

**PERCEPTIONS OF HIV AND AIDS - RELATED STIGMA AMONG EMPLOYEES IN
THE PARLIAMENT OF THE REPUBLIC OF SOUTH AFRICA**

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KEY WORDS

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3. Parliament
4. Anti-stigma interventions
5. Employee wellness
6. Workplace HIV policy
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8. HIV Disclosure
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10. Psychological impact



ABSTRACT

The threat that HIV/AIDS poses to most institutions, including the Parliament of the Republic of South Africa, can potentially be decreased by reducing stigma and discrimination. Parliament's Policy on HIV and AIDS provides protection for people living with HIV and AIDS (PLWHA) against stigma and discrimination. The purpose of this study was to explore employee perceptions of HIV/AIDS stigma in the Parliament of the Republic of South Africa in order to inform improved anti-stigma strategies and interventions. This exploratory qualitative cross-sectional study used individual interviews and focus group discussions among Parliamentary employees to examine perceptions of: HIV/AIDS related stigma in the workplace, the effectiveness of Parliament's HIV/AIDS response strategy, and how HIV/AIDS-related stigma might be effectively addressed. A total of 49 respondents participated in:

- a) *19 individual interviews* across five employment grades (A-Band to E-Band).
- b) *4 focus group discussions of 6- 9 people each.*

Data was analysed using thematic analysis. Five main themes were identified, as well as additional sub-themes. The main themes were: the actual acts of discrimination (enacted stigma), concerns related to disclosure, assumptions and preconceptions about causes and signs of HIV infection, concerns about psychological impact and lack of knowledge and education. Discrimination was generally described as being treated differently, as well as prejudice and negative attitude to a person with HIV/AIDS. More specifically, it was understood as labelling those who are HIV positive negatively and ostracizing them. Gossip and lack of confidentiality were the main barriers to disclosure and testing while weight loss and long term sick leave were interpreted as classic signs of a person who is HIV positive in Parliament. Fear played a major role in these respondents' accounts of HIV/AIDS related stigma, while the perceived widespread ignorance was attributed to lack of information, knowledge and education. Respondents perceived Parliament's HIV/AIDS response strategy to be ineffective. They suggested more awareness and training, establishment of support groups, involvement of PLWHA and involvement of Senior Management in addressing HIV/AIDS related stigma in Parliament.

DECLARATION

I declare that *Perceptions of HIV and AIDS - Related Stigma Among Employees in the Parliament of the Republic of South Africa* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

BUYILE SIMON BASHE

DATE



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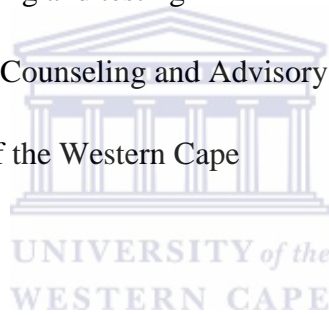
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ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
HIV	Human immunodeficiency virus
IPU	Inter-parliamentary union
MPs	Member(s) of parliament
STI	Sexually transmitted infection
NSP	National HIV/AIDS and sexually transmitted infection (STI) strategic plan (2007-2011)
	National strategic plan on HIV, STI and TB 2012-2016.
PLWHA	People living with HIV and AIDS
TB	Tuberculosis
VCT	Voluntary counseling and testing
NA	National Assembly
NCOP	National Council of Provinces
SHE	Safety, health and environment
UNAIDS	Joint United Nations Programme on HIV/AIDS
HSRC	Human Sciences Research Council
SANAC	South African National Aids Council
ILO	International labour organisation
MSM	Men who have sex with men
MSW	Men who have sex with women
MDGs	Millennium Development Goals
UNGASS	United Nations General Assembly Special Session

WHO	World Health Organisation
LRA	Labour Relations Act No. 66 of 1995
EEA	Employment Equity Act No. 55 of 1998
DoL	Department of Labour
SAA	South African Airways
PLWHIV	People living with HIV
CCMA	Council for Conciliation, Mediation and Arbitration
FGD	Focus group discussion
PMP	Parliamentary Millennium Programme
HCT	HIV counseling and testing
ICAS	Independent Counseling and Advisory Service
UWC	University of the Western Cape



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CHAPTER 1: BACKGROUND AND PROBLEM STATEMENT

1.1 HIV, STIGMA, AND PARLIAMENT AS A WORKPLACE

HIV/AIDS has a major impact on the South African society and Parliament as an employer is not immune from this impact on both Members of Parliament and Parliamentary staff. The International Parliamentary Union (IPU) reported that in numerous countries, members of parliament (MPs) and parliamentary staff are either affected by or infected with HIV (IPU, 2007). MPs are further confronted with the realities of AIDS in their constituencies and therefore, according to the IPU (2007:41) they should: *“take the lead and break the silence about HIV/AIDS; empower themselves with facts and show to their constituencies how AIDS has affected countries”*. According to the IPU (2007), one of the main impediments in successfully addressing the HIV and AIDS epidemic is stigma and discrimination. Despite national government’s commitments to take action against stigma and discrimination, it still persists in workplaces due to lack of implementation, resulting in unnecessary fear to attend an HIV test during voluntary counseling and testing sessions. Parliamentarians are encouraged to eliminate stigma and discrimination in workplaces and across society (IPU, 2007).

Parliament views stigmatization and discrimination of people living with HIV and AIDS as an act of serious misconduct which might result in a disciplinary hearing and even termination of service. The focus in the Parliamentary context tends to have an outward look when dealing with critical issues, because the very nature of Parliament’s work is targeted to better the lives of the people in the country, or communities. Nevertheless, Parliament’s Policy on HIV and AIDS (2009), also addresses the “inward” or workplace dimension, clearly communicating Parliament’s position on stigma and discrimination in the workplace on the basis of HIV status. According to the Policy on HIV and AIDS (2009:5), *‘employees living with HIV and AIDS must be treated fairly and/not be discriminated against or victimized, managers must protect employees living with HIV and AIDS from stigmatization and unfair discrimination; HIV and AIDS status must not be a basis for pre-employment testing or for refusing to employ an applicant’*.

The Parliament of the Republic of South Africa has a Policy on HIV/AIDS, a Strategic Plan based on the National HIV/AIDS and Sexually Transmitted Infection (STI) Strategic Plan 2007-2011. The Policy on HIV and AIDS was approved in 2009. It mainly provides protection of employees with HIV and AIDS against stigma and discrimination. It emphasizes that all occupational benefits should be extended to all Parliamentary employees irrespective of their HIV status. It also proposes voluntary counseling and

testing and general training and education. It also ensures that those who acquire HIV out of and in the course of their work are compensated.

The HIV and AIDS Strategic Plan of Parliament (2009 – 2012) has four priority areas which are in line with the National HIV/AIDS and Sexually Transmitted Infection (STI) Strategic Plan (NSP) (2007-2011):

- *Developing prevention, education and health promotion programmes*
- *Improving the health of PLWHA by increasing access to treatment, care and support services*
- *Development of the research, monitoring and surveillance system for HIV/AIDS*
- *Human rights and access to justice*

The actions to be taken to achieve each of the above priority areas are mainly driven by the Wellness Unit and Peer Educators. These Peer Educators did not receive specific support from their managers to fulfill their duties since this was viewed as a voluntary function. Since 2011, more support is given to peer educators by their managers. They are allowed to run programmes and attend the necessary training. The Strategic Plan of Parliament on HIV and AIDS is currently being revised to align it with the new National Strategic Plan on HIV, STI and TB 2012-2016.

Despite statements such as those by the International Parliamentary Union (IPU 2007) and robust policy frameworks such as those described above for the Parliament of South Africa, a literature search failed to find any study specifically examining HIV-related stigma amongst Parliament employees anywhere in the world, nor any published evidence on whether Parliaments have an enabling environment for their own employees to openly disclose their status without fear of stigmatization or discrimination. In the Parliament of the Republic of South Africa, the researcher's own experience as Manager of Parliament's Wellness Programme over the past four years suggests that there appears to be a general apathy amongst both management and staff towards HIV/AIDS activities. During the annual AIDS day, not even 1% of the staff attends the event. During the 2009 AIDS day event, Voluntary Counseling and Testing (VCT) was offered at no cost to employees but only 46 people got tested, out of a total workforce of over 1200. HIV/AIDS does not appear to be regarded as a priority by Senior Management, and there is little funding for HIV/AIDS activities. One wonders whether stigma towards HIV/AIDS could be a cause of this apathy and the perceived lack of interest in HIV/AIDS in the institution.

The purpose of this study therefore was to explore employee perceptions of HIV/AIDS stigma in the Parliament of the Republic of South Africa. The findings of this study will directly inform quality improvement in the Employee Wellness Program and will give Parliament an opportunity to devise improved anti-stigma strategies and interventions.

1.2 STUDY SETTING: PARLIAMENT OF THE REPUBLIC OF SOUTH AFRICA

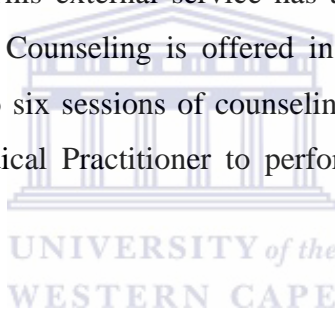
Parliament is situated in Cape Town in the Central Business Area. Parliament consists of two Houses called the National Assembly (NA) and National Council of Provinces (NCOP). Each House has its own distinct role and functions, as set out in the Constitution. However, there are many instances when the two Houses act together to conduct what is called “joint business”. Every five years the people of South Africa have an opportunity to cast their votes for a new Parliament. The Presiding Officer of the NA is called the Speaker of the NA while the Presiding Officer for the NCOP is called the Chairperson of the NCOP. Both Presiding Officers are in charge of the Parliament Administration. Reporting to the Presiding Officers is the Secretary to Parliament often referred to as the Accounting Officer. There are 7 Divisions in Parliament Administration with Division Managers reporting to the Secretary to Parliament. The Office of the Secretary, the Office of the Speaker to NA and the Office of the Chairperson to NCOP personnel report to the Secretary to Parliament.

1.2.1 Workforce profile

Parliament has 1300 permanent employees and 454 elected Members of Parliament. The employee profile of Parliament is made up of the following race groups: African 52%, Coloured 34%, White 11% and Indian 3%. The gender profile as of the 31 March 2012 consists of 57% females and 43% males. Parliament has nine people with disabilities. The employees are classified according to Patterson’s grading system where the A-Band is unskilled workforce, B-Band is Semi-skilled, C-Band is skilled, D-Band is Professional/Specialist/Management, and E-Band is for Senior Management while F-Band is for Top management. Further occupational and demographic data on the overall workforce are presented in Chapter 4, in comparison with the study participants. Members of Parliament are excluded in the profile since the research was only conducted amongst employees.

1.2.2 The Wellness Program

Parliament's Wellness Programme is managed by the Organisational Wellness Section is part of the overall Human Resources Division. It consists of sixteen staff members including myself and my secretary. It has three units, namely: Employee Relations Unit with four (4) employees, Employee Wellness and Engagement Unit which has four (4) employees, and the Safety, Health and Environment [SHE] Unit with six (6) staff members. All employees working in the three units are permanent staff who are paid a salary while supporting the three units is a powerful, diverse but integrated wellness team from other work areas who volunteered their services. These are; HIV/AIDS Peer educators, Safety Representatives, representatives from the Sporting codes, and First Aiders. Parliament's Wellness Programme has both internal and external services. Internally the Wellness Practitioner provides counselling and other Employee Assistance Programmes while externally, a Service Provider is contracted to provide professional counselling. This external service has a confidential, toll free line that is open twenty four hours a day, every day. Counseling is offered in all languages and both employees and Members of Parliament are entitled to six sessions of counseling should it be necessary. Parliament has also contracted an Occupational Medical Practitioner to perform medical surveillance and assist with incapacity matters.



Parliament has a dedicated HIV/AIDS Programme Officer who assists in the implementation of the HIV/AIDS response strategy. Parliament's Wellness vision is *"To provide proactive world class wellness interventions that will improve the quality of life for all"*.

1.3 STUDY AIMS AND OBJECTIVES

1.3.1 Aim of the study

The aim of this study was to explore employee perceptions of HIV/AIDS stigma in the Parliament of the Republic of South Africa in order to devise improved anti-stigma strategies and interventions.

1.3.2 Objectives of the study

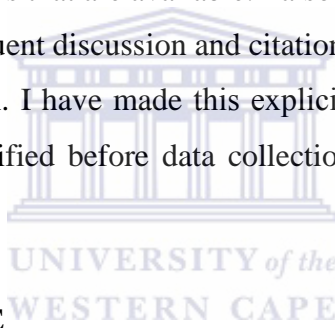
- To explore employees' understanding of the meaning of HIV/AIDS- related stigma.
- To explore perceptions of stigma in the Parliamentary Service

- To explore perceptions of the effectiveness of Parliament's HIV/AIDS response strategy
- To explore employee perspectives on how HIV/AIDS-related stigma might be effectively addressed in the workplace.



CHAPTER 2: LITERATURE REVIEW

In this chapter, literature will be reviewed from a global, regional and national perspective. Regional perspective will be limited to the Sub-Saharan Africa. It will move from the latest UNAIDS report on HIV prevalence to the various commitments on ways to address HIV/AIDS related stigma. I have searched Academic Search Premier data base, the internet with google under these terms: HIV/AIDS stigma, workplace, Parliament gender, ostracize, to find information on HIV/AIDS stigma in Parliaments. While there is a massive literature on HIV in general and on stigma, there is very little on Parliaments. I therefore used information that refers to other workplace contexts. The rest of the literature review will be divided into: HIV/AIDS epidemic update, understanding HIV/AIDS related stigma; types of HIV/AIDS stigma, HIV/AIDS related stigma in the workplace; barriers to testing and disclosure; HIV-related stigma and gender; social, racial, cultural and religious aspects. The literature review seeks to document at some length the kinds of research and analysis that are available. I also note that there are some enduring themes and concepts, as witnessed by the frequent discussion and citation of older work in more recent work, both overviews and new empirical research. I have made this explicit by “*citing the citations*”. The literature review includes both references identified before data collection, and further readings reviewed during data analysis and interpretation.



2.1 HIV/AIDS EPIDEMIC UPDATE

2.1.1 *The global epidemic*

UNAIDS (2011) reported that more are living with HIV due a combination of factors; firstly the antiretroviral treatment allows people to live longer with HIV; secondly the increase in new infections adds to the growing number of people living with HIV. UNAIDS (2011) further reported that 34 million people worldwide, were living with HIV, an increase of 17 percent compared to 2001. New infections decreased by 21 percent globally compared to 1997. Approximately 50% of people living with HIV are women, in 2010, (UNAIDS, 2011).

2.1.2 *The regional epidemic*

The UNAIDS (2011:1) reported that “*Sub-Saharan Africa remains the region most heavily affected by HIV. In 2010, about 68% of all people living with HIV resided in sub-Saharan Africa*”. The UNAIDS (2011), further reported that despite a notable decline in the regional rate of new infections, Sub-Saharan

Africa still accounted for 70% of new HIV infections in 2010. The total number of new HIV infections in Sub-Saharan Africa has dropped by more than 26% compared to 1997 when it was at its peak, (UNAIDS, 2011). According to the UNAIDS World Aids report, *“in 22 Sub-Saharan countries, research shows HIV incidence declined by more than 25% between 2001 and 2009. This includes some of the world’s largest epidemics in Ethiopia, Nigeria, South Africa, Zambia and Zimbabwe”*, (UNAIDS, 2011: 6). Despite the proportion of women living with HIV stabilizing at 50 percent globally, women are more affected in Sub-Saharan Africa constituting 59 percent of all people living with HIV (UNAIDS, 2011).

2.1.3 The national epidemic

The Southern Africa is still the most affected region in the world. According to the UNAIDS (2010), South Africa has more people living with HIV than any other country in the world, an estimated 5.6 million people (UNAIDS, 2010). The annual HIV incidence in South Africa, though still high, dropped by a third between 2001 and 2009 from 2.4% to 1.5% (UNAIDS, 2010). Despite the decline, the national prevalence is 17.8 percent among those aged 15-49 years with younger adults being particularly affected (UNAIDS, 2010). The Human Sciences Research Council (HSRC) reported that the national HIV prevalence among those aged two and older also varies by province with the Western Cape (3.8 percent) and Northern Cape (5.9 percent) being least affected, and Mpumalanga (15.4 percent) and KwaZulu-Natal (15.8 percent) being the most affected (HSRC, 2009).

There is a positive common thread from the global, regional and national incidence, prevalence and mortality rate due to the HIV/AIDS epidemic. The UNAIDS (2011) report confirmed that there is an increase in prevalence due to the fact that more people are on antiretroviral treatment (47 percent of those infected who are eligible, are on treatment) and the incidence is still high in some countries as seen in those in the Sub-Saharan Africa. Global efforts to reduce the incidence (new infections) and mortality due to AIDS related illnesses (AIDS related deaths) are successful (UNAIDS, 2011). The successes on HIV/AIDS response suggest that HIV/AIDS stigma should not be such a huge a problem, but the literature reviewed in this study still cite various aspects of stigmatisation in communities and workplaces. Therefore the emphasis on eliminating the stigma and discrimination in the fight against HIV/AIDS in any context is justified. This study focused on HIV/AIDS related stigma in the workplace and more specifically in the Parliamentary context. Due to limited literature in the Parliamentary context, other contexts were used to demonstrate some of the aspects raised. Before going into detail, it is important to first understand the concept of HIV/AIDS related stigma.

2.2. UNDERSTANDING HIV/AIDS RELATED STIGMA

Goffman (1963:13), defined stigma as “*an attribute that is deeply discrediting*”, where a person’s social identity is “*reduced in our minds from a whole and usual person to a tainted, discounted one*”. These attributes emerge through social interactions. Goffman (1963) reported three different types of stigma; firstly the abnormalities of the body that include disabilities; secondly the blemishes of the individual character which are perceived as weak will or unnatural passions, these include but not limited to: mental disorder, homosexuality and addictions. Finally, he reported that there is tribal stigma of race, nationality and religion, which can be transmitted to all family members, (Goffman, 1963).

Herek & Glunt (1988:886), defined AIDS – related stigma as the ‘*social psychological processes through which people are discredited when they are perceived to be infected with HIV, regardless of whether they actually are infected and of whether they manifest symptoms of AIDS or AIDS related complex*’. Herek and Glunt (1988) made an important observation that AIDS in the society is associated with gay men, and therefore marginalized groupings with AIDS tend to suffer AIDS related stigma upon pre-existing stigma of being gay. Herek and Glunt’s paper was particularly relevant to this study as it is concerned with the social psychological processes through which people are discredited when they are perceived to be infected with HIV. It examined individual attitudes and behaviours that express fear or hostility towards people with AIDS, as well as institutional policies that impose hardships on them without slowing the spread of AIDS. Finally, it provides suggestions on how to address AIDS related stigma.

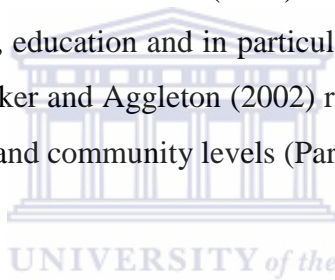
Link and Phelan (2001) define stigma as the co-occurrence of its components which are “*labeling, stereotyping, separation, status loss, and discrimination*”. They further indicate that for stigmatization to occur, power must be exercised, (Link and Phelan, 2001).

According to Van Niekerk (2005:1), “*when stigma is acted upon, the result is discrimination*”. In the workplace context, people living with HIV and known by their peers, supervisors and managers suffer from stigma and discrimination (Dickinson, 2005). In contrast, if the workplace environment is conducive, and everyone knows that should they discriminate or stigmatise people living with HIV, there will be a consequence, are protected from stigma and discrimination, being open about one’s HIV status can, in the right environment, reduce discrimination since everyone will now know and actions can be taken to those discriminating (Dickinson, 2005). Similarly, studies by UNAIDS note that openness about AIDS are ‘*prerequisites*’ for mobilizing government, communities and individuals to respond to the epidemic, (Van

Niekerk, 2005:1). Unfortunately even though peer Educators assist people living with HIV/AIDS, they are assumed to be HIV positive (Dickinson, 2005).

2.3 TYPES OF HIV/AIDS RELATED STIGMA

MacQuarrie, Eckhaus, and Nyblade (2009), proposed two types of stigma, internalised stigma which is common among men and enacted stigma which is experienced more by women. Similarly, Wyrod (2011) reported two types of stigma; the intrapersonal stigma which is referred to as internalised stigma (self-stigmatisation) or felt stigma (perceived discrimination) and interpersonal stigma which is referred to as external or enacted stigma. Herek and Glunt (1988) mentioned two levels of AIDS related stigma; that is individual and societal levels. At individual level the person mainly fears hostility from the society, fear of being discriminated against thus deters the person from HIV testing and starting treatment early (Herek and Glunt, 1988). At societal level, Herek and Glunt (1988) mentioned the problems encountered at the time for funding Aids related research, education and in particular any activity that will promote safe sex amongst homosexuals. In contrast, Parker and Aggleton (2002) reported three levels of HIV/AIDS related stigma. These are: individual, societal and community levels (Parker and Aggleton (2002).



In research conducted by Masindi (2004) in South Africa, two types of stigma were identified namely enacted stigma and internal stigma. “*Enacted stigma refers to actual experiences of discrimination and stigma which originates from fear and perceptions of PLWHA as immoral and dirty*” (Masindi, 2004:7). In this form of stigma PLWHA are given names, they are rejected, they are labeled as if they deserve it and so on (Masindi, 2004). The fear of HIV/AIDS has created a culture of suspicion resulting in even people who are passionate about the disease being labeled as HIV positive too (Masindi, 2004). In the workplace people who are passionate about HIV are peer educators and lay counselors. “*Internal stigma refers to PLWHA having shame for themselves and fearing to be stigmatized. This tends to lead to social withdrawal, self exclusion, and PLWHA may not apply for positions due to fear of being found HIV-positive*”, (Masindi, 2004:7).

2.4 BARRIERS TO HIV TESTING AND DISCLOSURE

There are various barriers to HIV testing and disclosure. Essex et al (2002), highlighted HIV and AIDS related stigma and discrimination as a major barrier for HIV testing and disclosure to an extent that

females were not willing to use existing facilities. Palitza (2010:1) states that “*stigma continues to be a seriously neglected issue, particularly in sub-Saharan countries, including South Africa, regardless of the fact that it has detrimental effects on public health and human rights*”. In the workplace, an environment that is not conducive for disclosure prevents people from going for an HIV test (Palitza, 2010).

According to Brown, BeLueb and Airhihenbuw (2010) families are the strongest support system for people living with HIV and AIDS. Brown et al (2010) reported that individuals’ perception of familial support influences their willingness to disclose. However, family relations do not always provide the support that PLWHA require. In a study conducted by Brown et al (2010), participants felt that more emphasis should be placed on eradicating the stigma associated with HIV within families of PLWHA. Brown et al (2010) indicated that the benefits of disclosure for the person with HIV are: increased emotional and social support, family participation in the care of the PLWHA and an overall reduction in stress related to living with HIV.

According to Sambisa, Curtis and Mishra (2010), several empirical studies have shown that AIDS stigma experiences such as violence, ostracism, and discrimination are barriers to HIV testing and disclosure. These authors conducted research on AIDS stigma as an obstacle to uptake of HIV testing in a Zimbabwean national population-based survey using a sample of women (6839) and men (5315), (Sambisa et al. 2010). Their study revealed that the most common form of AIDS stigma was based upon the dimension of *disclosure concerns*, where a high proportion of women and men reported that they would not want others to know that their family member had HIV or TB; *social rejection stigma* was higher among women than men, while more women reported *prejudiced attitudes stigma* than men, (Sambisa et.al 2010). Individuals’ testing behaviour was influenced by various factors such as age, education, religion, marital status and media exposure, (Sambisa et.al 2010).

Flowers, Knussen and Church (2003), conducted a study on psychosocial factors associated with HIV testing amongst Scottish gay men and found that psychosocial factors that distinguished testers from non-testers were significantly related to: fear of a positive result, perceived problems with clinics especially waiting for test results, negative attitudes to sex with HIV positive men and being more likely to assume that others are HIV negative. These authors concluded that fear associated with positive HIV result was huge barrier to HIV testing (Flowers et.al. 2003).

Jürgensen, Tuba, Fylkesnes and Blystad (2012) conducted a study to explore HIV testing decisions in one rural and one urban district in Zambia with high HIV prevalence and available antiretroviral treatment. They found that the informants' fear of HIV testing stems from the association of an HIV positive result with a death sentence; anticipation of severe stigma; implied loss of moral standing, support and future opportunities (Jürgensen et al, 2012).. *"It meant living with a warning light flashing for everyone to see and talk about.* (Jürgensen et al, 2012:8). Negative preconceived ideas about an HIV positive status surpassed the benefits of prevention and early treatment (Jürgensen et al, 2012). *"Informants were worried about being seen at or leaving the voluntary counselling and testing (VCT) centre after testing and about how they would manage to keep a straight face in front of all the people at the clinic"* (Jürgensen et al, 2012:8). When they asked informants why they would not go for VCT, informants reported a general fear of knowing their status, although they knew that people could live for long periods with treatment (Jürgensen et.al 2012).. *"Several suspected that they could be HIV-positive because of previous risk behaviour, but the diagnosis frightened them so much that they would rather not know"*, Jürgensen et.al (2012:8).

HIV/AIDS is one illness that is extremely difficult to disclose, particularly in the workplace. If HIV positive people find it difficult to disclose to their families, one would deduce that it will be even more difficult to disclose at work. However, a study conducted by Fesko (2001), where she interviewed eighteen respondents, six of them disclosed their status to everyone in the workplace while seven of them disclosed it to selected people in the workplace and requested them to keep it confidential while the other five did not disclose at all. Women were less likely than men to disclose their status at work because of stigma associated with the disease, (Fesko, 2001). These women were particularly concerned about being 'labelled' and being asked how they acquired the disease, (Fesko, 2001: 238). When one respondent disclosed his status and requested to be reasonable accommodated by his employer, he was fired the next day (Fesko, 2001). *"This individual experienced what he called discriminatory response to his request for accommodation"*, (Fesko, 2001: 238). According to Fesko (2001), some of the respondents partially disclosed to their supervisors. *"One respondent described the process of disclosing as a struggle, she said 'You have to be so carefulI do not trust people, I do not want to be looked down at because I am positive'*, (Fesko, 2001:238). Some of the reasons cited in this study for non-disclosure were: racial issues; gossip; insensitivity of the supervisor; rejection by co-workers; stereotypical judgements and termination of employment (Fesko, 2001). . This study was very useful for this research. It clearly mapped out the reasons for disclosure at work and barriers for disclosure and these will be of great value

when designing anti-stigma strategies. It would have been more enhanced by having focus group discussion as well.

In the South Africa, we saw some of our leaders like Dr Nelson Mandela, Chief Mangosuthu Buthelezi, Judge Edwin Cameron, Zackie Achmat, Nkosi Johnson, Patricia de Lille and others, coming forward to be counted as to how they are affected or infected by HIV/AIDS (Van Niekerk, 2005). Unless people speak openly about HIV and can test in public without having to reveal their status, curbing this epidemic will be a mammoth task.

2.5 SOCIAL, RACIAL, CULTURAL AND RELIGIOUS ASPECTS

Though social and cultural factors contribute to AIDS-related stigma and misinformation, political discourses, policies and role players are also key (Forsyth, Vandormael, Kershaw and Grobbelaar, 2008). Forsyth et al (2008) mainly focused on the perception of governments' response to the AIDS epidemic during the Mbeki era in a South African township. These authors found that individuals' political perceptions around AIDS and how the government responded to the epidemic were somewhat consistent (Forsyth et al, 2008).

UNAIDS (2010), identified social division, inequality and exclusion as drivers for the HIV epidemic. The salient forces are gender inequality, the stigmatisation of people living with HIV and legal environments that pose obstacles to accessing HIV programmes. According to Brown et.al, (2010), certain health conditions were associated with particular race groups, especially HIV/AIDS which led to people suffering more HIV/AIDS-related stigma. Brown et. al (2010) reported that at the beginning of the pandemic, HIV/AIDS-related stigma was framed as an 'African disease', an illness of poor Black communities, with women receiving much of the blame (Brown et.al, 2010).

One of the key challenges for the global HIV response identified by UNAIDS (2010), was social justice. According UNAIDS (2010:19), "*stigma and discrimination, homophobia, gender inequality, violence against women and girls and other HIV-related abuses of human rights remain widespread*". This discourages people from seeking information and services that will protect them from getting infected with HIV; adopting safe behaviour and from accessing HIV treatment and care, (UNAIDS, 2010). The UNAIDS (2010:19) further asserted that persistence of such social injustices will hamper the efforts of achieving the global vision of '*zero discrimination*'.

UNAIDS, (2010:24) asserted that *“the existence of HIV in the society has given the society an opportunity to strengthen its social fabric by combating inequality, improving social justice and reinforcing systems that deliver critical services for the most vulnerable members of the community”*. In support of this assertion, indeed the roll out of the HIV programme in South Africa has forced government to think beyond the HIV domain. For example even in a small village of Qoqodala, clinics and hospitals do not just provide services for HIV but the comprehensive health services needed by the rural women and men.

According to Seale (2004), HIV/AIDS related stigma and discrimination pose a serious threat to the basic human rights for all people infected and affected by the disease. Some of the human rights impacted on are: to security, confidentiality, health care and the right to life, (Searle, 2004). The society tends to reject people with HIV/AIDS and mental illnesses, and it does not reject those suffering from sexual transmitted diseases, cancer, diabetes, heart diseases, or any other diseases (Stine, 2007). For example, Seale, (2004) reported that there are incidences where families disowned people living with HIV/AIDS and some employers fired them from their jobs. . In a study conducted by Wingood et al (2008), the impact of HIV/AIDS stigma was found to be associated with significantly more depressive symptomatology and lower quality of life among Xhosa speaking women living with HIV in the Western Cape. According to Wingood et al (2008), HIV stigma not just affect the mental health of people living with HIV but even those at risk of contracting it.

According to (SANAC, 2011), there are social norms that promote discrimination against certain members of the community particularly those suffering from TB or HIV; and against those with different sexual orientations which consequently result in reluctance to attend health services for fear of discrimination. Similarly, social norms that condone gender violence prevent abused women to seek redress (SANAC, 2011). According to SANAC (2011), gender norms that condone multiple partnerships, violence and alcohol abuse are some of the drivers of behaviours that place individuals at increased risk of HIV acquisition. SANAC (2011:39) proposed that *“social interventions include efforts to change cultural and social norms that increase vulnerability to HIV and STIs and to reinforce those norms and behaviours that are protective”*. Such interventions must aim at decreasing alcohol abuse and other substance abuse, including illegal substances since these play a huge role in the spread of HIV, (SANAC, 2011).

SANAC, (2011) reported that data from the 2010 – 2011 national HIV Counselling and Testing (HCT) campaign indicates that men are still reluctant to test and therefore efforts must be made to increase men’s health-seeking behaviour and participation in HCT.

Brown, BeLueb and Airhihenbuw (2010), conducted a study on HIV and AIDS-related stigma in the context of family support and race in South Africa amongst the Black and Coloured communities in Cape Town. The aim of their study was to examine the role of race and identity in HIV/AIDS-related stigma within the context of the family. Participants were asked to identify where emphasis should be placed for future efforts targeted toward eliminating the shame and rejection associated with HIV/AIDS, both Black Africans and Coloureds ranked the family at the top; hospitals and clinics was the second choice of Black Africans and third choice for Coloreds; and national government was the third choice for Black Africans and second choice for Coloreds. Both groups identified the same top three choices, but not in the same order of importance (Brown et al., 2010). In this study, Brown et. al (2010: 450), found that “nearly one-quarter of the respondents felt that people shame their family members living with HIV/AIDS because of their religious or spiritual values”. This actually justifies why both groups chose family interventions as a top priority. According to Brown et al (2010), efforts to address stigma and discrimination are mainly directed to issues of policy and human rights protection for PLWHA with none of them focusing at addressing the families of those living with HIV and AIDS.

2.6 HIV-RELATED STIGMA AND GENDER

Lorber (1994), views gender as a social institution that creates distinguishable unequal social statuses where men are ranked above women of the same class and race. It is these inequalities of gender that created a platform for abuse of women by men and subordination of women in society.

ILO (2001) reported that women are more susceptible to HIV/AIDS infection due to their biological structure than men; their social status also makes it difficult for them to use preventive measures for example safe sex or refusal of unsafe sex. Gender imbalances in workplaces expose women to the threat of sexual harassment (ILO, 2001). “The greater the gender discrimination in societies and the lower the position of women, the more negatively they are affected by HIV”, (ILO, 2001:3). The ILO (2001) recommends that all programmes should be gender and race-sensitive taking into account sexual orientation. Other recommendations by SANAC include challenging gender roles, norms and inequalities that increase women’s vulnerability to HIV; prevention of gender based violence; education of men on women’s rights and engaging men on socialisation practices, (SANAC, 2011).

According to the UNAIDS (2010:43), *“in Sub-Saharan Africa, 60% of the people living with HIV are women and girls, but most funding dedicated to women provides antiretroviral therapy for prevention of vertical transmission (prevention of mother to child transmission)”*. UNAIDS (2010), proposed that funding for HIV should cover the full range of issues impacting on women’s health; these include young women, female sex workers and for changing harmful gender norms and economic disempowerment.

According to SANAC (2011), Men who have sex with men (MSM) and transgender persons are at higher risk of being HIV-positive. *“Owing to lack of knowledge and understanding of this community, and because of stigma, this population is often at risk for sexual abuse and marginalised from accessing prevention, care and treatment services”*, (SANAC (2011:26). Medical male circumcision has thus been included as part of sexual and reproductive health services to reduce the risk of HIV infection, SANAC (2011).

Wyrod (2011) conducted research in Uganda to determine the linkage between men’s experiences of AIDS stigma to conceptions of masculinity. The research was based on fieldwork with the Bwaise Positive Men’s Union, a support group for HIV-positive men in Kampala, Uganda. In general, this research with the union demonstrated that intrapersonal forms of AIDS stigma are especially salient for men in urban Uganda especially internalised stigma, among men (Wyrod, 2011).

Wyrod (2011) argued that various studies on gender and AIDS stigma in Africa has mainly focused on the discrimination experienced by women and its effects on HIV testing, access to care and social support but fail to demonstrate the how African men experience stigma. Wyrod (2011: 444) further argued that *“stigma studies including both African women and men living with HIV indicate important gender differences where men are more likely to internalise blame for becoming infected and express greater shame living with HIV”*. According to Wyrod (2011), studies on heterosexual African men found that HIV-positive men suffered from internalised psychological distress.

Wyrod (2011: 447), when attending the ‘*The Bwaise Positive Men’s Union*’ meeting discovered that most members echoed the goals stated in the union’s draft constitution which prioritised confronting men’s ‘*shock, fear, and denial*’ regarding HIV. These union members also stressed that fear of AIDS has negatively affected men to such an extent that they deny the dangers posed by HIV and were unlikely to support each other (Wyrod, 2011). Most men in the union rarely recounted any actual experiences of being discriminated against for being HIV-positive. The interpersonal forms of stigma were much less

salient in their narratives than were the repeated articulations of their feelings of diminished self-worth and fears of being stigmatised as men living with HIV. Wyrod (2011) therefore discovered that men in urban Uganda suffer from intrapersonal stigma, especially internalised stigma.

Wyrod reported that some HIV-positive African men were willing to take steps to address the stigma associated with HIV and AIDS. He recommended that harnessing such enthusiasm is crucial for transforming those aspects of masculinity that place both men and women at risk of HIV infection across the African continent (Wyrod, 2011). I found the study by Wyrod particularly relevant for my research. It actually demonstrated how men especially African men, experienced HIV stigma and the type of HIV stigma they mostly suffer from.

Cloete, Simbayi, Kalichman, Strebel and Henda (2008), conducted a study on stigma and discrimination experiences of HIV-positive men who have sex with men in Cape Town, South Africa. Anonymous surveys were completed by 92 men who have sex with men (MSM) and 330 men who have sex with women (MSW), all of whom were living with HIV/AIDS. Internalised AIDS stigma was high among these HIV-positive men, with 57% did not disclose their status, 47% experienced guilt while 43% was ashamed of being HIV-positive. There were no differences between MSM and MSW for feelings of internalised stigma (Cloete et.al, 2008).

Cloete et al (2008) further reported that HIV positive MSM experienced greater social discrimination. According to Cloete et.al (2008), men who have sex with women seemed to have more supportive experiences, with 74% of them having had talked to a friend about AIDS compared to 58% of their MSM counterparts. There were no significant difference of being treated differently (Cloete et.al, 2008).

Cloete et.al, (2008) concluded that even though all HIV-positive men in South Africa, irrespective of sexual orientation, experienced considerable internalised AIDS stigma, emotional distress and discrimination, MSM generally experienced more discrimination related to their HIV status than their non-MSM counterparts. *“It therefore appears that HIV-positive MSM suffer from double or multiple discrimination or super-discrimination”* (Cloete et.al, 2008:1107).

Van Hollen (2010) conducted research on HIV/AIDS and the gendering of stigma in Tamil Nadu, South India. The focus of her research was on heterosexual HIV-positive women’s own perspectives on the gendering of stigma. Van Hollen (2010) discovered that the opinions of HIV-positive women in Tamil

Nadu supported the widely held view that HIV-positive women face greater stigma and discrimination than HIV-positive men. Due to prevailing gender ideologies about sexuality, HIV-positive women tend to be blamed for spreading HIV to their husbands (Van Hollen, 2010). According to Van Hollen (2010), gendering of stigma in Tamil Nadu was found to be more complex in several ways. Firstly, some women reported that they experienced more stigma and blame privately, while interacting with their in-laws while in the public domain, they encounter more sympathy and pity than men (Van Hollen, 2010). The differences between the stigma experienced privately compared to the one experienced publicly was found to reflect some of the deeply held cultural understandings of gendered bodies and at times it was used to avoid financial responsibility for widows and children (Van Hollen, 2010).

A limitation of Van Hollen's (2010) study is that it only interviewed women and cannot show whether stigma affects men differently to women. It would have been useful to have interviewed men also, to capture the direct perceptions of both men and women. Nevertheless, the women's experiences in the Indian context were useful in demonstrating the gendered dynamics of stigma.

2.7 THE POLICY AND LEGAL FRAMEWORK

According to the National Strategic Plan on HIV, STI and TB 2012-2016 (NSP, 2011), the 2009 HIV prevalence in the adult population (aged 15–49) was estimated to be 17, 8%. In other words, HIV mainly affects the economically active population. It is therefore very important to develop policies and programmes that will be accessed by people in the workplace.

The NSP 2012 – 2016 aims to align and be consistent with national, regional and international obligations, commitments and targets, which include but not limited to:

- *the Constitution of South Africa*
- *the Millennium Declaration and the millennium development goals (MDGs)*
- *United Nations General Assembly Special Session (UNGASS) Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS, June 2011*
- *UNAIDS 2011 – 2015 Strategy: Getting to Zero*
- *WHO Health Strategy for HIV and AIDS 2011 – 2015*
- *Southern African Development Community commitments*
- *International Labour Organisation (ILO) Recommendation on HIV and AIDS and the World of*

Work, 2010 (SANAC, 2011: 28).

The NSP is very encouraging; firstly it is located within the Constitution of the Republic. In addressing stigma it calls for innovative and clear methods of stigma elimination. It commits in implementation of a stigma mitigation framework, monitoring of stigma and discrimination using stigma index (SANAC, 2011). South Africa's response to HIV, STIs and TB recognises the centrality of constitutional values and human rights. It is based on the understanding that public interest is best served when the rights of those living with HIV and/or TB respected, protected and promoted. Not only is this globally accepted public policy; but it is also in line with the rights entrenched in Chapter 2 of the Constitution and these include the rights to equality, dignity, life, freedom and security of the person and privacy (SANAC 2011:53). Other recommendations by SANAC (2011:53) include:

- Training of employees on human rights and law is crucial and it will need to be incorporated in Parliament's strategy on HIV/AIDS.
- Reviews and assessments of laws and policies that may impact negatively on the response to HIV and TB will be conducted expeditiously
- Implementation of campaigns to address unfair discrimination in the workplace

The International Labour Organisation (ILO) developed a Code of Practice on HIV/AIDS and the world of work. According to the ILO (2001), the code will be instrumental in helping to prevent the spread of the epidemic, mitigate its impact on workers and their families and provide social protection to help cope with the disease (ILO, 2001). The main objective of the code is to provide a set of guidelines on how to address HIV/AIDS epidemic in the workplace within the framework of promotion of decent work (ILO, 2001). Key areas covered in this code are: prevention of HIV/AIDS, management and mitigation of the impact of HIV/AIDS in the workplace, care and support of workers infected by HIV/AIDS, and elimination of stigma and discrimination on the basis of real or perceived HIV status (ILO, 2001). .

It covers key principles, such as the recognition of HIV/AIDS as a workplace issue, non-discrimination in employment, gender equality, screening and confidentiality, social dialogue, prevention and care and support, as the basis for addressing the epidemic in the workplace (ILO, 2001). In as far as non-discrimination is concerned, (ILO, 2001) reported that discrimination and stigmatisation of people living with HIV/AIDS inhibits efforts aimed at promoting HIV/AIDS prevention and therefore there should be no discrimination against workers on the basis of real or perceived HIV status.

ILO (2001:5), recommended that *“in order to eliminated workplace discrimination and ensure workplace prevention and social protection, governments in consultation with their social partners and experts in the field of HIV/AIDS, should provide the relevant regulatory framework and, where necessary, revise labour laws and other legislation”*. Similarly, (WHO, 2011:29), reported that *“laws should be reviewed and if necessary reformed in order to decrease HIV vulnerability, improve access to health services and protect human rights. Legislation should be enacted to uphold non-discrimination in all areas”*.

Formally, the legal framework in South Africa is very progressive and it protects those living with HIV and AIDS. Chapter two of the Constitution of the Republic of South Africa Act (1996) provides a bill of rights for every citizen of the country. The most relevant for this study is equality where *“The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth”*, (Constitution, 1996:5).

The Labour Relations Act (1995), in Section 187 regulates automatically unfair dismissals. A dismissal is dimmed to be automatically unfair if *“the employer unfairly discriminated against an employee, directly or indirectly, on any arbitrary ground, including, but not limited to race, gender, sex, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, political opinion, culture, language, marital status or family responsibility”* (LRA, 1995:187).

The Employment Equity Act (EEA), No. 55 of 1998 prohibits unfair discrimination and it has listed HIV specifically so that no one is discriminated due to the HIV status. Section 6 of the EEA (1998) affirms that *“No person may unfairly discriminate, directly or indirectly, against an employee in any employment policy or practice, on one or more grounds including race, gender, pregnancy, marital status, family responsibility, ethnic or social origin, colour, sexual orientation, age, disability, religion, HIV status, conscience, belief, political opinion, culture, language, and birth”*. Section 7 of the EEA (1998) prohibits HIV testing as a prerequisite for employment unless permission has been granted by the Labour Court. All these measures are to ensure that employees are not discriminated in the workplace including applicants who want to enter the job market.

In 2000, the Department of Labour (DoL) published a Code of Good Practice on Key Aspects of HIV/Aids and Employment referred here as the ‘Code’. The Code’s primary objective is to set out guidelines for employers and trade unions to implement so as to ensure individuals with HIV

infection are not unfairly discriminated against in the workplace. This includes provisions regarding: creating a non-discriminatory work environment; dealing with HIV testing, confidentiality and disclosure; providing equitable employee benefits; dealing with dismissals; and managing grievance procedures (DoL, 2000). The Code provides all the requirements as stipulated in the ILO code of good practice on HIV/AIDS. Over and above this, it provides for compensation for occupationally acquired HIV. According to Section 6 of the code, *“no person with HIV or AIDS shall be unfairly discriminated against within the employment relationship or within any employment policies or practices”*, (DoL, 2000). These include but not limited to: recruitment, appointments, training and development, and termination of services. (DoL, 2000). The code also regulates HIV testing, confidentiality and disclosure. *“Where an employee chooses to voluntarily disclose his or her HIV status to the employer or to other employees, this information may not be disclosed to others without the employee’s express written consent. Where written consent is not possible, steps must be taken to confirm that the employee wishes to disclose his or her status”*. (DoL, 2000:9).

The most important aspect of this code is that it provides a framework or guidelines on how to develop a workplace policy on HIV/AIDS and how to develop workplace HIV/AIDS programmes.

Parliament’s Policy on HIV and AIDS complies with the global and national legislative framework. It is based on the Code of Good Practice on Key Aspects of HIV/Aids and Employment. According to the Policy on HIV and AIDS (2009:5), *‘employees living with HIV and AIDS must be treated fairly and not be discriminated against or victimized, managers must protect employees living with HIV and AIDS from stigmatization and unfair discrimination; HIV and AIDS status must not be a basis for pre-employment testing or for refusing to employ an applicant’*.

In some aspects which are proposed by WHO, it falls short in that legalized sex work and drug use is still a criminal offence and therefore people engaged in these behaviours might not necessarily have access to health services

The stigma against people with HIV undermines dignity and hinders the effective response to HIV/AIDS. Francis and Francis (2006) asserted that the negative treatment directed to people living with HIV/AIDS by those who are HIV negative and those who are unaware of their HIV status constitute oppression. These authors therefore used the term HIVism to name the oppression of people living with HIV/AIDS

(Francis and Francis, 2006). Fortunately, the legal framework in South Africa does not allow people with HIV and AIDS to be discriminated. As stated before, in Parliament any discrimination of PLWHA is viewed as a serious offence that can lead to termination of employment. Parliament leadership will be expected to speak out against stigma, support the development of a strong movement of people living with HIV, and have increased interaction with other stakeholders in the fight against HIV/AIDS. In an institution like Parliament, which needs to uphold the constitutional requirements of South Africa, HIV/AIDS as a human rights issue has to be addressed. According to Essex et al (2002:641), the HIV/AIDS epidemic “*requires attention to human rights on the part of policy makers, programme managers, researchers and activists*”. Essex et al (2002) proposed that these leaders address the adverse impact of discrimination to the vulnerable groups to HIV/AIDS and these include women, children, people with disabilities, and those who are economically disadvantaged. Section 6(1) of the Employment Equity Act no 55 of 1998 prohibits any discrimination of any form including discrimination to those living with HIV and AIDS.

The case of Hoffman versus South African Airways (SAA) is an important lesson for all employers to ensure that they develop proper policies around HIV in the workplace. Ngwema (2001) reported that Hoffman applied for a job of flight attendant in SAA. After passing the interview and the medical examination, his blood tests came back positive with HIV and he was declared unfit to work as a flight attendant. Hoffman then challenged this decision, arguing that it constituted unfair discrimination and was a violation of the right to equality contrary to section nine (9) of the Constitution. While he lost this case in High Court, the Constitutional Court reversed the High Court decision in a unanimous judgment that the refusal by SAA to employ Hoffmann as a flight attendant constituted unfair discrimination and was a violation of the right to equality under Section nine (9) of the Constitution (Ngwema, 2001).

In some cases, discrimination of people living with HIV/AIDS in the workplace is associated with class or status in the society. Pereira (2010) documents two employment decisions in Portugal which, together, reveal this differential discrimination. In one case, a cook was considered incapable of working by the Supreme Court of Justice because of her HIV Status while in the second case, an HIV positive surgeon was allowed to continue practicing his profession including performing (laparoscopic) surgery, following expert technical advice from the Physicians’ Society. More than a health-related discrimination, these two parallel cases show how HIV highlights existing discrimination between professionals and “*lower*” social classes. Pereira (2010:147) writes: “*Whereas the physician’s case was analyzed by a panel of scientists*

and colleagues and the surgeon allowed to continue his work; the cook was rapidly dismissed by the employer and the courts of law never granted that citizen a fair trial, with accurate scientific expertise”.

2.8 HIV/AIDS RELATED STIGMA: THE WORKPLACE

As HIV/AIDS continues to spread, its impact on most organizations is becoming increasingly evident in both the private sector and the public sector (ILO, 2001). At the level of individual organizations, HIV/AIDS among managers and individuals will impose significant direct and indirect costs. Direct costs include costs of health care and employee benefits. The most significant costs are likely to be indirect. These include the costs of absenteeism due to illness or funeral attendance, lost skills, training and recruitment costs, and reduced work performance and lower productivity (ILO, 2001).

The threat that HIV/AIDS poses to most institutions, including Parliament of RSA, can be reduced by a better coordinated HIV/AIDS strategy. Parliament had an HIV/AIDS strategy that was in line with the National Strategic Plan (NSP) for HIV/AIDS and Sexually Transmitted Infection (STI): 2007-2011. This strategy is being reviewed to be in line with the new NSP 2012-2016 which has now focuses on elimination of stigma. Parliament’s strategy proposes various ways of dealing with Stigma.

The IPU (2007) warns that organisations readily propose and commit to strategies to deal with stigma and discrimination but fail to deliver on the promises. Similarly, Dickson (2005) reported that most HIV/AIDS workplace programmes put emphasis on stigma and discrimination but fail to achieve any change (Dickinson, 2005). According to Dickinson (2005), the stigma and discrimination associated with HIV/AIDS is so prevalent that the UNAIDS regards it as the greatest barrier to combating the disease around the world. According to Stine (2007: 369), throughout the world and in a very short space of time, people have learnt to “*categorize, rationalize, stigmatize, and persecutize those with HIV and AIDS*”. With AIDS, people have found verbal mechanisms to distance themselves from the thoughts of personal infection (Stine, 2007).

2.9 MANAGING HIV/AIDS RELATED STIGMA IN THE WORKPLACE.

The global vision for HIV/AIDS is “*Zero new infections, zero aids related deaths and zero discrimination in a world where people living with HIV are able to live long, healthy lives*”, (WHO, 2011:7). In order to

achieve universal access to HIV prevention, diagnoses, treatment, care and support, WHO developed a global health sector strategy on HIV/AIDS, 2011-2015 which guides the health sector responses to the HIV epidemic (WHO, 2011). The WHO strategy has four strategic directions which have their own core elements. The four strategic directions are:

1. *Optimize HIV prevention, diagnoses, treatment and care outcomes.*
2. *Leverage broader health outcomes through HIV responses*
3. *Build strong sustainable systems*
4. *Reduce vulnerability and remove structural barriers to accessing services. (WHO, 2011: 1).*

The fourth WHO strategic direction is relevant to this study because it advocates promotion of human rights, mobilization of communities and it addresses social determinants of health. Its core elements are: *promote gender equality and remove harmful gender norms; advance human rights and promote health equity; ensure health in all policies, laws and regulations* (WHO, 2011:27).

In order to achieve this strategic objective in the workplace, HIV programming will need to promote equity between males and females in sexual decision making including the use of male or female condom as suggested by (WHO, 2011). Other aspects that need particular attention in the workplace like Parliament will be inclusion of drug users and men who have sex with men or females who have sex with females since Parliament is not immune to these social issues. WHO also recommends the inclusion of people living with HIV/AIDS in the design, implementation and evaluation of HIV/AIDS responses (WHO, 2011). Gender issues needs to be included in the design, delivery and monitoring of health and wellness services in Parliament as suggested by (WHO, 2011).

The World Health Organisation is also part of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and as such has contributed to the development of the UNAIDS 2011-2015 Strategy: Getting to Zero. UNAIDS (2010), has three strategic objectives which are designed to achieve the global vision of HIV/AIDS. These are:

1. *Revolutionize HIV prevention*
2. *Catalyse the next phase of treatment, care and support*
3. *Advance human rights and gender equality for the HIV response (UNAIDS, 2010:7).*

The third objective is particularly relevant for this study. The intent of this strategic objective is to get

zero discrimination (UNAIDS, 2010). According to UNAIDS (2010:10), Advancing human rights and gender equality for the HIV response means “*ending the HIV-related stigma, discrimination, gender inequality and violence against women and girls that drive the risk of, and vulnerability to, HIV infection by keeping people from accessing prevention, treatment, care and support services*”. The UNAIDS (2010), further defined it to mean putting laws, policies and programmes in place to create legal environments that protect people from infection and support access to justice. UNAIDS (2010) explained that the core of these efforts are to protect human rights in the context of HIV including the rights of people living with HIV (PLWHIV), women, young people, men who have sex with men, people who use drugs, and sex workers and their clients.

ILO (2001) recommended training of managers, supervisors and personnel officers in order for them to be well informed about HIV/AIDS and thereby help others to overcome misconceptions about the spread of HIV/AIDS. Other categories of employees to be trained includes: Health and safety representatives, peer educators, worker representatives (unions), and training of those who come to contact with blood and other body fluids (nurses and first aiders), (ILO, 2001).

In South Africa, addressing the HIV/AIDS related stigma is of utmost priority given the fact that HIV infection is amongst the highest in the world (Forsyth, Vandormael, Kershaw and Grobbelaar, 2008). In 2011, the South African National Aids Council (SANAC) which is chaired by the Deputy President of the Republic of South Africa developed the National Strategic Plan (NSP) on HIV, STI and TB for 2012-2016. The NSP has a 20 year long term vision which was adopted from the three zero’s advocated by the Joint United Nations Programme on HIV/AIDS (UNAIDS). South Africa’s 20 year vision is: zero new HIV and TB infections, zero new infections due to vertical transmission; zero preventable deaths associated with HIV and TB; and zero discrimination associated with HIV and TB, (SANAC, 2011). In order to achieve its vision, the NSP has four strategic objectives and these are:

- 1. Addressing social and structural barriers to HIV, STI and TB prevention, care and impact*
- 2. Preventing new HIV, STI and TB infections*
- 3. Sustaining health and wellness*
- 4. Increasing the protection of human rights and improving access to justice (SANAC, 2011:12).*

The fourth strategic objective also ensures that no human rights violations exist when the first three strategic objectives are implemented, reducing HIV and TB discrimination especially in the workplace and reducing unfair discrimination in access to social services, (SANAC, 2011).

SANAC, (2011:44) recommended that “*All high-risk workplaces should have clear management policies on confidentiality, discrimination, routine medical screening and testing of employees, respiratory infection control, treatment, sick leave, psychosocial support, and job modification/alternative placement, where necessary. All workplace wellness programmes should address HIV, STIs and TB in an integrated manner and aligned with national standards*”. SANAC, 2011: 48) further proposes that in workplaces employees are tested and screened annually and have equitable access to prevention, treatment and wellness services.

Parker and Aggleton (2002) proposed that at individual level, strategies may include: education, counselling, and improved self-efficacy. At environmental level, strategies may include provision of social and health services, community organisation and unionisation. At structural level, they may include legislative lobbying, civil and human rights activism, and legal reform.

The IPU (2007:87) is very clear on what is expected from Parliamentarians, *‘Take action against stigma and discrimination and support people living with HIV’*.

While “stigma” is a word that is constantly linked to “HIV”, it is often just left there. This study wanted to explore with fresh eyes whether stigma was perceived as an issue, and how it is understood, perceived, and experienced in Parliament.

Conclusion:

The literature reviewed here has managed to place stigma in the various contexts in which it was intended to and it addressed the objectives of the study. The stigma concept and its various types were explored. The impact of stigma in the society and gender including the legislative framework that exist was thoroughly reviewed to ensure that stigma in Parliament will be addressed comprehensively. All the global commitments and achievements were noted as well to maintain a balanced view.

CHAPTER 3: METHODOLOGY

3.1 Study Design

A cross-sectional descriptive qualitative *study design* was used in this exploratory research. I sought detailed information on perceptions about stigma in Parliament.

3.2 Study Population

All employees of Parliament (n = 1300) including permanent, contract and temporary employees who were at work at the time of the study formed the population of the study. Only employees on Parliament's pay roll were included and therefore, Members of Parliament and employees working for political parties were not included in this target population.

3.3 Sampling Technique



In this study, a non-probability sampling technique called purposive sampling was used. The main reason for use of purposive sampling in this study is that I attempted to construct a sample that would be likely to ensure that a wide range of perceptions would be included in the study, as the Parliamentary Strategy and the Wellness Programme are meant to address the full range of Parliamentary employees and their needs. I was interested in obtaining information about HIV/AIDS stigma in Parliament from employees on shop floor (A-Band) through specialist level (D- Band) up to senior management level (E-band). The top level (F-Band) was not included because it would have been difficult to maintain confidentiality.

3.4 Sample

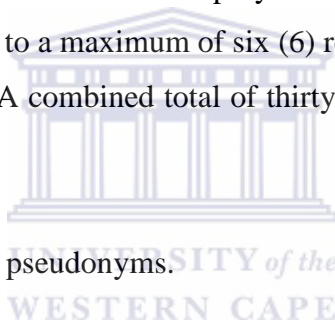
To identify and select the participants for individual interviews, I used the staff establishment report. I arranged the data per Occupational Category (Band) in excel spreadsheet and chose employees in each category trying to ensure that they cover the Parliamentary Service demographics as far as possible. A minimum of two participants to a maximum of six were chosen. I allocated the selected participants to the staff that helped me perform interviews. The selected participants were telephonically contacted to make

appointment for the interview. It was explained that the appointment is for them to participate in research on HIV/AIDS related stigma in Parliament.

For focus group discussion, two focus groups were purposefully selected while the last two were a convenience sample. The first focus group was made up of active HIV/AIDS Peer Educators in Parliament while the second focus group was made up of First Aiders. They were both recruited and interviewed after their routine monthly meetings. They were informed that participation is voluntary and no disclosure of HIV status is allowed. The third and fourth focus groups were made up of members of the hiking club in Parliament. They were recruited during their Whale trail hiking activity which took place in Bredarsdorp in the De Hoop Nature Reserve. They were also informed that participation is voluntary and no disclosure of HIV status is allowed. In total the sample size of 49 respondents was broken down as follows:

- a) *19 individual interviews.* This covered five employment grades (A-Band to E-Band). From each category a minimum of two (2) to a maximum of six (6) respondents were interviewed.
- b) *4 focus groups of 6- 9 people.* A combined total of thirty participants were interviewed during the focus group discussions.

All of the names used in this study, are pseudonyms.



3.5 Data Collection

The data was collected by me and research assistants. Research assistants were used only to collect individual interview data. I conducted the focus group discussions. Before the instruments were used, I conducted a pretesting interview to test the instruments. The focus group instrument was based on the individual interview instrument and therefore only the individual interview instrument was pre-tested. No concerns were raised.

Research assistants were all from the Organisational Wellness Section. They are very clear of the services provided by the Section. They are all qualified graduates in the specialty fields as listed below:

- a. Two Employee Relations Specialists (male and female).
- b. Social Worker (male)
- c. HIV/AIDS Programme Officer (male)

- d. Wellness Coordinator (female)
- e. Employee Engagement Specialist (male).

All the above research assistants were chosen on the basis that they work with all employees of Parliament on a daily basis in tasks that require maintaining of confidentiality. An interview skill is a core competence in all of them. The Employee Relations Specialists conducts interviews frequently in preparation for cases in the Council for Conciliation, Mediation and Arbitration (CCMA). All other Wellness Practitioners do this on daily basis helping employees of Parliament with their Wellness problems or needs. I have trained all Research Assistants on the consent form, the questionnaire (interview schedule) and data control. Training records are attached in Appendix 3.

I reviewed the data collected by the research assistants for consistency and its quality. There were no quality problems identified. Research assistants were also informed that they can record the interview as well but this was not compulsory.

3.6 Data Collection methods

A structured questionnaire with closed and open-ended questions was used for individual interviews and a semi-structured interview guide was used for focus group discussions. Some structured questions about demographics and specific information on HIV/AIDS stigma and discrimination were included. The interview guides are presented in Appendix 1 and 2.

The data was collected from the individual interviews and focus group discussions. All interviews were conducted in English. The data was collected through the following methods:

1. Individual interviewing using an individual interviewing guide attached in Appendix 1. A total of 19 individual interviews were conducted. These covered employees from A-Band level (low level) to the E-Band level (Senior Management). Individual interviews were conducted by me and five research assistants. The individual interviews were captured in the interview guide itself. However some interviews (eight) were recorded while the other eleven were not recorded but rather captured on the interview tool itself. Recording of interviews was just a back up mechanism when the interviewer was unsure and not compulsory. Individual interviews were conducted in individual offices in Parliament. The recorded individual interviews lasted between 19 minutes and 40 minutes.

2. Focus group discussion (FGD) using a focus group discussion guide attached in Appendix 2. A focus group discussion is a qualitative method used to obtain in-depth information on concepts, perceptions and ideas of a group with an idea that the group members discuss the topic among themselves, with guidance from the facilitator (Varkevisser et al, 2003). I have facilitated all the focus group discussions and were audio-recorded as well. All recordings were saved on the desktop so that I can play and replay the recordings while writing up the data. A total of four focus groups were interviewed. The focus group discussions lasted between one and two hours and were held in Parliament or in the De Hoop Nature Reserve conference room.

3.7 Data Capturing

The collected data was captured on Microsoft Excel Programme manually. All interviews were loaded into a spreadsheet. One spreadsheet was for individual interviews, and the other four spreadsheets were for the four focus group discussions. The templates for analysis are attached as appendix 5 for individual interviews and appendix 6 for focus group discussions.

When all the responses were entered into Excel Spreadsheet, the demographic information was analysed using Excel into tables and graphs. I read and summarized the information from each respondent in individual themes. The same exercise was done for focus group discussions. Below each focus group discussion data, a summary of emerging themes was written. All spreadsheets were printed in order to make analysis easier.

From the exercise above, I then categorized sentences that spoke to one theme. These were called sub-themes which were then further grouped to five main themes. In essence, the sub-themes culminated to five main themes that emerged from the data. These themes will form part of the discussion (chapter 5).

CHAPTER 4: RESULTS PART 1: PARLIAMENTARY EMPLOYEES' PERSPECTIVES ABOUT HIV STIGMA AND PARLIAMENTS' HIV POLICIES AND PROGRAMMES

INTRODUCTION

This chapter presents the results of the study in relation to the four specific objectives of the study and the questions respondents were asked to discuss. Chapter 5 presents a further analysis and discussion of the themes that emerged from the study as a whole. This chapter presents results by individual interview and then focus group discussions, in order to capture and convey both the common themes and the divergent perspectives. The quotations and comments are presented as said by named individuals in order to convey the interactive and interpersonal nature of this study; as noted in Chapter 3, all of the names are pseudonyms. Each set of results is preceded by a brief description of the participants. The chapter concludes with a brief summary of the results by objective.

4.1 INDIVIDUAL INTERVIEWS

4.1.1 DEMOGRAPHIC CHARACTERISTICS OF INDIVIDUAL INTERVIEWS PARTICIPANTS

Demographic characteristics of the 19 participants in the individual interviews compared to the profile of Parliament employees in general are presented in Table 1. As seen in Table 1, the majority of respondents were females (74%) compared to 26% of males. Similarly, the profile of Parliament employees has more females (56%) than males (44%). Black participants were the majority at 47% while 26% of participants described themselves as Coloured. 16% of participants described themselves as White while 11 % described themselves as Indian. In contrast, the profile of Parliament employees as depicted in Table 1 shows that White employees are 11% while Indians are 3%. Most participants' age was between 36-45 years (47%), and 46-55 (37%). This was similar to Parliament's profile (see Table 1 below).

Parliament's jobs are graded using Paterson's grading system which is based on the decision making process. The lowest Band is for unskilled workers while the highest Band, is for top management, (Paterson, 1978). In Parliamentary, the lowest Band is A-Band and it is equivalent to Paterson's O- Band while F-Band in Parliament is for Top management and equivalent to Paterson's E-Band. The B-Band is for Semi-skilled, C-Band is for Skilled, D-Band is for Professional/Specialist/Management, and E-Band is for Senior Management.

Table 1. Demographic characteristics of the 19 participants in the individual interviews and profile of Parliament Employees

Characteristic	Individual Interviews (n= 19)		Parliament (n = 1300)	
	n	%	n	%
Gender				
Male	5	26	572	44
Female	14	74	728	56
Age				
18-25	0	0	15	1
26-35	3	16	299	23
36-45	9	47	559	43
46-55	7	37	342	26
56-65	0	0	85	7
Race				
Black	9	47	686	53
Coloured	5	26	437	33
White	3	16	138	11
Indian	2	11	39	3
Marital Status				
Married	11	58	643	49
Single	7	37	592	46
Divorced	0	0	44	3
Widowed	1	5	14	1
Other	0	0	7	1
Occupational Category				
A-Band	2	11	162	13
B-Band	6	31	287	22
C-Band	6	31	680	52
D-Band	2	11	154	12
E-Band	3	16	15	1

4.1.2 RESULTS OF THE INDIVIDUAL INTERVIEWS

The first objective was to explore employees' understanding of the meaning of HIV/AIDS related stigma. Participants were asked **“Please tell me what the term “HIV/AIDS stigma” means to you?”** Most participants defined HIV/AIDS related stigma as the negative attitude that is given to people with HIV to the extent of *“passing judgement”* to them. Respondents also reported that this emanates from the ***lack of education and knowledge*** about the disease itself. One respondent said that it's *“people's misperception about the disease and it shows how uninformed people are about the disease”*. The behaviours reported to be associated with this general definition of stigma were that a person who is HIV positive would be treated differently, isolated, and not accepted by family, friends, peers and community at large.

When asked **“How is it relevant in Parliamentary Service?”**, participants' responses centred around *disclosure*. Participants felt that HIV status is still kept secret in Parliament and people do not disclose. *“No one opens up and there is quietness about it at the moment”*, some respondents reported. Most participants actually did not know anyone who is HIV positive.

Zuko reported that *“Hugging stops and people do not want to be associated with you if you are HIV positive”*. Leila felt that it is *“extremely relevant”* since in Parliament there are different cultures. *“It's everybody's responsibility to embrace diversity and make people inclusive regardless of their status”* Kate said. Jake felt that it is relevant since Parliament is not exempt from the community.

Participants were further requested to detail the extent to which HIV/AIDS stigma as they have defined it has occurred in Parliament in the past 12 months. So when they were asked **“In your opinion, in the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?”** The majority of respondents could not identify any specific incidents of stigmatizing attitudes and behaviours in Parliament in the past 12 months. However, Jane and Zuko reported that there were two incidents of stigmatizing attitudes and behaviours which were based on assumptions or appearance. These attitudes and behaviours were related to dramatic weight loss and long term sick leave.

In order to address the second objective of this study which was *“to assess employee's perceptions towards people living with HIV/AIDS”*, participants were asked **“When someone becomes aware of a person diagnosed or living with HIV, what is the general response to the news?”** In responding to this question, respondents spoke about reactions in the communities that they know about, and reported their

views of how people in general react to HIV, not focusing or referring specifically to reactions only within the Parliamentary workplace. Respondents said that people generally become afraid. This fear had many dimensions: fear that a person would not live long, fear of getting infected, and fear of the community response. Other emotional feelings that were reported are those of dismay, shock, denial, anger and disbelief. It was also reported that people who are HIV positive are negatively labeled. They are labeled as *“promiscuous or gay/lesbian”*, with the latter being a negative label and not a neutral description of sexual orientation.

Respondents reported that people distance themselves from a person who is HIV positive. Kate reported that *“People generally exclude themselves from those infected”*. Some of the behaviours associated with this exclusion include isolation where physical contact stops. According to Leila, such social exclusion results in *“community blocking you off”*. Leila said HIV/AIDS is still a shock in the community especially the Moslem community. Zuko reported that *“sharing stops and the body language indicates you are not welcome”*. In contrast, Jeremy reported that you sympathise with the person and even feel sorry for the person. Some respondents reported that the feelings in the community are mixed in that some people will be curious about *“how you got the HIV”* while others will *“gossip about it”*. Naledi reported that she is HIV positive and she received a very positive response from the peers and the community. She was informed during the signing of the consent form that she must not disclose her status but she did nevertheless.

When asked **“When you become aware of a person diagnosed or living with HIV, what is your response to the news?”** The responses were similar to the previous question but were more positive in nature. Most participants reported that they would show support for the person and have comfort knowing that it’s not the end of the world since the antiretroviral treatment is being rolled out. Again some participants expressed mixed feelings ranging from feeling sorry, crying, and sad, to shock, angry, curious and to even wanting to share religion. Zuki shared that she felt feelings of fear to ask the person because of fear of a negative reaction. Respondents expressed fear of what the illness means for the person’s loved ones. Naledi was so angry initially she wanted to *“kill the person and the whole family since they all knew”*. Zoleka was working with a colleague who was diagnosed of HIV, who has opened up to her and she referred her to the Wellness Unit. Aviwe had three friends who were HIV positive and she responded the same way on all three where she said *“I showed my weakness of feeling sorry, I cried”*. Aviwe shared that in all three incidents she felt sorry for her friends, she regards this as a weakness and she cried in all three of them.

Further within this objective of exploring perceptions of HIV, the study sought to learn whether there were any barriers for employees to go for an HIV test in the Parliamentary Service. Participants were asked ***“If you were going to be tested in future for some reason, how concerned are you that you might be treated differently or stigmatized if your test results were to come out positive for the AIDS virus?”*** The majority of them would be concerned and even very concerned (n= 11). Johan would be very concerned and afraid that other people will know while Carol would be scared of how they will treat her and being referred to as *“gay or promiscuous”*. Leila even feared how the family, colleagues and community would treat her. Similarly, Aviwe said she will be concerned and have fear of rejection, fear of not fulfilling her dreams, and *“it’s fear that is just there”*. Generally participants were concerned about how they would be treated (treated differently) because of a positive HIV test result. Zuko actually reflected how even in Public Hospitals the folders are written *“ARV”*, especially in Nolongile in Site C. In this Hospital, there is a separate side for HIV and TB patients, he reported.

However, 8 of the participants (42%) were not worried about a positive test result or being stigmatized. Jane, a *“B-Band”* (semi-skilled) employee, and Thobeka an *“E-Band”* (senior management) employee said that results are actually confidential and therefore they were not concerned about being stigmatized while Zoleka another *“E-Band”* employee preferred to deal with it when it comes. Naledi said she is not concerned at all since she is already positive. This is due to the amount and the quality of support that she gets from colleagues at work and the community where she comes from. Nomthandazo summed it up as *“you will be aware that you will get different treatment from different people, might not be accepted by everybody”*.

When the participants were asked ***“How is the thought of possible stigmatization affecting your decision to get tested for HIV?”*** The majority of them reported (n=14) that they will not be affected. This is despite their fears of being stigmatized or being treated differently. Aviwe said *“obviously you drag your feet, due to fear of rejection within the family”*. Ndumiso on the other hand reported that he has gone past that stage and is therefore not affected at all by the thought of being stigmatized. The rest of the participants (n=5), reported that the thought of being stigmatized indeed does affect their decision to test. Zwelakhe said *“it is never a pleasant thought”*. Jane on the other hand reported that Parliament is not that liberal for people to freely disclose their status while Johan would be reluctant to be tested. In contrast, Leila would still go and test despite the fear.

When participants were asked **“In Parliament what is the primary way employees know if someone is HIV positive?”**, the majority of participants (n=13) mentioned that it’s through gossip/grapevine or rumours. Only five participants said it was based on assumption where one would lose weight all of a sudden, being off sick for long period and signs and symptoms of HIV/AIDS related illness. One participant did not know. Generally, other ways of knowing if someone if HIV positive in Parliament is perceived to include testing regularly, disclosure by the infected and people’s reaction after HIV Counseling and Testing during wellness days.

The third objective for this study was “To explore perceptions of the effectiveness of Parliament’s HIV/AIDS response strategy”. Participants were asked a number of questions. When asked **“Do you know about Parliament’s Policy on HIV/AIDS?”** The majority of participants (n=10), did not know about the policy on HIV/AIDS. Even some of those who knew its existence (n=9) they did not necessarily remember or recall the detail. Zoleka was even unsure if it was signed off.

When asked **“How do you think this policy addresses the issue of stigmatization?”** There were mixed feelings amongst participants, some of those who knew its existence (n=9) believed that it is not comprehensively addressing the issue of stigmatization while others believed it does. Ndumiso said it addresses judgement on people’s health; policies are there to better people’s lives he said. Zwelakhe supported this view adding that *“There was no one ever fired, or not promoted or hired”*. Johan and Kate both said the policy is very clear and it addresses the issue of stigma. Jane reported that the policy is good on paper but not implemented as it should be, while Zoleka believed that it was too general and could not remember whether the policy was approved. In contrast, Leila felt that it is not addressing stigma comprehensively as it should. Zuko was adamant that it is *“not addressing it at all”*.

When asked **“In your opinion, how well and in what ways do the existing Health and Wellness Programmes in Parliament meet the needs of People Living with HIV and AIDS?”** Zwelakhe said Parliament contributes to Medical Aid, has a counseling service, and it has a peer education programme. Zoleka concurred with this view saying there is general awareness, AIDS day, Voluntary Counseling and Testing, education and awareness. Johan said Wellness has regular programmes where people get tested while Ndumiso added that wellness programmes provide therapy through the wellness office which provides support formally and informally. Naledi said that *“very well especially in the past twelve (12) months”*. In contrast other respondents reported that even though wellness programmes exist, there should be testing during the week and not focus only once a year as in the first of December. It should be

continuous support throughout the year. Aviwe said that “*wellness programmes do not cover the environment and culture where people can openly disclose*”. Zuko felt that “*it does not since the Employee Assistance programme statistics also do not engender confidentiality*”. There were respondents that were either not aware of the wellness programmes or did not have time to attend them.

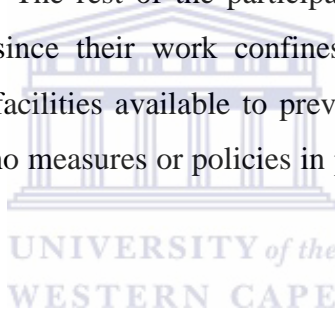
When asked “**What else might help to make it easier to discuss, get tested for, and deal with HIV and AIDS in this workplace?**” This question was structured to assist in developing the anti-stigma strategy as well as to address the fourth objective of “*Exploring employee perspectives on how HIV/AIDS-related stigma might be effectively addressed in the workplace?*” All participants responded enthusiastically to this question and had many suggestions on how to deal with HIV/AIDS in the workplace. Some participants proposed that a platform should be created for those living with HIV to have regular presence. It was reported that employees need to be exposed to people who are already ill from AIDS so that they can change their behaviour. It was also suggested that a platform be created where people can just talk about HIV/AIDS. Carol felt that it is “*regarded too sensitive*”. People should be made aware that it is like any other illness, she said. Similarly Naledi said that Wellness Unit should “*tackle it differently*” and first address chronic illnesses comprehensively. At least five (n=5) participants suggested that *support groups* must be established in Parliament. These participants were from all race groups and the B and C- Band levels.

Zoleka advocated for training of staff and addressing of the confidentiality issues in Human Resources in general. Similarly Ellen said more education and information is important to combat stigma and self-stigma. Intensified awareness campaigns and information dissemination was suggested which will need to include formal and informal engagements. Participants listed the ways in which this could be achieved. These include; workshops, newsletters, talks sharing statistics, using people living with HIV/AIDS, dialogues and discussions. Zuko concurred with this view using the analogy of the “*around the fire discussion*” as seen in rural villages where elders sit around fire and deliberate on important community issues.

Jane said Parliament should “*dispel fear*” and encourage informed talks on HIV/AIDS on how it relates to other spheres of life. Other suggestions included; intensifying wellness weeks, special talks about stigma, more talk on HIV/AIDS, information dissemination, quarterly sessions on HIV and AIDS. Consistent and continuous programmes are proposed instead of the event like approach currently happening. Marhaba said that there should be a shift from “*events to programmes*”. Another important suggestion was that of

Divisional dialogues where each Division to take responsibility by including the HIV/AIDS programme as part of the Divisional forums that happen quarterly.

I wanted to check whether employees know how HIV/AIDS is prevented and whether they know what facilities exist in Parliament for them to ensure that they do not contract HIV /AIDS at work. Participants were therefore asked **“How does Parliament Service ensure that you are not occupationally exposed to HIV/AIDS while you are at work?”** Indeed, some participants (n=6) knew that there is a Sister (Registered Nurse) in the premises who can deal with employees injured on duty with bleeding as well. They also mentioned the environment is safe and hygienic, the Safety Health Environment (SHE) representatives and the Wellness Unit are part of infrastructure that can minimize occupational exposure, respondents shared. Other participants (n=5) associated the occupational exposure to the available male condoms that are provided in the toilets as means in which the employer ensures that people cannot be exposed to HIV/AIDS while at work. The rest of the participants did not believe they were at risk of contracting HIV/AIDS in any way since their work confines them to the office. In contrast some participants (n=6) did not know any facilities available to prevent them from occupational exposure to HIV/AIDS. Wendy felt that there are no measures or policies in place to ensure that universal precautions are observed.



When asked, **“In your opinion, how is the Senior Management’s leadership in managing HIV/AIDS in Parliament?”** The majority of participants (n=12), do not believe that Senior Management is doing enough or even visible in responding to the HIV/AIDS epidemic. Senior Leadership is perceived to have distanced itself from it. Participants would like to see Management taking a leading role and being more visible and proactive in dealing with HIV/AIDS in Parliament. In fact Zoleka even suggested that HIV/AIDS should be in the *“Agenda of the Management Team Meeting”*. This is the second highest decision making body in the Institution. Other forums include Management Forum where a topic on HIV/AIDS could feature. Nomthandazo reported that she has *“Never seen them on a VCT clinic during wellness days”*. Zwelakhe felt that *“they are not visible as a way of motivating staff to partake”*.

In contrast, some participants indeed agreed that management is doing its best to deal with HIV/AIDS in the workplace (Parliament). Ndumiso actually mentioned that the *“Creation of the Wellness Unit, budget allocation, resources, space, and support to staff that is provided”* are all means that demonstrate that Parliament’s Management is serious about dealing with this illness and Health and Wellness of Employees in general. Despite this Aviwe felt that *“they brought Wellness so in their minds, Wellness will take care*

of it”. Ellen felt that Senior Management can more proactive in their approach while Thobeka (E-Band) said “we could do more”.

When asked “Do you have anything else you would like to add?”, I wanted to capture anything else the structured questionnaire would not elicit and also to address the fourth objective which is *to explore employee’s perspectives on how HIV/AIDS-related stigma might be effectively addressed in the workplace?*. The majority of participants (n=15), responded comprehensively to the question. Only few participants did not have something to add (n=4). Participants felt that the establishment of support groups for people living with HIV/AIDS, employees and communities will assist. They felt that more needs to be done to support those who are affected and infected. Leila suggested that we use the existing platforms within Parliament to reach out to the communities e.g. the Public Education Programme, Parliamentary Millennium Programme (PMP). Zoleka said HIV/AIDS programme should be institutionalised and provided on a continuous basis not as an event during Wellness days or Aids day. Providing other wellness programmes like programmes for cancer and linking HIV/AIDS to social programmes were also suggested. Regular HIV Counseling and Testing (HCT) was another suggestion that came out of these individual interviews.

Kate said that Parliament should “always ensure that people’s information is kept safe and confidential” Policy improvement, Zuko said that the policy should have “*support mechanisms built into it*”. Jane advised that everyone must be “*sensitized*” in Parliament. In this theme Zuko said “*Secretary to Parliament to lead by example*”.

4.2 FOCUS GROUP DISCUSSIONS

4.2.1 BRIEF DESCRIPTION OF THE FOCUS GROUP DISCUSSION

PARTICIPANTS

Four focus group discussions were conducted. These constituted about 8 to 10 participants. Two focus groups were purposefully selected since they come in contact with many employees in their day to day work. These were the first aiders and peer educators. The other two groups were chosen group of hikers divided into two. The hiking club has employees from various Divisions in Parliament as well just like the First Aiders and Peer Educators.

Thirty two (32) participants participated in these focus group discussions of which two were excluded since they were interns and erroneously participated and one was excluded due to incomplete information. Participants in the focus group discussions described themselves as Black (65%) and Coloured (35%) and females (65%) were more than males (35%). There were no white and Indian participants in the focus group discussions.

No employees were allowed to participate in both individual interviews and focus group discussions. All names used here are pseudonyms. The total sample for the focus group is thirty (30) broken down in Table 2 below:



Table 2: Demographic characteristics of the 29 participants in the focus group discussions and profile of Parliament Employees

<i>Characteristic</i>	Focus group discussions (n= 29)		Parliament (n = 1300)	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Gender				
Male	10	35	572	44
Female	19	65	728	56
Age				
18-25	0	0	15	1
26-35	2	7	299	23
36-45	18	62	559	43
46-55	9	31	342	26
56-65	0	0	85	7
Race				
Black	19	65	686	53
Coloured	10	35	437	33
White	0	0	138	11
Indian	0	0	39	3
Marital Status				
Married	12	41	643	49
Single	9	31	592	46
Divorced	6	21	44	3
Widowed	1	3	14	1
Other	1 (separation)	3	7	1
Occupational Category				
A-Band	2	7	162	13
B-Band	5	17	287	22
C-Band	22	76	680	52
D-Band	0	0	154	12
E-Band	0	0	15	1

4.2.2 RESULTS OF THE FOCUS GROUP DISCUSSION

The focus group discussions were asked four questions to stimulate discussion, and then some specific questions were also posed. The discussions were intended to be free flowing but I also expected that there will be different areas of focus across the four groups. While there were many common themes and issues raised across all four focus group discussions, the relative emphasis varied across groups. For example, the first group spent more time discussing the theme of “*negative labeling*”, while other groups emphasized other themes. The themes emerging across all focus group discussions are presented below, with supporting quotations.

When participants were asked “**What does the term HIV/AIDS stigma means to you?**”, the participants in the first instance associated HIV/AIDS stigma with the actual acts of **discrimination** (enacted stigma). These manifested themselves in the form of *prejudice, ostracization and negative labeling*. Gail said “*it’s like a bad tag attached to you. It affects you in a bad way. You will never be the same again*”. This negative labeling was associated with some degree of poor moral judgement and “*lack of education*”. Gill for example reflected that “*the disease is sexually transmitted, so people think you are morally compromised*”. Similarly, Zama said “*it’s judging a person as someone with no good moral judgement*”. “*Promiscuous*”, “*stripper*”, “*extramarital affairs*” and “*whore*” (sic), are the negative labels or ‘tags’ that were given to people who are HIV positive.

The community blames the person who is HIV positive in such a way that the social ties are even cut (ostracization). Participants shared the various ways in which the community actively cut ties with people who are HIV positive. Cebo said that “*the community can isolate you, no visitors, not eating with you, not allowed to even talk to their kids, you just a curse*”. Thantaswa reflected that “*people treat you as an alien; they do not want to be with you. You are alienated*”. Chubby said that people with HIV/AIDS are not accepted even in the church or religious environment. Similarly, Noluvuyo said that in her own family, if her brothers found out that the HIV positive brother cooked food, they refused to eat his food because of his status. Buurman said in his community, HIV positive person was “*hidden in the backroom or backyard*”. Madam E said that people who are HIV positive are ‘*blamed and shunned*’. Trompies was very clear and direct about how he understood HIV/AIDS stigma to be. He said “*not accepting people who are HIV positive in a way like other diseases. Ostracizing and non acceptance*”.

Secondly, **lack of knowledge and education** about HIV/AIDS emerged as an important aspect of HIV/AIDS related stigma. Buhle reported that people label you because they lack information while Carol shared that it is how it was initially presented as if you sleep around with lots of partners. Noluvuyo also supported Carol's view that initially HIV positive people were told they will die in five years. MK emphasized that *"It comes from ignorance, lack of information and knowledge; people do not know how to handle it"*. Kim associated the lack of knowledge to people's belief that those who are positive cannot live a normal life at workplaces and home. Zama regarded people gossiping in corridors as *"uninformed, insensitive, ignorant and unprofessional"*. Debora reflected that there is not much information about HIV in Parliament, only December 2010 campaign she could remember. Interestingly, Rorisang shared his personal experience by saying he has been *"blind to the existence of the disease, ignorance on my side, eyes only opened today after the talk"*.

Thirdly, **concerns about psychological impact** emerged as a significant theme. *Fear* was the most dominant psychological impact or concern, expressed by the respondents in relation to the possible experience of a person who is HIV positive, people with whom that person might interact, and to their own experience and reactions. Respondents reported that people actually become afraid of you, if you are HIV positive. Debora said it is fear of HIV/AIDS by both the affected and infected, *"fear of being judged"*. Similarly, Gill said that there is *"fear and judgement of the person who is HIV positive"*. Baxter reflected how it will impact him psychologically. He said *"living with an HIV positive person will create a profound feeling towards the person compared to work where there is no close contact"*. One participant, Theophillus, was unusually open in sharing his own reactions to HIV, reactions of which he is not proud but felt it important to bring out into the open. He said he was hit by fear and never wanted to see his uncle with full blown AIDS in the Hospital. He confessed that he has fear and a negative attitude towards people with HIV. He has feelings of *'disgust'* towards people with HIV. He is *'paranoid'* about breathing the same air with them. Patrick shared how his colleagues were afraid of a peer who was known to be HIV positive.

Another form of fear was *fear by the person with HIV/AIDS*. People are fearful of death because they were told that they will die in five years when it was first presented, Noluvuyo said. Another form of psychological impact that emanated from this question was *"denial"*. Dolly said that *"it comes with denial, not easy to accept status by family"*. Rorisang added that this denial comes because HIV/AIDS is about being *"loose in your life, sleeping around with lots of people"*.

Issues related to disclosure and assumptions and preconceptions about causes and signs of HIV infection are the two main themes that emerged when participants were asked “**In the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?**” Firstly, issues related to disclosure were: *secrecy, concerns about confidentiality, gossip/grapevine and concern about family, friends and peers*. Gossip/grapevine was the most prominent sub-theme. Cebo shared that “*when a person gets thin, she is judged. Awukwazi noxoxa nomuntu (meaning you cannot even talk to a person) otherwise they gossip about it*”. In this example, issues related to disclosure as a main theme emerged through *gossip*, but *concerns about confidentiality* were also associated with people’s willingness to disclose. Cebo reported that there are “*low levels of confidentiality in the institution*” hence people go around gossiping about other’s HIV status. Chubby said the current method of testing poses a challenge for testing. He said people look at the reaction of those who went for the testing as they collect their results. Deborah supported Chubby on the process of HIV counseling and testing saying, “*The way they are doing testing, you can guess who is positive and who is negative. If you are negative, you stay two minutes while if you are positive you stay longer*”.

Buhle said that it was a Peer Educator who gossiped about a person’s status, so “*how are we going to know if a person is committed or just being nose*”. Similarly, Pattle shared the plight of employees disclosing to senior people who in turn gossip about the HIV positive employee “*some seniors referred people to me, in other cases it would be that senior person who will gossip and be judgmental*”. Zama had a recent experience of people saying “*so and so died and he liked women*”, in the corridors.

Secondly, **Assumptions and preconceptions about causes and signs of HIV infection** as a main theme manifested in the form “*weight loss, long term sick leave, promiscuity and being gay/lesbian*”. Gill shared that in her working environment, “*when a senior colleague was away on sick leave for a long period, when he came back, there were stories doing rounds*”. He was dubbed to suffer from ‘*the other cancer, or the big C or the C*’. This means that people were already **assuming** that he is HIV positive. When Trompies saw his colleague being darker, he said “*that is where my own stigma and assumptions came*”. He reflected how he stigmatised. Similarly, Baxter in the same focus group also shared how he stigmatised his colleague. When he saw how the colleague lost lots of weight, he thought it was ‘Tik’, (an illegal substance). Then he saw his colleague taking lots of tablets in the kitchen, Baxter then changed his ‘Tik’ view to ‘HIV/AIDS’. Theophilus told the group that he is very “*paranoid*” about HIV. In his work area when someone was rumoured to be HIV positive, he wanted to see the person. The person disappeared for a long time, lost weight and felt sick and all these confirmed his fear and the rumour.

Theophillus confirmed that the person is now fine and healthy, so it was just assumptions people made based on signs and symptoms of HIV/AIDS. This suggests that another **assumption and preconception about causes of HIV infection** that people have, is that if you are “*fine and healthy*” you cannot possibly be HIV positive. The availability of antiretroviral treatment and the early stages of the HIV progression can make people to appear healthy but that does not necessarily mean they are not HIV positive. Participants did not recognize this assumption and preconception about HIV infection.

Promiscuity is another assumption/preconception made about people who are HIV positive. Carol said it is how HIV/AIDS was presented initially, as if it’s for promiscuous people. She said “*it’s like if you slept with Joseph, Harry and Dick*”. Zama shared a similar view saying a person is judged as if he or she had “*lots of partners, extramarital relationships and promiscuous*”. Chubby on the other hand reported that when you are HIV positive, you are assumed to be “*gay/lesbian*”. In the context of HIV/AIDS, it appears that being gay/lesbian is pejorative. If one suffered from any symptoms that can sometimes be HIV/AIDS related *symptoms* or illnesses, they were automatically assumed to be HIV positive, even though many of these symptoms or illnesses are not specific to HIV. Ngaka reported that if her own father saw that she has pimples or become thin, he assumes she is positive. “*Physical appearance is associated with HIV positive status and if you have TB, you are automatically positive*”, Ngaka said. Buurman supported this saying when you “lose weight”, it is assumed that you are HIV positive.

When participants were asked, “**In the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?**” the conversation also centred on weight loss. Noluvuyo reported that a staff member came to her and asked if Cindy has the ‘virus’ since she was a size 42, but lost a lot of weight and was ill for more than three months. She was stigmatised and referred to as having “*Groote Griep*” meaning “*big flu*”. Another theme that emerged was *fear*. Basily said that HIV/AIDS is a taboo subject and people are very scared to engage the subject. “*They feel intimidated as if you are probing or prying about their lives*”.

When participants were asked “**In your opinion, how effective is Parliament’s HIV/AIDS response**”. Participants felt that Parliament is not doing enough to address HIV/AIDS. Participants felt that senior Management is not visible and driving HIV/AIDS response from the top. Gail said “*no one has the support from the top*”. Similarly, Basily defined Parliament’s HIV/AIDS response as being ‘*passive*’ because leadership is not taking the frontline.

Despite some of the interventions that were done which include distribution of condoms, HIV/AIDS information dissemination, counseling support, AIDS day event, HIV Counseling and Testing, participants felt that if condoms are distributed, there must be a message with them. MK reflected that people do not get involved in the HIV programmes and associated it with ‘*stigmatisation*’. Communicating through intranet (Faranani) is not enough; they want to see more visibility especially by Peer Educators and Management. Ngaka also proposed establishment of peer Education Committee. Thantaswa suggested that a person stationed in Parliament permanently to do testing instead of the current once-off approach. The attempts done were dubbed impersonal and participants called for establishment of support groups. Gill advised that Parliament should put more emphasis on morals and values in dealing with stigma while Gail advised that Parliament should address the issue of fear. Pattle also said that Parliament should have a Wellness day every three months and organise speakers and theatre or drama. This view was supported by Carol who said Peer Educators can create music, theatre or drama. Despite policy and procedure on HIV/AIDS being in place, its implementation was reported to be ‘*non-existent*’. Chubby proposed that Parliament ‘*confronts stigma*’ and make everyone know that it is like any other illness.

Laurienzo suggested that Parliament should employ people who are HIV positive to talk to staff about HIV/AIDS. Kim and Basily at least knew that Parliament has a policy on HIV/AIDS which prevents any form of stigmatization and discrimination of people living with HIV/AIDS. Laurienzo was aware of the Counseling Service provided for staff but said it is “*ineffective and does not engage those who are HIV positive*”.

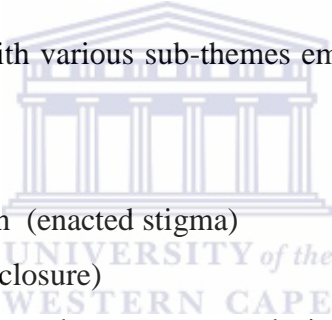
In the fourth question, participants were asked “**What do you believe should be in order to effectively address HIV/AIDS-related stigma in the workplace?**” Participants felt that ongoing *education, training and awareness* which are done in multi-lingual and vibrant manner can assist in addressing stigma in Parliament. Nicholas said Peer Educators must be trained on an accredited course. Staff to be given general training that includes *injuries on duty*. HIV/AIDS awareness movies were also suggested as a way of information dissemination. Participants also suggested “*proactive sharing of HIV/AIDS information and establishment of a helpline*”.

Chubby advised that Secretary to Parliament needs to take a stand for HIV/AIDS awareness and training of his Senior Managers. He further advised that the Senior Managers to report to Secretary to Parliament on their Divisional HIV programmes monthly. Participants felt that leadership involvement must even ensure that all managers are measured on HIV/AIDS in their performance contracts. They felt that

HIV/AIDS must be included in every meeting and Peer Educators must be actively involved and be exemplary. Similarly, Ngaka emphasized that Peer Educators need to champion HIV programmes and be the presenters. On the other hand, Pattle felt that more males must be involved in dealing with HIV/AIDS. She said *“involve more males because they think its gender based”*.

Other suggestions included promoting the counseling service on 'pop-ups' with the toll free number, encouraging everybody to own the programme, and taking away the fear from people. The Wellness Team to visit line groups and promote wellness and how to utilize the services. A dedicated HIV Unit which is separated from Human Resources was proposed. Fragmentation of programmes according to stage and development of HIV and programmes for the infected and affected was also suggested. Another suggestion was the use of HIV positive counselors. Participants also reported that the gossip in the corridors must be reduced and everybody must commit to reverse the stigma in Parliament.

In conclusion, five (5) main themes with various sub-themes emerged from the focus group discussions. These were:

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1. The actual acts of discrimination (enacted stigma)
 2. Issues related to disclosure (disclosure)
 3. Assumptions and preconceptions about causes and signs of HIV infection (Assumptions and preconceptions)
 4. Concerns about psychological impact
 5. Lack of Knowledge and Education

These main themes will be discussed in detail in the next chapter.

CHAPTER 5: RESULTS PART 2 - EMERGING THEMES: ANALYSIS AND DISCUSSION

INTRODUCTION

This chapter discusses in more detail the themes that emerged and that were mentioned in the results chapter above. These are discussed in relation to existing literature on the themes, and also in relation to the ideas originally developed in the literature review underlying this study. Quotations illustrate the themes and allow the reader to see how the responses by individual and FGD participants map against the identified themes.

ANALYSIS AND DISCUSSION OF EMERGING THEMES

According to Taylor-Powell and Renner (2003), one can have a list of present themes or you may have emergent themes which the researcher will come across as he/she works with the data. Instead of analysing this data with pre-conceived categories or (list of present themes), I first went through the data over and over again. It is only through working with the data that the sub-themes and main themes emerged. Initially I had a long list of themes that emerged from the data and through working with the data I managed to combine these and condense theme to five main themes. These were:

1. The actual acts of discrimination (enacted stigma)
2. Issues related to disclosure (disclosure)
3. Assumptions and preconceptions about causes and signs of HIV infection (Assumptions and preconceptions)
4. Concerns about psychological impact
5. Lack of knowledge and education

5.1 The actual acts of discrimination (enacted stigma)

This study began with a focus on discrimination in the context of HIV/AIDS related stigma. According to Herek and Glunt (1988:886), AIDS – related stigma is defined as the *'social psychological processes through which people are discredited when they are perceived to be infected with HIV, regardless of whether they actually are infected and of whether they manifest symptoms of AIDS or AIDS related complex'*. Stigma is a barrier in provision of HIV/AIDS prevention and care as it interferes with HIV

testing, access to care and treatment and thereby shortening the individual's life (Holzemer and Uys, 2004). When stigma is acted upon, it results in discrimination, (Van Niekerk, 2005). Dickinson, (2005:1), defined discrimination as "*when we treat people differently*".

In this study, Parliamentary employees were asked open ended questions to explore their understandings and experiences of stigma. The respondents' replies were congruent with the major themes identified in the literature. They defined HIV/AIDS related stigma as the negative attitude that is given to people with HIV to the extent of *passing judgement* to them. This definition suggests that negative attitudes per se do not necessarily constitute "*stigma*", but rather negative attitudes that include a moral judgement. This appears to be different from negative attitudes towards other people's political views or taste in music. People with positive HIV status are judged as being "*promiscuous or gay/lesbian*". Participants reported that behaviours associated with this general definition of HIV/AIDS related stigma were; being treated differently, isolated, and not accepted by family, friends, peers and community at large. They perceived stigma generally with being *treated differently*. One employee mentioned that "*people look at you differently, its like a shock especially to the Islam community which is associated with cleanliness*". The cultural aspect of discrimination was mentioned in both the individual and focus group discussions. One respondent said that in the Muslim community, the community can just "*block you off*" and this result in people being scared of opening up. One peer educator was chairing a peer educator meeting when one employee said she has never seen an HIV positive person since does not happen in her "*culture*".

In the workplace one employee mentioned that you get looked down upon by staff, the hugging stops, avoidance of the person and not wanting to be associated with him/her. Participants reported that people distance themselves from a person who is HIV positive. Some of the behaviours associated with this exclusion include isolation where physical contact stops. According to Leila, such social exclusion results in "*community blocking you off*" (sic). Leila said HIV/AIDS is still a shock in the community especially the Moslem community. Respondents were describing how people react to HIV in general, while there does not seem to be a serious problem of stigma/discrimination specific to Parliament, the respondents report and describe pervasive stigma and discrimination that seems to describe the atmosphere within Parliament. This is an atmosphere that is not conducive for people with HIV to open up or disclose. Dickinson (2005) reported that discrimination can come from fellow employees, managers and supervisors where employees might even refuse to work with a PLWHA. In contrast, in Parliament, Naledi had a different and positive experience when she disclosed to her peers and manager. She said both peers and manager supported her very well. According to Dickinson, (2005), discrimination in the

workplace can result in a PLWHA being unfairly dismissed or not being considered for training and promotion opportunities. In this study there were no cases reported where employees were denied opportunities for growth and development on the basis of their HIV status. Other expressions that were used to treat people differently were “shunning” and “avoidance”. During the focus group discussions, it came out that you do not just shun the person but you also blame them for being HIV positive. In a study conducted in India in a Hospital setting by Mahendra, Gilborn, Bharat, Mudoji, Gupta, George, Samson, Daly and Pulerwitz (2004), almost 40% of the respondents indicated that men with HIV deserve to be infected and ill. Avoiding going near the HIV infected patient, disclosing the patient’s HIV status to non-treating staff who have nothing to do with the patient and informing the relatives about the patient’s HIV status are some of the discriminatory practices that were discovered by Mahendra et al. (2007). Despite the fact that Parliament is not a Hospital setting, the discriminatory practices of being treated differently were found to be similar.

The second aspect of discrimination a more general manner was the *prejudice and negative attitude* to a person with HIV/AIDS. In individual interviews it was reported that people have prejudice to those whose HIV status is positive. The HIV-positive person is judged as if he/she has no good moral judgement. Similarly, in a study conducted by Masindi (2007:7), this form of form of discrimination is called “*enacted stigma and it originates from people’s fear and perceptions that people living with HIV and Aids are immoral and dirty*”. According to Mahendra et al. (2007), the majority of health workers (68%), indicated that HIV is spread by immoral behaviours. In Parliament, a respondent in the focus group interviews reported that after her family realized that her brother was HIV positive, they refused to eat the food he cooked because of his status. Another respondent shared that people still pull away from those who are positive, they are prejudged and assumptions made.

On further probing, respondents’ comments appeared to coalesce around two more specific sub-themes, negative labeling and ostracize/ostracism. The first one is *negative labeling*, calling of names to those who are positive. In the individual interviews, it was reported HIV positive people were referred to as gay or lesbian. In focus group discussions they were even referred to as strippers, prostitutes, players and people who got what they deserve. One respondent claimed that “*It’s like a bad tag attached to you, it affects you in a bad way, and you will never be the same again*”. One respondent added that a person with HIV is negatively labeled as if it is their own doing. People associate the HIV status with as if it is the way they lived their lives, that is irresponsibly, a respondent noted in one of the focus groups.

The second sub-theme is *ostracize* which is the active cutting of social ties. In individual interviews, one respondent mentioned that the “*Community can isolate you, no visitors, no eating with you, not even allowed to talk to their kids, you’re just a curse*”. Another respondent reflected that you lose friends and people distance themselves from you. You get isolated wherever you go. Similarly, respondents in focus group discussions reflected that “*you get isolated by friends, family, peers and community where people treat you like an “alien” and do not want to be associated with you*”. The family does not even want your food and they blame you for making them a “curse family”, one responded in a focus group discussion claimed. The family does not accept you nor support you, when you have HIV. It also came out that some families hide the person in the backroom or backyard. In Parliament, an employee who disclosed was isolated by the very person he/she disclosed to.

These responses echo several studies described in chapter 2. Brown et al. (2010) reported that family relations do not always embody the type of emotional support and physical care that PLWHA require. Seale (2004:1) reported that “*people with HIV/AIDS have been disowned by their families and friends, fired from their jobs and asked to leave their schools and homes. They have faced discrimination in health care settings and in extreme cases, they have even been physically attacked or murdered in their communities*”. Similarly HIV-positive people in India often face discrimination at their workplaces, have been rejected and abused by families, spouses and communities and in many cases are refused medical treatment at hospitals and clinics (Sreeraman, 2008).

In South Africa, Gugu Dlamini was killed by her KwaZulu Natal community because of disclosing her status, (Van Niekerk, 2005). Studies have also shown that the fear of experiencing violence, ostracism, and discrimination inhibits disclosure of HIV-positive status (Sambisa et al., 2010).

5.2 Issues related to disclosure (Disclosure)

When the environment within which employees that are HIV positive is not seen to be supportive or is perceived to be intolerant, employees might be hesitant to disclose their HIV status. *Issues related to disclosure* were identified to be the second main theme during this research. I explored whether there were any barriers to testing and disclosure. It also appears that this HIV stigma and its impact in general is gendered. MK added that women disclose far easier than men. *Secrecy* has been identified as one of the barriers to testing and disclosure. During individual interviews Carol reported that there was silence about HIV, nobody talks about it and she has never heard of anyone with HIV. MK from the focus group

discussion supported this view, *"It is still a state secret in Parliament"*. MK knows two women who are HIV positive, but the whole thing is kept so secretive that he referred to it as a *"state secret"*. In contrast, Buurman shared a different experience where even if one is going for a test, it makes him or her a suspect of the *"big flu/ groote griep"* as HIV is referred to in Parliament. Buurman shared that in Parliament if you reveal your status it becomes an open secret, everyone will know. Sambisa et al. (2010) found that the most common form of AIDS stigma was based upon the dimension of disclosure concerns where a high proportion of women and men reported that they would not want others to know that their family member had HIV or TB. "Secrets" thus link to "open secrets" and concerns about confidentiality and gossip.

The second barrier was *concerns around confidentiality*. Participants felt that there were low levels of confidentiality in Parliament as far as HIV is concerned. Participants in the individual interviews reported that when Wellness Unit conducts HIV testing done onsite, people look at others after the test to see how they react. Participants from the focus group discussions reported that during the Men's Health in March 2011 when HIV Testing was conducted, people who tested first waited for those who went for the test later to check how long they took and how they looked in their faces. Similarly, in a study conducted by Jürgensen et al, (2012:8), *"informants were worried about being seen at or leaving the voluntary counselling and testing (VCT) centre after testing and about how they would manage to keep a straight face in front of all the people at the clinic"*. This requires a different way of managing the testing process.

In Parliament, managers were also implicated in not keeping confidentiality whereas some senior managers have managed to keep confidentiality when staff members disclosed. For example, Zoleka (Senior Manager) referred the staff member to the Wellness Office. Majority of people in the individual interviews reported that the only way you will know if someone is positive is when the person discloses or through gossiping and assumptions not necessarily leakage of information. Confidentiality gets broken by those whom the staff member disclosed to, be it managers or other employees (peers). Some respondents recommended that a permanent counselor be employed onsite to do HIV testing continuously and not wait for the mass campaigns. Others called for a fully fledged Occupational Health Clinic that will manage HIV as part of its programmes on continuous basis. In both Individual interviews and focus group discussions, respondents want Parliament to treat all information on the person's status confidential. To deal with Gossipers respondents wanted Management to deal with them harshly as stipulated in Policy on HIV/AIDS.

The third barrier to testing and disclosure was *gossip/grapevine/corridor talk*. One respondent in the focus group discussion reflected that “*it is the things we do and the things we say*” that discourages people to come out for example "Amagama amathathu" the three letter word. The casual conversations may lead to people not being able to come out. Gossiping and corridor talk will continue to discourage people in openly disclosing their status in Parliament. Ngaka referred to the staff as running a story like "journalists" and they use real names. Casual talking by senior people (Managers) in corridors also prevented people to openly disclose their status. Similarly, in a study conducted by Fesko (2001), respondents felt that the working environment was not yet conducive for them to share their status because it was an environment where people tended to ‘*gossip*’ (Fesko, 2001: 240). In this study, one respondent suggested that professionalism and ethical behaviour should be exercised by managers. Some senior people also referred people to local peer educator. Unfortunately the very same senior person is dubbed to be the gossipier himself.

A stark contrast was reflected by Wendy in the individual interviews, where a staff member was supported by colleagues, they were sympathetic and treated him/her with respect and gave her/him the confidentiality necessary. Naledi also reflected the support she got from peers instead of gossiping about her status they supported her. Even her line managers supported her instead of gossiping about her as reported by other respondents. One can argue therefore that disclosing at work is not necessarily wrong and will not provoke a negative reaction. For example in the study conducted by Fesko (2001), where she interviewed eighteen (18) respondents on disclosing HIV status in the workplace, six (6) of them disclosed their status fully to everyone in the workplace while seven (7) of them disclosed it to selected people in the workplace and requested them to keep it confidential while the other five (5) did not disclose at all. Women were less likely than men to disclose their status at work (Fesko, 2001).

The last barrier was *concern about family, friends and peers*. This barrier was mainly discussed in focus group discussions. This theme revolves around what the family/friends and peers will do, how they will react, and how will they treat you as an HIV positive person. One respondent reflected that you cannot really predict how people will react once they found out that you are HIV positive. The fear of discrimination creates problems for disclosure. According to Skinner and Mfecane (2004), disclosure evokes a common reaction of rejection, leaving people with HIV alone. Similarly, according to Seale (2004) PLWHA have been rejected by their families and friends and some have been fired from their jobs.

5.3 Assumptions and preconceptions about causes and signs of HIV infection

The third main theme that emerged was *assumption and preconceptions*. In Parliament, certain *signs and symptoms* made people to assume that the person is HIV positive. These include loss of weight, lumps behind ears, skin getting darker. Various names are given to the type of illness (HIV positive) that a person is assumed to have. Masindi, (2004) reported that symptoms like persistent cough or weight loss is often associated with AIDS. In Parliament, words like ‘*grootte griep*’, the ‘*big C*’, the ‘*other cancer*’, were used to describe people assumed to be HIV positive based on signs and symptoms.

After people rumoured that someone was positive, even said if you check the person behind the ear, you will see lumps. Similarly, Dickinson (2005) reported that in the workplace people look for signs of HIV/AIDS such as weight loss or skin rashes and make assumption that the person is HIV positive. This result in people even becoming fearful of falling ill, (Dickinson, 2005). In Parliament, one participant even went on to check the person out due to curiosity. His suspicion was confirmed when the individual was away for a long period on sick leave. In the focus group discussion Cebo shared that when a person is thin, she/he gets judged, "*awukwazi noxoxa nomuntu*" meaning “*you cannot even have a conversation with a person*”, and otherwise they gossip about it. When Ngaka's father saw her with a pimple, he refused her to cook.

Long term sick leave (sick leave of more than three days) was the second *assumption and preconception* where the participants reflected that when a staff member is away for a long period it must be HIV. In one focus discussion a participant reported that "*a colleague was away for extended period (sick leave), when the person was back, there were stories doing rounds, quiet a senior person*". The group felt that this quote just illustrated the culture in Parliament where there is no sensitivity and respect to fellow colleagues. When a respondent was asked in what extent have the stigma examples or definition been happening in Parliament in the past 12 months, she responded that it is based on assumption; people base their assumptions on staff who lose weight and take long leave.

The third *assumption and preconception* that was revealed during both individual interviews and focus group discussions is *promiscuity*. Respondents shared that once a person is HIV positive she/he is assumed to have slept around with lots of partners or practiced promiscuity. The fourth assumption and preconception that was revealed during these sessions was “*gay/lesbian*”. At times HIV positive people

were referred to as either lesbian or gay, as though these terms were interchangeable.

5.4. Concerns about psychological impact

Concerns about psychological impact were the fourth main theme that emerged from this study. *Fear* emerged as the most dominant *concern about psychological impact*. In Parliament, *fear* manifested itself in various forms. The first form of fear was *fear by the infected person*. One respondent said that its fear of how the family or people will react, fear of not fulfilling ones dream, rejection, and fear that you may not get support and there is fear that is just there. The fear of rejection is not unfounded. In South Africa, Skinner and Mfecane (2004), reported cases of exclusion or attempted exclusion from the workplace within the military service, exclusion from home communities and rejection by family members. According to Masindi (2004: 1), “*the fear of HIV/AIDS has created a culture of suspicion, as a result even employees working with HIV/AIDS programmes and those passionate about the subject are considered to be HIV positive*”. In this study, one respondent knows of a person who is HIV positive, leads a normal life but fears being accepted because HIV is a dreaded disease. Another respondent knows a person who fears to be rejected by family. The person infected was also reported to fear isolation and treated differently by the society. It is in focus group discussions that the issue of fear by the person was raised most prominently compared to individual interviews. Fear that grows within a person who is about to test. This deters people from testing because people talk about other’s HIV status in Parliament and not discretely so. Some people are fearful to die because when it was introduced; people were told they have five years to live. “*You get scared to test because it is like a death sentence*”, one respondent reflected.

Fear of being judged as immoral was a particular form of fear by the infected individual. This featured in the focus group discussion while there was no mention of it in individual interviews. In focus group discussion, one respondent reflected that since the disease is sexually transmitted, people think you are morally compromised. They become scared of you, gossip about you and pass judgement because of your status. Rorisang reflected that denial comes because HIV/AIDS is about being “*loose*” in your life, sleeping around with lots of people.

The second form of fear that was perceived to contribute to *the concerns about psychological impact* of HIV/AIDS related stigma was *fear by the family of the person with HIV/AIDS*. Fear and judgement of the person with HIV/AIDS was noted during individual interviews. In focus group discussion, one respondent reported that she disclosed the cause of death in her brother's funeral, (HIV); the family members thought

they were a "cursed family". It was very clear that some families are ashamed of having someone with HIV.

The last form of fear that was reported was *fear by the respondents themselves/society in general*. One respondent reflected that *"You get scared because it's real"*. Fear and disrespect of the person alleged to be HIV positive was reported in the individual interviews. Some people also feared being infected by the person with HIV. When respondents were asked how people react after hearing someone is positive, they worry for the person not to live long. Some become scared even to confront the person due to anticipated aggression. Respondents advised the researcher to address the issue of fear and encourage openness and more talks around HIV in order to eradicate stigma. Julia lives with the people who are HIV positive, and despite the fact that she has never seen people who are that healthy, she still *"attaches"* fear to them because of their status. Some people even fear to engage with the subject of HIV and AIDS. It came out that some focus group discussion members were fearful of the person with HIV, especially full blown AIDS. Theophilus had severe fear of getting HIV from someone that he called himself *"paranoid"* of even breathing the same air with people who are positive. He had fear and sense of disgust that a person could be positive.

The *concerns about psychological impact* of HIV/AIDS related stigma also manifest through *anger and vengefulness*. In this study, anger and reventfulness emerged from few interviews and one focus group discussion. One respondent wanted to kill the whole family of her boyfriend since they knew that her partner was positive, while the other respondent expressed feelings of anger to people who are vengeful after contracting HIV. She emotionally shared that *"people who have HIV must stop sleeping around and give it to other people because they do not want to die alone"*. This appeared to be a criminal act where a person wanted to harm others. One respondent felt angry because HIV affects more women than men. Besides the feelings of anger, she reacted the same way she did to the previous two people who disclosed to her, she cried and felt sorry for them. Some respondents expressed feelings of sadness instead of anger when confronted by someone who is positive. Some felt that it was terrible to hear the news.

I was moved by one of the focus groups and interestingly that it was not the peer educators, who may have already had an opportunity to admit to and process their own negative perceptions. Participants from this particular focus group did not point to others stigmatizing, but rather reflected on how they stigmatized. That level of honesty and feeling safe to be able to share this in a group discussion touched me personally.

It was in this focus group discussion that the last aspect of psychological impact emerged. This is a *sense of dismay* that a person can be HIV positive. In this focus group discussion, respondents responded with *dismay* and at times with *disgust* to the person who is positive. Baxter strongly felt a sense of dismay that a person can contract HIV. He felt that he will definitely be different to that person, so the whole issue of stigmatisation does not leave him 'neutral'. He reported that he feels better at work than at home where he would be too close to the person. The characteristic of this focus group was that they reflected on how they stigmatised more than how people stigmatise. It is also in this focus group discussion that Theophillus Duiker said he felt *disgusted* to someone who is HIV positive while Julia attached fear to the person who is HIV positive. In contrast, during the individual interviews, one respondent shared that when people hear that someone is HIV positive, they respond with "*dismay*", but when she hears that someone is positive, she responds by wanting to support the person emotionally and professionally without passing judgement. This was a common feature in individual interviews where people reflected that they will respond positively to the news of someone being positive.

5.5 Lack of knowledge and education

The fifth and last main theme that emerged from this study was *lack of knowledge and education*. This simply means that stigma exists because people are not well informed about HIV and AIDS. This manifests itself through *perceived ignorance* towards people living with HIV. One respondent explained that "*negative perception that we give to the society who has this disease to the extent that we pass judgement to the person*". One respondent said he was very blind and ignorant about the disease till the day of the focus group discussion. So even the very interview at least allowed employees to share and express their honest opinions on the illness. When respondents were asked **“What do you believe should be in order to effectively address HIV/AIDS-related stigma in the workplace?”** they advised that inviting people with HIV who have disclosed their status would help deal with the stigma in the workplace. A top down approach was proposed where Secretary to Parliament takes a stand on HIV awareness and training for senior Managers. In both the individual interviews and focus group discussions, there was a call to have managers trained on HIV and AIDS.

Lack of knowledge about internal programme also emerged during this study. Respondents did not really know how the existing wellness programmes meet the needs of the people living with HIV and AIDS. There is a belief that people who are HIV positive cannot live a normal life at workplace and at home. This shows some areas of improvement in communication and marketing of the current health and

wellness programmes. Another sub-theme that emerged was *lack of information*. In individual interviews, it was reported that information sharing on how the disease is contracted and existing precautionary measures ensures that employees working in Parliament will not be occupationally exposed to the HIV. Respondents also felt that proper education and ongoing awareness coupled with regular testing is necessary to minimise occupational exposure. When the question was asked “*what else could be done to make it easier to test and deal with HIV*”; respondents felt that training of staff, more information and education is important to combat stigma and self stigma. Even though some respondents agreed that there is communication, information sharing and awareness and in the focus group discussion, others felt that there is not enough time to attend wellness programmes due to work demands. The group felt that the *labeling* was due to lack of information. It also proposed that more education (multilingual) must be implemented. Also more awareness instead of once off events is needed. It was also proposed that the STP needs to take a stand for HIV awareness training for his senior managers. Respondents proposed that general training for staff and accredited training for peer educators must be implemented. In contrast, some felt that there is lots of information on Faranani but people do not read it. One respondent reflected that “*people are uninformed, insensitive, ignorant and unprofessional*”.

Another sub-theme that emerged was *persistent misperception*. The way the community treats people with HIV/AIDS, for example if you lose weight you have HIV. Respondent felt that this misperception is also perpetuated by media. The perception about people who live with the disease shows how uninformed people are about the disease. There was an expressed misperception that if you went for an HIV test and stay longer, it automatically mean you are positive, while if you went for few minutes, you were clean. Despite the fact that one is conscientised and familiar with the HIV/AIDS programme, Baxter felt that living with a positive person will still create a profound feeling towards the positive person whereas at work it will be less due to the fact that there is no close contact.

Denial was the last manifestation of lack of knowledge and education that emerged during the interviews and focus group discussions. A respondent in the group said that while chairing a Peer Educators meeting a person said she has never seen someone with HIV in her culture because it does not happen in her culture.

CHAPTER 6: REFLECTIONS, LIMITATIONS AND CREDIBILITY OF THE STUDY

INTRODUCTION

In this chapter I reflected on my personal experience of conducting this study. I also discussed the credibility and trustworthiness of the study, study limitations and ethical considerations.

6.1 REFLEXIVITY

I approached the study with some worries of whether people will participate or not. This was due to the sensitivity HIV and AIDS holds. Indeed some participants did not want to avail themselves. At least three of them did not want to participate while others were just not available at the time. They were not comfortable to be part of the study as they did not see any value from it. These employees were long – service employees of more than fifteen years of service. I really enjoyed the engagement and discussion about HIV/AIDS related stigma with those who participated. The participants shared more than what was expected in answering the structured interview questions. At times they related their own personal stories. I thought participants will know the existence of the HIV policy but not necessary the contents of it. Unfortunately most participants did not know nor read the policy. I also thought people will find it difficult to define the HIV/AIDS stigma. In contrast they were spontaneous and spoke about it in a lot of detail with ease. There was one or two who had difficulty expressing themselves but even there they eventually spoke in similar terms to others. I further expected that participants will report that senior management does not do enough to address the impact of HIV/AIDS. Again most participants confirmed that Senior Management is not really involved in HIV/AIDS programme. More encouraging was the fact that participants gave input into solutions to the problem.

As far as the wellness programmes on offer are concerned, I thought participants would only want to tell me what I want to hear as just good things or have difficulty in openly criticizing them, since I am the Wellness Manager. Surprisingly, participants actually criticized the wellness approach and programmes as falling short in addressing the needs of people living with HIV/AIDS.

Conducting this research made me feel closer to the participant's needs and confirmed that some of my own views about what needs to happen were in line with their needs. The overall intent of this study is to inform the HIV/AIDS anti-stigma strategy. I found participants giving me valuable information on how to

address stigma at work. These suggestions came throughout the interviews and not only in the questions designed to address the issue. Deeper and more varied responses were reported from the focus group discussions, which appear to have succeeded in their intent of stimulating deeper reflection through discussion and debate compared to a “*first reaction*” tendency in individual interviews. Even though I had an interview guide with some structured questions, participants discussed the real issues and their real time experiences of the stigma on the ground, among themselves and not in relation to me as the facilitator. They are faced with this in their day to day work. I have learned the terms used to categorize people perceived to have HIV/AIDS. They include “*The other C, the other cancer, big flu, Grootte griep etc*”. In the individual interviews, I reported that HIV positive people were referred to as *gay or lesbian*, other than these two words, no other harsh/pejorative language was used. I felt uncomfortable reporting the actual names used by the focus groups. In focus group discussions, HIV positive people were even referred to as *strippers, prostitutes, players and people who got what they deserve*.

The highlight of this study for me was when one focus group went far beyond superficial and socially desirable self-representations. The participants in that focus group revealed how they themselves stigmatize PLWHA, referring to their own behaviours and emotions. I found the level of this honesty humbling and overwhelming indeed. But this is how relaxed they were and willing to just share among themselves how they experience HIV/AIDS stigma. An interesting observation was that, anger and revengefulness was only reported in individual interviews. This suggests that some issues, like anger and wanting revenge, appear to be “*safe*” to mention in individual interviews but not in focus group discussions while in other ways the support of the group appeared to “allow” people to admit to reactions that did not appear to be as socially acceptable to express one on one – and again that was only in one group. I think this does show how important it is to create safe spaces to share taboo reactions and “*get over them*”, as opposed to rallying around a moralistic or vengeful flag. It also shows how close to the surface some of these “*taboo*” feelings and reactions are, and that at least some people are ready and willing to deal with them. Personally, I know people and family members who have hidden their HIV status until death. What is still a mystery is why people never disclosed nor asked for help. Some of them committed suicide. It is only through this study that I have found some answers. Even then I can only assume but never be sure that these were the real reasons why the people hide their HIV status till death. Masculinity plays a huge role in concealing one’s feelings and pain. For example, as an African man myself, I do not cry easily, I endure the pain in silence. So when designing these anti-stigma programmes I will have to include practical means of getting men to “speak out” and express their feelings.

6.2 CREDIBILITY AND TRUSTWORTHINESS

Rigour seeks to ensure the soundness of the research in four different dimensions: ‘credibility, transferability, dependability and conformability’ (Gifford, undated: 552). Key ways of increasing rigour in qualitative research are to utilize methods of triangulation which is the practice of using multiple ways to investigating a problem (Gifford, undated). There are four kinds of triangulation (*data source triangulation, methods triangulation, researcher triangulation and theory triangulation*) (Gifford, undated: 553). In this study, data source and methods triangulation has been used by the researcher. Rigour in sampling was ensured through the following criterion when recruiting for this study: respondents are from different age-groups, race, gender, educational level and occupational category (salary level) and marital status. The above is not for representivity but for diversity in views.

Rigour in data collection was ensured by using qualified employees to assist the researcher with collection of data. Interviewers were trained. They have been chosen because of their good listening skills and academic background. In their training they have done research and they are also familiar with Parliamentary context. The researcher and the five assistants rehearsed the interview schedule and questions before going to the field, in order to minimise errors and for consistency. A pilot study was conducted by the researcher to ensure validity and amend questions if necessary. All focus group interviews were done by the researcher to maintain consistency.

In order to ensure rigour *in data analysis*, I dated the data as I worked on it on that day. I kept all versions so that I can go back and check if all issues are captured. All the focus groups were taped so I went back to listen to the tapes when I was not clear of what participants were saying. I also declared the limitations of the study. For example exclusion of the Members of Parliament is a limitation since they play the important role in the very existence of the Parliament. Assumptions were declared, for example the researcher assumes that there might errors in some of the data leading to it being not used. The researcher did not speculate and did not use his views and beliefs to skew the findings of this study but rather recommends further research where necessary.

6.3 LIMITATIONS

The key limitation of this study is that it is a small study and it is based on a small slice of people’s experience and lives. For example, the differences between the focus groups might reflect real differences

in perspectives, or it just might be the direction that a particular conversation took. The combination of the purposeful sampling and convenience sampling of the focus group discussions was also a limitation in this study. The last two focus groups were from the hiking club which might have a particular ‘culture’ even though they are from the various areas of the Institution. The focus groups selected in this study, first aiders, peer educators and hikers, are used to working as a team and have a focus beyond their individual jobs which keeps them more engaged, compared to other parliamentary employees who do not participate in any activity. Conducting individual interviews on the HIV and AIDS topic while I also oversee the function as part of my role as the Wellness Manager could have resulted to a potential bias and participants withholding valuable information.

6.4 ETHICAL CONSIDERATIONS

The results of this study will benefit Parliament in many ways. The behaviours, attitudes and feelings of staff towards people living with HIV/AIDS was explored and thus giving an opportunity for Parliament to devise anti-stigma strategies and interventions. All participants signed a consent form and participation was voluntary, with confidentiality highly maintained. No one knew which two people were selected for interview from each occupational band. There were no disclosures requested. During the focus group discussions, the questions were not oriented to personal disclosures and the focus group was told this as well. A pseudonym was used for every participant in both the individual interviews and the focus group discussions.

The Parliamentary Wellbeing Programme is generally accepted by employees and it has great credibility in terms of protection of confidentiality. The individual that was distressed during the interview was referred to the Internal Wellness Practitioner or ICAS, the external wellness support service provider. The toll free number was given to the participant. All employees were aware of the external service provider and they are utilizing the service very well.

I sought and received written informed consent from all participants, I have discussed and the focus group participants agreed to maintain the confidentiality of the discussion. The ethical clearance was obtained from the UWC Senate Research Committee and permission for the study was obtained from the Secretary to Parliament.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

7.1 CONCLUSION

This study has achieved its aim and objectives in that Parliamentary employees have shared their understanding of HIV/AIDS related stigma and cited some examples of how the behaviours associated with stigmatisation and discrimination are experienced in the community and to Parliament. They have defined HIV/AIDS related stigma as “*the negative attitude that is given to people with HIV to the extent of passing judgement*”. At a general level, the behaviours reported to be associated with this definition of stigma were that a person who is HIV positive would be *treated differently, isolated, and not accepted by family, friends, peers and community at large*, and more specifically, HIV/AIDS related stigma was associated with *negative labeling, ostracizing and prejudice*. This definition is congruent with Link and Phelan’s (2001), definition which defines stigma as the co-occurrence of its components which are “labeling, stereotyping, separation, status loss and discrimination”.

As I was further exploring their perceptions of stigma in the Parliamentary Service, employees shared that the actual acts of discrimination; lack of knowledge and education; concerns related to disclosure, assumptions and preconceptions about the HIV infection; and concerns about psychological impact were key in eliminating HIV/AIDS related stigma in Parliament and in community at large.

The literature reviewed in this paper was also very useful as it has highlighted the spheres in which HIV/AIDS related stigma occurs. These include the individual, environmental and structural levels. What was more encouraging was that employees in Parliament did not only state the problems but proposed actions to be taken to rid Parliament of this HIV/AIDS related stigma. Their proposals were in line with those proposed by (WHO, 2011; UNAIDS, 2010; ILO, 2001; and SANAC, 2011). These include but not limited to: leadership involvement; training and awareness; gender and targeted programmes. This paper has managed to reveal some of the behaviours in Parliament which can prevent PLWHA in accessing the much needed care and support that is available to them at no cost. In this study fear emerged as the most dominant concern about the psychological impact while gossip and concerns about confidentiality were the main barriers for testing and disclosure. Similarly, in Fesko (2001) employees felt uncomfortable to disclose their status in an environment where ‘gossip’ thrives. Various studies (Sambisa, et al (2010); Flowers et al. (2003); Jürgensen et al (2012), identified fear as one of the main barriers in knowing ones status to such an extent that the burden of knowing outweighed the benefits of prevention and treatment.

In line with the literature reviewed, in this study employees felt that families were not as supportive environments as one would assume. In fact some respondents feared the family's reaction and social rejection in general. It also emerged that women are more likely to disclose than men and bear the brunt of enacted stigma while men suffer from internal stigma.

What I think is going on Parliament is that people are ready to engage on issues of HIV AIDS in the workplace. They know what needs to be done. The awareness campaigns and HCT campaigns could be improved to address their concerns. This was helpful as I often wondered why the uptake was low and picking up too slowly. Confidentiality was the main issue. Services provided by the Counseling Services provider are well known and participants are using them. The lower echelons tended to be closer to real issues around stigma than senior employees. People are ready to engage, but they need a forum and someone to "break the silence" created and maintained by the stigma that is still so strongly associated with HIV.

An important finding of this study is that employees do not seal off their private and community lives from their workplace concerns. This specific study focused on how the Wellness Programme and Parliament might address HIV-related stigma in the workplace, but workplaces are part of the wider community. Parliament in particular has a responsibility to contribute to the transformation of South Africa. The ways it deals with employee concerns and experience can also affect the surrounding communities and society at large.

7.2 RECOMMENDATIONS

- a. Further research would be needed to explore the findings more deeply and see how representative they are of staff and also of actual experience in the community, and to explore what senior and top management feel, what Parliamentarians feel, and any areas where there might be conflicting or divergent experience/views which would need to be taken into account in policy and programming
- b. There are some policy implications right away and while some can likely be implemented immediately, others would need further discussion and validation through consultative workshops or whatever happens in Parliament and elsewhere. For example, communicating Parliament's Policy on HIV and AIDS to all employees, creating a blog where employees can share ideas and express their feelings using pseudonyms as well, inclusion of HIV and AIDS in the various meetings in parliament as a standing item on the agenda, encouraging parliamentary employees to do community outreach

through the Peer Education programme. These are the short term policy implications that can be implemented immediately. Conducting a knowledge, attitude, behaviour and perceptions survey can be a medium term issue due to supply chain processes to be followed. Mainstreaming HIV and AIDS in all our programmes in Parliament will be a long term policy matter due to the various stakeholders involved.

- c. The various practical suggestions made by study participants and reported in this thesis, including training and testing processes, will be implemented to the extent that they are within the mandate of the Wellness Programme and will be incorporated to the drafting of the anti-stigma strategy for Parliament. The anti-stigma strategy will be built within the overall HIV/AIDS, STI and TB Strategy for Parliament. A separating cost centre for funding the HIV/AIDS, STI and TB Strategy will be created. The Wellness Team will ensure that senior leadership in Parliament is involved in implementing all HIV/AIDS initiatives.
- d. The revised HIV strategy for Parliament must include targeted programmes and address gender, family and societal aspects, in line with Parliament's key role in influencing social norms and the wider community.



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**APPENDIX 1: INDIVIDUAL INTERVIEW SCHEDULE: MANAGING THE HIV AND AIDS –
RELATED STIGMA IN THE PARLIAMENT OF THE REPUBLIC OF SOUTH
AFRICA**

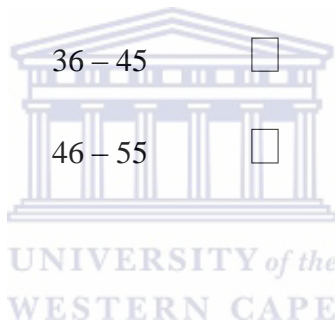
1. DEMOGRAPHIC PROFILE (MARK WITH X IN APPROPRIATE BOX)

1.1 GENDER

Male Female

1.2 AGE GROUP

18 - 25 36 – 45
26 – 35 46 – 55
56 – 65



1.2 MARITAL STATUS

SINGLE MARRIED

DIVORCED WIDOWED

OTHER (SPECIFY) _____

1.3 RACE

BLACK WHITE

INDIAN COLOURED

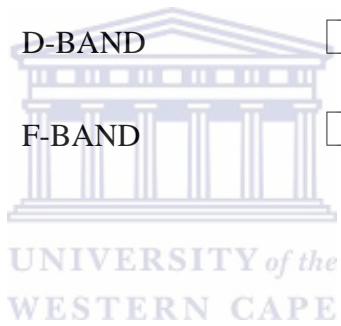
OTHER (SPECIFY) _____

1.4 EDUCATIONAL BACKGROUND

- NO FORMAL EDUCATION BELOW MATRIC
- GRADE 1 – GRADE 11 MATRIC
- POST GRADUATE DIPLOMA/DEGREE
- DIPLOMA/DEGREE
- OTHER (SPECIFY)

1.5 OCCUPATIONAL CATEGORY

- A-BAND B-BAND
- C-BAND D-BAND
- E-BAND F-BAND

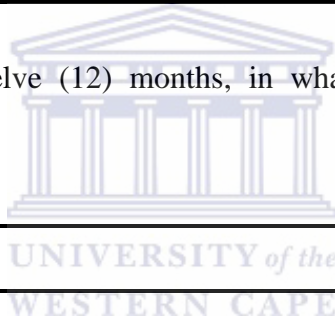


2. KNOWLEDGE OF HIV AND AIDS RELATED STIGMA

a) Please tell me what the term “HIV/AIDS stigma” means to you? (probe for examples)

b) How is it relevant in Parliamentary Service?

c) In your opinion, in the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?



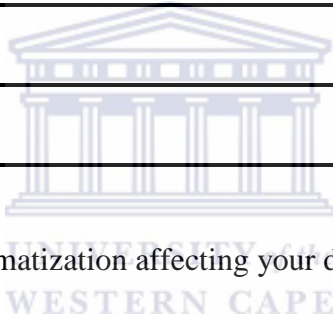
3. ASSESSMENT OF EMPLOYEES PERCEPTIONS TOWARDS PEOPLE LIVING WITH HIV AND AIDS.

a. When someone becomes aware of a person diagnosed or living with HIV, what is the general response to the news? *Probe feelings, attitudes and behaviours.*

b. When you become aware of a person diagnosed or living with HIV, what is your response to the news? *Probe feelings, attitudes and behaviours.*

4. BARRIERS TO TESTING AND DISCLOSURE

a) If you were going to be tested in the future for some reason, how concerned would you be that you might be treated differently or stigmatized if your test result were to come out positive for the AIDS virus?



b) How is the thought of possible stigmatization affecting your decision to get tested for HIV?

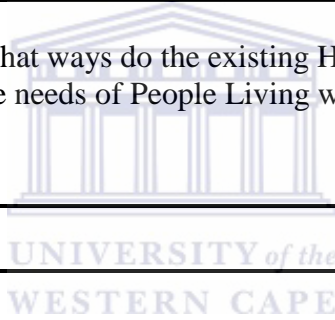
c) In Parliament, what is the primary way employees know if someone has HIV?

5. To determine whether Parliament’s HIV/AIDS response strategy is effective

a) Do you know about Parliament’s Policy on HIV and AIDS?

b) How do you think this policy addresses the issue of stigmatization?

c) In your opinion, how well and in what ways do the existing Health and Wellness Programmes in Parliament meet the needs of People Living with HIV and AIDS?



d) What else might help to make it easier to discuss, get tested for, and deal with HIV and AIDS in this workplace?

e) How does Parliament Service ensure that you are not occupationally exposed to HIV/AIDS while you are at work?

f) In your opinion, how is the Senior Management's leadership in managing HIV/AIDS in Parliament?

g) Do you have anything else you would like to add?



Thank you very much your participation and cooperation

APPENDIX 2: FOCUS GROUP DISCUSSION GUIDE

1. In your understanding, what does the term “HIV/AIDS stigma” means to you? (probe for examples)

2. In the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?

3. In your opinion, how effective is Parliament’s HIV/AIDS response. (Give examples): Probe the policy matters on stigma and discrimination, prevention of occupational exposure, wellness programme, leadership etc.



4. What do you believe should be in order to effectively address HIV/AIDS-related stigma in the workplace?

Thank you very much your participation and cooperation

APPENDIX 3



PARLIAMENT
OF THE REPUBLIC OF SOUTH AFRICA

HUMAN RESOURCES
PO Box 15 Cape Town 8000 Republic of South Africa
Tel: 27 (21) 403 2911
www.parliament.gov.za

ATTENDANCE REGISTER FOR THE TRAINING SESSION FOR THE HIV/AIDS STUDY IN PARLIAMENT

SESSION 1				
SURNAME	NAME	POSITION	SIGNATURE	DATE
Bashe	Buyile Simon	MPH Student (Trainer)		2011-06-27
Cookson	Igshaan	Assistant Interviewer		2011-06-27
Zisile	Sambona	Assistant Interviewer		2011-06-27
Jacobs-Andipatin	Sandra	Assistant Interviewer		2011-06-27
SESSION 2				
Gie	Ralda	Assistant Interviewer		27/06/2011
Mncwabe	Moses	Assistant Interviewer		04/07/11
TABATA	Mpumelelo	"		2011-06-29

UNIVERSITY of the
WESTERN CAPE

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APPENDIX 4 a: INFORMED CONSENT- INDIVIDUAL INTERVIEW

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

Date: _____

Interviewer: Buyile Simon Bashe

UWC Student no: 2836651

Tel: +27 21 403 8044 **Fax:** +27 21 403 3333

E-mail: bbashe@parliament.gov.za

Institution: Parliament (RSA)

Interviewee's pseudonym: _____

Place at which the interview was conducted: _____

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview. You are asked to give your consent to me on tape when we meet to conduct the interview.

1. Information about the interviewer

I am Buyile Simon Bashe, a student at the SOPH, University of the Western Cape. As part of my Masters in Public Health, I am required to write a mini thesis as part of completion of my Master's Programme. I will be focusing on HIV/AIDS related stigma in Parliament of RSA. I am accountable to Christina Zarowsky who is contactable at 021 959 2591 or 079 336 1066 (cell) or SOPH Fax: 021 959 2872 or by e-mail at czarowsky@uwc.ac.za

Here is some information to explain the purpose and usage of my interview.

2. Purpose and contents of interview

The interview will assist me to explore your understanding of HIV/AIDS related stigma, explore your perceptions of HIV/AIDS stigma in the Parliamentary Service, assess the perceptions of the effectiveness of Parliament's HIV/AIDS response strategy and explore your perspective on how HIV/AIDS related stigma might be effectively addressed in the workplace.

3. The interview process

I ask the questions and at times will probe further from your responses. We will start by completing the basic demographic information and then a few open ended questions will be asked. The interview will be recorded. During interview please use a pseudonym before you speak just shout the pseudo name.

4. Anonymity of contributors

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. See name above. I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected.

5. Things that may affect your willingness to participate

The interview may touch on issues which may be sensitive or affect you emotionally. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

6. Agreement

6.1 Interviewee's agreement

The interviewee will be asked to give his/her consent below.

6.2 Interviewer's agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.



Signed by interviewer:

Date:

Place:

Signed by participant:

Date:

Place:

APPENDIX 4 b: INFORMED CONSENT- FOCUS GROUP DISCUSSION

RECORD OF INFORMED CONSENT TO PARTICIPATE IN FOCUS GROUP DISCUSSION

Date:

Interviewer: Buyile Simon Bashe

UWC Student no: 2836651

Tel: +27 21 403 8044 **Fax:** +27 21 403 3333

E-mail: bbashe@parliament.gov.za

Institution: Parliament (RSA)

Interviewee's pseudonym: _____

Place at which the interview was conducted:

Thank you for agreeing to participate in a focus group discussion. What follows is an explanation of the purpose and process of this type of group interview. You are asked to give your consent to me on tape when we meet to conduct the focus group discussion.

1. Information about the interviewer

I am Buyile Simon Bashe, a student at the SOPH, University of the Western Cape. As part of my Masters in Public Health, I am required to write a mini thesis as part of completion of my Master's Programme. I will be focusing on HIV/AIDS related stigma in Parliament of RSA. I am accountable to Christina Zarowsky who is contactable at 021 959 2591 or 079 336 1066 (cell) or SOPH Fax: 021 959 2872 or by e-mail at czarowsky@uwc.ac.za

Here is some information to explain the purpose and usage of the focus group discussion.

2. Purpose and contents of interview

A focus group discussion is a kind of group interview. It will assist me to explore understandings of HIV/AIDS related stigma, explore perceptions of HIV/AIDS stigma in the Parliamentary Service, assess the perceptions of the effectiveness of Parliament's HIV/AIDS response strategy and explore perspectives on how HIV/AIDS related stigma might be effectively addressed in the workplace. A focus group discussion allows participants to interact with each other and discuss other points of view that they might not think of in an individual interview.

3. The interview process

I ask questions to start and guide a discussion among the participants and at times will probe further based on the responses of participants in order to facilitate a wider discussion. At times I may encourage more quiet participants to share their views but at no time will anyone be forced to say anything. All participants are asked to participate freely while respecting the views of other participants. As the purpose of the discussion is to explore perceptions of HIV/AIDS stigma and how stigma might be effectively addressed in the workplace, at no time will you or anyone else be asked to reveal any personal information or reveal or ask about HIV status. Please do not reveal your HIV status – whether positive or negative – or ask any other participant to reveal their HIV status or any other sensitive personal information. We will start by completing the basic demographic information about participants. The focus group discussion will be recorded.

4. Anonymity and confidentiality of contributors

Protecting the anonymity and confidentiality of all participants, including yourself, is of utmost importance. By agreeing to participate in this discussion, you also agree to keeping the identities of all participants confidential, and to avoid divulging or discussing their identities or anything that was said by participants outside of this discussion.

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected and analysed.

5. Things that may affect your willingness to participate

The discussion may touch on issues which may be sensitive or affect you emotionally. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I or other participants ask anything which you see as intrusive.

6. Agreement

6.1 Participant's agreement

I, the interview participant, indicate my consent to participate by signing below. I understand that consent to participate in the Focus Group Discussion also means that I promise not to divulge the identity of any of the participants, or to divulge or disclose anything that was said by participants during the discussion outside of this Focus Group Discussion.

6.2 Interviewer's agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed by interviewer:

Date:

Place:

Signed by participant:

Date:

Place:



APPENDIX 5: INDIVIDUAL INTERVIEWS ANALYSIS TEMPLATE

	RESPONDENTS			
QUESTION				
KNOWLEDGE OF HIV AND AIDS RELATED STIGMA				
a) Please tell me what the term “HIV/AIDS stigma” means to you? (probe for examples)				
b) How is it relevant in Parliamentary Service?				
c) In your opinion, in the past twelve (12) months, in what extent have these been occurring in Parliamentary Service?				
ASSESSMENT OF EMPLOYEES PERCEPTIONS TOWARDS PEOPLE LIVING WITH HIV AND AIDS.				
a) When someone becomes aware of a person diagnosed or living with HIV, what is the general response to the news? <i>Probe feelings, attitudes and behaviours.</i>				
b) When you become aware of a person diagnosed or living with HIV, what is your response to the news? <i>Probe feelings, attitudes and behaviours.</i>				
BARRIERS TO TESTING AND DISCLOSURE				
a) If you were going to be tested in the future for some reason, how concerned would you be that you might be treated differently or stigmatized if your test result were to come out positive for the AIDS virus?				
b) How is the thought of possible stigmatization affecting your decision to get tested for HIV?				
c) In Parliament, what is the primary way employees know if someone has HIV?				
TO DETERMINE WHETHER PARLIAMENT’S HIV/AIDS RESPONSE STRATEGY IS EFFECTIVE				
a) Do you know about Parliament’s Policy on HIV and AIDS?				
b) How do you think this policy addresses the issue of stigmatization				
c) In your opinion, how well and in what ways do the existing Health and Wellness Programmes in Parliament meet the needs of People Living with HIV and AIDS?				
d) What else might help to make it easier to discuss, get tested for, and deal with HIV and AIDS in this workplace?				
e) How does Parliament Service ensure that you are not occupationally exposed to HIV/AIDS while you are at work?				
f) In your opinion, how is the Senior Management’s leadership in managing HIV/AIDS in Parliament?				
g) Do you have anything else you would like to add?				

