

**FACTORS RELATED TO THE STIGMA ASSOCIATED WITH HIV/AIDS IN
ATTRIDGEVILLE AND MAMELODI**

BY

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Declaration

I hereby declare that an exploratory study on the factors contributing to the stigma associated with HIV/AIDS in the community is my own work and all the resources that I have used or cited have been indicated and acknowledged by means of complete references.

Signed at on the..... by.....

M.A. RAGIMANA

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ABSTRACT

This research is an exploratory study, examining how people feel about HIV/AIDS and their reaction towards a person who tested HIV positive. The purpose of the study was to explore factors contributing to the stigma associated with HIV/AIDS in Mamelodi and Atteridgeville. Thirty fieldworkers interviewed a convenient sample of 1077 respondents from different ethnic groups, gender, educational level, marital status and age groups and found that respondents tend to stigmatising persons with HIV/AIDS.

This research uses both quantitative and qualitative methods as a research approach. The two methodologies were used with the intention of making some contribution to the methodology of social psychological HIV/AIDS studies. The questionnaire was employed as a quantitative instrument with a view to identify the respondents' views. The questionnaire consists of five (5) sections: Personal information, health related questions, an HIV knowledge scale consisting of 16 questions and two HIV stigma scales used to assess personal and perceived community stigma.

The level of personal stigma attached to HIV/AIDS was found to be lower than the level of stigma perceived in the community. This indicates that people perceive a collective stigma in the community that is negative, blaming, judging and restrictive towards interaction with people with HIV/AIDS. The perception of highly stigmatising attitudes in the community was shared by all sub-groups in the study. Only 22% of people surveyed would be scared or felt uncomfortable sending their child to school with children living with AIDS. Almost 42% of respondents believe that people who were exposed to AIDS through sex got what they deserved. In general, research shows that knowledge of HIV is quite high (95%).

LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency syndrome
ANOVA	Analysis of Variance
ARV	Anti-retroviral treatment
HIV	Human Immunodeficiency Virus
PLWHA	People Living with HIV/AIDS
UNAIDS	The Joint United Nations Programme on HIV/AIDS

KEY TERMS

Attitude
Discrimination
Prejudice
HIV related Stigma
Stigmatisation

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CHAPTER 1: INTRODUCTION¹

1.1 INTRODUCTION

Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) is currently one of the most devastating health conditions affecting the health of millions of people throughout the world. HIV/AIDS affects entire populations, societies, and countries with enormous and tragic consequences at the national, community, family, and individual level. An estimated 25.4 million people are living with HIV/AIDS in Sub-Saharan Africa and approximately 3.1 million new infections occurred in 2004, and the access to care and treatment is severely limited (Fredrickson & Kanabus, 2005). The Joint United Nations Programme on HIV/AIDS (2004) reported that Sub Saharan Africa remains by far the region worst affected by HIV/AIDS. With just over 10 percent of the world's population, almost two thirds of people in the world are living HIV in the Sub-Saharan Africa. Young people (15-24 years old) accounted for half of all new HIV infections worldwide and more than 600 000 become infected with HIV every day (UNAIDS, 2004). In 2003, an estimated 5 million people became newly infected with HIV; the greatest number in every one-year since the beginning of the epidemic, and 2.2 million people died from HIV/AIDS related illness globally that year (UNAIDS, 2004). The sheer scale of HIV – related deaths and infections has made this a global crisis. At the global level, the number of people living with HIV continues to grow – from 35 million in 2001 to 38 million in 2003 with an estimated range from 34.6 to 42.3 million, about 35.7 million were adults, and 2.1 million were children younger than 15 years (UNAIDS, 2004). Almost over 20 million people have died since the first cases of AIDS were identified in 1981 in the world (UNAIDS, 2004).

In just the past year the epidemic has claimed the lives of an estimated 2.3 million people in Sub-Saharan Africa region. Around 2 million children under 15 are living with HIV and more than 12 million children have been orphaned by AIDS (Fredrickson & Kanabus, 2005). Approximately 95 percent of all AIDS

¹ This chapter focus on HIV/AIDS world wide and South Africa.

orphans in the world live in Sub-Saharan Africa. Although Sub-Saharan Africa shows the highest number of adults and children living with HIV/AIDS, some other regions may be very far behind. Large variations exist between individual countries. In some African countries like Kenya, Uganda, Swaziland and Zimbabwe, the epidemic is still growing despite its severity, and is expected to significantly contribute to future shortages of professionals such as skilled teachers (World Bank, 1999). In Somalia and Gambia the prevalence is under 2 percent of the adult population, whereas in South Africa and Zambia around 20 percent of the adult population is infected.

1.2 HIV/AIDS IN SOUTH AFRICA

The HIV/AIDS epidemic in South Africa started later than in most African countries, but currently has the fastest growing infections rate in the world. South Africa has a population of 44.8 million people, and is currently living with the largest number of HIV infected people in the world, an estimated number of more than 5 million people. The province of KwaZulu-Natal is the most affected region. Kelly (2003) estimated that these numbers will be more than double over the next 5 years, resulting in 5 to 7 million AIDS deaths in South Africa by 2010. Over the past decade, the country has worked to pick up the pieces left by its painful history of apartheid while also dealing with an HIV/AIDS rate that took off from less than one percent in 1990 to over 12 percent in the general population (Department of Health, 2005). This figure is expected to reach 25 percent by 2010.

As the pandemic have increased, critical prevention programs have increased, but treatment programs are just beginning with an effort to provide low cost AIDS medication to South African citizens. This creates major challenges for both government and civil society groups, who are doing their utmost to curb the spread of HIV/AIDS and help those who are affected by the disease (Gradwell, 2004).

South Africa now stands on the brink of a full-blown AIDS crisis. Recent demographic work summarized in two reports prepared by Barings (1999, 2000), estimates that, since the onset of the AIDS epidemic, more than 500,000 South Africans have died of AIDS-related complications. By 2008, overall life expectancy in South Africa is forecast to fall from its pre-epidemic high of 65 years to only 40 years. While modification of high-risk behaviours could reduce AIDS-related death rates, due to the long delays between infection and death (approximately 8-10 years), behaviour change now would reduce the number of AIDS deaths primarily in the 2010-2015 period. Although the effect of antiretroviral drugs (ARV) is not known yet, an HIV infection rate currently estimated at more than 12 percent of the population (and projected to increase), prospects for avoiding a major human development crisis over the next decade and beyond are weak (Kelly, 2003). The provision of antiretroviral drugs can prolong life of people with HIV/AIDS for an unknown period and change the face of HIV from a death sentence to a chronic disease.

Though President Nelson Mandela has taken a strong leadership role by confronting AIDS and mobilising efforts to fight it, many have criticized the current government for not responding with the same speed and clarity, particularly in terms of the effort to provide treatment to those suffering from HIV/AIDS (Shisana & Simbayi, 2003).

1.3 STIGMA RELATED TO HIV/AIDS

HIV/AIDS has been described in terms of three phases of the epidemic, namely:

- The first phase is characterized by the epidemic of HIV silently and unnoticed causing unpleasant feelings of fear in the community.
- The second phase is shown by the epidemic of AIDS as a life threatening infection.
- The third phase is characterized by the epidemic of stigma, discrimination, and denial. The third phase is said to be a global challenge because it is attached with unacceptable sexual behaviour at community, national, and

global levels. It makes prevention difficult by forcing the epidemic out of sight and underground.

The concept stigma has been applied to an exceptionally wide array of different circumstances, particularly in relation to health, ranging from leprosy to cancer and mental illness (Parker & Aggleton, 2003). Since the beginning of the epidemic, people living with HIV/AIDS or believed to be vulnerable to infection, have consistently being the target of stigma and discrimination. Breinbauer, Foreman and Lyra (2003) stated that experiences such as loss of family, friends, work and housing, verbal and physical abuse have been widely documented across social and political boundaries.

Stigma is a broad and multidimensional concept with the essence centering on the issue of deviance. Goffman (1963) defined stigma as an attribute that is significantly discrediting which in the eyes of the society serves to reduce the people who possess it. It also has important consequences for the way in which individuals come to see themselves. Goffman (1963) described stigma in terms of individual characteristics. He argued that the stigmatised individual is thus seen to be a person who possesses “an undesirable difference” which then leads to social devaluation and discrimination. Stigma is conceptualised by society through rules and sanctions resulting in what Goffman (1963) described as a kind of “spoiled identity” for the person concerned.

Much stigma related to HIV/AIDS builds upon and reinforces earlier negative thoughts. People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong. Often these “wrongdoings” are associated with illegal and socially frowned upon activities, such as sex, injecting drugs, prostitution and infidelity.

Parker and Aggleton (2003) stated that stigma could also be defined in terms of social processes linked to competition for power. HIV/AIDS stigmatisation acts to reinforce other forms of social exclusion and inequality such as poverty, racism, and religious conflict and serves to legitimise dominant power relations. They suggested that the best way to address the problem is through poverty

alleviation, legal rights protection, social activism, and other broad-brush social measures. Parker and Aggleton's approach does help to explain the strength and persistence of stigma, but the fact that educational programs do have some effect in combating stigma and/or discrimination (Brown, Trujillo & Macintyre, 2001) suggested the need to address individual ignorance as well as social power in understanding stigma.

1.4 IMPACT OF STIGMA

The HIV/AIDS pandemic has evoked a wide range of reactions from individuals, communities, and even nations, from sympathy and caring to silence, denial, fear, anger, and even violence. Stigma is an important factor in the type and magnitude of the reactions to this epidemic (UNAIDS, 2002a). We know much less about the level and reasons for silence and denials than we know about violent, hostile, or isolationist reactions. Physical harm of people living with HIV/AIDS (PLHA) has been documented in the United States (Zierler, 2000). Although the level and form of stigma changed during the past two decades people are still showing negative attitudes towards people who are HIV positive (Herek, Capitanio & Widaman, 2002).

Stigma related to HIV/AIDS often leads to discrimination and this, in turn, leads to human rights violations for PLWHA and their families. Stigma and discrimination fuel the HIV/AIDS epidemic by hampering prevention and care efforts, sustaining silence and denial about HIV/AIDS. It also reinforces the marginalization of PLWHA and those who are particularly vulnerable to HIV infection (Herek, Mintick, Burries, Chesney, Devine, Fullilove, Gunther, Levi, Michaels, Novick, Pryor, Snyder and Sweeney, 1998).

The stigma associated with HIV/AIDS has many other effects. In particular, it has powerful psychological consequences for how people with HIV/AIDS come to see themselves contributing in some cases, to depression, lack of self worth, despair and making them vulnerable to blame, and self-imposed isolation (Aggleton, Wood, Malcolm & Parker, 2005). Stigma also undermines prevention by making

people afraid to find out whether or not they are infected, for fear of the reactions of others (UNAIDS, 2002a). Stigma makes those who are infected with HIV/AIDS and affected by the disease feel guilty and ashamed, unable to express their views and fearful that they will not be taken seriously.

Throughout history, the stigma attached to epidemic illnesses and the social groups linked to them has often weighed down treatment and prevention, and has inflicted extra suffering on sick individuals and their loved ones. Since HIV/AIDS is linked to social taboos, such as sex, drug use, and death, there are enormous levels of ignorance, denial, fear, and intolerance about the disease in most communities. And it is partly because of these fears and prejudices that people stigmatise and discriminate (Aggleton et al., 2005).

People with HIV/AIDS have been segregated in schools and hospitals under brutal and degrading conditions. Ms Gugu Dlamini, an AIDS activist in Durban in South Africa has been beaten to death because she told her community she was HIV positive (UNAIDS, 2002b). In the United States, “Ryan White was thrown out of school, taunted by his neighbours, and ostracized by his community, all because he had AIDS” (HRSA, 2003,p.1). Nkosi Johnson was refused access to his school because he had the HIV virus. People are being ostracised by their relatives because the family doesn’t want to be associated with HIV or AIDS. All in all, stigma is found throughout the South African society.

HIV/AIDS related stigma is associated with negative attitudes that stigmatise people with HIV and groups that are associated with HIV in the public perception. For example, historically AIDS was associated with drug use. The target of programmes was to effect public policy about injecting drug users. Many people express negative attitudes towards those people with HIV/AIDS and would prefer not to treat them in hospitals. In South Africa health care professionals and support staff, especially those who are working with this disease, can be insensitive to people living with HIV (PLWHA) (Hlalele, 2004).

Herek et al. (2002) pointed out that most research indicates that AIDS stigma is expressed in a variety of ways e.g. attributions of responsibility to blame people

who are living with AIDS and the belief that they do not care about infecting others. Assessing community views on stigma and person's view on stigma associated with HIV/AIDS will help to understand, extend, and deepen the AIDS stigma to many who are infected with or affected by the disease. Consequences of stigma can be viewed along a continuum from mild reactions (e.g., silence and denial), to ostracism (disallowed from the society) and ultimately violence (Almond, 1996).

In the community, people living with HIV/AIDS felt discrimination in various contexts:

1.4.1 Medical context

The epidemic of fear, stigmatisation and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate preventive behaviours, including family planning (Mbwambo & Kilonzo, 2004). People living with HIV/AIDS experience and fear the seemingly limitless expression of stigma that surround them in their communities. One of the major consequences of this stigma is the government's slow response to the epidemic and the provision of available treatment programme (Shisana & Simbayi, 2003).

1.4.2 Work situation

Despite an increase in HIV/AIDS over the past years HIV-positive people still deal with stigma that can be, at times, overwhelming and result in devastating consequences of loss of jobs and violence. Milan (2005) pointed that the fear of losing one's job, or the fear of being treated unfairly by one's employer, supervisor, or shop steward are reinforced easily by stigma, negative attitudes and lack of workplace policies. These fears can be as strong as the fears of being

rejected by one's own family, spouse, or friends. This fear is life threatening to those who do know their status, but who are afraid that seeking medical care may result in employer misperceptions of excessive absenteeism, illness or loss of productivity.

1.4.3 Educational sector

The link between AIDS stigma and education has only gained attention recently; yet, the AIDS pandemic is proving to be a destructive element for education systems (World Bank, 2002). HIV/AIDS is draining the supply of educators, eroding the quality of education, weakening demand and access, drying up the countries' pool of skilled workers, and increasing the sector's costs. However, HIV/AIDS makes a greater impact in those countries where the education system was already struggling to grow, teachers are dying faster than they can be replaced, or are too sick to teach. And every year more children are losing their parents and the support that allows them to go to school (Piot & Seck, 2001).

1.5. MOTIVATION FOR THE STUDY

There are various factors, which motivated the researcher to pursue this study. Some of the factors are as follows:

- People are largely unaware that their attitudes and actions are stigmatising towards people living with HIV.
- HIV/AIDS is associated with unacceptable sexual behaviour, morality, shame, blame and judgement.
- People observe that disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual.
- Widespread care and support for people living with HIV/AIDS co-exists with stigma and discrimination.
- Little is known about the consequences of HIV/AIDS stigma. In this country, the topic of HIV/AIDS has been brought more into the open, to

reduce the stigma associated with the disease, and enabling progress related to prevention, treatment, and care, however stigma needs to be addressed at the community level.

According to Goffman (1963) stigma provides an unfavourable condition to people who are living with HIV/AIDS, for example prejudice, discounting, discrediting and discrimination directed toward persons who are ill or perceived to be ill. Many people with AIDS have been rejected by strangers and family members, discriminated against in employment and health care, driven from their homes, and subjected to physical abuse. Fear of stigma has deterred individuals from being tested for HIV and from disclosing their seropositive status to sexual partners, family, and friends (Herek, Capitanio & Widaman, 2002).

HIV/AIDS stigma is widely recognised as a problem (Malcolm, Aggleton, Brofman, Galvao, Mane & Verall, 1998). In this research the stigma related to HIV/AIDS in the South African community will be investigated because each community attaches their own meanings and explanations to situations. There is still insufficient documented research that investigates the nature and the level of stigma attached to HIV in the South African community.

There is also insufficient research to understand the relationship between knowledge of HIV and level of stigma and which groups of people are the most stigmatising, towards which intervention should be aimed. The results of the study can be used to develop interventions to change the stigma. If knowledge is related to stigma, programmes can focus to increase people's knowledge about HIV.

The Mamelodi and Atteridgeville communities were chosen for the research because patients from these communities are served by Kalafong hospital and the HIV positive people from these communities attended the hospital programmes. It is necessary to understand the community's attitude in order to help HIV positive people from these communities.

1.6 OBJECTIVES OF THE STUDY

The study had the following five main objectives:

- To explore the level of knowledge about HIV/AIDS in these communities.
- To explore the level of HIV/AIDS stigma in these communities.
- To investigate the relationship between HIV/AIDS knowledge and stigma attached to HIV/AIDS.
- To identify groups with highly stigmatising attitudes.
- To understand the type of stigmatising behaviour observed in these communities that can influence people's attitudes.

1.7 OUTLINE OF THE STUDY

This research is an exploratory study, examining how people feel about HIV and their reaction towards a person who tests HIV positive. It also investigates factors related to the levels of stigma.

This chapter has provided a background of the extent of the pandemic worldwide and in South Africa, pointing out some of the factors that have perpetuated the increase of the pandemic and the impacts of HIV/AIDS stigma.

Chapter 2 will look at relevant literature and a theoretical approach that can be used to explore the relationships between HIV/AIDS knowledge, demographics and stigma attached to HIV/AIDS in the community.

In Chapter 3 a discussion of the methodology that had been used to collect data will be presented and analysis will be discussed.

Chapter 4 presents the findings of the analysis and in chapter 5 these findings are interpreted and discussed.

CHAPTER 2: LITERATURE STUDY AND THEORETICAL FRAMEWORK²

This chapter introduces the existing documented research on HIV/AIDS related stigma and discrimination. The literature review first focuses on social psychology as a theoretical framework. The origin of stigma and development of HIV/AIDS stigma are explored. Hence, factors related to HIV/AIDS stigma are discussed.

2.1 SOCIAL PSYCHOLOGY AS THEORETICAL FRAMEWORK

Social psychology attempts to understand and explain how the thoughts, feelings, and behaviours of individuals are influenced by the actual, imagined, or implied presence of others. In a contemporary social psychology text, Baron, Byrne and Johnson (1998) defined social psychology as “the scientific field that seeks to understand the nature and causes of individual behaviour and thought in social situations”. According to Halonen and Davis (2001) social psychological research has been traditionally divided into three general topic areas, based on whether the emphasis is on the internal factors to the individual or broader social processes. At the most intrapsychic level, research topics that have been center stage have included self and attribution processes, impression formation, and attitudes. Research at the interpersonal level has focused on attraction and close relationships, prosocial behaviour and aggression. At the intergroup level, research has been aimed at understanding stereotyping and prejudice, social influence processes, and the impact of groups on the individual.

The field of social psychology concentrates on human behaviour in groups. Many aspects of behaviour are determined by the direct or indirect influences of others, even some aspects that are believed to be “innate” or “inside” and therefore beyond the control of others (Fan, Conner & Villarreal, 2004). Attitude and beliefs are also shaped and reshaped through discussion and interchange with other people. Indeed, because people are social beings who live in groups, few aspects of the inner or outer selves are unaffected by other people. According to

² Social psychology as theoretical framework

Fan et al. (2004) role theories and cognitive theories are particularly relevant to our understanding of the human and societal dimensions of HIV/AIDS.

Social psychologists understand stigma as an attitude consisting of emotional, cognitive and behavioural components. Petty (1995) defined an attitude as the “general evaluation that people hold of themselves, other people, objects, and issues”. According to Judd, Drake, Downing and Krosnic (1991), attitudes are lasting evaluations of various aspects that strongly influence social thought and how they process social information. It is difficult to change this attitude because it often functions as schemas, or cognitive frameworks that hold and organise information about specific concepts, situations, or events (Wyer & Srull, 1994).

Baron and Byrne (2003) state that attitudes have been a focus of research because researchers assume that attitude influence behaviour. According to Petty (1995), beliefs, emotions, and behaviours can all contribute separately to people’s attitudes. Millar and Tesser (1986) stress that attitudes can also be based on only one or two of these components. Some attitudes may be based mostly on thoughts stimulated by the object. Attitudes that appear identical when measured can be quite different in terms of their underlying basis or structure “and thus can be quite different in their temporal persistence, resistance or ability to predict behaviour” (Petty, 1995, p.237).

Baron and Byrne (2003) defined prejudice as an attitude toward the members of some group, based solely on their membership in that group. Discrimination refers to negative behaviours (actions) directed toward members of social groups who are the object of prejudice. Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude, and exercise power over individuals who show certain characteristics. Stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, discrediting, disregarding, underrating and social distance. It often leads to discrimination and prejudice.

In the cognitive and emotional point of view, stigma towards HIV/AIDS is shown by anger and negative feelings towards those with HIV/AIDS. There is a belief

that those with HIV/AIDS deserve to be ignored and ostracised because the disease is incurable. Other research is based on cognitive formation of schemas. This includes attitudes based on misunderstanding and misconceptions of how HIV/AIDS spread and the effects of physical contact with an infected person and negative attitudes towards groups that have high rates of infection, such as homosexuals, bisexuals, prostitutes and drug users (Herek & Capitanio, 1998).

The stigma related to HIV/AIDS is strongly related to the link between the disease and its sexually transmitted nature and the disturbing physical symptoms that appear externally on patients as the disease develops. These stigmas allow people to think that AIDS is the result of deviant sexual behaviour such as anal sex, promiscuity, and sex with drug users. By differentiating those acts as deviant from their own sexual practices, they gain a sense of security. People use stigmas especially when they feel threatened. Byong - Hee (2005) reported that to eliminate the threat, people isolate a group as being different and regain their safety through the distance created.

There are certain characteristics that appear in those who are the object of stigmatisation. Some deny the fact that they are positively diagnosed with HIV/AIDS, others attempt suicide under the intense stress and some act in self-destructive ways because of built-up self-resentment and self hatred (Herek, 1990). These people internalise the social stigmas (Lee, Kochman & Sikkema, 2002). They want to disclose their status and hide at the same time. In order to hide their health condition (Klizman, 1997), they restrict their range of activities and human interactions to decrease the chance of people finding out about their illness (Green & Serovich, 1996).

This type of research done by the Lee *et al.* (2002) have made a great contribution to a better understanding of social and psychological characteristics of stigma and the lives of stigmatised people. The social psychology and cognitive approach seek to understand the causes of social behaviour and thought of individuals – their actions, feelings, beliefs, memories, and inferences with respect to other persons. HIV/AIDS stigma is conceptualised as a

psychological attitude or as a facet of public opinion. Herek and Capitanio (1997) states that HIV/AIDS related attitudes have been conceptualised in multiple ways, including affective reactions to people with AIDS, attributions of blame and responsibility to PLWHA, avoidance of interpersonal contact with PLWHA, and support for various public policies related to AIDS.

Green (1995) emphasised that ignoring the needs of a person infected with HIV/AIDS can harm or stigmatise them psychologically, physically and emotionally. Failure to address stigma can discourage individuals from seeking voluntary counselling and testing for HIV and proper medical care. Carrying condoms may be stigmatised by those who view it as evidence of "loose" morals. In order to cope with this problem, conceptually or in society, it is very important to understand the HIV virus, its transmission, and range of diseases that it causes. Among the public, AIDS stigma has been manifested in the form of anger and other negative feelings toward people who are living with AIDS.

2.2 ORIGIN OF STIGMA

Goffman (1963, p.3) defined stigma as an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one." The concept has been applied to an enormous array of different circumstances from schizophrenia to exotic dancing and that it has been studied from the perspective of many disciplines for instance in anthropology and psychology. Stigma is characterised by rejection, denial, discrediting, disregarding, underrating and social distance.

Stigma can be conceptualised as a process. It begins when dominant groups distinguish human differences, whether "real" or not. It continues if the observed difference is believed to connote unfavourable information about the designated persons. As this occurs, social labelling of the observed difference is achieved. Labelled persons are set apart in a distinct category that separates "us" from "them" (Hamma & Sixtensson, 2005, p.9). The culmination of the stigma process

occurs when designated differences lead to various forms of disapproval, rejection, elimination and discrimination. The stigma process is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the labelling of persons as different and the execution of disapproval and discrimination.

Stigma is as old as history. Stigma is a broad and multidimensional concept with the essence centering on the issue of deviance. In ancient Greece, citizens pricked marks on their slaves using a pointed instrument, both to demonstrate ownership and to signify that such individuals were unfit for citizenship. The ancient Greek word for prick is stig, and the resulting mark, a stigma. The concept is universal, it is originated from a tattoo mark branding iron or pointed instrument, and “symbolic branding” used to signify social ostracism, disgrace, shame, or condemnation on the skin of an individual as a result of some incriminating action, identifying the person as someone to be avoided (Crawford, 1996). Modern social scientists have used the word to refer to our response to socially undesirable characteristics, and have examined the phenomenon within the context of the specific social interactions and expectations that give rise to the formation of stigmatising reactions (Mann, Tarantola, & Netter, 1992).

Katz (1981) pointed that some writers use the term stigma to denote the common aspect of all socially disqualifying attributes, however different they may be in other respects. Goffman (1963) appears to be the only investigator who has tried to define it explicitly and described stigma as a disgraceful attribute. Stigma affected persons or groups apart from the normalisation, social order, and this separation implies devaluation (Gilmore & Somerville, 1994). With regard to HIV/AIDS, the stigma may be the actual infection or it may be based on behaviours believed to lead to infection. In this cases, “the stigma attached to AIDS as an illness is layered upon pre-existing stigma” (Herek & Glunt, 1988, p.887).

The society attached stigma to those considered being disgusting by society. Those with mental diseases, physical handicaps, homosexuals and those who

have deviant behaviour are stigmatised because of their disgraceful attributes. Those who are the object of stigmatisation find themselves trying to reject the stigma, but these only results in suppression. Eventually, they accept the stigma as part of their destiny, internalise it and then they start living according to the stigma and adopt the stigma (Byong-Hee, 2005). Today the physical mark have gone, but stigma remains, based on one or more factors, such as age, caste, class, colour, ethnicity, religious belief, sex and sexuality (Breinbauer, Lyra & Foreman, 2003). Katz (1981) states that the word is widely used in something like the original literal sense but is applied more to the disgrace itself than to the bodily evidence it used to represents.

2.3 HIV/AIDS STIGMA DEFINITION

Atcherson (2002) states that the general issue of stigma has been described directly and indirectly by a number of authors in four majors areas: psychology, sociology, anthropology, and public health (e.g., Goffman, 1963; Ablon, 1981; Becker, 1981; Gilbert, 2001).

In the social sciences stigma can be described as a social construction of deviation from an ideal or expectation, contributing to powerful discrediting social label that radically changes the way individuals see themselves and are viewed as persons (Goffman, 1963). Goffman (1963, p.3) defined stigma as “an attribute that is deeply discrediting” which in the eyes of the society serves to reduce the people who possess it. In the HIV/AIDS context, stigma is mostly defined as negative thoughts about a person or group of people based on a prejudice position and is derived from the most elemental parts of the human experience such as sex, blood, disease and death (UNAIDS, 2001).

Stigma is attached to HIV positive persons because they are often blamed for their condition and viewed as causing their own misfortune rather than people suffering from other diseases (UNAIDS, 2001). According to Letamo (2003, p.349) stigma generally refers to a negatively perceived defining characteristic, either “tangible” or “intangible” such as judgement that dramatically changes the

way individuals see themselves and is seen by others. Stigma is mostly a social disease by which society imposes this negative status on a person or groups of people (Links & Phelan, 2001); however a person may self stigmatise their own conditions due to feelings of shame and embarrassment (Davidoff, 2002).

To develop an adequate understanding of the concept stigma, one must take account of the important ways in which stigmas can differ from one another. For example Goffman (1963) grossly distinguish three types of stigma:

- The abominations of the body: this type of stigma is consisting of various physical deformities, disabilities, and chronic diseases.
- Stigma related to blemishes of individual character: these are those people who are considered to be weak-willed, to have unnatural passions or to be dishonest and have socially deviant and irritable behaviour.
- Tribal stigma or stigma relating to race, nation and region or membership of a despised social group.

This of course is not a complete taxonomy, although it seems a useful starting point for thinking about stigma variations and their differential effects on the possessor and the stigmatised observer.

In terms of the above definition to be stigmatised is to be oppressed by society. Stigmatisation is the societal labelling of an individual or group as different or deviant. Another way of defining is through social processes that are linked to actions and attitudes towards people who are living with HIV/AIDS. Stigmatisation and discrimination are not only the expression of individual attitudes, but are social processes based on social, economic and political power. Power is required to be able to introduce stigma and to remove power from the stigmatised person (Link & Phelan, 2002).

Stigmatisation and discrimination as social processes are used to create and maintain social control and to produce and reproduce social inequality. Stigma contributes to the creation of social hierarchy in a community and then in turn legitimises and perpetuates social inequality (Parker et al., 2002). Stigma is a

complex social phenomenon involving interplay between social and economic factors in the environment and psychosocial issues of affected individuals.

Sociologists have identified stigmas from different perspectives than that of psychologists. Sociologists are more interested in the structural conditions that allow stigmas to thrive. Because stigmas always occur in specific cultural and power related situations, stigmas related to HIV/AIDS result from the process of conflict and struggle for rights and privileges. Stigmatised people then, enter a phase where they are oppressed under this power and rule (Parker & Aggleton, 2003). For example AIDS is frequently discussed in association with homosexuals. Members of society often regard homosexual behaviour as inappropriate, disgusting and avoid them because homosexuality challenges monogamous heterosexual relationships that are established by social norms (Bullock, 2004).

While Goffman (1963) focuses on individual aspects of stigma, Parker and Aggleton (2003) offer a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control. They also examine how stigma is used to turn difference into sexual inequality based on gender, age, sexual orientation, class, race, or ethnicity that allow some groups to devalue others based on these differences.

According to Parker and Aggleton (2002) concepts of symbolic violence and hegemony highlight the role of stigmatisation in establishing social order and control, and identify stigmatisation as part of the struggle for power. Symbolic violence is a process where words, images and practices promote the interests of dominant groups and hegemony is achieved through the use of political, social and cultural forces to promote dominant meanings and values that legitimise unequal social structures. So all cultural meanings and practices embody interests and are used to enhance social distinctions between individuals, groups and institutions.

For dominant groups to legitimise and perpetuate inequalities, they also use stigmatisation. The concepts of symbolic violence and hegemony can also help

us understand how it is that those who are stigmatised and discriminated against so often accept, even internalise, the stigma to which they are subjected. This is because the processes of symbolic violence and hegemony convince the dominated to accept existing hierarchies and allow social hierarchies to persist over generations, without generating conscious recognition from those who are dominated. In addition, these processes limit the ability of the oppressed and stigmatised groups and individuals to resist the forces that discriminate against them (Parker & Aggleton, 2003).

The concept of stigma and discrimination has to be examined within the broader social, cultural, political, and economic framework rather than only individual processes. A better understanding of the processes that produce stigma and discrimination, as well as of the processes that produce resistance to stigma and discrimination would enable us to develop more effective responses to HIV/AIDS related stigma and discrimination.

Stigma refers to the negative thoughts about a person or group based on prejudice positions. Fredrickson and Kanabus (2004,p.1) also note that negative responses to HIV/AIDS “often feed upon and reinforce dominant ideas of good and bad with respect to sex, and proper and improper behaviours”. Negative opinion, attitudes, and beliefs about those infected with HIV/AIDS, as well as those associated with people with HIV/AIDS, are deeply rooted in moral assessments, blame about the ways HIV/AIDS is transmitted, and continuing bias against the people the disease has most affected. According to Fredricksson and Kanabus (2004), the epidemic has always been associated with fear, denial, discrimination, and stigma.

Stigma is linked to power and domination throughout society as a whole. It plays a key role in producing and reproducing relations of power. Ultimately, stigma creates, and is reinforced by, social inequality. It has its origins deep within the structure of society as a whole, and in the norms and values that govern much of everyday life. Stigma is harmful, both in itself, since it can lead to feelings of shame, guilt and isolation of people living with HIV/AIDS, and also because negative thoughts often lead individuals to do things that harm others (Aggleton &

Parker, 2003). Stigma in this study is referred to as unjustified fear, negative thoughts or actions and judgemental attitudes towards people with HIV/AIDS.

2.4 HIV/AIDS RELATED STIGMA AND DISCRIMINATION

All over the world people with AIDS are stigmatised and go through some form of discrimination. South Africa has reported a large number of incidents of stigma. These include the murder of Gugu Dlamini in December 1998 for openly stating that she was HIV positive (Baleta, 1999); the murder of Mpho Mtloung together with her mother by her husband, who then also committed suicide (TAC, 2000); not allowing HIV – positive children into schools and rejections from families (Altenrexel, 2000). A recent case, in 2004, is that of Lorna Mlofane who was raped and later murdered after her three rapists had learned that she was HIV positive (Mbamato & Huisman, 2004). These and many other scenarios are well known and have been covered in the mass media.

Nowell and Van der Merwe (2003) described stigma as irrational responses directed towards HIV positive people. These responses include being shunned by family members, being discriminated against in places of work, unfair medical treatment, funeral homes refusing to take remains of HIV victims or violence (Herek et al, 2002). Recently HIV/AIDS related stigma has been more specifically conceptualised and defined as a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, prejudice, discounting, discrediting, and discrimination which are directed at people perceived to have HIV or AIDS and at the individuals, groups, and communities they are associated with (Herek, 1999).

UNAIDS (2003) theorises that HIV/AIDS related stigma is a process of devaluation which in turn leads to the violation of human rights for people living with HIV/AIDS. This process of HIV/AIDS related discrimination is action that results from stigma. It occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on basis of his or her actual or presumed HIV status or belonging or being perceived to belong to a

particular group (UNAIDS, 2001). AIDS stigma is expressed around the world in a variety of ways, including:

- Ostracism, rejection, and avoidance of people with AIDS.
- Discrimination against people with AIDS.
- Compulsory HIV testing without prior consent or protection of confidentiality.
- Violence against persons who are perceived to have AIDS or to be infected with HIV.
- Quarantine of persons with HIV/AIDS.

HIV-related discrimination is action that results from stigma attached to AIDS. The stigma is associated with shame and fear: shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgement, and fear because AIDS is relatively new and considered deadly (Piot & Seck, 2001). Responding to AIDS with blame, or abuse towards people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. HIV/AIDS related stigma comes as a result of linking the disease with inappropriate sexual behaviour, disgrace, blame and dishonour (De Cock, Mbori-Ngacha & Marum, 2002). HIV/AIDS stigma is also linked with certain groups of people referred to as risk groups. Patterson and London (2002) observed that the category of people in the risk group of infection were those already discriminated against and marginalized even before the HIV/AIDS era. Linking HIV risk with a particular category of people it created a false illusion of safety since everybody was vulnerable to being infected, more so with the existing misconception about the mode of transmission of the HIV virus.

HIV/AIDS stigma is a phenomenon that is universal, but it varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably (UNAIDS, 2002).

The qualities to which stigma adheres (the colour of the skin, the way someone talks, the things they do) can be quite arbitrary. Within a particular culture setting, certain attributes are seized and defined by others as discreditable or unworthy.

Discrimination occurs when a distinction is made between people that results in a person or a group of people being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong to a particular group.

Discrimination occurs when negative thoughts lead people or institutions to take, or omit to take, action that treats a person unfairly and unjustly on the basis of their presumed or actual HIV/AIDS status. Some examples of discrimination include hospital or prison staff denying health services to a person living with HIV/AIDS; employers terminating a worker from his/her job on the grounds of his or her actual or presumed HIV status; or families/communities rejecting those living with, or believed to be living with HIV/AIDS. Such discriminatory acts, based on presumed or actual HIV status, are violations of human rights (UNAIDS, 2002).

2.4.1 THE SOURCES OF STIGMATISATION AND DISCRIMINATION

Valdiserri (2002) emphasise that stigma is a complicated issue that has deep roots in the complex domains of class, sexuality, gender, race, ethnicity, legal context, education and school, and culture. Parker, Aggleton, Attawell, Pulerwitz and Brown (2002) stated that to understand the way in which HIV/AIDS related stigma and discrimination appear and the context in which they occur, we first need to understand how they interact with pre-existing stigma and discrimination associated with class, sexuality, race and ethnicity, poverty and legal context.

- **Class:** The HIV/AIDS epidemic has developed during a period of globalization and growing polarization between rich and poor. New forms of social exclusion associated with these global changes have reinforced pre-existing social inequalities and stigmatization of the poor, homeless, landless and jobless. As a result, poverty increased vulnerability to HIV/AIDS, and exacerbates poverty.

- Sexuality: HIV/AIDS related stigma and discrimination are closely connected with sexual stigma because HIV is mainly transmitted through sex and blood transfusion and in most areas of the world, the epidemic initially affected populations whose sexual practices or identities are different from the norm (Parker et al; 2002). HIV/AIDS related stigma and discrimination reinforce pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution, and sexual deviance.
- Gender: HIV/AIDS related stigma and discrimination are also linked to gender issues. Huidrom (2004) stated that HIV/AIDS related stigma and discrimination reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services related to women who are living with HIV/AIDS.
- Race and ethnicity: Racial and ethnic stigma and discrimination also interact with HIV/AIDS related stigma and discrimination and the epidemic has been characterized both by racist assumptions about "African sexuality" and by perceptions in the developing world of the West's immoral behaviour" (Parker & Aggleton, 2003). Racial and ethnic stigma and discrimination contribute to the marginalization of minority population groups, increasing their vulnerability to HIV/AIDS, which in turn exacerbates stigmatization and discrimination.

2.4.2 MANIFESTATION OF STIGMA AND DISCRIMINATION

HIV/AIDS related stigma is described as the holding of derogatory social attitudes or cognitive beliefs, the expression of negative effect, or display of hostile or discriminatory behaviour while discrimination is the manifestation of stigma. HIV/AIDS stigma has been manifested in discrimination, violence, and personal rejection of people with AIDS. In some social groups people living with HIV/AIDS are often seen as dishonourable. In other societies the infection is associated with minority groups or certain behaviours, for example, homosexual behaviour.

In some cases HIV/AIDS may be linked to ‘perversion’ and those infected are being punished. HIV/AIDS is seen as a result of personal irresponsibility, believed to bring shame upon the family or community. The belief that AIDS is easily spread and that people with AIDS should be blamed for their illness are important ingredients of stigma and can be based on pre-existing negative thoughts directed at specific groups. Most communities believe that affected people deserve what has happened because their activities lie outside the moral boundaries of society.

Fredriksson and Kanabus (2004) identified five main reasons contributing to HIV/AIDS – related stigma:

- HIV/AIDS is a life-threatening disease, deadly without a cure, perceived to be contagious and threatening to the community.
- HIV/AIDS is mainly sexually transmitted.
- The disease is associated with behaviours (such as sex between men and injecting drug-use) that are already stigmatised in many societies.
- Religious or moral beliefs that lead some people to believe that having HIV/AIDS is the result of moral fault (such as promiscuity or deviant sex) and that deserves to be punished.
- People living with HIV/AIDS are often thought of as being responsible for becoming infected. Stigma is most frequently associated with diseases that have severe, disfiguring, incurable and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behaviour.

This HIV/AIDS related stigma affects men and women, young and old, rich and poor. It affects people known to have contracted the virus, people suspected of having contracted it or of being vulnerable to the virus, such as homosexual, commercial sex workers, and the families and caregivers of those who are ill.

The stigma is therefore born especially from fear, denial, ignorance, lack of knowledge and social judgement.

Green and Platt (1997) suggested that HIV stigma may be divided into *felt* or *perceived* stigma and *enacted* stigma.

- Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute or disease (such as HIV), or association with a particular group. According to Emlet (2005) felt stigma relates to feelings of shame, guilt and oppressive fear of enacted stigma. For example, an individual may refuse to admit the truth or existence of his/her risk of HIV, refuse to use condoms, or refuse to disclose HIV status for fear of the possible negative reactions of family, friends, and community.
- Enacted stigma, on the other hand, refers to individually or collectively applied sanctions such as the real experience of discrimination or prejudice. For example, the disclosure of an individual's HIV-positive status could lead to loss of a job, health benefits, or social ostracism. Felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma, such as when someone deny their risk of infection or fails to disclose HIV status in order to avoid being ostracized (Herek & Capitanio, 1998).

In the community HIV/AIDS –related stigmatisation occurs at many levels. Green (1995) distinguishes between the ways of assessing community stigma.

- One way is to assess the personal perceptions of HIV/AIDS in group of people. These attitudes may be related to some behaviour of individuals towards people living with HIV. Stigma can cause people to perceive individuals with or at risk of HIV as the out groups ("them"), reinforcing the feeling that HIV "couldn't happen to me."
- Another way is to assess the perceived community stigma – that is how an individual perceives the stigma the community attach to HIV. The perceived collective stigma can be seen as a generalised construction or social norm that can have an impact on the behaviour of individuals.

Herek et al. (2002) states that stigma can also perpetuate harmful practices, such as discrimination against or poor treatment of people living with HIV. Programs that fail to address stigma help perpetuate discriminatory laws and practices and, in some cases, result in failure to enforce laws against people who stigmatise people who are living with HIV/AIDS.

Stigma and discrimination are often used interchangeably, but meanings do differ. Stigma is attached with negative thoughts and discrimination is associated with actions. Stigma and discrimination can occur in various contexts. They occur in the family, community, schools, place of worship, workplace, legal, and health-care settings. People can discriminate both in their personal and professional capacities, while systems and institutions can discriminate through their practices and policies. The stigma has led politicians and policy makers in numerous countries to deny that there is a problem, and that urgent action needs to be taken. Stigma and discrimination occur in the following contexts:

- Legal Context: Stigma can be manifested in the form of laws, policies and administrative procedures, which are often justified as necessary to protect the general population. Examples of stigmatization and discriminatory measures include compulsory screening and testing, compulsory notification of AIDS cases, restrictions of the right to anonymity, prohibition of people living with HIV/AIDS from certain occupations, and medical examination, isolation, detention and compulsory treatment of infected persons.

In many countries, laws, policies and regulations have contributed towards the development of a supportive environment for HIV/AIDS prevention, care and support. But even in places where supportive policies and legislation exist, non-existent or weak enforcement of these laws may facilitate the perpetuation of stigma and discrimination. The reason is because there is often little accountability for discriminatory action or redress for those who have been stigmatised and discriminated against

AIDS-related stigma and discrimination. These actions directly hamper the effectiveness of AIDS responses (Parker & Aggleton, 2003).

- Education and schools: Children with HIV/AIDS or associated with HIV through infected family members have been stigmatised and discriminated against in educational settings in many countries (Parker & Aggleton, 2003). Stigma has led to teasing by classmates of HIV-positive school children.
- Health care system: some people have been reported from health care settings of testing other people HIV without consent, breaches of confidentiality, and denial of treatment and care. Failure to respect confidentiality by clearly identifying patients with HIV/AIDS, revealing serostatus to relatives without prior consent, or releasing information to the media or police appear to be problems in some health services. Factors contributing to these stigmatization and discriminatory responses include lack of knowledge, moral attitudes, and perceptions that caring for PLWHA is pointless because HIV/AIDS is incurable (Herek, Mintick, Burris, Chesney, Devine, Fullilove, Gunther, Levi, Michaels, Novick, Pryor, Snyder & Sweeney, 1998).
- HIV/AIDS policies and programme: HIV/AIDS policies and programmes for the general population reinforce the perception that it is less important to protect population that practice high-risk behaviours than the innocent and unsuspecting general population (Parker, Easton & Klein, 2000). It may result in discrimination against marginalized groups, since those at greatest risk do not receive the resources they need.
- Religious institutions: In some contexts, HIV/AIDS related stigma and discrimination has been reinforced by religious leaders and organizations, which have used their power to maintain the status quo rather than to challenge negative attitudes towards marginalized groups and PLWHA.

- Community contexts: In societies with cultural systems that place greater emphasis on individualism, HIV/AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for contracting the infection. In contrast, in societies where cultural systems place greater emphasis on collectivism, HIV/AIDS may be perceived as bringing shame on the family and community.
- Family contexts: In individuals, the way in which HIV/AIDS related stigma and discrimination are manifested depends on family and social support and the degree to which people are able to be open about such issues such as their sexuality as well as their serostatus. In contexts where HIV/AIDS is highly stigmatised, fear of HIV/AIDS related stigma and discrimination may cause individuals to isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access to the services and support they need. This has been called internalised stigma (Huidrom, 2004).

All over the world, the AIDS epidemic is having a profound impact, bringing the best and the worst out in people. It triggers the best when individuals group together in solidarity to combat government, community and individual denial, and to offer support and care to people living with HIV and AIDS. It brings out the worst when individuals are stigmatised and ostracized by their loved ones, their family and their communities, and discriminated against individually as well as institutionally (Letamo, 2003).

Another context of stigma arises through internalisation by people living with HIV/AIDS of their negative perceptions of themselves. The stigma and discrimination associated with the disease can have powerful psychological consequences for how people living with HIV/AIDS come to see themselves - leading, in some cases, to depression, lack of self-worth and despair (Parker & Aggleton, 2003). And they can cause people with HIV/AIDS to be erroneously seen as some kind of 'problem', rather than as part of the solution to containing and managing the epidemic.

Most people ask themselves why AIDS should be seen as such a special case nowadays. Almond (1996) noted that it is a deadly disease lacking a medical means of prevention and cure. Stigma is a common human reaction to disease. Throughout history many diseases have carried considerable stigma, including leprosy, tuberculosis, cancer, mental illness, and many sexual transmitted diseases.

2.5 LITERATURE RELATING STIGMA TO HIV/AIDS KNOWLEDGE

According to Pape (2005), HIV/AIDS has always been linked to negative social reactions due to lack of accurate knowledge on transmission, assumptions about people living with it, and fear of contracting the diseases.

It was shown in a number of studies that “large numbers of people blame people with AIDS for their illness and don’t understand how AIDS is spread” (Herek, Capitanio, & Widaman, 2002, p.1). “The social perception of AIDS is the worst and the most ignorant. Because the media has made people think AIDS is only for prostitutes, and people who use prostitutes in foreign countries. They think that AIDS is caused by being dirty. So people think it can be transmitted by any casual contact. People with AIDS are treated as monsters” (Byong - Hee, 2005, p.19). This conveys the need for better education about AIDS and its transmission in order to combat such prevalent and paralysing stigmas.

Ogden and Nyblade (2005, p.15) reported that lack of knowledge results in the “fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV/AIDS that involve exchange of body fluids was common”. For example some people still believe that HIV/AIDS transmits through kissing, shaking hands, sleeping together in the same room, and eating together with an affected person.

Gaps in knowledge and lack of in-depth information about HIV/AIDS fuel the fear of causal transmission, leading to stigmatising action to avoid them. They are seen as sick therefore the belief that people with HIV/AIDS are non-productive community members. People still need education on the difference between HIV and AIDS, what it means to live with HIV, including the fact that opportunistic infections are treatable. Simbayi, Kalichman, Jooste, Cherry, Mfecane and Cain (2005) in the research conducted in South Africa reported that although knowledge about HIV transmission was generally high, there was evidence that misconception about AIDS persists, particularly myths related to HIV transmission.

According to a study conducted by Sihlangu (2000), participants explained that stigma was due to ignorance of the disease and predicted that with appropriate knowledge the levels of stigma attached to the disease could decline. Other participants believed that once a cure has been found HIV/AIDS will be just like any other disease and people will no longer be stigmatised. Few believe that if people disclose their HIV positive status openly the issues of stigma would cease. In spite of these views, misconception of the transmission is the main cause of stigma.

Herek, Capitanio and Widaman (2002) conducted research on HIV-related knowledge in the United States. AIDS stigma has been manifested in the form of anger and other negative feelings towards PLWHA. People believe that they deserve their illness, avoidance and threat to their human rights were strongly correlated with misunderstanding the mechanisms of HIV transmission and overestimating the risks of causal contact and with negative attitudes towards social groups disproportionately affected by the epidemic, especially gay men and injecting drug users (Herek, 2002).

Valdiserri (2002) and Herek et al. (2002) suggested that since stigma is the result of the misconception of the transmission of the HIV virus, educating the public on how HIV/AIDS is not transmitted and transmitted could help in eradicating stigma attached to the disease. Policies and programmes should be adapted to help root

out stigma. This approach stems from individual definition of stigma and ignores other definitions.

2.6 LITERATURE RELATING DEMOGRAPHIC FACTORS IN COMMUNITY TO STIGMA

Although HIV/AIDS is a highly stigmatised disease worldwide, Malcolm, Aggleton, Bronfman, Galvao, Mane and Verrall (1998) pointed out that the exact form of stigma is probably unique in each community because each community attaches their own meanings and explanations to situations. In respect of social psychology and cognitive theory, stigma needs to be considered in a specific social and cultural context.

In international research there were some significant associations between demographic characteristics of research samples and the level of stigma associated with HIV:

- Females reported less stigmatising attitudes towards people with HIV (Crawford, 1996; Herek & Capitanio, 1993)
- People older than 25 years were found to be more stigmatising (Green, 1995)
- Less educated people had less knowledge about HIV and more restrictive attitudes (Green, 1995)
- There was a significant difference in personal stigma levels between respondents who knew someone with HIV and those who did not (Herek & Capitanio, 1997).

The data from South African studies is limited, therefore this research aims to investigate what factors contribute to HIV-related stigma in a South African community.

2.7 SUMMARY

This chapter attempted to present arguments that can possibly help to explain the HIV/AIDS related stigma and discrimination. This chapter utilised social psychology as a theoretical framework and explained the origin and definitions of stigma. The lack of research regarding HIV stigma in the South African contexts is a major motivation to investigate this theme in communities in South Africa.

CHAPTER 3: METHODOLOGY

This chapter will discuss the research methodology that was used to perform the study. The data obtained from Mamelodi and Atteridgeville communities was collected using a questionnaire containing questions on a quantitative and qualitative level. Attention was paid to the hypotheses, the research design, questionnaire construction, method of data collection, sampling methods, sample size and data analysis.

3.1 RESEARCH HYPOTHESIS

According to Royse (1991) a hypothesis is an assumption that is expressed as a statement, and is a premise that can be used as a basis for investigation. Kruger and Welman (2002) affirms that hypotheses are advanced from logical chains of inferences arising from the evaluation of the interrelationship of data regarding factors thought to be contributing to the problem. The study attempts to assess the level of the stigma attached to HIV and knowledge related to HIV/AIDS in these two communities. The demographic factors that may impact on the level of stigma in the community are investigated.

The following hypotheses are explored in this study:

- There is a high level of knowledge about HIV/AIDS in Mamelodi and Atteridgeville community.
- There is high level of stigma associated with HIV/AIDS in Mamelodi and Atteridgeville community.
- There is a reverse correlation between level of knowledge about HIV and the level of stigma.
- There is a relationship between gender, age, educational level, marital status, close contact with people with HIV and level of stigmatisation.
- The level of stigmatisation is reversely related to the openness of discussing HIV in the community.

- The level of stigmatisation is related to the awareness and experience of discriminatory events in the community.

3.2 RESEARCH DESIGN

The survey method was deemed to be the most appropriate to assess knowledge, community opinion and the level of stigma in the community. According to Pirow (1993) the survey method is generally used when the researcher wishes to extract opinions from a large sample of people.

3.3 MEASURING INSTRUMENT

The questionnaire consists of the following sections:

Section 1: Personal information such as the respondent's gender, age, marital status, level of education and employment.

Section 2: Health related questions such as level of contact with people with HIV, frequency of talk about HIV in the community, in families and by the community leaders. The specific questions were:

- "How often do people you know talk about HIV/AIDS?"
- "How often do you hear leaders in your community- politicians, church leaders or heads of organisation talk about AIDS?"
- "Have you ever talked to your partner/husband/wife about ways to avoid getting HIV/AIDS?"

Section 3: HIV knowledge was assessed using 16 questions about HIV/AIDS that was compiled into a scale. Item analysis was done using the data of 1077 respondents. The item total correlations of the questions varied from 0, 27 to 0, 42. The reliability of the scale as a whole for the two communities was 0,655, which is average (Cook & Campbell, 1979). This means that some questions were easy to answer and others not. Knowledge about different aspects of HIV/AIDS was also assessed.

Section 4: Two HIV stigma scales consisting of 24 items each were used to assess personal and perceived community stigma. These two measures of stigma were used to measure subjective perceptions of stigma by people who are living in Mamelodi and Atteridgeville communities. In the first scale the respondent was required to answer questions regarding his/her own perception and reaction towards people with HIV/AIDS – reflecting the personal stigma related to HIV/AIDS. In the second scale the same questions were asked but the focus was on how he/she thinks most people in the community perceived and reacted towards HIV/AIDS. The second scale gives an indication of the perceived community stigma towards people with HIV/AIDS. This is how an individual perceives the stigma that other community members attach to HIV. These two scales were used to compare the respondents' beliefs about people who have HIV/AIDS and their perception of the community's attitude.

The stigma scales were developed from various questions used in international research such as the work of Herek (1999), Westbrook and Bauman (1996) and Green (1995). To adapt the potential questions for the local situation, two focus group discussions were held, one with a group of older women from the communities and one with health care workers in the local hospital to gain understanding of how people in this community view HIV/AIDS and the stigma related to HIV/AIDS.

In an interview situation the questions were answered in terms of “agree” and “disagree”. Factor analysis was done using the data of 1077 respondents. The following factors were identified underlying the results.

Personal stigma scale

- Blame and judgement: 10 items with the reliability of 0,665. Item - total correlations varied from 0,32 to 0,45.
- Interpersonal distance: 10 items with the reliability of 0,700. Item - total correlations varied from 0,38 to 0,54.

- Value items: 4 items with the reliability of 0,600. Item – total - correlations varied from 0, 37 to 0, 55.
- The reliability of the scale as a whole was 0.657.

The reliability of the scales was considered as moderate and appropriate to use in this community (Powers & Xie, 2000).

Community stigma scale

- Blame and judgement: 10 items with the reliability of 0,813. Item - total - correlations from 0,49 to 0,62.
- Interpersonal distance: 10 items with the reliability of 0,841. Item – total - correlations varied from 0, 36 to 0, 46.
- Value items: 4 items with the reliability of 0,603. Item – total - correlations varied from 0, 36 to 0, 46.
- The reliability of the scale as a whole was 0,752 which is considered as appropriate to use in this community (Powers & Xie, 2000).

Section 5: In addition to the stigma scales the experience or any witness of discrimination towards people with HIV in the community were asked using an open ended question that can be interpreted qualitatively. The question asked was:

- “Can you tell me of community behaviour you have experienced or witnessed where people with HIV/AIDS were badly treated in this community? For instance, where people are gossiping about HIV+ people, or excluding them or physically hurting them”.

The questionnaire was developed in English but translated into Tswana and Sipeedi. The questionnaire was piloted amongst a small sample of respondents, to determine the understanding of instructions and language used in the questionnaire in the specific community. The questionnaire took about 20-30 minutes to complete in an interview situation.

3.4 SAMPLING METHOD

The questionnaire was used in two communities, Atteridgeville and Mamelodi. These communities were chosen because the patients from these communities were served by Kalafong hospital and the HIV positive people from these communities attended the hospital programmes. It was necessary to understand the community's attitude toward HIV/AIDS in order to help the HIV positive people from these communities.

A sampling method was used because it enables the researcher to indicate the probability with which sample results (for example, sample means) deviate in differing degrees from the corresponding population values (for example, population means) (Kruger & Welman, 2002).

A proportional sample of two communities was used to be able to generalise the results to the whole community. A proportional sample was classified by age and gender. Atteridgeville community consists of a population of 99484 people (Figure 1), the proportion of males/females and ages were calculated as follows:

- 13% males are in the age group of 18 – 25 years
- 12% females are in the age group of 18 – 25 years
- 32% males are in the age group of 26 – 50 years
- 27% females are in the age group of 26 – 50 years
- 7% males are in the age group of 50+ years
- 9% females are in the age group of 50+ years.

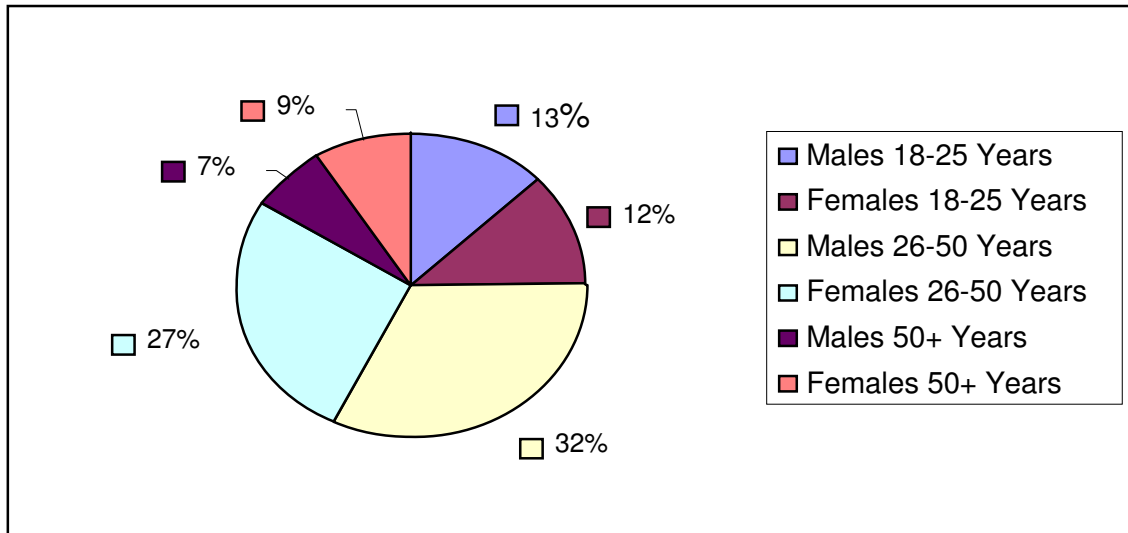


Figure 1. Atteridgeville

In Mamelodi there were 180 880 people (Figure 2), the proportion of males/females and ages were calculated as follows:

- 14% males are in the age group of 18 – 25 years
- 13% females are in the age group of 18 – 25 years
- 32% males are in the age group of 26 – 50 years
- 27% females are in the age group of 26 – 50 years
- 6% males are 50+ years
- 8% females are 50+ years.

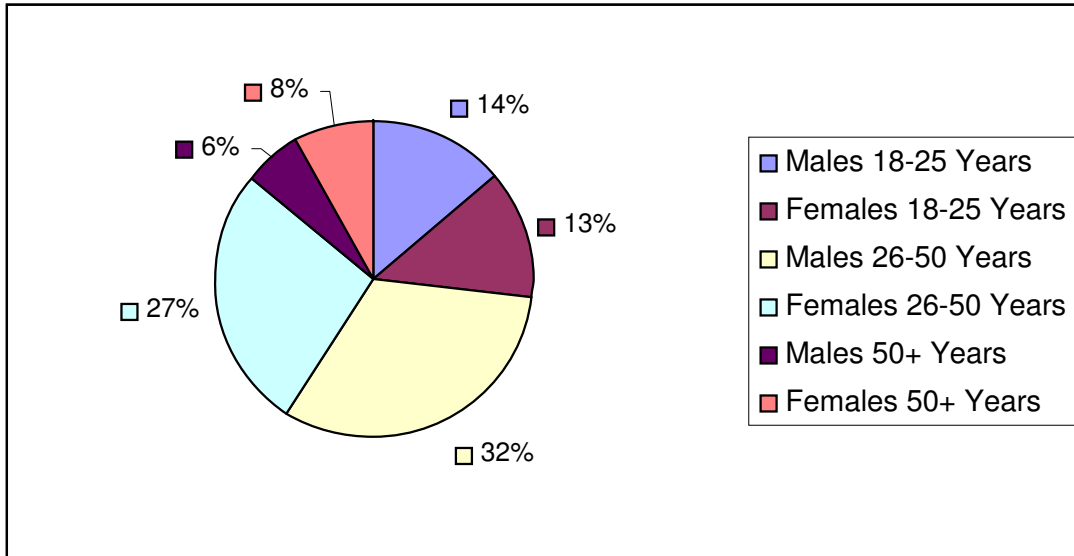


Figure 2. Mamelodi

It was the aim to interview 1000 respondents, 500 in each of the communities, in these proportions to represent the population. Respondents to include in the study were recruited from sites in the community where people gather during the day such as shopping centres, taxi ranks, and the community centre. In both communities Mamelodi and Atteridgeville there were four identified locations.

To choose when to interview participants, a systematic sampling technique was used. Systematic sampling includes a procedure in which an initial point is selected by random process and then every *n*th number on the list is selected to be interviewed (Struwig & Stead, 2001). Field workers approached the third person passing them and asked the person for an interview. The interviewer introduced herself/himself and gave an explanation what the research was all about. When a person accepted to be interviewed, the interviewer continued with the interviewee. When the interview was done, she/he again asked the 3rd person that walked past.

Although the technique of sampling was not completely random, it was decided on because of practical considerations such as the safety of field workers and obtaining a representative group of people. In this way a sample of 1077 respondents were interviewed.

3.5 DATA COLLECTION

Interviews were conducted by thirty field workers (research assistants) recruited from the third year psychology students from University of Pretoria. The interviewers were thoroughly trained. They received training in building relationships with respondents, recruiting and completing the questionnaire. Groups of 5 students went into the community to recruit respondents from the specified chosen areas. The interviewers were closely supervised by Masters Research students during data collection in each spot to assure the quality of the data. The supervisor also had to keep record of the number of people interviewed in each age and gender category to assure a proportional sample. The supervisors thoroughly checked that relevant questions had been responded to and completed.

Each trained field worker received three different types of questionnaires with the same information developed in English but translated into Tswana and Sepedi. During the initial contact with respondents, the study was briefly described, and asked if they were willing to be interviewed. For those who were interested, the study was described in detail and participants were asked to give their consent to continue with the interview. If they were not willing to participate, the interview was not continued. The questionnaire took about 20-30 minutes to complete.

After the survey was successfully completed, participants were given a thank you and a pack of snacks. It was the experience of the field workers that people were interested in the research. Most participants came to the researchers and offered to be interviewed. To improve the quality of data collected, anonymity and confidentiality of information were ensured throughout the duration of the study. For the protection of human participants the University of Pretoria research committee approved all the study procedures.

3.5.1 ETHICAL PROCEDURES OF DATA COLLECTION

The study procedures adopted were standardised and made uniform for all respondents. Permission to enter into the community was obtained from the council members and councillors of the region. They were informed about the project and their consent was important to the community. A newspaper article was written about the project and published the week before the project started to alert the community members of the project and to request their participation. Recruited participants were told about the research objectives. Permission was obtained from respondents to indicate their willingness to participate in the survey. Respondents were assured that the information obtained would be treated as confidential. The results will be used for research purposes, to develop community interventions and health care services. They were assured that they may choose to stop the interview at any time and they may choose not to answer some of the questions.

3.6 DATA ANALYSIS

The data obtained from the questionnaire were analysed by both quantitative and qualitative techniques. Frequency analysis was done to get the total percentages of the demographic details in both areas.

Descriptive statistics was used to get baseline data and to present information in a convenient, usable, and understandable form using the SAS programme. Information was provided in the form of tables to give a clear picture of the data analysis. The reliability coefficients were calculated for the knowledge, personal, and community stigma scales. Item analysis was used to validate the stigma and knowledge scales. Correlations were calculated between knowledge and personal stigma and community stigma scales. Then Duncan's multiple range test was performed for analysis of variance to determine if there are any differences among the means of stigma scores with regard to age, gender, education level to determine factors contributing to the level of stigma. This will

determine the extent to which the independent variables predict a dependent variable.

The responses to one open-ended question was analysed according to thematic analysis (Neuman, 1997). Based on the experiences of community perceptions and discrimination situations of HIV/AIDS stigma, data was analysed according to themes. The findings are given under each theme.

3.7 SUMMARY

This chapter presented the research hypothesis of the study, the research design and measuring instrument used. The chapter finally looked at the sampling method, data collection, ethical procedures, and methods used in data analysis. In the following chapter the results of the study are given.

CHAPTER 4: RESULTS

The data obtained from the questionnaire was analysed using a combination of quantitative and qualitative techniques. The demographic description of the sample is given in section 4.1. Thereafter the level of knowledge and stigma in the community are discussed. An analysis of variance was carried out to identify variables related to knowledge and stigma scores.

4.1 DEMOGRAPHIC DATA

The demographical information below are based on a total of 1077 respondents from Mamelodi and Atteridgeville communities. Respondents were grouped according to gender, age, language, marital status and educational level. The sample consisted of the following respondents.

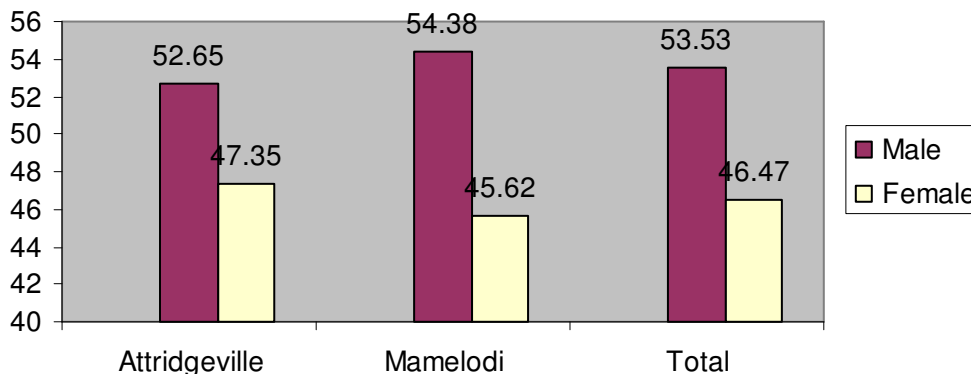


Figure 3. Gender

- In Atteridgeville 278 respondents were males (52.65%) while 250 respondents were female (47.35%) (Figure 3).
- In Mamelodi 298 respondents were males (54.38%) while 250 respondents were female (45.62%) (Figure 3).
- 576 (53.53%) of the sample as a whole were male, 500 (46.47%) were female and one respondent did not indicate his/her gender.

Given the above graph one can conclude that the majority of the respondents in both areas (Atteridgeville and Mamelodi) were males, and representative of the community population.

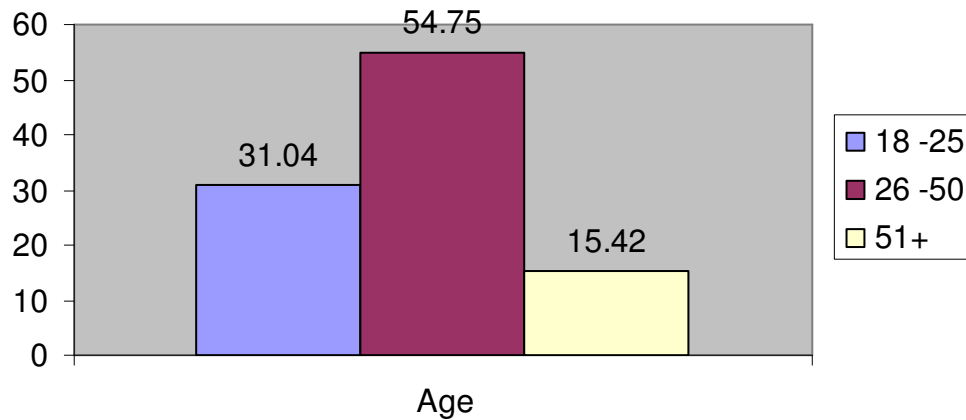


Figure 4. Age

- 589 (54.75%) of the respondents were 26 to 50 years, 334(31.04%) were between the ages 18 and 25 years and 153 (15.42%) were 51+ year (Figure 4). (One person did not indicate her/his age). The age distribution was thus almost the same as the statistics for the area from the census data.

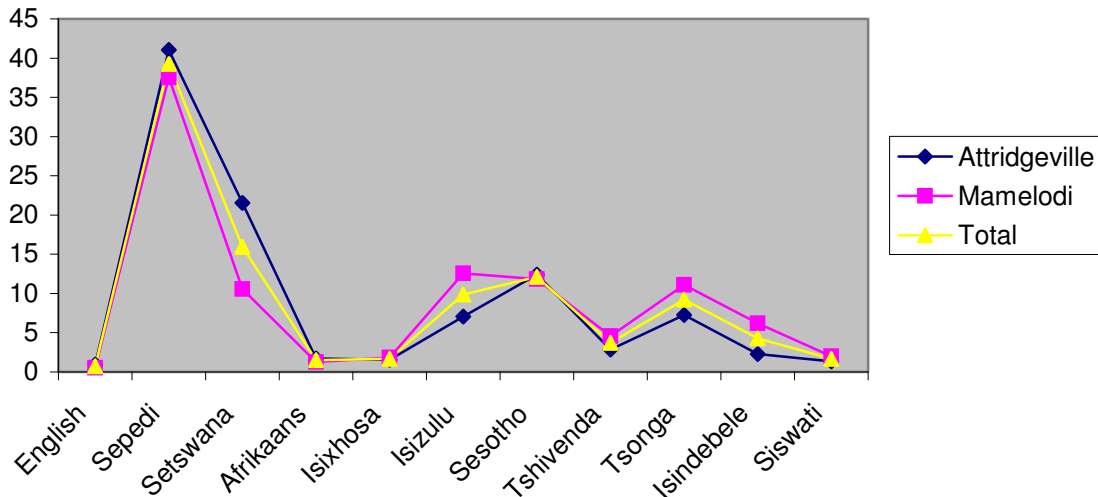


Figure 5. Language

- The majority of the respondents were speaking Sepedi 421 (39.24%), 171 (15.94%) were speaking Setswana, and 130 (12.12%) were speaking Sesotho (Figure 5). Smaller groups of participants also spoke Isizulu, Xitsonga, Isindebele, Tshivenda, SiSwati, Isixhosa, Afrikaans and English. Four of the respondents did not indicate their language category.

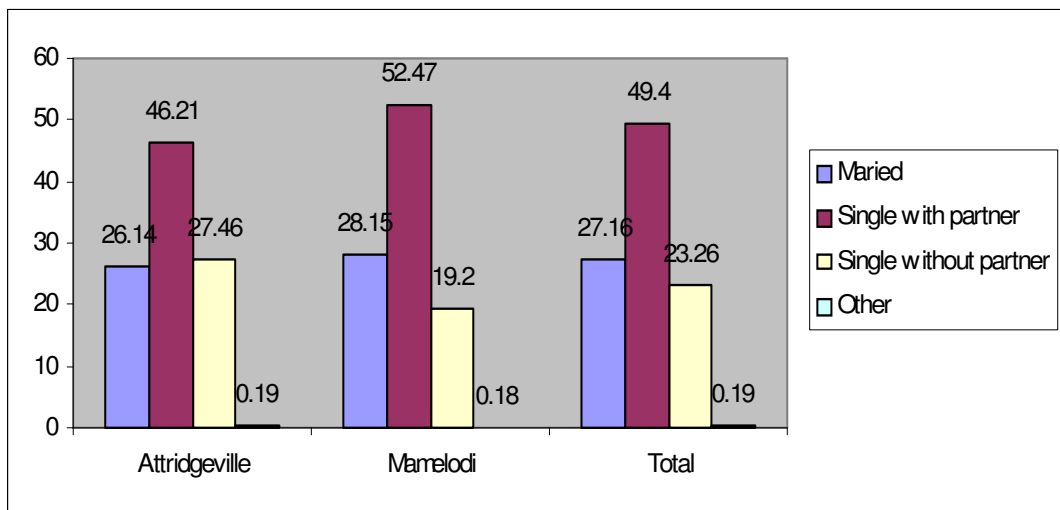


Figure 6. Marital status

- The majority of the respondents 531 (49.4%) were single with a partner, 292 (27.16%) were married, 250(23.21%) single without partner and 2 (0.19%) of the group did not indicate their marital status.

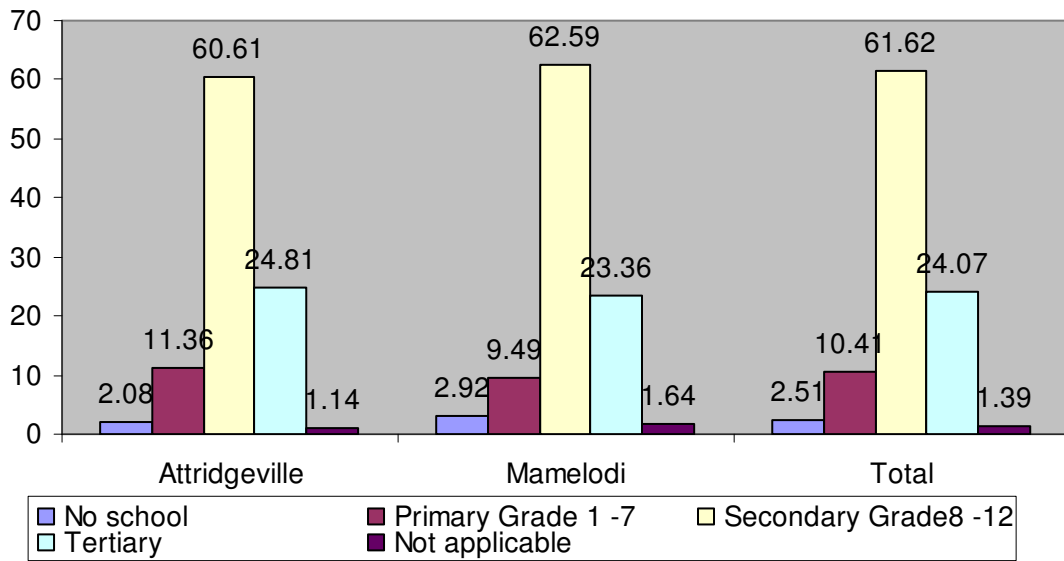


Figure. 7 Educational level

- 663 (61.62%) of respondents have secondary level education, grade (8 to 12) 259 (24.07%) tertiary level education, 112 (10.41%) have primary level education, and 27 (2.51%) no schooling. Lastly 15(1.39%) responded not applicable. There was one value reported to be missing.

The sample used in this study is therefore a representative sample of the population composition in Mamelodi and Atteridgeville communities.

4.2. LEVEL OF HIV/AIDS KNOWLEDGE

In order to understand the level of HIV/AIDS knowledge, responses on the individual items are given in Table 4.1. The percentage of correct answer is given below.

Table 4.1 HIV/AIDS Knowledge scale (N= 1077)

	Correct %
1. A person can get HIV from drinking from the same cup as someone with HIV / AIDS	87%
2. When someone gets HIV they always lose weight very quickly	46%
3. A person can get HIV by being bitten by a mosquito or similar insect	56%
4. All babies born to pregnant women with HIV will get HIV	33%
5. A person can get HIV by sharing a bathroom with someone with HIV	81%
6. Traditional healers can cure AIDS	67%
7. People with HIV / AIDS are bewitched or cursed (boloi)	91%
8. A person can get HIV by not using condoms during sexual intercourse	92%
9. A person can get HIV by touching an HIV+ person's blood, if that person has a small cut on the hand	91%
10. The HIV test can remain negative for many months after someone becomes infected with HIV	57%
11. A person can have HIV for many years without becoming ill with AIDS	83%
12. A healthy lifestyle can help someone with HIV to stay healthy for longer	92%
13. If a pregnant woman with HIV takes "AIDS" medicine before that baby is born, it is less likely that the baby will get HIV	73%
14. A healthy looking person can have HIV /AIDS	83%
15. HIV can be transmitted from mother to baby, through breast feeding	61%
16. Having sex with many people increases the risk of HIV infection	95%

Based on the responses of 1077 respondents extremely high percentages (91%) of them do not believe that people with HIV/AIDS are bewitched or cursed (boloi). In terms of casual contact, 87% respondents knew that a person cannot get HIV from drinking from the same cup as someone with HIV/AIDS and 81% knew that HIV transmission is not possible by sharing a bathroom with someone with HIV, 56% knew that HIV transmission is not possible through mosquito's bites or similar insect. Sixty seven percent (67%) knew that traditional healers cannot cure AIDS and, 46% showed lack of knowledge with regard to the idea of weight loss when HIV positive. There was a lack of knowledge regarding mother to child transmission as 33% believed that all babies born to pregnant women with HIV may get HIV.

Based on data of the 1077 respondents, 95% knew that having sex with many people increase the risk of HIV infection, 92% knew that it is true that a person can get HIV by not using condoms during sexual intercourse and a healthy lifestyle can help someone with HIV to stay healthy for longer. Ninety one percent (91%) knew that HIV transmission was possible through touching an HIV+ person's blood, if that person has a small cut on the hand, 83% knew that it is true that a person can have HIV for many years without being ill with AIDS and a healthy looking person can have HIV/AIDS. Seventy three percent (73%) knew that, it is true that if a pregnant woman with HIV takes "AIDS" medicine before that baby is born, it is less likely that the baby may get HIV. Sixty one percent (61%) knew that HIV can be transmitted from mother to baby, through breast feeding and 57% showed that it was true that an HIV test can remain negative for many months after someone becomes infected with HIV.

The frequency distribution of the knowledge scale is graphically presented in Figure 8. The mean score was = 11.8719, range from 0 to 16 which can be considered an above average knowledge about HIV/AIDS.

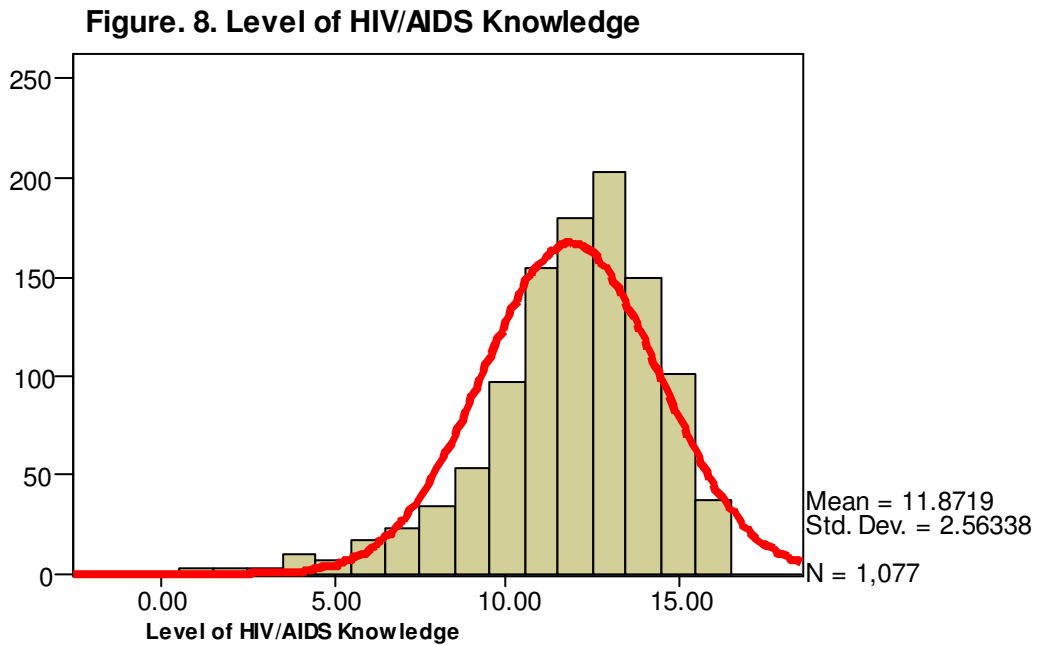


Figure 8. Level of HIV/AIDS Knowledge scale: frequency distribution of scale scores

Summary

Many respondents appeared to have adequate information regarding HIV, and the ways in which HIV is actually transmitted. Almost all of the respondents in both communities (>90%) knew that HIV can be transmitted by having sex with many people and can get it by not using condoms during sexual intercourse.

4.3 PERSONAL AND PERCEIVED COMMUNITY STIGMA

In order to understand the personal and perceived community stigma the responses on the individual items are given in Table 4.2. The categories are “agree” (stigmatising answer) and “disagree” (non-stigmatising).

Table. 4.2. Personal and Perceived community stigma

Blame and judgement	Personal stigma	Perceived stigma
	% Agree	% Agree
Getting HIV is a punishment for bad behaviour	42%	60%
Having HIV is bad luck	18%	46%
Think less of someone because they have HIV	11%	62%
People with HIV have themselves to blame	34%	65%
If you have HIV you must have done something wrong to deserve it	31%	65%
People with HIV should be ashamed of themselves	23%	61%
If a family member has HIV I will keep it a secret	24%	72%
People with HIV should be isolated	20%	54%
Names of HIV/AIDS patients should be made public to avoid getting AIDS	33%	53%
AIDS patients do not deserve free medication	14%	32%
Interpersonal distance		
Would not like to sit next to someone with HIV in public or private transport	17%	51%
Would not like someone with HIV to be living next door	14%	47%
Would not like to be friends with someone with HIV	16%	60%
Not date a person with HIV	43%	71%
Afraid to be around people with HIV	17%	66%
Would not hire someone with HIV to work for them	29%	66%
Would not drink from a tap if a person with HIV had just drunk from it	20%	55%
Feel uncomfortable around people with HIV	23%	66%
Not like children with AIDS in same school as my children	22%	61%
Is safe for a person with HIV to look after somebody else's children	52%	32%

Value items	%Disagree	%Disagree
People with HIV can teach us a lot about life	85%	63%
People with HIV deserve as much respect as anyone else	88%	57%
Would care for family member sick with HIV	88%	59%
Have a right to quality medical care	90%	71%

Personal stigma

Responses to the personal stigma items in the sample of 1077 are presented in Table 4.2. Note that 42% of respondents responded that getting HIV is a punishment for bad behaviour. Thirty four percent (34%) said people with HIV have themselves to blame and 31% respondents felt that if you have HIV you must have done something wrong to deserve the illness, While 33% of respondents expressed that the names of HIV/AIDS patients should be made public to avoid spreading of AIDS.

A large number of respondents reported having difficulty relating to people living with HIV. Forty three percent (43%) of the respondents felt that they would not date a person with HIV while 20% felt that people with HIV should be isolated. These results showed that about 20% respondents felt uncomfortable and afraid and did not want close contact with people with HIV/AIDS, the closer the contact and the more likely that transmission could take place, the more they responded negatively.

It can also be noted that many respondents portrayed positive attitude towards people living with HIV. They believed that people with HIV can teach others a lot about life (85%). Eighty eight percent said they deserve as much respect as anyone else and 90% felt that they have a right to quality medical care. Eighty eight percent (88%) they indicated that they would care for family members sick with HIV.

The frequency distribution of the scale scores for the stigma scale is graphically presented in Figure 9. The minimum value on the scale is 0.00 and the maximum

value is 24. A high score indicates a high level of stigma. The mean scale score is 5.497, which represents a low level of stigma.

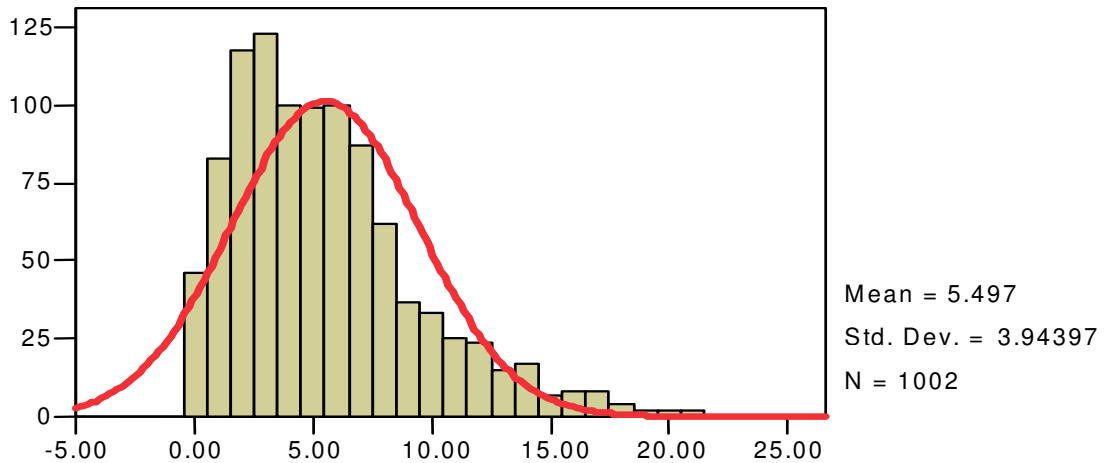


Figure 9. Personal stigma

Perceived community stigma

In order to understand perceived community stigma, responses on the individual items are given in Table 4.2. The perceived community stigma scores are higher in general than personal stigma. For example, 72% of the respondents felt that if a family member has HIV, people in the community would keep it secret. Sixty five percent (65%) of the respondents thought the community blame people with HIV and that they should be ashamed of themselves. Sixty two percent (62%) respondents perceived other community members to think less of someone because they have HIV.

It was noted that many respondents perceived the community to keep distance from people living with HIV. For example, 71% of the respondents perceived that people in their community would not date a person with HIV, 66% perceived that others feel afraid to be around people with HIV, would not hire someone with HIV to work for them and feel uncomfortable around people with HIV. Sixty percent (60%) perceived others not wanting to be friends with someone with HIV. Sixty

one percent (61%) respondents felt that others would not like children with AIDS in the same school as their children and think the community would not drink from a tap if a person with HIV had just drunk from it.

The frequency distribution of the scale score for the perceived community stigma is presented in Figure 10. The average score is 13.3373 with $n = 996$. This forms more of a normal distribution than the personal stigma scores that was skewed to the left.

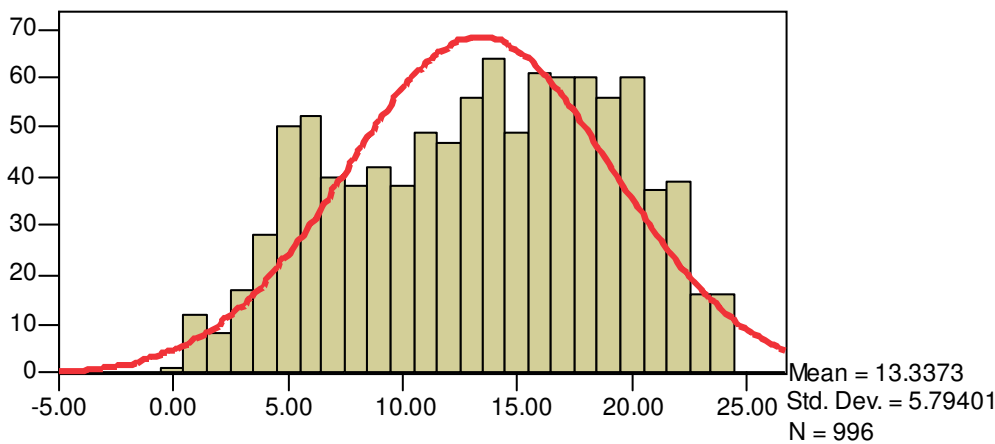


Figure 10. Community Perceived stigma

4.4 Correlations between personal stigma, perceived community stigma and knowledge

The correlation procedures were followed using simple statistics for three variables namely: personal stigma, perceived community stigma and knowledge. Pearson correlation coefficients was use to determine the relationship among the variables. Personal stigma mean was 5.49002 with standard deviation of 3.94978. Perceived community stigma mean was 13.33735 with standard deviation of 5.79401 and knowledge means was 11.84440 with standard deviation of 2.55390. The results of variables that showed relationship will be presented below.

- Personal stigma Mean and community perceived stigma: relationship is significant at (0.01410 $p < 0.01$).
- Personal stigma and Knowledge: there is a negative relationship at (-0.48265 $p < .0001$). Results of this study shows that people who are aware that causal transmission is impossible are less likely to discriminate and prejudice against PLHA than those people who are less knowledgeable about HIV transmission. Poor level of knowledge about HIV/AIDS, acts to increase stigma surrounding HIV/AIDS.
- Perceived community stigma versus knowledge: there is a positive relationship at (0.13863 $p < 0.0001$). Respondents think that people in the community perceived to be stigmatising HIV.

4.5 Factors contributing to personal stigma

An overall ANOVA table for personal stigma is given below to indicate factors that were found to contribute significantly to the stigma score (Table 4.4.1) In table 4.4.2 – 4.4.4. ANOVA tables are presented for the subscales: blame and judgement, interpersonal distance and value items. The following variables were included in the analysis: gender, age, language, attended church, marital status, educational level, know someone close who has HIV/AIDS, discuss HIV/AIDS in the community, leaders talk about HIV/AIDS, discussion of HIV prevention in close relationships and whether they tested for HIV. The analysis was done to find out which factors contributed to personal stigma.

Table 4.5.1 Overall ANOVA of the stigma scale

Source	Df	SS	MS	Pr > F
Gender	1	133.982	133.982	0.0017**
Age	2	192.204	96.1024	0.0009**
Language	6	74.496	12.416	0.4810
Religion attended	1	6.022	6.022	0.5048
Marital status	2	9.562	4.781	0.7023
Education level	2	365.096	182.548	<0.0001**
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	64.353	64.353	0.0294*
How often do people you know talk about HIV/AIDS?	3	99.978	33.326	0.0611
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS?	3	61.220	20.406	0.2107
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	121.321	60.660	0.0115*
Have you ever been tested for HIV/AIDS?	2	143.761	71.880	0.0051**

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table 4.5.2 ANOVA of the personal stigma subscale: blame and judgement

Source	Df	SS	MS	Pr > F
Gender	1	74.151	74.151	<. 0001**
Age	2	24.574	12.287	0.0475 *
Language	6	19.820	3.303	0.5529
Religion attended	1	0.371	0.371	0.7611
Marital status	2	6.120	3.060	0.4672
Education level	2	66.276	33.138	0.0003**
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	5.853	5.853	0.2278
How often do people you know talk about HIV/AIDS?	3	12.556	4.185	0.3734
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS?	3	3.370	1.123	0.8402
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	14.650	7.325	0.1622
Have you ever been tested for HIV/AIDS?	2	44.110	22.055	0.0043**

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table 4.5.3 ANOVA of the personal stigma sub-scale: interpersonal distance

Source	Df	SS	MS	Pr > F
Gender	1	4.128	4.128	0.2928
Age	2	42.478	21.239	0.0035**
Language	6	20.452	3.408	0.4834
Religion attended	1	3.166	3.166	0.3569
Marital status	2	2.968	1.484	0.6715
Education level	2	47.198	23.599	0.0019**
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	13.350	13.350	0.0587*
How often do people you know talk about HIV/AIDS?	3	36.332	12.110	0.0213*
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	16.642	5.547	0.2161
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	36.271	18.135	0.0079**
Have you ever been tested for HIV/AIDS?	2	40.910	20.455	0.0043**

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table 4.5.4 ANOVA of the personal stigma sub-scale: value items

Source	Df	SS	MS	Pr > F
Gender	1	0.868	0.868	0.4001
Age	2	12.088	6.044	0.0074**
Language	6	17.752	2.958	0.0255*
Religion attended	1	1.648	1.648	0.2464
Marital status	2	4.888	2.444	0.1367
Education level	2	20.372	10.186	0.0003**
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	3.797	3.797	0.0787*
How often do people you know talk about HIV/AIDS?	3	3.947	1.315	0.3593
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	10.153	3.384	0.0411*
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	2.280	1.140	0.3948
Have you ever been tested for HIV/AIDS?	2	0.379	0.189	0.8566

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

The results of all factors that showed significant relationship will be presented below.

Gender

In comparing the gender groups, male respondents consistently had higher mean stigma scores across all three-sub scales. The score were slightly higher but were not statistically significant for interpersonal distance and value items. The results showed that males blame HIV positive people more for their condition than females ($p < 0,0001$, Table 4.4.1.)

Age

Those respondents in the older age group (50+) had much higher overall stigma scores than the younger counterparts in all three subscales. There are statistical significant differences in terms of the blame and judgement subscales, interpersonal distance subscale and value items. In terms of interpersonal distance all age groups differed meaningfully from the others, with the older age group (50+) having the most stigmatising attitudes.

Language

Language was not a significant predictor for the total stigma score. In the subscales some differences were found. The Duncan multiple range test showed that Venda speakers had significantly higher scores on the blame and judgement subscale than the other groups. The same applies to the Xitsonga speakers on the value items. This means people who speak Tshivenda and Xitsonga are most stigmatising on the two subscales. This might be because their cultures perceive AIDS as the disease that affect people who do not stick to one partner.

Church attendance

A comparison of findings shows that the majority of participants attended church. The analysis shows that the mean scores are very high and that there is no

statistical significant difference between people who attend and do not attend churches in all the three subscales as well as the total score.

Educational level

There were significant differences in the total stigma scores and all the subscales of people with different educational levels ($p < 0,0001$). The people with low levels of education were found to be more stigmatising.

Is there someone close to you who has HIV/AIDS or have died of AIDS?

Respondents were asked if they knew someone close to them with HIV. It was found that knowing someone with HIV related significantly with personal stigma scores ($p < 0,05$). The mean values were found to be very low and not stigmatising in all three subscales for the people who knew someone with HIV or died of AIDS. The level of stigma attached to HIV/AIDS was statistically significantly higher in the group of people who do not know someone with HIV/AIDS or died of AIDS.

How often do people you know talk about HIV/AIDS?

In examining how often people they know talk about AIDS, the Duncan multiple range test found significant difference on the blame and judgement subscales, as well as on the interpersonal distance subscales and value items on people who never talk about AIDS. People who indicated that they never talked about HIV/AIDS in his/her community showed a higher level of stigmatising attitude while Seventy percent (70%) of the respondents felt that the community leaders discussed HIV/AIDS issues weekly.

Have you ever talked to your partner/husband/wife about ways to avoid getting HIV/AIDS?

Responses to the scale to talk to the partners about the ways to avoid getting HIV/AIDS were found to be significant on the blame and judgement as well as on

the interpersonal distance subscales. Means were found to be very high on “no answer” category. The level of stigma attached to HIV/AIDS was statistically significantly higher in the group who never talked to their partner, husband or wife on blame and judgement.

Have you ever been tested for HIV/AIDS?

Respondents were asked if they have ever been tested for HIV/AIDS. There was a significant difference between the levels of stigma especially on the blame and judgement subscales ($p < 0.001$). This means that people who tested for HIV showed a higher level of stigma.

4.6 Factors contributing to perceived community stigma

An overall ANOVA table for perceived community stigma were given below to indicate the variables that contributed statistical significantly to perceived community stigma. The three stigma sub-scales, blame and judgement, interpersonal distance and value items were also analysed. In analysis of the perceived community stigma scales, the following was found.

Table 4.6.1 ANOVA for the overall stigma scale: perceived community stigma.

Source	Df	SS	MS	Pr > F
Gender	1	0.767	0.767	0.8784
Age	2	503.868	251.934	0.0005**
Language	6	112.500	18.750	0.7528
Religion attended	1	35.137	35.137	0.3008
Marital status	2	86.572	43.286	0.2675
Education level	2	153.931	76.965	0.0962
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	217.452	217.452	0.0102**
How often do people you know talk about HIV/AIDS?	3	13.043	4.347	0.9406
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS?	3	85.769	28.589	0.4550
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	14.299	7.14	0.8041
Have you ever been tested for HIV/AIDS?	2	2.474	1.237	0.9630

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table. 4.6.2 ANOVA of the perceived community stigma sub-scale: blame and judgement

Source	Df	SS	MS	Pr > F
Gender	1	6.090	6.090	0.3937
Age	2	108.880	54.440	0.0016**
Language	6	32.432	5.405	0.6931
Religion attended	1	11.532	11.532	0.2406
Marital status	2	11.053	5.526	0.5166
Education level	2	36.710	18.355	0.1120
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	67.153	67.153	0.0047**
How often do people you know talk about HIV/AIDS?	3	13.345	4.448	0.6604
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	19.203	6.401	0.5135
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	13.885	6.942	0.4363
Have you ever been tested for HIV/AIDS?	2	1.383	0.691	0.9206

*Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table 4.6.3 ANOVA of the perceived community stigma Sub-scale: interpersonal distance

Source	Df	SS	MS	Pr > F
Gender	1	12.030	12.030	0.2211
Age	2	115.425	57.712	0.0008**
Language	6	30.908	5.151	0.6967
Religion attended	1	1.413	1.413	0.6748
Marital status	2	29.240	14.620	0.1623
Education level	2	12.697	6.348	0.4537
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	41.274	41.274	0.0236*
How often do people you know talk about HIV/AIDS?	3	7.663	2.554	0.8122
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	30.764	10.254	0.2807
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	0.392	0.196	0.9758
Have you ever been tested for HIV/AIDS?	2	2.069	1.034	0.8791

*Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Table 4.6.4 ANOVA of the perceived community stigma sub-scale: value items

Source	Df	SS	MS	Pr > F
Gender	1	0.105	0.015	0.9317
Age	2	4.599	2.299	0.3362
Language	6	22.172	3.695	0.1057
Religion attended	1	1.803	1.803	0.3552
Marital status	2	0.720	0.360	0.8428
Education level	2	19.462	9.731	0.0101*
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	0.016	0.016	0.9303
How often do people you know talk about HIV/AIDS?	3	8.774	2.924	0.2450
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	10.447	3.482	0.1757
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	4.087	2.043	0.3795
Have you ever been tested for HIV/AIDS?	2	2.281	1.140	0.5822

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

There were insignificant differences with regard to gender, church attendance, marital status, how often do people talk about HIV/AIDS, have you ever talk to your partner about ways to avoid getting HIV/AIDS and HIV testing questions, and perceived community stigma. The following variables impacted on the stigma scores.

Age

There was a significant difference with regard to age. Respondents in the age group (18-25 years) were found to be stigmatising than those in other groups ($p < 0.01$).

Is there someone close to you who has HIV/AIDS or have died of AIDS?

The respondents who knew someone who lives or died of HIV/AIDS perceived the community stigma to be statistically significantly higher than people who did

not know someone. This was found for two stigma subscales: blame and judgement, and interpersonal distance. They probably understood the experience or anticipated anxiety of the person with HIV related to community stigma. Only these variables impacted on respondent's perception of community stigma.

4.7 Factors contributing to the level of HIV/AIDS knowledge

To find out which groups were more knowledgeable about HIV/AIDS, an analysis of variance was performed and is presented in the table below.

Table 4.7.1 ANOVA of factors contributing to the level of HIV/AIDS knowledge

Source	Df	SS	MS	Pr > F
Gender	1	26.648	26.648	0.0246*
Age	2	149.584	74.792	<. 0001**
Language	6	53.223	8.870	0.1212
Religion attended	1	22.603	22.603	0.0385*
Marital status	2	8.027	4.013	<. 0001**
Education level	2	229.922	114.961	<. 0001**
Is there someone close to you who has HIV/AIDS or have died of AIDS?	1	28.978	28.978	0.0191*
How often do people you know talk about HIV/AIDS?	3	37.978	12.659	0.0660*
How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS	3	15.812	5.270	0.3913
Have you ever talked to your partner/husband, wife about ways to avoid getting HIV/AIDS?	2	22.172	11.086	0.1222
Have you ever been tested for HIV/AIDS?	2	50.313	25.156	0.0086**

* Significantly at $p < 0.05$, ** Highly significant at $p < 0.01$

Significant differences were found on the following factors: age, gender, marital status and testing for HIV/AIDS.

Gender

In comparing the gender groups, female respondents consistently had higher knowledge about HIV/AIDS transmission compared to males ($p < 0.05$).

Age

Those respondents in the younger age (18 – 25) group had a much higher mean knowledge score compared to the older age group (51 – 80). This means young people have more knowledge on HIV/AIDS as compared to the older group. All the groups differed meaningfully from the others and the 18-25 years age group was most knowledgeable ($p < 0.01$).

Educational level

There were significant differences between the levels of knowledge about HIV/AIDS, among people with different levels of education ($P < 0.01$). The group of people with tertiary education shows higher knowledge as compared to people with secondary school education or less than that.

Marital status

An analysis of variance showed a significant difference in level of knowledge about HIV between people with different marital status ($p < 0.01$). The Duncan multiple range test found significant differences between people who are currently married, single with partner and those who are single without partner. Single people with or without partner had the highest level of knowledge. This may mean that married people might not regard themselves as at risk for getting HIV and do not gain knowledge about HIV.

Have you ever been tested for HIV/AIDS?

Respondents who tested for HIV had higher levels of knowledge about HIV/AIDS. Significant difference was ($p < 0.01$). This might be because they got counselling after being tested. Though, some respondents were not willing to answer the question.

4.8 QUALITATIVE ANALYSIS

The qualitative data analysis is presented according to themes identified from the 192 responses of the participants to the questions on experiences of observable discrimination. The following types of discrimination were observed in the community.

Theme 1: Avoidance

People living with HIV/AIDS are being avoided by others, often because of the fear of causal transmission of HIV. Avoidance may take the form of not wanting to share items or to buy food from a person who is HIV+. For example:

“They say do not go and visit their houses and go to their businesses because you are going to get AIDS”.

“People were saying that we must be careful, that person is HIV positive, if we buy food”.

“They didn’t want to drink water in a tap where a person with HIV has just drunk”.

Theme 2: Rejection

Many people have suffered rejection from their families, spouses, friends and colleagues. Rejection is often related to the perception that HIV/AIDS results from bad behaviour and lack parental respect. For example: *“Some people chase away their own family members because they are HIV positive”.*

“People used to think less about a person who is HIV positive and they reject them”.

Theme 3: Unwillingness to invest in PLWHA

People with HIV have been denied opportunities to invest in their future because of the HIV positive status. Some people don’t want to invest in people who are living with HIV because they think they are not going to live long.

For example:

“Mother denied their money for further schooling for the child who is HIV+ and give to the younger sister who has more life”.

Theme 4: Excluded from social situations

People with HIV have been discriminated against in a number of occasions because many people felt that it is not easy to accept these people. Some people still belittle and dehumanise a person with HIV/AIDS. For example:

“At the shebeen, one who was suspected of being infected with HIV was not welcomed in the group where people were drinking”.

“They do not talk to them or do things with the people who are HIV positive and they think less of them”.

Theme 5: Verbal Abuse

Some people living with AIDS have experienced verbal abuse by others because they were perceived as a threat to the community. This verbal abuse includes name – calling, insults and threats. For example:

“People can’t accept that HIV/AIDS is just a disease like any other disease therefore they gossip about people with HIV and they call people with HIV that they have Z3”. (Z3 is a faster car which for someone who is HIV+ will die fast).

“They judge the person and throw missiles to him”.

“They bad mouth people with HIV/AIDS a lot in this community and criticise their actions a lot”.

“They bad mouth people with HIV/AIDS and call them bad names and also gossip”.

“They were saying the person has 3 words HIV”. (They do not want to call it in full because is a dangerous disease).

“People talk bad things like calling them names such as “skinny”.

“They make jokes about them, and they don’t want them around.”

Theme 6: Physical Abuse

Some people have experienced or observed physical abuse in several occasions. This includes cases of violence by others. For example:

“One AIDS patient’s mother used to mistreat her. She used to lock her in a room and did not take care or look after her and she insulted her”.

“It mostly happens in hospitals and clinics. They treat them badly”.

“They were beating someone who could not go to the toilet on her own”.

Theme 7: Blame and judgement

Blame and judgement involves viewing PLWHA as either “guilty” or “innocent” in terms of how they contracted HIV. Such thinking allocates blame and allows people to distance themselves from PLWHA.

“They say the person was searching for AIDS now she has it, it is a reward”

“They were saying that the person is a prostitute, he used to sleep with foreigners”.

“Whenever people are drunk they tend to tease those who are gay and then in most cases think that they are the ones who cause these things of AIDS”.

4.9 SUMMARY OF QUALITATIVE ANALYSIS

Most of the observable stigmatising language and behaviour centred on abuse, blame, judgement and avoidance. Most people think that those with HIV get it through their own bad behaviour.

In this chapter the data obtained from the questionnaire was analysed using a combination of quantitative and qualitative techniques. The main findings were as follows: People living with HIV/AIDS are being avoided by others, often because of the fear of causal transmission of HIV. Some of the respondents perceived people with HIV to be rejected by their families, spouses, friends and colleagues. Some people living with HIV have experienced verbal abuse by others because they were perceived as threat to the community.

Factors contributing to personal and perceived community stigma were identified as Age, Gender, and educational level. This study shows that there is a relationship between knowledge and stigma. Knowledge was found to be high, age, educational level and marital status was also contributed to stigma.

CHAPTER 5: DISCUSSION OF RESULTS

In the third decade of the HIV/AIDS epidemic, stigma still enables people to believe they are not at risk for HIV/AIDS. People who express stigmatising attitudes about HIV often have retained some misinformation about transmission of HIV/AIDS. In this study respondents indicated that there are still highly stigmatising attitudes towards people living with HIV/AIDS and that language is a powerful tool to indicate stigma or support. Some attitudes may be based mostly on thoughts stipulated by people in the community.

One of the most important findings that emerged from the study is the fact that people living with HIV/AIDS are often subjected to considerable prejudice and discrimination. Thus it was important to investigate factors contributing to the stigma associated with HIV/AIDS in these communities. Findings of the study will be discussed in terms of hypothesis set in chapter 3.

- **There is a high level of stigma associated with HIV/AIDS in Mamelodi and Atteridgeville communities.**

The perceived community stigma scores were found to be higher than the personal stigma score of participants. When participants reflected their personal attitudes 34% said that people infected with HIV/AIDS have themselves to blame, 23% said that people with HIV should be ashamed of themselves and 20% said people with HIV/AIDS should be isolated from the society. Even though many of the participants do not have contact with infected persons and they have a high level of knowledge about the disease, some expressed fear and wished to avoid people with HIV/AIDS.

Seventy two percent (72%) of the respondents felt that if a family member had HIV, people in their community would keep it secret from others. Sixty five percent (65%) of the respondents thought that the community blamed people with HIV and that they should be ashamed of themselves. Sixty two percent (62%) of the respondents thought other community members think less of someone

because they have HIV. These findings support the hypothesis that community members perceived stigma associated with HIV/AIDS in Mamelodi and Atteridgeville community.

The frequency distribution indicated the level of personal stigma attached to HIV/AIDS to be lower than the level of stigma perceived in the community. This indicates that people perceive a collective stigma in the community that is negative, blaming, judging and restrictive towards interaction with people with HIV/AIDS. Herek and Capitanio states that HIV/AIDS related attitudes have been conceptualised in multiple ways, including affective reaction to people with AIDS, attributions of blame and responsibility to PLWHA, avoidance of interpersonal contact with PLWHA. All sub-groups in the study shared the perceptions of highly stigmatising attitudes in the communities. This indicates that there is perceived collective stigma in the community that is more negative and blaming and that people distance themselves interpersonally and feel uncomfortable around people with HIV/AIDS. Stigma arises through internalisation by people living with HIV/AIDS of their negative perceptions of themselves can have a powerful psychological consequences for how people living with HIV/AIDS come to see themselves - leading to depression, lack of self worth and despair (Parker & Aggleton, 2003).

According to Visser, Makin and Lehobye (2006), 17% of a sample of people in South Africa indicated that they still had highly stigmatising attitudes towards people living with HIV/AIDS and 42% of them perceived the community to attach a high stigma towards HIV/AIDS. Community members think that the community blame and judge people who are living with HIV/AIDS. Deacon *et al.* (2005) states that PLWHA respond to stigma and discrimination based not only on their own experiences, but also on what they encounter in the media and hear from others.

Few respondents answered the qualitative questions. Only 192 of 1077 participants gave examples of how the community stigmatise people who are living with HIV/AIDS in their community.

The difference between personal stigma and perceived community stigma was also found in the research of Green (1995) done in Scotland, with the public view of HIV/AIDS being highly stigmatised. Although research from different countries cannot be compared directly because of different sampling methods, and cultural backgrounds, some comparisons may be interesting. If the personal responses of the South African respondents are compared to those in the studies of Herek, Capitanio and Widaman (2002) in the United States it can be seen that the South African group was almost similar in terms of stigmatising attitudes, for example:

- In the US study 20% of the respondents expressed fear towards someone with HIV/AIDS, in this study it was 17%;
 - 25% blamed the individuals who are living with HIV/AIDS, they said they got what they deserve, compared to 31% in the South African sample;
 - 25% felt uncomfortable around people with HIV, compared to 23% in this sample.
-
- **There is a relationship between gender, age, educational level, marital status, close contact with people with HIV and level of stigmatisation.**

Results from this study indicated that there is a correlation between gender, age, educational level, marital status, close contact with people with HIV and level of stigmatisation. In terms of gender, males were found to be more stigmatising compared to females in South Africa. According to Matchaba (2000) low social status of females and economic dependence on males are also factors that contribute to stigmatisation. These factors affect women's capacity to determine their sexual lives, with sexual decision making being constrained by coercion and violence (HIV Insite, 2001).

As in other international studies (Crawford, 1996; Herek & Capitanio, 1993) females reported significantly less stigmatising attitudes towards people with HIV/AIDS than male respondents. This might be because men believe that women get HIV because of their bad behaviour. Female respondents do not believe that they are at risk of HIV because they trust their partners (Caldwell, Orubuloye & Caldwell, 1999).

People older than 50 years were found to be the most stigmatising age group. It is difficult to change this attitude because it often functions as schemas, or cognitive frameworks that hold and organise information about specific people or events. Similarly Green (1995) found that older people are not so much exposed to HIV and less educated people had less knowledge about HIV, which in turn was related to negative and restrictive attitudes towards HIV/AIDS.

The Duncan multiple range test found significant difference between people who are currently married and those who are single without a partner. Those who were single without partners were found to be more stigmatising in terms of the blame and judgement scale. People with low levels of education were also found to be more stigmatising. The level of stigma attached to HIV/AIDS was statistically significantly higher in the group of people who do not know someone with HIV/AIDS or died of AIDS because most people avoid talking about HIV/AIDS. There was also a significant difference in the personal stigma between respondents who knew someone living with HIV and those who did not. This is because most people are distancing themselves and feel uncomfortable living with people who are HIV positive. Therefore this stigma leads to discrimination, self blame and negative psychological outcomes.

- **There is a high level of knowledge about HIV/AIDS in Mamelodi and Atteridgeville communities.**

Most people in the study appeared to be informed about the ways in which HIV/AIDS is transmitted. In general, research shows that knowledge of HIV is quite high (95%). However there was a percentage of the sample that indicated low knowledge regarding aspects of the transmission. Sixty six 66% respondents believe that all babies born to pregnant women with HIV will get HIV, 44% of the people surveyed believed that HIV could be transmitted through a mosquito bite or similar insect and 13% believed that HIV could be transmitted by using the same drinking cup or glass with someone with HIV/AIDS.

Fifty four percent (54%) believes that when someone gets HIV they always lose weight very quickly. According to Petty (1995), beliefs, emotions, and behaviours can all contribute separately to people attitudes. The results of this study shows that those infected with HIV were restricted to attend the funerals because of the disease and afraid of being teased. People with HIV feared their condition would be exposed and people would avoid and discriminate against them because people think HIV/AIDS is a life threatening disease, deadly without a cure, perceives to be contagious and threatening to the community. The social psychology and cognitive approach seek to understand the causes of social behaviour and thought of individual, their actions, feelings and beliefs with respect to other persons.

Simbayi, Kalichman, Toefy and Kagee (2004) who analysed responses of the Muslim community of the Western Cape indicated that 93% stated that a pregnant woman could give AIDS to her baby. Seventy two percent (72%) said they would send their children to school with someone with HIV/AIDS and a high percentage 88% said they would care for a family member sick with HIV/AIDS. This is due to the fact that most people are willing to make contact with people who are HIV positive but they still fear the possibility of contact with someone with HIV/AIDS.

- **There is a reverse correlation between level of knowledge about HIV and the level of stigma.**

Ogden and Nyblade (2005, p.15) reported that lack of knowledge results in the *“fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV/AIDS that involve exchange of body fluids, was common”*. Results of this study shows that a small percentage of people still believe that HIV/AIDS is transmitted through mosquito bites (44%), sharing the same bathroom (9%), drinking from the same cup (13%). This means despite high level of knowledge of HIV/AIDS respondents still think the community is stigmatising people with HIV. This lack of knowledge is based on misunderstanding and

misconception of how HIV/AIDS spread and the effects of physical contact with infected person. This creates negative attitudes towards people who are living with HIV/AIDS because some people use stigma to eliminate and threaten them.

Correlation between knowledge and stigma revealed the following significant relationship: there is a negative relationship associated with knowledge and stigma at -0.5 , $p < .00001$. The results indicate that when a person knows someone with HIV, the level of personal stigma scores is lower and the level of perceived community stigma scores is higher. They develop an understanding of the person as an individual, but also experience the person's fear of being stigmatized and perhaps also enacted stigma from the community. This research shows that people who are aware that casual transmission is impossible are less likely to discriminate and shows prejudice against PLWHA than those people who are less knowledgeable about HIV transmission.

There is a positive relationship at (0.13863 $p < 0.0001$) between knowledge and perceived community stigma. Respondents think that people in the community perceived to be stigmatising HIV/AIDS.

- **The level of stigmatisation is reversely related to the openness of discussing HIV in the community.**

In both communities, a quantitative question, “how often do the people hear leaders in the community, like politicians, church leaders or heads of organisations, talk about HIV/AIDS”? Seventy percent (70%) of the respondents felt that the community leaders discussed HIV/AIDS issues weekly.

In both communities 58% respondents shows family members do go for help when they find that they are HIV positive. Forty seven percent (47%) indicated that friends in their community do not go for help and support when they find out they are HIV positive. Forty nine percent (49%) still believe that most people in their community consult traditional healers for help and support after they find out they are HIV positive, this is because, in some communities people still believe

that traditional healers can cure HIV/AIDS. Ninety eight percent (98%) consult a local clinic; this might be because they know that they can get medication like Antiretroviral Treatment. Sixty two percent (62%) shows that they can get help and support from the church because some people still believe that this disease is a curse from God, if they obey his rule they will be cured. Sixty two percent (62%) shows that they go for help and support from AIDS organisations and NGO's, 65% go for support groups in their community and lastly 59% of the respondent shows they do not go anywhere for help and support. Failure to seek support and voluntarily counselling can discourage other individuals to get proper medical care. This might be because among the public, AIDS stigma has been manifested in the form of anger and other negative feelings towards people living with AIDS. The results of this study indicate that the majority of people openly declare that they have AIDS but they are afraid to seek help from the community because they are afraid that their situation can be stigmatised. The results of the study support the hypothesis of this study because the level of stigmatisation is reversely related to the openness of discussing HIV in the community. The moment you openly declare that you have HIV/AIDS in the community the more they stigmatise the situation because of discrimination against and discreditation of their status.

- **The level of stigmatisation is related to the awareness and experience of discriminatory events in the community.**

The study revealed high levels of stigma associated with HIV/AIDS and attitudes that influence behaviour. Many respondents said they think that there is something wrong with a person who is HIV positive. Some people also declared that they had personally experienced or witnessed acts of stigma and discrimination. The following are some examples of insulting ways in which PLWHA are viewed by small number of responses in the community:

"They have Z3" which is a faster car, meaning that they are dying.

"He's finished"

"PLWHA are prostitutes". In these communities prostitution is viewed as a serious violation of social norms and values. Prostitutes are, by definition, considered to be anti-models in society. In the responses of the Muslim communities in South

Africa Simbayi, *et al.* (2004) reported that 5.9% stated, “*People who have AIDS are dirty*”. Avoidance, rejection, unwillingness to invest in people living with HIV, excluded from social situations, verbal abuse, blame and judgement were experienced on the community level. Baron and Byrne (2003) define this as attitudes because it is characterised by rejection, denial, discrediting, disregarding, underrating, and social distance.

These responses reflected the enacted stigma drawn from the qualitative questions, but only few answered the question and mentioned mostly subtle discrimination such as gossiping, and not much real isolation and physical violence. According to Bennett (1990), this also reinforces the concept of “enacted” stigma because some people decided to keep their status secret in order to avoid being ostracised. In a cognitive and emotional point of view, stigma towards HIV/AIDS is shown by anger and negative feelings towards those with HIV/AIDS. There is a belief that those with HIV/AIDS deserve to be ignored and ostracised because the disease is incurable. Kalichman and Simbayi (2004) found that among men and women living in a black township in CapeTown, individuals who were not tested for HIV demonstrated significantly greater AIDS related stigmas, ascribing greater shame, and guilt to people living with HIV than those who were tested for HIV. The study indicates that on a personal level many people are more understanding, especially when they are actually exposed to people with HIV/AIDS.

5.1 CONCLUSION

The results of this study indicate that there is a great deal of work to be done around the issues of HIV and AIDS stigma in Mamelodi and Atteridgeville communities. There seems to be a gap between the relatively small body of research on what stigma is, and what to do about stigma in the community level. Many people perceive that the community have negative attitudes towards people who are living with HIV/AIDS.

Understanding stigma as a problem of fear and blame, rather than a problem of ignorance, can help us to understand the stigmatisation process without resorting to individualism. People often blame and judge those who are living with HIV/AIDS as if they deserve it because HIV/AIDS is associated with unacceptable sexual behaviour. The perception is that HIV/AIDS is a “bad disease” linked to high-risk behaviour such as promiscuity, drug use and people distance themselves from it.

Exposure of knowing someone living with HIV/AIDS has a profound impact on individual and community perception of HIV/AIDS. HIV/AIDS is strongly associated with stigmatisation, discrimination, blame and judgement. The overall conclusion that can be drawn from this research finding is that there is a high level of stigma associated with HIV/AIDS in a community level in Mamelodi and Atteridgeville community. In a personal level people expressed negative attitudes towards people who are living with HIV/AIDS. People who express stigmatising attitudes about HIV/AIDS often have retained misinformation about the transmission of HIV. This study has demonstrated that some people still believe that HIV can be transmitted by casual contact. Twenty two percent (22%) of people surveyed would be scared or uncomfortable sending their child to school with children living with AIDS. Almost 42% of respondents believe that people who were exposed to AIDS through sex got what they deserved.

There are important limitations to this research that should be pointed out:

- Firstly, the technique of sampling was not completely random, it was decided on because of practical consideration such as the safety of field workers and obtaining a representative group of people.
- Secondly, it was aimed to interview 1000 people, 500 from each of the communities, in these proportions to represent the population.
- Lastly, all participants included in the study were selected from one municipal area even though the sample was drawn from two different communities.

Possible implication of the study: The results of this study may help people living with HIV/AIDS to understand that their perception and fear of stigma in the community could well be overvalued. The study suggests that community interventions may be developed to reduce the fear about HIV/AIDS and moral judgements that are still widespread. The study shows the difference between the two measures of stigma. The research results show that the level of community perceived stigma is higher than personal stigma. This means that the level of stigma that individual respondents attached to HIV/AIDS was significantly lower than the level of stigma that they perceived others in the community to attach to HIV/AIDS. This indicates that people in the community perceive a collective stigma in the community that is negative, blaming and restrictive towards interaction with people with HIV/AIDS. All sub-scales in the study shared the perception of highly stigmatising attitudes in the community. This indicates that the community needs to be made aware of their own prejudice, discrimination and how these attitudes influence their behaviour.

On a personal level exposure to HIV/AIDS plays a major role in mitigating people's attitudes towards those with HIV. People with HIV should therefore be encouraged to disclose their status to public, openness to their family and friends since that would increase personal interaction, which may contribute to change in the level of blame and judgement and personal stigma.

In order to avoid stigmatising behaviour in the community level and to change a community perception, this would require an open commitment from all sectors of government, community leaders, church leaders, schools and media to support and care for people with HIV. The whole community should be involved in the fight against HIV/AIDS. The focus of communities should be on positive beliefs and values that can be built into HIV/AIDS intervention programmes. Community leaders and church leaders should all be involved in developing these programmes.

The study shows that most respondents indicated that some people in the community experience discrimination and prejudice. Therefore laws to protect discrimination to people living with HIV/AIDS required to be implemented. The

greater involvement of people living with HIV/AIDS in the development and implementation of intervention programmes at all levels should be encouraged to reduce HIV/AIDS stigma in the community. Men should be encouraged to initiate HIV/AIDS intervention programmes in the community. Men must be sensitized and mobilized to a greater extent for an effective response to HIV/AIDS stigma. Since men occupy most positions of influence, their participation in advocating gender-sensitive policies and programmes are essential. Both men and women have to challenge societal expectations that put men at risk e.g. social expectations that expect men/boys to be more (innately) knowledgeable and experienced about sex, have a direct impact on HIV/AIDS stigma. The collaboration of village headmen, male religious authorities and businessmen in educational interventions and home, faith, NGO's and community-based care are most important. Information and behavioural change programmes specifically targeting factors that contribute to stigmatisation must be designed and implemented.

5.2 RECOMMENDATIONS

People at the community level need to move away from the notion that being HIV positive is shameful, and that having a family member or friend with HIV/AIDS is a dark secret to be ashamed of. This study recommends that people must change attitudes for blaming people living with HIV/AIDS due to the possibility that their behaviour caused them to contract the disease. Blaming results in discrimination and stigmatisation, promotes misunderstanding of the illness, and increases society's confusion to provide help where it is most desperately needed.

The study indicates that on a personal level many people are more understanding, especially when they are actually exposed to people who are living with HIV/AIDS. Stigma needs to be addressed at the community level in order to minimise its impacts. Rather than rejecting cultural values, HIV/AIDS programme providers should focus on the impression of those attitudes; encourage positive and culturally-appropriate messages about HIV/AIDS stigma.

Individuals and organisations can implement some of these interventions but this need to be a process, preferably driven by national government, which takes an integrated and systemic approach to stigma mitigation.

The study suggests that people must be careful of explaining all behaviour of PLWHA in terms of HIV or related stigma. It is important to examine one's feelings, thoughts, and attitudes about AIDS, particularly in relation to community perceived stigma. HIV/AIDS is a disease that is often associated with fear, stigma, prejudice, and highly charged emotions. There have been many myths and misunderstanding about HIV/AIDS. If people do not address their feelings and attitudes about HIV, they may consciously or subconsciously treat people who are HIV positive, or perceived to be infected or at risk, differently.

The stigma contributing factors observed in these communities such as suspicion, blame and judgement, fear, prejudice, attitudes, may all have influence on stigmatising HIV/AIDS. There is a clear need to establish stigma-related interventions on a community level. Although many of the AIDS prevention programmes incorporate action against stigma, there is still a need for programmes to be implemented in the community, aimed at changing HIV related stigma and the existing interventions are generally insufficiently evaluated and documented. Interventions are needed on all levels of the community targeting the community perception on HIV/AIDS. On the individual level, education is needed to develop realistic risk-perception and improved self-efficacy to reduce stigma, negative attitudes towards people living with HIV/AIDS and perception of HIV/AIDS. This would contribute towards changing the context within which individuals and communities respond to HIV/AIDS (Parker *et al.*, 2002).

Although the results of this study correspond to those of international studies, more research of this nature needs to be conducted in South Africa. Due to the data limitations to two communities, there is a call to other researchers to verify the findings of this study. It is however very challenging to link the findings of such a study to theory. Detailed and additional research needs to be conducted to a larger and more generalisable population to improve an understanding of HIV/AIDS stigma in a community level.

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APPENDIX A**TABLE 4.1.1.1 PERSONAL STIGMA**

Variables	Blame and Judgement	Interpersonal distance	Value Items	Total score
	Mean	Mean	Mean	Mean
Gender				
Male (479)	2.7474 A	2.1253	0.97495	5.8476 A
Female (428)	2.1355 B	1.9650	0.92523	5.0257 B
Age				
18 – 25 (278)	2.2806 B	1.6223 C	0.7806 B	4.6835 C
26 – 50 (502)	2.3665 B	2.1036 B	0.9422 B	5.4124 B
51 – 80 (127)	3.2126 A	2.7717 A	1.3622 A	7.3465 A
Language				
Tshivenda (37)	2.7838	2.5135 A	1.1351 B	6.4324 A
Sepedi (374)	2.5588	2.0802 B	0.9759 B	5.6150 A
Setswana (157)	2.5223	2.0127 B	0.7580 B	5.2930 A
Xitsonga (87)	2.3678	2.0345 B	1.2069 A	5.6092 A
Isizulu (94)	2.2872	1.6915 B	1.1277 B	5.1064 B
Sesotho (116)	2.2500	2.2069 B	0.7500 B	5.2069 A
Isindebele (42)	2.1905	1.9048 B	0.9286 B	5.0238 B
Religion attended				
Yes (547)	2.4694	2.0274	0.93053	5.4095
NO (360)	2.4516	2.0833	0.98333	5.5361
Marital status				
Married (249)	2.5444	2.3548 A	1.03226	5.9315 A
Single with partner (446)	2.3578	1.8289 B	0.94889	5.1356 B
Single without partner (208)	2.5742	2.1627 A	0.86124	5.5981 A
Educational level				
No education/Primary (119)	3.3025 A	2.7899 A	1.4706 A	7.5630 A
Secondary (569)	2.4499 B	2.0879 B	0.9244 B	5.4622 B
Tertiary (219)	2.0228 C	1.5479 C	0.7397 B	4.3105 C
Is there someone close to you who has HIV/AIDS or have died of AIDS?				
Yes (457)	2.2757A	1.8643 A	0.8665 A	5.0066 B
No (450)	2.6444 B	2.2378 B	1.0377 B	5.9200 A

How often do people you know talk about HIV/AIDS?

Weekly (628)	2.3455 B	1.9363 B	0.9793 A	5.2611 B
Monthly (143)	2.6434 B	2.1608 B	0.9650 A	5.7692 B
Less than monthly (78)	2.3590 B	1.9103 B	0.6282 B	4.8974 B
Never (58)	3.3621 A	3.1897 A	1.0517 A	7.6034 A

How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS?

Weekly (528)	2.3958	2.0909	1.0246 A	5.5114
Monthly (170)	2.6824	2.0882	0.9765 A	5.7471
Less than monthly (95)	2.5263	2.0421	0.6947 B	5.2632
Never (114)	2.3596	1.8070	0.7895 A	4.9561

Have you ever talked to your partner/husband/wife about ways to avoid getting HIV/AIDS?

Yes (637)	2.3485 B	1.8964 B	0.9278	5.1727 B
No (146)	2.9863 A	2.6918 A	1.1027	6.7808 A
N/A (124)	2.4032 B	2.0806 B	0.8952	5.3790 B

Have you ever been tested for HIV/AIDS?

Yes (362)	2.0773 C	1.8315 B	0.90608	4.8149 C
No (375)	2.5893 B	2.0160 B	0.99733	5.6027 B
No answer (170)	2.9824 A	2.5882 A	0.94706	6.5176 A

Means with the same letter are not significantly different.

APPENDIX B**TABLE 4.2.1.1 PERCEIVED COMMUNITY STIGMA**

Variables Blame and Judgement Interpersonal distance Value Items Total score

	Mean	Mean	Mean	Mean
Gender				
Male (474)	5.8059	5.3418	2.13924	13.2869
Female (429)	5.5991	5.5618	2.11888	13.2797
Age				
18 – 25 (278)	6.2266 A	5.9532 A	2.2374	14.4173 A
26 – 50 (499)	5.5090 B	5.3186 B	2.0681	12.8958 B
51 – 80 (126)	5.3492 B	4.8333 B	2.1349	12.3175 B
Language				
Tshivenda (38)	6.1842	5.9474	2.1842 A	14.3158
Sepedi (373)	5.5979	5.3405	2.2493 A	13.1877
Setswana (153)	5.9281	5.6013	1.9085 B	13.4379
Xitsonga (88)	5.2727	5.1023	2.0227 B	12.3977
Isizulu (93)	5.7634	5.7204	2.4194 A	13.9032
Sesotho (116)	5.9224	5.5517	1.8879 B	13.3621
Isindebele (42)	5.6429	5.1905	2.0714 A	12.9048
Religion attended				
Yes (546)	5.5989	5.4048	2.10073	13.1044
No (357)	5.8739	5.5098	2.17367	13.5574
Marital status				
Married (249)	5.6305	5.3855	2.1365	13.1526
Single with partner (446)	5.8430	5.6054	2.1435	13.5919
Single without partner (208)	5.5096	5.1779	2.0913	12.7788
Educational level				
No education/Primary (118)	5.0678 B	4.8390 B	2.1864 B	12.0932
Secondary (568)	5.6743 A	5.4771 A	2.0229 B	13.1743
Tertiary (217)	6.1429 A	5.6959 A	2.3779 A	14.2166
Is there someone close to you who has HIV/AIDS or have died of AIDS?				
Yes (457)	6.0503 A	5.7374 A	2.15536	13.9431A
No (446)	5.3565 B	5.1480 B	2.10314	12.6076B

How often do people you know talk about HIV/AIDS?

Weekly (630)	5.6825	5.3937	2.1984	13.2746
Monthly (140)	5.7000	5.6714	1.9643	13.3357
Less than monthly (77)	5.7662	5.5065	2.0519	13.3247
Never (56)	5.9286	5.3929	1.8750	13.1964

How often do you hear leaders in your community-politicians, church leaders or heads of organisation talk about AIDS?

Weekly (527)	5.6243	5.3264	2.1651 B	13.1157
Monthly (166)	5.8554	5.6566	1.8614 B	13.3735
Less than monthly (95)	5.6842	5.3789	2.2211 A	13.2842
Never (115)	5.8957	5.7478	2.2783 A	13.9217

Have you ever talked to your partner/husband/wife about ways to avoid getting HIV/AIDS?

Yes (634)	5.8281	5.5284	2.1183	13.4748
No (145)	5.4483	5.3172	2.2621	13.0276
N/A (124)	5.3952	5.1774	2.0323	12.6048

Have you ever been tested for HIV/AIDS?

Yes (358)	5.8017	5.5196	2.1620	13.4832
No (375)	5.5893	5.4053	2.1600	13.1547
No answer (170)	5.7706	5.3824	1.9941	13.1471

Means with the same letter are not significantly different.

APPENDIX C**TABLE 4.3.1.1 KNOWLEDGE ABOUT HIV/AIDS TRANSMISSION**

Variables	Knowledge
	Mean
Gender	
Male (481)	11.6881 A
Female (432)	12.0486 B
Age	
18 – 25 (278)	12.5791 A
26 – 50 (505)	11.9168 B
51 – 80 (130)	10.0923 C
Language	
Tshivenda (38)	12.0789 B
Sepedi (377)	11.7427 B
Setswana (157)	12.1465 B
Xitsonga (88)	11.4432 B
Isizulu (95)	11.9474 B
Sesotho (116)	11.7241 B
Isindebele (42)	12.6667 A
Religion attended	
Yes (552)	11.9366
No (361)	11.7396
Marital status	
Married (253)	11.2332 B
Single with partner (450)	12.1533 A
Single without partner (210)	11.9810 A
Educational level	
No education/Primary (121)	9.8512 C
Secondary (573)	11.9860 B
Tertiary (219)	12.6347 A
Is there someone close to you who has HIV/AIDS or have died of AIDS?	
Yes (461)	12.1996 A
No (452)	11.5111 B

How often do people you
know talk about HIV/AIDS?

Weekly (633)	11.9874 A
Monthly (143)	11.6923 A
Less than monthly (79)	12.1899 A
Never (58)	10.4138 B

How often do you hear
leaders in your community-
politicians, church leaders or
heads of organisation talk
about AIDS?

Weekly (531)	11.8456
Monthly (171)	11.6784
Less than monthly (96)	12.0000
Never (115)	12.0696

Have you ever talked to
your partner/husband/wife
about ways to avoid getting
HIV/AIDS?

Yes (640)	12.0531 A
No (147)	11.1224 B
N/A (126)	11.7302 A

Have you ever been tested
for HIV/AIDS?

Yes (365)	12.3342 A
No (377)	11.6764 B
No answer (171)	11.2456 C

Means with the same letter are not significantly different.