues, go through a number of different stages. But I think that the challenge that HIV poses for psychologists or counsellors is that the initial stages have certain challenges that the person who is HIV positive needs to deal with and later on there are other things that come up. So you might see them for about six sessions or about ten sessions initially as they get used to the news. Then they go on and a year or so later they come back and they encounter something that is stressful or something that requires a little bit of support.

So personal resources, support be it support from ones family, friends and others is actually quite important. And clearly any other illness, so if the person was generally healthy, likely to survive, their self esteem is likely to survive the initial experience of finding out more so than someone who does not have those kind of resources.

Researcher: So in a sense it can be predetermined, based on your internal resources?

Participant 7: Because then it becomes an additional stress that you have to deal with, using resources that are stretched already.

Researcher: Do you think there is a relationship between stigma experienced by someone who is HIV positive and his or her self esteem?

Participant 7: Being stigmatised definitely affects someone's self esteem. Because stigma is a kind of violence in that it is some kind of an attack on your sense of worth, self worth. If you are being excluded or ridiculed or you experience negative treatment from people because you are HIV positive it is something that you cannot change, it is something that you cannot do anything about. It is only after you have enough information, counselling after you have adjusted to the reality that you are HIV positive, it is only then that your self esteem won't be affected that badly. Initially when you are first flooded with the news, there is a leak in your family that you are HIV positive. And suddenly you visit your aunt they don't want you in the kitchen, they wont drink your tea, you used to be able to sleep on the same bed with one of your siblings, they don't want to sleep on the same bed with you anymore. So initially that kind of treatment can impact negatively on your self esteem, but later on after you have adjusted it is much easier.

Researcher: So it is something that can progress or decrease as time goes on

Participant 7: But like I've said there are certain crises people who are HIV positive encounter as they go along. If you get stigmatised at a point when you are going through some form of stress, maybe you have just been attacked by some of these opportunistic diseases, during that time you are struggling with that and you get stigmatised around that which means your resources are quite stretched in trying to cope with challenges. Chances are that you might be more vulnerable at that point and your self esteem will be more vulnerable to the stigma compared to when you are not dealing with anything in particular at that point.

Researcher: Relationship between stigma experienced from the family and his or her self esteem?

Participant 7: My sense is always, rightly or wrongly so a place that you can expect love and protection or so when a negative response comes from someone who is in the family

it tends to be more painful. Firstly because it comes unexpected. It can be more devastating than from a stranger. So if you are stigmatised by family it is almost will I go to them if the negative response comes from the people whom I have considered to be a sanctuary.

Researcher: Relationship between stigma experienced at the workplace and the self esteem?

Participant 7: There again it depends on the workplace dynamics. There are certain workplaces that try to treat their employees as family. Which has it's own advantages, but also it has it's disadvantages. Because in the same way these are people that are close to you, these are people that interact with you on an ongoing basis, these are people that will know when you are not at work. These are people that if you are to get sick at work, which is to raise alarm to the help that you need. So it is almost like there is certain closeness that develops between colleagues. The clearly if you are to experience stigma at the workplace it will impact negatively, essentially on your occupational functioning. Also depending on whether the stigma comes from your seniors or your peers. If it comes from the seniors you might feel that you do not get the benefits of working in that work place. You do not get promoted, you do not get sent to courses, and you do not get tasked with more serious types of responsibilities. I think what I am saying is that occupationally your functioning gets affected. Your occupational functioning and your social functioning is related to your friends, those things are not mutually excluded, so one aspect impacts on other aspects. So it is important as you try to maintain a stigma free social environment, the workplace or occupational environment should also be looked at as well.

Researcher: Do you think that women and men experience HIV stigma differently?

Participant 7: I think that relates to the general way in which women and men respond to being HIV positive. Women are more likely to seek help and in that process risk being stigmatised in certain ways, because then they are exposed in certain ways to other people. Men on the other hand take a very long time, there are men who die without having have disclosed that they are HIV positive. It's almost like it impacts very negatively on their sense of masculinity, their sense of strength and also their pride. Especially certain types of men, men that are healthy, that are virile. So I would say stigma affects men and women differently because women being more likely to risk being stigmatised and get help. Men are more likely to keep their HIV status to themselves in an attempt not to be stigmatised, especially in so far how they are perceived as men.

Researcher: In the case where both have disclosed, for example in the workplace or the family, would you say that there would be more of a stigma against the one rather the other?

Participant 7: Once they have both disclosed, my sense is that there would not be much of a difference. Except for certain stereotypes where a woman is more likely to be blamed because they have brought upon themselves whereas it is more acceptable for men to have multiple partners.

But my sense is, especially at the work place, people are past the stage where they do not have information about HIV.

Researcher: Do you think that there is a difference in the self esteem of men and women who are HIV positive?

Participant 7: That would be difficult to say. I think society construct men in certain ways so their self esteem is likely to take more of a knock if they are being stigmatised or if it is found that they are HIV positive and they have not adjusted properly ,because that affects their standing in society in some way or their ability to continue performing masculinity in certain ways. Society constructs women in certain ways that makes it easier for women to disclose.

Researcher: Do you think the stigma attached to taking medication affects persons self esteem?

Participant 7: There again, I would expect that to some extend it would fluctuate. There would be certain times where the stigma associated to taking medication would impact quite negatively on one. It depends on the given stressors at the moment. They might be going through a difficult relationship, they might be unemployed. I think it all comes back to a sense of self, how well adjusted you are. A sense of adjustment also fluctuates with the stressors that you are dealing with at a given point in time. So there would be certain times when the stigma of taking medication would impact quite negatively on your sense of self and there would be other times when it would have less of an impact.

Researcher: Can you make any suggestions for future research regarding the self esteem of people who are HIV positive?

Participant 7: It is an extensively researched area at the moment, especially when it comes to masculinity and so on. What has become a social problem are AIDS orphans. There needs to be more research in terms of the realities of those kids. If you don't research their realities of those kids properly there is a chance that they can become the burden of society. Whereas if we are to understand their realities and their needs a little better, interventions could be improved. I am sure that we could deliver to society adults that are not to depend on the welfare system. I do not think that we have enough information to look after the needs of these orphans

Researcher: And then how to let them become independent will then also impact on their feelings of self worth when they are adults?

Participant 7: Sure, sure. I think that is important. Because in most cases that is the responsibility of their parents and if their parents are not there how do they survive, how do they become the adults that are delivered to society. What kind of adults do they become?

Participant 8

Researcher: Please describe the work that you do?
Participant 8: Independent psychologist in private practice. Also consult for various organisations offering psychological services ranging from individual counselling, trauma debriefing HIV/AIDS counselling and EAP services

Researcher: How long have you been working in this field?

Participant 8: 10 years

Researcher 8: Please describe the self esteem of someone who is HIV positive.

Participant 8: Varied depending on factors such as stage of the disease, levels of support etc. Generally low, especially for those who experiences rejection after disclosure.

Researcher: Please describe the pride of someone who is HIV positive?

Participant 8: Low for someone who has not accepted his/her status, but for those who have integrated their status into their life, and are living positively with it, their pride will enhanced.

Researcher: How do people who are HIV positive compare themselves to other people?

Participant 8: Given the negative connotations associated with the disease, the general view they have of themselves is that they are different to others. This is especially true for those who have begun wasting physically as their disease stage deteriorate.

Researcher: What influences the self esteem of someone who is HIV positive?

Participant 8: A variety of factors- Acceptance of diagnosis. – those who have accepted their status may enjoy increased self-esteem.

Levels of social support – acceptance and support of the infected enhances their feelings of worth .

Health status. – those whose disease is at an advanced stage may experience lowered esteem.

Socioeconomic status. – note the general impact of poverty on self-esteem.

Researcher: Do you think there is a relationship between the stigma experienced by someone who is HIV positive and his or her self esteem? Please elaborate on your answer?

Participant 8: Certainly. Stigma related to HIV takes away the dignity and pride of the infected, thus lowering his/her feelings of self-worth. Those experiencing stigma are often rejected and may subsequently be deprived of social support resulting in poor self-esteem.

Researcher: Please describe the relationship between stigma a person who is HIV positive may experience from family and his or her self esteem?
NB: this response is applicable also to 9 below.

Participant 8: The impact of stigma from the home and workplace may be similar. The stigmatised are often depressed which then lowers their esteem.

Researcher: Please describe the relationship between stigma a person who is HIV positive may experience from the workplace and his or her self esteem. Do you think that women and men experience HIV-related stigma differently? Please elaborate.

Participant 8: I believe gender plays very little role in this context. The impact / experience is often mediated by factors identified in q 6 above.

Researcher: If yes, do you think that there is a difference in the self esteem of women and men who are HIV positive? Do you think the stigma attached to taking medication affects HIV positive peoples self esteem? Rather stigma in general and not necessary the one associated with taking the medication.

Researcher: Please provide suggestions for future research regarding self-esteem of people living with HIV.

Participant 8: Factors that enhance / inhibits self esteem of the HIV-infected.