

UNIVERSITY OF THE WESTERN CAPE

INSTITUTE OF SOCIAL DEVELOPMENT

**THE SOCIAL CONSTRUCTIONS OF HIV/AIDS STIGMA IN ONE COMMUNITY IN
CAPE TOWN, SOUTH AFRICA.**

**A FULL THESIS SUBMITTED IN FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTERS IN ARTS, DEVELOPMENT STUDIES.**



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THE SOCIAL CONSTRUCTIONS OF HIV/AIDS STIGMA IN ONE COMMUNITY IN CAPE TOWN, SOUTH AFRICA.

KEY WORDS:

Community

Cape Town

Gender

HIV/AIDS

Mitchell's Plain

People living with HIV/AIDS (PLWHA)

'Race'

Social Constructions

South Africa

Stigma



DECLARATION

I declare that “**The social constructions of HIV/AIDS stigma in a community in Cape Town, South Africa**” is my own work, that it has not been submitted for any degree of examination in any other University, and that all the sources I have used or quoted have been indicated and acknowledged by means of references.

Yvette Kayonga



Signature

November 2009

Witnesses:

.....

Professor T Shefer

.....

Professor M K Lees

DEDICATION

To My Dearest Mother MUKARUTIMBO AURELIE, to whom I am eternally grateful for her love and understanding. I, dedicate to you this work. May your soul rest in peace.



ACKNOWLEDGEMENTS

Upon accomplishment of this study, I would like to thank the following:

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My friends and colleagues Sisa Ngabaza, Zulfa Ellis and Tigist Shewarega for showing love and support at all times. I needed this.

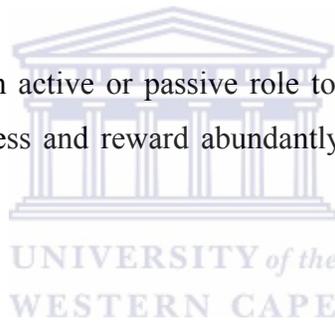
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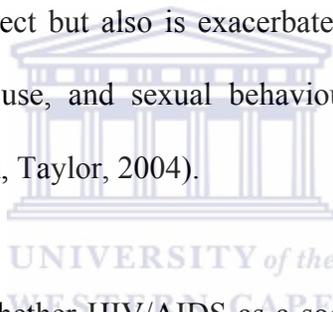
My husband for his support, I want you to know that your love means the world to me. Further I would like to extend my love and thankful message to my children Axel, Tricia, Nick and Militia for your sacrifices during the last six years of my studies from my first year of my junior degree up to completion of this current degree.

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ABSTRACT

Due to tremendous stigma attached to HIV/AIDS, revelation of HIV positive sero-status of an individual has become a significant risk in communities of South Africa (Kalichman et al., 2003; Deacon et al., 2004; Kalichman et al., 2005, Simbayi et al., 2007). Several researchers have argued that HIV/AIDS stigma poses severe problems which include that it delays HIV testing; stops people living with HIV and AIDS (PLWHA) from seeking care; inhibits incorporation of prevention behaviours; increases violence against HIV-positive people; and extends beyond PLWHA to families, providers and volunteers. HIV/AIDS stigma is widespread, and it is widely accepted that it does not only reflect but also is exacerbated by co-existing stigmas related to poverty, race, gender, substance use, and sexual behaviour (Parker et al., 2002; Parker & Aggleton, 2003; Holloway, Seaton, Taylor, 2004).



This study aimed to understand whether HIV/AIDS as a social construct and those living with HIV/AIDS are understood and responded to differently by males and females and those previously classified by the apartheid divisive policy as African and Coloured participants in the context of their daily encounters. Hence, the study investigated whether there is a relationship between race, gender and HIV/AIDS stigma among participants and whether this relationship is mediated by age, educational level, and participants' household situation. In addition, the study explored whether gendered stigmatization is subscribed to by participants, while it further sought to assess the extent to which participants were exposed to HIV and AIDS; and whether there were gender and racial differences with respect to participants' perceptions about PLWHA. Finally, the study scrutinized participants' perceived levels where they believe interventions to eliminate stigma could be prioritized.

This study utilized a survey questionnaire drawn up on the basis of qualitative findings in earlier studies on stigma and HIV/AIDS in both 'African' and 'coloured' communities. Two hundred participants were recruited through a convenience sampling method in the Mitchell's Plain area of Cape Town, South Africa. The sample was stratified by 'race' and gender with the majority between the age of 35 and 49 years; 50.3 % of the respondents in the sample were males, while 49.7 % were females. The majority of the respondents were Africans of Xhosa speaking descent (49.2 %) and coloureds (48.2 %) with a small proportion of whites (2.5 %). All standard ethical procedures for research with human participants were adhered to and the project was registered with the UWC Research & Ethics Committee. All participants responded on the basis of informed consent and consent forms were signed to confirm ethical assurances. Confidentiality of the data was observed and the data was kept in a locked up and secure place for a period of five years after the study. Completed survey questionnaires were coded, and analyzed quantitatively using the Statistical Package for Social Sciences version 17.0 (SPSS) and SAS.

Inferential statistics showed highly significant gender differences in participants' personal stigmatization. More so, personal stigma attitudes were more likely to be found among older males and with means to support their households. Descriptive results showed these older males were less likely to know someone with HIV. The study acknowledged that HIV and AIDS as well as PLWHA are socially constructed and intersected with existing social inequalities on difference and hence, recommends that interventions to address HIV/AIDS stigma need to take cognizance of the contexts in which it occurs. It seems important to address de-stigmatization efforts at coloured families since descriptive results reflect some denial that HIV is a challenge

and/or that PLWHA are stigmatized in families and community at large. Gendered constructions of stigma, while impacting on both men and women (since both appear to be stigmatized differently), are clearly still salient and it is recommended that efforts be continually made to raise the way in which gender, class, racialised and other differences of power are being played in community responses to HIV and those living with HIV/AIDS.



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CHAPTER ONE: INTRODUCTION

1. 1 Contextualizing HIV/AIDS and stigma

HIV/AIDS has been cited as the most feared and stigmatized disease that has challenged contemporary societies. The epidemiological aspect of this disease needs to be introduced in order to highlight some of the key aspect of HIV/AIDS pandemic. Thus, global estimates of people living with HIV in 2007 stood at 33 million in 2007 and in the same year 2.7 million of infections occurred while 2 million died of HIV related illnesses. Of the 2.7 million of infections that occurred in 2007, it was estimated that 1.9 million occurred in sub-Saharan Africa (UNAIDS 2008, cited in Shisana et al., 2008). These statistics are devastating, not only for families and communities but also for the broader society and development of the world (Roman, 2006; World Bank, 2003; ICRW, 2003). In the World Bank Gender and Development Group research (2003), it has been noted that HIV/AIDS threatens human welfare, socio-economic advances, productivity and social cohesion (World Bank, 2003).

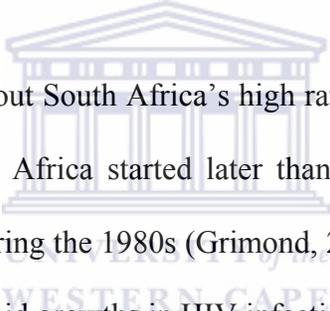
Most importantly it has been argued that HIV/AIDS does not affect all people equally (Shisana et al., 2003; World Bank, 2003; Shisana et al., 2005-2008). The imbalances between female and male risks and vulnerabilities have become evident as the differences in the rates of infection have grown (Lule, 2003; Shefer, 2003; Shisana et al., 2005; Brendan & Brown, 2006; Shisana et al., 2008). In Africa, where HIV/AIDS is the leading cause of death, 68 percent of all young persons infected are female (World Bank, 2003; Shisana et al., 2005; Shisana et al., 2008). South Africa, a country in which this research is being conducted, is known to have had the highest

number of people living with HIV in the world (UNAIDS/ World Health Organization, 2007, cited in Shefer et al., 2008) and HIV infection has reached epidemic proportions and has serious consequences for individuals as well as for the country's health resources and economy (Visser, Makin and Lehobye, 2006). Many authors have indicated as well that in Sub-Saharan Africa, HIV/AIDS has reached pandemic proportions and presents challenges to the well being of individuals, communities and to the public health in general (Kalipeni et al., 2004; Cameron, 2005; Simbayi, Kalichman, Strebel, Cloete, Henda, Mgeketo, 2007).

According to a nationally representative survey of HIV prevalence in South Africa (Shisana & Simbayi, 2008), HIV prevalence remains disproportionately high for females overall in comparison with males. It has been found in this survey that this proportion remained unchanged over the last 5 years (found in surveys of 2003, 2005 and 2008). It was indicated that the prevalence of HIV peaks in the 25-29 years group and one in three (32.7%) were found to be HIV positive in 2008. HIV prevalence among females is more than twice as high as that of males in the age groups 20-24, and 25-29. Among males the prevalence of HIV was more likely to increase in the age of 30-34 years old group, while a quarter (25.8%) were found to be HIV-positive in 2008 (Shisana et al., 2008). In the same line, the latest Joint UN Action Plan on HIV/AIDS statistics also estimated 5.5 million South Africans as being infected with HIV (UNAIDS, 2006a, cited in Baxen & Breidlid, 2009). More importantly, it has been reinstated that the virus is unevenly distributed among the various population groups in South Africa, being most prevalent among the black population, almost six times as frequent as among the second worst affected population group, ie the Coloured group. What is even more alarming and need to

be taken into account is the increase in the prevalence rate among black people, in the context of decline among other groups (Chirambo, 2008:144; cited in Baxen & Breidlid, 2009).

More generally, the seriousness of this situation as argued by Baxen and Breidlid (2009) can be illustrated by projections indicating life expectancy with or without AIDS, it is stated that these figures will affect 'black people' the most. According to the UN Development Programme and the US Bureau of Cencus (Chirambo, 2008), the life expectancy projections for South Africans without AIDS in 2010 is 68.3 years and with AIDS , 35.5 years. It is alarming, therefore that these figures signal a bleak future if interventions fail to make a difference.



In trying to answer the question about South Africa's high rate of HIV/AIDS, it has been argued that although HIV/AIDS in South Africa started later than in other countries due to relative political and economic isolation during the 1980s (Grimond, 2001; cited in Visser et al., 2006), it has experienced one of the most rapid growths in HIV infections in the world (Baxen & Breidlid, 2009). It has been argued that rapid increase in South Africa's HIV prevalence took place between 1993 and 2000, during which time the country was distracted by major political changes (Judge, 2005; Visser et al., 2006). At this time the country was involved in a political turmoil due to a long history of apartheid. While the attention of the South African people and the world's media was focused on the political and social changes occurring in the country, it is argued that HIV was rapidly becoming more widespread.

Moreover, as it has been shown in the above discussion, South Africa's rates of infection vary among different population groups and the stigmatisation of HIV and PLWHA has also been

racialised. It has been argued that during the time of political changes in South African history, relationships were characterized by mistrust, suspicion and aggression and all communication was seen as political, and part of an ongoing 'racial war'(Visser et al., 2006). It was in this atmosphere that misconceptions regarding HIV emerged, such as that HIV was a war strategy invented by the apartheid government or a disease to stop black population growth (Visser et al., 2006).

However, previous literature suggest also that stigmatization of this disease has played a role in pushing HIV/AIDS undercover and thus playing a huge contribution in the spread of the AIDS epidemic. Moreover, it has been argued that even if HIV/AIDS is a highly stigmatized disease worldwide (Malcolm et al., 1998), the exact form of stigma is probably unique in each community because each community attaches its own meanings and explanations to situations. Therefore, stigma needs to be considered in a specific social context. Further, given the fact that biomedical model has proven inadequate in providing the cure for those infected, it is suggested that strategies to counter the detrimental effects of stigma are a vital component in the global fight against HIV/AIDS.

According to Kalipeni et al. (2004) perhaps the best way to locate HIV/AIDS in Africa is to unpack dominant interpretations of how AIDS has been socially constructed in Africa, how it has progressed as well as why it doesn't diminish. Kalipeni et al. (2004) continue to argue that media representations in the U.S have been one significant source making AIDS in Africa an 'epidemic of significations' (Treicher, 1999 cited in Kalipeni et al., 2004:3). It is argued that even if these statistics and sources on the one hand bring visibility to the AIDS epidemic which remains

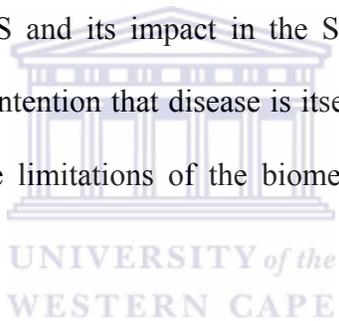
relatively misunderstood in the west, they (the west) have often done so by couching the epidemic in terms that too often resonate with neocolonialist understandings of African culture and sexuality and serve then to 'other' HIV as an African illness (Kalipeni et al., 2004).

Evidently, Kalipeni et al. (2004) argue that intervening into these predominant understanding of AIDS in Africa is important for various reasons. In this matter, it has been argued that dominant interpretations of AIDS are aiding in the reproduction of problematic colonial and postcolonial African representations, practices, and social politics. Arguably, this should not only be understood as troubling from a geopolitical and moral stand point; but also problematic gender and racialized representations of sexual practices, social behaviors, and government actions generated within and outside of Africa are proving detrimental to the lives of millions currently suffering from HIV/AIDS. Thus, women are represented as 'reservoirs of infection', 'African as promiscuous', and finally 'African governments as incompetent' (Craddock, 2004: 4).

In the same context, these interpretations and their effects are insidious for stigmatization, misguided interventions, and help to produce indifference towards the lives that continue to be lost. It is arguable that they have in some instances contributed to national ambivalences about African AIDS as argued before.

More generally put, these representations and interpretations also intersect with debates over how much preeminence biomedical models of AIDS should have in the highly varied and complex contexts in which the disease gets played out. It is suggested that this is profoundly true in the situation when biomedical solutions have thus far proven inadequate in turning the tide of infections and providing cure for those already infected (Kalipeni et al., 2004).

South Africa's AIDS interpretations have been suggested as perhaps a visible example of what is still at stake in conflicting interpretations of HIV/AIDS internationally. An example in this context has been the South African former President, Thabo Mbeki's controversial stance on AIDS as a disease of poverty rather than an epidemic driven by HIV. This interpretation created profound contestation among international researchers as well as frustration among physicians and AIDS activists within South Africa. While these concerns are more than understandable given the confusion that this interpretation created, it is argued that the dominance of biomedical models placing HIV front and center have silenced Mbeki's more insightful statements on poverty's role in facilitating AIDS and its impact in the South African context. AIDS is no exception, then, to Rosenberg's contention that disease is itself a social actor (Rosenberg, 1992: xvi in Kalipeni et al., 2004). The limitations of the biomedical mode will be discussed and developed further in chapter two.

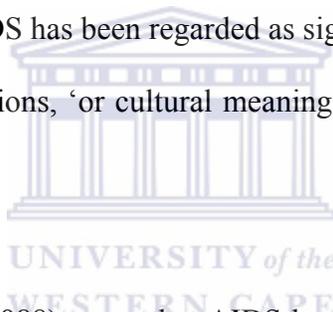


1.2 The social determinants of HIV/AIDS stigma

It is best suggested that to be able to understand the ways in which HIV/AIDS stigma appear and the contexts in which it appear, there is a need to first understand how AIDS stigma interact with pre-existing stigmas and social discrimination associated with sexuality, gender, race, and poverty (Parker & Aggleton, Attawell, Pulerwitz & Brown, 2002). Parker et al. (2002) argue that HIV/AIDS stigmas interact with pre-existing fears about contagion and disease. As such, early associations of HIV with death, punishment, guilt, shame and othering, have exacerbated these fears, reinforcing and legitimizing stigmatization and discrimination (Parker & Aggleton et al., 2002).

In the same context, research in the area of stigmatization has shown that individuals with HIV do not necessarily experience the same stigma (Sontag, 1990; World Bank, 2003, Barroso, Lambe & Sandelowski, 2004). There is an argument that some population groups are more likely to be regarded by society as ‘innocent victims of HIV’ (Sontag, 1990).

It has been widely argued that dominant discourses on HIV/AIDS in South Africa and elsewhere in the world, represent a collective social process, and operate by producing and reproducing existing structures of power, hierarchy and exclusion (Parker & Aggleton, 2003; Deacon et al., 2005; Judge, 2005). Thus HIV/AIDS has been regarded as signifying not only a disease epidemic but also an ‘epidemic of significations, ‘or cultural meanings’ (Treichler, 1990; in Sandelowski et al., 2004:122).



As such, Aggleton and Homans (1988) argue that AIDS has fed easily into wider anxieties and fear that find focus in powerful streams of racism, sexism and homophobia. The result, according to Aggleton et al. (1988:11) has been predictable and disastrous: ‘a moral panic rooted in genuine fear of the disease, but seeking scapegoats in those who were the chief sufferers from it’. The linkage between HIV/AIDS stigma and social control will be discussed in chapter two of this study. For now, as already suggested above it can be assumed that HIV/AIDS stigma manifest differently in different social context; thus there is a need to understand how to intervene in different social contexts.

1.3 Understanding different contexts of HIV/AIDS stigma interventions

Keeping in mind the above, it is important to acknowledge that the fight against stigma cannot be won until people are aware of the power relations that keep stigma alive. It has been suggested that common beliefs about what is socially acceptable are often based on unequal power relations, and that the key imperative is for people to address and challenge such power relations in their own lives (Simbayi, Kalichman, Strebel, Cloete , Henda, Mgeketo, 2007). Thus, a key stage in preparing to challenge power relations, as argued by Simbayi et al. (2007) is to develop critical thinking about how stigma manifests and is sustained and establish the social roots of the stigma.

Furthermore, it is argued that when communities get together to think critically about stigma, they are often able to see inequalities in social relations that contribute to stigma. Such community participation is a powerful weapon against stigma. It is arguably just as powerful as information (Simbayi et al., 2007).

Mwambo et al. (2004) suggest that research on determinants of AIDS stigma is lacking in developing countries and it has been noted that there is an urgent need to define elements of stigma-reducing interventions (Mwambo, Schalma and Bos, 2004). In this perspective, ICRW-led research revealed five important guidelines for AIDS stigma intervention in the African context, which should be taken into consideration when conducting research on HIV/AIDS stigma: Firstly, interventions should create greater recognition about stigma by focusing more on community participation; secondly, programmes addressing the AIDS pandemic should provide in-depth knowledge about different aspects of HIV and AIDS; thirdly, programme developers

are urged to provide safe spaces for community to discuss stigma-related values and beliefs, precisely because AIDS stigma interventions often tackle difficult issues that are taboo; the fourth suggestion proposes to use the language of the target population; and lastly the PLWHA should be involved as they have personal experience and knowledge needed to design appropriate AIDS stigma interventions.

As discussed above there is a need to understand the elements of stigma reduction intervention by focusing more on its context. On a global scale, a growing number of arguments hold that tackling the ‘social drivers’ of HIV epidemic requires a need to combine a range of action at different levels (Vincent, 2008). Recent arguments indicate that research and interventions that do not take into consideration the structural dimensions of AIDS pandemic are failing to improve long-term population health outcomes (Parker & Aggleton, 2003; Deacon et al., 2005). This observation reflects what may be regarded as the most serious health and development issue in most parts of sub-Saharan Africa and for many South African individuals and families the reality of HIV/AIDS exacerbates poverty and undermines development. How stigma further hampers social life in the South African context will be unpacked in chapter three of this study.

In conclusion, there is no doubt that HIV/AIDS stigma still persists even in areas where HIV prevalence is high. One would have expected stigma to decrease with increased visibility of HIV, but this does not appear to be the case in much of sub-Saharan Africa. Given the fact that HIV/AIDS stigma introduces enormous barriers to public health, from denial to silence, to problems of disclosure, health seeking behavior, and to the communal violence that ended Gugu

Dlamini²'s life for example; it becomes imperative to begin to use more creative way to design interventions and to implement them on a significant scale.

It is against this background that the study is located and aimed specifically towards highlighting the social and structural dimensions of discrimination and stigma attached to HIV/AIDS disease in general and to the people living with HIV/AIDS (PLWHA) in particular.

1.4 Rationale of the study

Although a lot of AIDS research has documented the widespread discrimination against people living with HIV/AIDS (PLWHA) in South Africa and elsewhere in the world (World Bank, 2003; Parker et al., 2003; Nyblade et al., 2003; ICRW, 2004; Skinner & Mfecane, 2004; Nyblade et al., 2005), there still remains a need for more research on the social constructions of HIV/AIDS stigma as they are manifested differently. In particular there is a scarcity of research on the processes by which such constructions are experienced, understood, reacted to, and perhaps reconstructed through social and interpersonal interactions in particular communities.

More importantly, understanding the process by which stigma is constructed as mentioned above is important simply because stigma has a profound impact on families and significant others. This further affects the individual living with the illness. If these problems resulting from stigmatization are to be addressed effectively, it is critical that the social mechanisms by which stigma operates are understood.

² Gugu Dlamini was murdered in 1998 after disclosing publicly her HIV in Kwazulu Natal , SA.

Also research shows that relatively few interventions to reduce HIV/AIDS stigma have been conducted (or at least rigorously evaluated, documented, and published) in developing countries. It has been suggested that many more need to be tested (Brown et al., 2001; Barroso et al., 2004; Kalichman et al., 2005).

In addition, it is problematic to assume that all types of interventions that have been tested are suitable in all settings or populations. For example, Brown et al. (2001) state that interventions such as inducing empathy for PLWHA through direct contact has proven successful in reducing stigma and increasing positive attitudes in the USA; however, one needs to rethink about how effective this approach could be in developing countries considering that so many HIV positive people are living in many communities in Africa and South Africa, and yet stigma remains despite their presence.



The links between gender, 'race' and HIV/AIDS risk are also very complex issues and are considered culturally specific, such that HIV/AIDS has been regarded as particularly a problem of women and African communities in general (Barroso, 2004; Strebel et al., 2006). This is due to the fact that stigmatization of people living with HIV/AIDS is related to the incidence of other social stigma, discrimination and marginalization (Parker et al., 2003; Skinner & Mfecane, 2004). Given the history of racism and discrimination in the South African context, there is a clear need to conduct research that will stimulate prioritization of the development of a greater understanding of the nature and practice of stigma against HIV-positive people.

In this context, this study aims to assess the effects of gender and race with respect to community perceptions and attitudes towards HIV/AIDS and PLWHA and their stigmatization thereof in one community in South Africa that was historically classified as Coloured.

In particular, the study evaluates through the use of a survey questionnaire, the attitudes and perceptions of families living in Mitchell's Plain towards PLWHA. It also seeks to determine the interactions between gender and race and societal attitudes/perceptions towards HIV/AIDS and the related stigma.

1.6 Overview of chapters

The introductory chapter presents the context and rationale for the study. This chapter reviewed the broad epidemiological aspect of HIV/AIDS and contextualized the focus on stigma globally and locally particularly in relation to how it needs to be prioritized in understanding critical contextual factors which contribute to stigmatization of PLWHA and HIV/AIDS in general ..

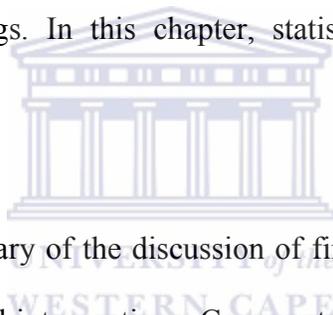
Chapter two provides the theoretical framework within which this study is located. The chapter critically examines the wider debates that relate to the way HIV/AIDS and those living with HIV/AIDS are socially constructed. In this regards, the social process of HIV/AIDS stigmatization is discussed. In doing so, literature on how stigma has been defined, how it functions and its link to social control are highlighted. In this chapter, literature on the role of biomedical model in HIV/AIDS stigmatization process is also critically discussed.

Chapter three discusses empirical studies reviewed in relation to disease stigmatization and in particular HIV/AIDS stigmatization. In this chapter, the review of literature also covers discussion on the social construction of HIV/AIDS stigma based on gender and 'race' among other social identities and its link to power and domination.

Chapter four overviews how the study was conducted by presenting the methodology of choice, which is defended and compared to others. Procedures for participant selection and recruitment, data collection, data analysis, ethical issues and self-reflexivity are also outlined in this chapter.

Chapter five analyses the findings. In this chapter, statistical results in numeral form are presented and discussed.

Chapter six presents a final summary of the discussion of findings as well as recommendations that emerge for future research and interventions. Comments are made regarding the limitations of the study



CHAPTER TWO: THEORETICAL FRAMEWORK

2.1 Introduction

This chapter focuses on theoretical frameworks and concepts reviewed in relation to the way HIV/AIDS and those living with HIV/AIDS are socially constructed. The theoretical framework stresses the importance of understanding stigmatization processes and the manner in which HIV/AIDS stigma has been defined and discussed. In order to be able to do so, this research draws upon scholarship and research published predominantly in the sub-disciplines of medical sociology/sociology of health and illness, and makes excursions into the insights offered by feminism and mostly a feminist social constructionist framework.

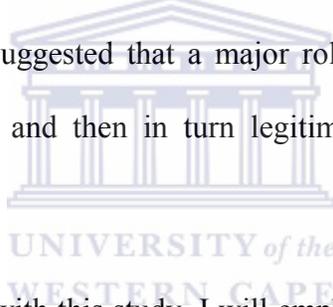
2.2 Feminist Social Constructionist Framework

It is often difficult to give a meaning of what social constructionism entails since it involves different assumptions and viewpoints from various theorists. According to Burr (1995), there is no clear cut definition of what social constructionism is, and instead, she argues that any approach that has the following key assumptions should be grouped as social constructionist. These assumptions are as follow:

This first assumption implies a critical stance towards the taken-for-granted knowledge, in which social constructionism invites us to be critical of our assumptions about how the world appears to be (ibid, 1995:3). In the second assumption, it has been argued that our common understanding of the world, the categories and concepts we use are historically and culturally specific (ibid, 1995:3). Thirdly, it has been suggested that knowledge is sustained by social processes. Burr (1995:4) poses in this instance that people's common understanding of the world is constructed

between them. Lastly, it is stated that knowledge and social action go together. In this perspective, Burr (1995:5) posits that what has been referred to as ‘understandings of the world’ are negotiated and that they take different forms, and therefore she talks of numerous possible ‘social constructions’ of the world. Burr (1995) suggests that each different construction also brings with it, a different kind of action from human beings.

Arguably, as already suggested this research has been launched within a feminist social constructionist framework and follows the assumption that stigma disempowers and undermines the stigmatized person and enhances differences by reducing the stigmatized group or person’s social status and self worth (Link & Phelan, 2002). In the same line, Parker, Aggleton, Attawell, Pulerwitz, and Brown (2002: 9) suggested that a major role of stigma in society is to create ‘difference’ and social hierarchy, and then in turn legitimizing and perpetuating this social inequality’.



Similarly to the above and in line with this study, I will emphasize Burr’s (1995:5) argument that it is through the daily interactions between people in the course of social life that their versions of knowledge become fabricated; the study also follows the assumption that all ways of understanding are historically and culturally relative, not only are they specific to particular cultures and periods of history, but they are seen as products of that culture and history, and are dependent upon the particular social and economic arrangements prevailing in that culture at that time (Burr, 1995:4-5).

This discussion is also supported by pertinent examples from empirical research studies which have attempted to provide empirical evidence of lived experience of these phenomena, and

‘gives due recognition to the macro-political processes which frame, shape and constrain such experiences and knowledges’ (Lupton, 2003: 3).

In the same context, as it will be discussed in the empirical research, HIV/AIDS carries its own kind of stigma and is linked to the notions of ‘others are to blame’ as well as a powerful association with ‘deviance’. Throughout the thesis I have been guided by the social constructionist assumption that all ways of knowing are socially fabricated and are products of a certain history and culture. This implies unpacking how social institutions such as medicine and biomedical model shape ways in which society responds to diseases in general and the ill person in particular.



2.3 Theoretical Perspectives on Health and Illness

There has been a lot of work done on theorizing the role of medicine and illness in western societies that have tried to understand the socio-cultural dimension of medicine, illness and the body. In this section, I will try to discuss the applicability of these ideas to a definition of disease stigma. According to Lupton (2003), there have been three dominant theoretical perspectives of medical sociology or sociology of health and illness: functionalism, political economy approach and social constructionism. It is argued that variants of all three are currently in circulation in the scholarship in the sociology of health and illness. However, it has been noted that functionalism and to a lesser extent, the political economy approach have been on the wane, while it is clearly stated that the social constructionist perspective, which is mainly the theoretical perspective adopted in this study, continues to prosper (Lupton, 2003).

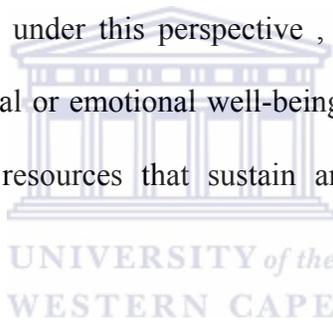
The functionalist approach views 'illness as unnatural state of the human body, causing both physical and social dysfunction, and therefore a state which must be alleviated as soon as possible' (Lupton, 2003:7). Functionalists argue that the feelings of stigma, shame and vulnerability accompany many diseases. They continue to suggest that in this regard, the role of the medical profession is to act as a necessary institution of social control, or a moral guardian of society, using its power to distinguish between normality and 'deviance' as church once did (Lupton, 2003:7).

The leading scholar in the application of functionalist theory to medicine was the American sociologist Talcott Parsons. According to Parsons and his followers, a person afflicted with serious illness is physically disabled and thereby forced to rely upon others, and hence is deviating from the expectations of social obligations. Parsons argued that conforming to the norms of the sick role legitimates such deviance. He described four major components of the sick role and asserts that on the one hand ill persons are exempted from the performance of social obligations which they are normally expected to fulfill; they are not supposed to be blamed for their condition, and should not feel guilty when they do not fulfill their normal social duties.

However, Parsons argued that on the other hand, ill people must want to try and get well, if they do not, they can be accused of malingering; and according to Parsons being sick is defined in this instance, as being in need of medical help to return to 'normality' (Parsons, 1987/1951:151-2 in Lupton, 2003). In this regard, the ill person is a patient who is therefore laced in the role of the socially vulnerable supplicant, seeking official verification from the doctor that she or he is not 'malingering' (Lupton, 2003:7).

While Parsons' work was ground-breaking in elucidating the social dimension of the medical encounter, the functionalist perspective has been subject to criticism. In this regard, the political economy approach developed as a critical response to functionalism in the context of larger changes in social thought occurring in the 1970s, particularly Marxist views on the capitalist economic system. Lupton (2003) stated that this approach is also known as critical structuralism and was a dominant intellectual movement in the 1970s and early 1980s, and remains influential in the sociology of health and illness.

Unlike the functionalist approach, under this perspective, good health is defined in political terms not only as a state of physical or emotional well-being but as 'access to and control over basic material and non-material resources that sustain and promote life as high level of satisfaction' (Lupton, 2003:8-9).



For political economists, ill, ageing or physically disabled people are marginalized by society because they do not contribute to the production and consumption of commodities. They continue to argue that other marginalized groups, such as women, the aged, the unemployed and members of the working-class, tend to endure greater social and economic disadvantage than those from privileged groups, have restricted access to health care services and suffer poorer health result. This reinforces the assumption mentioned above whereby, Burr stated that ways of understandings are dependent upon the particular social and economic arrangements prevailing in that culture at that time (Burr, 1995:4-5).

From this perspective the institution of medicine exists to attempt to ensure that the population remains healthy enough to contribute to the economic system as workers and consumers, but unwilling to devote resources for those who do not respond to treatment and are unable to return to the labour market (Lupton, 2003). Medicine is thus portrayed in this instance as a means which serves to perpetuate social inequalities, the divide between the privileged and the underprivileged, rather than to ameliorate them.

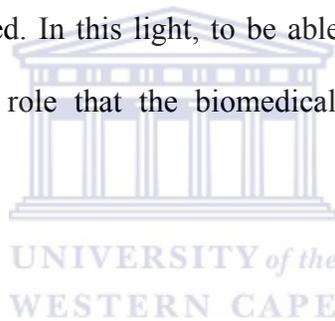
Following the discussion above, like functionalists, political economists see medicine as a moral exercise, used to define normality, punish deviance and maintain social order. However, Lupton (2003) suggested that the two approaches differ in the sense that political economists believe that this power is harmful rather than benevolent and is abused by the medical profession. The political economist critique questions the values of biomedicine and focuses on the identification of the political, economic and historical factors that shape health, disease and treatment issues. The limitations of biomedical model will be a point of discussion in this study and shall come back to this point in much more details.

This approach has been criticized for ignoring the micro-social aspects of doctor-patient relationship but nonetheless, remains an important perspective of the social aspects of health and illness. Within this broad discussion on the social aspects of health and illness, the discussion will turn to the social constructionism perspective on health and illness.

As already mentioned before, social constructionism is an approach which questions the existence of essential truths. In this regard, Lupton (2003) argues that experiences such as

illnesses, disease and pain exist as biological realities, but emphasize that such experiences are always inevitably given meaning and therefore understood and experienced through cultural and social processes. More generally, it has been stated that those who adopt the social constructionist perspective argue that medical power not only resides in institutions or elite individuals, but is deployed by every individual by way of socialization to accept certain values and norms of behaviors through a process of self-regulation

Following the social constructionist perspective, it becomes imperative in this research to examine ways in which people's common knowledge which sustains and constitutes a society or culture is generated and reproduced. In this light, to be able to illustrate this, the next sections will focus on understanding the role that the biomedical model has played in HIV/AIDS stigmatization processes.

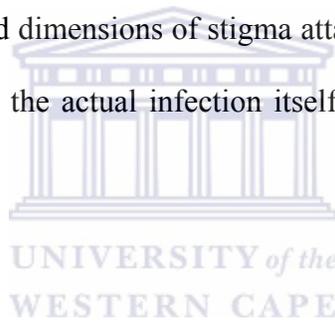


2.4 The Role of the Biomedical Model in HIV/AIDS stigmatization

As discussed before, the role of medicine and biomedical discourses in the stigmatization of diseases cannot be overlooked if one has to understand the stigmatization process of diseases in general and HIV/AIDS in particular. Biological factors are often used to explain why HIV/AIDS has attracted more stigma than other diseases in some contexts. Deacon et al. (2005) state that what makes HIV/AIDS more of a stigmatizing disease than any other diseases is the role that factors such as the stage of the disease and of the epidemic play within the stigmatization process of this disease.

Others have argued that particularly strong stigma attached to HIV/AIDS, for example in the west, was driven by ‘its concealability, the unpredictability of illness onset, its terminal nature, the development of visible and unaesthetic skin conditions such as Kaposi sarcoma, and its early associations with the gay community and with Africa’ (Chapman, 1998, in Deacon et al., 2005 : 8).

However, it has been suggested that when arguing about how the specific nature of the biology of a disease can produce stigma, we have to be very careful because one cannot always assume that the biological nature of the disease can automatically produce stigma. Aggleton et al. (2002) argue that there are many types and dimensions of stigma attached to HIV/AIDS and that stigma is very convergent; linked both to the actual infection itself and to behaviors believed to have lead to the infection.



Within the academic arena, funding priorities have determined that biomedical models remain dominant in generating understandings of AIDS in Africa (Schoepf & Baylies, 2004, cited in Ghosh et al., 2004). Kalipeni et al. (2004) argued that from early days of the discovery of the HI virus, most researchers in the biomedical field focused largely on particular ‘risk’ groups such as military men, truck drivers, and prostitutes; this focus on these particular groups was primarily an attempt to discern the driving mechanisms of the epidemic. In order to be able to achieve this, it has been argued that the precise sexual practices of members of these occupations were explored, including for example the numbers of partners per day or month, geographic origins of clients, usual partners of travel, STDs rates, and level of condom use.

However, it has been noted that while there cannot be any doubt that these studies have contributed a lot towards providing relevant information on HIV infection rates and practices of individuals within these prescribed occupations, there have been some limitations to this choice. It has been argued that the undoubted consequence of this tendency to focus on the sexual practices of 'risk groups; was that over and above facilitating stigma towards those groups, these studies have ignored socio-economic contexts, and the emphasis on rational action models of behavior change, have led to the problematic assumption that people only need to be more aware of AIDS in order to change their behavior (Kalipeni et al., 2004).

This has also consequences in the way that this focus leaves unexamined the vulnerability of individuals outside of these 'risk groups' and as Schoepf (2004) makes it clear, the unfortunate part is that most national AIDS prevention programs have been designed according to these biomedical models of individual risk and rational behavior change, and their lack of success in intervening into the epidemic has been evident. This focus on individual 'risk group' led also to HIV/AIDS being constructed as a disease of the 'other' and set up a 'blaming' discourse towards such groups.

However, in trying to understand the process of 'othering' that disease stigma usually deploys, one need to keep in mind that the way stigma has been defined structures our understanding of how it operates and how to address it, says Deacon et al. (2005). Arguably, understanding the process of stigmatization requires one to understand its social context and how it is defined. Consequently, this will help to highlight some of the key features of disease stigma specifically HIV/AIDS.

2.5 The Social Process of HIV/AIDS Stigmatization

2.5.1 Defining stigma

One way of responding to HIV/AIDS epidemic is to try to unpack the stigma attached to it as well as how it is socially defined and produced. In this regard, researchers particularly social psychologists have elucidated the ways in which people construct cognitive categories and link those categories to stereotyped beliefs. These beliefs are in turn responsible for the creation of the social process of stigmatization (Link & Phelan, 2001-2002). Moreover, the ‘social’ has been said to be an encompassing phrase and there is a need to capitalize this in this discussion to signal the understanding of HIV/AIDS stigma as a phenomenon whose complex embeddedness in the social demands multiple points of analytical entry within this term (Kalipeni et al., 2004).

Accordingly, the discussions that follow will focus on theoretical literature that highlight firstly how stigma has been conceptualized and how it functions, while in the last part the focus is on gender power and social control.

The origin of the word stigma has been traced back to the classical Greek where the term was used to describe the branding of outcast groups as a ‘permanent mark’ of their status (Parker & Aggleton, 2003). However, most discussions on stigma, particularly with respect to HIV/AIDS, have taken their point of departure the now classic work of Goffman (1963) who defines stigma as ‘an attribute that is significantly discrediting, which in the eyes of society serves to reduce the person who possesses it’ (Goffman, 1963 as cited in Parker & Aggleton, 2003: 14).

In the above perspective, many authors have argued that in a broad sense, stigma is a term that 'marks' and creates exclusion of the person, who becomes less valuable and 'blameworthy' in his or her community for possessing such a 'mark'(Parker et al., 2002; Link & Phelan, 2001-2002; Pillay, 2008). In the same vein, it has been argued that this 'victim-blaming' status of the individual ill results in being redefined as 'being guilty' (Minkler, 1999:128).

Arguably, Parker and Aggleton (2003) state that stigma need to be described as a social construction of deviation from an ideal or expectation, contributing to a powerful discrediting social label that reduces the way individuals see themselves and are viewed as persons. Visser et al. (2009) argue in this regard, that attributes that produce stigma are not inherently deviant, but deviations derive from the culturally embedded meanings of a particular historical period or 'cultural milieu'(Visser, Makin, Vandormael, Sikkema and Forsyth, 2009:197).

However, several other authors divide stigma into *felt* or *perceived* stigma and *enacted* stigma (Jacoby, 1994; Scrambler and Hopkins, 1986; Malcolm et al., 1998; cited in Brown et al., 2001). Felt stigma has been referred to as 'real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as HIV), or association with a particular group'. Enacted stigma, on the other hand, has been conceived as 'the real experience of discrimination' referring to lived experiences of discriminatory and abusive practice on the basis of such stigma (Brown et al., 2001: 4).

Brown et al. (2001) state that felt stigma can be understood as a survival strategy to limit the occurrence of enacted stigma, such as 'when people someone deny their risk of infection or fails

to disclose HIV status in order to avoid being ostracized' (Brown et al., 2001:4). On the other hand, Brown et al. (2001) continues to argue that when it comes to individuals who hold negative attitudes or who enact stigmatizing or discriminatory behavior; these individuals are referred to by some as the perpetrators of stigma and discrimination, whereas PLWHA and those affected or associated with HIV are the targets (Herek and Capitanio, 1998).

A further differentiation in defining stigma is unpacked by Kretschmar (1998) who distinguishes between external stigma and internal stigma. External stigmatization, according to Kretschmar is an outcome of external oppression. Kretschmar continued to argue that this external oppression is a manifestation of perceptions, rules and laws imposed in order to discriminate against marginalized groups. Pillay (2008) stated further that this external stigma includes the 'branding' of those who are living with HIV and AIDS as sexually promiscuous and is reflected mostly in the way PLWHA are treated and judged as 'deserving it'. On the other hand, internal stigma, refers to the internalization of such stigma by the person living with HIV. As Edwin Cameron explains, internal stigma is the feeling of shame that one has to live with for having contracted such a preventable disease, from an 'intimate, expressive, hopefully loving act' (Sunday Times, 17 April 2006:19; as cited in Pillay, 2008:22).

Pillay (2008) also continues to argue that while it might be perceived that societal hostility towards infected and affected people may have declined, she asserted that AIDS stigma has not disappeared; it continues to surface in communities and it progresses differently from one community to the other. The role that cultural and socio-political factors play in creating variability in stigma will be discussed further below. At this stage, it is important to note that a

number of factors including disease biology and epidemiology and societal attitudes converge to influence how and how much a disease such as HIV/AIDS, is stigmatized.

However, it has been prominently evident that Goffman's elaborated definitions of the concept of stigma have varied considerably. Moreover, of many reasons that definitions of stigma vary, one prominent challenge to its use (Link & Phelan, 2001) is relevant to this study. This includes the fact that research on stigma has had a decidedly individualistic focus (Aggleton & Parker, 2003). Arguably, Goffman's framework has been appropriated in much research on stigma, whether in relation to HIV/AIDS or other issues, as though stigma were a static attitude rather than a constantly changing and often resisted social process (Fife & Asch, 1988; Parker & Aggleton, 2003: 14). Aggleton et al. (2003) argue that this has seriously limited the ways in which HIV/AIDS stigma has been understood and approached. In this light, for example, Parker and Aggleton (2003) indicated that most references to stigma and stigmatization in work on HIV/AIDS rarely frame the meaning of discrimination, but indeed it is taken for granted, as though it were a given or obvious on the basis of simple common usage.

Similarly but differently argued, Deacon et al. (2005) suggest that instead of assuming that stigma results automatically in discrimination, one needs to redefine stigma by acknowledging it as an 'ideology'. They continue to argue that this ideology is reinforced by the linkage between the presence of a biological disease agent and any physical signs of a disease and the negatively-defined behaviors or groups in society. Deacon et al. (2005) continue to argue that the social constructions of disease are formulated within the framework of the 'biological' event that shapes 'the variety of choices available to societies in developing conceptual and institutional

responses to disease'. Rosenberg (1992) in this regard, stressed that 'a disease is a complex intellectual construct, an amalgam of biological state and social definition' (Rosenberg, 1992:305-7).

Consequently, Parker and Aggleton (2003) argued that there is a need of a sociological emphasis on the structural dimensions of discrimination, which will be particularly useful in helping researchers to think more sensibly about HIV/AIDS stigmatization and discrimination.

It can be argued however, that because of the complexity of the stigma phenomenon, it seems wise to continue to allow variation in definition so long as investigators are clear and aware as to what is meant by stigma when the term is used. In this regard, Link and Phelan (2001) suggested that one of the ways in which the criticism about the use of the stigma concept could be addressed, is to provide a fuller understanding of the stigma concept in locating its meaning in relation to other concepts. Moreover, it is also argued that the criticism of stigma concept could be used as the starting point for reassessment of the conceptualization of stigma as well as how it functions.

As has been suggested above, one needs to be aware of the assumptions followed when using the stigma concept; in this light, one of the assumptions followed in defining stigma in this study is that stigma create difference and social hierarchy , which reduce a person's or group's social status and self worth (Link & Phelan, 2001-2002; Aggleton & Parker, 2003).

Using Link and Phelan's insights offered above, it can be argued that the stigmatized person experiences status loss and discrimination in a power situation that allows such practices to

occur. Moreover, it is also arguable that this is due to the fact that the person is connected to undesirable characteristics that reduce his or her status in the eyes of the stigmatizer (Link & Phelan, 2001-2002). Following this discussion, it is important to highlight how stigma has been shown to function in the social context, especially in relation to HIV/AIDS.

2.5.2 The function of stigma

Unlike Deacon et al., (2005) who argued that stigma needs to be understood as a problem of fear and blame, it is important to start unpacking how both HIV/AIDS as well stigma attached to it are socially constructed in different settings and to show how HIV/AIDS is linked to power and domination (Aggleton & Parker, 2003).

To put this in Parker's words 'stigma arises and stigmatization takes place in specific contexts of culture and power' (Aggleton & Parker, 2003:14). Beyond this though, Aggleton et al., (2003) insists that 'to better understand how stigma is used to reproduce social inequality, it is equally important to recognize how understanding of stigma and discrimination in these terms encourages a focus on the political economy of stigmatization and its links to social exclusion' (Aggleton et al., 2003:16).

In this context, Gilmore & Somerville (2001) assert that stigma serves to reinforce social norms by defining deviance. 'Dis-identification' may strengthen and homogenize a community and its values by actually or metaphorically ridding it of unwanted or undesirable traits' (Taylor, 2001:794). Hence, stigmatization functions as 'an exercise of power over people' and a means of

social control by marginalizing or excluding a group from the wider community, and so reinforcing societal values' (Gilmore & Somerville, 2001; cited in Taylor: 2001: 796).

And so, helpful in understanding how stigma functions is to investigate how in the process, it reflects and produces, as mentioned, differences and relations of power and dominance. Thus, this understanding requires one to think broadly about how for example, some individuals and groups come to be socially excluded, and about the forces that create and reinforce such exclusion in different settings (Parker & Aggleton, 2003). In this light, the role of 'culturally constituted' stigmatization, which Parker and Aggleton (2003) have defined as the production of negatively valued difference, need to be understood as central to the establishment and maintenance of the social order. Thus, within such framework, the construction of stigma and stigmatization involves the 'marking of significant differences between categories of people, and through such marking, their insertion in systems or structures of power' (Aggleton & Parker, 2003: p.17).

Accordingly, it has been argued that 'risk-enhancing' characteristics are mostly attributed to the 'other' , and this is due to the fact that people articulate their own group identities as different in key 'risk-reducing' ways from groups stigmatized as deviant and 'other' (Deacon, 2005:7). Foege et al. (1988) also emphasize that by attributing such risk-enhancing behavior to the 'other', blaming 'outgroups' for being at risk, this helps people to gain an illusion of control and distance from the illness (Foege , 1988 ; Nelkin & Gilman, 1988; cited in Deacon et al., 2005).

As discussed elsewhere in the empirical literature, HIV/AIDS stigma is not experienced nor directed in the same way by and towards the same category of people. Women and especially black women in general, have been found to carry the burden of HIV/AIDS disease more than any other category of people. The particularity of this phenomenon has been said to be attached to the fact that HIV/AIDS stigma is build upon pre-existing stigma attached to gender, 'race', sexuality, poverty and many others. To be able to illustrate this, many theorists have theorized why women especially black, poor women are 'deviant' and therefore the 'other to blame' (Schur, 1984; Shefer, 2003; Shefer, 2004; Skinner & Mfecane, 2004; Shefer, Crawford , Strebel , Simbayi, Henda , Cloete , Kaufman & Kalichman, 2008).

2.5.3 Gender, Stigma and Social Control

As illustrated before, HIV/AIDS stigma is linked to the notion of deviance and has been set up as in sub-Saharan Africa mostly women's, and especially particularly groups of women's deviance (such as sex-workers and women who are perceived to transgress stereotypic female norms of sexual practice). In order to be able to explore the relation of women to definitions of deviance one needs to unpack how gender stigmas operate.

Moreover, deviance has been defined as a 'designation, a way of characterizing behavior' (Schur, 1984:3-4). Such definition, however, gives one a starting point to think about the process from which deviance leads to stigmatization. As such, it is argued that it is often the very process of defining and reacting to the behavior or condition as deviant that is of greatest interest in the process of stigmatization. Becker (1963: 9; cited in Schur, 1984:5) emphasized this point in his oft-quoted statement: 'Social groups create deviance by making the rules whose infraction

constitutes deviance’, and Schur (1984) continues to suggest that this process of stigmatization is achieved by applying the above mentioned rules to particular people and labeling them as outsiders.

From this point of view, it has been argued that deviance is not a quality of a the act the person commits, but rather it has been suggested in this instance that it is a consequence of the application by others of rules and sanctions to the ‘offender’ (Schur, 1984: 7). Becker (1963) concludes in this regard by saying that the deviant is one to whom that label has successfully been applied; and on the other hand deviant behavior becomes the behavior that people so label.

Schur (1984) argued that this conceptualization of ideas about deviance, and the companion notion of stigma, or ‘spoiled identity’ (Goffman, 1963) that I have discussed before, direct our attention to the devaluation phenomenon itself as the core ingredient common to deviance situations. Women’s deviance, like any deviance, is therefore a social construct. It result, according to Becker’s statement, from ‘a particular kind of definition and response’; the acts and individuals are not intrinsically deviant (Kitsuse, 1962; Erickson, 1962; cited in Schur, 1984). Rather it is suggested that they acquire their ‘deviantness’ (Schur, 1979) through a characteristic process of meaning attachment.

In many respects then, how people perceive and react to a given behavior or condition is what ‘counts most’ socially. This has been said to be so because the very same behavior or condition may be defined and responded to differently by different persons.

Recalling Becker's definition of deviance, it is arguable that it implies that definitions of deviance operate to impose control. Thus, some people control others by defining the latter's behavior as deviant. Many current definitions of deviance and ways in which they are used function to keep women under control, or in their 'place', regardless of whether anyone has consciously intended that effect (Schur, 1984: 8).

Furthermore, many feminists place a special emphasis on social control agents and agencies as being in a sense 'contributors' to deviance problems, but they also recognize the extent to which deviance definers may benefit through the labeling of others as deviant. It is imperative, however, to take into account the various ways in which men or society as a whole may gain or think or feel that they do, as a result of the deviance labeling of women (Schur, 1984; Aggleton, Parker & Maluwa, 2002; Parker & Aggleton, 2003).

Research have shown in this perspective that effects of deviance defining typically are grounded in the definers' perceptions that the 'deviants' pose some kind of threat to their specific interests or overall social position (Becker, 1963; Gusfield, 1966; Cohen, 1974; Lauderdale, 1976; Spector & Kitsuse, 1977; and Aggleton et al., 2002; Parker & Aggleton, 2003; cited in Schur, 1984). There can be little doubt of the relevance of this notion to the situation of women and especially HIV/AIDS positive women.

As discussed before, stigma and especially gender stigmas need to be understood in relation to power and domination (Aggleton et al., 2002; Aggleton & Parker, 2002; Parker et al., 2003; Deacon et al., 2005). To be able to understand this relation, there is a need to fully comprehend

how the broader gender systems operate. It has been argued in this regard, that exploring the deviance labeling of women highlights the socio-cultural connections between and among what have been treated as separate ‘problems’ or ‘private’ in some cases. It is asserted that these ‘separate problems’ are all shaped by, and constitute important parts of, an overall system of subordination and devaluation (Schur, 1984: 8-9).

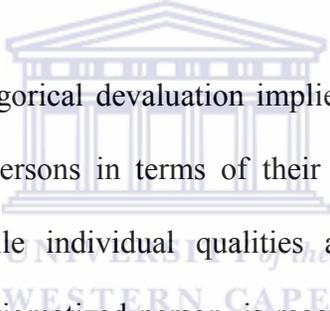
Arguably, it has been suggested that one way of understanding the gender system is to discuss primarily gender as a ‘normative system and a pervasive network of interrelated norms and sanctions through which female (male) behavior is evaluated and controlled’ (Schur, 1984:10).

Diverse studies of the gender system have irrefutably shown how the subordination of women is sustained through their being socialized for, and restricted to, limited aspirations, options, roles, and rewards for women. The heavy implications of such factors, learning processes and the societal institutions that produce and perpetuate them, are unquestionable (Schur, 1984). Equally important to keep an eye on, is the role of interpersonal evaluation in ordinary life situations. In many ways, then, it is argued that societal stigmatization must be recognized as a key mechanism that ‘backs up and enforces’ many restrictions and limitations placed on women (Schur, 1984:11-12).

There are various ways, then, in which gender as a socio-cultural complex of meanings, behaviors and assessments is produced and reproduced. Direct attention to these processes of meaning attachment is what is of interest in this study. In this light, as it has been mentioned in the last discussion, a specific way of behaving or acting may not always be needed for

‘deviantizing’ to occur (Schur, 1984: 22); it is , however, said that often what one is perceived to ‘be’, more than what one is believed to have done, gives rise to stigmatization.

The familiar example relevant to this study, which is seen widely in connection with women’s devaluation, is the numerous stigmatizing of women for violating gender norms, such as sex workers who have been stigmatized socially, labeled as prostitutes; while their male counterparts engaged in this activity are not stigmatized or labeled in any negative fashion. This process of devaluation which leads to stigmatization has been said to be linked to the objectification of people’s bodies.



Accordingly, it is argued that categorical devaluation implies treating people as objects. Thus, people respond to the devalued persons in terms of their membership in the ‘stigma-laden’ category (Schur, 1984: 30), while individual qualities and actions become a secondary consideration. Consequently, the stigmatized person, is reacted to primarily as an ‘instance’ of the category; in the extreme cases, it is argued that she or he is viewed as having no other noteworthy status or identity.

Following the discussion above, it is arguable that when such a level of devaluation is reached, the person becomes in the eyes of others, practically nothing but a ‘delinquent’, a ‘cripple’, a ‘homosexual’, a ‘black’, a ‘woman’ and mostly an ‘HIV positive woman’ in the case of the AIDS stigmatization process (Schur, 1984: 30-31). Stigmatized persons, then, are little valued as persons in this instance. Society may claim authority or use this opportunity to implicitly if not explicitly treat the stigmatized individuals in exploitative and degrading ways. The logical

endpoint of this process would involve treating them exclusively as ‘non persons’, the ‘other’ or simply as mere objects.

One would understand in this regard, the directions in which HIV/AIDS stigmatization processes have ended up in the ‘depersonalization’ of women and others such as gay men in some contexts which facilitated them being considered socially as ‘deviant carriers of AIDS’. Moreover, the devaluation process of women in particular has been said to be indeed substantial, and its manifestations are extremely widespread. There have been four major grounds on which basis this devaluation process of womanhood has been justified from.

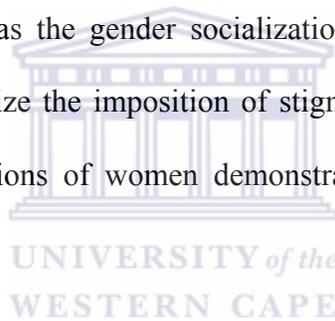
The first has been the well documented existence of pronounced gender inequality within our social and economic system. A second reason to accept the claim that femaleness is devalued has to do with the widespread categorical and objectification tendencies discussed above. A third and closely related point is the pervasive devaluation of women in ‘cultural symbolism’ (Firestone, 1971; Gornick & Moran, 1972; and Gottman, 1979; Stockard & Johnson, 1980; cited in Schur, 1984: 35). The latter implies that common language usage often ‘trivializes’, ‘slights’, ‘derogates’, or unnecessarily sexualizes woman (Lokoff, 1975; Adams & Ware, 1979; Richardson, 1981; Thorne & Henley, 1975 in Schur, 1984: 35-36).

However, the same can be applied to images of women in the mass media and advertising, especially in relation to HIV/AIDS. In this light, widespread public exposure of black African woman as the predominant image of HIV/AIDS, currently serves to further reproduce blaming

and othering discourse which set up black African and poor women as responsible for HIV/AIDS.

The fourth reason to view femaleness as devalued which is perhaps most closely relevant to this study, is reflected in the central concern in this discussion, namely woman's relation to definitions of deviance.

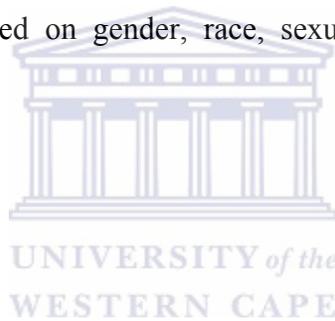
There have been various and a wide range of situations in which women in our society are subject to deviance labeling, these situations include the discussed earlier ones such as the objectification processes as well as the gender socialization itself. It is argued that although attempts may be made to rationalize the imposition of stigma in some of these circumstances, collectively the many stigmatizations of women demonstrate the deep-seated devaluation of femaleness itself (Schur, 1984).



In conclusion, the main argument made in the above section regarding gender, stigma and social control, highlights how gender stigmas and especially HIV/AIDS gendered stigma are linked to notions of deviance and social control. In doing so, I have first introduced how the notion of deviance is defined and applied to women as a category. To be able to illustrate the forces behind the process of the construction of deviance, I have discussed how constructions of gender more broadly contributes and feeds into the devaluation process of women and their association with HIV/AIDS. This was followed by a discussion on the objectification of women as one way that society reinforces women's devaluation and construction as deviant. It has been said that this notion of objectifying human beings through deviance labeling facilitates them being considered

as ‘non persons’ which legitimates exclusionary practices and abuse. Finally, it can be argued that deviance is constructed through social interaction and its endpoint is to produce social control of certain groups over others, allowing those in power to continue distancing themselves from those constructed as deviant and rationalize any stigmatizing practices towards them.

Overall, in this chapter we have looked at HIV/AIDS and stigma from a theoretical point of view. The assumptions followed in arguing about the process of HIV/AIDS stigmatization were based on theoretical constructs that have been applied to stigma and disease stigma more broadly. The central argument made here is that stigma functions to both reflect and create difference and social control based on gender, race, sexuality, poverty and other forms of inequality.



CHAPTER THREE: HIV/AIDS STIGMA: EMPIRICAL EVIDENCE OF STIGMATIZATION OF HIV AND THOSE LIVING WITH HIV/AIDS

3.1 Introduction

This chapter presents a review of empirical studies that have highlighted how diseases including HIV/AIDS have been stigmatized; it also emphasizes the specific nature of AIDS stigmatization as has been documented locally and internationally. This is followed by literature that has highlighted the social constructions of HIV/AIDS stigma, namely gender, race and other social identities and the ways in which the pre-existing stigma attached to these identities shape people's understandings of HIV/AIDS and their response to those living with HIV/AIDS.

3.2 HIV/AIDS and Other Illnesses

Both the empirical and theoretical literature on HIV/AIDS and stigma in South Africa and elsewhere show that there is a long way to go in reconstructing HIV/AIDS as 'just another illness' and mitigating the additional effects of such stigma on those living with HIV/AIDS (Aggleton, Parker & Maluwa, 2003: p2). More generally, according to Garcia & Koyama (2008) throughout history many diseases such as the Black Death in the 14th century and cholera in the 19th century have been stigmatized, however, HIV/AIDS has been said to be associated with stigmatization of its own kind.

Medical sociologists have examined the stigmatizing nature of a wide range of diseases including mental illness, tuberculosis, leprosy, cancer and HIV/AIDS among others (link et al., 1987; Stahly, 1988; Volinn, 1989; Weitz, 1989; Walkey, Taylor & Green, 1990; Gilmore and

Somerville, 1994; Doka, 1997; cited in Garcia & Koyama, 2008), and have noted that illnesses are stigmatized because they represent potential or existing physical limitations; they are associated with particular negative images and myths, and therefore they take on symbolic meaning.

However, the specific nature of the stigma associated with a serious illness has been said to be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, whether there are outward manifestations of the illness, and/or whether it results in decreased levels of competence (Fife & Wright, 2000).

As such, for example a study conducted in India to explore whether the impact of stigma on the self differs by illness type shows that there are important differences in the sources of stigma in HIV/AIDS and Cancer. Moreover, levels of stigmatization experienced by persons in each of these illness categories were also shown to differ considerably (Fife & Wright, 2000). In this study, the findings suggested that HIV/AIDS patients experienced significantly greater feelings of stigma than cancer patients, regardless of the particular stigma dimension (Fife & Wright, 2000). It was shown that the respondents with HIV/AIDS had significantly poorer self-esteem than the respondents with cancer.

More generally as illustrated in discussions that follow, the HIV/AIDS pandemic has been identified with behavior considered to be deviant, is classified as a sexually transmitted disease, is viewed as the responsibility of the individual, is thought to be acquired by way of immoral

behavior, and it is perceived as contagious and dangerous to the community (Fife & Wright, 2000). Therefore, it is not surprising that HIV/AIDS is associated with ‘a blame-victim-ideology’ as well as all types of Goffman’s (1963) stigmatized statuses which were discussed in chapter two of this study (Wright & Fife, 2002: 52; Deacon et al., 2005).

In the above respect, it can be argued that the degree to which stigmatized persons can blame themselves reflects their degree of shame and responsibility that society bestows on them for the disease (Wright & Fife, 2002). It is important; however, to keep in mind that social notion of a person’s moral responsibility is central to stigma and shame associated with many diseases including HIV/AIDS. Weiner (1993) indicated for example, that overweight people are perceived as responsible for their condition, because they are considered to have control over their eating habits and therefore, being overweight becomes a stigmatized condition.

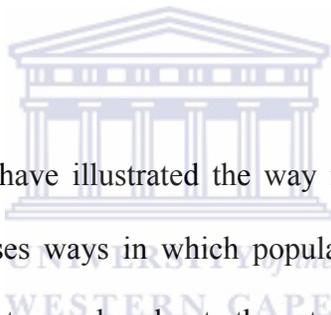
Furthermore, Weiner (1993) described a study in which he examined the relationship between stigma, perceived responsibility, and emotions. In that study, adults rated the following ten stigmata on personal responsibility: AIDS, Alzheimer’s disease, blindness, cancer, paraplegia, drug addiction, heart disease, obesity, child abuse, and Vietnam War syndrome. The results revealed that six of these stigmata, which are Alzheimer’s disease, blindness, cancer, heart disease, paraplegia, and Vietnam War syndrome, were rated low on perceived responsibility, whereas AIDS, abusing children, having a drug addiction, and obesity were rated high on personal responsibility.

On the other hand, literature supports the idea that stigma causes shame. In this regard, it is argued that there exist certain standards, rules and goals which are necessary and need to be incorporated in individuals' cognitive capacities for them to judge whether or not their behavior meets or does not meet these standards(Weiner, 1993).

From the point of view of standards, it is quite clear that the stigma that an individual possesses represents a deviation from the accepted standards of the society; this deviation, it is argued may be in appearance, in behavior, or in conduct. Nonetheless, the person is stigmatized by possessing characteristics which do not match the standard. It is, of course well recognized that these standards may change with time and with culture, but such standards exist, and individuals whose appearances and behavior deviate from them can be said to suffer from a 'stigma' (Wright & Fife, 2002). This could be illustrated in what follows as reported in the empirical research that was conducted to disentangle HIV and stigma in Ethiopia, Tanzania and Zambia.

In all these three countries, respondents reported that having HIV was considered as a result of 'deviant behavior', and people with HIV/AIDS were regarded as 'adulterers, prostitutes, and generally immoral or shameful'. The stigma associated with HIV/AIDS in this instance was due mostly to the breaking of sexual norms, which heightened in turn the fact that people with HIV/AIDS are deemed responsible for their 'sexual behavior' and are 'blamed' for their illness as a consequence of having deviated from sexual morals and norms (Nyblabe, Pande, Martur; MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mwambo & Bond, 2003: 19).

It has also become abundantly clear that there are significant similarities between AIDS and other sexually transmitted infections which go beyond the 'mere' fact of sexual transmission (Brand, 1988:367) and facilitate the construction of these as diseases of 'deviance and irresponsibility'. In particular, Shefer (2004) argues that AIDS powerfully reflects dominant aspects of norms and constraints with respect to sexuality since it has been largely understood to be sexually transmitted. In the same vein, Syphilis, for example, has been noted to have had severe pathological effects and to have been greatly feared and stigmatized (Brand, 1988). In the light of this analogue, it has been suggested that unpacking the social history of disease control in general and STDs in particular, may serve to inform our assessment of the current epidemic (Brand, 1988).



Arguably, empirical local studies have illustrated the way in which HIV and other STDs are stigmatized. Shefer (2004) discusses ways in which popular community beliefs and meaning construction reflect the arguments made about the strong component of blame which characterizes the social representation of STDs in general and HIV/AIDS in particular. Shefer (2004) indicated that in a national study on STDs, involving a range of focus groups with members of diverse communities in South Africa, it was found that 'stigmatizing, pathologising and 'othering' discourses were omnipresent in the ways in which participants spoke about what it meant to have an STD, with those inflicted almost inevitably constructed as 'other' and /or deviant in some of other respect' (Ratele & Shefer, 2002: 188; cited in Shefer, 2004).

Meanwhile, it is also suggested that even if it makes sense to draw upon past history to address the problems posed by the current AIDS crisis, there is a need to be critical in drawing simple

analogies; to recognize not only how AIDS is like past epidemics, but the precise ways in which it is different (Brand, 1988). A discussion of the specific nature of the stigma associated with HIV/AIDS will be elaborated in the next section.

3.3 HIV/AIDS stigmatization

As suggested in the previous discussion, HIV/AIDS carries its own ‘kind of stigma’; but also it is important to highlight that in order to be able to give an account of why it is more stigmatized than many other ‘deadly’ diseases, one needs to keep in mind that stigma is not a singular concept expressed and experienced in a common way (Fife & Wright, 2000). But rather, it has been suggested that it is a complex phenomenon expressed both subtly and overtly, and it is subjectively experienced in multiple ways that are partially dependent upon the nature of the stigmatizing condition and the social circumstances of the individual (Fife & Wright, 2000). Such an understanding points to the need to focus on interventions that take into consideration actions that consider distinct cultural and local context.

In this perspective, population surveys conducted in Brazil by Garcia et al. (2008) have enabled the assessment of some discrimination opinions in relation to HIV, and also the magnitude of this problem. The first national population based study that documented and related discriminatory opinions in relation to people with HIV, provided data with implications for public policies to fight stigma and discrimination in the country. The findings in this research show in general that individual actions reflect ideas and beliefs that are part of their economic and political structures which influence life in society. The study argued for a relationship between certain religious beliefs and increased stigma. In particular, it was shown, that the percentage of Evangelicals

increased from 9% in 1991 to 15.4% in 2000. This increase has been said to have had impacted on ways in which PLWHA are viewed and responded to among their communities in general and their church members in particular. This increase was attributed partly to the strengthening of political-religious leaderships reflected in the people's participation in their country's public life. Consequently this strengthening supported the demand for followers to adopt more conservative positions, which in return has been translated into drawing a moral line so that HIV/AIDS are viewed and treated as 'a virus and a disease from those who are sinners'(Garcia et al., 2008, unpaginated).

In another study conducted in five different African countries including South Africa, it was found that PLWHA experienced abuse in many ways. It was indicated in this study that abuse was experienced by men and women living with HIV/AIDS in all of these five countries. This study stipulated that verbal and physical abuse were frequently accompanied by neglect and refusal of basic services by the family, community, and health institutions. On this note, it was suggested that one has to look at other possible components of the environment to explain the incidence of this kind of stigma (Dlamini, Kobi, Uys, Phetlbu, Chirwa, Naidoo, Holzemer, Greeff, and Makoae, 2007).

Similarly, abuse of PLWHA has also been found in a study that was conducted in Tanzania by Nyblade et al. (2003). In this study PLWHA were verbally abused and called prostitutes and immoral. They were considered to have deserved contracting the disease, and hence a punishment from God. Therefore, PLWHA were blamed for getting HIV through bad behavior,

or from what has been termed by Hong et al.(2004) ‘the social evils’(Hong et al., 2004, cited in Dlamini et al., 2007: p.397).

Other local studies have shown that although AIDS stigmas appear to be declining somehow in the Republic of South Africa, it is still prevalent in some communities. In this light, a study conducted by the National HIV/AIDS household survey in South Africa in 2005 showed that AIDS stigmatizing beliefs had declined from the previous households survey reported in 2003 (Shisana et al., 2005). Nevertheless, it was highlighted in this study that 29% of South Africans stated that they would not buy food from a vendor who has HIV and 20% of South Africans stated in the same survey that HIV positive children should be kept separate from other children to prevent infection (Shisana et al., 2005).

Furthermore, research has also shown that stigma can impact on disclosure. This contribute to people’s hiding of their HIV status which may also have direct negative effects on disease progression for HIV positive individuals and an increased likelihood of engaging in unsafe sexual practices (Chesney & Smith, 1999; Thomas et al., 2005). In this respect, in a study conducted in Chennai in South India, it was found that there was a highly significant negative correlation between internalized stigma and quality of life (Thomas et al., 2005). This implies that when individuals internalize stigma they in-turn deny themselves the possibility of getting the support from their family and community which could in turn impact negatively on the quality of their lives and the likelihood to make them more sensitive to both actual and anticipated rejection.

In the same context, Kalichman et al. (2005) indicated that AIDS stigma poses barriers both for prevention and treatment in South Africa. In this regard, in a study that Kalichman and Simbayi conducted in 2003, it was shown on the one hand that people who had tested for HIV/AIDS had fewer AIDS stigmatizing beliefs than people who had not tested; on the other hand, it was suggested in this same survey that more than one in five people who had tested for HIV believed that people with AIDS cannot be trusted, should feel guilty, and should not be allowed to work with children. These findings suggested that AIDS stigmatizing beliefs were widely held in some population segments in South Africa, and these beliefs pose a substantial barrier to HIV prevention efforts, even among people who have been tested and counseled.

Moreover, it has been shown that people living in Cape Town, South Africa frequently endorse AIDS stigmatizing beliefs (Deacon, Stephney, & Prosalendis, 2005; Kalichman et al., 2005). For example in a qualitative research that focused on perceptions of HIV/AIDS stigma among Muslims in Cape Town, the findings show that Muslims in Mitchell's Plain were indeed engaging in various forms of HIV/AIDS stigma such as 'othering' the disease and passing moral judgment on people living with HIV/AIDS (PLWHA) (Abrahams, 2006).

Another study conducted in Cape Town aimed to examine the prevalence of discrimination experiences and internalized stigma among HIV-positive men and women. Findings in this study indicated an urgent need for 'social reform to reduce AIDS stigmas and the design of interventions to assist people living with HIV/AIDS to adjust and adapt to the social conditions of AIDS in South Africa (Simbayi, Kalichman, Strebel, Cloete, Henda & Mgeketo, 2007: 123). This survey indicated that 40% of persons with HIV/AIDS had experienced discrimination

resulting from having HIV infection and one in five had lost a place to stay or a job because of their HIV status.

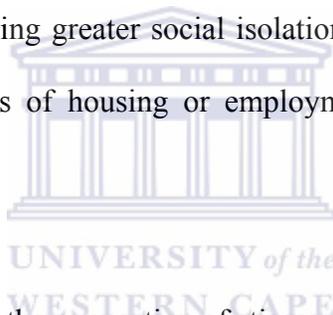
Arguably, it has been indicated that the HIV/AIDS epidemic has elicited both negative and positive responses from families and communities in South Africa (Siyam'kela, 2002). In this regard, it is important to understand the dynamics of family and community responses towards people living with HIV/AIDS. Finally, as argued before in the theoretical literature, AIDS stigma is sustained by power and domination. In the next section the discussion focuses on studies which provide empirical evidence of lived experience of these phenomena.

3.4 Gender, Sexuality, Power and HIV/AIDS stigma

As argued earlier, key to HIV/AIDS stigma has been a blaming discourse in which those living with HIV/AIDS have been viewed as responsible for their situation through what has been viewed as deviant and irresponsible sexual or other social practice. In this instance, Shefer (2004) noted that both popular and academic discourses on HIV/AIDS have served to construct blaming discourses, and inadvertently to produce and reproduce a picture of the illness as primarily a poor, black woman's illness who are then seen as responsible for the epidemic and for challenging it. Many authors and researchers (for example, Shefer, Strebel, Wilson, Shabalala, Simbayi, Ratele, Potgieter, and Andipatin, 2002; Skinner & Mfecane, 2004) argue that the intersection of gender inequality and HIV stigma has led to women in particular being blamed for spreading HIV and therefore experience more stigma than men.

In a study conducted by Simbayi et al. (2007) in Cape Town South Africa, it was noted that a small but consistent pattern of gender differences in AIDS discrimination experiences and internalized stigma was observed. This research shows that men and women experienced AIDS stigma differently. For example, while women were rejected after disclosing their HIV status, men were more likely to have suffered loss of a place to stay or job due to their HIV status.

The link of HIV stigma with other forms of sexual stigma, in particular gay sexuality is also evident in the local context. In a study which aimed to examine stigma and discrimination experiences of men having sex with other men, it was found that HIV positive men who have sex with other men reported experiencing greater social isolation and discrimination resulting from being HIV-positive, including loss of housing or employment (Cloete, Simbayi, Kalichman, Strebel, Henda, 2008).



Other studies have highlighted that the connection of stigma around HIV to historical racism and gender has developed a particular form of power and discrimination against PLWHA. It has been argued that blame is often assigned to black people or to women. Men blame women for infecting them and spreading the virus (Shefer, 1999; Madlala, 1997-2002) and AIDS has been mainly associated with black people (Skinner & Mfecane, 2004).

More generally, as argued before, HIV/AIDS plays to some deep-seated fears and anxieties; it also reinforces the pre-existing stigmas. As a result, racial and ethnic stigmas also contribute to the marginalization of minority population groups, increasing their vulnerability to HIV/AIDS, which in turn exacerbates stigmatization and discrimination. Arguably, media images of

HIV/AIDS as a woman's disease as suggested above, also as a disease of the prostitute, as an African disease or gay 'plague' reinforce these stereotypes and beliefs (Aggleton, Parker & Maluwa, 2003). It is argued that although these images are varied, they should not be seen as being random. They should be considered, in fact, as patterned in a way that ensures that HIV/AIDS stigma plays into, and reinforces, existing social inequalities (Aggleton et al., 2003).

Furthermore, studies have also shown that internalization of negative cultural views of HIV infection contribute to the pervasiveness of the stigma felt by PLWHA and the frequently blurring perception of the actual stigma in the community. In this regard in a meta-synthesis of qualitative findings on stigma in HIV-positive women; it was found that women anticipated being stigmatized, or felt stigmatized, even when they reported no specific stigmatizing act directed toward them (Sandelowski, Lambe & Barroso, 2004). On the other hand, it was found in this meta-synthesis that although most of the women studied contracted HIV infection in heterosexual and monogamous relationships, HIV positive women were often blamed for becoming infected and mostly the blame was linked to the assumption that they have contracted HIV through the use of drugs, promiscuity or prostitution (Ibid, 2004). Thus, women who had abused drugs felt more stigmatized or reported more instances of stigmatization because of their drug use than because of their HIV status (Sandelowski et al., 2004).

In conclusion, the empirical evidence in this review of literature has highlighted how HIV/AIDS stigma is, therefore, linked to power and domination throughout society and that the stigmatization of individuals and groups plays a key role in producing and reproducing relations of power and control (Aggleton et al., 2002; Aggleton et al., 2003; Parker & Aggleton, 2003).

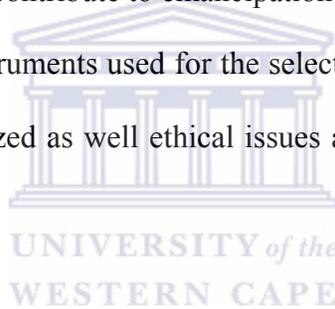
The empirical literature resonates with the theoretical literature in connection to how stigma is linked to notion of deviance and social control.



CHAPTER FOUR: METHODOLOGICAL FRAMEWORK

4.1 Introduction

This chapter provides the methodological framework of this study. The study is located within a feminist social constructionist framework and the prevailing motivation for the proposed research methodology is to highlight how gender power operates and how it is intersected with other forms of power and social identity such as race, class and illness identity amongst others. Feminist research methodology will also provide a basis for exploring how individuals construct their realities, while attempting to contribute to emancipation and transformation (Mies, 1991). A discussion of the methods and instruments used for the selection and recruitment of participants, how data was collected and analyzed as well ethical issues and reflexivity are presented in this chapter.



4.2 Feminist Scholarship and Gender

This study uses feminist theories that highlight how gender power operates. However, it is important to first introduce how feminist scholarship intersects with gender and ways in which gender as a social construct is used in the establishment of feminist scholarship. Davis et al (1991) argue that it is ‘mandatory’ to develop relevant philosophical and psychological grounds on which to discuss power relationships beyond the simple traditional conceptual framework.

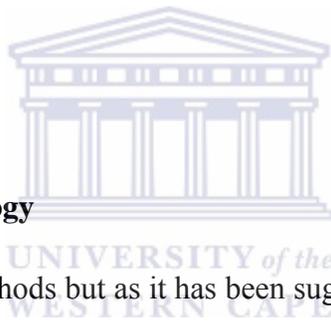
Moreover, in the history of how theory of power came to be included in academic scholarship, early feminists had to convince the predominantly male gatekeepers of academic resources that

gender inequality existed and, therefore, should be studied. It is argued in this instance that it was by introducing gender as a theoretical construct, that it became possible to transfer the understanding of relations between sexes from biological determinism to social constructionism (Davis, Leijenaar & Oldersma, 1991). Davis et al. (1991) continue to suggest that by establishing sexual difference as a social or cultural product, this shift helped in locating relations between the sexes with other socially structured relations of power.

Following this, it is argued that gender inequalities became part of the realm of the social and, 'more to the point, the political which implies in this instance, that power relations and gender asymmetries were acknowledged as socially produced and reproduced and, therefore, subject to transformation' (Davis et al., 1991:4). In short, Davis et al. (1991) assert that 'gender as a theoretical construct was instrumental in the emergence of feminist scholarship'. It is not surprising that it has created a platform for feminists to study a whole range of issues which had not been previously given merit and serious scholarly attention. It is, therefore, argued that the concept of gender has since moved from its original function, in which gender was used to distinguish between biology and society, and it has taken a new meaning where gender is used as a 'central' theoretical construct within the field of feminist scholarship (Davis et al., 1991: 8-9).

However, Davis et al. (1991) argue that the conceptualization of gender as the 'fundamental principle' for explaining gender divisions and inequalities does have some limitations. This implies the point made within feminist academic first limitation to the use of this concept within feminist academic which suggested that gender continues to be useful in revealing differences in male and female experiences, social positions and behavior. However, gender difference theories

have proven not to be useful on their own in providing account of why power comes to be produced, reproduced and transformed in the various contexts of everyday life (Davis et al., 1991). In this instance, it is important to keep in mind as Fee (1986) argues that relations involving domination and subordination are unequal in more than one way and that when investigated, it is discovered that all sorts of structured forms of domination are redefined in the process of political and ideological struggles; and that ‘they are never static’(Fee, 1986:53). The important point made then is to consider theoretical accounts that look at the problem of power in a much more critical and nuanced way. The application of these theories to the focus of the study has been illustrated in chapter two of this study and will inform the analysis and the discussion as well.



4.3 Feminist Research Methodology

This study utilizes quantitative methods but as it has been suggested before, it also uses gendered analysis. It is, however important to discuss the prevailing motivation to use feminist research methodology, as suggested above. In order to stay committed to feminist epistemology, as Burman (1991:124) states, this study will ‘highlight theoretical and political analysis that critiques dominant conceptions of knowledge, and poses questions about the gendered orientation of, and criteria for knowledge’.

Similarly, feminist research methodology provides a basis for exploring how individuals construct their realities, while attempting to contribute to emancipation and transformation (Mies, 1991). It has been often argued that a feminist approach to knowledge production needs to recognize essentially the importance of examining women’s experience. It is also of best interest

within feminist approach to stick to a constructive critical stance as highlighted above towards traditional knowledge-building claims that argue for ‘universal truths’ (Biber, Leavy & Yaiser, 2004: p3). In other words, Biber et al. (2004) argue that research that is conducted within a feminist framework should always be attentive to issues of difference, it should be more interested in questioning issues of social power, resistance to scientific oppression, and a commitment to political activism and social justice.

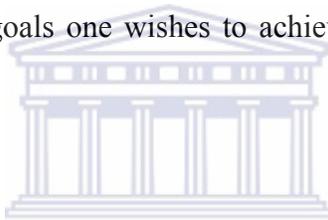
However, feminist researchers employ various strategies of enquiry that will differ depending on the purpose of the study, the nature of the research question and the skills and resources available to the research (Morse, 1994; Rubin & Rubin, 1995).

This research project used survey questionnaires as methods to collect data. This method enabled the researcher to gather sensitive data required for understanding the circumstances of the target community and its perceptions and viewpoints in terms of the topic of research. It can be argued that there are many research methods prescribed by feminist methodologies or research procedures (Kelly, Burton & Regan, 1994). What constitutes feminist methods depends on how the piece of research is evaluated in relation to its purposes or goals and what it seeks to achieve (Burman, 1991).

Some feminist researchers argue that feminism has a method of conducting social research, which is specific to it. However, it can be argued that there is no one feminist research method, as suggested above, a feminist method is evaluated via the ways in which the research is carried out and its purpose and goal. Maynard and Purvis (1994) conclude by saying that there are many

contestations surrounding the definition of what feminist research is, therefore, there is no one answer to this question. This also implies that to some extent the conflicting views about feminism and feminist research provide strong ground for feminism that is the acceptance of much different feminisms instead of one. This also requires the existence of many different feminists.

Moreover, there exist different ways in which feminist research methodologies are defined. As pointed out by Stanley and Wise (1990), feminist research is a focus on women carried out by feminist women, for women. But others argue that studies of men can be feminist too, as Burman (1994) argues it is the particular goals one wishes to achieve through research process, which constitutes a feminist study.



Furthermore, Mies (1983) argued that within feminist research, there is a contradiction between the prevalent theories of social science and methodology and the political aims of the women's movement, in other words, feminist research should be understood as political in its purposes and goals, and should be committed to the transformation of women's lives. This provides space for a critical analysis of men's lives, for example in a study that aims to explore the construction of male privilege. Similarly, Purvis (1991) indicated that studying women's lives as a feminist means that male dominance, masculinity and men are always part of, and will be challenged by the research.

With regards to this research which seeks to assess the difference between male and female with respect to stigmatization of PLWHA in one South African community, a feminist approach is

political in its attempt to acknowledge the existence of an unequal gendered treatment of PLWHA within this community and transformative in creating space for people to voice their views.

In conclusion, Roman (2006) suggests that even if there are many contestations within the ‘terrain of feminist methodology’, it should be noted that there some keys concepts and goals that most feminists researchers have in common. These include that research should be socially relevant; that it is never neutral, objective or unbiased; and finally that the importance of dynamics of research and therefore of self-reflexivity and acknowledgement of the researcher, should always be included in every piece of research.



4.4 Aims and objectives

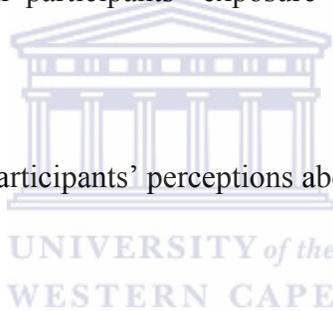
The present study is conducted as part of a larger project initiated by the Pennsylvania State University (PSU) and the Human Sciences Research Council (HSRC) in collaboration with the University of the Western Cape and the University of Limpopo from 2004 - 2008. The goal that has been set by this project is to be able to develop and sustain cultural and gender-based interventions for the elimination of stigma associated with HIV/AIDS prevention, care and support in South Africa.

In line with the above broad aim, the present study aims to investigate how HIV/AIDS, as a social construct, and those living with HIV/AIDS are understood and responded to by those living in one township in Cape Town that includes both those historically constructed by the

divisive policies of apartheid as ‘coloured’ and ‘African’, in the context of their daily encounters.

Within this aim the following key objectives guided the research:

- To explore the interaction of gender and race and their effect in HIV/AIDS stigmatization.
- To determine whether age, education and household situation are possible confounding factors on personal stigma attitudes and behaviours.
- To assess whether HIV/AIDS stigma is gendered and racialized.
- To illustrate differences in participants’ exposure to disclosure and familiarity with PLWHA.
- To indicate differences in participants’ perceptions about PLWHA.
- To describe participants’ perceived levels where they believe interventions to eliminate stigma should be prioritized.



4.5 Research Procedures

4.5.1 Methods of data collection

For this study, I recruited two hundred participants living in Mitchell’s Plain in Cape Town which was the target population. Mitchell’s Plain was chosen for one main reason, which is to allow comparison with previously collected qualitative data on stigma in this community. I recruited potential participants with the assistance of community leaders. The entry into this

community was facilitated by a contact person living in this community. I introduced myself to the leadership of this community one month before I started to collect data. As mentioned before this study is part of a broader research project that involves the partnership between the Human Sciences Research Council (HSRC), the Pennsylvania State University (PSU), UWC (University of the Western Cape) and the UL (University of Limpopo). An introduction letter from the HSRC office in Cape Town (Appendix 1), that introduces both the researcher and the research project to the community, was presented. I then followed the procedures that were asked from the community leadership in order to start collecting data. An informed consent (see appendix 2) form as well as the questionnaire (see appendix 3) of this study was approved by the Penn State University ethics committee as well as the University of the Western Cape research committee.

Data collection for the study took place between June 2008 and December 2008. Training of the data collection team was conducted at the HSRC offices in Cape Town in January 2008, with the HSRC coordinators of the HIV/AIDS stigma project. The researcher team included 7 students, Masters Candidates and research followers in this project as well as their mentors. The training lasted for one week and covered the following topics: understanding HIV/AIDS stigma based on the results from previous qualitative studies conducted in the last 4 years of this project, the study (project objectives), different areas of research focus and finally data collection procedures and ethics. Before we could start the collection of data, questionnaires were edited by the research team in August 2008.

For the purpose of accessibility, convenience sampling was used to acquire participants from communities representing both African and Coloured population in Mitchell's Plain. Field

workers approached people in different communities and efforts were made to recruit a diverse sample within this community. The sample was representative of the proportions of people in categories of gender and population group, with the majority between the age of 35 and 49 years (see table1 below). Participants were recruited from multiple venues in Mitchell's Plain area located about 20 km from Cape Town. It is South Africa's 4th largest townships, although looking at Mitchell's Plain's growth rate it is probably the 3rd largest township in South Africa and in Cape Town is 2nd in size only to Khayelitsha. It is located on the Cape Flats on the False Bay coast between Strandfontein and Khayelisha. Conceived of as a "model township" by the apartheid government, it was built during the 1970s to provide housing for coloured victims of forced removal due to the implementation of the Group Areas Act. However, Mitchell's Plain is no longer officially considered a 'coloured' township, as it is slowly changing into "a coloured African township". In a population profile of Mitchell's plain, which was compiled by statistics SA census data; it is indicated that 84.2% of the Mitchell's plain population indicated their population group as coloured, and 14.9% as Black African (statistics SA census, 2005).

As already mentioned above, in order to be able to choose respondents to include in the study, we recruited them from sites in the communities where people gather mostly for different activities such as community centre and libraries as well as at work in a textile factory shop that generally employ a large amount of women in Mitchell' Plain. Together with fieldworkers, we recruited 200 participants. 40% of participants were recruited at the community center as well as in the factory shop, the rest 60% of the total sample were recruited via community meetings. The researcher in collaboration with a trained field worker in building relationship with people as well in data collection methods have identified different contact people living in different sites in

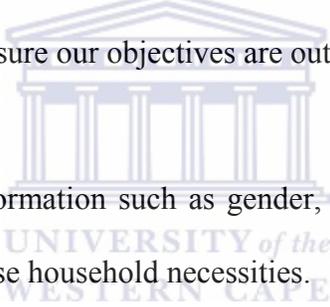
Mitchell's Plain community. These contact people organized 4 community meetings in 4 different sites from which 140 people both men and women and African and Coloured were randomly selected. We recruited 20 males and 20 females in the first meeting, in the second meeting we were able to recruit 40 (both males and females) and finally in the third and fourth meeting we were able to recruit 60 more participants. The selected people were each time asked if they will be interested to participate in this study. They were briefed about the aim and objective of the study and after satisfaction and accepting to participate willingly, a date was given to them for the survey. The interview took place in three different days, each on a Saturday as most participants preferred so. The total number of people who agreed to participate was 140 and on the first two days we interviewed 100 participants both male and female, on the third day we interviewed 40 people. There were some discrepancies where some identified themselves as blacks while in the recruitment process the assumption was that they are coloureds, reason why the percentage of blacks is slightly higher of 1% than coloureds. The questionnaire took about 30-45 minutes to complete.

In the factory shop, the researcher and the fieldworker approached the managers of the factory shop and requested to conduct the research. The aims and objectives were explained and the manager extended the invitation to start the survey. We were given time slots for the interviews to be taken without causing inconvenience to the work. We recruited 60 people from the factory including 40 women and 20 men. We were given a list from the manager of all people both men and women in different age category who reside in Mitchell's Plain and every third person on the list was selected. The interview took place during tea time and lunch time in four days. In order

to get same proportions of male and female, we recruited 20 participants at a community library mostly youngsters aged from 18 and above. A sample of 200 participants was then obtained.

4.5.2 Measures

Participants completed anonymous self-administered surveys in English, with translation in both Afrikaans and IsiXhosa, which was provided in times when required. As I have mentioned elsewhere, this study is part of a larger project being conducted by the HSRC with its partners and therefore the instrument used (see appendix 3) was designed for this larger project. For the purpose of assessing stigmatization discourses, the study drew on other studies to set up clear domains of stigma which all included a number of different items on the questionnaire. Measures chosen from this instrument to measure our objectives are outlined below:



Section 1: Socio-demographic information such as gender, population group, age, educational level and people's ability to purchase household necessities.

Section 2: Respondents' exposure to and familiarity with HIV/AIDS and people living with HIV. Six items from the questionnaire (see question 3.1 appendix 3) formed this domain. These questions served to measure the degree to which participants have experienced disclosure of HIV status by members of their family and community at large. This domain was included mostly because it is assumed that there may be some link between stigma in the community and families and the extent to which people are exposed to disclosures, since such disclosure or lack thereof may be indicative of the degree of comfort of those living with HIV to be open about their status in their families and communities. Participants were asked to report whether a partner, a parent, own child, colleague, friend and relative have disclosed to them. A reliability test was performed

for the total items and the Cronbach's Alpha was 0.581. The scale was considered average to use in this present study (Cook & Campbell, 1979).

Section 3: Perceptions about PLWHA were assessed using 4 questions concerning how HIV/AIDS and PLWHA are socially constructed, including items which assess the extent to which participants subscribe to some of the incorrect stereotypes related to those living with HIV/AIDS. The questions asked participants whether they can recognize someone with HIV or AIDS and whether AIDS is detectable by appearance. The items were used to classify participants into groups based on whether they perceive HIV and AIDS and those living with it to be recognizable by simple appearance and therefore as different from others. The reliability of the scale was considered as moderate to use in this present study with Cronbach's Alpha of 0.622. The specific questions were:

“Can you recognize someone with HIV?”

“Can you recognize someone with AIDS?”

“Thin people are more likely to contract HIV”

“People who lose weight are more likely to be HIV positive”

Section 4: this section consisted of questions related to participants' perceptions of the need to address HIV stigma. The questionnaire included 6 items that asked participants to report where they think emphasis to eliminate shame and rejection associated to HIV and AIDS and PLWHA should be prioritized. Such items also give one an idea of where participants think most of the problems with stigma and its impact lie. Participants ranked 3 most important levels between

family, community, hospital, provincial government and national government. This domain was included in order to inform future interventions.

Section 5: Gendered stigmatization discourses were assessed using 5 items which asked gendered questions about how men and women living with HIV and AIDS are responded to in their family and community. These questions were drawn on to assess whether participants subscribed themselves to gendered stigmatization and/or whether they believe that HIV/AIDS stigma is gendered. The reliability scale was performed for these items and the Cronbach's Alpha was 0.778 which is considered appropriate to use in this present study. The specific questions are as follow:

Females living with HIV/AIDS are treated worse by their families than their male counterpart

If a female member of my family is/was HIV positive I would more likely to reject her than a male member who is HIV positive

If a male member of my family is/was HIV positive I would be more likely to reject him than a female member of my family who is HIV positive

Female are to blame for the spread of HIV

Men are to be blamed for the spread of HIV

Section 6: a stigma scale consisting of 10 items were used to measure personal stigma attitudes and behaviours. The questions used reflected different underlying components of HIV/AIDS stigma, namely shame, blame and judgment of PLWHA as well as individual support/discomfort of PLWHA. In this regard, previous research found that shame, blame, and judgment are key underlying components of HIV/AIDS stigma (Horizons et al., 2003; Nyblade et al., 2003; POLICY Project 2003; Nyblade et al., 2005, Visser et al., 2008-2009). In addition, Green, (1995

cited in Visser et al., 2006) argues that in order to be able to assess the level of stigma in a community, one need to assess the personal perceptions or beliefs about HIV/AIDS within members of the community.

Thus, this domain measured primarily what Visser et al (2006-2008) term personal stigma. They have designed two stigma scales adapted for the South African context. These two stigma scales included personal and perceived community stigma. They have defined personal stigma as the individual's attitude based on personal experiences, while the perceived community stigma focuses on the observation of the reaction of other people in a particular community (Visser et al., 2008-2009).

The stigma scale was obtained with the help of the statistician who is a visiting Professor at UWC from the University of Missouri in USA. A total score for Stigma was obtained as follows: Ten items measuring personal stigma answered as 1 for agree and 2 for disagree were used. A 3 (corresponding to undecided relative to agree or disagree) was set to missing. However there were also a few missing values where an item may have been skipped. The responses to the 10 questions were recorded to a 1 (for agree) and a 0 (otherwise). When values were missing, they were replaced with the mean score of the non-missing values for that subject. The Stigma score was then taken to be the sum of all 10 responses. The following items formed the personal stigma scale:

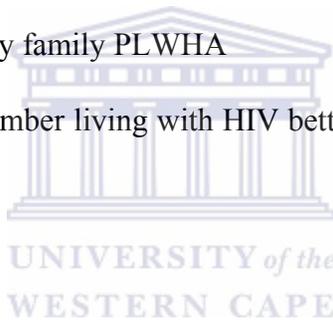
1. Shame and judgment

- A person who contract HIV should be shamed
- A person who contract HIV trough sex should be shamed

- A person who contracts HIV through the use of drugs should be shamed
- PLWHA are a financial drain to our economy
- Given two well-qualified applicants for a job I will support hiring an HIV negative

2. Individual support of PLWHA and/or personal distancing for people living with HIV and AIDS.

- I support community events that support PLWHA
- I participate in community events that support PLWHA
- I would eat meals cooked by my family member if they ever lived with HIV and AIDS
- I would share meals with my family PLWHA
- I would treat my family member living with HIV better than I treat the one who does not have a job



4.5.3 Validity and Reliability

For the purpose of this study, content validity has been applied to ensure validity of items chosen to measure stigma. Content validity has been referred to as a scale which relates to the extent to which an item, or specific set of items, truly reflects the content of a particular domain. It is also believed that content validity is assured by choosing items that are supported by existing data and by having experts review items. In this regard, as it has been noted elsewhere, this study is part of a bigger project that involves the partnership between the Human Sciences Research Council (HSRC), the Pennsylvania State University (PSU), UWC (University of the Western Cape) and the UL (University of Limpopo). For this reason, the questions used in this study were reviewed by experts in the quantitative research field from the above mentioned institutions. The

choice of items in the questionnaire were also chosen based on existing data, in particular the collective work and expertise of the working report measuring HIV stigma in Tanzania, supported and published by the USAID in 2005 (Ogden & Nyblade, 2005) as well the stigma scale compiled by Visser et al. (2008) for the south African context and Kalichman et al. (2005). In addition to content validity, a reliability test was performed for items that measured different stigma domains.

4.5.4 Managing the Survey Data

In November 2008, all survey responses were captured in Microsoft Excel and they were checked for errors, consistencies, and gaps. Data entry was also checked for accuracy by an outside corroborator. Subsequently the Excel file was imported into SPSS for analysis. Once in SPSS all data were prepared for analysis. Descriptive Statistics have been calculated in order to check and verify the sample size (n) and range (maximum and minimum) for each variable.

4.5.5 Analytic Methods

Both descriptive and inferential statistics were used to analyze data in this study. Descriptive statistics namely frequencies expressed as percentages were used to describe the characteristics of the sample. The descriptive data was presented in the form of tables and bar-charts. Cross-tabulation was performed to assess gender and racial differences with respect to respondents' exposure to HIV, respondents' perceptions about PLWHA as well as participants' subscription to gendered stigmatization. Measures of associations such as Chi-Square, Phi and Cramer's V were used to identify the significance of the differences (alpha) at 0.05. In order to be able to examine the relationship between personal stigma and factors of race and gender (and their interaction) as

well as to determine whether age, education and household situation were possible confounding factors on this relationship, an analysis of variance was used. This was followed by calculating the mean difference in personal stigma score and age and education by gender and race category. A correlation between personal stigma and age, education and household situation was also given.

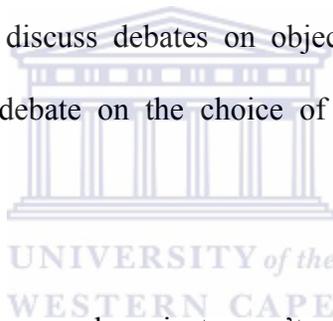
4.6 Ethical Considerations

In line with standard social science code of ethics and the ethical requirements of UWC and Arts faculty ethics committee, participants were assured of confidentiality and anonymity. They were advised not to use their names during the completion of the survey. Participants were given an informed consent contract, which was carefully explained to them before they signed it and which served to protect both the researcher and the participants. Major element of 'informed consent contract' according to ASA Code of Ethics (1988) is that participants must be informed about the aims and the nature of the study. The informed consent form also stated clearly that participants have the right to withdraw from the study at any time without any further consequences. Goduka (1990) points out that the researcher must make sure that participants understand the complexities of the research process for it is mostly assumed that they understand the whole informed consent form, which they sign and return to the researcher before their participation into the research project. The questionnaires were available in three different languages namely English, Afrikaans and IsiXhosa. Participants had a choice of using one of these languages. The HSRC further organized an interpreter in each of these three languages and for those participants who cannot read and write, the survey questionnaire was self-administered

4.7 Reflexivity

As has been discussed before, this study uses a feminist methodology, and it is framed within feminist social constructionism. Arising from the historical context of feminist consciousness-raising and summarized within the phrase ‘the personal is the political’, it is argued that experience is central to feminist politics and forms the cornerstone of conducting research (Hughes, 2002).

My decision to reflect on my experience of undertaking this research project comes in striving to illustrate the centrality of experience to feminist epistemology. In this regard, as Hughes (2002) also suggested it is important to discuss debates on objectivity and the role of personal in feminist theory and research. A debate on the choice of the method used in this study is important to illustrate this.



Using quantitative methods in this research project wasn't entirely a personal choice but mostly what is important to mention is that it has helped me to rethink feminism or rather feminisms. As a feminist academic, I was aware of many criticisms that have been associated with the use of positivistic observations. Under this framework the researcher must develop hypotheses about causal relationships between variables. While, I have designed my study in a similar manner, and have tried to understand the relationship between different variables, I was very aware that the social patterns which were being studied in this research project are not ordered and thus cannot be predictable.

Similarly, while it has been argued that positivist science has historically denied the relationship between theories of knowledge and the use of methods, I have tried to understand this linkage and it became obvious to me during the process of conducting this research that one cannot conduct research which disconnects theories from the selection and application of research methods. Thus, feminist theories have informed the whole process of conducting this research project, from the choice of the topic, its aims and objectives to the collection of data and its analysis.

In doing so, I have tried to follow feminist critiques of empiricism which began asking important questions about the nature of social reality (Nielsen, 1990 cited in Biber et al., 2004). It was through such guidance that I was able to understand that issues such as stigmatization of PLWHA cannot be addressed from an individualist point of view. It was also through constant reflectivity on the methods used that I kept in mind that power is the key underlying stigmatization discourses and practices. Therefore, one cannot just compare and contrast variables and report descriptively on them, but one also needs to link the finding to theories that address and question issues of power and social reality.

However, I am also aware that some key criticisms of conducting empirical and especially quantitative studies were not easy to overcome. For example, while I have tried to minimize the power relations between the researcher as the knower and participants by providing information and explaining the aims and objectives of this study to my participants; I have observed that the design of survey questionnaire do not give enough room of discussion on the topic. Some of the answers to questions in my study have actually stimulated a further investigation.

I have however learned a range of lessons through the use of quantitative methods. I feel that a survey questionnaire alone is limited in what it can offer, and would argue that mixed methods in a research project could offer more holistic insights when conducting research on social realities.



CHAPTER FIVE: DATA ANALYSIS

5.1 Introduction

This chapter deals with the presentation of findings and their analysis. The primary aim of this study was to understand whether HIV/AIDS as a social construct and those living with HIV/AIDS are responded to differently by males and females; and previously classified as African and Coloured participants in the context of their daily encounters. Hence, results were analyzed and presented within the framework of the key research objectives of this study. Descriptive statistics (frequencies and percentages) was used to describe the characteristics of the sample. Cross-tabulations were performed to illustrate whether there were gender and racial differences with respect to respondents' exposure to HIV, respondents' perceptions about PLWHA as well as participants' subscription to gendered stigmatization. Measures of associations such as Chi-Square, Phi and Cramer's V were used to identify the significance of the differences (α) at 0.05. Mean as a measure of central tendency was used to describe differences in personal stigma score with age and education by gender and race categories. Correlation between personal stigma and age, education and household situation was also carried out. Finally, an analysis of variance was used to explore the interaction between gender and race; their effects on personal stigma as well as to determine whether age, education and household situation are possible confounding factors.

5.2 Participants' demographic background

The sample was conveniently selected in Mitchell's Plain sub-communities. With respect to population group and gender 50.3 % of the respondents were male, while 49.7 % were female

with the majority between age 35 and 49 years; the majority of the respondents were Africans of Xhosa speaking heritage (49.2 %) and coloureds (48.2 %) (Table 5.1). Half of the participants were unemployed, but majority had secondary school education or some form of education beyond high school. A 37.2 % of the respondents had no means to survive (e.g. they could not afford to buy food or clothes) while a 38.7 % reported being able to afford basic things such as buying foods and clothes (see Table 5.1).

5.3 Respondents' exposure to and familiarity with HIV and AIDS and PLWHA

5.3.1 Description of respondents' exposure to HIV

The willingness of people in disclosing their HIV/AIDS status to family members and community as a whole is an important feature to be evaluated in this study. This is relevant because studies have shown that there exist positive correlation between disclosure and stigmatization of PLWHA. It has also been indicated that the more people are exposed to HIV, the lesser stigma attitudes they display (Herek et al., 2003; Kalichman & Simbayi, 2003). Respondents' HIV/AIDS experiences, which broadly refers to exposure to those disclosing or living with HIV/AIDS is shown in Table 5.2. The majority of the respondents reported they have not had a person disclosing his or her HIV status to them, be it a partner (95.5 %), parents (97 %), own child (96 %), colleague (92 %), neighbor (85.9 %), relative (84.9 %) and friends (79.4 %). Conversely, a meager 4.5 % indicated their partner had disclosed to them, 3 % reported their parents have disclosed to them, while 4 % reported their children had disclosed their HIV status to them. Moving away from the family setting, it was observed that a small but consistent growing percentage of people had experienced disclosure of HIV status by their neighbour (14.1 %), relatives (15.1 %) and friends (20.6 %).

Table 5.1: Demographic background of respondents

<i>Socio-demographics Background</i>	<i>n (%)</i>
Total Sample	200(100)
Gender:	
<i>Male</i>	100(50.3)
<i>Female</i>	99(49.7)
Population group:	
<i>Coloured</i>	98(49.2%)
<i>African</i>	96(48.2%)
Age:	
<i>18 - 34 years</i>	75(38.3)
<i>35 - 49 years</i>	88(44.9)
<i>50+ years</i>	33(16.8)
Education:	
<i>No formal Education</i>	2(1.0)
<i>Primary</i>	25(12.9)
<i>High School</i>	98(50.5)
<i>Matric</i>	54(27.8)
<i>Tertiary</i>	15(7.7)
Employment Status:	
<i>Yes</i>	101(53.4)
<i>No</i>	80(42.3)
<i>No response</i>	8(4.2)
Household Purchases:	
<i>No money</i>	74(37.2)
<i>Money Basic</i>	77(38.7)
<i>No luxury</i>	30(15.1)
<i>Extra luxury</i>	3 (1.5)
<i>Don't know</i>	1(0.5)
<i>No response</i>	14(7.0)

Table 5.2: Respondents' exposure to HIV and AIDS

Indicate if someone you know/knew has disclosed his/her HIV status to you	Yes N (%)	No N (%)	Total N (%)
Partner disclose	9(4.5%)	190(95.5%)	199(100%)
Parent disclose	6(3%)	193(97%)	199(100%)
Own child disclose	8(4%)	191(96%)	199(100%)
Neighbor disclose	28(14.1%)	171(85.9%)	199(100%)
Relative disclose	30(15.1%)	169(84.9%)	199(100%)
Friend disclose	41(20.6%)	158(79.4%)	199(100%)

5.3.2 Respondents' exposure to HIV and AIDS by gender and 'race'

Table 5.3 summarizes respondents' indication of knowing someone disclosing his/her HIV status to them. This includes those respondents who know someone living with HIV and those who indicated they have not had either a partner, a parent, own child, neighbor, relative and finally friend disclosing his/her HIV status. In analyzing variations between Africans and coloureds; male and female with respect to disclosure or knowing someone living with HIV, differences along racial and gender line was evident in that more African females have been exposed to disclosure of HIV status by a member of their families than the African males had been. Hence, it appears that amongst participants, African females are more likely to be exposed to HIV by their relatives than the rest of participants. 35.3 % of African females compared to 14.9 % of African males have had a relative disclosing to them. The standard chi-square test of independence indicates evidence of the significance of the gender and racial difference in relation to participants' exposure to HIV and their familiarity with PLWHA ($p=0.021$).

Furthermore, it can be inferred from Table 5.3 that the difference between male and female in terms of their exposure to and familiarity to HIV/AIDS and PLWHA was mediated by their race.

However, this was significant among the African population only, which is indicative that among coloured families, PLWHA are less likely to disclose their HIV status to their family members or their community in general. Studies have shown that stigma and internalised stigma may deter HIV positive people from disclosing their HIV statuses to members of their family and community in general (Hays et al., 1993; Chesney & Smith, 1999; Thomas, Suryanarayanan, Josephine, Dilip, Dorairaj, & Swaminathan, 2005; Simbayi et al., 2007). On the other hand, research have also shown that the rate of HIV is higher among Africans than coloureds which might had been the reason why more Africans have had someone disclosing to them than the coloureds had been.

Table 5.3: Disclosure of HIV status by a family member or friend to respondents

Relative disclose***		Gender			Chi-square	Phi	Cramer's V
		Male N (%)	Female N (%)	Total %			
African	Never	40 (85.1%)	33(64.7%)	73(74.5%)	0.021*	0.021	0.021
	Yes	7 (14.9%)	18(35.3%)	25(25.5%)			
	Total	47(100%)	51(100%)	98(100%)			
Coloured	Never	49(98.0%)	42(91.3%)	91(94.8%)	0.140**	0.140	0.140
	Yes	1(2.0%)	4(8.7%)	5(5.2%)			
	Total	50(100%)	46(100%)	96(100%)			

Notes: * shows where p-value is significant ($p < 0.05$)

** shows where p-value is not significant

*** Only items with p value significant ($p < 0.05$) are reported

5.4 Participants' perceptions of the need to address HIV/AIDS stigma

The focus on the family regarding stigma emerged from responses to the question about where emphasis should be placed for eliminating shame and rejection associated to HIV and AIDS. The participants were asked to rank where they think emphasis for eliminating shame and rejection associated with HIV/AIDS should be prioritized (see Appendix 3, Question 11). As shown in Table 5.4, most of the participants appear to feel that the family is most important in the elimination of stigma associated with HIV/AIDS.

Table 5.4: Eliminating shame and rejection associated with HIV/AIDS

	Yes N (%)	No N (%)	Total
Family level	182 (91.5%)	17 (8.5%)	199(100%)
Community level	159 (79.9%)	40 (20.1%)	199(100%)
Hospital level	124 (62.3%)	75 (37.7%)	199(100%)
Provincial Government	27 (13.6%)	172(86.4%)	199(100%)

Note: N=200 (One questionnaire was dropped because of missing data)

5.5 Perceptions about PLWHA

5.5.1 Descriptive results: perceptions about PLWHA

Given the huge concern that PLWHA are stigmatized in families and communities; the existence of numerous myths about who is living with HIV; and a strong association of PLWHA with illness and poverty, this study on the contrary reported majority of the respondents' perceptions of PLWHA were non-stereotypical. Majority of participants did not subscribe to the myth that HIV/AIDS can be detected by simply looking at the person, and a large proportion of

participants reported not being able to recognize someone with AIDS (Fig. 5.1, 5.2, 5.3 & 5.4). While the findings of this study is indicative that the majority of people are not subscribing to ‘othering’, mythologizing and stigmatizing discourses which socially construct PLWHA as different from other individuals, it is of concern that the majority had never had any of their family members disclosing to them which may relate to issues of trust linked to stigma (see Table 5.4 where 91.5% indicated family as a source of shame and rejection). Fig. 5.1, 5.2, 5.3 & 5.4 illustrated the proportion of those who believe that people infected with HIV are different from others or that PLWHA are recognizable by their appearance. In addition to this, although the percentages of these findings appear to be low, the percentages of those who agree are still meaningful number that one can’t ignore considering the effects and impact of stigmatizing attitudes and behaviours (e.g. on fig.5.1 19.6% indicated that they can recognize someone with HIV and in fig. 5.2, 27% indicated that AIDS is visible).

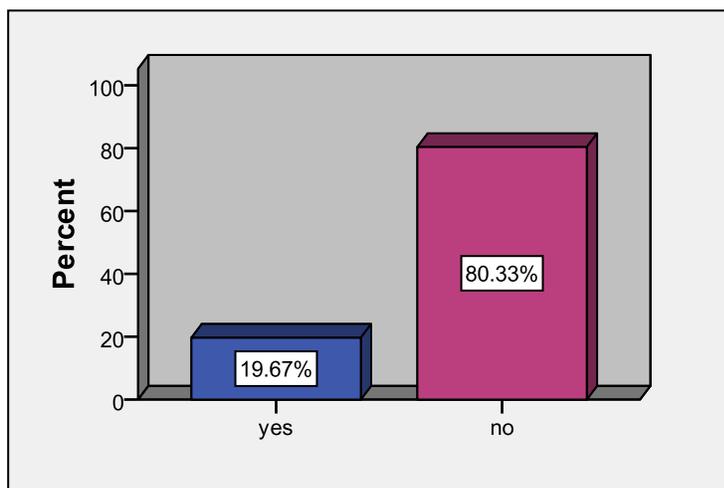
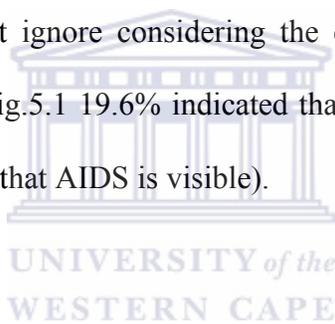


Fig. 5.1: Recognizing someone with HIV

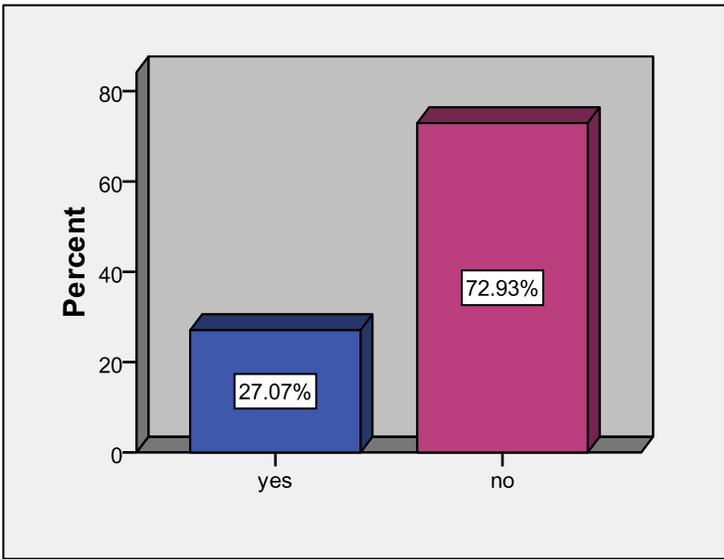


Fig. 5.2: Recognizing someone with AIDS

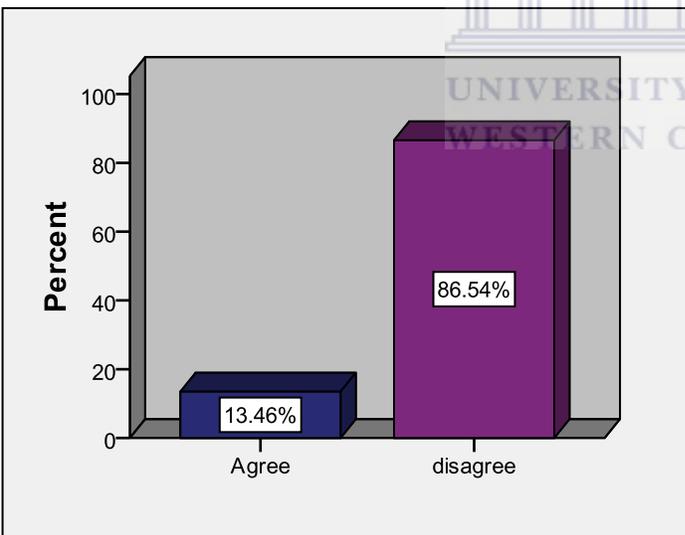


Fig. 5.3: Perception that HIV positive people lose weight

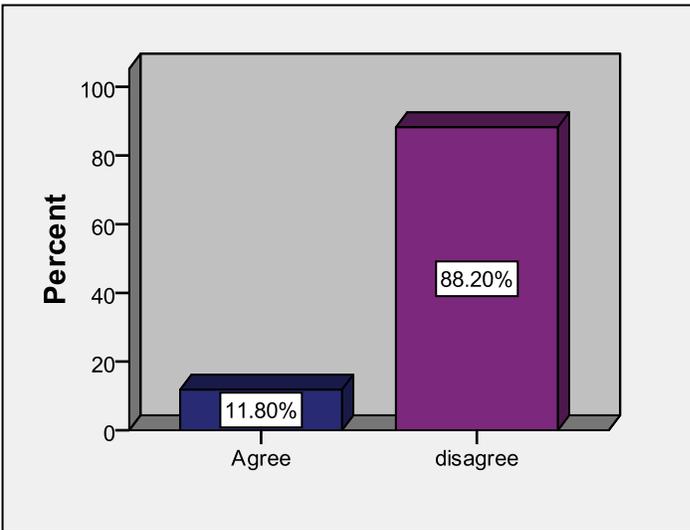


Fig. 5.4: Perception that thin people are more likely to be HIV positive

5.5.2 Gender and racial differences in participants' perceptions about PLWHA

In analyzing differences that could be present between male and female and African and Coloured participants, there were no significant gender differences observed among participants nor any differences across 'race' in terms of their perceptions (subscriptions to stereotypical notions that you can 'tell' someone living with HIV) about PLWHA ($p > 0.05$) as shown in Table 5.5. It can only be speculated why perceptions about PLWHA do not differ among male and female and African and coloured participants. One of the interpretations of this finding could be that knowledge about HIV/AIDS could be high in this community, and therefore people understand that HIV and AIDS cannot be detected by simple appearance. This finding could also be an indication that the availability of anti-retrovirals has made a difference in the lives of PLWHA which subsequently reduces the tendency for others to perceive those living with HIV/AIDS as different from other people as used has been documented as a common tendency previously.

Table 5.5: Differences in participants' perceptions about PLWHA by gender and 'race'

Population group		Can you recognize someone with HIV			p-value (sig.2sided)	Can you recognize someone with AIDS			p-value (sig.2sided)
		Male n (%)	Female n (%)	Total n(%)	Chi-Square	Male n (%)	Female n (%)	Total %	Chi-Square
African	Yes	13(23.3%)	13(27.1%)	26(27.7%)	0.247*	22(55%)	20(42.6%)	42(48.3%)	0.898*
	No	33(71.7%)	35(72.9%)	68(72.3%)		18(45%)	27(57.4%)	45(51.7%)	
	Total	46(100%)	48(100%)	94(100%)		40(100%)	47(100%)	87(100%)	
Coloured	Yes	3(6.8%)	5(12.2%)	8(9.4%)	0.786*	4(8.5%)	3(7%)	7(7.8%)	0.396*
	No	41(93.2%)	36(87.8%)	77(90.6%)		43(91.5%)	40(93%)	83(92.2%)	
	Total	44(100%)	41(100%)	85(100%)		47(100%)	43(100%)	90(100%)	
		People who lose weight are HIV positive				Thin people are more likely to be HIV positive			
African		Male	Female	Total	p-value (sig.2sided)	Male	Female	Total	p-value (sig.2sided)
	Yes	7(20.6%)	7(18.9%)	14(19.7%)		7(20%)	8(19%)	15(19%)	
	No	27(79.4%)	30(81.1%)	57(80.3%)		28(80%)	34(81%)	62(80.5%)	
	Total	34(100%)	37(100%)	71(100%)		35(100%)	42(100%)	77(100%)	
Coloured	Yes	2(4.5%)	5(13.9%)	7(8.8%)	0.141*	1(2.4%)	3(7.9%)	4(5.1%)	0.269*
	No	42(95.5%)	31(86.1%)	73(91.3%)		40(97.6%)	35(92.1%)	75(94.9%)	
	Total	44(100%)	36(100%)	80(100%)		41(100%)	38(100%)	79(100%)	

Note * shows where p-value is not significant ($p > 0.05$)

5.6 Gendered stigmatization

5.6.1 Participants' subscription to gendered stigmatization

As indicated in the aims of this study, in addition to exploring gender and racial differences in respect to how participants responded to those living with HIV/AIDS and HIV/AIDS in general, the study also sought to examine whether stigma was gendered. Table 5.6 illustrates the frequencies and proportions of participants' responses with individual items measuring gendered stigmatization.

Table 5.6: Descriptive results: Gendered stigmatization

Gendered stigma attitudes	Agree N (%)	Disagree N (%)	Total (Both) %
Females living with HIV/ AIDS are treated worse by their families than their male counterparts	63(31.7%)	74(37.2%)	137(68.8%)
If a female member of my family was HIV positive I would be more likely to reject her than a male member who is HIV positive	29(14.6%)	134(67.3%)	163(81.9%)
If a male member was HIV positive I would be more likely to reject him than a female member who is HIV positive	24(12.1%)	132(66.3%)	156(78.4%)
Male are to blame for the spread of HIV	52(26.1%)	115(57.8%)	167(83.9%)
Female are to blame for the spread of HIV	23(11.6%)	148(74.4%)	171(85.9%)

Note:N=200

As shown in Table 5.6, the majority of participants disagreed on almost all items measuring gendered stigmatization. However, given the fact that stigma hampers efforts to combat HIV, the small proportions of those who agree on a number of items are still considered to be high in terms of stigma level. Results show that 26 % of participants blame males for spreading the HIV/AIDS pandemic while only 11.6 % blame females. These results are in contradiction with previous qualitative studies indicating that women are more likely to be blamed for the spread of HIV/AIDS than their male counterparts. However, it is also important to note that 31.7 % of the participants indicated female HIV positive people are treated worse than their male counterparts within their own families. As indicated earlier, these proportions are still considerably high given the impact of stigma on PLWHA and AIDS prevention in general.



5.6.2 Gender and racial differences in participants' subscription to gendered stigmatization

Given the impact of pre-existing stigma associated with gender, race, sexuality and many other social identities, it is imperative to give more attention to issues of difference in this study. As suggested, previous studies have argued PLWHA are stigmatized as a result of belonging to a group or community that are already stigmatized or defined in a negatively manner. Herek and Glunt (1988) argued HIV/AIDS stigma is layered on pre-existing stigma and as a consequence, reactions to PLWHA and HIV/AIDS are generally directed to gay men, women, drug users and racial minorities as well those considered outsiders in general. It has been strongly argued by many researchers that women and African people in general are more stigmatized than others. Hence, in addition to looking at gender and racial differences in participants' personal stigma attitudes and behaviours, the extent to which there were gender and racial differences in participants' subscription to some of the 'othering' discourses about PLWHA was explored.

In analyzing gender differences, we observed that male and female did not differ in terms of their responses to the items that measured gendered stigmatization.

Table 5.7: Participants' subscriptions to gendered stigmatization by gender

Gendered stigma	Male N (%)			Female N (%)			Exact sig. (2 sided)
	Agree	Disagree	Total	Agree	Disagree	Total	
Female are treated badly	66(66%)	34(34%)	100(100%)	55(57.9%)	40(42.1%)	95(100%)	0.244**
Male are rejected	36(36.4%)	63(63.6%)	99(100%)	26(27.4%)	69(72.6%)	95(100%)	0.179**
Female are rejected	36(36%)	64(64%)	100(100%)	25(26.3)	70(73.7%)	95(100%)	0.145**
Male are to blame	39(48.1%)	42(51.9%)	81(100%)	13(15.9%)	69(84.1%)	82(100%)	0.110**
Female are to blame	15(18.3%)	67(81.7%)	82(100%)	8(9.5%)	76(90.5%)	84(100%)	0.521**

Note: * indicate where $p < 0.05$, ** indicate where $p > 0.05$; Total N=200

Table 5.7 shows the differences between male and female with respect to their subscriptions to 'othering' discourses that define males and females differently and allow different justifications for stigmatizing them in different manner. Results revealed the difference between males and females was not statistically significant for all items measuring this domain. However, although the difference between males and females is not statistically significant, it is still relevant to indicate that the proportions for some of the items measuring this domain are high. For instance, the majority of both males (66 %) and females (57 %) agreed women living with HIV/AIDS are treated worse in their families than their male counterparts are. On an interesting note, almost the

majority of males (48.1 %) compared to 15.9 % of females blamed males for spreading HIV and AIDS.

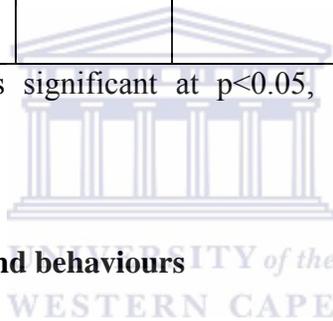
Furthermore, the relationship between being identified as African and/or coloured and the belief that PLWHA are shamed, blamed and or judged by their communities or by their family members; and/or the ability to display behaviors which include shame, blame and judgment towards PLWHA was significant for various items measuring this stigma domain. It can be seen that the same items that were scored highly by both males and females are now statistically significant between African and Coloured participants.

As shown in Table 5.8, majority of African participants (70.4 %) compared to 53.3 % of coloureds believed female HIV positive people are treated worse by their family members than their male counterparts, while 48.1 % of Africans compared to 15.9 % coloured participants believed that males are to blame for the spread of HIV/AIDS. As shown earlier, African participants have been exposed to HIV/AIDS and PLWHA more than coloured had been; hence, racial difference reported with respect to gendered stigmatization could be an indication of Africans' familiarity of such stigma. On the other hand, these findings could be a warning of possible risks of coloured participants to engage in risks behaviours if they are not acknowledging HIV and AIDS in their community and family and 'othering' the disease as happening to other groups.

Table 5.8: Participants' subscriptions to gendered stigmatization by race

Gendered stigma	African			Coloured			Exact sig. (2 sided)	Phi
	Agree	Disagree	Total	Agree	Disagree	Total		
Female are treated badly	69(70.4%)	29(29.6%)	98(100%)	49(53.3%)	43(46.7%)	92(100%)	0.015*	0.177
Male are rejected	36(37.1%)	61(62.9%)	97(100%)	25(27.2%)	67(72.8%)	92(100%)	0.144**	0.106
Female are rejected	36(36.7%)	62(63.3%)	98(100%)	24(26.1%)	68(73.9%)	92(100%)	0.115**	0.114
Male are to blame	39(48.1%)	42(51.9%)	81(100%)	13(15.9%)	69(84.1%)	82(100%)	0.000*	0.346
Female are to blame	15(18.3%)	67(81.7%)	82(100%)	8(9.5%)	76(90.5%)	84(100%)	0.102**	0.127

Note:* indicate where p-value is significant at $p < 0.05$, ** indicate where p-value is not significant ($p > 0.05$)



5.7 HIV/AIDS stigma attitudes and behaviours

The proportions of people who agreed with each of the items measuring personal stigma attitudes and behaviours were assessed in this study. There are two domains which have been used to assess different aspects of personal stigma at different levels (family, community/interpersonal levels). These domains reflect the following two underlying factors: questions reflecting shame, blame and judgment; and questions reflecting individual support of PLWHA and/or personal distancing for people living with HIV and AIDS.

5.7.1. Descriptive results: shame, blame and judgment

Fig. 5.5 showed a small percentage (13.5 %) agreed that a person who contracts HIV/AIDS should be ashamed of him or herself. There are various reasons for this answer. One way of

interpreting this result could be that of political correctness, since through education people are aware that stigma is negative and problematic and would not therefore want to share their real opinions on such statements that clearly indicate stigmatization of PLWHA. On the other hand, since this study have not asked people to disclose their HIV status for ethical purposes; the answer to the above question could mean that some of the participants could be HIV positive and hence, explain why they would disagree with such statement.

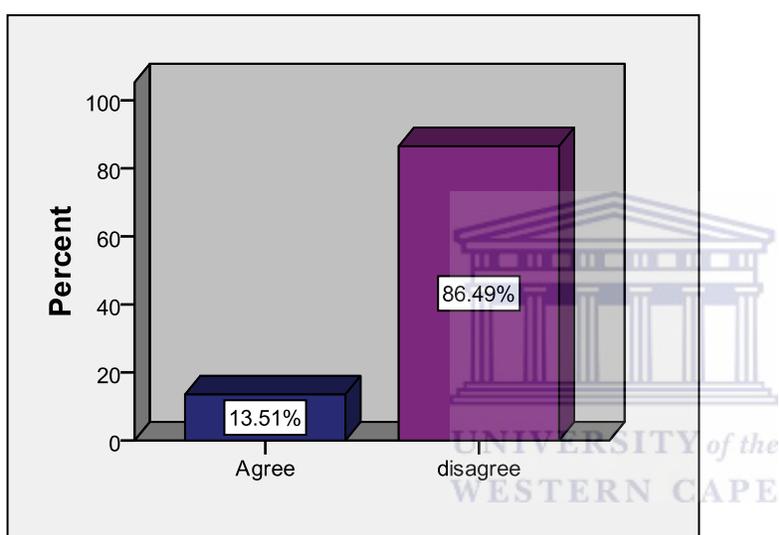


Fig. 5.5: PLWHA should be ashamed

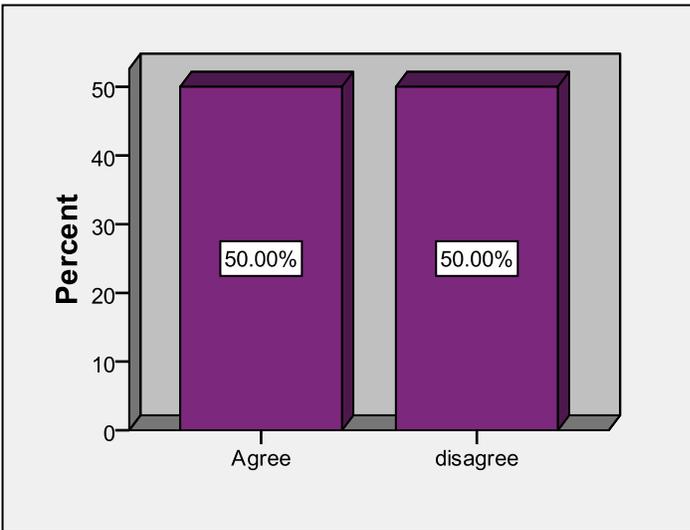


Fig. 5.6: Contracting HIV through drugs is shameful

Previous studies have shown that shame, blame and judgments of PLWHA has been linked to various beliefs about how HIV was contracted and that stigma has been differently associated with how a person was perceived to contract the disease. Thus, those who are drug users and those who are perceived to be sexually immoral and promiscuous have been more stigmatized than those who are viewed as ‘innocents’ (such as children and those who receive contaminated blood). As shown in Fig. 5.6, stigma related to drug use is adhered to by 50 % of participants, showing a clearly divided response in this respect. However, given the association of HIV/AIDS with drugs in the early detection of this disease, it is still important to highlight that despite the fact that opinions are divided on this statement, 50 % is still a high proportion in this perspective. However, the association of shame with sex is strongly rejected in participants’ responses. More so, as shown in Fig. 5.7, 75 % of participants disagree with the statement that it is shameful to contract HIV through sex. Interestingly, when asked if they believe that shame associated to HIV/AIDS is due to its association with sex, majority of participants (60 %) agreed with this

statement (Fig. 5.8) showing their awareness that the association of HIV with sex plays a role in the stigma but yet, they are not subscribing to this personally.

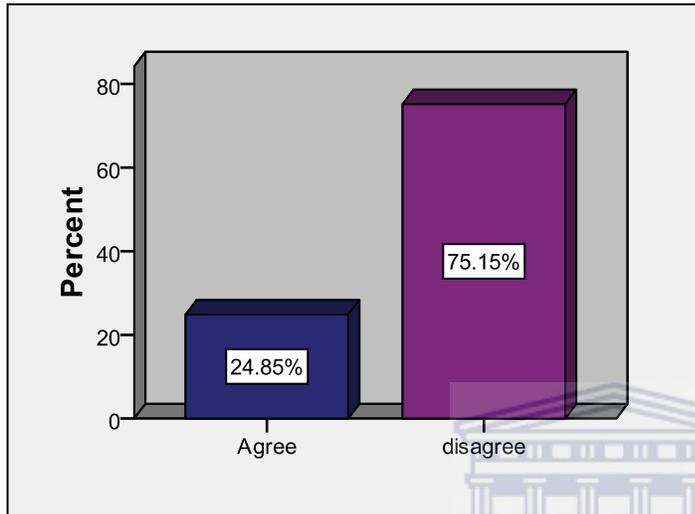


Fig. 5.7: Contracting HIV through sex is shameful

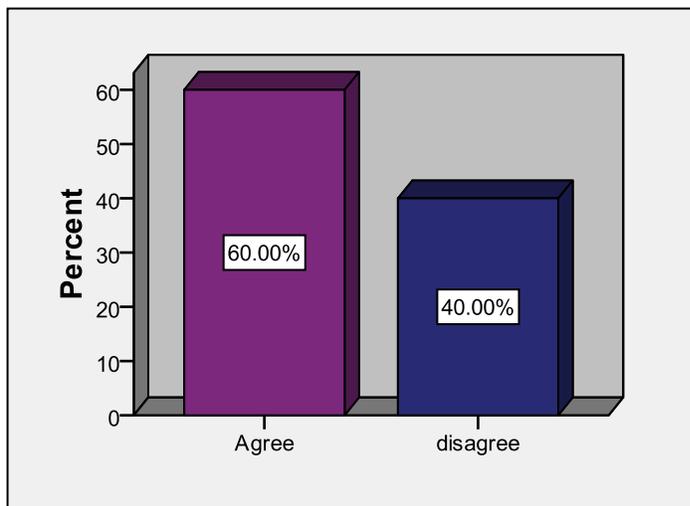


Fig. 5.8: Belief that shame associated with HIV is due to its association with sex

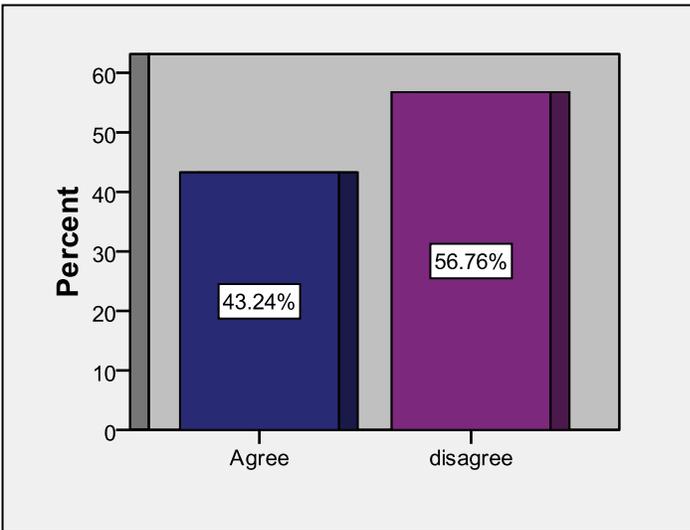


Fig. 5.9 PLWHA are source of financial drain to our economy

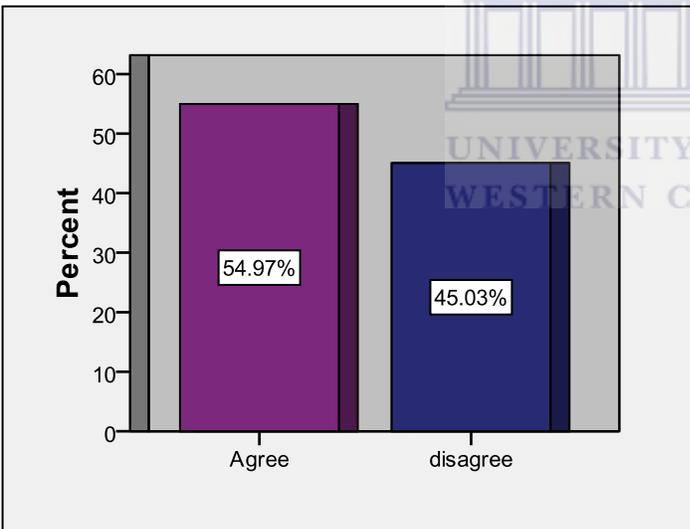


Fig. 5.10: Differential treatment of PLWHA based on their financial status

Fig. 5.9 showed 43 % of participants reported PLWHA are an additional cost to the national economy. Although this proportion is smaller than the proportions of those who disagree; this

finding revealed PLWHA are still seen as responsible for their illness and considered differently to those living with other illnesses. This assertion was reinforced by the finding that a majority (54.9 %) of the respondents reported that PLWHA who are poor are not treated the same as those who are rich and wealthy (Fig. 5.10). Overall, it can be concluded that shame and judgment of PLWHA is associated primarily with socio-economic factors (poor people are more stigmatized, PLWHA are a drain on the economy) and to some extent, the negative perception as regards associating HIV/AIDS with drug use and sex.

5.7.2 Descriptive results: community and interpersonal support or distancing towards people living with HIV and AIDS

Responses are generally positive with respect to supporting PLWHA at community level and within their families with some exceptions observed at the interpersonal level.

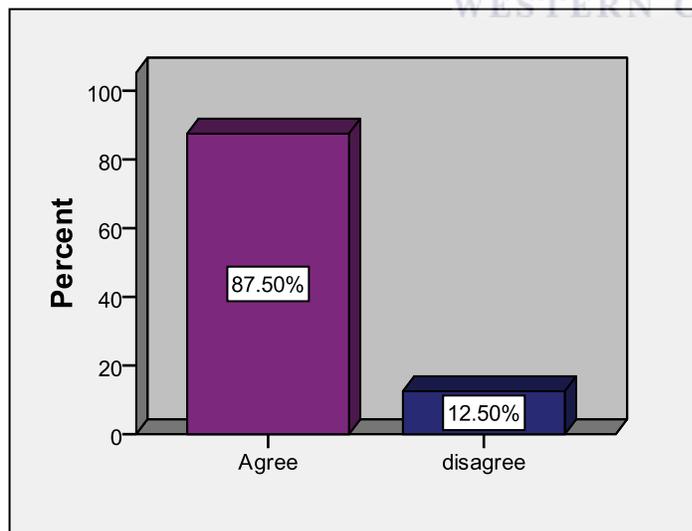


Fig. 5.11: Police should protect PLWHA from abuse and violence

Contradictory results emerge when looking at participants' personal support and /or how they think that PLWHA should be treated and responded to in their everyday lives. On one hand, there was strong support for the human rights of PLWHA; 87 % of participants said police should protect PLWHA from abuse and violence (Fig. 5.11). On the other hand, a small majority of the sample (53.6%) agreed that given two well qualified individuals, they will consider hiring an HIV negative person (Fig. 5.12).

Given that previous studies have shown PLWHA been discriminated against on the basis of their HIV status, results shown in Fig. 5.11 & 5.12 is an indication of discrimination but it is lower than expectation. However, this could be interpreted as due to the fact that HIV and AIDS have been considered as a death sentence leading to the belief that PLWHA are not good enough. Further interpretation could be due to the fear of casual transmission of HIV/AIDS which has been one of the main reasons why people distance themselves from PLWHA. Furthermore, these findings could be an indication of progress that has been made with regard to the development of non-discriminatory laws and policies that protect the human rights of people living with HIV/AIDS.

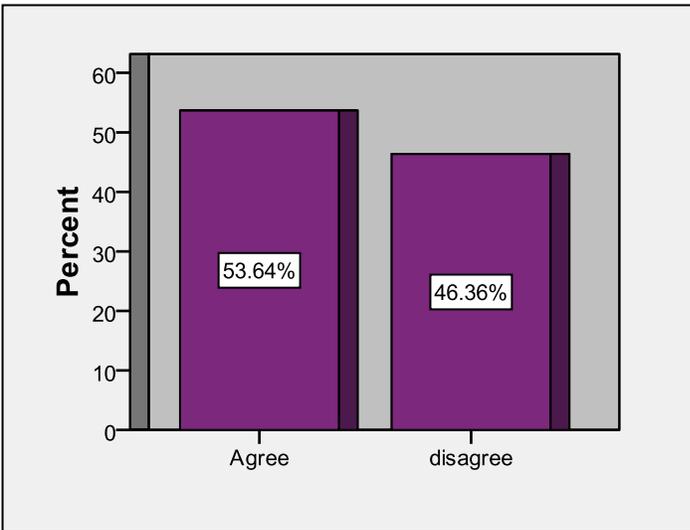


Fig. 5.12: Support hiring an HIV negative person

The level of individual support or discomfort towards PLWHA at both community and family level was also assessed. However, contrary to perceptions that family and community could be a source of rejection of PLWHA, participants' personal responses towards PLWHA are shown to be very positive at community and family levels. A large proportion of respondents (87 %) reported they would always support community events that support PLWHA (Fig.5.13), 77 % reported they participated in community events that support PLWHA (Fig. 5.14). At the family level, the majority of respondents (89 %) reported that they would always share meals with family member if they ever lived with HIV/AIDS (Fig. 5.15) and even stated in Fig. 5.16 they would always eat meals cooked by PLWHA (85 %). These results show no indication of respondents feeling uncomfortable around people living with HIV/AIDS whatsoever at the community or family level. Support for this observation comes from previous studies conducted in Cape Town which showed the level of personal stigma seems to be declining (Kalichman et al., 2005). However, studies conducted in two townships in the Tshwane Metropolitan area

(Gauteng Province of South Africa) showed people tend to report less personal stigma and are more likely to attribute stigma attitudes to the community (Visser et al., 2009). This finding appears to resonate with the current study as well.

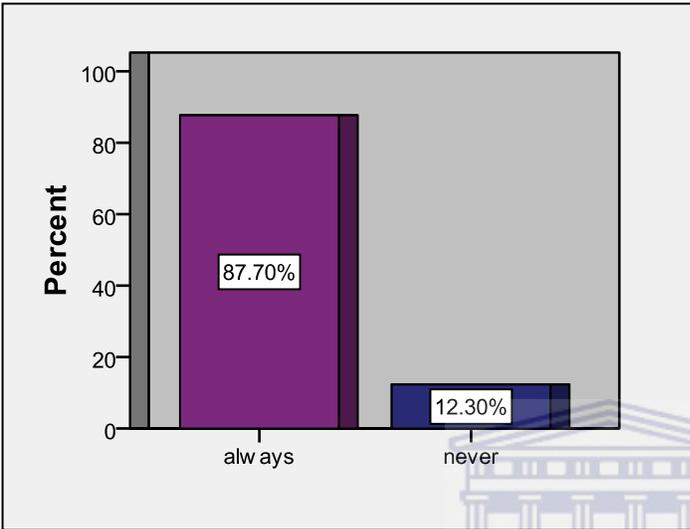


Fig. 5.13: Support for community events that support PLWHA

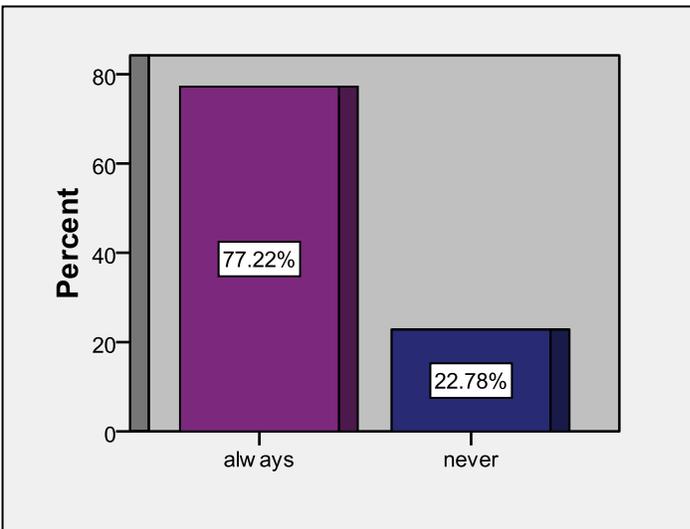


Fig. 5.14: Participation in community events supporting PLWHA

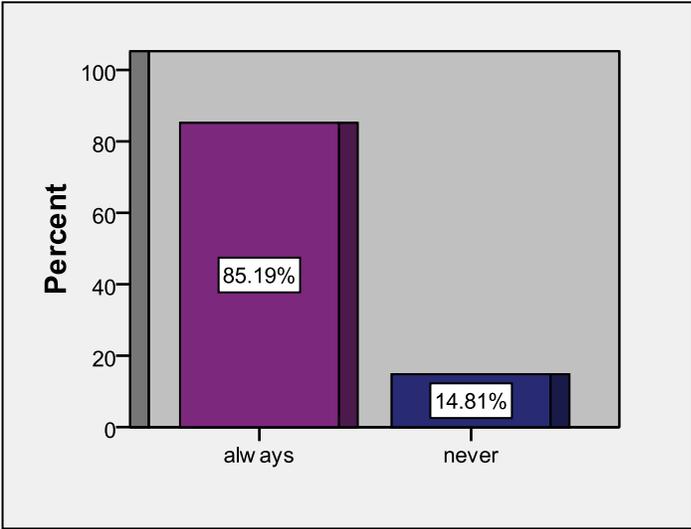


Fig. 5.15: Eat meals cooked by PLWHA

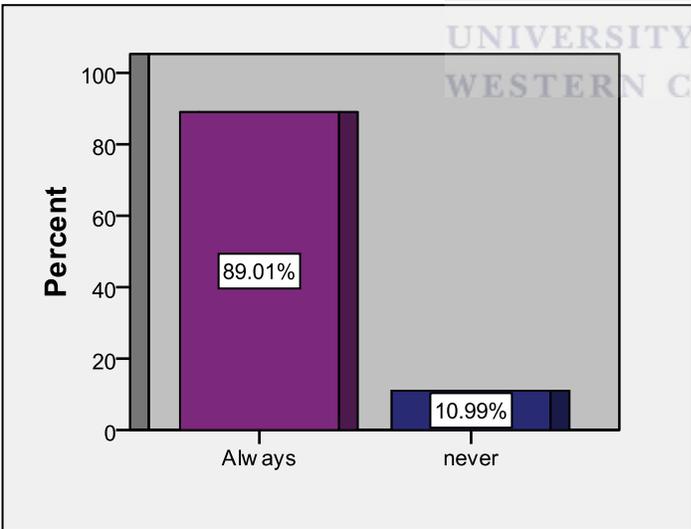


Fig. 5.16: Share meals with family members living with HIV/AIDS

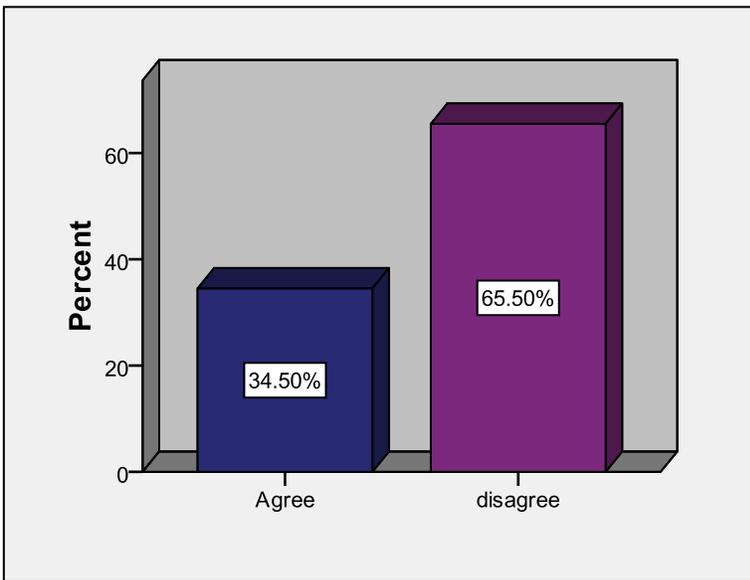


Fig. 5.17: Treatment of family member based on ability to secure a job

Overall, the findings from this study illustrated the proportion of subjects indicating agreement with each of the items measuring personal stigma attitudes and behaviours. As can be seen, the items that reflect personal support for PLWHA are the most frequently endorsed; while those that had to do with blame and shame were less frequently endorsed by respondents.

5.8 The relationship between personal stigma and factors of race and gender and other factors influencing the interaction

The primary aim of this study was to explore the interaction of gender and race with HIV/AIDS stigma and to determine whether age, education and household situation are possible confounding factors of this relationship. The relationship between stigma and factors of race and gender (and their interaction) using an analysis of variance was examined. Also examined were the residuals from the fitted model, which was found to be approximately normally distributed.

The results indicated there is no significant interaction of gender and race on stigma score and nor significant race effect ($p>0.05$). However, gender has been found to be highly significant ($p<0.0001$). Male participants have a higher mean than females by approximately 1.1 units (on a scale of 0 to 10) (see Table 5.13).

5.8.1 Descriptive statistics for personal stigma score with age, education and household situation by gender and race.

The results in Table 5.9 shows the mean differences in personal stigma score for age and education by population group. The age mean difference in stigma score was very small (approximately 0.4 on a scale 0-10) among Africans than coloureds and was slightly higher for education among African than Coloured about 0.7 unit on a scale of 0-10. However, in analyzing differences between males and females, it was shown that males have a higher score in personal stigma than females with a mean score difference of approximately 1.1 units on a scale of 0 to 10. Furthermore, descriptive statistics for household situation by gender category was also evaluated as shown Table 5.11. Although in this study the questionnaire used did not have measures of income level, participants' ability to purchase their household necessities was measured. The results showed females have less means to purchase their household necessities than males. Compared to 28 % of males who cannot afford basics necessities in their household, almost fifty percent of females (47.8 %) indicated they cannot afford to purchase basic necessities such as food and clothes; while 42 % of males compared to 38 % indicated they can only get money to spend for basic necessities. Evident in both categories is that few people have money to spend on luxury or extra luxury things such as holidays.

Table 5.9: Descriptive statistics: Mean difference in personal stigma score for age and education by race category

Population group	N Obs	Variable	N	Mean	Median	Std Dev	Minimum	Maximum
African	98	stigma	94	2.557	2.857	1.840	0.000	7.500
		Age	96	36.938	38.000	13.477	18.000	73.000
		Education	94	6.819	7.000	1.685	1.000	11.000
Coloured	96	stigma	78	2.197	2.000	1.742	0.000	6.000
		Age	95	39.189	40.000	11.112	18.000	81.000
		Education	95	6.147	6.000	1.913	1.000	11.000

Note: N Obs: indicate number of observations; N is the total number of respondents

Table 5.10: Descriptive statistics: Mean difference in personal stigma score for age and education by gender category

Gender	N Obs	Variable	N	Mean	Median	Std Dev	Minimum	Maximum
Male	97	stigma	84	2.931	3.000	1.896	0.000	7.500
		Age	94	38.096	39.500	13.443	18.000	81.000
		Education	95	6.663	7.000	1.802	1.000	10.000
Female	97	stigma	88	1.881	2.000	1.548	0.000	6.000
		Age	97	38.021	40.000	11.317	18.000	62.000
		Education	94	6.298	6.000	1.848	2.000	11.000

Note: N Obs: indicate number of observations; N is the total number of respondents

Table 5.11: Descriptive Statistics for household purchases by gender category

Gender of the respondent	No money for basics n (%)	Money for basics n (%)	Money for luxury n (%)	Money for extra luxury	No response	Don't know	Total
Male	27(28.42%)	40(42.11)	18(18.95%)	2(2.11%)	1(1.05%)	7(7.37%)	95
Female	45(47.87)	36(38.30)	11(11.70%)	1(1.05%)	0(0.00%)	1(1.06%)	94
Total	72	76	29	3	1	8	189

5.8.2 Correlation between stigma and age, education, and household situation

Both Pearson and Spearman correlation coefficients show significant correlations between personal stigma score and age, education, and household situation. Table 5.12, showed the correlation between age and personal stigma was significantly positive ($r = 0.21$ and $p > 0.05$). This is an indication that stigma is more likely to increase as the age increases and vice versa in so far as younger aged people would be less likely to subscribe to stigmatizing attitudes. Conversely, both Pearson and Spearman correlation show that the correlation between stigma, education and household situation is not significant; which is an indication that both education and household situation are less likely to influence the outcomes in personal stigma among participants in this study. The results of the correlation analysis supported the observation from the descriptive results which showed age mean in stigma score was higher among males than females (1 unit difference on a scale of 0 to 10). This difference was confirmed by the analysis of variance between stigma and age, education and household situation as covariates. The results of the analysis of variance (ANOVA) are well illustrated in the next section of this thesis.

Table 5.12: Correlations between personal stigma and age, education and household situation

		Age group	Education level	Household situation
Stigma score	Pearson Correlation	0.21487*	-0.07780	0.06730
	Sig. (1-tailed)	0.005*	0.3176	0.2605
	N	169	167	168
	Spearman Correlation	0.17275	-0.07843	-0.01658
	Sig. (1-tailed)	0.0247	0.3137	0.8311
	N	171	169	170

Note: *indicates ($p < 0.05$)

5.8.3 Analysis of variance with only gender and race

The results from the two-way ANOVA shown in Table 5.13 provided the means and standard deviation for each group (male and female) and the F-values and their associated significance levels for the main effects and the two-way interaction. In the descriptive statistics, it was shown that the mean scores in the levels of personal stigma vary between males and females and African and coloured participants (see Tables 5.9 & 5.10). However, it is only the contribution of gender to the ANOVA that is significant ($F=15.8$, $p=0.0001$). In addition, there was no significant ($p>0.05$) interaction between gender and race with personal stigma which is an indication that, when considered together, these two independent variables (gender and race) do not contribute significantly to the effect on individual stigmatization of PLWHA. The values for the effect of race and the interaction of race*gender are shown in Table 5.13. As shown, the F-value for race was 1.82 with $p=0.17$, while the F-value for the interaction is 0.04 with $p=0.83$. As indicated, these p-values are way too far to be significant, leading to the conclusion that the gender of the respondent is highly important with respect to stigmatization of PLWHA.

Table 5.13: Two-way analysis of variance (ANOVA): Gender and Race

Effect	Num DF	Den DF	F Value	P-value
Gender	1	168	15.86	0.0001*
Race	1	168	1.82	0.1793
Gender*race	1	168	0.04	0.8370

Least Squares Means

Effect	Gender	Estimate	Standard Error	DF	t Value	P-value	Alpha	Lower	Upper
	Male	2.9166	0.1893	168	15.41	<0.0001	0.05	2.5429	3.2904
	Female	1.8627	0.1849	168	10.07	<0.0001	0.05	1.4976	2.2277

Differences of Least Squares Means

Effect	Estimate	Standard Error	DF	t Value	P-value	Alpha	Lower	Upper
Male and female	1.0540**	0.2646	168	3.98	0.0001	0.05	0.5315	1.5764

Notes: * indicates significant; ** indicates mean difference

5.8.4 Analysis of variance including age and education as covariates

As earlier indicated, gender has been shown to be highly significant in stigma outcomes. However, this study sought to determine whether age, education and household situation could be possible confounding factors in the race*gender interaction with stigma. The results shown in Table 5.13 would hold if other variables were included in the analysis; age was first included followed by education, both serving as covariates in the model. Adjusting for possible effects of age and education, results showed gender is still highly significant ($p < 0.0004$) and the estimated mean difference between race groups is about 1 unit (Table 5.14).

More so, it was observed that although gender is still significant, the mean difference have slightly changed from <0.0001 to being <0.001 , which is an indication that some of the added variables might have had an effect on the effect of gender on personal stigma when combined together. Also shown in Table 5.14 is that age is significant among other covariates variables ($p<0.05$), which confirmed results from descriptive statistics that the age mean difference in stigma score was higher among males than females. In addition, a positive correlation between personal stigma and age was also observed. Hence, it can be inferred from these results that the age of the respondents when considered together with gender might impact on the stigma outcome. Furthermore, using gender of respondents and their age separately reveals differences in personal stigma, a complete analysis that takes both the correlation and the ANOVA show that older males are more likely to stigmatize PLWHA than the rest of the groups.

5.8.5 Analysis of variance including Age and Education and Household situation as covariates

In the final model, household situation was added to the analysis as a categorical variable. It should be noted that outcomes 4, 5 and 6 were combined into an 'other' category of household situation. The results are about the same i.e. there is no significant effect of gender ($p>0.05$), neither an interaction between gender and race. However, gender is still highly significant with the same p-value ($p=0.0004$) (Table 5.15). Moreover, the mean difference have slightly increased from the previous one. An interpretation for this increase could be the difference in male and female household situation that was shown in the descriptive results earlier (see Table 5.11).

Table 5.14: Analysis of variance including age and education as covariates

Effect	Num DF	Den DF	F Value	P-value
Age	1	158	5.23	0.0235
Education	1	158	0.01	0.9404
Gender	1	158	13.23	0.0004*
Race	1	158	3.51	0.0629
Gender*race	1	158	0.14	0.7042

Least Squares Means

Effect	G.	P.G	Standard		DF	t Value	P-value	Alpha	Lower	Upper
			Estimate	Error						
African		1	2.6234	0.1803	158	14.55	<0.0001	0.05	2.2674	2.9795
Coloured		3	2.1229	0.1942	158	10.93	<0.0001	0.05	1.7393	2.5065
Male	1		2.8547	0.1900	158	15.02	<0.0001	0.05	2.4794	3.2300
Female	2		1.8916	0.1830	158	10.34	<0.0001	0.05	1.5303	2.2530

Differences of Least Squares Means

Effect	G	P.G	G	P.G	Standard		DF	t Value	P-value	Alpha	Lower	Upper
					Estimate	Error						
Race		1		3	0.5005	0.2672	158	1.87	0.0629	0.05	-0.02720	1.0282
Gender	1		2		0.9631**	0.2648	158	3.64	0.0004	0.05	0.4401	1.4861

Notes: P.G means population group

G means gender

(1) Indicate that African was recorded as category 1

(2) Indicate that Coloured was recorded as category 3

* indicates significant; ** indicates mean difference

Table 5.15: Analysis including Age and Education and Household situation as covariates

Effect	Num DF	Den DF	F Value	P-value
Household situation	3	153	0.89	0.4475
Age	1	153	5.32	0.0224
Education	1	153	0.07	0.7875
Gender	1	153	13.29	0.0004*
Race	1	153	3.10	0.0804
Gender*race	1	153	0.18	0.6710

Least Squares Means

Effect	G	P.G	Standard Estimate	Error	DF	t Value	P-value	Alpha	Lower	Upper
Race	1		2.8116	0.2495	153	11.27	<0.0001	0.05	2.3187	3.3045
Race		3	2.2705	0.2313	153	9.81	<0.0001	0.05	1.8135	2.7276
Gender	1		3.0302	0.2187	153	13.85	<0.0001	0.05	2.5981	3.4624
Gender		2	2.0519	0.2381	153	8.62	<0.0001	0.05	1.5816	2.5223

Differences of Least Squares Means

Effect	P.G	G	P.G	Standard Estimate	Error	DF	t Value	P-value	Alpha	Lower	Upper
race	1		3	0.5411	0.3074	153	1.76	0.0804	0.05	-0.06620	1.1484
gender		1	2	0.9783**	0.2683	153	3.65	0.0004	0.05	0.4482	1.5084

Notes: P.G means population group

G means gender

(1) Indicate that African was recorded as category 1

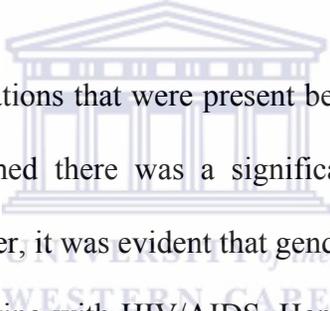
(2) Indicate that Coloured was recorded as category 3

* indicates significant; ** indicates mean difference

5.9 Conclusion

The results of this study have shown that male and female participants have had different experiences with regard to exposure to HIV and familiarity with PLWHA which might have

been the cause of the difference observed in personal stigma attitudes. On the other hand, the majority do not subscribe to myths and discourses that construct PLWHA as different from others, possibly indicating that national efforts to educate the public about HIV and AIDS have been successful. This is in agreement with previous studies conducted in communities in Cape Town (Kalichman & Simbayi, 2003). However, regardless of the fact that they have not subscribed to myths and stereotyping ideas about PLWHA, it is still obvious that stigmatization is prevalent among some groups and subscribed to more by men than women in some communities. It should also be noted that the majority of participants indicated that family and community still remains in need of attention when it comes to care and support of PLWHA.



Furthermore, in analyzing the variations that were present between African and coloured; males and females, results have confirmed there was a significant difference between males and females in personal stigma. However, it was evident that gender has a highly significant effect on people's stigmatization of those living with HIV/AIDS. Hence, male participants have a higher mean score in personal stigma than female by approximately 1.1 units (on a scale of 0 to 10). When controlling for other possible confounding factors on stigma, the results show that gender was still highly significant but the level of significance dropped from $p < 0.0001$ to $p < 0.001$. This drop was due to the age mean difference in stigma score, in addition to a relatively weak but positive correlation between age and personal stigma.

CHAPTER SIX: DISCUSSION AND CONCLUSION

6.1 Introduction

This chapter provides the discussion and conclusion of the study. It highlights key emerging results and reflects on their implications in relation to the aims and objectives of this study. Finally, key limitations of this study and recommendations for future research are also highlighted.

6.2 A brief summary of methods and methodological framework of the study

In order to discuss results emerging from this study, it is important to keep abreast with the main focus of the study and establish the discussion within the prevailing methodology of choice and theoretical framework. The primary aim of this study was to understand how HIV/AIDS and PLWHA are socially constructed and the process by which such constructions are experienced through daily interactions. Hence, the study was launched within feminist social construction frameworks and follow the arguments made by Burr (1995), Link and Phelan (2001-2002); Parker and Aggleton et al. (2002); Parker and Aggleton (2003); Shefer (2004) and Deacon et al. (2005) amongst other. The main assumption followed throughout this study is that stigma reinforces pre-existing social inequalities based on gender, race, sexuality and poverty among many others and in return, functions by creating hierarchal differences and by legitimizing these inequalities. The study was also guided by the argument made by many authors that stigma manifests differently in different communities and therefore needs to be understood within its social context.

A feminist research methodology was used in this study and the prevailing motive was to highlight how gender power operates and how it is intersected with other forms of power and social identity such as race, class and illness identity amongst others. Certainly, feminist research methodology provided a basis for exploring how individuals construct their realities, while attempting to contribute to emancipation and transformation (Mies, 1991). Furthermore, data was analyzed quantitatively using SPSS and SAS.

In order to assess the level of stigma in this community both descriptive and inferential statistics were used. A stigma scale has been calculated and a score ranging from 0 to 10 was obtained. This scale was used in confirmatory analysis that illustrated the extent to which HIV/AIDS stigma is constructed differently by male and female and African and Coloured living in Mitchell's Plain community. It was also used to illustrate whether age, education and household situation were possible confounding factors in the interaction of gender and 'race' and their effect on personal stigma. An analysis of variance was then used to measure the level of interaction between these variables. A correlation was also performed in order to illustrate whether the level of personal stigma was related to the age, education as well as the respondent's household situation.

Measures of associations were used to analyze the relationship between gender, race and perceptions about PLWHA as well as in illustrating whether there was a relationship between gender, race and level of openness of disclosure of HIV status in the family and community. A p-value of 0.05 was considered satisfactory in terms of significance of the results.

6.3 Respondents' exposure to HIV/AIDS

Results show that there is a significant gender and racial difference in terms of participants' exposure to HIV/AIDS. Far more women, in particular African women have experienced disclosure from community or family members than African men, and Coloured women and men in the sample. Results also show certain measures of stigma were more prevalent among male participants than females. These results are in agreement with previous studies which indicated that the more people are exposed to HIV, the less stigma beliefs they have (Kalichman & Simbayi, 2003; Visser et al., 2009).

On the other hand, it has been found that stigma can affect disclosure (Hays et al., 1993; Chesney & Smith, 1999; Kalichman & Simbayi, 2003). It is argued that hiding one's status may not only preclude HIV-related social support and its attendant benefits but may also have direct negative effects on disease progression for HIV positive individuals (Crandall & Coleman, 1992, cited in Thomas, Rehman, Suryanarayanan, Josephine, Dilip, Dorairaj & Swaminathan, 2005) and an increased likelihood of engaging in unsafe sexual practices (Wenger et al., 1994).

6.2 Perceptions about PLWHA

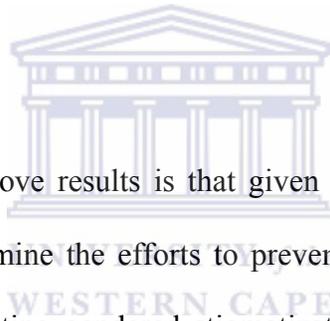
There was no significant difference observed between males and females and African and coloured participants in terms of their perceptions about PLWHA with respect to documented stereotypes about the appearance of PLWHA. The majority indicated that a person with HIV does not look different from others and that AIDS cannot be detectable by simply looking at

them. These results indicated that the majority of participants have not subscribed to myths and ‘othering’ discourses that construct PLWHA as different from others.

The above results reject the hypothesis that perceptions about PLWHA depend on whether you are an African male or female and/or a Coloured male or female. However, as shown, this finding could be an indication that the level of knowledge about HIV and AIDS has attained a higher level in this community which might have had an impact on the way people perceive those living with HIV and AIDS. In this respect, previous studies conducted in Cape Town have shown that AIDS knowledge of participants was generally high and that there were no significant differences between people who knew their HIV status and those who did not test for HIV (Kalichman & Simbayi, 2003). Studies have also shown that the introduction of anti-retroviral therapy has made a difference in the lives of PLWHA (Shisana et al., 2008). This may have impacted on the way they are perceived by members of their community. However, as it is shown from this study knowledge is not enough to change people’s attitudes and behaviours with regard to stigmatization of PLWHA. Arguably caution should be made about these findings with regard to the percentages of people who agreed on a number of items measuring this domain of stigma. It can be argued that although the results indicated that low level of negative perceptions about PLWHA, it still relevant to mention that as many of 19.5% of participants who indicated that they can recognize someone with HIV is a meaningful number as well as 27% of those who agree that AIDS is detectable by the appearance of a person.

6.3 Gendered stigmatization

As previously stated, one of the objectives of this study is to scrutinize gendered stigmatization among participants, that is to explore the extent to which participants have subscribed to gendered stigmatization attitudes. Statistics showed the majority of participants have not subscribed to gendered stigmatization. However, caution should be made with respect to percentages of those who agreed on individual items measuring this domain. The results showed that more participants blame men for spreading HIV than they blame women, yet a relatively high percentage, almost one third of the sample feel that women living with HIV/AIDS are treated worse than men by their families indicating their belief that stigma is gendered in their communities.



One of the implications of the above results is that given the harmful effects of stigmatizing attitudes and beliefs which undermine the efforts to prevent and treat HIV/AIDS, it could be argued that the proportions indicating gendered stigmatization are still considerably high and therefore important to be taken into account. These results are however in contradiction to previous studies which have shown that women have been subjected to blaming discourses which served to produce a picture of HIV/AIDS as a woman's illness, and therefore 'women's fault' since a higher proportion of participants agreed with the statement that men are to blame for the spread than those who agreed women are to be blamed (Shefer, 2004; Skinner & Mfecane, 2004). Elsewhere, Skinner & Mfecane (2004) amongst a wide range of other authors (Shefer, Strelbel, Wilson, Shabalala, Simbayi, Ratele, Potgieter, and Andipatin, 2002) argued that the attachment of gender discrimination to HIV stigma has led to women in particular being blamed for the spread of HIV/AIDS. In this light, studies have found that HIV infection rates for

men and women vary widely in South Africa (Shisana et al., 2008) and that in a situation where men outnumber women, women tend to be infected at younger ages than men (Williams et al., 2000 cited in Petros et al., 2006). However, it is argued this high rate of infection among women contributes in some cases to an ‘othering’ of women as sexually promiscuous, as ‘loose’, ‘as prostitutes’, and as ‘dirty’ (Petros et al., 2006: p.72).

On the other hand, previous studies suggest that stigma does not always automatically result in discrimination (Deacon et al. (2005). Thus, the finding above which suggested that men are to blame but women are the most likely to be treated badly could be an indication that one needs to separate out belief-based stigma and discrimination-based stigma. This is in agreement also with previous studies that argue that stigmatization is a complex phenomenon which needs to be understood in terms of power and domination. Thus, the stigmatized person experiences status loss and discrimination in a situation of unequal power that allows such practices to occur (Parker & Aggleton, 2003).

6.4 The interaction between gender and race with HIV/AIDS stigma

As depicted in this study, there is a significant relationship between HIV/AIDS stigma attitudes and the gender of the respondents. In this respect, the difference between males and females in terms of their responses towards PLWHA are evident in the reported results. However, the results show that the interaction of gender and race in personal stigma attitudes was not statistically significant. Findings indicate that gender is highly significant ($p < 0.0001$) and that this significance is consistent even after adding other demographic variables. In this respect, male participants have a higher mean than female by approximately 1.2 units (on a scale of 0 to

10) which is a confirmation that stigma is experienced differently and that this context is needed to be taken into account when addressing stigma in this community. Arguably, as it has been mentioned before in this study that it is imperative to develop critical thinking about how stigma manifest, is sustained and establish its social roots. Hence, the power relations that keep stigma alive can be challenged. Furthermore, it is argued that getting together of communities to think critically about stigma results in been able to see inequalities in social relations that contribute to such. Such community participation is a powerful weapon against stigma. It is just as powerful as information (Simbayi et al., 2007).

6.5 Analysis of other possible factors influencing stigma attitudes and behaviours

A significant positive correlation was found between stigma and age. Although this correlation was relatively weak, it indicates that stigma increase as age increases. Therefore, older people are more likely to hold stigma attitudes and behaviours in this community. It was also found in the analysis of covariates that the significance of gender difference decreased from $p < 0.0001$ to $p < 0.001$. Hence, the interpretation of this decrease is that age is the only variable that was also significant as a covariate and therefore might have had an effect on the relationship of stigma and gender that was observed.

6.6 Recommendations

Several studies including the current study have shown that stigma is a social phenomenon which needs to be understood at both individual and social levels. This work can lay the basis for directed campaigns and interventions against the practice of discrimination against PLWHA.

This study has also shown that stigma is socially constructed and that stigmatization of PLWHA is related to the incidence of other kinds of stigma particularly those based on gender among other social identities. Therefore, it is recommended that interventions to address stigma need to take cognizance of the intersection of these different points of discrimination.

Given the fact that results of the current study showed male participants still hold stigmatizing beliefs more than females, and there is indication that they are aware that female PLWHA in particular are still not treated well by families and the community at large, interventions which deal with the intersection of gender with stigma are needed. More specifically, this study recommends that specific interventions to address gender inequalities with regard to HIV/AIDS are of necessity in this community.

Given that it appears that people in this study report less personal stigma, yet report that stigma is present in their community, the study further recommends future research to further explore whether there were differences in terms of personal stigma and perceived community stigma across gender and race in this community. Further research is also needed to explore the effects of pre-existing stigmas on HIV/AIDS stigmatization.

Finally, it is important to acknowledge some changes that have happened in this community. At least, on the attitudinal level there seems to be less use of stigmatizing and ‘othering’ discourse than might be expected. It was also observed that gendered stigma is not adhered to by most participants though they do acknowledge that women are treated worse than men by their families. The study does point to the need however for more work on stigma, since confirmatory

results indicated men are more likely to stigmatize PLWHA and also as shown in the descriptive results, there are still some implicit blaming discourses, as reflected for example in the widely held attitude that PLWHA are a drain on the economy.

6.7 Limitations of the study

Adopting a quantitative methodology for this project was limited to empirical evidence by stigma measures adapted from a set of questions chosen from a questionnaire that was designed for a broader research project. While the results of this study provide factors that potentially indicated how HIV/AIDS stigma is socially constructed, there are important limitations to the study that should be considered when interpreting these findings. The instrument used is not yet standardized and hence, some of the aims were measured using individual items. The study reported here was conducted in one community historically classified as a Coloured township in Cape Town, South Africa. Therefore, caution should be exercised before generalizing the study to other geographical regions and demographic group.

Similarly, although this survey sample was sizable ($n=200$), it was recruited through a convenience sampling method and hence, it is not possible to make general claims to the Mitchell's Plain community or to the general population of Cape Town area as a whole. In addition, Visser et al. (2009) have indicated that a survey study conducted in a community is limited in its ability to reflect all of the complexities that contribute to stigma and may not reflect the behaviours of respondents in social situations where various social dynamics can influence behaviour. Social desirability and the knowledge that it is not politically correct to stigmatize

may have provided a distorted picture of actual stigma attitudes and practices in this community. Taking these methodological limitations into account, findings from this study demonstrated an urgent need for structural measures to combat stigma. Research is also needed to explore further barriers to disclosure among different population groups.



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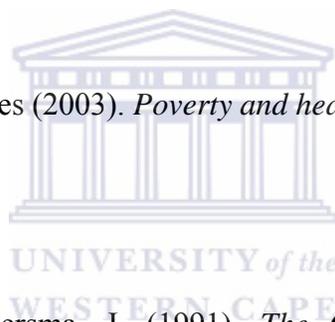
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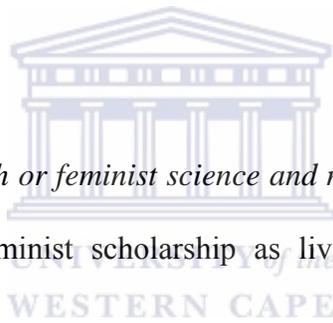
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LIST OF APPENDICES

APPENDIX 1: LETTER REQUESTING ASSISTANCE FOR DATA ENTRY

APPENDIX 2: INFORMED CONSENT FORM

APPENDIX 3: THE QUESTIONNAIRE





2008/05/06

Dear Sir/ Madam

Re: Stigma Capacity Building Fellowship Fieldwork: Mrs Yvette Kayonga

Mrs Yvette Kayonga has been awarded a fellowship to study the stigma related to HIV/AIDS. This study is funded by the National Institutes of Mental Health and is a five year partnership between Pennsylvania State University (PSU), the Human Sciences Research Council (HSRC), the University of the Western Cape (UWC) and the University of Limpopo.

As part of this project, **Mrs Yvette Kayonga** will be administering a survey questionnaire to a selected population on experiences of stigma related to HIV/AIDS. The data collected will be used to inform interventions to reduce stigma in South Africa.

Please could you give the above Researcher access and support for the Research.

Should you require more information or have any queries about the study, feel free to contact the Project Director, Ms Nompumelelelo Zungu at the following number (021) 466 7936 or e-mail her at mzdirwayi@hsrc.ac.za.

Yours Sincerely

A handwritten signature in black ink, appearing to read 'Leickness Simbayi'.

Prof Leickness Simbayi
Acting Executive: Behavioural & Social Aspects of HIV/AIDS and Health



Informed Consent Form for Social Science Research
The Pennsylvania State University

ORP USE ONLY: IRB# Doc.#
The Pennsylvania State University
Office for Research Protections
Approval Date:
Expiration Date:
Social Science Institutional Review Board

Title of Project: Capacity Building for Research on HIV/AIDS in South Africa

Principal Investigator: Collins Ó. Airhihenbuwa, Professor
Department of Biobehavioral Health
The Pennsylvania State University
University Park, PA 16802
USA
+1(814) 865-1382; aou@psu.edu

Advisor: Leickness Simbayi, Deputy Executive Director
Social Aspects of HIV/AIDS and Health
Human Sciences Research Council
Private Bag x9182
Cape Town 8000
South Africa
+27(0)21 466 7910; L.Simbayi@hsrc.ac.za

Other Investigator(s): Olive Shisana and Edward A. Smith

- Purpose of the Study:** This research study involves the administration of a survey that will look into behaviors related to HIV/AIDS stigma among South Africans. The results from this study will be used by researchers from four organizations. These organizations are the Pennsylvania State University (PSU), Human Sciences Research Council (HSRC), The University of the Western Cape (UWC), and the University of Limpopo (UL). The purpose of the survey is to gain a better understanding of the family and health care contexts of HIV/AIDS related stigma. The data collected will be used to look at ways to reduce HIV/AIDS related stigma in South Africa.
- Procedures to be followed:** You will be asked individually to answer questions on a survey as honestly as you can. You must be 18 years of age or older to complete this survey.
- Discomforts and Risks:** Some of the questions that will be asked will be of a sensitive nature, such as living with HIV and AIDS, attitudes of health workers toward people living with HIV/AIDS (PLWHA), and sexual practices. Some participants may experience discomfort related to the topic. However you have the right to decide whether or not to answer any questions and to withdraw your consent at any time during the interview without any negative consequences to you.
- Benefits:** There are no direct benefits to you, however the benefits of the study and the results should help to plan an effective campaign to fight HIV/AIDS related stigma in South Africa.
- Duration:** The survey will take approximately 30-45 minutes to complete.
- Statement of Confidentiality:** Your answers to the survey questions will be kept confidential. All completed surveys will be kept in the office of the Project Director at HSRC, and the PI, Co-PI and the research team members from UWC and UL are the only people who will have access to the surveys. When all surveys have been completed and submitted, they will be securely packaged and sent to the PI at Penn State University via Overnight Express courier delivery service. This will ensure an expedient transfer and minimize the risk of any outside persons accessing the data. Penn State University's Office for Research Protections, the Social Science Institutional Review Board, and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this project. Also, the answers you give on the survey will be kept for five years after the project ends in 2008.

The members of the research team administering the survey will keep anything they may know about you confidential. The answers you give will be used by researchers at PSU, HSRC, UWC, and UL. In an event of a publication or presentation resulting from the research, no information that can identify you will be shared.

7. **Right to Ask Questions:** If you have any questions about your rights, or if you do not like what is being done, you can contact – anonymously, if you wish – Ms Nompumelelo Zungu, Project Director, at the HSRC at Tel: 021 466 7936 or Fax: 021 461 0299 or at mzdirwayi@hsrc.ac.za.
8. **Payment for participation:** You will receive transportation which is 50 ZAR for your participation in this survey.
9. **Cost of participating:** There will be no additional cost to you that will result from your participation in this research.
10. **Voluntary Participation:** Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty.

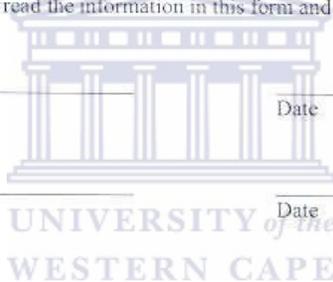
You must be 18 years of age or older to take part in this research study. We are not requesting your signature, but if you agree to the stipulations outlined on this form, you may sign on the line below if you so choose. Completion and return of this survey implies that you have read the information in this form and consent to take part in the research.

Participant Signature

Date

Person Obtaining Consent

Date



Record No

C	M			
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ADULT - ENGLISH Community

QUESTIONNAIRE



CAPACITY BUILDING FOR HIV/AIDS RESEARCH in SOUTH AFRICA

IRB#: 14972

Project number	P	C	L	A	L	A
Province						

1. ADULT RESPONDENT'S BIOGRAPHICAL DATA

1.1. **How old are you?** (Age of the respondent in years)

1.2 **Sex of the respondent**

Male	Female
1	2

1.3 **Race/
population group**

African	White	Coloured	Indian	Other
1	2	3	4	5

1.4 **In which province do you live?**

Eastern Cape	01	Northern Province/Limpopo	06
Free State	02	Northwest	07
Gauteng	03	Northern Cape	08
KwaZulu/Natal	04	Western Cape	09
Mpumalanga	05	Other country	10

1.5 **What is your home language?** (Language spoken most often at home)

Afrikaans	01	Setswana	09
English	02	Tshivenda	10
Isindebele	03	Xitsonga	11
Isiswati	04	Other African	12
Isixhosa	05	Other European	13
Isizulu	06	Indian language	14
Sesotho sa borwa	07	Northern Sotho	15
Sepedi	08	Other _____	

1.6 **What is your highest educational qualification?**

a No schooling / no formal education	01
b Up to Std 1/Gr 3 / ABET 1	02
c Std 2 - Std 3/ Gr 4 - Gr 5 / ABET 2	03
d Std 4 - Std 5/ Gr 6 - Gr 7 / ABET 3	04
e Std 6 - Std 7/ Gr 8 - Gr 9 / ABET 4	05
f Std 8/ Gr 10 / N1	06
g Std 9/ Gr 11 / N2	07
h Std 10/Matric/ N3	08
i Diploma(s) / Occupational certificate(s)	09
j First degree(s)/ Higher diploma(s)	10
k Honours / Master's degree(s)	11

I Doctorate(s) 12

1.7 Are you a member of any faith or religious grouping	Yes	No
a Christian	1	0
b Islam	1	0
c African traditional	1	0
d Buddhism	1	0
e Other specify _____	1	0

1.8 How important is religion to you?

a Not important at all	1
b Slightly important	2
c Somewhat important	3
d Important	4
e Very important	5
f Not applicable (e.g. atheist)	6



1.9 Do you currently work?

Yes	No	No response
1	2	3

1.10 Which one best describes your household situation?

a Not enough money for basic things like food and clothes	1
b Have money for food and clothes, but short on many other things	2
c We have most of the important things, but few luxury goods	3
d Some money for extra things such as going away for holidays and luxury goods	4
e Don't know	5
f No response	6

2 KNOWLEDGE OF HIV AND AIDS

2.1 Can you recognise someone who is HIV positive?

Yes	No
1	2
←	

2.2 How?

.....

2.3 Can you recognise a person with AIDS?

Yes	No
------------	-----------

3. HIV/AIDS and Relationships

3.1 Please mark an X indicating if and when someone you know/knew disclosed their status to you.

Has a friend or relative told you that he/she is HIV positive?	Never	Past six months	Past yr.	Past 5 yrs.	Past 10 yrs.
	1	2	3	4	5
Husband	1	2	3	4	5
Wife	1	2	3	4	5
Brother	1	2	3	4	5
Sister	1	2	3	4	5
Partner	1	2	3	4	5
Parent	1	2	3	4	5
Friend	1	2	3	4	5
Relative	1	2	3	4	5
Neighbour/member of my community	1	2	3	4	5
Colleague at work	1	2	3	4	5
Own Child	1	2	3	4	5
Community or relative's child	1	2	3	4	5
Acquaintance I knew	1	2	3	4	5
Other _____	1	2	3	4	5

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3.2 Please mark an X indicating if and when someone you know/knew died of HIV/AIDS

Do you know someone who you think or know has died of AIDS?	Never	Past six months	Past yr.	Past 5 yrs.	Past 10 yrs.
	1	2	3	4	5
Husband	1	2	3	4	5
Wife	1	2	3	4	5
Brother	1	2	3	4	5
Sister	1	2	3	4	5
Partner	1	2	3	4	5
Parent	1	2	3	4	5
Friend	1	2	3	4	5
Relative	1	2	3	4	5
Neighbour/member of my community	1	2	3	4	5
Colleague at work	1	2	3	4	5
Own Child	1	2	3	4	5
Community or relative's child	1	2	3	4	5
Acquaintance I knew	1	2	3	4	5
Other _____	1	2	3	4	5

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3.3 READ EACH STATEMENT and circle the response that fits best

	Never	Only once	Sometimes (2 – 4 times)	Many times (5 – 7 times)	Always (8 or more times)
a. Have you attended a funeral of a person who is said to have died of an AIDS related illness?	1	2	3	4	5
b. Attended community meetings on AIDS	1	2	3	4	5
c. Joined an AIDS organization as a member	1	2	3	4	5
d. Volunteered for AIDS activities	1	2	3	4	5
e. Attended a local AIDS rally, march or event	1	2	3	4	5
f. Attended HIV/AIDS meetings in the workplace	1	2	3	4	5
g. Attended an AIDS play or educational event	1	2	3	4	5
h. Given advice to others about HIV/AIDS	1	2	3	4	5
i. Cared for a person who is sick with AIDS	1	2	3	4	5
j. Helped a family who has someone who is sick or has died of AIDS	1	2	3	4	5
k. Visited someone living with HIV/AIDS	1	2	3	4	5
l. I talk to people about HIV/AIDS	1	2	3	4	5

4. GOVERNMENT SUPPORT

For people living with HIV and AIDS, government should:

4.1	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. Support organizations that offer assistance to PLWHA.	1	2	3	4	5	6
b. Provide food.	1	2	3	4	5	6
c. Provide housing.	1	2	3	4	5	6
d. Provide ARV treatment.	1	2	3	4	5	6

5. HEALTH INSTITUTION SUPPORT & USE OF SERVICES

5.1 In the past 12 months have you visited? (check all that apply with an X)

a Private Medical Doctor	<input type="checkbox"/>
b Private Hospital	<input type="checkbox"/>
c Government Clinic	<input type="checkbox"/>
d Traditional healer	<input type="checkbox"/>
e Religious faith healers	<input type="checkbox"/>
f Other	<input type="checkbox"/>

5.2 Think about what usually happens when you get health care

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a The nurses treat me with respect.	1	2	3	4	5	6
b The doctors treat me with respect.	1	2	3	4	5	6
c You are treated worse in the clinic because of your race.	1	2	3	4	5	6
d You are treated worse in the clinic because of your sex.	1	2	3	4	5	6
e You are treated worse in the clinic because you are from a different ethnic group than the health care provider.	1	2	3	4	5	6
f You are treated worse in the clinic because you are from a different cultural group than the health care provider.	1	2	3	4	5	6
g. Women living with HIV and AIDS are treated poorly in the clinic compared to men living with HIV and AIDS	1	2	3	4	5	6
h. People living with HIV are treated poorly in the clinic.	1	2	3	4	5	6
i. Men living with HIV and AIDS are treated poorly in the clinic compared to women living with HIV and AIDS.	1	2	3	4	5	6

6. FAMILY SUPPORT

6.1 : The reason people shame their family members living with HIV/AIDS is because of:

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. Their cultural values.	1	2	3	4	5	6
b. Their religious/spiritual values.	1	2	3	4	5	6

6.2: For the following questions, we would like to know your belief even if you have no family member living with HIV/AIDS. Please respond to the following statement:

I would be ashamed to admit in public that/if:

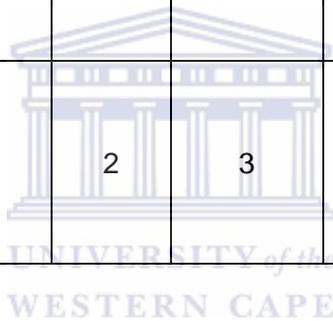
READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. My brother/sister is a PLWHA.	1	2	3	4	5	6
b. My wife/husband/partner is a PLWHA	1	2	3	4	5	6
c. My mother/father is a PLWHA	1	2	3	4	5	6
d. My son/daughter is a PLWHA.	1	2	3	4	5	6

6.3 For the following questions, we would like to know your belief even if you have no family member living with HIV/AIDS

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a Females living with HIV/AIDS are treated worse by their families than their male counterpart	1	2	3	4	5	6
b. If a female member of my family is/was HIV positive I would be more likely to reject her than a male member who is HIV positive.	1	2	3	4	5	6
c. If a male member of my family is/was HIV positive I would be more likely to reject him than a female member of my family who is HIV positive.	1	2	3	4	5	6
d. My family is/would be very supportive of PLWHA .	1	2	3	4	5	6
e. I would treat my family member living with HIV and AIDS who has a job better than I treat the one who does not have a job.	1	2	3	4	5	6

6.4 For the following questions, we would like to know your belief about trust and responsibility related to the spread HIV/AIDS

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. I would not trust a woman who asks her sex partner to use a condom.	1	2	3	4	5	6
b. I would not trust a man who asks his sex partner to use a condom.	1	2	3	4	5	6
c. When it comes to HIV, women should be held more responsible than men for the spread of the virus	1	2	3	4	5	6
d. When it comes to HIV, men should be held more responsible than women for the spread of the virus	1	2	3	4	5	6



7. General Questions

7.1 What is your opinion on the following statements?

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a Given a choice between two well-qualified applicants for a job, I would support hiring an HIV negative person.	1	2	3	4	5	6
b PLWHA who are poor are treated the same as PLWHA who are rich.	1	2	3	4	5	6
c People who are HIV positive are a financial drain on our national economy.	1	2	3	4	5	6
d I treat a PLWHA who has a job better than I treat one who does not have a job.	1	2	3	4	5	6
e Police officers should protect persons living with HIV and AIDS from abuse and violence.	1	2	3	4	5	6
f I would be ashamed to disclose my status if I ever test positive for HIV.	1	2	3	4	5	6
g HIV is more of a problem for other racial/ethnic groups than mine.	1	2	3	4	5	6
h. Men are to be blamed for the spread of HIV	1	2	3	4	5	6
i. People who lose weight are probably HIV positive	1	2	3	4	5	6
j. A thin person is more likely to get HIV than a heavy person	1	2	3	4	5	6

8. HIV Mode of Transmission

8.1 What is your opinion on the following statements?

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. A person who contracts HIV should be shamed.	1	2	3	4	5	6
b. A person who contracts HIV should be rejected.	1	2	3	4	5	6
c. It is more shameful to get HIV from consensual sex than to get it from rape.	1	2	3	4	5	6
d. It is more shameful to get HIV from a spouse in marital sex than from non-marital sexual partner.	1	2	3	4	5	6
e. A person who contracts HIV through sex is to be shamed.	1	2	3	4	5	6
f. A person who contracts HIV through intravenous drug use should be shamed.	1	2	3	4	5	6
g. I believe that the shame associated with HIV is because it is associated with sex.	1	2	3	4	5	6
h. I believe that the rejection associated with HIV is because it is associated with sex.	1	2	3	4	5	6
i. Men are to be blamed for the spread of HIV	1	2	3	4	5	6

9. COMMUNITY, CULTURE & FAITH

What is your opinion on the following statements?

READ EACH STATEMENT	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know
a. HIV is more of a problem for other religious/spiritual groups than mine	1	2	3	4	5	6
b. Shame for having HIV is not a problem in my community	1	2	3	4	5	6
d. Healers contribute to the rejection of PLWHA	1	2	3	4	5	6
e. Healers contribute to the shaming of PLWHA.	1	2	3	4	5	6
f. Religious leaders contribute to rejection of PLWHA.	1	2	3	4	5	6
g. Religious leaders contribute to shaming of PLWHA.	1	2	3	4	5	6
h. Traditional healers contribute to removing shame from HIV.	1	2	3	4	5	6
i. Doctors contribute to removing shame from HIV and AIDS	1	2	3	4	5	6
j. I have seen healers who discriminate against PLWHA.	1	2	3	4	5	6
k I have seen spiritual leaders who discriminate against PLWHA.	1	2	3	4	5	6
l. Women are to be blamed for the spread of HIV	1	2	3	4	5	6

10. INDIVIDUAL SUPPORT FOR PLWHA

How would you respond to the following statements?

	Always	Sometimes	Never	Not Sure	NA
a. I support community events that support PLWHA.	1	2	3	4	5
b. I participate in community events to support PLWHA	1	2	3	4	5
c I would share meals with members of my family if they lived with HIV and AIDS.	1	2	3	4	5
d I would eat meals cooked by my family member if they lived with HIV and AIDS	1	2	3	4	5
e I would share meals with someone living with HIV and AIDS	1	2	3	4	5

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11. Among the following where should we place the emphasis for eliminating shame and rejection associated with HIV/AIDS?

Please pick/check the 3 most important

A Family	
B Community members	
C Hospital/clinic_____	
D Provincial Government	
E National Government	
F Other (specify): _____	

Based on your response to the above question what should be done to eliminate shame and rejection associated with HIV/AIDS?

11.2 In what way? (please explain below):



The logo of the University of the Western Cape, featuring a classical building with columns and a pediment, with the text "UNIVERSITY of the WESTERN CAPE" below it.

End

**Thank you for participating on this project should you have any comments
please feel free to share them below**
