

CHAPTER 1

Introduction

Until 1998 South Africa had one of the fastest expanding HIV/AIDS epidemics in the world, but HIV prevalence now appears to have stabilized, and may even be declining slightly. This is mostly attributed to the campaigns and information given to the public about HIV. Among teenage girls, the rate fell from 15.9% in the 2005 survey to 13.7% in 2006, possibly indicating a drop in the rate of new infections. However, these results may vary, Van Dyk (2008) reported that UNAIDS declared in 2006 that South Africa's AIDS epidemic is one of the worst in the world and shows no evidence of a decline. In 2006, HIV was recorded as a cause of death in only 14,783 cases in South Africa, but researchers attributed this to numbers to unspecified deaths as HIV related (UNAIDS, 2006).

According to the World Health Organization (WHO) (2007), apart from HIV, cancer is a global burden that causes mortality across all nations. In 2004 44,448,470 people were estimated to have cancer in South Africa (National Cancer Institute of Canada, 2004). The number of global cancer deaths is projected to increase 45% from 2007 to 2030 (from 7.9 million to 11.5 million deaths), influenced in part by an increasing and aging global population. There are over 20 million people living with cancer in the world today. The majority live in the developing world. The estimated rise takes into account expected slight declines in death rates for some cancers in high resource countries. New cases of cancer in the same period are estimated to jump from 11.3 million in 2007 to 15.5 million in 2030 (WHO 2007).

The word "cancer" still conjures up deep fears of a silent killer that creeps up on people without warning. Cancer, evoking such desperation that it has become a metaphor for grief and pain, a thorn in the flesh straining intellectual and emotional resources.

In most developed countries, cancer is the second largest cause of death after cardiovascular disease, and epidemiological evidence points to this trend emerging in the less developed world. This is particularly true in countries in "transition" or middle-income countries, such as in South America and Asia. Already more than half of all cancer cases occur in developing countries (WHO, 2007).

According to (WHO 2007) the main types of cancer leading to overall cancer mortality are:

- Lung (1.3 million deaths/year);
- Stomach (almost 1 million deaths/year);
- Liver (662,000 deaths/year);
- Colon (655,000 deaths/year) and
- Breast (502,000 deaths/year).

And the most frequent cancer types worldwide are:

- Among men (in order of number of global deaths): lung, stomach, liver, colorectal, oesophagus and prostate.
- Among women (in order of number of global deaths): breast, lung, stomach, colorectal and cervical.

Lung cancer has been found to kill more people than any other cancer - a trend that is expected to continue until 2030, unless efforts for global tobacco control are greatly intensified. Some cancers are more common in developed countries: prostate, breast and colon. Liver, stomach and cervical cancer are more common in developing countries (National Cancer Institute of Canada, 2004).

A number of common risk factors have been linked to the development of cancer: an unhealthy lifestyle, including tobacco and alcohol use, inadequate diet, physical inactivity, and exposure to occupational (e.g. asbestos) or environmental carcinogens, (e.g. indoor air pollution), radiation (e.g. ultraviolet and ionizing radiation), and some infections (such as hepatitis B or human papilloma virus infection) (Cancer Association

of South Africa, 2009). HIV/AIDS is linked with unprotected sexual encounter with an infected person, blood transfusion, and wound to infected blood contact, and mother to child transmission. The method of HIV infection and causes of cancer also determine the extent of shame and stigma experience (Van Dyk, 2008).

According to Sadock and Sadock (2007), when persons learn that they have cancer or HIV, their psychological reactions include fear of: death, disfigurement, disability, abandonment, loss of independence, and disruption in relationships. They also worry about role functioning, and financial standings. Denial, anxiety, anger and guilt are also part of psychological reactions. Patients go through a number of emotions and psychological distress, before actually coming to terms with their diagnosis. Among these processes there is shame and stigma that has been found to be prevalent in HIV research, which this study aims to explore also focusing on cancer. A way of assessing the impact of HIV and cancer is by examining the shame, stigma and their impact on the psychological functioning.

Research Problem

Other factors that may have a bearing on the psychological functioning of HIV patients and have been studied by Lindner (2006). These factors include access to material factors such as economic stability, housing, nutrition, and healthcare. Personal factors such as coping styles, family factors and social factors are also included. Lindner (2006) has conducted a study on the relationship between stigma and psychological distress and focused only on external or enacted stigma among women with HIV/AIDS excluding cancer. However, this study will go further to examine shame and stigma as predictors of psychological dysfunctions and to include the three dimensions of stigma i.e. internal felt stigma, perceived community stigma and enacted stigma. This study will also include both males and females in its sample.

It has been noted that the exploration of shame and stigma on HIV patients have been significant, with research reporting particular incidents such as a woman being stoned after disclosing her status; children being barred from entering school because of their

HIV status, and patients' mortality caused by fear of enacted stigma in the health facilities because of fear of other people's reaction if found out that they are HIV positive.

More importantly, there has been limited research in South Africa examining how shame and stigma impacts psychological functioning among HIV/AIDS (Lindner, 2006) and cancer patients with the emphasis on the latter. Without enough research it is rather difficult to come up with strategies to assist patients. This study strives to provide answers to questions such as, does shame and stigma impact psychological functioning as well as create literature on cancer related shame and stigma in South Africa.

Aim of the study

The research aims to measure psychological functioning as an outcome variable of shame and stigma. It will also measure the influence of age and gender on the experience of shame and stigma and psychological dysfunctions.

Objectives of the study

- To determine whether there is any difference in the experience of shame and stigma and psychological dysfunctions among HIV and cancer patients.
- To explore shame and stigma experienced by HIV/AIDS and cancer patients and their influence on their psychological dysfunctions.
- To find out whether there is any gender differences in the experience of shame and stigma and psychological dysfunctions among HIV and cancer patients.
- To find out whether age group differences has an influence in the experience of shame and stigma and psychological dysfunctions among HIV/AIDS and cancer patients.

Significance of the study

- This study will contribute by adding to the literature of stigma and shame experienced by patients, especially with cancer, as there is lack of literature related to this topic.
- Reducing shame and stigma, which causes psychological disturbances among these patients should be the focus of public health policy. Therefore, it was felt that an understanding of shame and stigma and their impact on psychological functioning could contribute to the development of effective individual, family and community interventions.
- Relatively, little is known about which group of patients experience more shame and stigma and psychological dysfunctions than the other. This study will provide differences which will answer this question and also assist health policy makers to target the particular group that has been found to experience more stigma and shame than the other.

Chapter 2

This chapter will provide operational definition of terms used in this study as well as a theoretical framework for the whole study and theories covering variables to be measured.

Operational definition of terms

In this study:

Stigma is defined as an attribute or quality that significantly discredits an individual in the eyes of others, the person is seen as having an illness that is socially unacceptable, therefore he/she must be isolated or ostracized. It is measured with a shame and stigma scale developed by Westbrook & Bauman in 1996.

Shame is referred to as a negative emotion elicited when a person experiences failure in relation to personal or social standards, feels responsible for this failure, and believes that the failure reflects self-inadequacy and inappropriate behaviour

Predictor refers to forecasting an event or situation as caused by or having an effect on another event.

Psychological dysfunction refers to the disturbance in the behavioural, affective, somatic, interpersonal, and cognitive functioning of an individual. It is measured with GHQ-28 developed by Goldberg in 1972.

HIV/AIDS and Cancer Patients refer to those people who have been diagnosed with cancer or HIV/AIDS.

Cancer is defined as a group of diseases characterized by the presence of neoplastic cells that grow and spread without control. These new cells may form benign tumours, which

tend to remain limited to a small area, or tumours which tend to spread to other tissues and may spread to other organs and may be caused by smoking, diet, early age sexual engagement etc.

HIV/AIDS refers to a very small organism or germ called a virus which people become infected. It cannot be seen with the naked eye, but only under a microscope. It only survives and multiplies in body fluids such as sperm, vaginal fluids, breast milk, blood, and saliva. One can only become infected with HIV through contact with infected body fluids and it attacks the immune system, which is the body's natural ability to fight illness, and reduces the body's resistance to all kinds of illness including flu, diarrhoea, pneumonia, TB, and certain cancers. Overtime HIV progresses to AIDS, which a person immune system is vulnerable to the above-mentioned illnesses and if not treated with relevant medication (i.e. anti-retroviral medication) a person can die.

Theoretical framework of the study

Biopsychosocial model

Given the fact that psychological functioning is being studied as an outcome of shame and stigma it was fitting to use the biopsychosocial model, which was first, presented by George Engel at the University of Rochester (Engel, 1977). This model stressed an integrated approach to human behaviour and disease. It provides a conceptual framework for dealing with different information and serves as a reminder that they may be important issues beyond the purely biological. Throughout the last century there has been a progression away from the biomedical model and toward the biopsychosocial model in an attempt to understand and predict individuals' functioning in a healthcare context (Winiarski, 1997). Up until the 1960s, when trying to understand patients with chronic and/or terminal health conditions, a biomedical model was often utilized (Smith & Nicassio, 1995). This strict biomedical model posits that to understand a person's disease progression and functioning, one must only understand that person's biological status. For example, one would only need to understand the disease progression and symptoms

of HIV/AIDS or cancer in order to predict the functioning and health of an individual who is HIV or cancer diagnosed.

The biomedical model suggests that illness is only a result of biological malfunction, and, thus, that disease progression can be predicted by understanding biochemistry and physiology. The biomedical model in no way takes into account the fact that an individual's personality, social factors, and/or societal conditions may also impact his/her disease progression. It is therefore a reductionistic perspective which considers social and psychological factors irrelevant. The major weakness of the biomedical model is that it cannot explain why two individuals with the same disease might have different clinical presentations, symptom development, and disease progressions. In the 1960s it became evident that, although the biomedical model led to many significant medical discoveries, it did not fully explain patients' functioning. Scientists began to discuss the idea that other factors were likely interacting with biological factors and impacting patients' functioning.

Engel (1977) was the first scientist to use the term "biopsychosocial" and to highlight the need for a broader conceptualization of illness in the fields of medicine and psychiatry. In his influential papers, Engel (1977, 1980) presented the biopsychosocial model, which states that the onset, course, and treatment of physical illness are best understood by examining the patient at three levels: (1) biological; (2) psychological; and (3) social. Engel notes that his model is highly influenced by the principle in general systems theory stating that nature is organized in hierarchical units which increase in complexity (von Bertalanffy, 1968).

Each of these units is unique and distinctive; however, the units at each level interact with each other, and units at one level can influence the units at levels both above and below it. This notion highlights the interdependence of systems and asserts that to understand one system, one must understand the surrounding, interconnected systems (Smith & Nicassio, 1995). Engel (1980) applied this general systems principle when developing the biopsychosocial model by asserting the importance of thinking about a patient's

functioning at multiple, interacting levels. He presents the following interacting, hierarchical units (from lowest to most complex) that should be examined when working with a patient: cells, tissues, organs, nervous system, person, two person, family, community, and culture/subculture.

The biopsychosocial model therefore affirms that these units can be addressed by considering a patient's biological, psychological, and social aspects when attempting to understand his/her functioning. Sadock and Sadock (2007) gave the example of what should be considered under each of these aspects. The biological refers to the anatomical, structural, and molecular substrates of disease and its effects on patients biological functioning. The psychological system refers to the effects of psychodynamic factors, motivation, and personality on the experience of, and reaction to illness, and the social system examines cultural, environmental, community, age, gender and familial influences on the expression and experience of illness. They realized that the biological, social, and psychological levels are unique, but they interact and influence each other.

Winiarski (1997) points out that traditionally individuals in the healthcare setting consider only some of these aspects or consider each of these aspects separately. Winiarski emphasizes that the biopsychosocial model asserts the importance of looking at these processes together, rather than just examining one in isolation. It is fitting to use the biopsychosocial model to guide an examination of the way that shame and stigma impacts psychological functioning in patients with HIV/AIDS and cancer. This model emphasizes the importance of considering numerous psychological and social factors when trying to predict the impact of HIV and cancer, rather than just examining biological factors (e.g. CD4 count or tumour progression). Given that the researcher is interested in examining psychological functioning as an outcome, this model seems particularly relevant. Further, because this research study is one of the first few to examine the impact of shame and stigma on cancer patients in South Africa and is therefore exploratory in nature, in the first round examination the researcher will only focus on shame and stigma, age and gender as influences of psychological dysfunction.

Additionally, there has been precedence in the literature for applying the biopsychosocial model to understanding and guiding research and practice around HIV in the United States (Cohen, 1990; Cohen & Weisman, 1986; Marcus, Kerns, Rosenfeld, & Breitbart, 2000; Thomason, Jones, McClure, & Brantley, 1996; Winiarski, 1997; Wolfe, Dralle, Morse, Simon, Balson, Gaumer, & Williams, 1991) and also in South Africa (Schlebusch & Cassidy, 1995).

Drawing from the conceptual framework of the study (biopsychosocial model) the following theories were briefly used to explain this study: attribution theory, cognitive theory, labelling theory, ageism, and vulnerability hypothesis.

Attribution theory

It is a social psychology theory developed by Fritz Heider (1958), Edward E. Jones (1967), and Lee Ross (1977) and it will be used to provide a theoretical explanation of shame and stigma. This theory will assist in explaining why people with HIV/AIDS and cancer are stigmatised, why others experience more shame and stigma than do others.

Attributions also can be significantly driven by emotions and cognition. For instance, people tend to blame others for their troubles due to their uncontrolled behaviours or attitudes. The theory states that patients may experience shame and stigma when the disease they have is perceived as controllable, visible, and dangerous and such fears are associated with delay and avoidance of health seeking behaviour and the development of depression, anxiety, social isolation and many other psychological problems (Cobb & De Charbert, 2002). When people are held responsible for their illness or other conditions it will possibly invoke anger and resentment in the person attributing responsibility, which may consequently turn into social rejection and stigma (Breitkopf, 2004).

On the other hand, individuals who are not believed to be personally responsible for their condition may invoke a pity response from others i.e. cancer (Breitkopf, 2004). This theory describes how people perceive others' behaviour and situation, which determines

their reactions and attitudes toward those individuals (Myers & Spencer, 2004). The behaviour and condition of others can either be attributed to internal influences (i.e. motives and disposition) or external influences (i.e. the situation).

Unfortunately, people often commit the fundamental attribution error, which is the tendency for observers to underestimate situational influences and overestimate character influences, in their evaluation of others (Myers & Spencer, 2004). According to Breittkopf (2004), individuals who contracted HIV through no fault of theirs may invoke pity and sympathy, but a question remains whether this is the case for HIV/AIDS patients? There are some people who contract HIV through blood transfusion, which may be considered as an external or uncontrollable cause, but are still stigmatized. For instance, Ryan White contracted HIV through blood transfusion but was isolated and stigmatized in his school and community (White, 2006). In other words, irrespective of how people contracted the disease, they are still stigmatized but the intensity or degree of stigma may differ. As a result people who were infected through drug use or sexual relations with same sex partners are likely to experience more discrimination than those infected through blood transfusion. This is because behaviors like injection drug use, homosexuality are seen as internal; something that is within the individual and can be controlled, but transmission through blood transfusion is an external factor that is not controllable.

With HIV and AIDS, those infected or have the disease attract increased anger and decreased empathy because the public considers their illness a product of personal decisions, but with some kinds of cancer, the person may be accepted with empathy because the disease is mostly not associated with immorality and is seen as out of the person's control. A person who was a smoker and then diagnosed with lung cancer may not easily be accepted and empathized with, but will be blamed for his condition because he could have controlled his smoking. These kinds of attributions increase stigmatization and shame experienced by these patients, which leads to psychological dysfunctions.

Using the attribution theory helps give meaning to why people stigmatize and why some people experience more stigma than others. In exploring the reasons why people with

HIV and cancer feel shamed and stigmatized, it is also important to look at HIV and cancer related shame and stigma as a result of interaction between human beings and their environment, which have an impact on their psychic functioning.

Cognitive theory explaining shame, internal felt stigma, and perceived community stigma

Beck (1976) stated that psychological disorders could be caused by a combination of biological, environmental, and social factors interacting in a variety of ways, maintaining that thoughts, feelings, and behaviours are interconnected. Cognitive theory perceives psychological problems as stemming from commonplace processes such as faulty thinking, making incorrect inferences, on the basis of inadequate or incorrect information and failing to distinguish between fantasy and reality. This theory is based on the theoretical rationale that the way people feel and behave is determined by how they perceive and structure the experiences around them. When an individual perceives or anticipates a situation as threatening, his/her thinking tends to be distorted, which leads to changes in feelings and behaviours.

Using the basic cognitive distortions principles that HIV and cancer patients may engage in to explain the development of internal felt stigma and perceived community stigma will amount to the following:

- Arbitrary inferences which refers to making conclusions without supporting relevant evidences. These include catastrophizing or thinking the absolute worst scenarios and outcomes for most situations. A person with HIV or cancer may start thinking that his/her diagnosis will determine how people will treat him or her which may result in self isolation.
- Selective abstraction consists of forming conclusions based on an isolated detail of an event. In this process the other information is totally ignored and the significance of the total context is missed.
- Overgeneralization is a process of holding extreme beliefs on the basis of a single incident and applying them inappropriately to dissimilar events or settings.

- Magnification and minimization consists of perceiving a case or a situation in a greater or lesser light than it truly deserves.
- Personalization is a tendency for individuals to relate external events to themselves, even when there is no basis for making this connection.
- Labelling and mislabelling involve portraying ones identity on the basis of imperfections and past mistakes and allowing them to define one's true identity.
- Dichotomous thinking involves categorizing experience in either or extremes. With such polarized thinking events are labelled in black and white terms.

Patients with HIV/AIDS and cancer may engage in these cognitive distortions about themselves, community and their disease, leading them to experience internalized shame, internal felt and perceived community stigma. Beck (1976) reported that these cognitive distortions have been found to cause feelings of hopelessness, sleeping problems, anxiety, and suicidal thoughts. Cognitive theory provides explanation on how shame, internal felt stigma and perceived community stigma may be perpetuated by an individual's thoughts.

Labelling theory

It is important to understand how enacted stigma is explained theoretically. Labelling theory first appeared in 1966 when Thomas Scheff published *Being Mentally Ill*. Scheff challenged common perceptions of mental illness by claiming that mental illness is manifested solely as a result of societal influence. The theory hypothesizes that the labels applied to individuals influence their behaviour, particularly the application of negative/stigmatizing labels (i.e. promiscuity and prostitution) promote certain behaviours which reflect enacted stigma (Scheff, 1966).

An individual who is labelled as promiscuous because of HIV/AIDS or cervical cancer may not freely disclose his or her sickness, let alone after diagnosis seek further medical attention. This increases the patient's experiences of shame and stigma. When a person is labelled within the community and family institutions, the labellers tend to act in contempt overtly and covertly towards the labelled person. Labelling has been found to

causes depression, social exclusion, fear, and anxiety (Wikipedia, 2007). This theory provides understanding in terms of how enacted stigma plays out and its effects on the patient.

Ageism

It is also important to explore the theoretical explanation of how age plays a role in the experience of shame and stigma and psychological dysfunctions. The term ageism was coined in 1969 by US gerontologist, Robert N. Butler, to describe discrimination against seniors, and patterned on sexism and racism. It refers to the stereotyping of and discrimination against individuals or groups because of their age. It is a set of beliefs, attitudes, norms, and values used to justify age based prejudice and discrimination. This may be casual or systematic (Butler, 1969).

The term has also been used to describe prejudice and discrimination against teens, older people and children, including ignoring their ideas because they are too young, or assuming that they should behave in certain ways because of their age. Ageism commonly refers to negative discriminatory practices, regardless of the age towards which it is applied. There are several subsidiary forms of ageism. Adultism is a predisposition towards adults, which is seen as biased against children, youth, and all young people who are not addressed or viewed as adult. Jeunism is the discrimination against older people in favour of younger ones. When ageism occurs within the health context it is referred to as stigmatization (Emlet 2006). When patients are told that because of their age, their prognosis will be affected or they cannot be given treatment, this is referred to as stigmatization according to age. Ageism can also occur in the community where enacted stigma usually occurs. For instance, a person with HIV may be judged because he/she is either too old or too young and mocked for their irresponsibility.

Interestingly, studies have also found ageism as being present within the psychology profession. Psychologists were found to rate older clients less ideal and given significantly poorer prognoses than younger clients (Woolf, 1998).

Vulnerability hypothesis

Vulnerability derives from the Latin word “vulnerare” and means the state of being exposed to, or to be wounded and describes the potential to be harmed physically and psychologically. On the other hand hypothesis is referred to as an assumption that may need to be proved positive or negative. According to Uhl & Kobra (2003) vulnerability hypothesis is a psycho-social theory which holds the view that emotional impact of undesirable life events differs from individual to individual due to socio-demographic variables. In this study, for example gender is a demographic variable that is to be explored. This theory gives the explanation of whether males or females are differently vulnerable to the experience of shame and stigma and psychological dysfunctions. Most studies conducted always found women as vulnerable to a number of problems caused by culture; social standing, biological, and economical factors (Bennet, 1990, Bond, Chase, & Aggleton, 2002; Abdool - Karim, 1998 & De Bruyn, 1992). Men may also be affected by the above mentioned factors, but on a lesser standard. In simple terms, this theory holds the view that gender act as a marker for vulnerability to the experience of shame and stigma and psychological dysfunctions among HIV and cancer patients.

Chapter 3

Literature review

Understanding shame and stigma

The need to understand shame and stigma are of utmost importance as previous literature have reported these two aspects as having an impact on HIV and cancer patients, hindering them to seek health services, maintaining the continuance of HIV infection and shortening the lifespan of patients or increasing mortality (Lee, Kochman, and Sikkema 2002).

There are few published literature pertaining to shame, as it is one of the emotions that researchers are beginning to recognize in their studies. Lewis (1999) defined shame as a feeling of being flawed and defective as a human being. Repeated shame experiences can be so painful to the individual that it creates a rupture of the self with the self. The true self who has been shamed becomes isolated and hidden, and a false self may emerge. To further support this, Loughhead (1991) reported that shame is a complex set of attitudes, feelings, and behaviours that tends to motivate hiding and if provoked can lead to conflict with others. When you shame a person, it hurts. Shame becomes the purposeful assault on the soul, the inner spirit which animates the person. When ashamed, the victims usually accumulate its resources to protect the soul.

Lewis (1999) further stated that shame rarely remains a wholly conscious process, with the major defence against this pain being repression. The product of this process is usually psychological distress i.e. depression, anxiety. Parker (1996) also stated that shame being a painful, self-focused affect has been linked to many problematic psychological states including aggression, depression, somatisation, anxiety, obsessive compulsive disorder, interpersonal sensitivity, personality disorders, substance abuse, post traumatic stress disorder, and low self esteem. However, it may not be the

experience of shame per se, but rather how one copes with shame that leads to problematic outcomes.

According to research (UNAIDS, 2000a, Lee, Kochman *et al.*, 2002, Fortenberry, McFarlane, Bleakly, Sheana-Bull, Fishbein, Grimley, Malotte, & Stoner, 2002) shame has been found to be a product of internal felt stigma or an internalized reaction to stigma. Some researchers have described shame and stigma as related constructs (Lewis 1999, Corrigan & Penn, 1999, Herek, Mitnick, & Buris 1999, Link, & Phelan, 1999). Therefore in this study, it will not be measured as a variable, but as a whole with stigma. According to research, where there is shame there is stigma and vice versa (UNAIDS, 2000a).

To explore stigma, it is important to include the pioneers in stigma research such as Goffman (1963) who defined stigma as an attribute which is highly discrediting. The attribute could be both a physical and non-physical characteristics. Goffman also reported that stigma is less a feature of an individual than of a relationship, and stigmatising one person can confirm the unusualness of another. Therefore, people stigmatise others and feel better about themselves when they are not themselves part of the stigmatised condition. People also feel uncomfortable in the company of stigmatised people and avoid social contact with them (Herek & Capitanio, 1999).

Other theorists after Goffman such as Falk (2001) have defined stigma as an invisible sign of disapproval, which permits insiders to draw a line around outsiders in order to demarcate the limits of inclusion in any group. He further explained that the demarcation permits the insider to know who is in and who is out and thereby demonstrate what happens to people who deviate from the accepted norm. The stigmatisation can take the form of physical abuse, isolation, and mental suffering for those who are stigmatised. More specifically in interpersonal relationships stigma can take the forms of rejection and loathing. Leary and Schreindoffer (1998) have described stigma as interpersonal dissociation, which means that people start avoiding, excluding, ostracizing, or otherwise minimising interaction with individuals who are perceived to have certain characteristics.

There are three kinds of stigma that have been found to have an impact on people with certain stigmatized condition. These dimensions include, internal felt stigma/experienced personally stigma (to avoid confusion, in this study it will be referred to as internal felt stigma), perceived community stigma and enacted stigma (USAID Policy Project, 2006).

Internal felt stigma and perceived community stigma

Internal felt stigma and perceived community stigma is also described as imagined or self-stigma. Goffman (1963) coined the term “discreditable” identity in terms of choosing to keep one’s stigma hidden. This implies by definition the concept of secrecy and shame. The word shame itself is thought to derive from an Indo-European word meaning “hide” (Macdonald, 1998). Stigma is intimately linked to a sense of shame as mentioned earlier, and literature on stigma supports the idea of stigma as a cause of shame (Lewis, 1998).

Moreover, internal felt stigma is the product of internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with having a certain disease. Internal felt stigma could have a profound effect on disease prevention, treatment, and care. Internal felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma, such as when people deny their risk of infection or fails to disclose their disease in order to avoid being banished (UNAIDS, 2000b). It is intrinsically linked with enacted stigma as the fear of judgement or discrimination from others, and can profoundly influence the way people with certain diseases view themselves and cope with the diseases. One US study found that internal felt stigma contributes significantly to levels of depression, anxiety and hopelessness (Lee, Foster, Makufa, & Hinton 2002). It can affect people’s view of themselves, and of their surrounding community which lead to perceived community stigma.

Internal felt stigma enables individuals to experience the disease related stigma and suffer its impacts, without having been an actual target of enacted stigma. Internal felt stigma and fear of rejection can impair the individual’s perception of available support, and the

individual can become vulnerable to signs of possible rejection, possibly misinterpreting the behaviour of others as rejecting. It disposes individuals in this manner to conceal their diagnosis. It can often lead to the individual isolating him or herself, because he or she anticipates no support and possible rejection, thereby excluding him or herself from social support.

The internalisation of society's judgement can be seen as an act of perceived community stigma, which is defined as an individual's internalization of perceived or experienced societal attitudes (UNAIDS; 2001, Mdlalose, 2006). The negative attitudes of society towards people living with HIV/AIDS (PLWHA) are an important source of stigma. Through awareness of cultural representations, PLWHA know that others devalue their social identity.

Perceived community stigma can lead to depression, withdrawal and feelings of worthlessness (UNAIDS, 2002a), reinforcing shame, stigmatisation and social exclusion. Perceived community and internal felt stigma are examples of how stigma can exist without or outside the interactional context. Anticipation of negative interaction illustrates how the negative impact of HIV/AIDS-related stigma, does not necessarily require actual interaction. The experience of stigma can thus occur in the absence of other people, but not outside a meaning-giving cultural context (Insideout Research, 2004).

Enacted stigma

Enacted stigma is defined as the actual experience of stigma and discrimination (Mdlalose, 2006). Enacted stigma refers to sanctions that are individually or collectively applied to people on the basis of their belonging or perceived belonging to a particular group. Enacted HIV/AIDS-related stigma refers to the discrimination and violation of human rights that PLWHA or people assumed to be infected with HIV/AIDS may experience (Green, 1995).

Examples of enacted stigma within the context of HIV/AIDS include the following: when people with HIV/AIDS (PLWHA) are diagnosed, they bring shame upon their families, members of the family tend to stigmatise them, treating them with hostility and as less valuable members of the family. In many cases, PLWHA often experience stigmatisation at home and in the community through blame, rejection, abandonment, neglect, unjust treatment and punishment (Parker & Aggleton, 2002). Expulsions, separation, confiscation of property, and death threats have been documented (UNAIDS, 2002b). Several women in a Ghanaian study reported that their families no longer were willing to share meals with them after disclosure, and some were told not to touch anything belonging to family members (Mill, 2003).

In Uganda, PLWHA have been blamed for domestic instability, and given insufficient care and treatment (Muyinda, Seeley, Pickering, & Baron, 1997). In Zambia, women have also reported experiencing blame, rejection, bitterness, anger, insufficient treatment and neglect (Bond, *et al.*, 2002). In Nigeria, community members have encouraged family-members of PLWHA not to waste time or money on them, since the disease cannot be cured anyway (Alubo, Zwandor, Jolayemi, & Omudu, 2002). Communities may shun, mock, and gossip about those who have, or are perceived to have HIV/AIDS and stigma may manifest itself in the form of violence and murder (Parker & Aggleton, 2002). Common forms of stigma in Zambia are gossip, verbal abuse, name calling and public ridicule. People avoid sitting close to PLWHA, and avoid contact with items they have used (Bond *et al.*, 2002). In a review of disclosure amongst women in Ghana, negative outcomes were experienced in the forms of being avoided and isolate (Mill, 2003).

In Nigeria, community members have reportedly been treating PLWHA as if they were already dead, staring blankly at them, sitting far away from them, not paying them visits, spitting at them and not wanting to eat together or share pit latrines with them (Alubo *et al.*, 2002). In Uganda, people have avoided places where PLWHA have been. It has also been reported that community members have stopped buying produce from PLWHA (Muyinda *et al.*, 1997). In Tanzania, people have also avoided purchasing profitable

goods from PLWHA (Biswalo & Lie, 1995). PLWHA often find themselves in a position of weakness, abandonment and extreme isolation in the community, a situation which is difficult to deal with (UNAIDS, 2002b). A case study of enacted stigma through violence exists in South Africa where a woman was stoned to death after she revealed her HIV status (Van Dyk, 2008).

The Insideout research team (2004) in South Africa conducted 23 focus groups with a total of 205 HIV-infected and non-infected participants throughout the country in order to assess enacted HIV-stigma. This research team concluded that there were numerous themes in the way that people with HIV were treated which could qualify as enacted HIV-stigma: (1) avoidance; (2) rejection; (3) moral judgment; (4) stigma by association; (5) unwillingness to invest in people living with AIDS; (6) discrimination; and (7) abuse. The presence of these enacted stigma themes indicates that HIV-stigma is prevalent throughout the country.

In conclusion, shame, internal felt, community perceived and enacted stigma can have serious consequences for the individual. An individual can internalise stigma, resulting not only in the devaluation of one's identity in the eyes of society, but also in the eyes of oneself (Crocker, 1999).

HIV related shame, stigma, and its influence on psychological functioning

The stigma related to HIV is a major barrier to curbing the HIV/AIDS pandemic worldwide because it drives the epidemic underground. Stigma is considered as one of the main reasons why people do not wish to know their HIV status, do not protect themselves and others from the virus, do not go for treatment and do not care and support people living with HIV. It negatively affects all aspects of HIV prevention, diagnosis, treatment and care (Parker & Aggleton, 2002; Bond, *et. al.*, 2002; Brown, Trujillo, & Macintyre, 2001). In support of these findings, Chesney and Smith (1999) and Eisenman, Cunningham, Zierler, Nakazono, and Shapiro, (2003) reported that fear of being stigmatized leads some to avoid HIV testing, and among those who have been tested and

are HIV-positive, stigma constitutes a chronic stressor that may contribute to coping difficulties, inadequate self-care, and difficulties with safer sex negotiation and condom use.

HIV is highly stigmatized because of its historic association with subgroups of men and women who already experience marginalization within society, including gay men and injection drug users (Herek and Capitano, 1999). Bollinger (2002), Alonzo & Reynolds (1995) and De Bruyn (1999) identified four reasons why HIV is stigmatized:

- HIV/AIDS is a life threatening disease, perceived as contagious and threatening to the community because the disease is not well understood, which results in the fear of contracting it.
- People living with HIV are often seen as being responsible for having contracted the disease which increases the attribution of guilt.
- HIV/AIDS is related to behaviour sanctioned by religious and moral beliefs, which results in the perception that HIV/AIDS is the result of deviant behaviour and consequently deserving punishment.
- HIV/ AIDS is associated with pre-existing social prejudices such as sexual promiscuity, homosexuality and drug use, behaviour that is already considered “less worthy” in many societies. HIV, thus, adds to existing societal judgement.

The construction of stigma whether internal or external is facilitated by social processes and institutions in a particular society for example, education (the marginalization of children known to be born of parents who are HIV positive from going to schools); health systems (health staff not wanting to assist the HIV positive person); government policies and laws; the media; faith based organizations; the family and cultural organizations, and movements (USAID, 2006).

How HIV/AIDS is locally termed and expressed can also reflect the conceptualization of HIV/AIDS. Some places in Nigeria, AIDS has been termed “agolochen” (separation from people or isolation) and “ngu a igba ga” (person without kinsmen) Alubo, Zwandor, Jolayemi & Omudu (2002). A common metaphor in Swahili for contracting AIDS is

“stepping on the electric fence (France, 2000). To come closer to home, in Venda situated in the northern part of South Africa HIV/AIDS has been termed “tshifu” (death or the walking dead). Not only do these terms reflect how HIV/AIDS is conceptualized, they also illustrate how language can contribute to and maintain HIV/AIDS related stigma.

Mental health is jeopardized due to shame and stigma. The negative psychological consequences of shame and stigma includes increasing HIV/AIDS patients feelings’ of social isolation and depression and discouraging people from getting tested for HIV, which are barriers to seeking health care after diagnosis, and prevents disclosure which does not put a stop to further transmission (Major and O’Brien, 2005). Seropositive men and women are often shunned by family, friends, and intimate partners, and overt acts of discrimination in employment, health-care, and housing-related settings are not uncommon (Gostin and Webber, 1998).

A number of studies have been done in the United States reporting a high rate of depression, and anxiety among HIV infected people. (Schonnesson & Ross, 1999, Kaplan, Martens, Marks, 1997). Few studies by Mfusi & Mahabeer, (2000) and Olley, Seedat, Nei, & Stein (2004) in South Africa also reported a 35% rate of depressive symptoms and 15% of posttraumatic stress disorder among men and women with HIV infection. Lindner, (2006) also reported that HIV related community stigma was positively associated with depression and anxiety. Researchers (Olley, Seedat, *et al.*, 2004) found that there was no any significant gender or age differences in terms of the prevalence of mood disorders in South Africa.

Cancer related shame and stigma and its influence on psychological functioning.

Unlike for HIV/AIDS, published literature on cancer stigma is not as prevalent. In South Africa, the research done tended to focus more on the medical realm than the psychosocial aspects (Moodley, Moodley, & Kleinschmidt, 2001). Nonetheless, cancer is another disease that may be stigmatized. In previous studies, cancer was found to be stigmatized because the public did not have enough information about the disease, its risks, and prevention (Romano, 1986). Some people feel uncomfortable in the presence

of someone with cancer, and people with cancer are sometimes “victimized” or avoided by family members and friends, resulting in strain between people with cancer and with both family and friends (Cobb & Erbe, 1978; Wortman & Dunkel-Schetter, 1979).

Stahly (1988) found that the reasons for stigmatizing cancer patients are many, for instance if one was a smoker, a drinker or sexually active at a young age. A study by Tempelaar, De Haes, De Ruiter, Bakker, Van den Heuwel, & Van Nieuwenhuijzen, (1989) in the Netherlands looked at 217 cancer patients and compared their positive and negative social experiences to a similar size group without cancer. These cancer patients had more positive social experiences and fewer negative ones than a random population sample.

This may imply that some people respond supportively when someone is diagnosed with cancer. In another study by Zemore, Rinholm, Shepel, and Richards (1990), many women with cancer reported closer family ties and a more positive outlook on life rather than rejection and abandonment. Bloom and Kessler (1994) indicated that breast cancer no longer carries with it the stigma that might lead to a reduction in the level of women’s emotional support. In fact, their study showed that cancer patients reported receiving more emotional support than did women experiencing other kinds of surgery (Bloom & Kessler, 1994).

The experience of stigma may vary according to a type of cancer. In a qualitative study published recently in the *British Medical Journal*, researchers at Oxford University (Chaple, Ziebland, & McPherson 2004) found lung-cancer patients experienced stigma, shame, and blame from their family, friends, and doctors. Lung-cancer patients in particular felt prejudice, because the disease is so strongly associated with smoking. Many patients, even those who had stopped smoking many years ago or who had never smoked, felt unjustly blamed for their illness. According to the study, one participant said, "People automatically think you've brought it on yourself," Some patients conceal their illness, which sometimes has serious consequences, such as deterring patients from seeking all the help they need.

Greene (2000) stated that patients with cancer are often ashamed of their illness. They may regard their illness as a sign of weakness, and then have to expose themselves physically and psychologically to their physicians. With such attitudes, patients often delay seeking treatment or withhold vital information from their physician. Cancer patients are at particular risk for suffering from these emotions. The word malignant is often used which, in itself, is offensive. Patients may be blamed for being ill, on account of their state of mind or because of what they eat. Manifestations of this disease as well as treatment are often disfiguring and otherwise difficult for patients and their families to bear (ileostomies, mastectomies, throat and facial surgery, loss of hair, loss of ovarian function). This leads to feelings of shame and stigma.

Sadock and Sadock (2003) went further to report that about half of all cancer patients have mental disorders. The largest group is those with adjustment disorder (68 percent), and major depressive disorder (13 percent) and delirium (8 percent) are the next most common diagnosis. Most of these disorders are thought to be reactive to the knowledge of having cancer. However, psycho-oncology has been used to study the impact of cancer on how the psychological and behavioural variables may play in cancer risk and survival. Special attention has been given to family factors, in particular, pre-existing intra-family conflicts, family abandonment, and family exhaustion.

Psycho-oncology functions under the biopsychosocial model, taking into consideration the biological, social, and psychological factors involved. Sadock and Sadock (2003) further pointed out that psychological symptoms were not reported to be due to stigma, but due to the diagnosis itself, therefore there is a need for more studies in South Africa to explore shame and stigma among cancer patients alone.

Gender differences, shame and stigma, psychological dysfunctions among HIV and cancer patients

According to Bennet (1990), traditional attitudes towards women in South Africa help feed shame and stigma. A key similarity across all research sites was the role that gender plays in the nexus between HIV-related stigma, moral judgment, shame, and blame. Although this boundary was difficult to understand at first, it is clear that women generally bear the strongest impact of shame and stigma. The reason underlying this seems to be that women in all of these settings are expected to uphold the moral traditions of their societies. HIV is regarded as evidence that they have failed to fulfil this important social function.

To phrase the problem otherwise: women living with HIV and AIDS (or more often, suspected to be living with HIV and AIDS) are regarded as everything they should not be - sick and slim when they should be healthy; being cared for when they should be caring for others; sexually deviant when they should be sexually righteous. To be HIV-positive is not to be a proper woman (Bond, *et al.*, 2002, Olley, Gxamza, Seedat, Theron, Taljaard, Reid, Reuter, & Stein, 2003).

Stereotypes in which women are seen as subordinates to men socially, psychologically and economically help shape the way society can perceive HIV and cancer infected women. To support this statement Abdool- Karim (1998), De Bruyn (1992) reported that because of traditional gender roles, women are especially vulnerable as they are economically and socially disadvantaged and often lack equal access to societal institutions. Women are more erroneously perceived as the main transmitters of HIV/AIDS, while men are excused for high-risk sexual behaviour. Having multiple sexual partners is culturally more acceptable for males than for females (Warwick, Bharat, Castro, Garcia, Leshabari, Singhanetra-Renard & Aggleton, 1998).

Bond *et al.*, (2002) reported that HIV positive women are treated very different from men in many developing countries: men are likely to be 'excused' for their behaviour that

resulted in their infection, whereas women are not. This view leads women to face more stigmatization and suffer more negative effects than men. In the study of Olley, Gxamza *et al.*, (2004), previously mentioned, 149 (44 male and 105 female) newly diagnosed HIV/AIDS patients in Tygerberg hospital, South Africa, were assessed. The most frequent diagnosis was depression (34, 9%) followed by dysthymic disorder (21,5%). Women were more likely to suffer from post-traumatic stress disorder, while male patients were significantly more likely to abuse alcohol and have more non-protected sex. (Visser, 2007).

In a study conducted by Jennings, Mulaudzi, Everret, Richter, & Heywood (2002) they found that women were more stigmatized often than men infected with HIV. Another study reported that women were sometimes abandoned by their families or labelled as witches, and killed (South African National Council for Child and Family Welfare, 1999). There has not been many published studies examining the impact of stigma on women's psychological functioning, however studies done in the United States found that perceived stigma have been associated with poorer psychological functioning generally among both genders (Clark, Lindner, Armistead, & Austin, 2003), and more specifically with increased anxiety, depression, hopelessness, and suicidal thoughts (Van Dyk, 2001, Lee, Kochman *et al.*, 2002).

A recent study done only on black South African women by Lindner (2006) suggested that women had a large number of symptoms of both depression and anxiety due to their experience of enacted stigma. This study included a sample of women only. Perhaps more quantitative studies on this issue are needed in South Africa, using a larger sample and examining all dimensions of stigma. Although women with HIV are clearly at a high risk for stigmatization, there has been no research in South Africa examining the way that HIV stigma impacts psychological functioning. It is important to have more quantitative and qualitative research examining the level of HIV and cancer related shame and stigma in South Africa, and linking it to outcomes, such as psychological functioning according to different genders.

Age differences, shame, stigma and psychological dysfunctions among HIV/AIDS and cancer patients

Our understanding of the experience of HIV and cancer shame and stigma according to age groups is limited by the fact that research in South Africa has typically not included this aspect. (Bennett, 1990; Clark, *et al.*, 2003; Green & Platt, 1997; Laryea & Gien, 1993; Lee, Wu, Rotherum- Borus, Detel, Guan & Li, 2005; Surlis & Hyde, 2001). Other studies on HIV stigma have neglected age totally as a variable in the analysis (Crandall & Coleman, 1992; Varas-Díaz, Serrano-García, & Toro-Alfonso, 2005; Weitz, 1990). However some studies have reported that HIV/AIDS has been traditionally seen as a disease of younger people (Riley, 1989). USAID (2006) reported that approximately 30% of the reported individuals living with HIV/AIDS in South Africa are 50 years of age or older. There are number of studies with age as a variable done in the United States (US). The estimated number of individuals aged 50 years and older who are living with AIDS in the United States increased from 59,649 to 112,447 between 2000 and 2004 (Clark, *et al.*, 2003).

Uranga (2005) reported that more than 25% of the people living with AIDS in Los Angeles County are 50 years of age or older. Socio-cultural factors including age, gender, and race or ethnicity as well as individual factors such as substance use and mental health issues have been found to increase the risk of HIV infection in older adults. Whether age influences the experiences of shame and stigma and psychological dysfunction is still a question that remains unanswered yet in South Africa (Neundorfer, Harris, Britton, & Lynch, 2005).

A small number of US studies have examined various aspects of HIV stigma in older adults. Heckman, Kochman, and Sikkema (2002) studied 83 adults over the age of 50 with HIV/AIDS, and they found stigma associated with cognitive affective symptoms of depression, similar to younger adults. Lee, Makufa, *et al.*, (2002) examined internalized stigma in 268 HIV-infected men and women, including older adults and found no

significant difference in age between those with high and low levels of internalized stigma.

In a recent study of 44 older and 44 younger adults with HIV/AIDS, Emlet (2006) found that 50% of older adults reported they were ashamed of their illness sometimes or often, and 39% stated they had lost friends as a result of their illness. Younger adults reported similar feelings. Although it is questionable whether older adults experience greater levels of HIV shame and stigma than their younger counterparts, stigma continues to be a formidable psychosocial issue for older adults with HIV infection.

A qualitative study done by Emlet (2006) exploring whether ageism plays a role in the experience of stigma among HIV/AIDS patients revealed that the majority of the respondents experienced both ageism and HIV-associated stigma. Main themes that emerged from the interviews, included rejection, stereotyping, fear of contagion, violations of confidentiality, and internalized ageism. The themes seemed to fall under internal felt stigma and enacted stigma. Another study by Levine (1998) discovered that the older a person is, when they contract HIV, the more likely they are to progress more quickly and when this is explained to the patients by health professionals, they complained of being stigmatized. South Africa is in need of more qualitative and quantitative studies exploring the influence of age groups in the experience of shame and stigma among HIV/AIDS patients.

There have not been many published studies on cancer shame and stigma; however a case report has revealed that older people reported that they did not receive the same quality of cancer care as younger people. Although more than a third of cancer occurs in people over 75 years of age, their tumours are less fully diagnosed and less fully treated than younger patients, and this seemed to be an act of enacted stigma within the health institutions. To support this contention a study of the Yorkshire Cancer Registry covering close to 4 million people, found that older patients had fewer diagnostic and staging procedures and less treatment with advancing age and that survival rates specific to the types of cancer declined with age. They had fewer biopsies to confirm the tumour. With a given type of tumour, the elderly thus received less care and survived a shorter time.

Perhaps there is also a need for a study in South Africa to examine the shame and stigma experienced by cancer patients according to age groups.

Turner, Haward, Mulle, & Selby (1999) suggest the reduced levels of intervention in cancer in the elderly cannot be wholly explained by appropriate adjustments for frailty or comorbidity (coexisting diseases) and that a factor contributing to this situation is ageism, discrimination and stigma against the elderly. However, a study done by Greene (2000) found that if the cancer patient is of the same age with the community he or she anticipates stigma, but the patient usually will experience acceptance, care and empathy. This phenomenon is not yet understood and requires further exploration.

Previous studies done comparing HIV/AIDS and cancer related shame and stigma.

Although any diagnosis of HIV and cancer can be associated with fear and stigma (Chapple, *et al.*, 2004) research reports that cancer stigma does not invoke the attribution of blame that HIV or AIDS often carries, although different kinds of cancer may be perceived differently (Greene, 2000).

Researchers did a study on 45 patients with lung cancer and it was found that whether they smoked or not patients with lung cancers felt particularly stigmatized because the disease is strongly associated with smoking and people die in an unpleasant way. Those who had stopped smoking years ago or had never smoked felt unjustly blamed for their illness. Some patients concealed their illness, which sometimes had serious consequences such as death which could perhaps have been prevented (Chapple *et al.*, 2004).

Crawford (1996) and Greene (2000), for example, found that the stigma associated with HIV/AIDS is higher than that associated with other stigmatized conditions, such as cancer. Similar findings were reported in a study that examined reactions to people with AIDS, serum hepatitis, Legionnaire's disease, and genital herpes (Triplet & Sugarman, 1987). Only people with HIV/AIDS were rated as being interactionally undesirable, yet patients with other diseases had relatively neutral ratings of interactional desirability.

After reviewing the literature, the following hypotheses were established:

1. There will be a difference on the scores of shame and stigma and psychological functioning between HIV/AIDS and cancer patients.
2. Patients who experience shame and stigma are more likely to experience psychological dysfunction than those who do not.
3. Females will experience more shame and stigma, and then consequently report more psychological dysfunctions than males.
4. There will be a difference on the scores of shame and stigma and psychological functioning between age groups.

Chapter 4.

Methodology

The process of how this study was conducted will be discussed below. It will include the following: the study design, the statistical methods used to analyze data, the participants sampled for this study, the instruments used, and their psychometric properties including their scoring formats, procedure for data collection, as well as ethical considerations undertaken.

Research design

This is a quantitative study that utilized a factorial design. The independent variables to be measured are shame and stigma, gender (male and female), and age (-45 and 45+). The dependent variable is the psychological dysfunctions. Therefore, factorial design helps by assessing if there is an interaction effect between the different independent variables with the dependent variable.

Participants

A total of 100 participants (50 HIV/AIDS patients and 50 cancer patients) participated in this study. Of the participants, 38 (38.0%) were males and the majority of them were females 62 (62, 0%). Age of respondents ranged from 20-73 with a mean age of 44.42 (SD = 11.65). The percent of participants identifying with each ethnic group is as follows: Pedi and Sotho (3) 3.3 %, Tsonga (7) 7.0%, Venda (38) 41.8%, Caucasian (37) 40.7 %, Zulu and Xhosa represented (1) 1.1% of the sample. Nine percent did not mention their ethnic background. The sample was largely Venda (41.8 %) because the HIV clinic is within the area populated by Tshivenda speaking people followed by Caucasians (40.7%) due to the support groups involved as they were more prevalent.

Instruments

A questionnaire that is comprised of three sections (A, B and C) was used for this study.

Section A included demographic information such as age, gender, ethnicity, diagnosis, duration for the diagnosis. Section B contained the shame and stigma scale that contains three subscales, which are internal felt stigma, perceived community stigma and enacted stigma as well as shame items. Section C included the General Health Questionnaire (GHQ-28) used to measure psychological dysfunction.

The psychometric properties for these scales will be discussed below separately.

Shame and Stigma Subscales

Items from existing questionnaire (Westbrook and Bauman, 1996) were selected and adapted to constitute a shame and stigma scale for both HIV/AIDS and cancer patients. Similar items used to measure shame and stigma among people with HIV/AIDS was used for cancer patients (with the name of the disease changed). For example, “People with cancer should feel ashamed of having this cancer”. This scale has been used in South Africa and its validity and reliability has been found to be satisfactorily high, Cronbach Alpha reliability for the total shame and stigma scale was 0.79 and 0.82 (Visser & Makin, 2004). The measure showed good reliability in the present sample (alpha = 0.88). As previously reported, shame and stigma scale is divided into three subscales including the shame items which are discussed below.

- **Internal felt stigma and perceived community stigma scales**

Internal felt stigma (feelings of shame or guilt and the oppressive fear of enacted stigma) and perceived community stigma (thoughts about the community’s reaction towards patients with cancer or HIV) scales were administered to assess the level of internal stigma and perceived community stigma that these patients experience. These subscales are made out of 20 questions each. Examples being items such as “it is my fault to get this illness,” “I have done something to deserve this illness,” “people are afraid of me.” The items are phrased positively and negatively and respondents indicated their level of

agreement on a 4-point Likert type scale: 0. strongly disagree, 1. disagree, 2. agree, 3 and strongly agree. Total score of the scale was calculated in such a way that a high score means high levels of stigma (Westbrook & Bauman 1996). In this sample Cronbasch alpha for the internal felt stigma was 0.76 and for the perceived community stigma was 0.85 respectively.

- **Enacted stigma scale**

Another instrument used was the enacted stigma scale which assessed the actual experience of stigma. Enacted stigma is assessed by rating the level of experience of nine types of behaviours that could be discriminative in interpersonal relationships like avoiding interaction, ending relationships and forms of verbal and physical abuse. The examples of such items are as follows: “people do not touch me,” people do not want me around their children,” and “people do not want me to come to their houses.”

The questions were answered on a 3 point scale – 0-“no experience,” 1- “experienced” and 2- “a lot of experience.” A scale score was calculated for the level of enacted stigma ranging from 20 (maximum score) to 0 (minimum score) where no enacted stigma was experienced. Total scores of the scale was calculated in such a way that a high score means high levels of enacted stigma (Mdlalose, 2006). The Cronbasch Alpha for the enacted scale for the present sample was 0.84.

Shame items

Shame items were used to assess the level of shame the patients feel about their illnesses. The items are as follows: “I feel ashamed,” “People with HIV should feel ashamed”, “Most people are not attracted to someone with HIV”, “I feel less attractive”. The questions were answered on a 4 point scale (1. strongly agree, 2. agree, 3. disagree, 4. and strongly disagree). A scale score ranged from 16 (maximum score) to 4 (minimum score). Total score of the scale was calculated in such a way that a high score means high levels of shame (Westbrook & Bauman 1996). The measure showed good reliability in the present sample (alpha = 0.71).

General Health Questionnaire-28 (GHQ-28).

GHQ-28 was developed by David Goldberg in the United Kingdom in 1972 to detect a wide range of psychological disorders, mainly depression and anxiety (Goldberg, 1972). It is not used for children under the age of 15. It contains 28 items that, through factor analysis, have been divided into four sub-scales, which are as follows:

- A – Somatic symptoms (items 1-7) reliability (0.84)
- B – Anxiety/insomnia (items 8-14) reliability (0.85)
- C – Social dysfunction (items 15-21) reliability (0.83)
- D – Severe depression (items 22-28) reliability (0.83) (NferNelson, 2006).

When the psychometric properties of the GHQ-28 were evaluated using the Slovak population, it was found that the Cronbach's alpha coefficients of reliability of the subscales vary around 0.82 and the internal consistency of the total scale is 0.92 (Nagyova, Krol, Szilasiova, Stewart, van Dijk & van den Heuve, 2000). In the GHQ-28, the respondent is asked to compare his or her recent psychological state with his or her usual state. The examples of items include: "been feeling well and in good health", "been having hot or cold spells", "feel that life is entirely hopeless." For each item four answer possibilities are available (0-better than usual, 1-same as usual, 2- worse than usual, 3- much worse than usual). In this study, the Likert scoring procedure is applied and the total scale score ranges from 28 to 112. The higher the score, the poorer the psychological well-being of the patient (Nagyova, *et.al.*, 2000). The measure demonstrated good reliability (0.90) in the present sample. The subscales also showed good reliability in the present sample.

In addition when used in South Africa in the Limpopo province, in a study done to explore intervention aimed at meeting the needs of HIV positive individuals, it was found that the reliability was high and the most frequently reported symptoms were body pain, diarrhoea and weight loss; the highest scores on GHQ were on the somatic subscale (Dageid, 2004).

Procedures for data collection

The study procedures were approved by the University of Limpopo ethics committee in 2007 for the present study. HIV patients were recruited from the local AIDS service organization and informal informed consent from the organizations was obtained. Cancer patients were recruited from the support groups around Pretoria. Purposive sampling techniques were used because of the relatively small number of potential participants, especially with cancer patients.

Participants were given questionnaires at the local AIDS service organization to answer them and return them immediately. Those who reported inability to understand the questionnaire, the researcher took time to explain the questionnaire in simple terms. Cancer patients were interviewed in their respective support groups or their home. Interviews in public places were discouraged because of sensitivity and confidentiality issues, as well as the potential for disruptive background noise. Data for HIV/AIDS patients were collected between April and July, 2008 and for cancer patients this happened between January 2008 and January 2009.

Statistical methods used

Data was then entered in an SPSS system throughout data collection. In order to check for accuracy of data entry, 10% of the sample was randomly selected to be compared to the data entered.

First, descriptive analyses characterizing the frequency with which participants reported a range of shame and stigma related experiences according to age, gender, and diagnosis was done. For descriptive purposes on the shame, internal felt stigma and perceived community stigma items were coded as 3-strongly agree, 2- agree, 1-disagree and 0-strongly disagree. On the enacted stigma items were coded as 0- no experience, 1- experience, 2- a lot of experience. On the GHQ, the items were coded as 0-better as usual, 1-same as usual, 2- worse than usual, 3- much worse than usual

Second, Analysis of Variance (ANOVA) was used to establish between group differences and a Post Hoc (Bonferroni) test to establish within group differences the direction of the prediction.

Thirdly, graphical presentations were used to further illustrate analysis, and finally correlations were used to assess for relationships between stigmatization and psychological functioning.

Ethical consideration

Verbal consent was obtained from the patients. All information obtained from the participants was treated in confidence and there are no identifiable markers, therefore the participant's name was not required when responding to the questionnaire. The researcher ensured that the participants were protected from being physically or psychologically harmed by the research process by ensuring that those who were physically in pain were excluded from this study. Participants were informed of all the aspects of the research, and when a patient inquired about one aspect of a research, the researcher was always ready to provide the explanation for it. The researcher never forced the participants to participate in the study or bribe them with money. The participants were told that they had a right to withdraw their participation in the study should need arise.

Chapter 5

Results

Hypothesis one which reported that there would be a difference in the scores of shame and stigma and psychological functioning between HIV/AIDS and cancer patients was tested using ANOVA. The results did not reveal any significance on the total shame and stigma and total GHQ. However the results revealed a significant main effect on subscales, enacted stigma $F = (1.98), = 17.629, p < .001$ and anxiety $F = (1.98) = 5.750, p < .001$ (see table 1 below).

Table 1: Summary of a one way analysis of variance of the experience of shame and stigma and psychological distress as determined by diagnosis.

Diagnosis		SS	DF	\bar{X}	F	P
Total shame stigma	Between Groups	37.302	1	37.302	.079	ns
	Within Groups	45573.759	96	474.727		
	Total	45611.061	97			
Internal felt stigma	Between Groups	43.560	1	43.560	.394	ns
	Within Groups	10844.200	98	110.655		
	Total	10887.760	99			
Perceived community stigma	Between Groups	195.948	1	195.948	1.208	ns
	Within Groups	15729.688	97	162.162		
	Total	15925.636	98			
Enacted stigma	Between Groups	214.561	1	214.561	17.629	.0001**
	Within Groups	1180.611	97	12.171		
	Total	1395.172	98			
Somatic	Between Groups	7.514	1	7.514	.449	ns
	Within Groups	1624.122	97	16.744		
	Total	1631.636	98			
Anxiety	Between Groups	142.109	1	142.109	5.750	.001*
	Within Groups	2397.527	97	24.717		
	Total	2539.636	98			
Social functioning	Between Groups	.978	1	.978	.088	ns
	Within Groups	1074.436	97	11.077		
	Total	1075.414	98			
Depression	Between Groups	20.264	1	20.264	1.239	ns
	Within Groups	1586.281	97	16.353		
	Total	1606.545	98			
Total GHQ	Between Groups	151.290	1	151.290	.966	ns
	Within Groups	15346.420	98	156.596		
	Total	15497.710	99			

**P < 0.001, *P < .001

A post hoc Bonferroni was used to further compare the means to see the direction of the prediction. It showed that there was a significance difference ($p < 0.001$) in the experience of enacted stigma among HIV and cancer patients. The mean difference was present between HIV and cancer patients with HIV patients experiencing more enacted stigma ($\bar{X} = 4.22$) than cancer patients ($\bar{X} = 1.28$). In terms of anxiety the mean difference also shows that HIV patients ($\bar{X} = 8.81$) experience more anxiety than cancer patients ($\bar{X} = 6.42$) (See table 2 below).

Table 2: Mean scores in the experience of shame and stigma and psychological dysfunctions according to diagnosis.

Variables	<u>HIV Patients (N=48)</u>	<u>Cancer patients (N=50)</u>	
	\bar{X}	\bar{X}	
Total shame and stigma	52.14	53.38	
Internal felt stigma	22.66	23.98	
Perceived com. Stigma	29.30	28.12	
Enacted stigma	4.22	1.28	$p < .0001^{**}$
Somatic symptoms	5.44	6.00	
Anxiety	8.81	6.42	$p < .001^*$
Social Functioning	5.93	5.74	
Depression	4.24	4.77	
Total GHQ	23.9	21.50	

The difference was insignificant for other shame and stigma subscales and psychological subscales. However, the graph below depicted that HIV patients scored high on the GHQ than cancer patients, and cancer patients slightly reported more stigma than HIV patients.

But this remains statistically insignificant which can be attributed to two missing cases on the HIV data. (See figure 1 and 2).

Figure 1: A graphical illustration of the experience of psychological distress according to diagnosis.

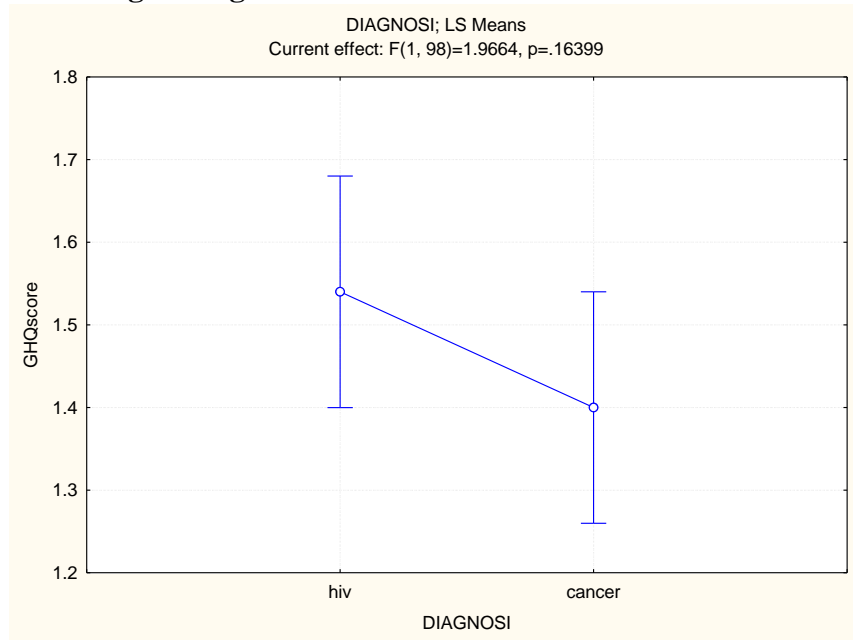
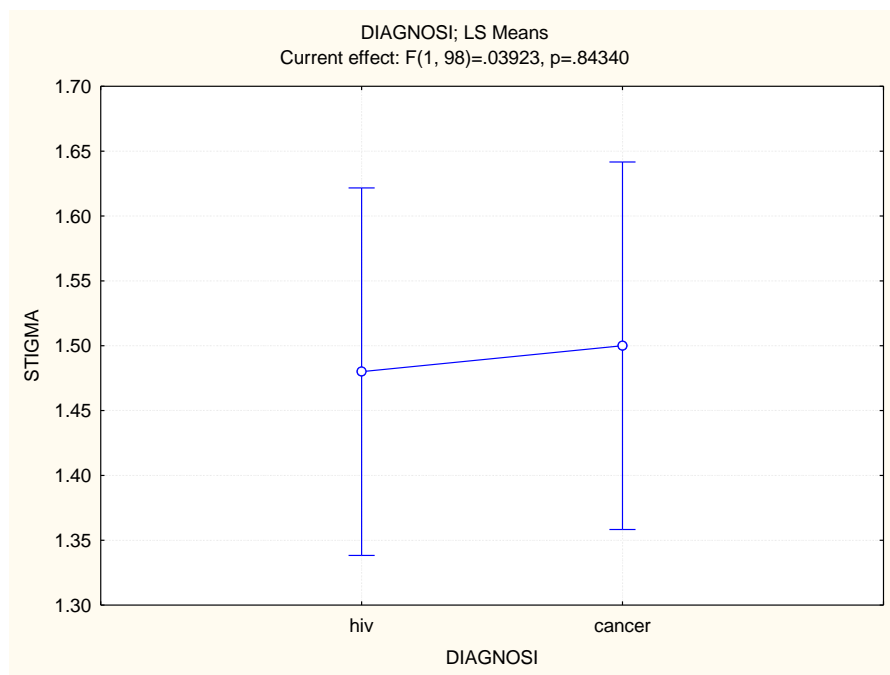


Figure 2: A graphical illustration of the experience of stigma according to diagnosis.



Hypothesis two which predicted that patients who experienced shame and stigma are more likely to experience psychological dysfunction than those who do not was measured using ANOVA. Results revealed an interaction between enacted stigma the total GHQ $F(98) = 1.700$, $p < .005$ was found, anxiety $F(97) = 2.578$, $p < .004$, and depression $F(97) = 3.390$ $p < .001$. An interaction was also present between perceived community stigma and depression $F(98) = 1.452$, $p < .05$. There was no significant effect between internal felt stigma and psychological dysfunctions (See table 3 and 4).

Table 3: Summary of the ANOVA of the influence of shame and stigma on psychological functioning for the total sample.

	Enacted stigma	Sum of Squares	DF	\bar{X}	F	P
Total GHQ	Between Groups	3393.870	14	242.419	1.700	.05*
	Within Groups	11975.544	84	142.566		
	Total	15369.414	98			
Somatic	Between Groups	172.098	14	12.293	.699	ns
	Within Groups	1459.463	83	17.584		
	Total	1631.561	97			
Anxiety	Between Groups	769.168	14	54.941	2.578	.004**
	Within Groups	1768.506	83	21.307		
	Total	2537.673	97			
Social functioning	Between Groups	188.095	14	13.435	1.259	ns
	Within Groups	885.956	83	10.674		
	Total	1074.051	97			
Depression	Between Groups	559.646	14	39.975	3.390	.000**
	Within Groups	978.773	83	11.792		
	Total	1538.418	97			

****P < 0.001, *P < 01**

Perceived comm. stigma		Sum of Squares	DF	\bar{X}	F	P
Total GHQ	Between Groups	5376.942	34	158.145	1.054	ns
	Within Groups	9598.896	64	149.983		
	Total	14975.838	98			
Somatic	Between Groups	486.315	34	14.303	.799	ns
	Within Groups	1145.321	64	17.896		
	Total	1631.636	98			
Anxiety	Between Groups	891.494	34	26.220	1.018	ns
	Within Groups	1648.143	64	25.752		
	Total	2539.636	98			
Social functioning	Between Groups	424.002	34	12.471	1.225	ns
	Within Groups	651.412	64	10.178		
	Total	1075.414	98			
Depression	Between Groups	699.516	34	20.574	1.452	.05*
	Within Groups	907.029	64	14.172		
	Total	1606.545	98			

****P < 0.001, *P < 01**

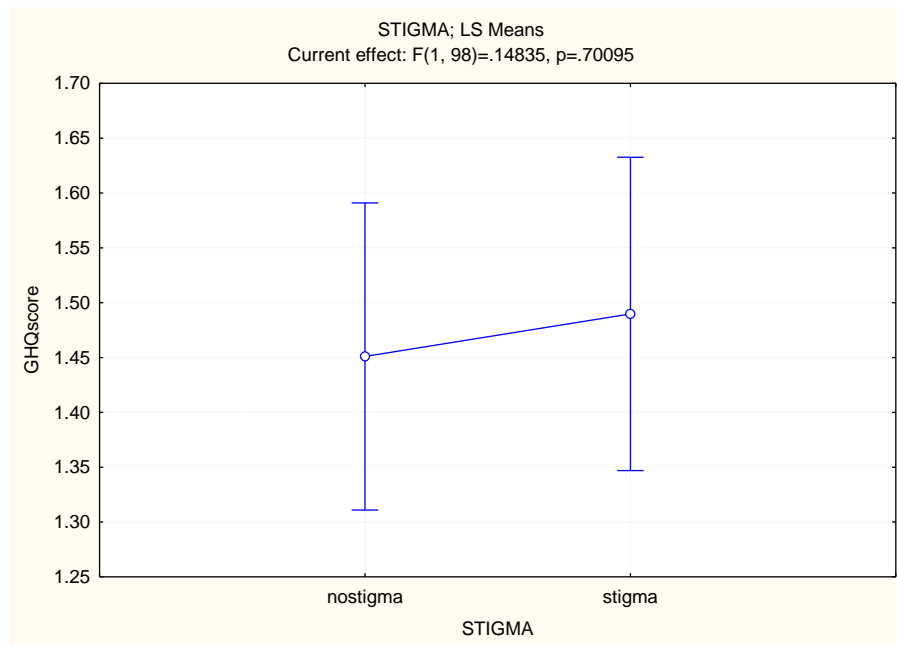
Internal felt stigma		Sum of Squares	DF	\bar{X}	F	Sig.
Total GHQ	Between Groups	3850.750	35	110.021	.605	ns
	Within Groups	11646.960	64	181.984		
	Total	15497.710	99			
Somatic	Between Groups	378.324	34	11.127	.568	ns
	Within Groups	1253.312	64	19.583		
	Total	1631.636	98			
Anxiety	Between Groups	789.463	34	23.219	.849	ns
	Within Groups	1750.174	64	27.346		
	Total	2539.636	98			
Social functioning	Between Groups	392.959	34	11.558	1.084	ns
	Within Groups	682.455	64	10.663		
	Total	1075.414	98			
Depression	Between Groups	413.265	34	12.155	.652	ns
	Within Groups	1193.281	64	18.645		
	Total	1606.545	98			

Table 4: Mean scores of stigma types on psychological functioning.

	Enacted stigma		Community stigma	Internal felt stigma
	N	\bar{X}	\bar{X}	\bar{X}
Total GHQ	99	22.61	22.95	22.73
Somatic symptoms	99	5.72	5.72	5.72
Anxiety	99	7.59	7.60	7.60
Social functioning	99	5.82	5.83	5.83
Depression	99	3.70	3.78	3.78

Results illustrated by a graph depicted that patients who reported shame and stigma reported more psychological distress (See figure 3).

Figure 3. A graphical illustration of the experience of shame and stigma and psychological functioning.



Hypothesis three which reported that females will experience more shame and stigma than males, and then consequently report more psychological dysfunction than males was

measured using ANOVA. Results revealed significant main effects on enacted stigma $F(1.96) = 6.760, p < .001$, internal felt stigma $F(1.97) = 3.359, p < .005$, with females experiencing more enacted stigma ($\bar{X} = 3.52$) than males ($\bar{X} = 1.52$) and with males experiencing more internal felt stigma ($\bar{X} = 26.07$) than females ($\bar{X} = 22.26$). (See tables 5 & 6). There was no significant effect for psychological dysfunctions.

Table 5: Summary of the ANOVA of the experiences of shame and stigma and psychological functioning as determined by gender.

Variables		SS	DF	\bar{X}	F	P
Enacted stigma	Between Groups	92.371	1	92.371	6.760	.001**
	Within Groups	1298.186	95	13.665		
	Total	1390.557	96			
Perceived comm. stigma	Between Groups	135.580	1	135.580	.855	ns
	Within Groups	15221.328	96	158.556		
	Total	15356.908	97			
Internal felt stigma	Between Groups	338.126	1	338.126	3.359	.005*
	Within Groups	9664.496	96	100.672		
	Total	10002.622	97			
Total shame stigma	Between Groups	333.319	1	333.319	.729	ns
	Within Groups	43429.135	95	457.149		
	Total	43762.454	96			
Total GHQ	Between Groups	48.090	1	48.090	.311	ns
	Within Groups	14863.746	96	154.831		
	Total	14911.837	97			
Depression	Between Groups	2.922	1	2.922	.175	ns
	Within Groups	1602.996	96	16.698		
	Total	1605.918	97			
Social functioning	Between Groups	.835	1	.835	.075	ns
	Within Groups	1073.216	96	11.179		
	Total	1074.051	97			
Anxiety	Between Groups	17.902	1	17.902	.694	ns
	Within Groups	2477.649	96	25.809		
	Total	2495.551	97			
Somatic	Between Groups	28.376	1	28.376	1.702	ns
	Within Groups	1600.246	96	16.669		
	Total	1628.622	97			

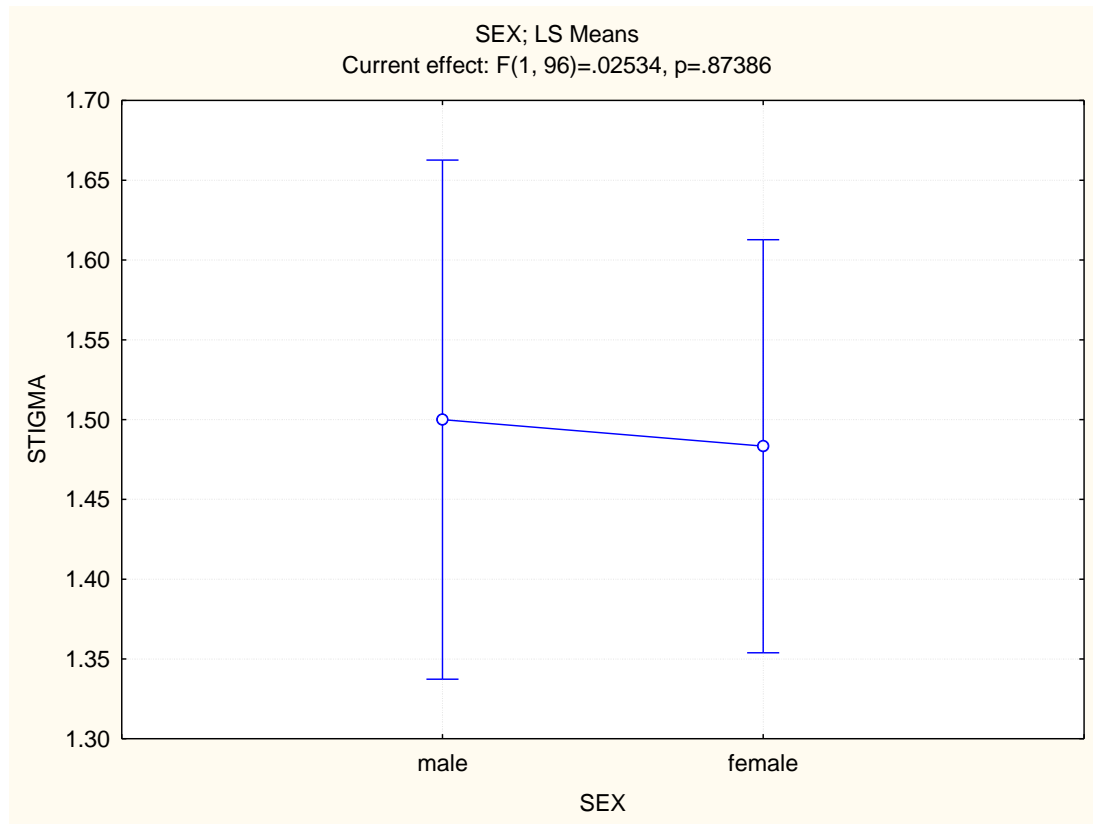
* $P < 0.05$, ** $P < .001$.

Table 6: Mean scores of shame and stigma and psychological functioning as determined by gender.

	<u>Males (N=38)</u>	<u>Females (60)</u>
	\bar{X}	\bar{X}
Variable		
Enacted stigma	1.52	3.52
Perceived com. stigma	28.44	26.03
Internal felt stigma	26.07	22.26
Total shame and stigma	55.52	51.72
Total GHQ	23.92	22.48
Depression	3.57	3.93
Social functioning	5.71	5.90
Anxiety	8.21	7.33
Somatic	6.42	5.31

Results depicted by a graph revealed a slight difference, which is that males experience more shame and stigma on the whole than females but the results remain statistically insignificant (see figure 4 below).

Figure 4 illustrating of the experience of shame and stigma according to gender.



Hypothesis four which predicted that there will be a difference in the score of shame and stigma and psychological dysfunction between age groups was measured using the ANOVA. Results showed a significance on internal felt stigma $F = (1.96) = 4.082$, $P < .004$ and somatic symptoms $F = (1.95) = .4189$, $P < .004$. (See table 7). Patients below age 45 ($\bar{X} = 25.32$) reported more internal felt stigma than those above 45 ($\bar{X} = 21.02$) years while those above 45 ($\bar{X} = 6.80$) reported more somatic symptoms than those below age 45 ($\bar{X} = 5.10$). (See table 8).

Table 7: Summary of the ANOVA of the experience of shame and stigma and psychological functioning as determined by age.

	Age	SS	DF	\bar{X}	F	P
Internal felt stigma	Between Groups	441.038	1	441.038	4.082	.004*
	Within Groups	10263.085	95	108.032		
	Total	10704.124	96			
Perceived com. stigma	Between Groups	24.778	1	24.778	154	ns
	Within Groups	15141.722	94	161.082		
	Total	15166.500	95			
Enacted stigma	Between Groups	14.585	1	14.585	1.01	ns
	Within Groups	1357.405	94	14.440		
	Total	1371.990	95			
Total shame stigma	Between Groups	636.892	1	636.892	1.376	ns
	Within Groups	43038.098	93	462.775		
	Total	43674.989	94			
Somatic	Between Groups	67.549	1	67.549	4.189	.004*
	Within Groups	1515.784	94	16.125		
	Total	1583.333	95			
Anxiety	Between Groups	5.064	1	5.064	.189	ns
	Within Groups	2520.592	94	26.815		
	Total	2525.656	95			
Social functioning	Between Groups	6.552	1	6.552	.577	ns
	Within Groups	1068.104	94	11.363		
	Total	1074.656	95			
Depression	Between Groups	2.803	1	2.803	.168	ns
	Within Groups	1570.436	94	16.707		
	Total	1573.240	95			
Total GHQ	Between Groups	55.423	1	55.423	.345	ns
	Within Groups	15239.546	95	160.416		
	Total	15294.969	96			

*P < .05, **P < .001

Table 8: Mean scores in the experience of shame and stigma and psychological dysfunctions according to age groups.

	Below 45(N=55)	45+(N=42)
	\bar{X}	\bar{X}
Variables		
Internal felt stigma	25.32	21.02
Perceived com. stigma	27.56	26.53
Enacted stigma	3.16	2.38
Total shame and stigma	55.66	50.43
Somatic	5.10	6.80
Anxiety	7.85	7.39
Social dysfunction	5.61	6.14
Depression	3.65	4.00
Total GHQ	22.23	23.76

Chapter 6

Discussion of results

This study examined whether shame and stigma has an influence on the psychological dysfunctions among HIV/AIDS and cancer patients with age and gender groups in consideration. Although a number of studies have documented the experience of shame and stigma among HIV patients, the study advances the literature by characterizing the degree to which cancer patients also report experiencing shame and stigma and by confirming the association between certain subtypes of stigma with certain psychological symptoms.

The first hypothesis looked at the difference in the scores of shame and stigma and psychological functioning between HIV/AIDS and cancer patients. Results did reveal the experience of enacted stigma and anxiety among HIV patients. Mean difference revealed that HIV/AIDS patients experienced enacted stigma and anxiety than cancer patients. Few previous studies have reported that patients with HIV will tend to experience more shame and stigma than cancer patients due to the association of HIV with behaviours that are already marginalized (Greene, 2000).

These findings are also consistent with the widely held assumptions of the attribution theory which states that individuals are held more responsibly for outcomes in situations where they are perceived to have control, and if the outcome is negative; the person receives more blame, less sympathy and pity (Cobb & de Charbert, 2002 Bloom & Kessler, 1994, Greene, 2000 Triplet & Sugarman, 1987, Crawford 1996). Those infected with HIV/AIDS reported more enacted stigma and anxiety probably due the attributions made towards them. Interestingly, different kinds of cancer tend also to invoke shame and stigma e.g. breast cancer and lung cancer. Consistent with previous researches (e.g. Crawford, 1996, Greene, 2000) this study shows that HIV/AIDS elicits more shame and stigmatizing reports than cancer.

Hypothesis two envisaged that patients who experienced shame and stigma are more likely to experience psychological dysfunction than those who do not. Results revealed enacted stigma

had an influence in the experience of psychological dysfunctions in general, anxiety and depression. Perceived community stigma was also found to have an influence on depression. No interaction was found between internal felt stigma and psychological symptoms.

The results are in agreement with past researches which also found that enacted stigma has been found to be associated with psychological dysfunction with symptoms such as depression and anxiety (Lindner 2006, Lee, Kochman *et al.*, 2002), hopelessness, and suicidal thoughts (Van Dyk, 2001, Heckman *et al.*, 2002). The process and nature of enacted stigma includes overt negative behaviours such as labelling towards people with stigmatized conditions, which can be a very painful experience leading to severe impact on the stigmatized person's mental health. Through these results, and with the support of previous researches, it became evident that when patients experience more enacted stigma, and perceived community stigma they will report more psychological dysfunctions.

Hypothesis three examined the experience of stigma according to gender differences. The results revealed experiences of different kinds of stigma. Females seem to experience more enacted stigma than males while males experience more internal felt stigma than females. However, the experience of internal felt stigma and enacted stigma was not found to have influence on the psychological functioning of patients according to different genders.

Although there was no significant difference in any of the subscales and psychological functioning as a whole, the mean difference revealed that males experienced more psychological dysfunction than females with more reports on anxiety. How this came about is a phenomenon that needs to be explored, with further research putting much emphasis on gender differences. Therefore, this hypothesis was only partially accepted on the basis of shame and stigma but could not reach the level of significance on the psychological distress although there are some slight mean differences. However, studies done have found that females experience more stigma than males (Jennings, *et al.*, 2002, South African National Council for Child and Family Welfare 1999) probably due to subordination, that women have been placed under because of social, cultural and psychological factors (Bond, *et al.*, 2002 Abdool- Karim, (1998), De Bruyn 1992, (Warwick *et al.*, 1998). Females have been found to be one of the disadvantaged groups with researches reporting that they are more stigmatized

because of their social standing and how they are perceived within a particular cultural environment (Uhl & Kobrina 2003). These results also partially concur with the vulnerability hypothesis which holds the assumption that people are vulnerable to a number of distresses due to a number of factors i.e. gender. On the other hand, Clark, *et al.*, (2003) found that shame and stigma affected both genders in the same way and there was no significant difference. Perhaps a qualitative and quantitative study can be done assessing the vulnerability hypothesis (gender, age, personality factors, and social factors) as the predictor of shame and stigma and psychological dysfunctions among HIV/AIDS and cancer patients in South Africa.

Hypothesis four predicted that there will be a difference in the score of shame and stigma and psychological dysfunction between age groups. Results revealed that patients over 45 reported more somatic symptoms, than patients below 45. However, patients below 45 reported experiencing more internal felt stigma than those above 45. Most studies done found that the experience of shame and stigma and psychological dysfunctions did not differ according to age groups (Lee, Kochman *et al.*, 2002, Emlet, 2006). If young or old, they both reported the experience of shame and stigma. The experience of internal felt stigma could be seen as a result of cognitive distortions generally (Beck, 1976).

However, a small case study with cancer patients reported that older people with cancer always felt that they were not treated in the same way as younger patients. This view is in agreement with the theory of ageism whose premise is the discrimination of people based on their age. This experience of ageism within the context of having a disease is referred to as stigmatization. The process of discriminating older people with a disease is referred to as adultism, whereas with younger people it is referred to as jeunism. Emlet (2006) did a study exploring the influence of ageism on the experience of shame and stigma among older HIV patients and found the presence of the influence of ageism on the experience of stigma. Whether ageism has an influence on the experience of shame and stigma is difficult to confirm as there has not yet been many studies (Emlet, 2006) to explore the influence of age on the experience of shame and stigma and psychological dysfunctions.

Conclusion

In conclusion, although these results have revealed that the experience of shame and stigma is more prevalent among HIV patients, that does not necessarily mean that cancer patients do not experience stigma (Greene, 2000, Chapple, 2004). In summary, this research serves to make known that cancer patients like HIV patients do experience shame and stigma which in turn influence psychological functioning, although for the latter it is not as severe compared to the HIV group. However, the major findings of this study are as follows:

- HIV/AIDS patients were found to experience more enacted stigma and anxiety than cancer patients.
- Patients who experienced more shame and stigma also reported more psychological dysfunctions in general.
- Patients who reported more enacted stigma were found to experience anxiety and depression.
- Perceived community stigma had a significant effect on depression while internal felt stigma had no effect on any psychological dysfunction.
- Patients below the age of 45 were found to experience more internal felt stigma than those above 45 of age while those above 45 reported more somatic symptoms than those below age 45.
- Females were found to experience more enacted stigma than males while males experienced more internal felt stigma than females.

Recommendations

Community interventions may be developed to restrain the fear and attributions that are still prevalent. People with HIV and cancer should therefore be encouraged to disclose their status to their families and friends since that would increase personal interaction and decrease internal felt stigma and perceived community stigma.

The highly negative enacted stigma that has evolved through various community processes over the past three decades needs to be addressed. To change a community construction

would require an open commitment from all sectors of the government, community leaders, and the media to support and care for people with HIV and cancer. More exposure and more talk in the community about how people with HIV and cancer can be supported may also contribute to a more realistic perception of community attitudes. This can be done through a process of the community counselling model which includes all sectors of the community.

Limitations

The strengths of this study included the fact that shame and stigma is reported across a broad spectrum of health related domain, using psychometrically reliable and valid measures, as well as the inclusion of men and women, however there are several limitations of the study worth considering. When interpreting the results it was very important to note that the respondents were not recruited in a systematic way, but that a sample of convenience was used. This resulted in an over-representation of males and this limit the generalizability of these findings. In a more representative sample the level of shame and stigma and psychological dysfunction might have proved different.

Further the study looked only at shame and stigma, age and gender as the predictors of psychological dysfunction and neglected factors such as personality factors, self-esteem, medical factors, and other social factors worth considering. There is therefore a need for a study exploring these factors. Also, this study compared HIV/AIDS and different kind of cancers which are acquired differently; if HIV was compared with breast cancer or cervical cancer (which seems to be stigmatized) or any other STD different results could have definitely been found.

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APPENDICES

APPENDIX 1.

Questionnaires

FACULTY OF THE SOCIAL SCIENCES

UNIVERSITY OF LIMPOPO

Dear Sir/ Madam

This is a social psychology survey and the following questions are designed to measure the shame and stigma as experienced by patients with HIV and cancer. There are many differences of opinions about this subject. We would like to know what you think of the subject. There are no rights or wrong answers; we are only interested in your opinion. It is important you answer every item. Please do not sign your name.

Section A. Bibliographical Information

1. Sex: male () female ()
2. Age (In years)
3. Religion.....
5. Ethnicity: 1. Pedi (), 2. Tsonga (), 3. Venda (), 4. Sotho (), others.....
6. Diagnosis
7. Duration of the diagnosis.....

Section B.

Read the following statements and please answer the questions as honestly as possible by writing the number of the answers that you agree with the most in the open space.

1. Strongly agree

2. Agree

3. Disagree

4. Strongly disagree

- 7. I feel ashamed of having this illness _____
- 8. I have done something to deserve this illness _____
- 9. It is my fault to get this illness _____
- 10. It is a matter of bad luck _____
- 11. This illness is a punishment of bad behaviour _____
- 12. I feel bewitched _____
- 13. In interaction with others I feel uncomfortable _____
- 14. I think less of myself _____
- 15. People have a right to be afraid of me _____
- 16. I feel less attractive _____
- 17. I can teach others about life _____
- 18. I can look after children _____
- 19. I deserve praise for handling this illness _____
- 20. I understand if people reject my friendship _____
- 21. Others do not drink from the same tap as me _____
- 22. Employers would not hire me _____
- 23. Neighbours would not like me living next door _____
- 24. People do not sit next to me in public transport _____
- 25. I deserve respect _____
- 26. I am no different _____
- 27. People with this illness should feel ashamed _____
- 28. They deserve the illness _____
- 29. The illness is their own fault _____

- 30. The illness is a matter of bad luck _____
- 31. The disease is a punishment for bad behaviour _____
- 32. People with HIV/cancer are bewitched _____
- 33. Most people feel uncomfortable interacting with someone with HIV/cancer _____
- 34. Most people think less of someone with HIV/cancer _____
- 35. Most people are afraid to be around someone with HIV _____
- 36. Most people are not attracted to someone with this illness _____
- 37. They can teach others about life _____
- 38. It is safe for them to look after children _____
- 39. People with this illness deserve praise _____
- 40. People would reject my friendship _____
- 41. People would not drink from the same tap as me _____
- 42. Employers would not hire someone with HIV/cancer _____
- 43. Neighbours would not want someone with HIV/cancer living next door to them _____
- 44. People would not sit next to someone with HIV/cancer in public transport _____
- 45. People with HIV/cancer deserve respect _____
- 46. Someone with HIV/cancer is not different from other people. _____

1. No experience

2. Experience

3. A lot of experience

- 48. I have lost friends because of this illness _____
- 49. I felt hurt by other people's reactions _____
- 50. People do not touch me _____
- 51. People do not want me around their children _____
- 52. People do not want me to come to their houses _____
- 53. I have been called bad names _____
- 54. I have been physically hurt _____
- 55. I have been threatened with death _____
- 56. My partner left me because of my diagnosis _____

Section B.

General Health Questionnaire (GHQ28)

We would like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions by writing the answer which best applies to you in the open space. Remember that we want to know about **PRESENT** and **RECENT** complaints, not those that you have had in the past.

It is important that you try to answer ALL the questions.

1. Better than usual

2. Same as usual

3. Worse than usual

4. Much worse than usual

- 1. Have you been feeling well and in good health? _____
- 2. Have you been feeling in need of a good energizer? _____
- 3. Have you been feeling run down and out of sorts? _____

4. Have you been feeling that you are ill?

5. Have you been getting pains in your head?

6. Have you been getting a feeling of tightness or pressure in the head? _____
7. Have you been having hot or cold spells?

8. Have you lost much sleep over worry?

9. Have you been having difficulty staying asleep once you are in bed?

10. Have you been feeling constantly under strain?

11. Have you been feeling edgy and short-tempered?

12. Have you been getting scared and panicky for no good reason?

13. Have you been finding everything getting on top of you?

14. Have you been feeling nervous and strung-up all the time?

15. Have you been managing to keep yourself busy and occupied?

16. Have you been taking longer to finish things you do?

17. Have you been feeling that overall, you were doing things well?

18. Have you been satisfied with the way you carry out a task?

19. Have you been feeling that you are playing a useful part/role in things?

20. Have you been feeling capable of making decisions about things?

21. Have you been able to enjoy your normal day-to-day activities?

22. Have you been thinking of yourself as a worthless person?

23. Have you been feeling that life is entirely hopeless?

24. Have you been feeling that life is not worth living?

25. Have you thought of the possibility that you might make away
with yourself?

26. Have you been finding that at times you could not do anything
because your nerves were so bad?

27. Have you been finding yourself wishing you were
dead and away from it all?

28. Have you been finding that the idea of taking your
own life kept coming into your mind?

THANK YOU FOR TAKING PART IN THIS STUDY.

APPENDIX 2

Ethics forms

UNIVERSITY OF LIMPOPO ETHICS COMMITTEE

APPLICATION FOR HUMAN EXPERIMENTATION

(Completed forms, preferably typed, should reach the Chairperson of the Ethics Committee at least one month before the experimentation is due to start. Projects where the researcher only receives human material for analysis without actually being involved with collection from the experimental group must still register in the normal way. Researchers who are involved with projects which have been approved by Ethical Committees of other Institutions should provide this Committee with the necessary information and provide it with a shortened protocol for approval).

PROJECT TITLE: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients.

PROJECT LEADER: N.A. Matamela

DECLARATION

I, the signatory, hereby apply for approval to execute the experiments described in the attached protocol and declare that:

1. I am fully aware of the contents of the Guidelines on Ethics for Medical Research, Revised Edition (1993) and that I will abide by the guidelines as set out in that document (available from the Chairperson of the Ethics Committee); and
2. I undertake to provide every person who participates in any of the stipulated experiments with the information in Part II. Every participant will be requested to sign Part III.

Name of Researcher: N.A. Matamela

Signature:

Date:

-

For Official use by the Ethics Committee:

Approved/Not approved

Remarks:

Signature of Chairperson:

Date:

PROJECT TITLE: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients.

PROJECT LEADER: N.A. Matamela

APPLICATION FOR HUMAN EXPERIMENTATION: PART II

Protocol for the execution of experiments involving humans

1. Department: Psychology
2. Title of project: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients
3. Full name, surname and qualifications of project leader: Nyambeni Asnath Matamela (B. Psych)
4. List the name(s) of all persons (Researchers and Technical Staff) involved with the project and identify their role(s) in the conduct of the experiment:

Name:	Qualifications:	Responsible for:
N.A. Matamela	B. Psych.	Project leader and analysis of data
Prof. S.E. Idemudia	PhD	Supervision

5. Name and address of supervisor: Prof. S.E. Idemudia

University of Limpopo
Department of Psychology (M-Block)
P/Bag x1106
Sovenga
0727

6. Procedures to be followed: The total of 100 participants of males and females will serve as the researcher's sample.
7. Nature of discomfort: No discomforts are expected but if there is a sign of psychological distress, psychological services will be given.
8. Description of the advantages that may be expected from the results of the experiment: The results of the study will address the issue of Shame and Stigma as predictors of psychological dysfunction among HIV/AIDS and cancer patients.

Signature of Project Leader:

Date

PROJECT TITLE: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients.

PROJECT LEADER: N.A. Matamela

APPLICATION FOR HUMAN EXPERIMENTATION: PART II

INFORMATION FOR PARTICIPANTS

1. You are invited to participate in the following research project/experiment: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients.
2. Participation in the project is voluntary and you are free to withdraw from the project/experiment (without providing any reasons) at any time. You are, however, requested not to withdraw without careful consideration since such action might negatively affect the project/experiment.
3. It is possible that you might not personally experience any advantages during the experiment/project, although the knowledge that may be accumulated through the project/experiment might prove advantageous to others.
4. You are encouraged to ask any questions that you might have in connection with this project/experiment at any stage. The project leader and her staff will gladly answer your question. They will also discuss the project/experiment in detail with you.
5. Your involvement in the project will be to assist the researcher by taking the time to fill in the scale.

**UNIVERSITY OF THE LIMPOPO
ETHICS COMMITTEE**

PROJECT TITLE: Shame and Stigma as Predictors of Psychological Dysfunction among HIV/AIDS and Cancer Patients.

PROJECT LEADER: N.A. Matamela

CONSENT FORM

I, _____ hereby voluntarily consent to participate in the following project: *(it is compulsory for the researcher to complete this field before submission to the ethics committee)*

I realise that:

1. The study deals with shame and stigma as predictors of psychological dysfunction among HIV/AIDS and cancer patients
2. The procedure or treatment envisaged may hold some risk for me that cannot be foreseen at this stage.
3. The Ethics Committee has approved that individuals may be approached to participate in the study
4. The experimental protocol, i.e. the extent, aims and methods of the research, has been explained to me
5. The protocol sets out the risks that can be reasonably expected as well as possible discomfort for persons participating in the research, an explanation of the anticipated advantages for myself or others that are reasonably expected from the research and alternative procedures that may be to my advantage.
6. I will be informed of any new information that may become available during the research that may influence my willingness to continue my participation.
7. Access to the records that pertain to my participation in the study will be restricted to persons directly involved in the research.

8. Any questions that I may have regarding the research, or related matters, will be answered by the researchers.
9. If I have any questions about, or problems regarding the study, or experience any undesirable effects, I may contact a member of the research team
10. Participation in this research is voluntary and I can withdraw my participation at any stage.
11. If any medical problem is identified at any stage during the research, or when I am vetted for participation, such condition will be discussed with me in confidence by a qualified person and/or I will be referred to my doctor.

Signature of researched person

Signature of witness

Signature of person that informed the researched person

Signature of parent/guardian

Signed at _____ this ____ day of _____ 200