PERCEPTIONS OF HIV/AIDS-RELATED STIGMA AMONG MUSLIMS IN A CAPE TOWN COMMUNITY

A minithesis submitted in partial fulfillment of the requirements for the degree of M. Psych in the Department of Psychology, University of the Western Cape, Bellville.

SHAHIEDA ABRAHAMS

Supervisor: Professor L.C. Simbayi

Co-Supervisor: M.E. Adam

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Shahieda Abrahams

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PLWHA as 'Innocent' versus 'guilty'

ABSTRACT

South Africa has the largest percentage of people living with HIV/AIDS in the world. However, the response against the further spread of HIV/AIDS in the country is being hindered by stigma and discrimination. In order to develop effective intervention programmes to control and reduce the further spread of the disease, it is first important to understand the nature of HIV/AIDS-related stigma and especially how people construct it. In the present study, the social construction of HIV/AIDS-related stigma among Muslims was investigated because high levels of stigma were found in this group. This was fuelled partly by the belief that HIV/AIDS was not a serious problem amongst Muslims. Two focus groups were conducted, one among Muslim women only and the second among Muslim men only. The main aim of the study was to examine the perceptions of HIV/AIDS-related stigma among Muslims. The transcripts were analyzed using thematic content analysis to determine the themes that emerged from the research material. The main findings of the study included that Muslims' religious identity/positioning was the most salient discourse that informed how they understood, made meaning of, and responded to HIV/AIDS. They engaged in various forms of stigma such as 'othering', and mediating factors of stigma included religious positioning. Stigma also served as a social barrier to VCT and disclosure of HIV status. However, supportive attitudes and behaviours were also evident. The findings yielded useful insights into possible elements of intervention programmes, both to reduce HIV/AIDS-related stigma, and also to encourage behavioural change in order to control and reduce the spread of HIV/AIDS in this community.

DECLARATION

I declare hereby that this thesis, 'Perceptions of HIV/AIDS-related Stigma among Muslims in a Cape Town community', unless specifically indicated to the contrary in the text, is my own original work and that it has not been previously submitted for any degree or examination in any other university. All sources I have used or quoted have been indicated and acknowledged as complete references.

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SHAHIEDA ABRAHAMS

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CHAPTER 1

INTRODUCTION

1.1   Introduction

South Africa has the largest percentage of persons living with HIV/AIDS (PLWHA) in the world with an estimated 5.5 million people infected in 2005 (Shisana *et al*., 2005; UNAIDS, 2006). Although, globally, all races are infected, the largest numbers are among Africans, with an estimated six out of every ten men, five out of every ten women, and nine out of every ten children living in sub-Saharan Africa. HIV prevalence in South Africa is highest amongst women aged 15-49 years (Shisana *et al*., 2005). As a consequence of these factors, Shisana *et al*. (2005) stress the importance of making sub-Saharan Africa and South Africa a priority, through taking immediate action to reduce the number of new infections and to plan for medical and social care needs with appropriate intervention programmes.
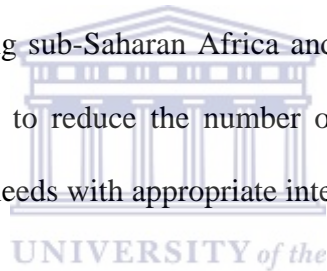
Over 20 years ago Acquired Immune Deficiency Syndrome (AIDS) was first documented and more than 15 years ago HIV was first identified as a causative agent for AIDS (Caelers, 2006). Caelers (2006) also postulated that there were behavioural and social aspects of HIV/AIDS. These included, amongst others, unsafe sex behaviours, stigma, denial, exclusion and discrimination, gender-related issues, migration, the military, poverty, incarceration in overcrowded prisons, male circumcision, female circumcision and/or initiation, rites of marriage, rites of death, alcohol and drug use, and indigenous healing practices. Although most HIV/AIDS service providers and organizations that worked at community level seemed to accept the link between HIV and AIDS, according to Shisana and Simbayi (2002) and Shisana *et al.* (2005) there seemed to be some uncertainty with regard to the

causal relationship between HIV and AIDS and HIV transmission. Modes of transmission of HIV infection in South Africa include heterosexual transmission, transmission through men who have sex with men, mother-to-child transmission, transfusion of blood and blood products, and unsafe injection and unsterile practices in healthcare settings (Shisana *et al.*, 2005).

Shisana and Simbayi (2002) and Shisana *et al.* (2005) postulated that the prevention of HIV/AIDS infection programmes included the South African national HIV/AIDS strategy. The national strategy included, amongst others, focusing on promoting safe and healthy sexual behaviour, improving the management and control of sexually transmitted infections (STIs), providing voluntary counseling and testing (VCT), addressing issues related to blood transfusion and HIV, preventing parent mother-to-child HIV transmission (PMTCT), and providing appropriate post-exposure services (Shisana & Simbayi, 2002; Shisana *et al.*, 2005).
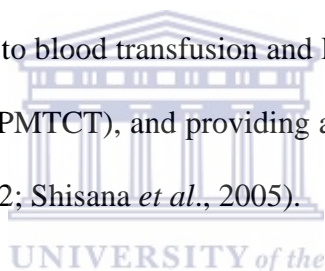
In the absence of a cure for HIV/AIDS (Ackermann, 2005; Deacon, Stephney & Prosalendis, 2005), the national strategy for treatment, care and support includes, for example, providing treatment, care and support services in health facilities; establishing poverty alleviation projects to address the root causes of HIV/AIDS and STIs; providing such projects in communities, that include the development and implementation models of home and community-based care; developing and implementing programmes to support the health and social needs of children affected by HIV/AIDS; and rolling out anti-retroviral therapy (Shisana & Simbayi, 2002). However, this is perceived as not happening at the preferred pace, particularly, with regard to the treatment of people with a CD4 count of less than 200, because it seems the government is seen as holding the view that dietary

elements are an alternative to anti-retrovirals to treat people with AIDS (Caelers, 2006). Shisana *et al*. (2005) posited that maybe the only practical solution to containing the HIV epidemic would be to develop a vaccine. Efforts are presently being made to develop this under the South African AIDS Vaccine Initiative with two clinical trials having been approved by the South African Medicines Control Council (Shisana *et al*., 2005).

There are numerous initiatives that take the form of intervention programmes for those infected and affected by HIV infection. These are happening across South Africa and are often initiated by community organizations, NGOs, government institutions, companies, as well as religious communities (Hivan, accessed 2006, 12 October). An example of such initiatives is 'The W.K. Kellogg Foundation's Orphans and Vulnerable Children Project' that focuses on interventions in Botswana, South Africa and Zimbabwe (Magome, 2006).

The main purpose of the above-mentioned project is to develop 'models of best practice' that will facilitate the development of community-driven strategies for responding to the increasing burden of orphans and vulnerable children (OVC) in Africa. The project has two components that include research that is geared to gather useful information that is necessary to inform the OVC strategy, and secondly, the interventions component that is geared to implement and test the OVC strategies and acquire information. Their specific objectives include improving the quality of life of OVC, supporting families and households coping with the increased burden of care for OVC, strengthening community-based support systems that support vulnerable children, and building capacity in community-based systems for

sustaining care and support to OVC and households, over the long term (Magome, 2006).

The response to the HIV/AIDS epidemic is hindered by stigma and discrimination, and these are contributing to the growth of the epidemic in South Africa (Soul City, 2004). Seale (2004) defines HIV/AIDS-related stigma as a real or perceived negative response to persons by individuals, communities or societies. It is characterized by rejection, denial, discrediting, disregarding, underrating as well as social distance. It often leads to discrimination and violation of human rights. It affects individuals and impacts on the broader society, disrupting the functioning of communities and complicating prevention and treatment of HIV (Skinner & Mfecane, 2004). Changes in the behaviours of people are reduced when HIV stigma is blocking it from public sight (Skinner & Mfecane, 2004). This is evident in the 'othering' of the disease by many South Africans (Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006) including many Muslims who believe a Muslim is immune to HIV infection because of the protection of their religious belief system (Positive Muslims, 2005). A Muslim is defined as a person who follows the religion of Islam (Hanks, 1979; Najjaar, 1994).

Globally, focus has been on HIV/AIDS-related stigma because it is seen as a significant barrier to HIV/AIDS prevention, care, and treatment (Ogden & Nyblade, 2005; Seale, 2004) and as central to the global AIDS challenge as the disease itself (Mann, 1987 in Parker & Aggleton, 2003). Although the 2002-3 World AIDS Campaign chose HIV/AIDS-related stigma and discrimination as its main theme (Parker & Aggleton, 2003), only a few stigma-reducing interventions have been conducted in developing countries (Bos, Schaalma & Mbwambo, 2004). The

existing notions of HIV/AIDS stigma and discrimination need to be interrogated to establish what people's conceptions are, so that they can contribute to the design of effective anti-stigma intervention programmes (Parker & Aggleton, 2003; Visser, Makin & Lehobye, 2006).

Intervention strategies need to be culturally informed to be effective because according to Airhihenbuwa and Webster (2004), the individual's behaviour in relation to family and community is one major cultural factor that has implications for sexual behaviour and HIV/AIDS prevention and control efforts. Thus, because Muslims are a large minority among the population of the Western Cape, it is important to establish their perceptions of HIV/AIDS in relation to their religious beliefs and cultural practices. This was done with a view to assist with the development of intervention programmes targeting them, as they are currently predominantly marginalized in the fight against HIV/AIDS due to the perception that HIV/AIDS is not yet a major problem in their community.

The present project was conducted as part of a larger project initiated by the Pennsylvania State University (PSU) and Human Sciences Research Council (HSRC) in 2004. It will be discussed in the next section.

1.2   The main research project

The title of the main research project is 'Capacity Building for HIV/AIDS Research in South Africa'. The overall goal of the project is to strengthen infrastructure and research capacity building of both academic staff members and postgraduate students at historically Black universities (HBUs) in South Africa. It included the University of the Western Cape (UWC) in Years 1 and 2 and the University of

Limpopo in Years 3 and 4. The goal is 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.

The specific objectives of this partnership project are: 1) four faculty members to mentor six graduate student trainees each year; 2) to conduct exploratory research on the stigmatization of PLWHA; 3) the trainees will develop two exploratory intervention research projects in one community; 4) the expectation is that these projects would lead to the development of a stigma index for S.A.; 5) the focus of the research will be to reduce and eliminate HIV/AIDS stigma in the community and health care centres.

In year 1 and 2 (this research project was a part of year 2) exploratory studies were conducted in various communities (phase 3). Phase 4 is to analyze the results and to develop interventions and new projects. Phase 5 will generate items for a stigma index.
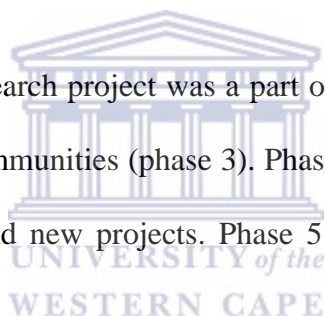
1.3   Rationale of the study

Although HIV/AIDS-related stigma affects many South Africans and is seen as a major limiting factor in primary and secondary HIV/AIDS prevention and care, very little rigorous research has been conducted on this issue (Holzemer & Uys, 2004). Most studies on stigma have been done either within a quantitative framework or used anecdotal evidence (Holzemer & Uys, 2004), and this highlighted a need for more rigorous qualitative studies that would allow the researcher to tap into the depth of cultural knowledge, particularly of groups that may be of particular interest in relation to the spreading of HIV/AIDS, such as amongst the Muslim community.

This is in agreement with Skinner and Mfecane (2004) who posit that stigma is a social phenomenon that needs to be understood at both individual and social levels. This is particularly important as the current understanding of HIV/AIDS-related stigma and discrimination in South Africa is based mostly on research done amongst Africans (see Kalichman & Simbayi, 2003, 2004). Kalichman *et al.* (2005) have recently also extended the study of stigma among Coloureds and Muslims in Cape Town, which will be discussed in the next chapter.

1.4   Aims and objectives

The main aim of this study was to establish the perceptions of HIV/AIDS-related stigma among Muslims in a Cape Town community.

The specific objectives were to explore:

a.   Muslims' views of HIV/AIDS

b.   How PLWHA were treated in the Muslim community

c.   Whether the Muslim community was supportive of PLWHA

d.   Muslims' views about PLWHA

e.   Muslims' views on testing for HIV.

1.5   Overview of the thesis

Chapter 1 includes an introduction to the study, the main research project, the rationale of the study, the aims and objectives of the study and an overview of the thesis. In Chapter 2 the researcher will focus on the literature review that includes

international and South African studies, and the theoretical framework. Chapter 3 will contain the methods used, that include the methodological framework, the research method, participants, selection of the participants, focus group guide, procedure, trustworthiness and credibility, data analysis, ethical considerations and reflexivity. Chapter 4 will communicate the results that emerged from the study. Chapter 5 will include the discussion and recommendations. These will encompass summarizing the main findings and an explanation of the findings in relation to the relevant theories and the previous literature, the limitations of the study, future research, recommendations, and the conclusion.

CHAPTER 2

LITERATURE REVIEW

2.1   Introduction

In this chapter the researcher documents some of the most recent literature in relation to HIV/AIDS-related stigma. The discussion first focuses on international studies that deal with the research topic. Thereafter, reference is made to studies conducted in South Africa. Points of discussion include, for example, that HIV/AIDS-related stigma is characterized by internal and external stigma and that it is associated with behaviour already stigmatized. Further discussion centres around what causes, perpetuates or mitigates stigma, the context in which it occurs, how stigma and discrimination are experienced, and how it affects access to HIV prevention, testing, disclosure, care and support efforts. This is followed by a discussion of the theoretical framework within which this research was done. The theoretical framework proposes HIV/AIDS-related stigma should integrate explanations of the complex dialectic of individual and society in order to be holistically understood.

2.2   International studies

Two recent literature reviews, Bollinger (2002, in Policy Project, 2002) and Deacon *et al.* (2005), have indicated that PLWHA are stigmatized because they are seen as having a fatal disease that causes fear of infection. HIV/AIDS is often associated with behaviour that is already stigmatized, for example, sex work, promiscuity, intravenous drug use, and homosexuality. Becoming infected is often seen as the

result of choices made by the individual. Also having HIV/AIDS is seen as being punished for deviant behaviour.

HIV/AIDS-related stigma is divided into internal stigma that is felt by PLWHA (e.g. the fear of the reaction of others when the individual discloses their HIV status), and external stigma that is the actual experience of discrimination (Deacon *et al*., 2005; Policy Project, 2002). Parker and Aggleton (2002 in Policy Project, 2002) postulate that external stigma may include the experience of, amongst others, blaming and devaluation of PLWHA.

Busza (2001) did a study in South-East Asia that looked at stigma, the contexts of discrimination and responses to it within communities. Their outcome showed many forms of stigma, for example, additional stigmatization of men having sex with men (MSMs), injection drug users (IDUs), and commercial sex workers (CSWs). Moral judgements were also used with PLWHA as to whether they were 'guilty' (having brought the disease onto themselves) or 'innocent' (got the disease not by their actions). PLWHA were stigmatized through isolating both the infected and affected due to fear of causal contact, restrictions on participation in local events, refusal to allow infected children in local schools, lack of support for affected bereaved family members (including orphans), violation of confidentiality in the health sector, and denial of religious rituals such as funeral practices.

A synthesis of studies done in Ethiopia, Tanzania, Zambia and Vietnam by Ogden and Nyblade (2005) looked at, amongst others, factors that perpetuated or mitigated stigma, the context in which it occurred, how stigma and discrimination were experienced, and how it affected access to HIV prevention, testing, disclosure, care and support efforts. The outcome was that although there were variants, HIV/AIDS-

related stigma and discrimination were remarkably consistent in what causes stigma, the forms in which stigma is expressed, and the consequences of stigma. Their findings showed the following: what causes stigma was lack of HIV/AIDS knowledge, morality, and fear of transmission. Assumptions are made about the moral integrity of PLWHA, hence, blame is apportioned them as being morally improper and 'guilty' of transgressions, resulting in shame felt by PLWHA. The perception is that HIV infection is the product of one's personal choice of engaging in social evils, and that it is a punishment for disobedience to God's laws. When dealing with a PLWHA the emphasis is on 'guilty' versus 'innocence' in regard to how the person became infected, and this informs the degree of stigmatization the person will experience. Women bear the brunt of stigma because they are supposed to uphold the moral fibre of society.

Forms of stigma found in these studies were physical, social, verbal and institutional, with the most frequently experienced forms being similar across all countries. Physical stigma included, amongst others, isolation, and violence. Social stigma included isolation, voyeurism, and loss of identity and/or roles, while language stigma included gossip, taunting, expressions of blame and shame, labeling and use of derogatory words to describe PLWHA. Institutional stigma included loss of livelihood/future, loss of housing, differential treatment in schools/health care settings/public places, and media and public health messages and campaigns (Francis (2002) in Francis & Francis, 2006; Ogden & Nyblade, 2005).

The consequences and impact of stigma were, amongst others, loss of livelihood, loss of marriage and childbearing options, poor care within the health sector, withdrawal of care giving in the home, and internalized stigma. Fear of stigma and

discrimination contributed to people not coming forward and being tested (Ogden & Nyblade, 2005).

It appears that hitherto HIV/AIDS-related stigma in Muslim communities has not been researched much. However, it is reported in the Muslim world that HIV/AIDS-related stigma takes many forms, for example, denial of the pandemic (Middle East News Online, accessed 2005, February 28). Furthermore, because they believe their religious doctrines prohibit premarital sex, they reject certain discussions related to HIV/AIDS. They believe, for example, that homosexuals and prostitutes are not common in Muslim communities (Middle East News Online, accessed 2005, February 28).

In Mauritania, an area predominantly inhabited by Muslims, talking publicly about AIDS is frowned upon, many believing that the Holy 'Quran' protects against AIDS, and 'good Muslims' who follow the Holy Book never get the disease (AIDS Weekly, 2004). However, authorities have recently persuaded religious leaders to start preaching about the dangers of AIDS and the need to stop its spread (AIDS Weekly, 2004).

It seems in Senegal the opposite is happening to that in Mauritania regarding the 'othering' of HIV/AIDS. Senegal, where 92% of the population is Muslim, has one of the lowest rates of HIV infection in Africa, with an estimated 2% of the population being infected (Aids in Muslim African countries, 2005). This is due to strong political support for prevention programmes from the very beginning of the disease. Instead of denying the reality of the danger of the disease, Senegal's government began to take strong measures to prevent the spread of the infection as long ago as 1989. The country's religious leaders tolerate open discussion about sex

education and do not discourage programmes which make condoms available to young people. Prostitution is carefully controlled. It is a country where people are tolerant and accepting. The tolerance and the existence of institutions such as JAMRA (i.e. spark), a highly successful Islamic organization that mainly focuses on HIV/AIDS, are just some of the possible reasons for the low number of HIV infected people in this country (Aids in Muslim African countries, 2005). It seems that HIV/ AIDS stigma has been counteracted because of the high level of focus and attitude of tolerance towards HIV/AIDS and PLWHA.

The above-mentioned is assumed because of an earlier study done in Dakar, Senegal by Niang *et al*. (2003), who posited that little attention and research was done, in particular on men who have sex with men and HIV/AIDS. The study found this group of people experiencing HIV/AIDS stigma, violence and rejection and that many of these men were at risk of HIV infection because of unprotected sex. The study made salient the need for non-stigmatizing, sexual health information and services. This seemed to have been responded to positively (Aids in Muslim African countries, 2005).

A study was conducted recently in Hong Kong by Mak *et al*. (2006) that compared stigma of HIV/AIDS, Severe Acute Respiratory Syndrome (SARS), and tuberculosis (TB) and showed that HIV/AIDS stigma is continuing to be expressed by many people. It further showed that public stigma was the highest towards HIV/AIDS. They found that the attributions of controllability, personal responsibility and blame were applicable in explaining stigma across the three disease types. Knowledge about the disease had no significant effect on stigma. Individuals with or suspected of having HIV/AIDS were denied health care services and employment, refused

entry to foreign countries, were shunned by neighbours and co-workers, and experienced social disruptions with family members and friends (Ackermann, 2005; Herek, 1999 in Mak, *et al*., 2006). HIV/AIDS was seen as a fatal condition, physical limitations were seen as chronic and incurable, and HIV/AIDS was regarded as posing the greatest level of threat to the general public in terms of lethality. Factual understanding of the disease played a small role in shaping stigmatizing attitudes towards PLWHA, while the public's perceptions or beliefs about the disease played a much greater role in stigma formation (Mak *et al*., 2006).

2.3   South African studies

In this section the researcher records some of the most recent literature in relation to HIV/AIDS-related stigma and reference is made to studies conducted mainly in South Africa. The focus of discussion includes, for example, the outcome of two South African national household surveys, the impact of traditional beliefs on HIV/AIDS stigma, and how HIV/AIDS stigma impacts on VCT and HIV/AIDS disclosure. Furthermore, the researcher discusses the findings of studies that explored the challenge stigma poses to the religious community, how stigma is practised particularly in the Muslim community, for example, 'othering' of HIV/AIDS, and positive responses to HIV/AIDS stigma. These will now be discussed.

As globally experienced, HIV/AIDS-related stigma is also practised in the various segments of South African society. In a South African national household survey (Shisana & Simbayi, 2002), a significant minority of respondents indicated their responses to PLWHA as, amongst others, not wanting to share a meal or sleep in the same room or talk with them.

A second in the series of household surveys was conducted by Shisana *et al.* (2005). Their results showed, as a form of 'othering', about two-thirds of the adult and youth participants in the study indicated that they would not get infected with HIV due to safer sex practices and abstinence, hence, they were less likely to get tested. Muslims (included in the 'Indian' category) showed they were amongst those who least perceived themselves to be at risk of HIV infection. However, the study found a notable increase in using VCT services in the last two years.

The above-mentioned study further found that there still seems to be inadequate levels of knowledge regarding some key aspects of HIV/AIDS. These include confusion about whether HIV causes AIDS, whether there is a cure for AIDS, knowledge of ARVs, the understanding that partner reduction is an effective HIV prevention strategy, and lack of information with regard to HIV vaccine research development (Shisana *et al.*, 2005).

The study by Shisana *et al.* (2005) further revealed that participants had varying degrees of feelings and attitudes regarding different aspects of HIV/AIDS and this mediated stigma. It was found that the majority of the respondents would be willing to care for a family member, including children with AIDS. However, there were also negative attitudes and perceptions towards PLWHA and some hesitance to marry PLWHA. Nearly half of respondents indicated that they would have a problem having protected sex with PLWHA because of their concern for personal consequences (e.g. being at risk of HIV infection). 'Othering' and exclusionary beliefs and practices were less likely to be engaged with in urban areas, because of people recognizing that HIV/AIDS is a population-wide phenomenon. Taking HIV/AIDS more seriously and talking more about it have increased primarily due to

television and radio programmes. A number of respondents admitted they would not reveal if their family member died of HIV-related illness because of the fear of being stigmatized.

Shisana *et al*. (2005) suggest that it is complex to conclude whether there was an increase or decrease in stigma over the past three years because of the complexity of the varying attitudes to different aspects of HIV/AIDS and the differing contextual situations of these respondents. Notwithstanding the latter, Shisana *et al*. (2005) posit that South Africans are accepting HIV/AIDS as a reality in South Africa, hence, stigmatizing attitudes are decreasing.
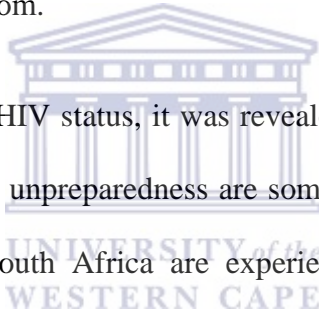
However, Jewkes (2006) asks the question: what drives this type of change in attitude? She suggests normalizing HIV/AIDS as a disease, and role modeling caring for PLWHA. Hence, shifting the discourse from the negative to empowering others to do the same, will help bring about this attitude change that could lead to decreasing discrimination against PLWHA and reducing stigma (Jewkes, 2006). This seemed possible because in a study conducted in a South African community, it was found that individual stigmatization was significantly less severe than the degree of stigmatization that respondents attributed to the community at large. They also found race group, personal knowledge of someone with HIV, area of residence, gender and age group impacted on the respondents' personal tendency to stigmatize PLWHA (Visser *et al.*, 2006).

Similar to the above, it was found that in many traditional African cultures, there is a belief that HIV/AIDS is caused by witchcraft or supernatural forces and this is commonly thought to be an underlying source of AIDS-related stigmas in South Africa (Shisana & Simbayi, 2002). A study by Kalichman and Simbayi (2004) that

looked at traditional beliefs about the causes of AIDS and AIDS-related stigma in South Africa showed that individuals who believed that AIDS results from spirits/the supernatural held significantly greater AIDS-related stigmas than those that did not believe AIDS was caused by supernatural forces. The also found that the former were more likely to endorse social sanctions against PLWHA such as engaging in negative attitudes towards PLWHA, seeing them as 'dirty', 'shameful' and 'guilty of wrongdoing', hence their freedom would be restricted. PLWHA were also seen as the victims of a curse, or being an outcast, or being possessed, as indicated in a study by Scher (2006).

It has been shown that HIV/AIDS-related stigma also impacts on the HIV testing behaviour of people. A study conducted by Kalichman and Simbayi (2003) that explored the relation between HIV testing history, attitudes towards VCT and AIDS stigmas in a Black township in Cape Town showed the following outcomes. People who had not been tested were more likely to avoid being tested because of social barriers to getting tested, particularly AIDS stigmas, and perceived adverse testing outcomes. Additionally, those not tested held significantly greater AIDS-related stigmas than individuals who had been tested. They were significantly more inclined to see PLWHA as dirty, guilty of wrong doing and to be avoided as friends, and that they should feel ashamed and should not be allowed to work with children. One could infer from this that people's anticipated HIV-positive test result would lead to anxiety regarding the possible external stigma they could experience. This could contribute to them not wanting to test. This was similar to the findings of the study by Hutchinson and Mahlalela (2006).

Health care workers are also observing the impact of stigma on VCT. This was evident in a study that aimed to develop a brief measure of AIDS-related stigma that could be used in multiple settings and contexts in South Africa (Kalichman *et al*., 2005). They found that AIDS stigma was a serious concern for HIV/AIDS services and prevention, in that health workers felt the most important reason why people did not get tested for HIV was AIDS-related stigma. These people feared rejection and harm resulting from an HIV-positive result. Also, stigmatizing beliefs served to distance people from HIV/AIDS, supporting the idea that AIDS only happened to other people. The outcome also showed strong endorsement of the belief that PLWHA should not be allowed to work with children and they should expect restrictions on their freedom.

Regarding disclosure of HIV status, it was revealed that stigma, lack of knowledge and skills, and emotional unpreparedness are some of the barriers to disclosure that primary caregivers in South Africa are experiencing in relation to telling their children that the latter are HIV-positive. This was found in a study conducted with care-givers of children with HIV who were seen at the Chris Hani Baragwanath Hospital in 2001 (Kouyoumdjian, Meyers & Mtshizana, 2005). The results indicated that caregivers never discussed HIV with their children. They felt their children were too young to understand and if their children knew their HIV-status, they might tell others. Consequently, this could result in the child and the family being discriminated against, similarly to how other PLWHA and their families were stigmatized. Caregivers indicated that they feared discrimination, social rejection and isolation, and the fear of being judged as being promiscuous or associated with a disease of people who are homosexual. Caregivers were ambivalent about telling their children about HIV and that disclosure challenged them emotionally and

psychologically. They found the subject painful to discuss because their non-disclosure was mediated by their own prejudices against PLWHA. An example was that they found it difficult to trust their children and wondered about the children's sexual activities.

In addition, the study by Kouyoumdjian *et al.* (2005) also found children were affected by stigma with regard to some aspects of their feedings. For example, an HIV-positive mother was subjected to stigma, in that she had little decision-making autonomy around the feeding of her child. These mothers were often uncertain about the safety of breastfeeding; whereas, health workers could be seen as being the gatekeepers to this knowledge as well as to resources such as formula milk that was often not available when needed. The mother feared the disclosure of her HIV status should she not breast feed in a community that encouraged it. This was similar to the findings of a study by Doherty, Chopra, Nkonki, Jackson and Greyner (2006) that showed these mothers often suffered social isolation because of non-disclosure to avoid stigma associated with HIV. Fear of AIDS stigma was also the primary reason why HIV-positive women in sub-Saharan Africa would not disclose their status, as revealed in the study conducted by Kilewo *et al.* (2001).

Responding to stigma poses a challenge particularly to the religious community. According to a study by Ackermann (2005), it was found that stigma includes dealing in lies, thriving on silence, denial, guilt and fear, using legitimate metaphors, such as AIDS being labeled as death, and ethnically and culturally-based stigma. She suggests Christians should confront the sinful nature of stigma, find hope in the scriptures and their traditions for communicating God's grace, mercy and compassion in their actions. Ackermann (2005) indicates stigma should be regarded

as sin because God is forgiving. She further says stigma breeds judgmental attitudes and it destroys human communities. Thus, religious communities should be compassionate and repudiate all forms of stigma, for example, have a concern for justice (Ackermann, 2005).

On a positive note, Francis and Francis (2006) examined how HIV-related stigma and its associated prejudice and discrimination could be addressed in a classroom. Their results showed students attributing descriptions of HIV and PLWHA as 'isifo' (disease commonly found in hostels), 'African sickness', 'punishment from God', 'people who were immoral', 'promiscuous', 'drug takers', 'prostitutes' and 'gay plague'. Through the discussions, film and panel, which were a part of the educational programme used in this study, students recognized and identified HIV/AIDS-related stigma in schools and communities. The results show that talking about HIV/AIDS and having educational programmes targeting students, such as, 'Diversity and Education', is a way of dealing with HIV/AIDS-related stigma.

A further positive response to HIV/AIDS stigma is that Robins (2006) has argued that HIV/AIDS activism in South Africa has contributed to a citizenship that is concerned with rights-based struggles and that some individual HIV/AIDS sufferers have created collectively shared meanings of their experiences of illness and the stigmatization thereof. He explains that the experience of having full-blown AIDS, profound stigma and 'social death' associated with the latter stages of the disease, produce the conditions for HIV/AIDS survivors' commitment to "new life" and social activism. It is the experience of profound negativity of experiences such as stigma, that brings about the activist's construction of a new positive HIV-positive identity of being a citizen-activist and a member of a social movement. Similarly, as

shown in a study conducted by Rohleder and Gibson (2006), it was found that women experienced stigma that they internalized as a 'spoiled identity'. However, some of these women resisted this through splitting off these bad representations and projecting them outside themselves.

Although Shisana *et al*. (2005) suggested that there was a decrease in stigma in South Africa, it was still prevalent amongst Muslims as was evident in a study conducted by Kajee, Simbayi, Toeffy and Kalichman (2005). They explored AIDS stigma amongst Muslims in the Cape Town metropole. They found that many Muslims were in denial and believed HIV cannot affect Muslims because, largely, Muslims do not engage with pre-marital, extra-marital and homosexual sex. However, it was found that 11% of the 4 000 social cases the Muslim Judicial Council dealt with in 1993 related to 'sex outside marriage' (Positive Muslims, 2005). Many held discriminatory views against PLWHA, in that they believed there should be restrictions put on their freedom, they shouldn't be allowed to work, and they would not want to be friends with PLWHA. The stigma was mostly caused by ignorance and fear. Muslims associate HIV with Blacks and, because they have not seen or touched PLWHA they believe they are unaffected by the virus. These are some examples of Muslims stigmatizing HIV/AIDS: "Saleem (not his real name) of Rylands in Cape Town was certified HIV-positive with full-blown AIDS. While still in the care of Groote Schuur Hospital, his parents, two brothers and a sister rejected him. He was told not to return home and to find his own way", and "I disclosed my status on a community radio station. It was met with mixed feelings as well as denial and often people would state that as a Muslim one could never contract this disease" (Positive Muslims, 2005).

A form of denial of HIV/AIDS is to engage in 'othering' of the disease as mentioned earlier. It is clear that Muslims are 'othering' HIV/AIDS because they believe they are not at risk but 'others' are. The 'othering' could be based on the perception of 'self=religious/good/obedient' and 'other=irreligious/bad/deviant'. This dichotomous thinking is explained in a study done by Petros *et al.* (2006) that looked at the key themes of 'othering' that emerged from formative research preceding a national population-based HIV/AIDS study in South Africa (see Shisana & Simbayi, 2002). Petros *et al.* (2006) sought to examine cultural and racial contexts of behaviour relevant to the risk of HIV infection among South Africans. They explained dichotomous thinking as 'self=same/good' and 'other=different/bad'. The outcome of the study showed that PLWHA were 'othered' in South Africa by using a number of different forms of 'othering'. These included religion, race, gender, health systems, homophobia, and xenophobic forms of 'othering'. They also showed that religious 'othering' is perceived as a safe space to deny and distance HIV/AIDS and it sometimes masks racial 'othering'. Their results also revealed how cultural and racial positionings mediate perceptions of those considered to be responsible and thus vulnerable to HIV infection and AIDS (Petros *et al.*, 2006).

Petros *et al.* (2006) further postulated that central to these positionings was the 'othering' of blame. Black women seemed to carry the heaviest burden of HIV/AIDS, including stigma. HIV/AIDS was found to be also connected to 'anal sex' and foreigners were blamed for bringing the virus to South Africa. The study (Petros *et al.*, 2006) raised important questions concerning social life in South Africa and the limitation of approaches that do not take into account critical contextual factors in the prevention of HIV and care for PLWHA. They made salient the need to sensitize people to the problem of 'othering' and its complex social dynamics.

Furthermore, they suggested that the message should be communicated that everyone is at risk of HIV infection irrespective of their perceived safe social space (Petros *et al.*, 2006). It is against this background that the researcher saw the necessity of understanding the social dynamics that underlie the 'othering' engaged in by Muslims in Mitchell's Plain, a Cape Town community.

2.4 Theoretical framework

In order to develop effective anti-stigma intervention programmes that will reduce stigma and discrimination, we need to theorize about it (Deacon *et al.*, 2005). According to Deacon *et al.* (2005, p. 3), "how we define stigma structures our understanding of how it operates and how to address it". Goffman (1963) regards HIV/AIDS-related stigma as embedded in the individual in that it is an attribute that is significantly discrediting which, in the eyes of society, serves to reduce the person who possesses it. He further explains that an individual has a characteristic (HIV/AIDS) which constitutes a spoiled identity, hence, society devalues the individual who is regarded as socially undesirable. This would lead to social devaluation and discrimination of this individual. It also means that the problem of stigma is partly or wholly a problem of individual ignorance. This implies, if the individual is educated about HIV/AIDS, this would result in a reduction of stigmatizing of PLWHA (Deacon *et al.*, 2005). However, the tendency to see HIV/AIDS stigma in individual psychological terms has been challenged (Parker & Aggleton, 2003).

Another approach focuses on the problems of social inequalities in society to which HIV/AIDS-related stigma is inextricably linked, in that it reinforces existing relations of power and domination that contribute to maintaining social control

(Ackermann, 2005; Parker & Aggleton, 2003). Parker and Aggleton (2003) understand HIV/AIDS-related stigma as inextricably linked to the existing hierarchical power relationships through which people discriminate against those seen as different/deviant. An example of this is homosexuals suffering social exclusion and dominance by society through the imposition of the dominant ideology of heterosexuality. Furthermore, they argue that HIV/AIDS-related stigma is a vehicle through which this is perpetuated and reinforced. The difficulty with this explanation is that it would not be able to explain why some people engage in stigmatization and the different forms it takes. It is also problematic to imply that discrimination and the exacerbation of inequalities are automatic, desired, or intended effects of stigmatization (Deacon *et al*., 2005).

Although the afore-mentioned theoretical approaches contribute to the understandings of the problem, they resorted to individualism and functionalism (Deacon *et al*., 2005). Campbell (2001) posits that theoretically, HIV/AIDS-related stigma should incorporate explanations of the complex dialectic of individual and society in order to be understood more holistically. According to Deacon *et al*. (2005), it is imperative to understand the process of stigmatization, the specific context within which it occurs and its effects, in order to help explain the variable nature of stigma and to devise context-specific interventions. This may be seen to encompass the understanding of the content of stigma as including explanations such as people making meaning of and assigning values to a biological phenomenon like HIV/AIDS. Alternatively, HIV/AIDS stigma draws on existing negative definitions of the 'other' (e.g. PLWHA). However, although there are similarities in global patterns of HIV/AIDS stigmatization, it reveals significant local variation. This seems so because stigma is influenced by a myriad of local social, political,

historical, cultural, gender and religious factors (Ackermann, 2005; Deacon *et al.*, 2005). Thus, a series of shared beliefs underlie much of the stigma against PLWHA. This makes it a social process in which individuals use their existing social representations to perceive, understand and respond to this phenomenon (Deacon *et al.*, 2005; Joffe, 1999; Patient & Orr, 2003). It is important to understand the afore-mentioned, and how this local content is constructed, in order to develop effective HIV/AIDS interventions (Deacon *et al.*, 2005; Rakotonanahary, Rafransoa & Bensaid, 2002).

This study located itself in the understanding of stigma according to Campbell (2001) and Deacon (*et al.,* 2005) as discussed previously. They have acknowledged that stigma and its effects evolve from the interaction between the individual and society and is historicoculturally-specific. This is in agreement with social constructionism which is the methodological framework used in this project. Social constructionism assumes that phenomena take place within a specific period of history and are culturally bound (Burr, 1995). This means perceptions and experiences of HIV/AIDS-related stigma should be understood as being socially constructed through the dialectic of the individual and the society. This approach gives the researcher the opportunity to understand the participants' specific perceptions of HIV/AIDS-related stigma as socially constructed by them.

2.5   Summary of chapter

Much research has been done in relation to HIV/AIDS-related stigma. Globally, as well as locally, and in particular in the Muslim community in Cape Town, HIV/AIDS stigma has shown many similarities in its manifestations. However, it has been shown that the content of HIV/AIDS stigma varies, and is dependent on the

context in which it occurs. This makes it dynamic, socioculturally and historically specific. It has been shown as evolving from the complex dialectic between individual and society and the meaning people make of HIV/AIDS and PLWHA. This informs how people understand and respond to these phenomena. The effects of stigma vary and are mostly negative. Conversely, stigma has engendered social activism in collective anti-HIV/AIDS stigma contestations and vigorous campaigning.

Current theories of disease stigma have been problematic in that there is continuing tension between individual and social explanations for this phenomenon. However, this has contributed to understanding HIV/AIDS stigma as the dynamic dialectic of individual and society and that to enable us to understand it holistically, one would have to take into consideration that stigma varies depending on the context in which it occurs. Additionally, it has variable effects for which one has to devise context-specific interventions.
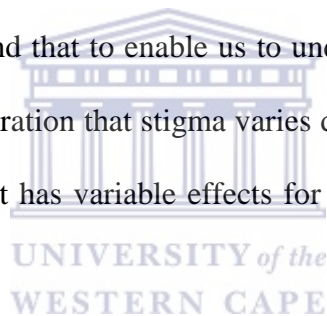
CHAPTER 3

METHODS

3.1   Introduction

This chapter will include the methodological framework which focuses on social constructionism, the framework within which this study was located. This will be followed by a discussion of the research method used – qualitative method in the form of focus group discussions. A discussion of the selection of participants, participants, focus group guide, procedure, trustworthiness and credibility of the study, data analysis, ethical consideration, reflexivity and a chapter summary will follow.

3.2   Methodological framework

Burr (1995) posits that social constructionism involves taking a critical stance towards taken-for-granted knowledge. It cautions us to be ever suspicious of our assumptions about how the world appears to be. It engages with historical and cultural specificity, meaning that the way we understand phenomena takes place within a historicocultural specific milieu, which is never static, but is specific to that culture and period of history. It also assumes that knowledge is sustained by social processes. This means that our knowledge of the world, our common ways of understanding it, are constructed through social processes and interactions, in which people are constantly engaged with each other. It also assumes that knowledge and social action go together; that each different construction of phenomena brings with it, or invites, a different kind of action from human beings. Descriptions or

constructions of phenomena therefore sustain some patterns of social action and exclude others.

This research project worked within a social constructionist framework because it is in agreement with Dean and Rhodes (1998 in Meyer, Moore & Viljoen, 2003) who posit that the way we make sense and give meaning to our world, our ideas and attitudes, is informed by our interaction with the particular social and cultural context in which we exist. It is within this framework that the researcher sought to understand how Muslims construct their realities, their ideas, their attitudes and responses to HIV/AIDS within their sociocultural context. According to Collin (1997), reality is a social process and it is what is believed to be 'real' or a 'fact', hence, societal cognitions create social 'fact'. It was thus hypothesized that Muslims, because of the religious tenets that inform their social processes, could believe they will not be affected by HIV/AIDS. Thus, to them this could be a 'fact' that they could accept as 'real'.

3.3   Research method

The project utilized a qualitative method that enabled the researcher to explore, as described by Mouton and Marais (1988) as well as Henning, van Rensburg and Smit (2004), deep and rich information, which would bring forth meanings that would show how people made sense of concepts that evolved from their perceptions. It allowed for the emerging of data that were socio-culturally specific. According to Mason (2000), qualitative research is grounded in a philosophical position that is concerned broadly with how the social world is interpreted, understood, experienced or produced.

On the other hand, the use of quantitative methods was regarded as Creswell (2003) explains, it uses measuring instruments to produce supposedly wide objective statistical data that answers different questions, for example, close questions used in survey questionnaires, in response to the research focus. This allows for a wider scope of information to emerge. Hence, the qualitative method is more suited to the research focus question of this project and affords the researcher the opportunity to facilitate the emerging of deep and rich descriptions by Muslims of their perceptions of HIV/AIDS that would otherwise have gone unexamined.

Focus group discussions were used for the data collection process. They are described by Patton (1987) and Bloor, Frankland, Thomas and Robson (2001) as typically based on homogeneous groups. They further explain that focus groups involve conducting open-ended interviews with small groups of between eight to 12 participants and use, optionally, the general interview guide approach. This guide serves as a basic checklist during the interview process and ensures that the same information about the phenomena studied is obtained from all the focus group discussions. Focus groups present an environment in which participants influence each other, as happens in life, in relation to their perceptions, feelings, and thinking about particular issues (Krueger & Casey, 2000). People make meaning of situations, and meanings are typically forged in discussions or interactions with other persons (Creswell, 2003). Hence, using focus groups allowed data to emerge about HIV/AIDS-related stigma that was socially constructed amongst Muslims.

3.4   Selection of the participants

The researcher asked the 'Imam' (religious leader) of Mitchell's Plain to help with gaining access to Muslim participants. The latter announced in the mosque that HIV/AIDS research was being done and asked those interested to avail themselves to meet the researcher. The researcher explained the project to those interested and asked them to volunteer to be participants. In order to explore the perceptions of HIV/AIDS-related stigma among the wider community of Muslims, participants were chosen as they volunteered. This was to make sure that all participants were not of a particular group of Muslims, for example, those who were either HIV-positive or those who attended an HIV/AIDS support group. A time and venue for the groups were then decided upon. The female group was held in the mosque and the male group was conducted in the home of an attendee of the mosque and religious school. Both groups took place after prayer times.

3.5   Participants

Two gendered focus groups were conducted among Muslims living in Mitchell's Plain, Cape Town, who preferred separate groups for males and females, as their religion encourages adult males and females to socialize separately. Participants were largely from an urban 'working class' background. Each group had 6-8 participants aged between 18 and 45 years. One group was males only and one females only.
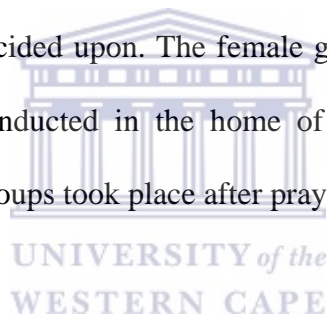
3.6   Focus group guide

A focus group guide was developed by the researcher together with the supervisor and the PSU-HSRC-UWC Project team (see Appendix A). It set out to measure indicators of internal and external HIV/AIDS-related stigma in relation to the Muslim individual, the Muslim family, and the Muslim community including Muslim religious leaders, and how it impacted on HIV/AIDS voluntary counselling and testing.

3.7   Procedure

The focus group discussions were digitally audio-recorded, and conducted in English. The duration of each group was about ninety minutes. A moderator facilitated the group discussion (the gender of the moderator and participants of the group was similar). An assistant moderator took notes of the content and processes of the group discussion that were used as a back-up to the audio-recorded research material and facilitated the data analysis process. An M. Research male student moderated the group with male participants and the assistant moderator was the female researcher of this project. The male participants of the group verbally consented to her presence. The female researcher of this project moderated the female group and an M. Research female student was the assistant moderator.

3.8   Trustworthiness and credibility

A research process was followed that, according to Krueger and Casey (2000), would ensure the results were trustworthy and an accurate reflection of how the participants felt and thought about the topic researched, hence, lending credibility to the research findings, as per Terre Blanche and Wassenaar (1999), who posit that

credible research produced findings that are convincing and believable. Furthermore, because people behaved differently in different contexts, qualitative methods ensured dependability of the findings, and ensured, according to Terre Blanche and Wassenaar (1999), that the findings occurred as the researcher said they did. This were ensured through a process called 'member checking' (Creswell, 2003). For this project it meant the assistant moderator compared her focus group interview notes with that of the typed transcripts of the content of the tape-recordings and ensured that the transcripts correctly reflected the content of the focus group interviews.

3.9   Data analysis

Thematic content analysis, which falls under the umbrella of interpretive methods, was used to analyze the research material. Terre Blanche, Durrheim and Painter (2006) postulate that interpretive methods assume people's subjective experiences are real and should be regarded seriously. This facilitates our understanding of others' experiences when we interact with them and listen to what they tell us. Furthermore, using qualitative research techniques are best suited to this task (Terre Blanche *et al*., 2006). The researcher endeavoured to regard participants' subjective experiences and perceptions of PLWHA and HIV/AIDS-related stigma as real, hence, it helped her to understand them, as described by Terre Blanche *et al*., (2006), from a position of empathic understanding.

The researcher did not work in exactly the way the analysis steps will be described. The researcher broadly followed the steps of analysis as described by Terre Blanche *et al.,* (2006), although they argue, that in reality, interpretive analysis rarely proceeds in an orderly manner as suggested by their step-wise presentation. The

main process of analysis that was followed is that described by Terre Blanche *et al*., (2006).

Step 1 is that the researcher is to become familiar with and immersed in the research material (Terre Blanche *et al*., 2006). The researcher was the facilitator in the focus group with female participants and the co-facilitator in the group with male participants. The co-facilitators made notes of the contents and processes of the groups. After the research material was collected and transcribed, the researcher checked the transcriptions with the content of the co-facilitators' notes. The meant reading through and checking the transcripts many times. This process enabled the researcher to become familiar with and immersed in the research material and to develop some ideas of various interpretations that could be made.

Step 2 is the induction of themes that means the researchers has to look at the research material and work out what the organizing principles are that 'naturally' underlie it (Terre Blanche *et al*., 2006). The researcher used language of the participants rather than abstract theoretical language, which is in agreement with what is advised by Terre Blanche *et al*., (2006). The researcher endeavoured to look for similarities and contradictions as well as the processes and functions that were present in the research material. This process was facilitated by coding, which is the next step that was followed.

Step 3 is coding, which, according to Terre Blanche *et al*. (2006), is the process of coding a word, phrase, line, sentence, or paragraph that becomes the textual quotes (free code) that are linked to the themes under consideration. The researcher found many quotes that were linked to more than one theme and sometimes quotes contained possible sub-themes. In this process some themes changed and additional

ones were identified. The research material was coded using NVIVO 2,0 (QSR International, 1999–2002), a software package designed to aid the analysis of qualitative data.

Step 4 is elaboration. According to Terre Blanche *et al*., (2006), it entails moving the research material around so that it is no longer in the linear sequence of the transcript, but that it is organized in a manner that groups material according to the themes. The process of elaboration is when you engage with the text in such a way that you compare the quotes that you grouped together, and in so doing might discover sub-themes and/or differences of opinions relevant to the same theme. The researcher first 'free coded' the research material, then the 'free codes' were grouped under 'tree codes' (quotes grouped together to support a theme). This process was used to organize the numerous quotes that supported a theme or sub-theme. In doing so, it enabled the researcher to engage with the elaboration process that Terre Blanche *et al*., (2006) speak about. The researcher coded, recoded, elaborated and recoded the research material until no more significant new themes emerged.

Step 5 is interpretation and checking. Terre Blanche *et al*., (2006) explain this as using the thematic categories of the analysis of the research material, interpreting and checking it, and then giving a written account of the phenomenon studied. The researcher first wrote up the themes that emerged from the research material and included the quotes linked to it. Then she checked it, to identify whether the quotes matched and explained the themes optimally. At this point the researcher also reflected on how her biases might impact on the interpretation process. This was to

make sure that the interpretation of the research material would optimally reflect the participants' experiences and perceptions of HIV/AIDS-related stigma.

3.10   Ethical considerations

Ethical approval was sought and obtained from the Faculty of Community and Health Sciences Higher Degrees Committee, UWC. Approval for the main project was also sought and obtained from both the HSRC's Ethics Committee and PSU's Institutional Review Board (IRB).

The researcher also obtained informed consent from the participants using an Informed Consent Form (see Appendix B). The participants agreed to take part in the project after fully understanding the aims of the research, the methodological process, and that they had the option to withdraw from the project at any time they wished to. They also approved the venues that were used for the focus groups. Confidentiality and anonymity were ensured by giving each participant a number instead of using their name, meaning no research material is identifiable. The research material will be kept locked up in a safe place and will be destroyed six months after the completion of the transcription process. A clinical psychologist was available for debriefing counselling of the participants and facilitators.

3.11   Reflexivity

The researcher is a Muslim woman living in Cape Town and has reflected continuously with regard to acknowledging and being cautious about how her religious understandings, experience and assumptions could influence the research analysis and results. According to Creswell (2003), researchers' introspection and acknowledgment of biases, values and interests typifies qualitative research today.

The researcher has met PLWHA and acknowledges that they have human rights equal to those not infected with HIV/AIDS. She also believes PLWHA are infected through various ways, and that one should be mindful of not forming moral judgements of others but should rather endeavour to empathically understand the difficulties PLWHA encounter once they gain the knowledge that they are HIV-positive. The researcher is involved in radio programme presentations that focus on HIV/AIDS awareness and educational programmes, and that particularly try to lessen HIV/AIDS-related stigma. She works collaboratively with community organizations in this regard. Doing this research project helped the researcher understand HIV/AIDS-related stigma, its effects and what mediates it in this community, in order to help ameliorate the situation.

3.12   Summary of chapter

This chapter discussed the methods used in the present study. The study worked within the methodological framework called social constructionism that assumes that how people make meaning, understand and respond to HIV/AIDS, including HIV/AIDS stigma, are historicoculturally specific, and hence are socially constructed, dynamic and with varying content. This was followed by a discussion of the research method used. A qualitative method in the form of focus group discussions was used because it allowed the researcher to tap into Muslims' perceptions of HIV/AIDS through the social interaction in the group. Participants, who were introduced by the 'Imam' at their mosque, volunteered to be part of the research process. They were Muslim males and females aged between 18 and 45 years. A focus group guide was used in gendered groups (one male and one female group). Focus groups had a moderator and assistant moderator and were audio-

recorded. The researcher ensured the trustworthiness and credibility of the data that emerged from the study and used a thematic content analysis process in doing so. Ethical considerations and reflexivity were engaged with by the researcher.

CHAPTER 4

RESULTS

4.1   Introduction

The following discussion will consider the main themes that emerged from the discussions of the participants in relation to their perceptions of HIV/AIDS and how HIV/AIDS-related stigma manifested itself amongst these Muslim participants. The main themes include the 'perceptions of HIV/AIDS', 'themes of religious identity', 'othering of HIV/AIDS', 'perceptions of PLWHA', 'gender and blaming', 'forms of stigma', 'mediating factors in expressions of stigma towards PLWHA', 'effects of stigma', and 'forms of support and positive responses to PLWHA'. In analyzing the transcripts, the researcher became aware that the majority of themes reflected the most salient underlying discourse -- that of religious identity and the effects thereof on how the person perceived, understood and experienced the world. In this chapter only the results will be discussed, whilst Chapter 5 will include a summary of the results and a discussion thereof. The quotations used are identified by making reference to the gender of the participants in the group, for example, GF indicates the group with female participants, and GM the group with male participants.

4.2   Perceptions of HIV/AIDS

4.2.1   HIV is curable, AIDS kills

Participants regarded HIV as a 'curable' disease. However, AIDS was seen as a disease that killed. It seemed HIV was regarded as being manageable by PLWHA through a healthy lifestyle, correct eating habits, taking prescribed medication and having a healthy self-esteem; as well as through the management by health care

workers and governmental institutions. Participants felt the more PLWHA knew and understood their health status the better they would be able to manage the illness and seek appropriate treatment. Participants felt PLWHA needed the support of individuals to help them do so, as stated in the following quotes:

> *I think personally, if eh, tell him to get a right medication, eat healthy, live healthy life, maybe he can get a cure and maybe prolong the life that his living.*
> *[GM]*

> *Did you uhm go to anybody to get treatment for it or are you just going about you know what you must do and what you mustn't do in the sense that […][1] she should like know how weak she is. [GF]*

4.3   Themes of religious identity

4.3.1   Causes of HIV infection

The overwhelming response from participants was that HIV was contracted through sexual relations, including pre-marital and extra-marital sexual relations. This contributed to internal and external stigma, and could be seen in participants' catastrophic responses to an anticipated HIV-positive result. This was because they would regard themselves as having brought the infection onto themselves through a sexual act, even though this could be seen as a contradiction, in that many of them implied they did not partake in sexual relations unless they were married. Participants indicated it was sinful to 'zina' (to have sex outside marriage, including pre-marital, extra-marital as well as homosexual relations) and if one did so it was shameful, which lead to the person experiencing marked guilt feelings about the sexual act:

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[1] […] The three dots between this type of brackets mean a section of the quote was left out.

Being it adultery, fornication, being it whatever. [GF]

I think that any person comes to you and says that I am HIV positive, the first thing that comes to mind is that, this person has been sleeping around, […] maybe he got it through blood transfusion or sharing the same the same needle, […] and its gonna make you feel bad and its gonna make them feel bad. [GM]

Its just like our religion Islam, you must just like get married and sleep with one person and that how can I say, sleeping around with lot of partners also may be the cause of you getting AIDS and being affected [meaning infected]^2. [GF]

Conversely, there were participants who felt there was an incorrect perception that HIV infection was caused only through sexual relations. These participants regarded contributing factors that caused HIV infection as including mother-to-child infection, through touching blood of another and blood transfusions, and that young people were at risk through drug-abuse and gangsterism:

Many people think that AIDS is only a sexually transmitted disease, which is not the case and because they think it's the only thing committed out of adultery or fornicating […], but at times its innocent people that's also being infected by this […] and the people can know that its not only people that are like gays […], that's carrying disease but also people that have been infected, they infect other people that is not aware about it, through marriage, and through child birth. [GF]

I think that Muslim we tend to just look at the one aspect and that is the sleeping around one, but there is another one that is affecting our children very commonly is the drug abuse […] They use the needles and injections and AIDS can actually be spread via that as well. [GF]

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^{2} [meaning infected] These brackets with text in between them indicate what the participant meant to say.

4.3.2 <u>HIV/AIDS a curse or punishment from 'Allah' (God)</u>

The majority of participants perceived HIV/AIDS as a curse or punishment from God. This seemed to have evolved from the understanding that Muslims were compelled by God to follow His rules and He punished them when they chose not to do so. Islam did not allow Muslims to have sex outside marriage. Therefore, when they did so, it was regarded as having committed a sin, hence, it was punishable by God through HIV/AIDS:

> *In all religions. […] HIV […] we talk about it as punishment from God. […], due to, […] if you look at the prostitutes, right, she or he knows that HIV/AIDS, is right outside. You can pick it up any time now why you still go out and do your thing outside and at the end of the day you get the disease. Why you get the warnings and […] reminders about the disease. […] So if you decide, that I wanna go that direction of HIV/AIDS that is a punishment. [GM]*

However, there seemed to be ambivalence about the belief that HIV/AIDS was a punishment from God. The divergent view was that it is a disease that could be contracted in different ways, including when a person helps someone who is HIV-positive and becomes infected through a means unknown to the person, and not only through sexual transmission. A participant explained it in this manner:

> *Some leaders do say that […] it is a punishment. Personally I do not feel it's a punishment from the creator. […] Sometimes you are not aware of what you are doing, helping the person that is getting the disease. […] It can be, you can get it from any means. [GM]*

4.3.3 Abstinence from pre-marital and extra-marital sexual relations

All participants held a similar view as that expressed in the community, which is that abstinence from sex outside marriage was the ultimate way in which one prevented becoming infected with HIV/AIDS:

> *Looking at Muslim community, […] if you stay away from sexual relationship, obviously that will be the best cure you can find. [GM]*

> *It's spoken as abstinence is the best way to prevent AIDS. [GF]*

4.3.4 Responses to condom campaign

Participants felt making condoms available was sending a message of it being acceptable to continue with sexual relations. This implied that participants might have had a concern that the message encouraging condom use could be interpreted as: if you used condoms you may have pre-marital or extra-marital sexual relations; which was against the laws of Islam:

> *Dishing out that other stuff [condoms], that is just saying go on with the stuff [have sex]. [GM]*

4.4 'Othering' of HV/AIDS

A dominant theme was that participants felt as Muslims they were protected from contracting HIV and therefore they were unaffected by the disease. This was because their religion, Islam, forbids them to have sex outside marriage. This implied that all Muslims believe they live strictly according to their religious laws, hence, no Muslims had sex outside marriage:

> *Most of us we think that we are Muslim […] and this topic of HIV doesn't affect us, […] because we Muslim we protect ourselves, and we can't get HIV. [GF]*

Muslims take it for granted it can't happen to us because uhm I understood like you can get AIDS through uhm sleeping with someone. […] But like how can I say uhm because we just take it for granted you just sleep with one person. [GF]

I think in the Muslim community we are sort of protected because we have this culture of looking after the laws of religion and that kind of thing and I think that's the main thing that's protecting us. [GF]

Because participants mostly denied the existence of the disease in their community, they said they did not know any PLWHA or were not in contact with them:

I'm not used to having a person with AIDS around me. [GF]

Because the prevalence is so low in the Muslim community people aren't actually exposed to that, […] you don't come into contact with people who are HIV-positive. [GF]

Participants felt insulted when others insinuated that Muslims might be infected with HIV/AIDS because it implied they were 'bad'-doers. This was expressed in the following quote:

She reckoned to me you think you are Muslim you don't have AIDS. […] I felt quite hurt by what she said, due to, by few people, the whole Muslim community now gets a bad name because of a few people that did wrong, the community gets blamed. [GM]

Participants also felt Blacks/Africans and homosexuals started the spread of HIV/AIDS. Homosexuals seem to be stigmatized in that they were stereotyped as having HIV/AIDS because of their 'gayness'. It seemed Muslims believed they did not engage with behaviours homosexuals did (implying having male to male sex),

hence, homosexuals were deserving of HIV infection, as a form of punishment for their behaviours:

This guy he is gay, he's got AIDS and […] people are not supportive because what they're saying is, agh! 's a moffie [homosexual]. He got it [HIV/AIDS], he deserves it. […] He's Muslim, we don't do things like that. […] They won't get into the same elevator as he does. They will look at him and while he's just turned his back they would say, did you see what he looks like, you can see he's got AIDS written all over his face. [GM]

Here we think it's only the Blacks that will get it, we think that it's only the non-Muslims that will get it, […] because of our way of life. The way we see sexual relationships the way we see marriage and the way we are taught. [GF]

However, some Muslims believed HIV/AIDS could infect everybody regardless of religion and race as alluded to by these responses:

My family their view would be uhm AIDS can happen to the best of us! [GF]

Like my mother […], she says it can happen to anybody. [GF]

What I think now, HIV can affect [meaning infect] anybody it doesn't matter what religion or what skin color or whatever. [GF]

4.5 Perceptions of PLWHA

4.5.1 'Innocent' versus 'guilty'

Perceptions of PLWHA could primarily be divided into a binary that included those seen as 'guilty', 'bad', and 'shameful'; and those seen as 'innocent' and 'good'. This could be understood against the background that Muslims' perception of PLWHA was embedded in their conception that when you were an obedient Muslim who followed the moral rules of Islam (abstaining from 'zina') then you would not

contract HIV. Thus, if you contracted the disease it would be through no doing of your own, hence, making you an 'innocent' victim of infection. An example of this was mother-to-child transmission and when spouses, unbeknown to themselves, were innocently infected by their HIV-positive spouses. The HIV-positive partner was then categorized as the 'guilty' that brought it onto himself/herself through wrong doing:

> *Because that is one of the fundamentals that uhm, you stay away from things that bring you near to performing sexual acts that are outside of the law of Islam and because of that I think people generally have the view you know if someone is got it through sleeping around and you know in terms of religion and in terms of culturally and socially that person uhm has transgressed the bounds and therefore should not be treated as someone who's got it through for example her husband, uhm whose then getting it from someone else and infecting the wife. [GF]*

> *Because now you are sleeping around, and its not like, because you were born with AIDS, now, and someone else sleep around and got AIDS, its not because you were born with AIDS, and you weren't asking for it, its not like emm, its not like the decision, that you made but, the person who was sleeping around he had a choice to protect himself. [GM]*

> *They would like find the person is HIV positive but they won't find out what's the real cause, if it was like something else, if it was forced on her and things like that. You would want the person to support you in that case [when you are "innocent"] and tell you like, gives you advice. [GF]*

A divergent view was that PLWHA were also seen as 'guilty', 'bad', and 'shameful'. This perception was engendered in the belief that PLWHA chose behaviours that put them at risk of HIV infection (e.g. prostitution). It was also based on the belief that if you have HIV/AIDS then you are 'guilty' of a

transgression against God through illegitimate behaviours that include sexual promiscuity, homosexual relationships and drug/needle-abuse, therefore you chose to be 'bad' and 'sinful', hence, you were deserving of punishment:

We talk about it as punishment from God. […] If you look at the prostitutes, right, she or he knows that HIV/AIDS is right out side, you can pick it up any time. Now why you still go out and do your thing […] and at the end of the day you get the disease. You get the warnings and […] reminders about the disease, […] so if you decide, that I wanna go that direction of HIV/AIDS that is a punishment. [GM]

That is the perception people have of people that has HIV/AIDS […] like you must have done something wrong to have got AIDS. […] That is how other people in the community […] would look at you and think probably you did bad thing. [GF]

4.6 Gender and blaming

Whilst some participants felt both genders should be treated in a similar manner and be supportive of each other, many participants felt men and women would be treated differently in the Muslim community. These opposing views were indicative of many participants' regarding males and females as occupying different status in Islam, hence, they would be treated differently. An example of this was that the males were regarded as superior and women as inferior to males. In contrast, there were Muslims who regarded both genders as enjoying equality in Islam which manifested in equitable treatment:

There isn't any females that I know […] that is living with HIV/AIDS, but I would say that ehh definitely, they will be treated differently. [GF]

Everybody is not always educated, where female are concerned and it's not always the female's fault, we as men we always think that we […] have the

upper hand. We are superior and females are inferior, so we treat females different or we treat them in a bad way, to us it's like a norm. [GM]

Be if you are a man or a woman, we are equal. […] You do not have to blame each other if it happens one of the family is infected, like for instance the wife, the husband must not treat her badly, same applies to the wife. [GF]

I don't see why they should be treated differently! [GF]

Many female participants regarded males as being guilty of infecting females with HIV and because of this, participants felt they needed to be treated more harshly. This attitude evolved from the understanding that men were often 'immoral' and would engage with sleeping around even though they were married. Additionally, men did not care whom they infected because they were 'self-centred' and only cared about their own sexual needs:

I think people will generally tend to be more empathic and […] sympathetic with females because people tend to see the males as the perpetrators and […] initiators of sexual intercourse. [GF]

An opposing theme was that male participants regarded females as 'flirtatious' and 'guilty' of infecting their husbands and 'bringing bad things', for example, ill-health into the home. Women seemed to be stereotyped as the bad representative of the human species who occupied a lower status than the men. These participants felt women should therefore be treated differently, implying harsher treatment, than when a man was infected. These arguments could be connected with the 'innocent' versus 'guilty' verdict, in that, if the person was seen as 'innocent' in regard to their

HIV-positive status, then they should receive better treatment than those regarded as 'guilty' of infecting themselves or others:

> *People have the perception that [...] men got it because he slept with a female. It's not his fault it's, her fault that he has the disease, so people will treat him differently than they will treat the female. [GM]*

> *Usually females always get [...] the bad side of the story. If you look for instance in marriage, [...] but now someone from the outside comes [...] into the relationship. He won't get the bad name but the female always get the bad name, she is always to be blamed. [GM]*

> *A female is always looked upon as she's the one that can infect you with the virus and [...] give you AIDS. So abstain from her, push her to one side. The male gets treated differently to the female. [GM]*

4.7   Forms of stigma

4.7.1   Shunning PLWHA

PLWHA were seemingly seen as having brought a curse to their homes and were subjected to being shunned, ignored and isolated (not socialized with), talked about, ridiculed, responded to in harsh words, being called names that had a derogatory connotation, and mocked and laughed at, and avoided because of fear of infection, as expressed by these participants:

> *She informs the partner or husband and he shuns her, and he doesn't want to be with her anymore or he blames it on her and he says she brings a curse into the house or she brought the disease in the house. [GF]*

> *They won't socialize with me, keep their distances you know. [GM]*

> *If you have the disease people will look down at you, they do mock at you they do make fun of you. [GM]*

In certain ways, people who are close to me, will be scared to come close to me because they'll think they'll get the disease. [GM]

4.7.2   Refusing PLWHA accommodation

There seemed an implication that families withheld accommodation from PLWHA which resulted in them living on the streets and begging for food. The researcher believes it could be because of the difficulty that Muslims had in accepting that HIV/AIDS were affecting them too and that it was not a shame to be affected by HIV/AIDS. There is a belief amongst Muslims that if one person did wrong then their Creator could punish all of them. Therefore, it could be, that should they regard PLWHA as 'sinners' then they might be fearful to house such a person, for fear of their Creator's anticipated wrath against the entire family. Furthermore, it could also be interpreted that the shame associated with pre-marital and extra-marital sexual relations would result in the family being ostracized by the community because the family was connected to a 'sinner':

I think, shame plays a very big role in a person's life who has HIV. [GM]

Most of the people that are homeless or on the streets, they are possibly HIV-positive. If their family or companions […] who look after them are treating them with respect, then they would not be on the street hanging around begging. [GM]

She didn't get that support immediately and that is probably because of people not being aware of […] all the facts about HIV/AIDS […]. They didn't accept her. […] She didn't get support from her family or […] the community. [GF]

4.7.3   Treating PLWHA as 'sinners' or 'wrong doers'

It seemed PLWHA carried a lot of shame, because the way their families and communities treated them implied they had done something wrong, therefore they contracted the disease:

> *I think, shame plays a very big role in a person's life who has HIV, because of the family [who] has a negative impact on the person who has HIV. [GM]*

> *I think […] that is the perception people have of people that has HIV/AIDS. Most people have that perception like you must have done something wrong to have got AIDS. [GF]*

4.7.4   No discussion of HIV/AIDS or sex

It seemed in this community sex and related matters, including HIV/AIDS, were often not spoken about. This would have made it very difficult for PLWHA to disclose and manage their status because there seemed to be a form of denial that the disease existed. By implication this would have invalidated the possible experiences of PLWHA. This might have been because some Muslims felt that it was better not to discuss sex at all because it might lead to 'zina', which is considered a major sin in Islam. There was a notion amongst Muslims that one must not go near something that led to sin, therefore, they might have believed staying away from discussing sex was a way of staying away from something that could lead to 'zina':

> *I think there's a lack of communication, and speaking about AIDS. There's a lack of education, even our Muslim leaders are not speaking about that. [GM]*

> *Like in my family […] my parents didn't speak to me about sex […] and stuff like that. [GF]*

Because […] that is one of the fundamentals. That you stay away from things that bring you near to performing sexual acts that are outside of the law. [GF]

4.7.5 Isolating PLWHA

Participants indicated that people stayed away from PLWHA and neglected them; and they kept their children away from HIV-positive children as well. This seemed so because there was fear of infection and at times a lack of HIV education:

One child has AIDS. You would keep your child away from that person because you all too scared that your child will also be infected. It's like you shut the next person out just because the next person has the virus. [GF]

Family members will say no I won't go near that person, […], I won't talk to that person, I won't go there […]. I think it's the fear they have of getting the disease. […] I would be very fearful and have it at the back on my mind, about this fear. [GM]

4.7.6 Refusal to wash or touch deceased PLWHA

Because people feared infection, it was a social barrier to washing the dead PLWHA. Muslims engaged with a specific ritualistic manner of washing the dead. This was normally done by specific members of the community who did this type of work. It was related by participants that such community members were refusing to wash PLWHA and the primary reason seemed to be that they feared becoming infected:

She was called if she could help with the washing of the body of a woman who was HIV-positive […]. She declined to go. She didn't want to touch the body of someone who is HIV-positive. […] I think because people are generally scared, you know because they think there might be a small cut in their finger and there might be cuts in the person's arm you know. [GF]

4.7.7   No confidentiality for PLWHA

There seemed to be a lack of confidentiality that PLWHA experienced. This often happened at the clinics because of the lack of resources at clinics and health care workers having to work under circumstances that made confidentiality quite a challenge:

> *I don't think that confidentiality is practised quite well because of the infrastructures […] that are in place at […] the clinics […]. Sometimes there is breaches of confidentiality because uhm I've noticed that in a couple of situations where there's thin curtains and uhm people come in for anti-retrovirals, and the doctor or the nurse would say uhm so are you on anti-retrovirals or are you taking your AZT pills and the person next door can also hear. [GF]*

4.8   Mediating factors in expressions of stigma towards PLWHA

4.8.1   Religious positioning mediates responses to PLWHA

What caused the PLWHAs' HIV infection and whether they were infected 'innocently' or 'brought it onto themselves' impacted on how PLWHA would be treated by Muslims. This could be understood against the background that religiously there was an understanding that Muslims were to remind each other to stay away from sin and to enjoin good. Hence, if they accepted and treated PLWHA who were 'guilty' well, it could be seen as condoning and even encouraging sinning. Because Islam is seen as engaging in a preventative system, it might be that Muslims understood them rejecting PLWHA as a way of encouraging others from abstaining from 'zina' and wrong doing. Yet it was interesting to note that Muslims supposedly saw 'illness' as a blessing from God in that it was a form of purification of one's sins. This would mean that Muslims in fact should be embracing PLWHA as those people loved by 'Allah' because of the notion that 'Allah' loved those on

whom 'Allah' imposed an illness. The latter part of this discussion was not mentioned by anyone in any of the groups, which could be interpreted that the need to see HIV/AIDS as a punishment and to show rejection of PLWHA were regarded as more important in the fight against HIV/AIDS and the prevention of Muslims engaging in 'zina':

They would find the person is HIV-positive, […] if it was forced on her […] and I think that's a time you should like help the person. [GF]

I think so yes! For the person who got it by like say for instance […] not sexually, then one would be more sympathetic towards that person because like we are taught that its haraam to zina, so I think that would influence how we think or how we see that person. [GF]

However, there were Muslims who purported that they would be supportive of PLWHA regardless of how they contracted the disease. Religiously, there was an understanding that Muslims should always be supportive of their fellow human-beings in need of their support and help. Participants also felt PLWHA should not be judged because the Creator would judge them:

Not only religious leaders but also the whole community itself, there's been a whole shift uhm with being more soft, sympathetic and empathetic to people with HIV/AIDS. I think that religious leaders are very supportive of the whole issue about HIV/AIDS and they are encouraging people to be supportive and to be non-judgmental towards people who are HIV-positive. […] You don't know the reason why someone might be HIV-positive and therefore you can't judge them. […] The only person who can judge is God, Allah. [GF]

4.8.2 Fear of HIV infection

Although Muslims were supportive or intended to do so, they were markedly aware of protecting themselves because they feared HIV infection. This could be seen as a barrier to reaching out to PLWHA. This could have stemmed from a lack of understanding of how HIV was transmitted:

> *I will be very cautious because I don't know what I am getting myself into. Once I start interacting with that person I will be compassionate but then I will have that cautiousness, that fear in me in gaining that disease. [GM]*

4.8.3 Knowledge of HIV/AIDS and PLWHA

Many participants said they did not know how to treat PLWHA because they had not met PLWHA and did not know much about HIV/AIDS. It seemed from these responses that knowledge and awareness about HIV/AIDS could be seen as a mediating factor in regard to the response to PLWHA. This implied if individuals had knowledge about HIV/AIDS they would treat PLWHA better:

> *Education about HIV/AIDS has a big part in this. People that know about HIV will treat people differently to people who don't know anything about HIV. People who knows about HIV, and how the disease get spread, they won't be scared in trying to have a conversation with the person, or to be friends with a person or to share stuff with a person [GM]*

4.9   Effects of stigma

4.9.1   Responses to VCT

Participants felt an overwhelming fear of a positive test outcome because of internal and anticipatory external stigma. This will be discussed further under point 4.9.2.2. A general discussion in regard to the response to VCT will be provided first. Some

of the participants in the groups reported having been tested before and receiving an HIV-negative result. It seemed Muslims would encourage others to test.

4.9.1.1 Positive response to testing

Some of the reasons mentioned were if you had an unfaithful husband, or to consider testing before an individual got married, to ensure you knew your prospective partner's HIV status:

> *People that should be encouraged to be tested are those that uhm have flirty husband or [who is] sleeping around […] then you should be tested. [GF]*

> *Especially if you get married, you should go for a test and find out if that person is affected [meaning infected] with AIDS. [GF]*

Other participants felt it would be difficult to speak about testing because it might result in the perception that there is a lack of trust between partners. This implied that Muslims, when requested to test, could see it as an indication that they might have engaged in pre-marital or extra-marital sexual relations and this could be an insult to their integrity:

> *For example if you should be married or have plans to get married and the AIDS sort of conversation comes up, and you suggest that should we not rather go have ourselves tested. You would in the family have an argument like don't you trust me, do you think I have it. […] What if they have a reputation of being unfaithful you don't know what they did before the two of you were together. [GF]*

Another reason given was the earlier you established your HIV-positive status the more helpful it would be to manage the disease. Other participants felt because they were Muslim and did not engage with pre-marital sexual relations, they would test,

because they knew what the outcome would be. However, there were participants that felt they might have contracted the disease through other means, for example, they might have had an accident and was infected with the HI-virus:

A positive thing is that if you take this you will know if you have the disease. If it's in an early stage you can still have time for a cure. [GM]

If I was very sexually active (participants laughing)[3] [implying Muslim men are not sexually active], then I would go and be tested. [GM]

Yes. Maybe I don't know, so I've got it by accident something like that. [GM]

4.9.1.2 Negative response to testing

Many participants would not test because they feared a positive test outcome. The most salient reasons given was fear of internal stigma, for example, them feeling 'ashamed' and 'cursed'; and external stigma, for example, being seen as a 'wrong-doer' (e.g. adulterer) in the community, in response to an HIV-positive status:

I'm scared that through some kind of way I could have been infected. I would be very shocked, I don't think that I would be able to handle it. I think I'd prefer to just vanish from this world if I must have positive results. That's why I was quite scared. [GF]

For others it was better not to know their status than to deal with the effects of having an HIV-positive status. Some reasons given were that HIV/AIDS equals death, therefore, knowing your status would mean knowing you have a 'death sentence' and that would be unbearable for these participants:

Because of the results (laughing) I mean what if I do have it, I would have a breakdown [emotional]. I don't really think I will be able to handle it. If you hear the word AIDS you think of death. [GF]

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[3] (participants laughing) Text between this type of brackets is referring to what was happening in the group at that time.

Other participants explained that some people preferred to continue believing that they were HIV-negative although they have not tested because it was easier to deal with a possible false belief than with the truth of their HIV status:

> *I'm not really sure if I want to be tested or not! […] Because you got this avoidance and fear of it happening to you. I think that might be the reason why I wouldn't want to be tested. [GM]*

4.9.1.3 Gendered response to testing

A dominant view was that men were perceived as being less inclined to be tested. They showed a lack of interest in wanting to know their HIV status, even though some of them would expect their partners to test. This might be understood against the notion that, because women were perceived as those that were primarily spreading the disease, it would be important to know what their status was in order to protect the men in their lives against HIV infection. It was also seemingly understood that women were the ones who went to clinics and engaged more in health-care seeking behaviour. The researcher felt it might also be that men felt health-care seeking behaviour would impact negatively on their macho image of themselves:

> *Because die vrouens is gewoonte gaan vir die pregnancy tests, daarom moet sy gaan [women are used to going for pregnancy tests therefore she must go for the test]. [GM]*

> *Men will say, you go. Because I am the man, I don't think I got it, but you will have it because you are a female. […] They go for contraceptive injections, and maybe they could have receive it via that [become infected with the virus]. [GM]*

4.9.2   Responses to test outcomes

4.9.2.1 Response to an HIV-negative test outcome

All participants would be happy with an HIV-negative test result and many said they would endeavour to behave in a manner that ensured their status remained negative. Some spoke about reflecting and changing behaviours that might lead to HIV infection. However, it was interesting to note that when behaviours were specifically mentioned, participants did not mention that they would stay away from prohibited sexual behaviours; instead they remained non-specific with regard to this. This could be interpreted that Muslims mostly preferred to be seen as those who followed their religious rules of abstinence from pre-marital and extra-marital sexual relations:

> *I'd be happy. […] Try not to take life for granted because, […] you came close to something that could have meant the end of you. [I will engage in] more positive behavior, try to cut out the negative things. [GF]*

4.9.2.2 Response to an HIV-positive test outcome

All participants said an HIV-positive test result would impact negatively on their emotions and their behaviour. This would mostly be because they feared the experience of internal stigma, for example, 'feeling ashamed' at having contracted the disease, and external stigma, for example, being seen as someone who did something 'bad' in the community. An example of this was the perception that PLWHA felt ashamed of having committed pre-marital and extra-marital sexual relations that resulted in their HIV infection, and that the community would regard them as 'bad' people:

> *I would cry […] I'd probably stay in dark room for the rest of my life. I think some people who are infected they feel shamed upon themselves because of this disease that they've got. […] The reason why maybe uhm portraying this*

negative person in the community because of what they did. Being it
adultery, fornication. [GF]

Another participant explained that a PLWHA could be seen as a hypocrite Islamically, because on the one hand you were supposedly a good practising Muslim and on the other hand you were HIV-positive; meaning you professed to be a good Muslim but you engaged in sinful behaviour, such as, 'zina':

I'm like a very holy person, I speak my religion and, but now you find out I
am HIV-positive. It's like I'm a hypocrite, now its like a bad sign to me also
[implying it is a curse from the Creator]. [GM]

Another example was the anticipatory anxiety and the embarrassment this participant would feel because of the anticipated experience of being watched and looked down upon; and by implication, the participant felt the community would judge him and this would be so distressing that he would prefer to die:

I donno what I'm gonna do. Jump down the bridge because it will save you
from embarrassment because people will be looking at you. They can see
that gut feeling inside yourself, because I am HIV-positive, and watching
what you do. So I will say it is better for me to die. [GM]

Participants spoke about how bad they would feel because their families would think they did something wrong and that this would also make their families feel bad and experience stigma from the community. This implied an assumption that PLWHA were 'wrong-doers' and engaged in sexual activities that were un-Islamic. It also connected with the Islamic notion that the head of the family should ensure that his family members performed good deeds and abstained from prohibited actions that included pre-marital and extra-marital sexual relations:

It will be difficult, […] due to the fact that maybe your parents they know that you have not been sleeping around but the person next door he might not have the same perception that your parents have. The first thing that comes to mind is you have been sleeping around, you done something bad and then again, you're Muslim. [GM]

I will hang me. […] Because my father will hang me. Because he's a very strict person and he'll think I was sleeping around and he will beat me. [GM]

4.9.3 Disclosure of HIV/AIDS

It seemed very difficult for Muslims to disclose their HIV status because of stigma, particularly in the form of 'othering'. Muslims seemed concerned about their perceptions that others regarded them as having proclaimed they were protected by their religion and that they had the 'Quran' that had a cure for everything. Therefore, it seemed when Muslims were HIV-positive, it might be seen by them as admitting that they were not as protected as they would have liked others to believe. Instead of experiencing disappointment in the 'Quran' for not having a cure for HIV/AIDS, it might be easier to 'other' the disease:

As Muslims we are afraid to come out publicly to say that I am HIV-positive, due to the fact that I'm a Muslim and what is people gonna think of me. Because non-Muslims have the perception that we Muslims our religion proclaim that […] we have a cure for everything. They [non-Muslims] say that the Quran has a cure for everything. So that's not an illness for them [for Muslims]. [GM]

Another difficulty in regard to disclosing one's HIV status, was not knowing what to expect from one's family, friends and the community, and fearing their responses:

I'll be scared. […] I don't know what the reaction from my parents gonna be, my friends, colleagues, if I tell them about my situation. [GM]

In contrast, there was a perception that because of the great awareness of HIV/AIDS currently, PLWHA would not be shunned. However, there seemed to be some ambivalence around the issue of how the person contracted the disease and whether this would impact on the response to PLWHA. Because there was a lack of disclosure of HIV status amongst Muslims, it resulted in them not knowing many PLWHA. This contributed to them not being familiar with how to treat PLWHA. As a consequence, this indirectly contributed to making it difficult for PLWHA to disclose their HIV status:

> *I think in the one case the female got it from her husband and he got through some kind of blood transfusion. I don't think that if there are HIV-positive Muslims they are bringing themselves out in the public. […] Because the prevalence is so low in the Muslim community people aren't actually exposed to that. You don't come into contact with people who are HIV-positive, […] you don't know how you going to react. [GF]*

> *Those people being completely innocently infected with this virus. I think at the beginning she said she didn't get that support immediately and that is probably because of people not being aware of or completely aware of all the facts about HIV/AIDS. [GF]*

4.10 Forms of support and positive responses to PLWHA

4.10.1 Individual support

A positive action was when PLWHA disclosed their status and then became HIV/AIDS activists. This was seen as educational and as possibly encouraging others to disclose and speak about their situation. These activists have attested to Muslims having become more supportive because of the increased awareness of HIV/AIDS:

Because he tells everybody that he's positive, but its also something good because his working, helping those who are infected with the disease. [GM]

In cases like […] [the first Muslim woman to disclose her HIV status publicly in the Muslim community]. She didn't get support from her family or neither from the outside community but she says ehh […] some of us are able to give better support because of our awareness of AIDS. [GF]

I know my family and the people that I know of, will be able to greet them and not sort of shun them away because of the great awareness of HIV/AIDS now. [GF]

Participants felt one must encourage PLWHA to talk freely about their HIV status and support them, stand by them and make them feel they're not alone:

You should actually encourage the person more to speak freely about it and actually support the person. Stand by them and make them feel they are not alone […] just because they have the virus. [GF]

4.10.2 Family support

Most participants spoke about family members that would be supportive of PLWHA. It was important to note that 'othering' was still taking place, in that participants spoke about how they would respond and not how they have responded, implying again that they had not met any PLWHA:

I know my family and the people that I know of, will be able to greet them and not sort of shun them away because of the great awareness of HIV/AIDS now. [GF]

4.10.3 Support by religious leaders

Amongst community members, religious leaders encouraged people not to judge PLWHA and to be supportive of them, since contracting the disease could happen to

anyone. Muslims believed only the Creator could judge and Islam said they should not judge one another. Religious leaders were also seen as encouraging PLWHA and being supportive of them:

> *Not only religious leaders but also the whole community, there's been a whole shift uhm with being more soft and sympathetic and empathetic to people with HIV/AIDS. I think that religious leaders are very supportive of the issue about HIV/AIDS. They are encouraging people to be supportive and to be non-judgmental towards people who are HIV-positive. […] HIV/AIDS can happen to anyone and that you don't know the reason why someone might be HIV positive. Therefore you can't judge them. The only person who can judge is God Allah. [GF]*

4.10.4 Community support

There was a supportive attitude towards PLWHA, especially by children because they learnt about HIV/AIDS in secular and Muslim schools:

> *Most people are being supportive in the Muslim community, because the children learn a lot about it in school and in Muslim school. [GM]*

4.10.5 Awareness and educational programmes

There was an understanding that over the last few years there have been many awareness and educational programmes that led to people having a better understanding of HIV/AIDS. Participants felt there were many different ways through which these programmes have been communicated so as to ensure the message reached the community, that included, posters, educational information, and information about condoms:

> *In the last five years, there's been great awareness programmes, and that's why much more people are aware now. […] If you asking this thing, they are most likely to be able to answer you and say what the actual virus is and how it can be transmitted. [GF]*

In today's life its actually uhm, more open. They are showing you and giving you all this information, wherever you go, in shops, you get it at school, you get on T.V, you get it everywhere. [GF]

4.10.6 NGOs and governmental support programmes

Participants mentioned NGOs that were involved in creating awareness of HIV/AIDS and that were being supportive of PLWHA:

There is a supportive group that's called Positive Muslims uhm that HIV infected people can contact and form part of the support group. They also have awareness programmes and different things that they do to motivate, encourage and inform people. [GF]

Participants felt government could do more in regard to HIV/AIDS, although they felt the roll-out of anti-retrovirals have been helpful:

With regards to health care, there is lot of things that are happening now in terms of health care for HIV/AIDS people. But I do think that the role-out of anti-retroviral is quite slow in a lot of areas, and the rate of infection is still high so there is actually still a lot to be done. [GF]

It was experienced that in health care settings much help and support were being extended to the community, especially to pregnant PLWHA in terms of supporting them and attending to their specific needs. Counselling and testing were offered without community members having to pay for it at these community health centres:

At the MOU's they have this structure in place whereby people that are pregnant, [….] they can go for counseling. They offer to do the test free of charge and its optional of course […]. You will get your pre-counseling. I think it's a very good thing because many people that are pregnant might not even know whether they have been infected. [GF]

4.10.7 <u>Media coverage of HIV/AIDS</u>

The media played a role in educating people about HIV/AIDS and aided in changing people's perceptions about HIV/AIDS and its many related issues:

> *I think one of the positive things that's happening and is very important, is […] Muslim radio stations. […] They have programmes on HIV/AIDS in educating people and in hoping to change some of the perceptions about AIDS. [GF]*

4.11   Summary of chapter

The main themes that emerged from the discussions in the focus groups were discussed in this chapter. The most salient theme that emerged was that religious discourses informed how Muslims understood, made sense of, and responded to HIV/AIDS and PLWHA. Included in the themes were 'perceptions of HIV/AIDS', 'themes of religious identity', 'othering of HIV/AIDS', the notion of 'innocent versus guilty', 'gender and blaming', 'forms of stigma', 'mediating factors in expressions of stigma towards PLWHA', the 'effects of stigma' that included it being a barrier to using VCT and disclosure of HIV status, and 'forms of support and positive responses to PLWHA'. In the next chapter the main themes will be summarized and discussed.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

5.1   Introduction

This chapter will include a summary of the main findings and a discussion thereof in relation to theory and the previous literature. It will also include the limitations of this study as well as future research that should be done. This will be followed by the recommendations, such as interventions that can be done in response to the themes that emerged from the results. This is then followed by a conclusion.

5.2   Summary of the main findings

There were eight major themes that emerged in the findings. These were as follows: 'religious identity', 'othering of HIV/AIDS and PLWHA', 'innocent versus guilty', 'blaming women', 'forms of stigma', 'mediating factors in expressions of stigma towards PLWHA', 'effects of stigma', and 'forms of support and positive responses to PLWHA'. The themes will now be discussed.

5.2.1   Religious identity

The findings showed that perceptions of and responses to HIV/AIDS and PLWHA, and HIV/AIDS stigma were intrinsically connected to the religious identity of the participants. They perceived HIV/AIDS as caused primarily through Islamically prohibited sexual intercourse outside of marriage ('zina', including pre-marital and extra-marital sexual relations*)*. They understood that PLWHA chose 'sinful' behaviour that led to HIV infection. This was thus seen as a curse and punishment

from 'Allah' (God). Because it was seen as a punishment from 'Allah', there was no cure for it and it could kill the PLWHA. In addition, because of the religious tenet of abstinence outside marriage, the 'condomize' campaign (that motivated individuals to use condoms when having sex to protect themselves against HIV infection) has been responded to negatively because it was primarily seen as condoning behaviour that was regarded by them as sinful.

5.2.2   'Othering' of HIV/AIDS and PLWHA

A marked majority of participants in the two focus groups felt that as Muslims they were protected from contracting the HI-virus and therefore they were unaffected by the disease. This sense of protection evolved from their belief that they were people who followed the rules of their religion, Islam that prohibited 'zina'. Therefore, it seemed Muslims believed they were protected from contracting the HI-virus because participants regarded 'zina' as the primary cause of HIV infection, and they further believed they did not engage in 'zina'. However, they seemed to believe that those people who engaged in sex outside marriage were the 'other' who were at risk of HIV infection and were HIV-positive.

5.2.3   'Innocent' versus 'guilty'

Perceptions of PLWHA could primarily be divided into a binary variable that included those seen as 'guilty', 'bad', and 'shameful', and those seen as 'innocent' and 'good'. Participants regarded those seen as 'guilty' as PLWHA who knew the implications of their choices. Because they chose to engage in 'bad' and 'shameful' behaviours, it led to their HIV infection, and this resulted in the verdict of being 'guilty'. Participants put people who committed 'zina', prostitutes and homosexuals

in this 'guilty' category. PLWHA who were regarded as 'innocent' were those seen as having been infected through no choice of their own. Therefore, they were the 'good' people who deserved no blame in regard to their HIV-positive status. Examples of these 'innocent' PLWHA mentioned by participants included spouses infected unknowingly by an HIV-infected spouse, who by implication committed 'zina', and the children who are infected through mother-to-child infection.

5.2.4   Blaming women

Gender could be seen as a binary variable that included females who regard males as 'guilty' of spreading HIV/AIDS, and visa versa. Males were seen as more 'immoral' and engaging in pre-marital and extra-marital sexual relations, and therefore, needed harsher treatment. They were also seen as being self-centred and only caring about their sexual needs, whereas females were often revered and enjoyed a high status in society. Conversely, females were regarded as 'flirtatious' and 'guilty' of infecting their husbands, and bringing the 'curse of bad things', such as, ill-health into their homes, and therefore, they should be treated more harshly than males.   These arguments could be connected to the 'innocent' versus 'guilty' verdict that was discussed under Section 5.2.3.

5.2.5   Forms of stigma

Because PLWHA were seen as having brought a 'curse' to their homes, they were subjected to being shunned, ignored, isolated, talked about, ridiculed, responded to in harsh words, called names that had a derogatory connotation, and mocked and laughed at. They were avoided because of fear of HIV infection. It was implied that families would withhold accommodation from PLWHA. PLWHA were treated as

'sinners' or 'wrong-doers', who because of their choice of behaviours, contracted the disease. Shame of pre-marital and extra-marital sexual relations was associated to PLWHA. It seemed one of the reasons why PLWHA and their families would be ostracized would be because the family was connected to a 'sinner'. Sex and related matters (including HIV/AIDS) were hardly discussed in this community. This contributed to Muslims denying the disease, and consequently invalidating the experiences of PLWHA. PLWHA were isolated, and in particular, HIV-positive children were not associated or played with.

Another form of stigma was that PLWHA experienced a lack of confidentiality, often due to lack of resources, when treated at community clinics. Those who washed the dead and prepared the body for burial have refused to do so. Homosexuals have been stigmatized in that by implication they were assumed to be HIV-positive. This was because of the assumption that they engage in male to male sex that was not allowed in Islam.

5.2.6   Mediating factors in expressions of stigma towards PLWHA

A significant mediating factor that contributed to HIV/AIDS-related stigma was the participants' religious positioning. Participants perceived PLWHA mostly as people who were not mindful of religious rules, and therefore, they engaged in 'zina'. This resulted in these PLWHA being seen as morally 'wrong-doers'. Furthermore. whether the PLWHA were seen as 'innocent' or 'guilty', as explained earlier, also impacted on whether they would be stigmatized or not. These notions mediated the forms of stigma Muslims engaged in.

Another mediating factor was Muslims' lack of HIV/AIDS education and awareness, and their lack of contact with PLWHA. It seemed when Muslims knew more about HIV/AIDS regarding the causes and effects of the disease, it would in some instances lessen the negative responses to PLWHA. Muslims were also highly aware of having to protect themselves against HIV infection. This could be seen as a barrier to reach out to PLWHA. At times this stemmed from lack of understanding of how the HI-virus was transmitted to another human being. At other times it could be seen as another way of 'othering', in that the 'self' was protecting itself through the awareness of the cost to the 'self' (HIV infection) when reaching out to the 'other'.

5.2.7   Effects of stigma

The most salient effects of stigma, namely, stigma being a barrier to using VCT and disclosure of HIV status, will be summarized here.
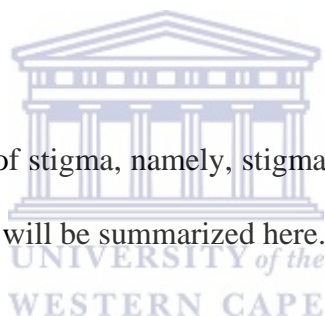
5.2.7.1 Response to VCT

Although participants would be encouraged to engage with VCT, they felt it would be difficult to broach the subject of the suggestion to test with prospective and existing partners/spouses. This was because HIV/AIDS was highly stigmatized and not spoken about. It could also indicate a lack of trust in the other partner with the implied assumption that the latter had committed 'zina'. This would be seen as an insult to the latter's integrity. Furthermore, participants would abstain from testing because they feared the outcome of the test results and the effects thereof, whilst others preferred not to know their status. This was primarily because of the fear of knowing they were going to die. There was also the fear of being stigmatized by

family and the community as someone who committed 'zina' and bearing the shame associated with it.

5.2.7.2 Disclosure of HIV/AIDS status

Participants felt it was or would be difficult for PLWHA to disclose their status because of the stigma in the form of 'othering' that was taking place in their community. This means that the community was denying the existence of the disease in their community and invalidated the experiences of PLWHA. This indicated that should participants be HIV-positive, they would have difficulty disclosing their status because of fear of not knowing what to expect with regard to the responses from their family, friends and the community. This was because of the existing high levels of stigma to which they (PLWHA) have been subjected.

5.2.8   Forms of support and positive responses to PLWHA

Forms of support that emerged in the study were individual support, for example, in the form of encouraging HIV/AIDS disclosure through anti-HIV/AIDS stigma activism. Family support included examples of pledging their support of PLWHA. Religious leaders encouraged people not to judge PLWHA and to be supportive of them. In the community, forms of support included educating children about HIV/AIDS at secular and Islamic schools, as well as having HIV/AIDS awareness and educational programmes that could help with gaining a better understanding of the disease. NGOs and government created HIV/AIDS awareness. Government rolled out anti-retrovirals. They were also supportive of pregnant HIV-positive mothers. The media also played a crucial role in awareness and educational programming.

5.3   Discussion of main findings

The findings showed that the discourse that informed the perceptions of HIV/AIDS among Muslims was primarily that of their religious identity and the Islamic tenets that guided it. This was applicable in all the themes that emerged from the findings. The afore-mentioned could be understood within the theoretical framework that, according to Deacon *et al*. (2005), stresses the importance of understanding the process of stigmatization and the specific context within which it occurs to help explain the variable nature of stigma. Therefore, HIV/AIDS-related stigma should integrate explanations of the intrinsically linked dialectic of individual and society in order to be understood more holistically. This is in agreement with the findings in the studies conducted by Shisana and Simbayi (2002) and Shisana *et al*. (2005). These studies highlighted that there were behavioural (implying the individual), and social (implying society) determinants of HIV/AIDS. Muslims have made meaning of HIV/AIDS and PLWHA that have evolved from existing negative definitions of the 'other' (PLWHA), for example, that PLWHA were 'disobedient to 'Allah's laws.

Ackermann (2005) and Deacon *et al*. (2005) have posited that there are similarities in patterns of HIV/AIDS stigmatization, but that there are significant local variations because stigma is influenced by local, social, political, historical, cultural, gender and religious factors. This could be seen in that the most significant underlying factor informing stigma in this community was Muslims' understanding of their religious beliefs and practices. The specific manner in which these Muslims made sense and gave meaning to HIV/AIDS and PLWHA was through the interaction between the Muslim individual, the community, and their religious value system.

This finding mentioned above, is consistent with previous findings reported by Petros *et al*. (2006) which showed that in South Africa PLWHA were subjected to different forms of 'othering' that included religion, race, gender and homophobia. They also found that cultural and racial positioning mediate perceptions of those considered as responsible and thus vulnerable to HIV infection and AIDS. This is in agreement with Airhihenbuwa and Webster (2004) and Visser *et al*. (2006) who found that within the South African community, the individual's personal tendency to stigmatize PLWHA is influenced by culture, race group, personal knowledge of someone with HIV, area of residence and gender. The aforementioned stresses the importance, similarly to Francis and Francis (2006), that prevention and intervention programmes need to be the result of the understanding of the perceptions of HIV/AIDS of the specific audience that are being focused on (Francis & Francis, 2006). This is also in agreement with the assumptions of Deacon *et al*. (2005), Parker and Aggleton (2003), and Visser *et al*. (2006).
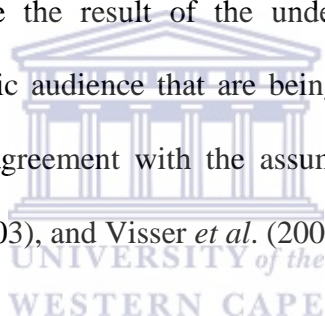
5.3.1   Religious identity

These participants seemed to have a very significant awareness of Islamic rules, particularly those that focused on sexual interaction. It seemed the religious tenet that requires a Muslim to be good and abstain from what is prohibited by 'Allah', for example, committing sin, greatly influenced their understanding of the different aspects of HIV/AIDS and could be seen as a major theme that emerged in the research material. Furthermore, because Islam embraces a preventative system, it also encourages Muslims to abstain from behaviour that will take them near what is considered as sin. Participants regarded 'zina' as one of the major sins. They understood people have a choice of behaviour, hence, if you choose to 'zina' then it

is punishable by 'Allah'. This was similar to what was found in the study conducted by Deacon *et al*. (2005) and a synthesis of international studies by Ogden and Nyblade (2005). They found that PLWHA were regarded as being punished with HIV/AIDS because they chose to engage in 'deviant' behaviour that led to their HIV infection.

Although Muslims believe only 'Allah' should judge people, there seemed to be an aversion to behaviour that implied an individual had chosen to do the wrong thing by committing a sin. This contributed to the negative responses to HIV/AIDS and PLWHA. It was interesting that all participants gave the impression that they were HIV-negative. This highlighted the immense importance of understanding phenomena through Campbell's theoretical approach that speaks about the importance of being aware of the interaction between the individual and society when wanting to understand the individual's stigmatizing behaviour holistically (2001). Therefore, one could understand this behaviour against the background that, given the underlying religious understanding, as explained above, these participants would be motivated to have others in their society believe that they were followers of Islamic tenets, who did not engage in 'zina', thus, they were HIV-negative. Similar findings were reported in the study conducted amongst Muslims in the Cape Town metropole (Kajee *et al*., 2005).

Thus, Muslims' understanding of and response to PLWHA were embedded within the understanding that 'zina', that is prohibited by Islam, caused HIV/AIDS. They further believed because PLWHA engaged in 'sinful' behaviour, this was punishable by 'Allah' and did not deserve a positive response by human beings. This was because a positive response to PLWHA could be seen as condoning and encouraging

sinful behaviour. According to and in agreement with the assumptions of Deacon *et al.* (2005), Joffe (1999), and Patient and Orr (2003), it is thus helpful to understand that Muslims' existing shared religious beliefs underlie the social representations of sexual relations that impact on how they perceive, understand and respond to PLWHA and HIV/AIDS.

5.3.2   'Othering' of HIV/AIDS and PLWHA

With Muslims internalizing the understanding of their religious tenets, it becomes clearer to comprehend their 'othering' of HIV/AIDS. Another major theme was that the Muslims in the study believe they followed the rules of abstinence from zina' in Islam; therefore it would be incongruent to see them as being at risk of HIV/AIDS. This is somewhat similar to what other religious communities have been saying (Ackermann, 2005). Muslims in Mauritania in North-West Africa had the same belief, in that they did not talk publicly about HIV/AIDS because they believed the 'Quran' protected them against AIDS. They also believed 'good' Muslims who followed the 'Quran' never got the disease (AIDS Weekly, 2004). It seems, they perceived themselves as not infected nor affected by the disease and also not being at risk of HIV infection because they were 'good' Muslims, similar to what was found in this study. This perception is similar to that found amongst Muslims in the study conducted by Kajee *et al.* (2005) and to some extent as well as that by Shisana *et al.* (2005). However, there has also been contradicting evidence, in that it was found that 11% of the 4 000 social cases the Muslim Judicial Council attended to in 1993, related to 'sex outside marriage' (Positive Muslims, 2005). This showed that Muslims were at risk of HIV infection as well.

In contrast to 'othering' attitudes outlined above, Muslims in Senegal seemed not to 'other' HIV/AIDS and have actively worked to reduce HIV infection. This has resulted in an estimated relatively low 2% HIV infection rate amongst 92% of the population that were Muslim (AIDS in Muslim African countries, 2005). Muslim participants' 'Othering' as described above, could best be understood through the explanation of Goffman (1963) that PLWHA have been given a characteristic that contributes to a spoiled identity. PLWHA are seen as people who do not follow religious injunctions therefore they are devalued by Muslim society who then discriminates against them.

5.3.3 'Innocent' versus 'guilty'

An important theme was that Muslims responded to PLWHA as either being 'guilty' of 'sinful' behaviour that caused them to be HIV-positive, or being 'innocent', in that the PLWHA were unknowingly infected by another. This could be understood again the background that Muslims believe all human beings have a choice between doing right or wrong. If the PLWHA chose to do wrong, they would carry the shame of it, which included stigmatization in its various forms, whereas, if it was known that they were a victim of infection, they would not be stigmatized. Goffman (1963) explained this as society devaluing an individual who has a characteristic that makes up a spoiled identity; hence, they will be devalued and discriminated against. This is seen in the stigmatizing of PLWHA, who are in this instance seen as being 'immoral' beings who are unacceptable to Muslims. Similar moral judgements against PLWHA were found in studies conducted in South East Asia (Busza, 2001), Hong Kong (Mak *et al.*, 2006), and Ethiopia, Tanzania, Zambia and Vietnam (Ogden & Nyblade, 2005).

5.3.4 Blaming women

Muslims blamed both women and men for infecting each other. This depended on how the particular gender was socialized by the group doing the blaming. Female participants stereotyped males as 'sinners', ego-centric, and uncaring and deserving of harsher punishment, whereas male participants stereotyped females as 'flirtatious' and 'guilty' of 'bringing curses' and ill-health to their homes. These women were, consequently, deserving of harsher punishment than that meted out to males. These responses seemed to be embedded in Muslims' understanding of Islamic tenets that prescribed spouses to be protective of each other's dignity; hence, adultery was strictly not allowed in Islam. When 'zina' was committed, the harshest punishment would be meted out to the offender.

Furthermore, it might be useful to draw on the explanation of Petros *et al*. (2006) for males and females stereotyping and stigmatizing the 'other', in that Petros *et al*. (2006) explained 'othering' evolves from the perception of 'self=religious/good/obedient' and 'other=irreligious/bad/deviant'. HIV/AIDS gendered 'othering' might be influenced by existing ways of 'othering'. An example might be, the 'othering' that might be linked to discussions in relation to the high prevalence of domestic abuse and violence against females; in that, males blamed females for being 'deviant' therefore the former reacted 'abusively' against them; alternatively, females saw males as the 'bad/deviant' perpetrators of abuse. However, in their study, Petros *et al*. (2006) found that the heaviest burden of HIV/AIDS, including stigma was put on black South African women. This was similar in Ethiopia, Tanzania, Zambia, and Vietnam, where Ogden and Nyblade

(2005) found women were stigmatized more because they were supposed to ensure the moral fibre of society.

Another explanation for the blaming of women could be that it seems to be the result of today's patriarchal societies that sees women as inferior to men and blames women mostly for the spread of HIV/AIDS. The understanding of Campbell (2001), that postulates stigma and its effects are engendered in the interaction between the individual and society and is historicoculturally-specific, helps us to understand the possibility that patriarchal attitudes are facilitating the blaming of HIV/AIDS on women. This could be because men see themselves as 'superior' to women and that women are the creation that are 'weaker' therefore more at risk of HIV infection. The assumption of 'othering' could also be used to explain most forms of stigma.

5.3.5   Forms of stigma

Participants' attitudes varied with regard to different aspects of HIV/AIDS and PLWHA. This manifested in various forms of HIV/AIDS stigma, as mentioned earlier. This was similar to the outcome of the study conducted by Shisana *et al*. (2005). Furthermore, although there were variants, HIV/AIDS stigma and discrimination were mostly similar regarding what causes stigma, the way in which stigma is expressed, and the effects of stigma. This was in agreement with the findings from the synthesis of studies by Ogden and Nyblade (2005). It seemed HIV/AIDS-related stigma strengthened existing social inequalities in the case of prostitutes and homosexuals. These are people whose lifestyles and sexual orientation were prohibited Islamically. They were thus stigmatized because of this, as well as because it was assumed they were HIV-positive.

Similar to the above, Francis and Francis (2006) and Petros *et al.* (2006) found that people described attributions of HIV/AIDS as 'promiscuous', 'prostitutes', 'people who are immoral', and 'gay plague'. This is also the experience amongst homosexuals in Senegal (AIDS in Muslim African countries, 2005); and is in agreement with Ackermann (2005) and Parker and Aggleton (2003), who argued that HIV/AIDS-related stigma was inextricably connected to existing stereotyping attitudes towards those seen as 'different/deviant' and reinforced discrimination that contributed to maintaining social control. In contrast, as a part of their 'othering' of HIV/AIDS, it was reported that in the Muslim world it is indicated that homosexuals and prostitutes were rarely found in their communities and this formed a part of their denial of the epidemic (Middle East News Online, accessed 2005, February 28).

5.3.6   Mediating factors in expressions of stigma towards PLWHA

Stigma appears to be mediated by many different factors, therefore it manifests in different forms. This is explained by Deacon *et al.* (2005), Joffe, 1999, and Patient and Orr (2003) as the social processes that facilitate the individuals' perception, understanding and response to phenomena; and that results in the content of the stigma varying. The most salient mediating factor in this study was participants' religious positioning. A moral judgement was passed on PLWHA, in that they were categorized as those who intentionally chose behaviours that were prohibited religiously and seen as 'sinful'. This type of religious understanding influenced the form of stigma and the extent to which individuals would stigmatize those who were HIV-positive. Stigma caused by moral judgement is also a factor mentioned amongst respondents from the synthesis of studies by Ogden and Nyblade (2005).

Another mediating factor of stigma is the individual's fear of HIV infection, as was also found in another study among Muslims in the Cape Town metropole (Kajee *et al*. 2005). Examples of this are the refusal to wash and bury dead PLWHA; and isolating HIV-positive children by refusing to play with them. This was also evident in the literature review done by Deacon *et al*. (2005) which showed how people saw PLWHA as having a fatal disease that contributed to them fearing infection. Similar experiences were evident in the study done in South East Asia where people also feared infection, therefore they denied PLWHA religious rituals such as funeral practices. Those infected and affected were also socially isolated (Busza, 2001).

In addition, the individual's lack of education and awareness of HIV/AIDS as well as contact with PLWHA mediates stigma too. It seems people will stigmatize PLWHA less if they know more about the different aspects of HIV/AIDS. Indirectly this was also linked to the fear of becoming infected by the virus, because of the lack of understanding of how the virus is transmitted. The findings revealed in the studies by Kajee *et al*. (2005) and Ogden and Nyblade (2005) also expressed these sentiments. However, Mak *et al*. (2006) explained that factual understanding of the disease played a minor role in shaping stigmatizing attitudes towards PLWHA. They believed the public's perceptions or beliefs about the disease played a more significant role in forming stigma. This is in agreement with Deacon *et al*. (2005), Joffe (1999), and Patient and Orr (2003) who posited that there is a series of shared beliefs that informed and/or mediated stigma, thus, making it a social process in which existing social representations to perceive, understand and respond to a phenomenon is used by an individual.

5.3.7   <u>Effects of stigma</u>

5.3.7.1 Response to VCT

Amongst others, the most significant effects of stigma have been the negative response to being tested and non-disclosure of HIV status. This could be seen as one of the major themes that emerged in this study. Not wanting to test or discuss it brought up issues of trust between partners and the assumption that when testing was suggested it implied the partner might have committed 'zina' and is a 'bad' Muslim. In addition, people feared that such a discussion created disharmony between partners because the individual's integrity was in question.

Furthermore, suggesting to be tested holds the implication of the possibility of a positive test result. People feared a positive test outcome because of the various forms of stigma (as discussed earlier) associated with it. This finding is in agreement with those obtained from studies by Kalichman and Simbayi (2003), Kalichman *et al*. (2005) and Hutchinson and Mahlalela (2006). There was a fear of dealing with the shame associated with 'zina' and the associated stigmatization, for example, rejection and isolation that PLWHA as well as their family would experience. Ogden and Nyblade (2005) also found that fear of stigma and discrimination contributed to people not wanting to test.

However, in contrast to the above, it seems that during the last two years people in South Africa have used VCT services more (Shisana *et al*., 2005). This might be due to the wider availability of free ARV treatment, although, in this study there seem to be some confusion around the government's commitment to rolling out ARV

treatment and their perception of how appropriate this treatment was, as suggested by Caelers (2006) as well.

5.3.7.2 Disclosure of HIV/AIDS status

'Othering' in the Muslim community is seen as a hindrance to disclosure of an individual's HIV status, as also found in a study by Skinner and Mfecane (2004). It is very difficult for an HIV-positive person to disclose their status because the community has denied the existence of the disease amongst them, and by doing this, has denied the experiences of the PLWHA. This may be understood as, if 'othering' is not taking place, then it means PLWHA are indeed engaging in 'zina', meaning that they are 'sinners' deserving of 'Allah's punishment.

In contrast to the above, if Muslims accept PLWHA, it can be misconstrued as condoning 'wrong-doing' through supposedly encouraging others to have pre-marital or extra-marital sexual relations. However, it could be hypothesized, that Muslims might be having an inner struggle, in wanting to help and support PLWHA because of their religious prescription that they must help those in need, particularly the sick and infirm.

Furthermore, it has also been found that HIV-positive women in sub-Saharan Africa refrain from disclosing their status because of the fear of AIDS stigma (Kilewo *et al*., 2001). Hence, this shows that fear of HIV/AIDS stigma is stopping people from disclosing their HIV status (Doherty *et al*., 2006; Shisana *et al*. 2005).

The effects of stigma, as well as forms of support and positive responses to PLWHA that are discussed under the next section, can best be understood according to Campbell (2001) and Deacon *et al*. (2005) who posited that we need to gain an

understanding of the process of stigmatization, the specific context within which it happens, and its effects to help explain how and why stigma varies. Thus, we need to understand that Muslims' religious positioning is the primary process through which they make meaning of HIV/AIDS, and that this informs both the stigmatization and their supportive behaviour.

5.3.8   Forms of support and positive responses to PLWHA

Although Muslims in this study revealed many stigmatizing attitudes and behaviours, they ultimately referred to this as their initial response to a disease that they did not know much about, but they would be supportive of PLWHA. This seems to stem from the Islamic prescription which says Muslims must help and reach out to 'Allah's creation that are infirm and in need. There seemed to have been a collaborative attempt by the various role players, including individuals, religious leaders, the broader community members, NGOs and government, in this community to increase HIV/AIDS education and awareness and to lessen HIV/AIDS-related stigma (e.g. religious leaders encouraging people not to judge PLWHA). A similar experience of steering away from 'blaming' and being judgemental of PLWHA was found in another religious community in the study conducted by Ackermann (2005).

Shisana *et al*. (2005) found HIV/AIDS stigma has decreased in South Africa, and they felt the reason for this was South Africans accepting that all populations are at risk of HIV infection. Another reason was that people were talking more openly about HIV/AIDS. Furthermore, Robins (2006) found the collective experience of stigma by some PLWHA has resulted in HIV/AIDS activism, similarly to what was found in this study. It seems evident from these South African studies, as well as the

experiences of Muslims in Senegal (Aids in Muslim African countries, 2005), that having continuous HIV/AIDS education and awareness programmes, as well as anti-HIV/AIDS stigma activism by PLWHA does result in a positive impact on the behaviours of people, including the lessening of HIV/AIDS stigma.

Jewkes (2006) agrees with the above and she suggested normalizing HIV/AIDS as a disease, and teaching people to care for PLWHA. Jewkes (2006) said this could contribute to shifting the discourse from the negative to empowering others to do the same. She felt this could help with lessening discrimination against PLWHA and reducing stigma. Shisana *et al*. (2005) suggested that the only possible practical solution to containing the HIV epidemic would be the development of a vaccine for HIV/AIDS. This might be a focus of future research – to explore how Muslims would respond to having themselves vaccinated against HIV infection, if they continue to 'other' the disease and see themselves as not at risk for HIV infection.
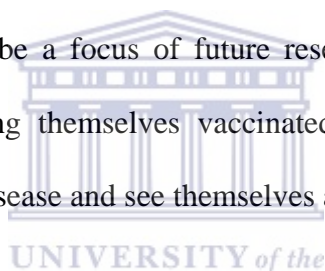
Another interesting question is whether Muslims would adopt orphans and vulnerable children into their homes, as described in the 'W.K. Kellogg Foundation's Orphans and Vulnerable Children Project' (Magome, 2006) discussed earlier. This is another aspect that could be researched in future, given that Muslims believe orphans and vulnerable children need the community's protection, and that specific verses in the 'Quran' address and encourage this matter. Other forms of support and positive responses to PLWHA were discussed under Section 5.2.8.

5.4   Limitations

Vaughn, Schumm and Sinagub (1996) posited that the intent of the focus group interview is to report the views of participants, rather than to generalize to larger

groups. Not being able to generalize the outcome of the study can be seen as a limitation of the study. The intention of these group discussions was to find out why these participants felt the way they did about the focus of the research. However, it gave the researcher a near consensus of salient common themes regarding the perceptions of HIV/AIDS amongst these Muslims.

Another limitation of the study was that the research was done with Muslims who lived in one geographical area of the community. It would have deepened and broadened our understanding of HIV/AIDS stigma if we included in this study Muslims from other geographical areas in Cape Town.

5.5 Future research

1) It is recommended that a study be done that includes quantitative and qualitative approaches to perceptions of HIV/AIDS amongst Muslims in the Western Cape, using the indicators of internal and external stigma that have been identified by this and other qualitative studies amongst this group of people. In this way it will help to have a broader and deeper understanding of HIV/AIDS stigma, to help with the development of stigma intervention programmes for this group.

2) Another research area of focus could be to establish Muslims' perceptions of or response to making use of HIV/AIDS vaccination, in relation to them continuing 'othering' HIV/AIDS and regarding themselves as not at risk of HIV infection.

3) A further area to research is whether Muslims will adopt or care for HIV-infected or affected orphans, since their religion recommends caring for orphans and children in need; and the numbers of orphans are growing world-wide.

5.6   Recommendations

Several recommendations can be made as follows:

1)   HIV/AIDS education and anti-stigma programmes are needed that target stigma amongst Muslims, particularly that of the concept of 'othering' the disease. This should be done in a manner that will help Muslims to realize that they are also at risk of contracting HIV/AIDS.

2)   The programmes could target the religious leaders of the Muslim community. This could help because if the leaders of this group of people engage in less stigmatizing of HIV/AIDS and have more knowledge about the disease, it would have a positive effect on how they deal with the topic of HIV/AIDS in the community.

3)   The programmes should target both genders, to help inform them of gender stereotyping and how this informs stigma, as well as how these issues could be putting them at risk of contracting HIV/AIDS, because they are engaging in gender 'othering' of the disease.

4)   Some intervention programmes highlighting the importance of VCT are also called for. This would be beneficial because when people know their status they can prevent themselves becoming infected, and engage in behaviours that will improve their health if their test outcome is positive.

5)   Finally, support groups for PLWHA who are Muslim and those in the community who are affected by HIV/AIDS are required. This will help attenuate the

high levels of stigma, especially internalized stigma, felt by both PLWHA and their families and friends.

5.7 Conclusion

HIV/AIDS stigma is seen as a barrier to effective prevention, intervention and support and care programmes. This contributes to the continuous increase of the spread of the disease. Muslims, who represent a large minority of people in the Western Cape, and who were the focus of this study, are engaging in both denial and 'othering' of the disease. This qualitative research was specifically done to help establish indicators of internal and external HIV/AIDS-related stigma in relation to the Muslim individual, the Muslim family, and the Muslim community, including Muslim religious leaders (Imams and Sheikhs). Such information will form the basis of future quantitative studies to test for generalizability of the findings, as well as the development of appropriate intervention programmes aimed at ameliorating the HIV/AIDS-related stigma found among Muslims in South Africa.

The present study found Muslims in Mitchell's Plain, a Cape Town community, were indeed engaging in various forms of HIV/AIDS stigma, such as, 'othering the disease' and passing moral judgements on PLWHA. It seemed Muslims perceived a decrease in the prevalence of HIV/AIDS stigma in their community, similarly to that found in South Africa by Shisana *et al*. (2005). The most salient factor that influenced almost all forms of stigma was that of religious positioning. However, supportive attitudes and behaviours were also expressed.

The main recommendation is to create anti-HIV/AIDS stigma programmes to lessen the prevalence of stigma. Future research could include quantitative studies that

might focus on the indicators of internal and external stigma to enable the results to be generalizable. This could be used to inform intervention and prevention programmes that target this particular sector of the community.

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APPENDIX A

FOCUS GROUP GUIDE

1. What are your views about HIV/AIDS?

a) What do you think influenced you to hold these views?

b) Are your views shared by others in the Muslim community?

c) What are some positive things in your community that are supportive of

PLWHA?

d) What are some negative things in your community that are against PLWHA?

2. How would you say PLWHA are treated in the Muslim community?

a) Are female PLWHA treated differently?

b) How about male PLWHA? Are they different (treated differently)?

c) How do you personally deal with PLWHA?

3. Is your community supportive of PLWHA?

a) Please share examples of how they may be supportive or not supportive?

b) What are your views about the role of the health care in this matter? Your

experiences in this regard.

4. What are your views about PLWHA?

a) Are your views different from those of your family and your community?

b) Different from religious leaders?

5. What are your views on testing for HIV?

a) Would you want to be tested? Reasons?

b) Are these views shared by others in the community and religious leaders?

c) How would you deal with an HIV result both negative and positive?

6. Is there anything else you might want to add regarding HIV/AIDS?

<center>**APPENDIX B**</center>

<center>**PARTICIPANT CONSENT FORM**</center>

<center>**VERIFICATION OF ADULT INFORMED CONSENT FOR OWN PARTICIPATION**</center>

I, ………………………………………………………… (Please print full name and surname),

Voluntarily give my consent to serve as a participant in the study entitled:

PERCEPTIONS OF HIV/AIDS-RELATED STIGMA AMONG MUSLIMS IN A

CAPE TOWN COMMUNITY.

I have received a satisfactory explanation of the general purpose and process of this study, as well as a description of what I will be asked to do and the conditions that I will be exposed to.

It is my understanding that my participation in this study is voluntary and I will receive no remuneration for my participation.

It is further my understanding that I may terminate my participation in this study at any time and that any data obtained will be held confidential. I am aware that the researcher has to report to her supervisor and that all data collected will be accessible to the supervisor as well.

Signature of participant:…………………….................

(Print name):……………………….

Date:……………………….