

**AN INVESTIGATION TO EXAMINE THE CONSTRUCTION OF  
MEANINGS, ATTITUDES AND PERCEPTIONS OF HIV/AIDS  
AMONG LAY AND PROFESSIONAL COUNSELLORS IN  
KWAZULU NATAL**

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## **ABSTRACT**

Short of a medical breakthrough, counselling is the only available tool to deal with the loss, pain and suffering that AIDS patients' experience. Studies have suggested that although there is a change in society's perception to AIDS, there still exist some negative attitudes and perceptions that occur among a variety of groups, which includes the health care workers. This study aims to investigate the construction of meaning, perceptions, and attitudes of HIV/AIDS among professional and lay counsellors. The researcher will compare lay and professional counsellors' attitudes, perceptions and meanings of AIDS.

The Social Representational Theory was used to provide an understanding of how these metaphors and attitudes emerged and still exist. Qualitative methodology was used, which allowed the researcher to gather in - depth data necessary for the study of psychological issues. The study made use of non- probability purposive sampling. Data were collected by use of in-depth interviews. A pilot study was conducted to 'test' the interview schedule. Three lay and three professional, female counsellors were recruited for the interviews. All the interviews were tape recorded and transcribed. Thematic analysis was used to analysis the data.

Essentially, the data reflected that there were many emergent metaphors which counsellors used that were similar to the general population. At times, these metaphors impacted on the counselling process. The findings of this study made recommendations in terms of more research around this area is needed, training programmes should include training in peer supervision and it should include more practical exposure to real situations.

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## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1. Introduction**

Over the past decades, there has been growing concern about the rapid spread of HIV/AIDS throughout the world because at present there exists no medical cure for AIDS (Pawluch, Cain & Gillett, 2000). The most effective responses to HIV/AIDS lie in the cultural, social and behavioural domains. In addition, HIV/AIDS has produced enormous personal and social suffering. Therefore, there is a need to develop tools to deal with the loss, grief and give hope to HIV/AIDS patients. The pain and suffering is real and it needs to be acknowledged (Bor & Miller, 1988).

Counselling is the appropriate tool because HIV/AIDS involves human psychological, interpersonal and social processes. Therefore, this gave rise to a fairly large body of material, which consisted of guidelines, summaries of the goals, processes and the different stages of HIV/AIDS counselling. The purpose of these publications was to inform the health and social personnel of the importance of HIV/AIDS counselling and provide them with some basic information for practice (Silverman, 1997). Although there is a substantial increase of public knowledge about HIV/AIDS (Asthana & Oostrogels, 2001), there is some evidence to suggest that general attitudes towards AIDS patients have not been altered. This occurs especially among a variety of groups including the general public, students and health care workers (Craig, 1999). These studies have demonstrated that there is considerable stigma attached to AIDS. Negative attitudes towards people with AIDS have also been widely reported among health care professionals (Craig, 1999).

Thus, according to the studies above, negative attitudes towards HIV/AIDS patients still exists and these were also reported among health care workers. Further, given that the appropriate treatment or tool used in dealing with HIV/AIDS is counselling, a clearer understanding of these attitudes needs to be, therefore considered. Further, if these attitudes exist, do they exist among counsellors? If so, what are the implications for the counselling process? There have been few substantial reviews of the field of HIV/AIDS counselling. There is clearly a notable lack of research in this area. In Africa, the current understanding of AIDS is not well established. The meanings, attitudes and concepts of AIDS and its impact on the counselling process have not been considered. Therefore, this motivated the researcher to conduct this study. The purpose of the study is to investigate the construction of meanings, perceptions and attitudes among lay and professional AIDS counsellors. However, an understanding of the origins of HIV/AIDS is initially required since it would be used later on in the study to explain certain meanings and attitudes.

This chapter will therefore, examine the origin of the HIV/AIDS virus within a global context. Thereafter, HIV/AIDS within the South African context will be considered. The research problem, goals and purpose of this study shall be discussed. The methodology that would be used to achieve the research goals will be outlined briefly. The various terminologies that are used in the study will be examined and a brief outline of the chapters that are to follow will be discussed.

## 1.2. The Global Picture

In order to appreciate the current status of the pandemic, it is essential to review the brief history of the global HIV/AIDS epidemic. (Gottlieb et al., 1989). The history can be divided into three periods: silence, initial discovery and global mobilization.

As the name suggests, the dominant feature of the first period was silence. The human immunodeficiency virus (HIV) was unknown, and transmission was not accompanied by signs or symptoms salient enough to be noticed. The second period involved the initial discovery of the virus, which was characterized by relatively rapid scientific advances in understanding of illnesses.

Twenty - three years have elapsed since the acquired immune deficiency syndrome (AIDS) was first identified in 1979 in the United States. Since then it has become the most infectious disease in contemporary history, and quite likely the most serious new menace to human health around the world this century (Eagle & Bedford, 1992). The origin of the virus is unclear. A review of medical records dating back to the 1950's in England and United States, has revealed cases of AIDS. These cases were confirmed as HIV related by intensive testing of frozen tissue and blood samples. Further investigations traced the virus to, as early as 1092, by descriptions of illnesses of people in Europe, America, Central Africa and even Venezuela (Weitz, 1991). It is generally acknowledged that the beginning of the 1980's signified the onset of the global epidemic (Vargo, 1992)

However, anecdotal reports of this illness first surfaced in 1979 among doctors working in New York, San Francisco and Los Angeles. These doctors had noticed that Kaposi's sarcoma, a rare form of cancer that normally affects elderly heterosexual Italian and Jewish men, had begun appearing in young gay men.

Moreover, whereas Kaposi's sarcoma was usually a mild, chronic condition, these new gay patients became terribly disfigured by purple lesions and then rapidly died (Weitz, 1991). Between 1979 to 1981, another curious disease began attacking and killing gay men. This time the disease was pneumocystis carini pneumonia (PCP), a rare form of pneumonia that generally affects only persons whose immune systems have been weakened by chemotherapy, certain serious illnesses, or drugs taken after organ transplants to suppress the immune system so it will not attack that "foreign" organ. Under these circumstances, people cannot fight infections. They subsequently fall ill because various microorganisms that usually live benignly in the body take advantage of this opportunity to multiply (Vargo, 1992). The resulting illnesses are known as opportunistic infections.

On 5<sup>th</sup> of June 1981, the Centre for Disease Control (CDC), which tracks the spread of disease in the United States, published the first official notice of the PCP outbreak. One month after the article on the PCP cases appeared, the CDC published a second article describing the outbreak of Kaposi's sarcoma among gay men, several of whom also had PCP.

On investigation, it was found that the rate of PCP had increased suddenly, suggesting that some new factors were at work. Because the original cases were all gay men, researchers unofficially began calling this new disease Gay Related Immune Disorder or GRID. About 49% of the reported cases came from sexually active homosexual men (Fan, Conner & Villarreal, 1998). Thus, researchers started the process of linking this new disease with homosexuality in people's thoughts (Purvis, 1996).

At this point, no one knew what had caused this strange outbreak of opportunistic infections. Clearly, however, something had destroyed the immune systems of these men. To understand what had caused this devastating illness, researchers sought to determine what persons with GRID had in common with how they differed from healthy gay men. Researchers found that the sexual practices and the number of partners seemingly contributed to the development of this disease. Thus, these early accounts contributed to the social construction of GRID as not only a “gay disease” but also a disease of gay men whose lifestyles seemed particularly alien and depraved. At this point, most scientists were convinced that some new infectious agent caused the epidemic.

This theory gained credence when researchers discovered that several of the earliest cases had, had sex with each other. These researchers hypothesized that a “fast-lane” sex life characterized the early cases because only those with many sexual partners would have come in contact with whatever rare virus was causing the epidemic (Purvis, 1996). Although this theory never won acceptance among scientists, publicity about the theory reinforced the popular notion that gay men were falling ill not because of a virus but because they chose to engage in unsafe behaviours. Thus, from an early point, the social construction of GRID emphasized that its sufferers had caused their own ill health. This view still underlies the responses of many members of the public and persons with the AIDS disease (Weitz, 1991).

However, by 1982 researchers realized that this illness did not affect only gay men. Cases of GRID were reported in Haitian and African men who denied ever engaging in gay sex, (Weitz, 1991) as well as in heterosexual women, hemophiliacs and persons who used illicit intravenous drugs. This indicated that the illness was transmitted through blood and semen and could infect anyone exposed to the virus regardless of sexual orientation or lifestyle. GRID still seemed to most Americans to be a disease of the “other”. “Other” included drug users and black foreigners as well as a few unfortunate “innocent” victims.

In September 1982, reflecting scientists, who were attempting to develop an understanding of the epidemic, coined the term Acquired Immune Deficiency Syndrome or AIDS. Later, the CDC added a second diagnostic category of AIDS – Related complex (ARC) to include the many persons who had developed serious health problems as a result of the same underlying immune disorder but who had not met the CDC’s definition of AIDS (Weitz, 1991).

These accounts point to the third period that is the global mobilization. To trace the spread of HIV/AIDS, the CDC began requiring that U.S doctors report all new cases to them. In July 1989, the number of reported AIDS cases passed 100,000, by which time the World Health Organisation had received official reports of AIDS cases from 149 countries. In addition to reporting demographic information, doctors were required to assign each case to a risk group, indicating the way the person was most likely to have become infected. The CDC’s definitions of the various risk groups unintentionally reinforced the social construction of AIDS as primarily a gay disease and secondarily as a disease of other deviants (Weitz, 1991).

In this way then, the definitions of the risk groups caused the CDC to overestimate the risk that gay male sexual activity would lead to AIDS and underestimate the risk that other behaviours especially heterosexual behaviour, would do so. Consequently, these definitions reinforced the social construction of AIDS as a gay disease. The connection between deviance and AIDS was also reinforced in the public’s mind by the CDC’s terminology of “risk groups” rather than “risk behaviours.”

This phrasing gave the impression that HIV/AIDS somehow sought out persons who belonged to certain communities, rather than striking persons who engaged in particular behaviours. Those who did not belong to such groups therefore could easily conceptualize AIDS as an illness that only affected persons inherently different from



themselves and from the majority of Americans. In May 1983, scientists' understanding of AIDS grew enormously following the isolation of Human Immunodeficiency Virus (HIV).

Two years later, researchers announced the development of a test to identify persons infected with the virus. The existence of a test for exposure to HIV greatly facilitated research on its spread (Weitz, 1991). Although many Americans had continued to regard AIDS disease as a mysteriously threatening illness, researchers quickly learnt, that HIV is only spread through sexual intercourse; through sharing unclean intravenous needles; through some unclear mechanism from mother to fetus and possibly through breast milk from mother to infant and through transfusions or accidental injections with blood or blood products.

The last mode of transmission has become less common in the developed world since the middle of 1985, when blood banks began to test blood routinely for the HIV virus (Heyman & Curran, 1988). Studies demonstrated conclusively that HIV did not spread through insects, spitting, sneezing, hugging, non-sexual touching or even sharing eating utensils. As of November 1989, 61 percent of adult AIDS cases reported to the CDC were traced to gay male activity.

Current data suggest that on average, persons develop AIDS about ten years after they are infected with the HIV virus (Heyman & Curran, 1988). However, no one yet knows whether all infected persons will develop AIDS, nor does anyone know the maximum number of years it can take before an infected individual will develop AIDS. Furthermore, no one knows why some persons develop AIDS sooner than others, although some clear patterns have emerged. For example, children generally develop AIDS much sooner after infection than do adults (Weitz, 1991).



While throughout the 1980's, researchers believed that most and perhaps all infected persons would eventually die from either AIDS or some other illness caused by the HIV virus. During the 1990's new therapies had significantly improved the prognosis for persons with HIV disease.

Some observers, especially clinicians and activists, now argue that AIDS disease should be considered a chronic, manageable illness, rather than a fatal one. The global picture highlights the pandemic consisting of distinct patterns of epidemics, with HIV/AIDS impacting significantly on the developing world.

### **1.3. AIDS in South Africa**

The World Health Organisation estimated that Africa had 60 percent of the world's HIV cases at the end of 1989 (Panos, 1990). However, before, one visits the situation in South Africa, it is important to have an overview of the rates of AIDS in sub-Saharan Africa. According to the provisional report of MAP (Monitoring the AIDS Pandemic, July 2000), the situation is the worst in sub-Saharan Africa. There are 24.5 million infections, where almost one in ten adults (15-49 years of age) are already living with the virus throughout the sub-continent (MAP, July 2000). While the first major epidemics were described in countries of central and Eastern Africa, the epidemic is now far worse in the southern part of the continent.

In South Africa, infection rates increased from less than 1% in the adult population at the beginning of the 90's, to about 20% within less than one decade. It is important to bear in mind that most HIV statistics in Africa are under representations of the true size of the epidemic. Many governments still seek to conceal the magnitude of the HIV infection statistics. According to Whiteside and Sunter (2000) there is a

fear amongst many government officials that public acknowledgment of the true size of the epidemic in their country may negatively affect tourism and foreign investment. Further, in many countries there is a lack of proper medical reportage. In rural areas for example, records may not be kept at all while in urban areas poor quality reporting and uneven coverage is often a problem.

In South Africa records of HIV/AIDS prevalence have been regularly gathered and made available to the public since the beginning of the decade. The primary source of HIV statistics comes from studies done on mothers attending antenatal clinics. Although the initial statistics on HIV infections in black communities were gathered in 1987, the seriousness of the HIV/AIDS epidemic was forthcoming from the antenatal clinics (Mohoebi, 1997). At the start of 1999, it was estimated that three million South Africans were seropositive for HIV/AIDS (MAP, 2000), with the epidemic showing no sign of slowing down.

Rather, recent surveys indicate that the disease is spreading rapidly and young people between the ages of 15 to 25 years are particularly at risk (Mohoebi, 1997). Currently it is estimated that 1500 people per day are contracting the HIV virus, resulting in a total of 50 000 new infections per month in South Africa (MAP, July 2000). The South African AIDS scenario is nowhere grimmer than in the province of KwaZulu-Natal. Routine antenatal testing indicated that by the end of 1998 an estimated 7500 000 people were living with HIV in the province. This represents about 1/3 of the country's total estimated three million HIV infections. From the start, this province has maintained its reputation as the epicenter for the AIDS epidemic, leading the country in both HIV infection and deaths due to AIDS.

Hermanus (cited in Crewe, 1992) stated that once HIV/AIDS has entered a society it veers towards the path of least resistance. Throughout the world that path runs through some of the world's least powerful societies and groups including the

poor disadvantaged and underdeveloped groups. The HIV/AIDS epidemic cannot be fully understood without taking this context into account. The present study takes place in a South African context, in a province with a high seroprevalence rate. It is characterized by poverty, unemployment with limited health and welfare resources. Evian (1993) stated that one of the striking features of the HIV/AIDS epidemic is its relationship to poverty. Whilst HIV infection is found in high numbers in poorer and disadvantaged communities, HIV/AIDS in turn promotes poverty. According to Evian (1993) income, loss, rejection, discrimination, stigmatization, ill health and death all contribute to individual and family misfortune. Thus, the cycle of poverty continues. Lamprey and Piot (1990) highlighted those demographic, political and economic variables that influenced the spread of HIV infection in various populations. Demographic variables include:

1. The age group between 15-40 years have a higher HIV prevalence problem.
2. Women have a higher HIV prevalence than men.
3. Rapid urbanization leads to the creation of an environment that is ideal for the spread of the virus.
4. Mobility of the country's population which facilitates the spread of HIV i.e. the more mobile the population the easier it is for the virus to reach various parts of the country.

Political and Economic variables includes:

1. The adequacy of the health care system impacts on both the spread of the virus as a whole and the impact of the virus on infected individuals.
2. The country's overall response to the epidemic in countries where a high level of political commitment to the issue of the AIDS has been evident – the response to HIV has been more successful.
3. A form of war or civil disturbance makes HIV prevention attempts extremely difficult.

These contributory factors were echoed in a UNAIDS paper (1996). Major political, social and demographic changes have occurred in sub-Saharan Africa over the last twenty years. These changes have contributed to population displacement, migration and rapid urbanization which impacts on the rapid spread of HIV/AIDS.

According to Crewe (1992), HIV/AIDS flourishes in the following conditions: high unemployment, large numbers of homeless people, a high level of welfare dependency and social unrest. In South Africa, the condition that facilitated the rapid spread of HIV/AIDS, in part, is a direct consequence of apartheid. In light of the above, the apartheid era in South Africa provided “perfect” conditions to facilitate the spread of HIV/AIDS. The unequal distribution of resources, limited literacy rates (especially among women), migrant workers living apart from partners for months at a time, compounded the problem. Crewe (1992) noted that although AIDS cannot be described as an illness of apartheid, there is no doubt that the policies and consequences of apartheid exacerbated the spread of HIV infection. The legacy of apartheid, racism and discrimination exacerbated the powerlessness that the AIDS epidemic created in South Africa (Crewe, 1992).

#### **1.4. Research Problem**

Although there is a great growing volume of literature and research around the psychosocial implications of HIV/AIDS, research in the area of the construction of meaning of AIDS from a counsellor’s perspective has been lacking. Studies indicated that the general attitudes towards people with HIV/AIDS have not altered especially among students in the health sciences and health care workers (Craig, 1999). These studies have demonstrated that there is a considerable stigma attached to AIDS.

Further, negative attitudes towards people with HIV/AIDS have also been widely reported among health care professionals (Craig, 1999). Knox and Dow (1991) found that health care workers have reported fear of contagion and discomfort working with the terminally ill. Further, according to Herek and Capitanio (1993), the stigma associated with AIDS continues to be a serious problem.

It threatens the well - being of people with HIV/AIDS and impairs society's ability to provide effective treatment to HIV/AIDS patients. According to Hoffman (1991, cited in Craig, 1999) workers that care for HIV/AIDS patients may have unresolved personal conflicts or issues concerning loss, death and dying activated for them. This may cause considerable anxiety and discomfort for the workers. If this occurs, what impact would this have on the counselling process? Furthermore, a young person dying of AIDS, challenges personal and societal myths of immortality (Craig, 1999). Accordingly, it is essential for health care workers to understand their personal reactions to death, and how HIV/AIDS may affect how they response to HIV/AIDS patients.

In another study by MacDonald, Ginzburg and Bolan (1991) the results revealed that discriminatory attitudes appeared as key issues. Nearly a fifth of those interviewed did not feel it was safe to sit close to somebody with HIV/AIDS or were unhappy with the proposition that people with HIV/AIDS should be allowed to live in the community normally. A fifth of the subjects interviewed felt that those children with the HIV virus should not be allowed to attend school and should not mix with other children as normal. Whereas nearly two-thirds of those interviewed were against doctors working with HIV/AIDS patients.

In Africa, the current understanding of HIV/AIDS is not well established. One important form of psychological intervention with potentially HIV positive people is counselling. HIV/AIDS counselling is a vital clinical intervention (Lindegger & Wood,

1995). However, the meanings, attitudes and metaphors of AIDS may have a great impact on the counselling process i.e. the counsellor's personal perceptions, beliefs and attitudes may impact on the counselling process. Therefore, the purpose of this research is to investigate the construction of meanings, perceptions and attitudes of HIV/AIDS held by lay and professional counsellors (see terminology for details).

### **1.5. Research Goals**

The current study consists of four focus areas, which forms the research goals. They are the following:

- An exploration of the various attitudes, meanings and perceptions of AIDS that are held by the AIDS counsellors.
- To identify and examine the emergent themes or metaphors of AIDS that are held by the counsellors.
- To compare the meanings, attitudes and perceptions held by lay counsellors to professional counsellors.
- An exploration of how this understanding / perceptions impact on the counselling process.

### **1.6. Research Design**

According to Grinnel (1988) the research design refers to the overall plan or strategy by which research questions are answered or the hypotheses tested. In this study, the design that was used was qualitative i.e. the non-numerical examination of phenomena focusing on the underlying meanings and patterns of relationships (Marlow, 1995). Qualitative research allows the researcher to gain an empathetic understanding of social phenomenon.

Qualitative methodology attempts to understand thoughts, feelings and emotions by getting to know people's values, symbols, beliefs and emotions. In this study, in-depth interviews were used to explore the counsellors' experiences, attitudes, meanings and metaphors of AIDS were captured.

This method produces a wealth of detailed data and is capable of capturing the richness of the counsellors' experiences in their own words (Marlow, 1995). The research design of the current study will be considered, later on, in detail in Chapter 3.

### **1.7. Terminology**

Stone and Kaleeba (cited in Lamprey & Piot, 1990) believed that counselling is a primary prevention tool which provides "sustained interaction, exchange and dialogue" (p. 189). Counselling should be offered by knowledgeable supportive and empathetic people (Vargo, 1992). The above description embodies an AIDS counsellor. However by definition there are various types of AIDS counsellors. For the purpose of this study two different AIDS counsellors are defined. They are the following:

#### **a) Professional Counsellors**

These counsellors are defined by their professional status i.e. these counsellors have a professional degree which may include a degree in nursing, psychology, social work or anthropology.

#### **b) Lay Counsellors**

As the name suggests these counsellors have some informal training in AIDS counselling. They do not have a degree in nursing, psychology, social work or anthropology. They sometimes work in a voluntarily capacity at various institutions.



## **1.8. Presentation of the Study**

This chapter focuses broadly on the origins of HIV/AIDS virus within a global context. But, because this study occurred in South Africa, this context was considered. The research problems, goals and the terminology were discussed.

Chapter 2 presents the literature review, which explores attitudes, perceptions and knowledge held by various health care workers and the general public. The various myths and metaphors surrounding terminal illnesses are considered and possible links are made to the HIV virus. These representations of illness that occur within societies are understood within a theoretical framework.

Chapter Three outlines the methodology used in research process. The design, sampling method, procedure for the collection of data and the analysis of data are explained. The reliability and validity of the study are discussed. The pilot study and its implications are also considered.

Chapter four focuses on an in-depth analysis of the results. The impact of attitudes, perceptions and understanding among AIDS counsellors are discussed. The literature reviewed on Chapter 2 is integrated into the findings of the study.

Chapter five draws out conclusions from the research and makes recommendations. The shortcomings of the study will also be considered.



## **CHAPTER TWO**

### **REVIEW OF LITERATURE**

#### **2.1 Introduction**

Chapter 1 examined the origins of the HIV/AIDS virus within a global and South African context. Having set the context, this chapter will attempt to define/describe the HIV/AIDS virus. Thereafter, the various attitudes and perceptions held by health professionals and lay people will be identified together with the various metaphors that surround the AIDS disease. These attitudes, perceptions and metaphors will be contextualized within a theoretical framework i.e. the Social Representational Theory. This theory will be used to explain the emergent metaphors and attitudes. Definitions and the background of the theory will be considered. Thereafter an overview of the theory, its application to the AIDS disease and a critique of the theory will be discussed.

#### **2.2 Meaning of the Disease**

HIV/AIDS affects not only those who are HIV positive, but also affects the family, the government, employment and financial sectors of society. Thus, HIV/AIDS has a multi-dimension affect and it is also important to consider.

In recent years, it has been recognized that HIV infection has a multidimensional biological, psychological and social crisis affected on many people

(Cohen, 1990). Not only do those diagnosed as being HIV positive face the impending possibility of severe illness, neuropsychiatric disorder and death, they are also likely to suffer psychological problems related to lack of self esteem, loss of sense of control, meaning and depression. These are exacerbated by a whole range of problems in interpersonal and social relationships, including housing, financial and employment prospects (Davie, 1997).

AIDS can be defined from the medical, biological, psychological and social perspectives. For the purpose of this study, the researcher would focus mainly on the psychological and social perspectives. According to Weitz (1991), the “AIDS disease is biologically devastating, producing progressive physical and sometimes mental disability and the likelihood of an early death” (p.10). Hoffman (1991) defines AIDS as a chronic, progress and debilitating disease that is highly stigmatized due to its association with sex, drugs and death. Thus, what is common among the definitions is that, AIDS is a chronic illness. As a chronic illness, it might be expected to challenge the patient’s sense of control and identity and profoundly disrupt normal ways of behaving, thinking and relating to the world. Fee and Krieger (1993) have argued that AIDS is seen both in terms of a plague and as a chronic disease.

Bury (1982, cited in Petchey, Fransworth & Williams, 2000) has proposed that chronic illness constitutes a three-fold “biographical disruption”, which in turn have psychological implications. They are the following:

- 1) There is a disruption of taken-for-granted assumptions and behaviours. For example, in general people believe that they will have a long life and thus they plan for a better, brighter future. They take for granted that they will be around to enjoy life. However, with AIDS, the HIV/AIDS patient is unsure when the end would be. Therefore, there is this disruption i.e. they can not take things for granted. They would have to be satisfied with the here and now.

- 2) A fundamental rethinking of a person's biography and self-image is involved. This process involves a HIV/AIDS patient rethinking and re-evaluating himself/herself. For example, a HIV/AIDS patient may undergo a number of changes such as loss of weight. A person, who was "proud" of their body image, now feels ashamed of it or they have to rethink or evaluate themselves to suit the "new picture of themselves".
- 3) There is the response to disruption involving the mobilization of resources in facing an altered situation. This may apply to the following situation. For example, when a person becomes ill due to his/her positive status, they are unable to do the things, they once did. Therefore, they have to rely on the caregivers to help them. Thus, the HIV/AIDS patient has to adjust and response to this new situation.

One of the psychological implications for the HIV/AIDS patient involves the need to cope with uncertainty. This uncertainty is intensified for many by the fact that they will certainly sero-converted. Moreover, by virtue of the social stigma that is attached to HIV infection, people with the disease are also confronted with the problems that are associated with the "management of a spoiled identity" (Petchey et al., 2000, p.237). Further, according to Pierret (2000), when the HIV infection occurs in a person's life, it creates a watershed separating "before" and "after". Previously taken for granted activities now become problems.

The illness takes on a particular meaning in a person's life story. This leads them to question himself/herself as to why me or why now? Kruger and Richter's (1997) subjects described "AIDS as a 'foreign' disease 'imposed' on black people in South Africa" (p.961). Further, according to Mogensen (1997) "AIDS is sometimes said to be a disease of God, but very different from other diseases sent by God, which are easily cured" (p.433).

These descriptions and definitions of the HIV/AIDS virus seem to have an underlying meaning, which seems to suggest common themes. Therefore, let's now examine the metaphors, meaning and attitudes that surround the AIDS disease.

### **2.2.1 The Gay Plague**

The mass media plays a crucial role in transforming scientific concepts into lay thinking (as mentioned earlier). It is found that because of this, HIV/AIDS was seen as a Gay Plague because the first reported cases occurred among the gay community. Further, these reports in the newspapers lead to the development of negative attitudes towards gay people.

The “gay plague” can also be understood in terms of the “chronic plague” of 1665, that has its beginning in Holland and it can also be seen from a religious perspective. Plague (from Latin, the word means stroke, wound) has long been used metaphorically as the highest standard of collective calamity, evil and scourge (Procopius, cited in Sontag, 1989). Diseases like leprosy and syphilis were regarded as plagues not because they killed, but often because it was disgracing, disempowering and disgusting. Other features of the plague were that the disease invariably came from somewhere else and it was foreign (Sontag, 1989). Kruger and Richter (1997) found that HIV/AIDS was also viewed in terms of the plague.

Further, they found that most of their subjects perceived AIDS to be a ‘foreign’ disease ‘imposed’ on black people in South Africa. According to Sontag (1989) AIDS is seen as the black death or worse. Hwang (2001) added that AIDS has become one of the greatest epidemics in history. Further, he indicated that AIDS has taken longer to build momentum than did the Black Death, but AIDS has a far more staying power.

Thus, because HIV/AIDS was associated with the plague, it gave rise to negative perceptions and attitudes. Studies by Pringle et al. (1988, cited in Taerk et al., 1993) and Gallop et al. (1991, cited in Taerk et al., 1993) found that fear of contagion and homophobia was inversely correlated with knowledge and the amount of previous experience in working with HIV/AIDS patients.

Van Servellen et al. (1988, cited in Taerk et al., 1993) found that nurses were afraid of contagion and experienced discomfort when caring for homosexuals who had AIDS. Kelly et al. (1988), it was found that there was a high incidence of bias toward the homosexual lifestyle and concluded that this was a major factor in the deficient care delivered to patients. According to Taerk et al. (1993) they found that health care workers generally operated under the assumption that HIV/AIDS was exclusively a homosexual disease in spite of knowledge to the contrary. Accordingly, health care workers characterized homosexuals as deviant, immoral, promiscuous individuals who engaged in forbidden pleasures. Therefore, they concluded that HIV/AIDS was a “deserving punishment” for them. The literature on AIDS has asserted that fear/ risk of contagion is a significant concern among health care workers (Gerbert et al., 1989, cited in Kunzel & Sadowsky, 1993). Further, health care workers’ attitudes, knowledge and perceptions are important because it may jeopardize the amount and quality of care provided.

With regard to counsellors, the literature does not report any investigations into their attitudes, knowledge and perceptions of AIDS and how it impacts on the counselling process. Therefore, health care workers’ attitudes, knowledge and perceptions are important to consider because they may inform us about counsellors’ experiences and responses to the disease. This perspective i.e. the gay plague stems from a religious understanding. In other words people who act in an immoral way would be punished. Punishment is thus another metaphor used to describe AIDS.

### 2.2.2 AIDS as a Punishment

It is believed that HIV/AIDS is the result of morally reprehensible behaviour and represents divine retribution, ostracism and blame, which are 'appropriate responses'. Therefore, this explanation leads to attitudes such as: 'public funds should not be spent on this scourge because most of the victims got what was coming to them'.

According to Taerk et al. (1993) found that having HIV/AIDS would mean that there would be an unquestionable evidence of sexual activity. From the beginning HIV/AIDS was associated with sexual deviance. Heterosexuals who contracted HIV/AIDS were treated as "innocent victims" or as nominal queers (Goldin, 1994). In the very early years of the epidemic, there was even speculation that anal sex itself caused HIV/AIDS, by making "unnatural" impositions on the body (Asthana & Oostrogels, 2001).

According to Stevens and Muskin (cited in Taerk et al., 1993), fantasies of acting in forbidden ways and of being punished may be embodied by the HIV/AIDS patients. Thus, the view is raised that AIDS is perceived as a punishment for deviance (sexual activity). Nutbeam, Catford, Smail and Griffith's (1989) study also suggested that a common view held by the majority of the subjects was that AIDS was "sent by God because of people's immoral behaviours" (p.210). Mogensen (1997) added that AIDS is something that happen because the world has change and because proper order of earlier times is not respected.

When Mogensen refers to proper order, he is referring to sexual practices. In other words, Mogensen implied that because people are practicing "inappropriate sexual habits". HIV/AIDS has occurred. This is because these inappropriate behaviours show disrespect to nature's rules.



Meanwhile, others such as the American Council of Christian Churches, have declared that AIDS is God's judgement against homosexuals (Weitz, 1991). Further, survey results suggested widespread support for a social construction of HIV disease as a deserved punishment for degenerate 'others' (Weitz, 1991). This led to the opinion that people with AIDS should be isolated from the rest of society. Kruger and Richter (1997) added that their subjects perceived AIDS as a moral issue, "something you get, fairly mysteriously, from bad behaviour with bad people" (p.959). Sontag (1989) pointed out that in the case of AIDS, the HIV/AIDS patient is ashamed to disclose their HIV positive status. This is because the shame is linked to an imputation of guilt and scandal because the affliction is not mysterious.

People know how they got it. The unsafe behaviour that produces HIV/AIDS is judged to be more than just weakness. Most people consider AIDS as a calamity, which one brings on oneself. Further, Bishop Falcon of Basil (cited in Sontag, 1989) declares AIDS to be the "moral consequences of moral decadence" (p.149). Taerk et al. (1993) found that one of the views held by health care workers towards AIDS is that "it is a disease of choice" (p.4). This implies that health care workers blame the HIV/AIDS patient for their HIV positive status. Weitz (1991) concluded that nursing, medical and chiropractic students, all consider persons with HIV/AIDS less competent and less morally worthy than persons with cancer, diabetes or heart disease. Thus, one finds that often AIDS is compared to other illnesses.

### **2.2.3 AIDS compared to other illnesses**

There still exists no known cure for AIDS. HIV/AIDS shares a number of common symptoms with other terminal illnesses. Therefore, to make sense of AIDS it was compared to other illnesses. The researcher found that AIDS was commonly compared to leprosy and cancer. Let's examine each one in detail.

#### 2.2.3.1 Cancer

Cancer is a terminal illness and to date, no known cure exist. However, medical scientists have found a way to control the disease. But, previous in history cancer was perceived as a death sentence.

Cancer was figuratively defined as “anything that frets, corrodes, corrupts or consumes slowly and secretly” (Sontag, 1989, p.10). Cancer is a latin word that means crab. The idea was inspired according to Galen (cited in Sontag, 1989) by the resemblance of an external tumor’s swollen veins to a crab’s leg and not, as many people think because it crawls or creeps like a crab.

Previously, it was seen as a death sentence because it is felt to be an ill omen, abominable, repugnant to the senses (Sontag, 1989). HIV/AIDS is also described along these lines. In a survey (cited in Weitz, 1991) of college students, they considered people with the AIDS disease more responsible for their illness than people with legionnaire’s disease or serum hepatitis, even though the latter is spread in the same way as HIV. Herek and Capitanio (1993) found that the most salient difference between AIDS, coronary heart disease and cancer, is that HIV/AIDS patients are more dangerous, dirty, foolish and worthless.

Weisman (1972, cited in Gordon & Paci, 1997) notes that with cancer, there exist a world of secrets and silences of cultivated vagueness and manipulated hope. The same exists with the AIDS disease. The person with HIV/AIDS often uses silence as an excruciating choice that is made out of the fear of stigmatization and rejection. (Funk, 1982 cited in Hoffman, 1991). Further, he added that patients’ fear of disclosure is often worse than the experience itself. AIDS is often a secret. concealed from their families by the patient. This stigmatization is also found among health care workers (Weitz, 1991).



In other words, health care workers discriminate against HIV/AIDS patients. So, the question to ask, is what effect would this attitude have on the treatment of HIV/AIDS patients? AIDS was also compared to leprosy disease.

#### 2.2.3.2. Leprosy Disease

Leprosy was a highly stigmatized disease. People who had this disease were separated from the rest of the society and placed in isolated villages that were designed for patients with this disease.

Sontag (1989) points out that if AIDS, a ‘new disease,’ has been quickly freighted with a traditional stigma, it should not be surprising that leprosy has been associated with various stigmatizing phenomena during its history. Gussow (1989, cited in Lieban, 1992) agrees with Sontag (1989). He found that after its early Biblical taints as an abomination and divine punishment for sins, the stigma of leprosy was subsequently sustained or renewed by new sources of defilement. Gussow (1989, cited in Lieban, 1992) observed that leprosy had virtually disappeared from Europe and its theological salience was declining by the end of the Middle Ages. However, in the 19<sup>th</sup> century, it was discovered to be hyperendemic in colonial areas. Further, he found that Europeans and Americans labeled leprosy as a disease of ‘inferior’ people.

Gussow (1989, cited in Lieban, 1992) goes on to state that, “in fearing that such a disease might contaminate the ‘civilized’ world, Western nations became intensely leprophobic by the century” (p.185). His study also described how American leprophobia was specially strengthened by a concatenation of events and attitudes regarding the Chinese i.e. the perception that China was a danger to western civilization. ‘the yellow peril’. This leprophobia can be compared to homophobia i.e. a

fear of homosexuals. Homosexuals, in particular, became marginalized and HIV/AIDS came to be seen as a disease of the “other”. Lets consider this sub- theme.

(a) AIDS as a disease of the “other”

The epidemiology of HIV/AIDS has also contributed to the stigma. In the western areas, the early cases of HIV/AIDS occurred frequency among male homosexuals. This led to AIDS being conceptualized in the early media as an illness that leaked from an infected homosexual source to the rest of the world.

Treichler (1990, cited in Goldin, 1994) notes that we understand HIV/AIDS by the opposition we use in discourse about it, such homosexuals / general population; vice / virtue and contagion / containment. Society or scientists define “not having HIV” by its opposition to being HIV positive. For those not possessing the virus, this opposition provides an affirmation of heterosexuality or ‘right living’ or drug – free lifestyle. All of these characteristics send a message that ‘I’m safe, it’s the others who are at risk’.

This highlights a crucial aspect of how people forge their identities. Identity is construed not only by what people affiliate with, but by comparison to other people. One gains a positive sense of identity through comparison with negatively valued groups. With HIV, the fear of infection intensifies the need to draw a distinction between ‘us’ and ‘them’.

According to Joffe (1999) mass, incurable illnesses, from syphilis to cholera, from the Black Death to leprosy, have been linked to the ‘other’ both historically and cross – culturally. The ‘other’ comprises of three inter-related phenomena: foreign nations, out – groups within a society and practices construed as deviant i.e. those associated with a lack of control and self – indulgence. The ‘other’ is a form of

scapegoating i.e. it is a way of ridding a community of the impure elements. According to Douglas (1995, cited in Joffe, 1999) the concept of scapegoating implies that one organism, totally innocent of causing the event for which it is being blamed, is sacrificed for the purification of others.

Joffe (1999) notes that the 'other' becomes intensified when there is a crisis. This chaos is ordered by means of self – protective representations i.e. when faced a crisis, people form representations which protect the positive identity of the in – group. Linking epidemics with out – groups, foreigners and 'perverse' practices serve this function. Since it is firmly established that group identity forms a component of self – identity, the process of linking epidemics with the 'other' sustains a positive self – identity. As seen previously, AIDS is seen as something that is deviant and it breaks nature's rules.

This representation then triggers off the self – other mechanism i.e. the way people /societies try to 'protect' themselves from blame. Therefore, out – groups such as homosexuals, drug users are blamed for causing AIDS. Thus, AIDS is seen as a disease of the 'other'. AIDS is also seen in terms of the military metaphor.

#### **2.2.4. AIDS and the Military Metaphor**

AIDS was compared to other illness like cancer, so that medical scientist could make sense of it. However, this led to AIDS being represented in terms of cancer.

As with cancer, where name added meaning to the illness, so too is the case with AIDS. AIDS is not the name of an illness at all. It is the name of a medical condition. the consequences of which are a spectrum of illnesses (Sontag, 1989). AIDS

is not a single illness but a syndrome consisting of a seemingly open-ended list of contributing or “presenting” illnesses, which constitute the disease.

AIDS has a “dual metaphoric genealogy” (Sontag, 1989, p.104) because the very definition of AIDS requires the presence of other illnesses, so called opportunistic infections and malignancies. If AIDS is seen as a micro-process, it can be described as cancer i.e. an invasion of the body (Sontag, 1989). However, this invasion of the body, implies some military action. Thus, the military metaphor arose.

Sontag (1989) described HIV/AIDS in the following way: the “enemy is what causes the disease, an infectious agent which comes from outside” (p.105). To illustrate the military metaphor, the following extract is taken from Sontag (1989). It describes the AIDS disease using the military metaphor,

“The invader is tiny, about one sixteen – thousandth the size of the head of a pin. Scouts of the body’s immune system, large cells called microphages, sense the presence of the diminutive foreigner and promptly alert the immune system. It begins to mobilize an array of cells that, among other things produces antibodies to deal with threat. Single – mindedly, the AIDS virus ignores many of the blood cells in its path, evades the rapidly advancing defenders with hones in on the master co-ordinator of the immune system, a helper cell. (p.105).

The way it is described, it is like a military plan put into action. Sontag (1989) argues that this military metaphor is also continued in the media. For example, in the front page of the New York Times, the following headlines appeared: “HIV virus found to hide in cells, Eluding Detection by Normal Tests” (Sontag, 1989,p.107). According to Goldin (1994) the military metaphor depicts the HIV virus as a secret

agent, employing a range of strategies to kill its host. It is a foreign body fighting the defending cell that leads to the altering of the immune system.

However, Goldin (1994) points out that there is an alternate way to view the military metaphor. He says that the military combat is a popular image used to describe confrontations between biomedicine and disease agents. Despite many successful ‘battle’ against infectious disease, biomedicine has not been able to ‘conquer’ HIV/AIDS, as well as a number of other sexually transmitted infections (STIs) and antibiotic – resistant bacterial diseases. The battle against the HIV virus is described as a struggle for territory in the human body, and the virus is described as an invading agent, a grenade, primed for detonation.

Often these metaphors cross over to describe the patients. This leads to patients being stigmatized and negative perceptions being held about them. Persons with AIDS are described with images similar to the images of the virus. Therefore, it is important to consider the stigma that surrounds AIDS. This may inform us about counsellors’ attitudes and perceptions.

### **2.3 AIDS and its Stigma**

The social science and biomedical literature on sexual transmitted infections (STIs) is replete with reference to stigmatization. The severity of the HIV/AIDS pandemic has permeated our thoughts and transformed our universe. The profound effects of stigmatization have created an environment in which the HIV/AIDS patient is afraid of disclosing his/her HIV status.

According to Goldin (1994) from the point of view of the outside observer, stigma may be interpreted in several different ways:

- (a) attention may be directed at psychological, interpersonal, sociological, economic and/or political effects on persons who possess certain characteristics.
- (b) Stigma may be understood as metaphors about social order and the body politics; the focus of attention may shift to those who identify themselves as not possessing the specified traits.
- (c) Stigma may be understood from an interactionalist perspective as the language of relationships, as the product of and inherent in a relationship between the “normal” and the “other”.

Goffman (1991, cited in Goldin, 1994) noted that the Greeks originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. He also identified three types of stigma: abominations of the body; blemishes of individual character and tribal stigma of race, nation and religion.

STIs, in particular, HIV/AIDS fit this typology well. For example, HIV/AIDS patients are associated to various physical deformities. It is suggested that there is evidence of moral weakness and transgression such as depictions of male homosexuals’ unnatural passions. Finally, HIV/AIDS patients may be associated with a particular ethnic or national groups.

This stigma seems to also exist among health care professionals. Wallack (1988, cited in Taerk et al., 1993) reported that 53% of the staff surveyed admitted to sometimes avoiding performing procedures on people with HIV/AIDS. Knox and Dow (1991) also found similar findings. They found that fear of contagion and the fears of working with the terminally ill were factors in the overall delivery of care to patients with HIV/AIDS. As mentioned earlier, studies by Taerk et al. (1993) found that health care workers believed that AIDS was a disease of choice and reported a fear of contagion.

This resulted in suggestions being put forward such as, “HIV/AIDS patients should be isolated and staff working on these isolation wards should be volunteers or be homosexuals themselves” (Taerk et al., 1993, p.4). Hoffman (1991) drew the following conclusions from an opinion survey that examined stigma towards HIV/AIDS infected persons:

- (a) a substantial minority saw AIDS as punishment for immoral or offensive behaviour
- (b) 18% said that they would take their child out of school owing to an infected classmate
- (c) nearly half said that they would refuse to work with someone who had AIDS and would support their employers’ rights to fire such workers.

These studies indicate that the health care workers and even the general public held negative attitudes and perceptions towards HIV/AIDS patients. For the health care workers, this belief has serious implications on the care provided. The researcher of this study therefore questions whether these attitudes and perceptions exist among counsellors?

If so, what are the implications of these attitudes and perceptions on the counselling process? The researcher also found that illness is not only seen in a negative light. Therefore, it is important to explore this as it may have implications on the findings of this study.



## 2.4 Illness as a Positive Social Symbol

To this point, the discussion occurred around illness as a socially devalued symbol. Since illness usually brings suffering, at least in some degree, it is not surprising to find unpleasant symbolic associations with illnesses.

This, of course, is not to ignore the fact that pain can be a source of pleasure. To explore connections between pain and personal gratification is quite another matter. However, the researcher shall briefly consider how illness, despite its discomforts or disabilities, can be symbolically invested with positive social values.

Even deadly illnesses may be identified with values prized by a group or a society. For example, Sontag (1989) discusses how pulmonary tuberculosis (T.B) in the 19<sup>th</sup> century was romanticized as an edifying and refined disease. "For snobs and parvenus and social climbers, T.B was one index of being genteel, delicate and sensitive" (Sontag, 1989, p.28). In this case, certain signs and symptoms of the disease, such as emaciation, languour and paleness, became metaphors of social graces. In Spain, Kenny (1963,cited in Lieban, 1992) observed that attitudes towards certain illnesses were related to social class values. Thus, certain illnesses might be considered prestigious, those "thought to be caused by or associated with a surfeit of the good things in life, for instance, ulcers, gout and high blood pressure" (p.185).

In another example of an illness, Bughat (a folk illness in Cebuano areas of the Philippines) means relapse. The symptoms of Bughat are attributed in part to a special health vulnerability that all women are thought to acquire after they give birth to a child. vulnerability produced by the mother's wear and tear on the body. This is thought to permanently lower a woman's resistance to illness after child birth. This continuing susceptibility to illness combined with physical or psychological insults at a particular time produces illnesses that are diagnosed as Bughat.



The insults are most commonly related to a woman's family responsibilities as a wife and mother and include such factors as neglect of her own health, worry, anxiety and overwork.

Given this etiology, Bughat can be interpreted as a metaphor for demands and costs of the role of mother, who sacrifices everything for her children. In this perspective, symptoms of Bughat can be seen as wounds of virtue. Thus, in some way illness can be seen in a positive way. However, today most of the illness such as AIDS is seen in a negative light. The researcher explored some of the metaphors, meanings and attitudes that surround the AIDS disease. But, the question that remains is how is a medical illness transformed into lay understanding? Therefore, there is a need to provide a theoretical framework to understand the emergence of the various metaphors, meanings and attitudes. The theoretical framework that will be used is the Social Representational Theory.

## **2.5. Social Representational Theory**

### **2.5.1 Background to the Theory**

The concept of social representation was introduced by the sociologist, Emile Durkheim (Moscovici, 1984). In sociology, social representation is seen as an explanatory device. Their theoretical function was similar to that of the atom in traditional mechanics or the gene in traditional genetics. In other words, atoms and genes were known to exist but nobody bothered about what they did, or what they were like. Similarly, this happened with social representation-nobody worried about their social structure or about their dynamics.

In Psychology, the very first step in social representation was taken by Piaget, when he studied the child's representations of the world. From Durkheim's point of view, collective representations describe a whole range of intellectual forms, which included science, religion, myth, modalities of time and space.

Indeed, any kind of idea, emotion or belief that occurred within a community was included. But, according to Moscovici (1984) this view presented a serious problem (i.e. by attempting to include too much, one grasps little; by attempting to grasp all, one understands little to nothing). Therefore, Moscovici (1984) suggested that they are heterogeneous in the first place and they cannot be defined by a few general characteristics. Thus, before one can consider the theory one has to consider the two basic assumptions proposed by Moscovici (1984). They are the following:

1. Social representations should be seen as a specific way of understanding and communicating what we know already.
2. The goal of social representations is to abstract meaning from the world and to order it, which in turn reproduces the world in a meaningful way.

Thus, one finds that social psychologists are not only interested in human behaviour but also in how these behaviours are fitted into episodes, systems or sequences. (Potter & Wetherell, 1987). Further, they suggested that this theory offer a new framework for understanding the organizations of attitudes, beliefs and attributions. Social representations provide the means for people to understand and evaluate their world. But, how does one define social representations?

### 2.5.2 What are Social Representations?

Social Representations are seen as mental schemata or images which people use to make sense of the world and to communicate with each other. According to Moscovici (1984), social representations are systems of values, ideas and practices with a two-fold function.

Firstly, they establish order, which enables individuals to orientate themselves in the material and social world and to master it. Secondly, they enable communication to take place among members of a community, by providing them with a code for social exchange and a code for naming and classifying.

According to Joffe (1999) the field of social representations is concerned with the explanations that people give for phenomena, which they encounter in a social world. In other words, social representational theory is the systematic study of common sense thinking. This theory has been used to examine a range of social phenomena such as alliances in a student protest, explanations of road accidents, health and illnesses. It taps into what goes on in people's minds when they are faced with, for example, life's great enigmas such as illness. This is why the researcher has opted to use this theory – because one needs to understand and deconstruct the metaphors and attitudes that surround the AIDS disease. Moscovici's theory on social representations also provides a more composite version of the development of common sense thinking.

Social Representational Theory highlights and seeks to understand people's spontaneous philosophies about new societal events. There is a particular emphasis upon how lay theories come about and operate. This is needed to understand the perceptions, attitudes and knowledge held by various counsellors. The researcher would now attempt to provide an overview of the social representational theory by Moscovici (1984) and would then attempt to apply the theory to explain the phenomena of AIDS.

### 2.5.3. Overview of the theory and its applications

Social representational theory is not an easy theory to describe. According to Potter and Wetherell (1987), Moscovici's writings are fragmented therefore many researchers have tended to interpret the theory in divergent ways. Social representations are mental entities, as was explained. But, according to Moscovici (1984) they are made up of both abstract and concrete elements (i.e. concepts and images, respectively). In each representation, these elements have a specific structure. According to Potter and Wetherell (1987) in these cases the representation is built around what Moscovici calls a "figurative nucleus" i.e. a complex of images that visibly reproduces a complex of ideas. For example, in traditional public opinion voting, people are often asked questions about, their interest in their political parties. People, in turn, give their opinion about the party. So, we have the party and the psychological entity; the opinion. However, social representational theory proposes a rather more complicated threefold model i.e. the political party, the person's social representation of the party and the person's opinion, which is derived from the representation.

It is believed that the elements comprising a representation are inter-dependent and are arranged in a certain hierarchical order. The core of the representation is the figurative nucleus. This nucleus is the fundamental element in the representation because it determines both the meaning and the structure of the representation. The structural core of a representation or nucleus takes care of two essential functions namely the creative function and the organizing function. The creation function ensures that the elements of that representation acquire meaning and value. The organizing function unifies and stabilizes the element in the representations.

The nucleus of representations is determined on the one hand by the nature of the object presented, and on the other by the relationship, which the subject has with this object. More precisely, it is the situation in which the representation is produced

which will determine one or more central elements. For example, one may presume that the valued elements (those which comprise the nucleus) might be a strong anchored stereotyped or a strongly held attitude on the subject's part with respect to the object of representation. Thus, it can be concluded that the nucleus is a sub-assemblage of the representation, comprising one or more elements whose absence would either dismantle or radically alter the representation.

Further, one can say that the nucleus is the creator or organizer of the representation. Thus, one can assume, if one takes the two characteristics into account, that the nucleus is the most stable element in the representation. In other words, the nucleus resists change. Therefore, the transformation of the nucleus calls into question the totality and structure of the representation. A representation is likely to evolve and change superficially by a change in the meaning or the nature of its peripheral elements. But it can be radically changed when the nucleus itself is called into question.

Thus, having a basic understanding about the concepts that are involved in social representations, the researcher shall now consider the processes involved in social representations. Moscovici (1984) proposes two mechanisms that are used by people to cope with new and unfamiliar experiences. Familiar experiences can, of course, be simply dealt with in terms of a person's existing storehouse of social representations. The unfamiliar is more problematic. Moscovici (1984) suggests that novel or strange objects are dealt with in two stages known as "anchoring" and objectification.

The first mechanism strives to anchor strange ideas, to reduce them to ordinary categories and images and to set them in a familiar context. Whereas the purpose of the second mechanism is to objectify them i.e. to turn something which is abstract into something that is almost concrete, or to transfer what is in the mind to something that

exists in the physical world. These mechanisms make the unfamiliar familiar, by first transferring it to a particular sphere where one is able to compare and interpret it. And secondly, by reproducing it among the things, one can see, touch and thus control.

Since representations are created by these two mechanisms it is essential that one understand how they function (Potter & Wetherell, 1987). While examining these mechanisms, links would be made to understand the metaphors, attitudes and perceptions that surround AIDS.

**(a) Anchoring**

This is a process that draws something foreign and disturbing. It intrigues us into our particular system of categories and is compared to the paradigm of a category, which one thinks to be suitable.

To anchor means to classify and name something. Things that are unclassified and unnamed are alien, non-existent and at the same time threatening. With regard to the HIV/AIDS, initial reports of this illness could not really explain or diagnose the illness. It was seen as alien or unfamiliar and threatening. According to Purvis (1996) no one knew what had caused this strange outbreak of this infection. According to the theory, one experiences a resistance, a distancing when one is unable to evaluate something, to describe it to ourselves or to other people. The first step towards overcoming such resistance, is to place it or place a familiar name. Once, a person can speak about something, assess it, and thus communicate it, then can one represent the unusual in the usual world.



With regard to AIDS, to make sense, of what was happening – AIDS was configured in terms of past epidemics, which had been linked to foreigners, out-groups and perverse practices. According to Joffe (1999) from the moment that scientists recognized the illness in a small number of people, they linked it to an out-group.

Earliest reports suggested that the disease was initially reported among the gay community (Purvis, 1996). Further, homosexuality was seen as deviant, immoral and the individuals concerned were seen as people engaging in forbidden pleasures (Taerk et al., 1993). Therefore, AIDS was seen as “punishment” for deviant behaviour. Further, according to Joffe (1999), the attribution of blame would be underpinned by a deeper, underlying social representation. For example individuals engineer the consequences which befall them.

Further, to make sense of the AIDS disease – AIDS was compared to other diseases, such as cancer, T.B and leprosy. Similar views are shared by cancer and AIDS i.e. both illnesses are seen as a death sentence, a pollution of the body and an invasion of the body.

By classifying what is unclassifiable, naming what is unnamable, we are able to imagine it, to represent it. Indeed, representation is a system of classification and denotation, of allotting categories and names. To classify something, means that we confine it to a set of behaviours and rules stipulating what is and is not permissible in relation to all the individuals included in this class. Further, this means that when we classify a person, we confine the person to a set of linguistics, spatial and behavioural constraints and to certain habits. To categorize someone amounts to choosing a paradigm from those stored in memory and to establish a positive or negative relation to it. When it is positive, we accept it but when it is negative, we reject it. The classification of positive or negative is compared to normal or abnormal. This discrepancy has practical consequences. For example, the emergence of ‘prejudices’.

AIDS was classified by using other terminal diseases. Therefore the negative attitude was developed around HIV/AIDS. This negative attitude, lead to the stigmatization that surrounds AIDS. Early studies found that people with HIV/AIDS were reluctant to use general practitioner services (Petchey et al., 2000).

The barriers that were identified by the general practitioners were the following: hostile attitudes towards homosexuality; patients concern about confidentiality and judgmental responses. According to Pierret (2000) AIDS has turned out to be an illness that is stigmatized owing to certain characteristics. For one thing, talk was rife (as explained later) about AIDS being a “divine punishment”, “the new leprosy” and the “curse of modern times” (Asthana & Oostrogels, 2001, p. 1590).

A moralizing discourse about deviant behaviour and life – styles put the blame on the infected (Herzlich & Pierret, 1998). Further, as Frankenberg (1986, cited in Pierret, 2000) pointed out, the illness experience always forces patients to cope with the metaphors produced and imposed by society.

The social discourse constructed around death, fear, deviant behaviour and the potential danger related to the HIV positive – are a few characteristics that help us explain the stigma. These characteristics of the stigma attached to AIDS account for the extent of rejection and discrimination against HIV infected persons.

To sum up, according to Moscovici (1984) that which was unidentified is given a social identity – the scientific concept becomes part of common speech and individual symptoms are no more than familiar technical and scientific terms. Naming is not a purely intellectual operation aiming at clarity or logical coherence. It is an operation related to a social attitude. In short, classifying and naming are two aspects of anchoring and representations.



In terms of HIV/AIDS – what was scientific knowledge was then transformed to lay thinking. However, this transformation is assisted by the mass media that is the public derives most of its information about AIDS from the mass media. The first article on HIV disease to appear in a national magazine, for example, was entitled “The Gay Plague” and until 1983 both the New York Times Index and the Reader’s Guide to Periodical Literature indexed articles on the AIDS disease only under the heading “homosexuality” (Weitz, 1991). Thus, from the start, heterosexuals were taught to associate AIDS with homosexuality.

The media’s consistent focus on the more esoteric aspects of the lifestyles of persons with AIDS disease further highlighted the differences between those groups considered at risk (especially gay men) and what the article referred to as “the general population” (Weitz 1991). Sensationalist accounts of gay sexual activity and of drug addicts enabled the public to distance themselves emotionally from those who had the HIV disease. People saw HIV/AIDS as a threat primarily to persons inherently different from themselves. Now, let us examine the second mechanism i.e. objectification.

#### **(b) Objectifying**

Objectification takes the idea of unfamiliarity and combines it with reality. This forms the very essence of reality. Thus every representation realizes a different level of reality. These levels are created and maintained by a collectivity and vanish with it, having no reality of their own (Moscovici, 1984).

To put it simply, to objectify is to discover the iconic quality of an imprecise idea or being and to reproduce a concept in an image. To compare is to provide a picture. Thus what was invisible now becomes visible in our minds. Further, it is a process in which the novel/unfamiliar object is transformed into a concrete, pictorial

element of the representation and it is anchored within the already existing representation. This new version of the representation is diffused, in the course of conversation throughout the social group. Thus, what was novel and disrupting now becomes for the group part of their concrete reality.

Again, if one refers to the role of the mass media especially considering the AIDS epidemic, one finds that it plays a crucial role. For example, the social construction of HIV/AIDS as an especially threatening disease was heightened by the media's reluctance to describe frankly the biological realities of the disease. Until well into 1985, stories about the illness avoided words like penis, intercourse and semen and instead talked about "intimate, sexual contact and exchange of bodily fluids" (Weitz, 1991, p. 19). Many who read these stories became worried unnecessarily about contracting the AIDS disease through saliva, tears or sweat spread by hugging, eating or shaking hand. (Weitz, 1991). Further, the media also contributed to the fear of the AIDS disease through its questionable use of "experts". Journalists are neither trained nor expected to evaluate conflicting scientific claims.

Rather, their job is to solicit and publish the view of various "authorities" without identifying one authority as more reliable than another. As a result, the media, in their attempt to present all sides of the story, have given substantial coverage to some highly questionable scientific theories. Thus, the mass media objectifies HIV/AIDS for society. It is hoped, that the researcher has sufficiently demonstrated how the social representation theory is useful to understand the different perceptions, attitudes and the emergence of the various metaphors used to describe AIDS. Despite the positive aspects of the theory, there are many problems that one needs to consider.

#### 2.5.4 Problems with the Social Representational Theory

Social Representational Theory throws light on to the constructive aspects of social life because it claims to provide an integrated frame for understanding attitudes, attributions and beliefs. However, according to Potter and Wetherell (1987) the Social Representational Theory is not easily applied or does not easily explain all situations. There are three such situations that exist: the relation between groups and representations, the nature of consensus assumed by the theory and the role of language and cognition. Let's consider each one.

##### **(a) Groups and Representations**

In this theory, there is an assumption that social groups are formed because of their shared social representations, which give rise to a group identity. Although this is theoretically correct, this assumption immediately raises practical difficulties when carrying out research. For example, empirical studies of social representations typically start with apparently well – defined and homogeneous social groups and researchers attempt to explicate their representations.

The first problem is that this presupposes the correctness of the notion that representations delimit groups. In other words, there is a vicious circle of identifying representations through groups and assuming groups define representations. A second problem is that researchers can not easily identify psychologically salient groups independently of participants' representations of those groups. This leads to inconsistencies. On one hand, group categories will be treated as naturally occurring phenomena which can be used as a base for research conclusions.

On the other hand, group categories can themselves be understood as social representations constructed in the course of participants' communication.

Finally, there are difficulties because of the ambiguous empirical status of social representations. If one is going to be related to social groups, then there must be some clear – cut, repeatable way of pointing to representations and discriminating one from the other. Yet Moscovici (1984) does not provide an analytic technique for performing this vital procedure. The problem here is that it involves some well – defined notions of consensus and we will see in the next section that it is not a simple matter.

#### **(b) Consensus in Representations**

The premise that representations are consensually shared across a number of people is a central feature of Moscovici's theory. The claim seems relatively precise and unambiguous, until we try to use it in practice. Studies of representations tend to simply presupposed consensus and smoothed over internal diversity. Some of the studies use numerical averaging techniques, which in their very nature, homogenize participants' responses. For example, studying students' representations of a protest movement with a word association technique, simply presented average scores for these associations across the sample. These scores seem to demonstrate that students share an undifferentiated representation but an average may disguise considerable variations among a sample.

**(c) Representations: Cognitive or Linguistic?**

A further problem with operationalizing social representations for research practice is at what level the operationalization should take place. Moscovici (1984) describes representations as mental entities made up of both abstract and concrete elements (i.e. both concepts and images). He seems to locate representations as cognitive units.

But, with research, one is inevitably faced with discourse. The cognitive assumptions underlying the theory are highly problematic. According to Potter and Wetherell (1987) Moscovici's dual processes of anchoring and objectification for dealing with unfamiliar objects is an exercise in speculative cognitive psychology. Given the metaphorical language in which it is couched, it is not clear how claims about the processes could be tested. For example, how would researchers know if they had found an instance of anchoring?

Furthermore, there are important contradictions in the way these cognitive processes are described. Moscovici (1984) states that all cognition, all mental experiences are based on representations. But if our perception of the world is entirely circumscribed by our representations of the world, then how can we even recognize new and unfamiliar social objects? How can the process of anchoring begin at all? Moscovici is vague at this point (Potter & Wetherell, 1987).

This chapter has attempted to define or describe the AIDS disease. Further, the different attitudes and metaphors that surround AIDS were identified, by reviewing the relevant literature. These attitudes and metaphors that were identified were contextualized within a theoretical framework i.e. The Social Representational Theory. The background to the theory and definitions were considered first before an outline of the theory and its application was presented. The critical overview of the theory was also explored. The next chapter examines the methodology used in this study.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

Chapter 2 identified and explored the metaphors, attitudes and perceptions that surround AIDS within a theoretical context. This chapter focuses on the methodology used in this study. It includes a discussion about the pilot study and the research design i.e. sampling methods, data collection and data analysis. It ends with a section on reliability and validity.

#### **3.2 The Pilot Study**

An interview schedule or what Patton (1987) termed the general interview guide approach was developed. It was based on the current literature on HIV/AIDS counselling. The researcher decided to carry out a pilot study to “test” the interview schedule in order to identify any limitations.

The interview schedule consisted of two sections: Section A examined the biographical details of the counsellors. Section B explored the meanings, attitudes, knowledge and perceptions held by AIDS counsellors. The questions in Section B were open – ended. According to Patton (1987) this would allow the person to answer in which, ever direction he/she chooses to.



Five female AIDS counsellors were interviewed. There were three professional counsellors and two lay counsellors. The professional counsellors consisted of one clinical psychologist, a social worker and a registered nurse. The clinical psychologist and social worker worked at an AIDS Centre in KwaZulu Natal, and had more than five years of experience working in the HIV/AIDS field. The registered nurse had 10 years of experience and worked at a Public Hospital in KwaZulu Natal, Midlands. The lay counsellors had a minimum of Standard Six Education and both worked at an AIDS Centre in KwaZulu Natal. The interviewees were briefed about the study and their consent received in writing. All the interviews were tape - recorded. These interviews were then transcribed. The researcher then identified the important themes, meanings and shared experiences among AIDS counsellors.

This process revealed that the interview schedule did not tap into the counsellors' personal feelings and thoughts about HIV/AIDS. They spoke about HIV/AIDS in a very clinical way. For example, when one of the counsellors was asked to describe AIDS. The counsellor said: " I think that it is a condition that results from the infection, with HIV and it turns out to be a terminal condition. A person can get sick and die as a result of a number of opportunistic infections – I assume the issue with AIDS is always how well or how long you can live with the disease." This extract reveals that personal feelings towards the illness, was not expressed. Further, it did not help to reveal significant meanings or attitudes. The interview schedule together with relevant literature, then helped the researcher, to revise the interview schedule. This was achieved by including questions that focussed on the counsellors' specific cases, to describe them and some of their feelings and thoughts about the case.

Examples of the revised questions are as follows:

- 1) From your experience with AIDS, how would you describe AIDS?
  - What are your feelings and thoughts about the disease?
  - Can you think about a case where these descriptions stood out?

- 2) Can you tell me about the most significant case/patient that you counselled or dealt with?
- Why did this case /patient stand out for you?
  - What did you learn from it?
  - How did you feel towards this patient?
  - What were some of the patient's issues?

The transcripts of counsellors also indicated that counsellors, who had over two years of experience working in the HIV/AIDS field, revealed more themes, attitudes, and perceptions than the counsellors who did not have this experience. Examples of these themes included the punishment metaphor; disease of the "other" and comparisons to other diseases especially cancer. Therefore, the researcher decided to use working experience (in terms of the number of years) as a criterion to select the participants. Now, let's consider the design of this study.

### **3.3 Design**

This study is a qualitative research, which is in the form of words rather than numbers. (Miles & Huberman, 1984). Qualitative research is a source of well – grounded, rich descriptions and explanations of processes occurring in local context.

Further, according to Miles and Huberman (1984) it allows the researcher to go beyond initial preconceptions and frameworks. Qualitative research allows for both in depth assessment and analysis of the issue being researched as well as enabling the investigation of sensitive issues. HIV/AIDS is a sensitive issue. Furthermore, counsellors would not be forthright about their attitudes and perceptions about AIDS. The researcher ensured that the type of questions used in the interview were non – intrusive and non-threatening to the counsellors. These questions also allowed them to



focus on a specific case. Therefore, for this study, the researcher used the qualitative method.

According to Patton (1991) decisions about designs, measurement, analysis and reporting all flow from the purpose of study. Therefore, the first step in a research process is getting clear about purpose. The purpose would also determine the audience, reporting style and expectations. The purpose of this study is to examine the meanings, attitudes, perceptions and knowledge among professional and lay AIDS counsellors. The study also seeks to understand and explain how the counsellors' knowledge, attitudes and meanings of HIV/AIDS impact on the counselling process. Thus, having identified the purpose of this study, the researcher can now look at the issues of sampling.

### 3.3.1 Sampling

Huysamen (1994) distinguishes between probability and non-probability samples. Examples of probability sample include random samples, cluster samples and stratified samples. Quota samples and purposive samples are examples of non- probability.

Probability sampling refers to where the size of the population under investigation is known to the researcher. Some of the other characteristics of probability sampling are for example: every individual or unit has a non- zero chance of being sampled; the researcher can make generalizations to the larger population and the sample size is large. Therefore, the probability that any element/ subject in the population can be included in the sample is high.

In non-probability sampling, by contrast, the size of the population is unknown. (Huysamen, 1994). Other characteristics of non – probability sampling are for example: the researcher can not make generalizations to the larger population and the sample size is small. This study used non-probability, purposeful sampling. According to Patton (1991) qualitative inquiry typically focuses in depth on relatively small samples, selected purposefully. Miles and Huberman (1984) agree with Patton (1991). They believe that qualitative samples tend to be more purposeful than random.

This is because the initial definition of the universe is more limited and social processes have a logic and coherence. Random sampling of events tends to reduce the information to uninterpretable material. Marlow (1993) noted that purposive sampling includes those elements of interest in the sample. In purposeful sampling, the logic and power lies in selecting information – rich cases for study in depth (Patton, 1991). Information rich cases are those from which one can learn a great deal about issues of central importance to the study. As mentioned earlier, the pilot study set a criterion for sampling (i.e. that counsellors who had over two years of counselling experience should be considered for the study). Therefore, in selecting participants, the researcher excluded participants who did not meet the criterion. Secondly, the counsellors had to meet the criterion for a “counsellor”, that is, the researcher defined what is a professional and lay counsellor (see chapter 1 for definitions). Therefore, when sampling the researcher considered these definitions. Anyone who did not meet this definition was excluded from the study. For example, there was a lay counsellor who was a voluntary counsellor at a tertiary institution. However, this counsellor did not have any formal training. Therefore, she was excluded from the study.

According to Patton (1991) there are several different strategies for purposefully selecting information rich cases. For this study, the researcher decided to use intensity purposeful sampling. Intensity sampling consists of information rich cases that manifest the phenomenon of interest intensely but not extremely.

The process that was used by the researcher for selecting information rich cases involved identifying which transcripts revealed more themes, attitudes and perceptions when compared to one another. Further, this strategy allows one to draw explicitly on the intense personal experiences. Intensity sampling involves some prior information or considerable judgement. The researcher obtained prior information from the pilot study.

### 3.3.2 Sampling Size

According to Patton (1991) there are no rules for sample size in a qualitative inquiry. Sample size depends on what one wants to know, the purpose of the inquiry, what's at stake, what will be useful, what will have creditability and what can be done with the available time resources.

Lincoln and Guba (1985) recommend sample selection to the point of redundancy i.e. sampling is terminated when no new information is forthcoming from new sampling units. Sampling to the point of redundancy is ideal. It works best for basic research, unlimited time lines and unconstrained resources.

The solution is judgment and negotiation. Patton (1991) recommend that "qualitative sampling designs specify minimum samples based on expected reasonable coverage of the phenomenon given with the study" (p. 186). According to Patton (1991), the researcher can determine the sample size but he/she may add to it as the fieldwork unfolds. The researcher can change the sample if information emerges which indicated the value of change. The design should be understood to be flexible and emergent.

Therefore taking all the suggestions made by the other researchers, the researcher decided that sampling to the point of redundancy would not work with this study. This is because the researcher experienced a problem with getting professional and lay counsellors who met the both criteria. Therefore, the researcher negotiated the sample size. In the pilot study the researcher interviewed five counsellors. The analysis of the data, in the pilot study, revealed that there was a reasonable coverage of the main issues. This is what Patton (1991) above suggests. Therefore, the researcher decided that a sample size of six would ensure reasonable coverage of the main issues. This may later serve as a shortcoming of the study. Having set the backdrop, the researcher can now proceed to describe the data collection procedure.

### **3.4 Data Collection**

#### **3.4.1 Participants**

A sample of six female AIDS counsellors was accessed from the KwaZulu Natal Area. The researcher originally wanted to interview both male and female counsellors. However, only female counsellors were available at the time of the study.

The AIDS counsellors included three lay counsellors and three professional counsellors. The researcher disregarded the participant's age, race, level of education and economic status. The two criteria used for selecting the participants were the number of years of experience in the HIV/AIDS field and the definition of a counsellor. With regard to experience, only counsellors who had over two years of HIV/AIDS counselling experience, were considered for the study. A detail profile of each counsellor and a comparison of the age, race, and educational level will be provided in the next chapter.

### 3.4.2 Interview Schedule

The pilot study was used to inform the interview schedule. A revised version of the original interview schedule was employed (see Appendix A). The revised interview schedule explored the feelings, thoughts and meanings of counsellors in relation to their cases. In other words, counsellors were asked to describe for example, their most significant case, an HIV positive case that was significant, an HIV negative that was significant and they were asked to relate their feelings and thoughts about these cases. Also, why these cases stood out for them and if they could identify any possible learning from the cases.

The interview schedule was used to measure the diversity of meaning among the AIDS counsellors. The interview schedule comprised of two sections: Section A included the biographical and work experience information of the counsellors. Section B comprised of open-ended questions, which tapped into the meaning, attitudes, beliefs, knowledge and metaphors used by the AIDS counsellors. This was achieved by asking the counsellors to describe cases that were significant to them. Thus, by reliving the case, the researcher tapped into the emotions and feelings that the counsellors were not aware of. This strategy was informed by the pilot study.

### 3.4.3 Procedure

Over a period of six weeks, the researcher conducted all the interviews. Initially, participants were briefed regarding the study, and any questions that the participants had were answered. Participants consented to the study in writing (see Appendix B).

According to Patton (1987) qualitative data can be collected using the following methods:

- In-depth, open-ended inter views which yields data that consists of direct quotations from people regarding their experiences, opinions, feelings and knowledge. The data begins as raw descriptive information.
- Direct observations
- Analysis of written documents

Given the nature of the study is to explore perceptions, attitudes and behaviour among AIDS counsellors, the researcher felt that in-depth interviews would be the most effective method to collect that data. Further, the researcher felt that it was necessary to do all the interviews herself, because it would make the researcher feel more in touch with the data.

If the researcher used direct observations as a method for collecting the data, there would be a number of problems. For example, counsellors do pre and post test counselling. It would be unethical to sit in on a post - test counselling session. However, even if the patient agrees, the researcher would not be able to “measure” the attitudes, behaviour and perceptions among AIDS counsellors. With regard to the analysis of written document method, there are very little written documenting counsellors’ experiences, in the South African context. Therefore, this was not an option.

Neutrality is important in any interview according to Patton (1987). However, this is a contentious issue as it is not always possible to be neutral. According to Patton (1987) interviewing is a skill which involves entering another person’s world. The interviewer must be sensitive, concentrate, and have interpersonal understanding and insight.

The role of the interviewer is to provide a framework within which the person being interviewed can respond to questions in a comfortable way. With HIV/AIDS it is important to take cognizance of the prejudice, stigma and discrimination surrounding the disease. This does not necessarily call for neutrality but an awareness of the issues. Qualitative data collection allows the researcher/interviewer to exhibit empathy. The interviewer /researcher used the technique of probing, which according to Miles and Huberman (1984), is useful in obtaining a deeper response to questions as well as increasing the richness of data collection.

The interviews were tape-recorded with the participants' permission. The data was transcribed word by word by the researcher and a research assistant. The research assistant was a person who worked for the linguistics department at a tertiary institution.

### **3.5 Analysis of Data**

According to Patton (1987) it is important to distinguish between analyzing and interpreting qualitative data. Analyzing data involves bringing order to the data, organizing the data into patterns and identifying relationships and links among the descriptive dimensions. On the other hand, interpreting data refers to the process of attaching meaning and significance to the analysis, for example, by explaining relationships and linkages. Patton (1987) noted that the analysis is difficult owing to responses that are not systematic or standardized. However, open ended responses to issues and feelings enable the researcher to view the world as seen by the respondent.

According to Marlow (1993) organizing qualitative data involves being faced with completely un-categorised data. The primary mission is to look for patterns in the data. The researcher must engage in careful observation, which leads to the



uncovering of connections and patterns in the data. These patterns and themes emerge from the data rather than being developed prior to the data collection phase. The method of analysis used in this study, was thematic analysis.

According to Boyatzis (1998), thematic analysis is a way of seeing. In other words, it is the ability to recognize patterns in seemingly random information. Researchers use thematic analysis to see something that is not evident to others. Thematic analysis is a process for encoding qualitative information. It is a procedure used for analyzing the social distribution of perspectives on a phenomenon. The underlying assumptions of thematic analysis are that in different social worlds or groups, there are differing views.

According to Boyatzis (1998) there are three limitations to using thematic analysis effectively in research. They are the researcher's: (a) projection (b) sampling and (c) mood and style. Projection means the stronger the researcher's ideology or theory, the more he/she will be tempted to project his/her values or conceptualization of the events onto the interviewees. The researcher therefore also engaged the assistance of a research psychologist to help also identify the emergent themes in the data. Thereafter, both compared the emergent themes. The research psychologist that was chosen was also working in the HIV/AIDS field.

With regard to sampling, Boyatzis (1998) states that the researcher's judgement is used to choose the participants. However, with this study, to a certain degree the criterion set out by the pilot study guided the researcher's choice of participants. The third limitation is mood and style. According to Boyatzis (1998) qualitative research is subjective. Therefore, many factors may threaten the quality of information, collection, processing and analysis.



Further, as the researcher's ability to conduct thematic analysis improves, his/her frustration, confusion or fatigue will decrease (Boyatzis, 1998). During the analysis of the data, in this study, the researcher ensured that there were "breaks" between the drafts. This allowed the researcher to be refreshed.

Boyatzis (1998) outlines the following steps in thematic analysis.

### **Step 1:**

In the first stage, the researcher must be able to sense themes i.e. to recognize a codable moment. To sense themes, or to begin the process of developing codes, researchers must be open to all information. All their senses should be ready to receive pertinent information. The researcher read up the relevant literature surrounding AIDS and also read the transcripts twice before beginning.

### **Step 2:**

In the second stage, the researcher must train or discipline him/herself to use themes, or codes, reliably. The second stage basically, involves the ability to see and "to see" consistently. The researcher after reading the transcripts began making marginal notes, in order to identify common themes. A research psychologist (as mentioned earlier) was also used to identify common themes. The research psychologist coded separately and the researcher also coded the data separately. Thereafter, the research psychologist and the researcher compared the codes which in turn led to an inter – code agreement between the two parties concerned. This then increased the inter – code reliability of the study.

### **Step 3:**

In the third stage, the researcher must develop a code to process and analyze or capture the essence of their observations. During this stage, the skill is primarily developed and refined through practice and more practice. With regard to practice, the researcher used the pilot study to learn how to code. Thereafter, this skill was applied to the themes of this study. All the common themes were written down (and even the number of times it appeared) on a separate paper. Thereafter, codes were given to the themes, in rank order.

### **Step 4:**

The researcher must interpret the information and themes in a way that contributes to the development of knowledge. Together, with the relevant literature, the researcher was able to interpret and discuss the emergent themes of the study.

## **3.6 Validity and Reliability**

Validity and reliability of research findings are critical to all studies (Brink, 1996). Validity refers to the extent to which the instrument captures what it is designed to measure. (Gaskell & Bauer, 2000). Reliability is concerned with the consistency of measurement (i.e. the extent to which the test is internally consistent and yields the same results on repeated trials (Gaskell & Bauer, 2000).

Qualitative research studies are often criticized owing to their supposed lack of validity and reliability and scientific rigour. These criticisms occur because the same rules used to judge the rigour of quantitative studies are used to judge qualitative methods. Qualitative research should develop its own standards and rules. There are two different ways of proceeding. These are top – down philosophical reflection or bottom – up empirical observation of “good practice”. Gaskell and Bauer (2000) attempt to mix the top – down development of criteria and the bottom – up observations. The outcome of this mixture is a set of criteria which is used to gain the confidence of peers, demonstrating the relevance of research and thus assuring public accountability of the research process.

Public accountability is not an accounting issue of costs and benefits, nor is it the idea that good research commands public support for its conclusion. Basically, it captures the idea that science operates in the public domain. It is not a private enterprise. In order to qualify as public knowledge, the study claims and warrants are objectified and made public and thereby open to public scrutiny.

Within public accountability, Gaskell and Bauer (2000) provide two broad categories for quality assurance i.e. confidence indicators (validity) and relevance indicators (reliability). Confidence indicators allow the reader to be “confident” that the results of the research represent “reality” and are more than the product of the vivid imagination of the researcher.

For qualitative research, confidence is indicated by (a) triangulation and reflexive understanding through inconsistencies (b) procedural clarity and (c) corpus construction. Let’s consider each one and its implications on this study.

(a) Triangulation and Reflexive understanding

Understanding of other people and also of textual materials feeds on the experience of diversity. The social researcher is always in a position of trying to make sense of another person from other social milieu. Understanding ourselves and the 'other' may be an unending quest, but it takes its starting point from the awareness of divergent perspectives which lead to reflexivity, the decentring of one's own position. Reflexivity implies that before and after the event the researcher is no longer the same person. Basically, it questions the way the research was conducted, including the behaviour of the researcher, the researcher's awareness of his/her own perspective and influence and whether or not the research process facilitates the personal growth of the researcher.

With regard to this study, the researcher's experience as a counsellor helped to understand the counselling process involved with AIDS. Further, as a counsellor it is believed that in general counsellors do not hold negative or prejudice attitudes towards the AIDS illness. However, this belief was challenged. The pilot study informed the researcher about the kind of "expected" data to be collected. This allowed the researcher to be more open – minded about the data. Further, the researcher was able to "practice" the interviewing and note taking skills, while conducting the pilot study. These skills were then implemented in the current study.

Another question one has to ask is how did the researcher deal with the data, including level of theorizing and the exploration of alternative interpretations? In this regard, the researcher used, as mentioned earlier, a research psychologist to help verify challenges and raise any issues that the researcher may have overlooked and a number of theories were used to explain the findings of the study.

(b) Transparency and Procedural Clarity

The primary function of documentation must be to enable other researchers to reconstruct what was done in order to check it or imitate it. In qualitative research, transparency performs functions similar to internal and external validity in quantitative research. It can be judged from a detailed description of the selection and characteristics of respondents and/or the topic guide of the interviews and/or the coding frame for a content analysis; the method of data collection, the type of interviewing or the type of content analysis.

With regard to this study, the researcher has given a detailed account of the sampling procedure, the sample size, the data collection procedure and the analysis of data. Thus, if anyone wants to reproduce this study, they will have all the necessary information required to reproduce it.

(c) Corpus Construction

Corpus construction is the functional equivalent to representative sampling and sample size, but with the different aim of maximizing the variety of unknown representations. Researchers want to map the representations in a population and not measure their relative distribution in the population. Sample size does not matter in corpus construction as long as there is some evidence of saturation. Corpus construction is an iterative process, where additional strata of people are added to the analysis until saturation is achieved and further data do not provide novel observations.

In terms of the research, the researcher is aware that this criterion is not met. The researcher negotiated the sample size because there was a problem getting counsellors who had over two years of experience and to find counsellors who met the 'definition' of a counsellor (as set out in Chapter 1). The analysis of the data, in the pilot study, revealed that there was a reasonable coverage of the main issues. Therefore, the researcher decided that if only six counsellors were interviewed, then this would ensure reasonable coverage of the main issues. However, the researcher recognizes that this is a shortcoming of this study.

Now let's consider reliability. Reliability is critical in using thematic analysis. In qualitative study, reliability is the consistency of observation, labeling or interpretation. It affects the potential for replication, extension and generalizability of the research. According to Boyatzis (1998) reliability is consistency of judgement that protects against or lessens the contamination of projection. Consistency of judgement with qualitative information appears in two basic forms:

- (a) consistency of judgement among various viewers and
- (b) consistency of judgement over time, events or settings.

**Consistency among viewers** is attained when different people observing or reading the information see the same themes in the same information. Inter-rater reliability is consistency of judgement among multiple observers. Kirk and Miller (1986, cited in Boyatzis, 1998) called this form of consistency of observation synchronic reliability, given that it refers to similarity of observations made within the same time period by multiple observers. The researcher of this study took into account inter-rater reliability. A research psychologist was used to identify the themes. Thereafter the researcher compared the themes.

Miles and Huberman (1984) also suggest the same method i.e. double coding. In this technique, two people observe the raw information independently. Each person makes judgements without interacting or seeing the judgement of the other observer.

Following the observation period, the two observers compare their results. In the simplest form of double coding, the two observers discuss each observation until agreement is reached. The researcher used this method as described by Miles and Huberman (1984).

**Consistency over time and events** is attained when a person makes the same observation at two different times or in two different settings. Although Kirk and Miller (1986, cited in Boyatzis, 1998) called this diachronic reliability, the usual label is test – retest reliability. Though test – retest reliability seems inappropriate for most qualitative research, it does bring up an important issue of comparability of samples (Smith, 1992, cited in Boyatzis, 1998).

In most qualitative research, a “retest” or repeat of the phenomenon of interest does not occur naturally. Although one may disregard test – retest reliability as inappropriate for many qualitative research, comparability of sample selection within a study remains an important methodological issue. The essential point is that the design of sampling in qualitative research should be driven by concerns for comprehensiveness rather than test – retest reliability. The researcher recognizes that this is a limitation of the study.

However, according to Boyatzis (1998) the researcher’s belief or trust that he/she has captured the phenomenon under investigation and that his/her judgements are sound: this can be considered as a form of reliability. Both the pilot and the main study’s information were similar i.e. there were similar themes and metaphors that

emerged from both the studies. For example, the punishment metaphor, the death sentence metaphor, mysterious disease metaphor and comparisons to other illnesses. Furthermore, the researcher noted that after the fourth interview (in the main study) there was no more new information that was being added. Therefore, the researcher used her judgement with regard to the sample and this ensured that the underlying meaning of AIDS was captured. Further, reliability in the study is realized through rigorous collection and presentation of the data, including verbatim quotes from the interviews.

This chapter has focused on the research methodology used in the study. The sampling method used was discussed. An outline of the tools used to collect and analyze the data was presented. Validity and reliability of the study was also considered. The next chapter presents the results of the study.



## **CHAPTER FOUR**

### **ANALYSIS AND DISCUSSION OF RESULTS**

#### **4.1 Introduction**

Chapter 3 examined the research methodology used in this study. This chapter presents the personal profiles of the counsellors that were interviewed. These personal profiles are an analysis of the biographical details for each counsellor. The chapter also highlights the analysis of the counsellors' experience and response to the HIV/AIDS epidemic. The study revealed that counsellors identified and used metaphors in the counselling process. The metaphors that were identified by the researcher were the following: AIDS is seen as a mysterious disease; comparisons to other illnesses e.g. leprosy and cancer; the death sentence metaphor; punishment; disease of the young; disease of the "other" and the military metaphor. These metaphors are examined in detail. Comparisons are drawn between lay and professional counsellors. The researcher attempts to explain how these metaphors are formed, within the Social Representational Theory.

#### **4.2 Personal Profiles of Counsellors**

The following descriptions capture some of the important details of the counsellors' background, working experience and occupation. The profiles are divided into two sections: descriptions of professional counsellors and descriptions of lay counsellors. Pseudonyms have been used to safeguard confidentiality. The researcher preferred to use names rather than numbers to describe the women interviewed. This gives a personal tone to the discussion and presents the participants in a more humane way.

#### 4.2.1 Descriptions of Professional Counsellors

##### **Profile of Clare**

Clare, who is 49 years old, is married and works at a tertiary institution for higher education. She initially graduated as a registered nurse and worked for about 13 years in the nursing field. Clare then furthered her studies, which led her to become a registered psychologist. She has about 10 years of AIDS counselling experience.

##### **Profile of Alice**

Alice is the Director of an AIDS Centre in KwaZulu Natal. She is 37 years old. By profession, Alice is a registered nurse. Her first contact with AIDS occurred in 1991, when she was working at the Point Water Front area in Durban. Alice has over eight years of AIDS counselling experience.

##### **Profile of Anita**

Anita is a 41 years old, registered psychologist. She was working (at the time of the study) at a tertiary institution for higher education. Her previous occupation included teaching at a senior secondary school for 10 years. Thereafter, she lectured at a tertiary institution. Anita's interest in the HIV/AIDS field started in 1990, with her own research.

#### 4.2.2 Descriptions of Lay Counsellors

##### **Profile of Ashika**

Ashika is a 37 years old woman, who worked as a voluntary AIDS counsellor. By profession, she is a human resource consultant. Before this, she was an executive secretary for 17 years and also worked as a health co-ordinator at a private company. As a health coordinator, she is responsible for staff health issues, running educational programmes and counselling.

##### **Profile of Sue**

Sue is 51 years old. She was the Head of an AIDS organization in Cape Town. At the time of the study, she was living in Durban doing voluntary AIDS counselling. Her organization is responsible for AIDS education, development of peer group counsellors in schools, counselling and outreach work, especially in the townships. Sue had over 10 years of AIDS counselling experience.

##### **Profile of Lungi**

Lungi is a 29 years old, lay counsellor at an AIDS Centre in Durban. She had been working with this organization for 3 years. Lungi decided to become an AIDS counsellor because she witnessed a number of loved ones dying of this illness. She therefore decided to do something to make a difference.

### 4.3 Personal Profiles Comparisons Between Lay and Professional Counsellors

In this study, it is important to compare the personal profiles of the counsellors. This is to provide a clearer picture, so that when comparisons are made later on in the chapter, these comparisons may be understood. The table below compares the personal profiles of the professional counsellors to the lay counsellors. The table is divided to consider the counsellors' age, number of work experience in the HIV/AIDS field, gender and racial grouping.

Table 1: Comparisons of the Profiles between Professional and Lay Counsellors

#### Professional Counsellors

Name	Age	Work exp.	Gender	Racial grp.
Clare	49	10 yrs	female	White
Alice	37	8 yrs	female	White
Anita	41	3 yrs	female	Indian

#### Lay Counsellors

Name	Age	Work exp.	Gender	Racial grp.
Ashika	37	17 yrs	Female	Indian
Sue	51	10 yrs	Female	White
Lungi	29	3 yrs	Female	Black

The above table indicates that all the counsellors were females. The majority of the counsellors were white and there was only one black counsellor. The average age for the professional counsellors was 42 years while the average age for the lay counsellors was 39 years.

Now lets consider the meanings and metaphors of AIDS that emerged from the analysis of the data. The researcher has transcribed the data verbatim. Any corrections that the researcher made to the transcripts occur within square bracket.

**4.4. Counsellors’ Experience and Responses**

The interviewer started off by asking counsellors to describe how they felt about HIV/AIDS, using case examples from their work experience. On analysis of the data, the following themes emerged namely, the military metaphor, the death sentence, a mysterious disease, the disease of the other, punishment and comparisons to other diseases. Before considering each metaphor in detail, a general comparison is made between professional and lay counsellors. Table 2 and Table 3 (below) identify the metaphors used by the professional and lay counsellors respectively. Examples of these metaphors are given. These tables illustrate that similar metaphors were used by professional and lay counsellors. Further, although professional counsellors were university graduates, they also made use of these metaphors. Thus, one can assume that the level of education does not play a role in the use of various metaphors.

Table 2: Meaning Attributed to AIDS by Professional Counsellors

Themes	Example: Quotation from the Extracts
Theme 1 Mysterious Disease	The disease itself, I find it very exciting. It's a very exciting disease. It's a mind – boggling disease. (Anita)
Theme 2 Comparisons to other diseases	
(a) Leprosy	From that day their salaries were cut down by half. They were not allowed to touch food anymore, they were not allowed to touch the children and immediately they were made to feel like total lepers. (Alice)
(b) Cancer	<p>If we look through history there's always been some kind of disease that cut off the extra population, that made man realizes that we are vulnerable. There was the plague and then small pox and then whatever and then T.B and then cancer and just when we sort of come to grips with each one, find a remedy or methods of prolonging the disease, here comes another one. (Anita)</p> <p><i>* Although the counsellor refers to other illnesses in the above extract, the researcher has chosen to refer only to cancer. This is because there is support for comparisons to cancer and leprosy. There is no evidence supporting comparisons to other illnesses such as T.B and small pox, in other extracts, by counsellors.</i></p>
(c) Stigma and Shame	It's not something you talk about easily and because AIDS is linked to sexual behaviour, there is a lot of shame, stigma, rejection and discrimination about it. (Clare)

Theme 3 Death Sentence	I've seen on the T.V and this woman was going on about retroviral [anti-retroviral] for pregnant women and just saying what a relief it would be knowing that her children would be alright. But at the same time, these drugs are not easily available. Thus, sometimes you are left feeling like you have sentenced your child to be HIV positive.
Theme 4 Punishment	She lived with her grand parents and her grand mom believed that it was a disease from God, it was a punishment. Anyone who had AIDS or HIV was a sinner. (Anita)
Theme 5 Military	I suppose it is something that has profound implications and repercussion for people. It's complicated complex because it's linked to sexuality. (Clare)
* In the following themes, the extracts are case examples of the counsellors' patients. From these descriptions, the researcher related it to a disease of the young and the "other". However, these meanings are not very explicit from the extracts below. These will be fully explained later on.	
*(a) Disease of the young	He was a young and healthy. He was still healthy. He wasn't in the ill stages of the disease. He was with his life ahead of him. He was doing a degree in Engineering. He was intelligent. He potentially had a bright future ahead of him. (Clare)
*(b) Disease of the "other"	I have images in my mind of 2 young students & I suppose it was these students who really made AIDS real for me. I suppose until then, it was something that was out there. (Clare)



Table 3: Meaning attributed to AIDS by Lay Counsellors

Themes	Example: Quotation from the Extracts
Theme 1 Mysterious Disease	I think that it is a mysterious disease with modern medicine the way it is – it's a shame that we can not find the cure for AIDS. I think my feelings, is that it is a horrible, scary disease because nobody knows how to cure it. Thus, it becomes a mysterious disease. (Lungi)
Theme 2 Comparisons to other diseases	
(a) Leprosy	Its like leprosy, it kills you. It's dreadful, it's not a quick death, its a slow and painful death. When you read the bible and it tells you how dreadful it was and how you never touch anybody with leprosy. (Ashika)
(b) Cancer	They came in together, as a couple and the husband was diagnosed as HIV positive and I remember that the wife said that we can not tell our family that he has AIDS. We will be rejected. It would be better if I tell them that he has cancer, it would be more acceptable. (Lungi)
(c) Stigma and Shame	So you see, there is still this negative perception about AIDS that is going around. You see AIDS is still stigmatized. (Lungi)

Theme 3 Death Sentence	You know I think that with AIDS there has be a shift or change in perception but I know that in the rural areas people still perceive AIDS as something that is terrible, as a death sentence. (Lungi)
Theme 4 Punishment	You see AIDS is still stigmatized that is it is a disease resulting from some kind of wrong doing which is a great pity. (Lungi)
Theme 5 Military	AIDS is a disease, it's a devastation right from the physical side of your body, it gets right into the core of the immune system and breaks down your defenses. It sorts of breaks down the body from within. (Sue)
(a) Disease of the young	You know the perception is that young people are very promiscuous. (Lungi)
(b) Disease of the "other"	The Blacks sleep around all the time and the Blacks have, they're dirty, you know and the Blacks will get it. (Ashika)

#### 4.5. Meaning of the disease

HIV/AIDS can be described in terms of physical, emotional and psychological aspects of the disease. The way counsellors choose to describe the disease. impacts on their meaning and understanding of the disease. The counsellor's meaning and understanding of AIDS has implications for the counselling process. These meanings of the disease have underlying themes and metaphors.

#### 4.5.1 Mysterious disease

Decades have passed and there still exists no cure for AIDS. Therefore, AIDS is seen as a mysterious and a mind-boggling disease. Anita describes AIDS in the following manner:

For me, I see two parts two sides to it. One is related to the disease itself and one relates to the effects of the disease on humanity. The disease itself, I find it's very exciting, it's a very exciting disease. It's a mind-boggling disease. It's a disease that if we had to sit and we were given everything to create something that was so devastating and so powerful – I don't think that most people in the world would be able to think of such a complex disease. So when we are looking at the disease itself, the way in which it functions, the way in which it goes about destroying the alpha cells in the body, from the pure clinical perspective, if I was a researcher, I would say wow, what a disease. **(EXTRACT 1)**

She further goes on to say that

It's a mystery, it's complex, it's exciting. Every time it has an answer for you. So I find it very exciting from that perspective. The clinical part of it. The other human part of me finds it to be devastating. Unfortunately, the havoc it wreaks on mankind, families, on children, just sensing a sense of apathy to a person who is HIV positive. **(EXTRACT 2)**

The counsellor views AIDS as a mysterious, mind – boggling disease that is very exciting. The excitement, for her, is that AIDS is seen as a challenge for medical researchers. It seems that her feelings of excitement indicate that she feels positive about HIV/AIDS. Although, it is a challenge for medical researchers, it is a positive challenge. But beyond this, she also finds that it is a devastating disease for society.

In an era where medical science is ahead, there is still no known cure for AIDS. Therefore, AIDS is a mystery. This was also confirmed by another counsellor. Lungi, in her description of AIDS, also indicated that AIDS is a mysterious disease.

I think that it is a mysterious disease with modern medicine the way it is – it's a shame that we can not find the cure for AIDS. I think, my feelings [towards AIDS] is that it is a horrible, scary disease because nobody knows how to cure it. Thus, it becomes a mysterious disease and I get so angry with the government and how they are responding to this disease. Instead of helping to get drugs they are debating about what causes HIV/AIDS. **(EXTRACT 3)**

Lungi feels scared and almost afraid of this disease because it has no cure. She gets angry at the government's response to HIV/AIDS. In this extract, one finds that it is very emotional. Lungi has strong feelings towards HIV/AIDS. The implication of these feelings on the counselling process is evident when she describes a difficult case she worked with. For example, she says that for her counselling a mother and child who are HIV positive is difficult. Lungi says:

The fact that it's infectious, that it can be transferred to children, which is probably the most difficult to deal with because I often find it's a situation where a healthy woman is diagnosed or comes to see that she is infected with a terminal disease which is what we are dealing with, because we got no drugs to make it a chronic manageable disease as they do in the North. **(EXTRACT 4)**

Lungi feels that without the help of drugs, AIDS is not a manageable disease. Working with mothers and their HIV positive children are difficult because there are no drugs. Thus, Lungi feels that the situation is hopeless. In the counselling process it feels like she is disempowered and therefore can not empower the patient. There is a sense of helplessness for her. It is also reflected in the following statement she makes:

That within a second so to speak AIDS can turn your life upside down and the pain and sorrow, that you can not do nothing about it. **(EXTRACT 5)**

Here again, there is a sense of helplessness and hopelessness. Lungi feels that without drugs to make the person feel better, the counselling process is not very useful. This is a strong statement but if one reflects on the statement where she says, “ you can not do nothing about it”, this reflects her feelings that she can not make a difference or help the patient. Alice in her description of a case also reported feeling very helpless.

And it just kind of stuck out to me, he actually, I became very close to him. We had to move him to the Arc and he died under very dreadful conditions and he didn't want to be there but there was nowhere else he could be because his family wouldn't have him and I just remember feeling very, very helpless and also just look, take a step back and think, you know, there are so many different facets to this thing. I put myself in the situation.

**(EXTRACT 6)**

In the above extract, the counsellor admits that she became emotionally involved with this particular client. This gave rise to a sense of helplessness because she felt that she was unable to help him. This impacted on the counselling process. However, the counsellor was aware of this fact. Therefore, she took “a step back” and tried to be objective about the situation. This self reflection method was used by the counsellor when faced with the issue of being emotionally involved with a patient. However, another method a counsellor can use to deal with emotional involvement in the counselling process – is to seek supervision from a senior counsellor or even peer supervision is recommended. This would allow the counsellor to deal effectively with the emotional attachment that he/she may experience with a patient. This process will also help to strengthen the counsellor's self reflection processes.

In extract 6 above, one also finds evidence of being rejected by family members because the patient was HIV positive. This rejection is linked to the stigma attached to AIDS. The researcher explores this in detail later on. In the extract below, Alice also reported feeling helpless.

Initially, I just felt incredibly helpless that I couldn't get through to him, you know. I felt how am I going to get this guy to understand that we are actually here to care? So I felt quite helpless what could we do for him. He was in quite a desperate situation.

**(EXTRACT 7)**

There is a sense that the counsellor is not adequately equipped to help the patient and that is where the sense of helplessness is probably stemming from. If one compares Lungi's statement to Anita's, one finds that Lungi, a lay counsellor, holds strong negative feelings towards AIDS. Anita, a professional counsellor indicates that the disease excites her. She sees AIDS as a challenge that needs to be overcome. In working in the HIV/AIDS field, both types of counsellors agreed that there is a sense of helplessness, which may be due to a lack of tools in the counselling process. Further, both the lay and professional counsellors agree that AIDS is a mysterious disease.

Kruger and Richter (1997) found that their subjects, who were school boys, perceived AIDS as a mystery. Sontag (1989) agrees with Kruger and Richter's findings, that "such a disease is by definition mysterious" (p. 5). Further, according to Purvis (1996) no one knew what had caused this strange outbreak of this infection.

According to the Social Representational Theory, one experiences a resistance, a distancing when one is unable to evaluate something, to describe it to ourselves or to others. Moscovici (1984) proposes two mechanisms that are used by people to cope with new and unfamiliar events: anchoring and objectification. For the counsellors, AIDS is something that is mysterious, unclassified and alien. To anchor is to classify and name something. By classifying what is unclassifiable, naming what is unnamable, we are able to image or represent it. This is dealt with in detail at the end of the chapter.



The first step towards overcoming the resistance is to place a familiar name. Therefore in order, to understand or represent AIDS, it was compared to other illnesses. History identifies two diseases (tuberculosis and cancer) that have been misunderstood in an era in which medicine's central premise is that all diseases can be cured.

#### 4.5.2 Comparisons to other diseases

Initially HIV/AIDS was undetected and a person with HIV/AIDS did not show any symptoms for years. AIDS is a 'new' disease, therefore to understand AIDS it is compared to other terminal illnesses such as the plague, leprosy, T.B, cancer and other illnesses that shared similar patterns. Only two diseases, namely leprosy and cancer, were identified in this study. Let's consider each disease.

##### **(a) Leprosy Disease**

Leprosy disease was seen as the Black Death. People who had this disease were isolated from society. Alice in her description of a particular case made reference to leprosy.

A woman decided to test her two domestic workers. There was nothing wrong with them and if they didn't test, they would lose their job, basically. So they went for testing. I phoned the doctor and said you can't do this. The doctor said well I've done it. I said well you won't divulge the results to the employer and the doctor said fine. But she gave the results to both these domestic workers. They were both [diagnosed as being] positive [which had] devastating implications. And the employer said to the two domestic workers, I know you've had your results and if you don't tell me I'll know you're positive. So they had to tell and from that day their salaries cut down by half, they were not allowed to touch food anymore. they were not allowed to touch the children and immediately they were made to feel like total lepers. (EXTRACT 8)



These two domestic workers were made to feel inferior and somewhat dirty. Diseases such as leprosy and syphilis were regarded as plagues not because they killed, but often they were disgracing, disempowering and disgusting (Procopius, cited in Sontag, 1989). This feeling of being disgraced and disempowered is also reflected in the above extract, where Alice's patients were not allowed to touch food or the children. They were made to feel like total outcasts. Ashika, a lay counsellor, was asked how she perceived AIDS. She responded in the following manner:

It's like leprosy, it kills you, it's dreadful, it is not a quick death, it is a slow and painful death. When you read the Bible and it tells you how dreadful it was and how you never touch anybody with leprosy. And that's basically what's happening here and that's why these people go to support groups in confidence because they know for a fact that society will shun them, they will never be accepted. **(EXTRACT 9)**

In the above extract, Ashika compares AIDS to leprosy disease. It seems both are dreadful, both will kill you and it's not a quick death. She further goes on to say that the Bible describes how horrible leprosy was and that you must never touch anybody. In general, it feels that people are therefore justified to reject people with leprosy because the Bible said that 'normal' people should not touch people who had leprosy. Ashika, believes that because of this, today HIV/AIDS patients are being stigmatized. The researcher would like to point out how negative attitudes and perceptions of one disease such as leprosy, is carried on to another disease like AIDS. There seems to be some processes involved and the researcher would examine these later within the Social Representational framework.

It seems that both the lay and professional counsellors, represent AIDS in terms of past epidemics. Therefore according to the theory, old mental schemata or images that were used to make sense of other illnesses, are now being reused to make sense of AIDS (Moscovici, 1984). This is evident when Ashika defines AIDS in terms of the leprosy disease and Alice says that the two domestic workers have become total lepers. In other words, these mental schemata or images are at play during the counselling process. Cancer was the other disease that AIDS was compared to.

(b) Cancer

Cancer is a terminal illness and society knows that you can die from it. However, today it is found that to have cancer is more acceptable. Alice relates a patient's difficulty disclosing the news to her partner.

The whole ground of everything, is at threat and it's like coming home and telling somebody you've given them a terminal disease, you know . It's a huge impact and it often takes some time to process all that before they're ready. (EXTRACT 10)

From Alice's experiences, she feels that when an HIV/AIDS patient discloses their HIV positive status to a partner, it feels like the HIV/AIDS patient is telling that partner that he/she has given them a terminal illness. Alice further goes on to say that within the counselling process, disclosure is something that counsellors in general have to help their patients with.

According to Sontag (1989) the very names of diseases such as tuberculosis, cancer and leprosy are felt to have "magical power". The Oxford English Dictionary (cited in Sontag, 1989) records "consumption" in use as a synonym for pulmonary tuberculosis as early as 1398. Whereas cancer was figuratively defined as "anything that frets, corrodes, corrupts or consumes slowly and secretly" (Sontag, 1989, p. 10).

Just as the word cancer added meaning to the illness, this is also true with AIDS. AIDS is not the name of an illness at all. It is the name of a condition, the consequences of which are a spectrum of illnesses (Sontag, 1989). AIDS is not a single illness but a syndrome consisting of a seemingly open – ended list of contributing or "presenting" illnesses, which constitute the disease. However, today cancer and tuberculosis, when compared to AIDS, is more acceptable. Lungi describes a patient's experience, where the wife was going to conceal that her husband was HIV positive.

I know of a patient once. They came in together as a couple and the husband was diagnosed as HIV positive and I remember that the wife said that we can not tell our family that he has AIDS. We will be rejected. It would be better if I tell them that he has cancer it would be more acceptable. (EXTRACT 11)

The wife feels that if she tells people that her husband has cancer, it would be more acceptable and HIV/AIDS would be unacceptable. There is a sense that there is a negative perception about AIDS. Patients who have HIV/AIDS report being stigmatized and ashamed of their illness. This stigma and shame forms a sub – theme. Let's consider it.

**(c) The stigma and Shame linked to AIDS**

As mentioned in the above extract, patients who have AIDS prefer not to disclose their HIV positive status because they are afraid of being rejected. This may be so because AIDS is seen as a punishment for some kind of wrongdoing. Further, because it is a sexually transmitted disease, there is a lot of blame and society feels that it is a disease of choice. Lungi goes on to confirm this. She says:

So you see, there is still this negative perception about AIDS that is going around. You see AIDS is still stigmatized. (EXTRACT 12)

Lungi is well aware of the negative stigma that surrounds AIDS. This perception impacts on the counselling process. In other words, the counsellors have to deal with their patient's denial about the disease. In a survey (cited in Weitz, 1991) college students considered people with HIV more responsible for their illness than people with legionnaire's disease or serum hepatitis, even though the latter is spread in the same way as HIV. Further, it was concluded in another study by Weitz (1991) that nursing, medical and chiropractic students, all considered persons with HIV/AIDS less competent and less morally worthy than persons with cancer, diabetes or heart disease.

Herek and Capitanio (1993) found that the most salient difference between AIDS, coronary heart disease and cancer, was that HIV/AIDS patients were more dangerous, dirty, foolish and worthless. Ashika, a lay counsellor is aware that people with AIDS are generally considered “dirty”:

It's a dirty disease and it's some thing you look down upon, it's a stigma . You will always be someone that has a dirty disease, that has that horrible disease. **(EXTRACT 13)**

It seems that Ashika's experiences of AIDS are negative. It is a “horrible disease” and people who have HIV/AIDS are considered to be “dirty”. From Clare's experience, she also finds that AIDS is highly stigmatized. She says:

I think the difficulty is that I mean for me and this is not just from my own experience and partly having read all the literature around HIV/AIDS, one of the biggest difficulties is that there is so much silence around HIV/AIDS. The silence actually feeds the disease and part of the reason that it's become so rampant in this country is because of the silence . And the silence is linked to the fact that it is largely a sexually transmitted disease. And I think in most cultures sexuality is not easy to talk about. I think may be particularly so in African cultures, I'm not sure but sexuality is kind of taboo subject. It's not something that you talk about easily and because AIDS is linked to sexual behaviour. There is a lot of shame, stigma, rejection and discrimination about it and fear of being or fear of disclosing HIV. So it's a silent kind of pervasive disease that you can not see. **(EXTRACT 14)**

Clare finds that both her experience of AIDS and her knowledge seem to suggest that there is a great deal of shame, stigma, rejection and discrimination associated with AIDS. This seems to be linked to the fact that AIDS is a sexually transmitted disease and it is a taboo subject in many cultures. Clare seems to suggest that because of this there is a lot of silence that surrounds AIDS. The silence, which may be a lack of understanding

or knowledge, leads to discrimination, rejection, shame and stigma. These negative feelings encourage HIV/AIDS patients not to disclose their HIV positive status. Thus, this cycle continues and will only be broken if people speak about AIDS and against its discrimination.

Both the lay and the professional counsellors have negative experiences of HIV/AIDS. They further agree that AIDS is linked to shame and stigma and that it is compared to other illnesses. Thus, because AIDS was compared to other illnesses in history, it also gave rise to similar metaphors. For example cancer was also seen as a death sentence because it is felt to be an ill omen, abominable and repugnant to the senses (Sontag, 1989). AIDS is also described along these lines. However, cancer and AIDS differ, in that, in today's society it is more acceptable to have cancer than AIDS. This is evident in extract 11, where a lay counsellor, Lungi, found that a couple agreed that they would tell their family that the husband has cancer because they were afraid of being rejected. Now, let's explore AIDS as a 'death sentence' metaphor.

#### 4.5.3 AIDS as a Death Sentence

AIDS is seen as a death sentence because it is felt that there is no cure for AIDS (that exists now). Thus, a person who has AIDS is sure to die. Therefore, society holds this perception.

Lungi described AIDS in the following manner:

You know I think that with AIDS there has to be a shift or change in perception but I know that in the rural areas people still perceives AIDS as something that is terrible. as a death sentence or punishment and therefore people are still stigmatized if they have AIDS. (EXTRACT 15)



Lungi, a lay counsellor believes that with regard to the perception of AIDS, there has been a change. However, she goes on to say that in rural areas, where people may still be uneducated. AIDS is seen as a death sentence or punishment. Further, this perception was also noted by Sue, another lay counsellor.

Sue says that

I think having been a mother your whole mindset changes and your child or your children just become so important to you. I've seen on the radio and this woman was going on about retroviral [anti- retroviral drugs] for pregnant women and just saying what a relief it would be knowing that her children will be alright. But at the same time, these drugs are not easily available, thus sometimes you are left feeling like you have sentenced your child to be HIV positive. **(EXTRACT 16)**

Sue feels that because she is a mother, she knows and has experienced how important her children are to her. Therefore, she in some way understands when this woman says that she is relieved that her children will be alright but is aware that she has sentenced them. It seems that both the lay counsellors believe that this perception exists in society. However, when the interviewer / researcher asked Sue if she believes that AIDS is seen as a death sentence from her experience, she responded as follows:

I resist that being spoken in those terms because in counselling it's got to be that you help somebody see the other side, that it's an opportunity to get your life rights and live it positively. So I don't like that term being said, but I've hear mothers talk about that, I've heard people talk about that. But, specifically I've heard mothers say that very much the child, that this fetus is so passive and yet it is infected and born out a chance. **(EXTRACT 17)**

Sue has very strong feelings about seeing AIDS as a death sentence. But from her experience she has found people referring to AIDS as a death sentence. She refers to children who are diagnosed as HIV positive, as born without a chance. This may imply

that these children do not have a chance to live or live out their dreams because of their diagnosis. Sue says that in counselling, the role of the counsellor is to help the patient see the other side, that there is life. Sue is very resistant to this belief, in that she says that she resists using the word and that she does not like the word. Even in the above extract, she does not use the word. This theme was also echoed by Anita, a professional counsellor.

Knowing that you have x number of years to live and as a student once told and when I told them that we can never know whether we are going to live in the next hours, anything could happen, you could go out here, walk onto the road, meet an accident that would be it. And she turned around and said yes but I'd rather not know that I'm going to meet with an accident and die in two hours time. Then it brought it home for me, yes it's all very well as counsellors to say ja, But you know, at least you have five years or eight years but the fact is that they don't want to know. **(EXTRACT 18)**

From Anita's experience, she found that patients see AIDS as a death sentence because they know that they are going to die. But the perception held by patients is that they do not want to know. Thus, both lay and professional counsellors agree that this perception exists in society. According to Pawluch's (2000) study, it was found that when subjects first received the diagnosis of being HIV positive, most of the subjects regarded the diagnosis as an "automatic death sentence" (p.253). Further, it was felt by the subjects that, AIDS was a punishment for wrong – doing. Therefore, the HIV/AIDS patient was symbolic of punishment from God. Let's examine this metaphor in detail.

#### 4.5.4 AIDS as a punishment

From the start, HIV/AIDS was associated with homosexuality. This meant that there was an unquestionable evidence of sexual activity, which was associated with sexual deviance. This sexual deviance was against nature's rules. Therefore, people were punished for this behaviour in the form of AIDS. Anita, a professional counsellor also views AIDS as a punishment. She said the following:



For me, I see it as a bigger picture for mankind and for humanity because through the age, if we look through history there's always been some kind of disease that cut off the extra population, that made man realizes that we are vulnerable. There was the plague and then small pox and then whatever and then T.B and then cancer and just when we sort of come to grips with each one, find a remedy or methods of prolonging the disease, here comes another one. And so, for me, I see it from that perspective, I see challenge, I also see it as something mankind has to deal with. **(EXTRACT 19)**

Anita believes that AIDS is a sign to show people how vulnerable they are. She uses the examples of other illnesses to illustrate her point. But, the question is who determines that there is extra population. Further according, to what Anita said it seemed that this illness was sent to teach humankind about its vulnerability, just like the other diseases. This perspective that Anita holds is a personal one. If one goes beyond what she said verbally, it seems that her statement implies that there is someone that is controlling all of this, possibly God. This is evident when she goes on to say that:

I see it more as something that makes man realize how vulnerable he is and that he doesn't control and rule everything. Not necessarily (pause) God , but Himself . It's a way of saying well here's another thing lets see how you deal with this. **(EXTRACT 20)**

In the above extract, Anita says again that human beings are vulnerable. She mentions God but does not complete what she was trying to saying. In some ways, this could indicate that she slipped up and possibly became conscious of what she saying and therefore stopped. So, for Anita it seems that in some way God determines who should get AIDS and who should not. It indicates that there is an underlying prejudice or attitude held towards the HIV/AIDS patient, that the researcher was unable to tap into. According to Steven and Muskins (cited in Taerk et al., 1993) because AIDS was associated with sexual deviance, it gave rise to fantasies of acting in forbidden ways and of being punished. This may be embodied by the HIV/AIDS patients. This perspective can be seen more clearly when Lungi says:

I know that in rural areas people still perceives AIDS as something that is terrible, as a death sentence or punishment. You see AIDS is still stigmatized, that is it is a disease resulting from some kind of wrongdoing – which is a great pity because people still perceive individuals as innocent or guilt. For example, in adults who are HIV positive they are seen as guilty while children are seen as innocent.

Because if you have HIV, then you must have slept around a lot. **(EXTRACT 21)**

Lungi talks about rural people, she is referring to uneducated people (the researcher sought to clarify this point) she implies that among uneducated or rural people the perception that AIDS is a punishment still exists. Thus, because of this people are stigmatized in a way that they are innocent or guilty. If you are guilty, then you have slept around. According to Kruger and Richter (1997), subjects perceived AIDS as a moral issue, “something you get, fairly mysteriously, from bad behaviour with bad people” (p. 959). However, according to Sontag (1989) the stigma or shame is linked to an imputation of guilt and scandal because the affliction is not mysterious. People know how they got it. The unsafe sexual behaviour that produces AIDS is judged to be more than just weakness. It is considered by most people as a calamity which one brings on oneself (Sontag, 1989).

In a study by Taerk et al. (1993), one of the views held by health care workers towards AIDS is that “it is disease of choice” (p. 4). Further, Bishop Falcon of Brazil (cited in Sontag, 1989) declares AIDS to be the “moral consequences of moral decadences” (p. 149). Ashika, a lay counsellor in her definition of AIDS also indicates that AIDS is a punishment. She says:

I think that it is very sad, my personal feelings is that I believe that it's come to pass maybe to wipe out the nation that kind of thing. By my spiritual belief but I also think that it is going to wipe out the nation and I believe that what we are seeing is but half of what is still to come. I believe that whatever happens in your life, it would never happen, if God didn't allow it to happen and if he allowed it to happen, then He has a reason why he's allowed it to happen. Yes you sleep around and you got AIDS. **(EXTRACT 22)**

In the above extracts, Ashika says that she personally believes that AIDS has come to wipe out the nation and this is only possible by God's will. She believes that if God will's it, it will happen and it is happening for a reason. For Ashika, the reason why AIDS is happening is if you slept around, you got AIDS.

Thus, for Ashika, AIDS is a punishment for sleeping around. According to Taerk's et al. (1993) study, they found that having AIDS would mean that there would be an unquestionable evidence of sexual activity. Further, because the first cases of AIDS were reported among the gay community, AIDS was associated with sexual deviance. According to Steven and Muskins (cited in Taerk et al., 1993) fantasies of acting in forbidden ways and being punished may be embodied by the HIV/AIDS patient. This could explain Ashika's perception that AIDS has come to wipe the nation because it is punishing society for acting in forbidden ways. Mogensen (1997) added that AIDS is but one of those things that happened because the world has changed, because proper order of earlier times is not respected. Nutbeam's et al. (1989) study, also found that a common view held by the majority of their subjects, was that AIDS was "sent by God because of people's immoral behaviours" (p.210). According to Pierret (2000) AIDS has turned out to be an illness that was stigmatized owing to certain characteristics. For one thing talk was rife about AIDS as a "divine punishment", "the new leprosy" and the "curse of modern times" (p.1570). A moralizing discourse about deviant behaviour and lifestyles put the blame on the infected (Herzlich & Pierret, 1998). Anita recalls a case where AIDS was perceived as a punishment.

She had come from a very rural background. My pre-test counselling had covered that she would not have got any support. She lived with her grandparents and her grandmother believed that it was a disease from God, it was a punishment. Anyone who had AIDS/ HIV was a sinner. So she came from that background. **(EXTRACT 23)**

This extract further illustrates and supports Lungi's perspective that rural people believe that AIDS is a disease sent from God, to punish mankind. Thus, there is an assumption, that can be made i.e. a person's level of education is correlated to the amount

of knowledge and understanding of AIDS. However, studies by Pringle et al. (1988, cited in Taerk et al., 1993) and Gallop et al. (1991, cited in Taerk et al., 1993) found that fear of contagion and homophobia was inversely correlated with knowledge and the amount of previous experience in working with HIV/AIDS patients.

However, the majority of the counsellors (i.e. both lay and professional counsellors) believed that AIDS as a punishment still exists within society. One lay counsellor (Ashika) indicated that she personally believed that AIDS was a punishment from God. This belief has implications on the counselling process and it can be seen in the following extract:

Yes, when somebody wanted to commit suicide. And I said to him that if he does he will go to hell for sure and if he lives he will go to heaven and God was forgiving .and that's what really got the gospel in . And we prayed for him. **(EXTRACT 24)**

It is evident from this extract, that Ashika's religious perspective impacts on the counselling process. She tells her client that if he kills himself – he will go to hell. Therefore, it can be concluded, from Ashika's case that, a counsellor's beliefs and attitudes impacts on the counselling process. Now, let's consider the next metaphor i.e. the military metaphor and examine its implications on the counselling process.

#### 4.5.5. AIDS and the Military Metaphor

AIDS is a disease that is foreign and mysterious which attacks a person. The attack is so devastating and powerful that medical scientists can not find a cure for it. Alice in her description of AIDS also makes reference to the military metaphor.

She says:

It's a disease that nobody ever dreamed about (pause) that there would be a disease like this. It's kind of a disease that's broken all the boundaries and gone against all the rules. It's a disease that you can't see it. It has this long period where people show no symptom at all. **(EXTRACT 25)**

Alice feels that this disease is so powerful and strong, in that it breaks all the rules and boundaries. The disease is also invisible. In other words, the enemy is unknown. Sontag (1989) describes AIDS as the enemy, an infectious agent that comes from outside the body. It is something that is foreign. Sue, a lay counsellor also described AIDS using the military metaphor.

AIDS is a disease, it's devastation right from the physical side of your body , it gets right into the core of the immune system and breaks down your defenses. It sort of breaks down the body from within. **(EXTRACT 26)**

Sue's description of AIDS, feels like a well planned out attack or war on the body. She indicates that AIDS is a devastation because it breaks down a person defenses. So that the person "can not fight back", can not resist any further attack. It's a well-planned out military attack, put into action. Weitz (1991) also defined AIDS as a biological devastating disease that produces a progressive physical and mental disability. In another extract, Sue talks about AIDS and the taboos that it goes against. But in her description, she uses a very important word. She says:

I think then more than now, it was very much a challenge because it  
- I don't want to use the word attacks - but because it gets at the basic taboos and people's sexual behaviours. **(EXTRACT 27)**

Although, Sue says that she does not want to use the word ‘attacks’, she may be unconsciously implying that AIDS attacks the taboos. Further, if one follows her description of AIDS (in extract 26), one can find that Sue used the military metaphor to describe AIDS and it seems in this extract she continues with the military line of thinking. Clare, a professional counsellor, in her definition of AIDS, describes AIDS using the military metaphor.

I suppose it is something that has profound implications and repercussion for people. It’s complicated and complex because it’s linked to sexuality. **(EXTRACT 28)**

It sounds like AIDS has the same effect as war has on people. Clare used words such as ‘profound implications and repercussions’. These words indicate the intensity of what she was saying. In other words, both lay and professional counsellors agree, AIDS is a horrible, powerful and devastating disease. The implications for counselling is evident when Lungi says:

I think I’ve worked with a number of cases and have a number of years of experience, with AIDS patients. And these experiences have always impacted on me because each case is unique. Although there are similar issues that they bring to counselling. But, one particular one that stands out for me. It is my first HIV/AIDS case. I guess I was new and although I had good training. It really does not equip you to deal with the real pain and sorrow, when you face an HIV positive person. This patient of mine was 25 years old, young and energetic. She had her whole life ahead of her and it took just one night to destroy everything for her. One night of unprotected sex, that changed her life. Therefore, I say that AIDS is a devastating disease. The implications of which are horrible. I find it a very difficult disease to deal with. **(EXTRACT 29)**



Lungi feels that each AIDS case that she has dealt with is unique, although there are similarities. But, she admits that the most difficult case that she ever experienced was her first case. Lungi feels that it took one night to destroy the life of her patient. Therefore, she believes that AIDS is a devastating disease, which turns your life up side down. As with war, its effects are equally horrible. Lungi goes on to say that she finds the disease very difficult to deal with.

The reason she gives for this is that although she had good training, it did not prepare her for the real pain and sorrow. For Lungi, this is difficult to deal with. This has implications on the counselling process. Here, Lungi admits that her personal feelings, interferes with the counselling. Thus, one can say that instead of being empathetic towards the patient, Lungi is being sympathetic. She therefore breaks the cardinal rule of counselling.

Further, within Lungi's extract one finds a sub –theme i.e. AIDS is a disease of the young. Let's consider this in detail.

**(a) AIDS is a disease of the young**

HIV/AIDS is a sexually transmitted disease and the age group of people who are the most sexually active falls between the ages of 15 to 40 years. Therefore, AIDS is termed the disease of the young.

In Lungi's extract, she described her patient, as a 25-year, young beautiful and energetic person. For Lungi, the patient has a good life ahead. Later on, Lungi goes on to say that:

You know the perception is that young people are very promiscuous - that's the perspective. But very often this is a woman who only had only one sexual partner and that sexual partner is the father of the child. And she is not necessarily someone who is sleeping around. (EXTRACT 30)



Lungi says that in society, it is believed that young people are very promiscuous. But, if she says that this is often not true because the person may have only one sexual partner and that's how people may get AIDS. Clare, a professional counsellor describes her patient in the following way:

He was a young [and] healthy[student], he was still healthy. He wasn't in the ill stages of the disease. He had his whole life ahead of him. He was doing a degree in engineering. He was intelligent. He potentially had a bright future ahead of him. So, I think that's why he stands out, for me. And then the other one, I mean, obviously because he was dying. He was also a young man. **(EXTRACT 31)**

Here, again, Clare's descriptions of her patients indicates that her patients were both young and they had a bright future ahead of them. This is why Clare feels that these cases stand out for her. It seems that both the lay and professional counsellors agree that AIDS is a disease of the young. Further, both agree, that AIDS is a difficult disease to deal with and this has implications for the counselling process. Asthana and Oostrogels (2001) also agree that the perception held by society is that, AIDS is a disease of the young. Besides this, they also found that the common perception held by society is that it is a disease of the "other".

#### 4.5.6. AIDS as a disease of the "other"

The first recorded cases of the HIV/AIDS were reported among gay men. Thus, medical researchers started the process of linking this new disease with homosexuality. The social construction of AIDS as a gay disease was foisted upon pre-existing views of gay people as alien and inferior. Further, researchers linked HIV/AIDS to foreigners, out – groups and perverse practices.

These views became used among lay chatter, which was transmitted via the mass media. Even today, this metaphor exists. But it does not exist in its original form. According to Weitz (1991) racism clearly has contributed to the social construction of the

AIDS disease as a disease of the “other”. This is evident when Ashika, lay counsellor reports that this belief is evident among her patients. However, these are Ashika’s own interpretation of her patient’s beliefs.

The blacks sleep around all the time and the blacks – they’re dirty, you know, and the blacks will get it.

I’d always feel that Indians are very, very backwards and they are very old fashioned. And they are very conservative. I mean they are so afraid of the word sex in their household and the majority of Indians think that it could never happen to them. **(EXTRACT 32)**

From Ashika’s experience, she finds that race “defines” who is at risk and who is not at risk. She indicates that a common belief held is that Blacks are dirty people and they sleep around. Therefore, this will make them get AIDS. While for Ashika, she finds that the majority of Indians believe that it could not happen to them. According to Weitz (1991) although the first cases of the AIDS disease were diagnosed in the U.S, researchers have focussed almost solely on Haiti and Africa as possible sources of the virus. This in itself suggests a strong willingness among white Americans to believe that people of colour somehow foisted HIV/AIDS on the West. This view seemed to be echoed by Clare, professional counsellor.

I suppose I’ve worked with a number of cases over the years and two of them kind of stand out particularly. I have images in my mind of two young students and I suppose it was these two students who really made AIDS real for me. I suppose until then it was something that was out there, it was something that was talked about a lot and a lot of concern was expressed about it. **(EXTRACT 33)**

For Clare, HIV/AIDS was never real. It was something that was out there. What is being implied in the above extract, is that HIV/AIDS could not happen to her or to her family or friends. It was something that was just out there. However, she admits that the two student cases made it real for her. This attitude of it ‘being out there’ has serious implications for the counselling process and it is evident when Clare describes a case.

I can remember one woman who I actually knew. She's a staff member on campus and in fact our paths crossed in a work context and actually still do. And she came in for an HIV test because she was wanting to get an insurance policy. And it was a condition that they had to have an AIDS test. So there was a kind of sense that she wasn't really at risk on her part and when the results came back positive, it was a huge shock for me. I wasn't anticipating a positive result and I'm not sure whether she was or not. Certainly, she hadn't indicated that she but possibly she was also in denial and maybe she was anticipating it more than I was. But she went into complete denial. She just actually didn't accept the results. And that was very difficult. **(EXTRACT 34)**

In this extract, Clare's attitude or belief that this patient could not be HIV positive, prevents her from preparing the patient for a positive or negative result. Clare, felt that she knew the person and so there was a sense that she wasn't really at risk. Therefore, pretest counselling wasn't carried out in the routine way. Thus, Clare's belief impacted on the counselling process. This could be because both the counsellor and the client shared the same racial group. Therefore, may be when the results came back, it was a huge shock for Clare. According to Weitz (1991) early reports suggested an African origin for HIV and they have received considerable publicity and have impacted on the public's image of the AIDS disease.

For example, in the British Sunday Telegraph dated 21 September 1986, the front-page headline read the following: "African AIDS deadly threat to Britain" (Weitz, 1991, p. 251). On the other hand, Kruger and Richter (1997) found that black students described AIDS as a 'foreign' disease 'imposed' "on black people in South Africa" (p. 961). This belief could be explained in terms of spirits. As one knows ancestral worship forms an important part of a Black person's life. Thus, everything that happens is due to the spirits. Ngubane's (1977, cited in Joffe, 1999) anthropological work on Zulu people's ideas concerning physical and mental illness provides an illuminating account of how "the alien" or the "other" is given a role in the meaning of illnesses.

The Zulu belief is that when physical and mental illness strike, this is the result of intruding spirits. Evil spirits are spirits of aliens. Aliens here could refer to other people of different racial groups or of a different tribe.

This section of the analysis explored the metaphors and meanings that surround the AIDS virus. Further, it examined how these meanings and metaphors impact on the counselling process. The next part of the analysis explores how Social Representational Theory understands and explains these metaphors.

#### **4.6. Social Representational Theory**

Joffe (1999) argues that Social Representational Theory is made up of three processes, which are inter-linked. They are:

- (a) transformation of expert ideas via modes of communication, into lay thinking,
- (b) anchoring i.e. the imposition of past ideas on the new event that needs to be understood and
- (c) objectification i.e. the saturation of the new event which requires interpretation with the symbolic meanings that exist in the culture.

Besides these processes, one needs to consider the social representations and their impact. According to Moscovici (1984) social representations are deep-seated attributional and optimistic 'errors' which are built upon deeper representational structures. It is believed that the elements comprising a representation are inter-dependent and are arranged in a certain hierarchical order. The core of the representation is the 'figurative nucleus'. This nucleus is the fundamental element in the representation because it determines both the meaning and the structure of the representation. The nucleus of the representation is determined by the nature of the object and by the relationship, which the subject has with this object. Thus, one can say that the nucleus is the creator or the heart of the representation.

According to Moscovici (1984) individuals and groups create representations in the course of communication and co – operation. Once created, however, they lead to a life of their own, circulate, merge and attract other representations, which in turn give birth to new representations. In order to understand and to explain a representation it is therefore, necessary to start with that, or those, from which it was born.

This study looks at HIV/AIDS and its meaning and to understand the representations that surrounds AIDS, one needs to have an understanding of the representations of illness. In other words how does society perceives terminal illnesses?

This understanding will form the heart or will become the ‘figurative nucleus’ of the representation of illnesses. According to Joffe (1999) at times of imminent danger or crises, the dual dehumanised desired representation of the ‘other’ becomes intensified. Moscovici (1984) added that specific historical events shape the way in which each crisis is understood.

The core motivation of the representation of the ‘other’ is identity protection i.e. illnesses or diseases are represented in the ‘other’ to protect in – groups and self – identity. At the same time as protecting self and in – group vulnerability to risks, the chosen, social representation maintains the status of certain groups in a society. Further, the ‘meaning’ of the new phenomena serves as a safety net for most members of a society. This makes the social world seem more familiar and manageable but simultaneously maintains the dominance over certain groups.

For example the plague of 1863, leprosy or cancer, these were and are diseases that could not be explained by medical scientists. Thus, these diseases heavily influenced the representations of illnesses. These were unfamiliar events, which evoked uneasiness within societies. As mentioned earlier, people’s representations serve to orientate them towards gaining feelings of comfort and security. Thus, it follows that the processes involved in forming the social representation will serve to defend individuals from a sense of personal vulnerability to the threat.

When new events are encountered, individuals draw on old ways of thinking (not consciously) that have always been and continue to be acceptable to the groups with which they identify. Further, groups favour the metaphors or images compatible with in – group values.

Different groups ascribe to different representations in accordance with the identities, which require protection. For example, in the case of AIDS, Kruger and Richter (1997) found that their subjects who were black perceived AIDS to be a ‘foreign’ disease imposed on black people in South Africa. In this study, it was found that Ashika (extract 32) a lay counsellor, felt that her White and Indian patients believed that it was a black disease. These two viewpoints demonstrate that different groups or racial groups have different social representations of the same illness.

Thus, one can conclude that at the heart of the representation, is the understanding that there is a need to protect the self and in – groups. Other diseases in history such as the plague, leprosy or cancer influenced this representation. It can be concluded that if any disease arises in the future, it would be linked to the ‘other’ in society. AIDS is an unfamiliar disease that can not be ‘really’ explained by medical scientists. The disease, AIDS, came into ‘existence’ via the mass media. This is the first process according to Moscovici’s theory i.e. the transformation phrase. The mass media plays a leading role in transforming expert knowledge into lay knowledge. This point was also confirmed in this study. A professional counsellor, Clare (extract 14) confirms that her knowledge about AIDS comes from her experience and from reading the literature that surrounds HIV/AIDS. Thus, a person’s first contact with a potential crisis is often via the news, media or via other people relaying items presented in the news.

However, it is important to note that the news media do not merely present a ‘photocopy’ of expert knowledge for lay people to assimilate. Further, they not only simplify expert issues, but also introduce exciting angles. With regard to AIDS, many of the early medical and scientific reports posited links between the syndrome and the ‘other’: foreigners, out – groups and aberrant practices.



HIV/AIDS was first reported among the homosexual population in society. This finding (whether true or not) serves to reinforce the representation of the 'other' with regard to illnesses. Thus, with AIDS being a 'new' unfamiliar disease it was initially considered a disease of the 'other', especially in terms of homosexuality. However, in this study the researcher found that the 'other' was defined in terms of racial groupings. According to Weitz (1991) he found that racism clearly contributed to the social construction of the AIDS disease as a disease of the 'other'. In extract 32, Ashika, a lay counsellor offers her own interpretations of her patient's beliefs. She says that other racial groups feel that because Blacks are dirty and they sleep around, they will get AIDS. She also felt that the majority of Indians feel that they would not get AIDS.

In another extract (33) Clare, a professional counsellor felt that AIDS was out 'there' and that she was 'immune' to it. The Social Representational Theory agrees with these findings, in that people tend to protect their own self-identity and those who share the same in – grouping. This was also evident in extract 34, when Clare personally experienced in – group identification within the counselling process. She found herself believing that one of her patient, who shared the same racial group as herself, could not have AIDS.

The 'other' which is represented by racial groupings in this study can be explained within the context of South Africa. These racial groups were highlighted and stemmed from the policy of Apartheid. People were forced to live separately from other racial groups. No social interactions among the racial groups were allowed. Thus, the legacy of Apartheid, racism and discrimination has impacted on the social construction of the 'other' in South Africa.

AIDS being a 'new' disease however, had different meanings. For example, 'new' contained inherently negative connotations such as 'strange', 'startling' and 'unwelcome'. Yet that which is new is also associated with novelty and excitement. This feeling of novelty and excitement was expressed by Anita (extract 1), a professional counsellor. It seems that AIDS is seen in this way because although modern medicine is ahead, medical scientists have found no cure, for AIDS.



This inability to treat AIDS, have led people to look for alternate explanations. One such explanation is from a religious perspective i.e. because 'no human being' can find the cure for AIDS, it must come from out of this world or may be God sent it. Therefore, it is mysterious. This mysterious theme was also echoed by Lungi, in extract 3.

The above discussion forms the 'figurative nucleus' or the core representation for AIDS. In other words, AIDS is seen mainly as a disease of the 'other' and a mysterious disease. The other findings or metaphors are explained in terms of the two processes involved in Social Representational Theory. They are anchoring and objectification. These processes ensure that the core values and norms of the society get stamped onto new events. They enable the person to forge ideas about new events in a way that induces comfort by maintaining the existing sense of the order.

The first process is anchoring i.e. when a new event, like AIDS, must be understood, its integration is accomplished by taking the event which is by definition unfamiliar and moulding it in such a way that it appears continuous with existing ideas. It is important to remember that anchoring is not an individual process of assimilation. Rather, the ideas, images and language shared by group members steer the direction in which members come to terms with the unfamiliar. With AIDS, there still exists no cure, thus to understand the disease, AIDS was compared to other illnesses such as the plague, leprosy, cancer, T.B and other illnesses. This study found that AIDS was only compared to two disease i.e. leprosy and cancer.

According to Moscovici (1984), to name a person or thing is to precipitate it and the consequences of this is three fold:

- (a) once named, the person/thing can be described and acquires certain characteristics and tendencies
- (b) the person/thing becomes distinct from the other persons/things through these characteristics and tendencies and
- (c) the person/thing becomes the object of a convention between those who adopt and share the same convention.

Thus, through the process of anchoring, the new phenomenon gains the characteristics of the category to which it appears similar and opinions, which were held in relation to the earlier phenomenon are transferred to the new one. In the case of AIDS, AIDS was configured in terms of other illnesses. In extract 9, Ashika, a lay counsellor, perceived AIDS in terms of the leprosy disease. She felt that the two diseases share similar symptoms such as it is dreadful and it's a slow and painful death. Ashika also adds that just as the people who had leprosy were shunned, the same is true with AIDS. In extract 8, Ashika gives an example of how two of her patients were made to feel like lepers, when their employer came to know that they were HIV positive. It seems that the characteristics of leprosy were transferred onto AIDS, in that AIDS is also viewed negatively. In extract 12, Lungi, a lay counsellor, agreed that AIDS is a disease that is stigmatized. From her experience, Ashika (extract 13) felt that AIDS was perceived as a dirty and horrible disease. Herek and Capitanio (1993) also confirmed it. They found that the most salient difference between AIDS, coronary heart disease and cancer was that AIDS patients were more dangerous, dirty, foolish and worthless.

Clare, a professional counsellor (extract 14) also found evidence of shame, rejection, stigma and discrimination among her patients. Further, if one considers these diseases (i.e. leprosy, cancer and AIDS) one finds that there is another common metaphor that has emerged from leprosy and cancer.

The Death Sentence metaphor is a relatively old one, but it is still used with AIDS. Characteristics, attitudes and feelings towards illnesses are now being transferred to AIDS. Lungi, a lay counsellor (extract 15) found that among rural people the perception that AIDS is a death sentence still exists. This death sentence metaphor has emerged because there still exists no known cure for AIDS and thus people feel hopeless. This process of anchoring helps people to name, classify and response to the AIDS disease. Another example of the death sentence metaphor was provided by Sue (a lay counsellor, extract 16 & 17). Sue found that among the mothers, who are HIV positive, they feel like they have sentenced their children to death.

However, besides these commonalities, there seems to be a shift in perception i.e. perviously (and even now) cancer was seen negatively. However, with the event of AIDS, when AIDS and cancer are compared, it seems that cancer is more acceptable.

This was evident in extract 11. Lungi describes a couple who agrees to tell their family that the husband has cancer rather than AIDS. Why is this so and can Social Representational Theory explain this shift? This shift/change in perception can be explained in terms of the transformation process. According to Joffe (1999) ideas which pervade the media may be accepted directly, yet their meaning may be negotiated. Further, according to Moscovici (1984) a particular outcome of the circulation of knowledge between science, the media and lay thinking is that scientific knowledge tends to acquire a moral dimension. It is integrated into a moral system, which regulates what is to be regarded as acceptable or unacceptable in a society. Brown et al. (1996, cited in Joffe, 1999) in their analysis of the news media found that health risks are framed in a manner more related to moral outrage than to scientific notion of calculable risks.

AIDS, was linked to homosexuality. But homosexuality was already associated with aberrant practices and sexual deviance. This sexual deviance was perceived as going against nature's rules. Therefore, the rest of 'society' perceived the AIDS patient as being punished for this wrong – doing. This perception was confirmed by Lungi, in extract 21. Kruger and Richter (1997) found that their subjects perceived AIDS as a moral issue, “something you get, fairly mysteriously, from bad behaviour with bad people” (p.959).

This study confirms the belief that people have about being punished for behaving in bad ways. Ashika (extract 22) believes that God has created this disease to wipe out the nation. Linked to this, is the perception that AIDS is a disease of choice i.e. if you are not promiscuous then you would not get HIV/AIDS. This perception feeds into the already existing negative perception, which lead to further stigmatization and discrimination. This was also evident in Ashika's statement (extract 22). Studies by Pringle et al. (1998, cited in Taerk et al., 1993) and Gallop et al. (1991, cited in Taerk et al., 1993) found that health workers expressed fear of contagion and homophobia when working with HIV/AIDS patients.

Thus, the anchoring process is a social form of the more cognitive categorization process. This act of classification, of naming, makes the alien, threatening event representable. With the AIDS disease, we have named and classified it. Thus, the next step is to concretize it. This is where objectification comes in. According to Moscovici (1984) objectification is a process when the novel/unfamiliar object (which is now named and classified) is transformed into a concrete, pictorial element of representation. In other words, it is compared to a picture. Thus, what was invisible now becomes visible in our minds.

The military metaphor, is an example of the objectification process because it provides an image of the disease. In extract 26, Sue, a lay counsellor, describes AIDS in terms of an attack on the body. Sontag (1989) describes AIDS as the enemy that is unknown, an infectious agent that comes from outside the body. Alice (extract 25) confirmed this. She described AIDS as a secret force that destroys everything and that knows no limits. It is like she is saying that the enemy is powerful and strong. The picture that one gets is that AIDS is a war or an 'attack' on the body. This was also evident in extract 27. As one knows, war has a devastating effect on people and societies. The same is true with this metaphor. Clare in extract 28 talks about the profound implications and repercussions of AIDS on people. Lungi (extract 29) and Anita (extract 1 & 2) also mentioned this devastation.

Although the researcher has used the Social Representational Theory to explain the findings, there are alternative explanations. The researcher will purposefully only considered explanations that explain the 'other' phenomena because this theme is the core representation in which all other representations or themes stem from. The theories that the researcher will consider are the following: aspects of the cognitive theory, attributional theory, psycho-dynamic theory, object relations theory and a religious perspective will be included.

In the early 1950s health psychologists in the United States found that the majority of people are 'unrealistically optimistic' in relation to a large of health and safety risks. Unrealistic optimism is defined as the underestimation of the likelihood or probability of experiencing negative events. By the 1980s the focus on denial had been



conceptualized as 'optimistic bias' (OB). The OB framework demonstrated that humans tend to respond self-protectively when asked to assess their risk of being affected by a potential hazard (Joffe, 1999). They imagine, unrealistically, that the future holds few adverse events (Taylor, 1989) and expect such events to strike others rather than themselves. According to Taylor and Brown (1989, cited in Taylor, 1989) optimism is unrelated to whether a risk is perceived as minor or major or to whether the respondent is at high or low risk in material terms.

This 'optimism bias' is linked to attributional theory and psycho-dynamic theory. Attributional theory is a cognitive theory of how people judge the causes of events. A major error that people make when explaining the cause of an event is to hold an egocentric illusion: the cause of positive events is attributed to the self and negative events to 'others.' This may be translatable into an ethnocentric bias: that people attribute positive events to their own group and negative events to other groups. Augmenting this, the 'fundamental attributional error' occurs.

'Others,' rather than oneself, are more likely to have caused negative events and their behaviour or their character, rather than a situation is linked with the cause. Since the cause of the event, which befalls the other lies in what is perceived to be the controllable element, human intention is implicated. Thus, we hold 'others' more responsible for actions that are perceived to be intentional. In the case of HIV/AIDS, people do not believe that they can get HIV/AIDS and those who have AIDS are to blame because they are responsible for getting HIV/AIDS. This in turn gives rise to the stigma and shame associated with AIDS. Further, the 'other' in AIDS was also emphasized by the 'fact' that the first reported case of AIDS occurred among the homosexuals, an already marginalized group. This served to reinforce the representation of the 'other'. One finds that although this theory is different, it supports the notion of the 'other' in Social Representational Theory. Now let's consider the psycho-dynamic theory.

Within the psycho-dynamic theory, one finds that the 'splitting off' process is important. The 'splitting off' comes from the object relation theory. Splitting is an unconscious defense which plays a part in shaping one's responses to potential crises in

life. Splitting is a way of viewing the world in simplistic terms, by seeing it as black or white. A middle ground is missing, when one splits. According to the Kleinian theory, the roots of the splitting process lies in the earliest moments of infancy. The researcher would not examine this theory in detail, however, only salient points would be considered. Basically, during the process of splitting, the child learns to dissociate negative aspects of self and he/she projects this negative part onto others. This process ensures that the self or 'I' is good and 'others' are perceived as bad.

But the question to ask is, can this theory, which explains early development offer an explanation for adult responses to disasters? A key emphasis of the Kleinian outlook is that humans do not merely resolve one situation and move to another. Rather, a situation leaves a residue on the developing human and all humans can be plunged back into operating as if they were in one of the early situations, in later life. When changes in the social environment make for insecurity, a strong sense of anxiety is evoked. Thus, the process of splitting occurs. This theory explain individual 'prejudices' but how can it explain group 'prejudices.' Social representational theory is also criticized for this because the exact processes that occur within a group are not clearly explained.

Therefore, Social Identity Theory (SIT) is used to explain the processes within a group. SIT provides a key link in the transition from the intra-individual to the inter-group level of thought. It provides strong evidence of social identities such as racial and gender identities, which forms part of personal identity. In the course of identifying with a group, the need to perceive oneself positively, on the inter-individual level, translates into a need to regard one's group favourably.

In the process of forming a personal identity, links are forged with certain group identities i.e. certain groups are integrated into the 'good' self and becomes one's in-group while the 'bad' part becomes the other and forms one's out-groups. However, it is important to be cautious in positing the individual identity with a fixed set of groups and view their in-groups as pure and their out-groups as potentially dangerous. Thus, the notion of fixed group identification has been challenged. Identity is a shifting entity. For example, being black or white does not necessarily fix a person to a particular set of

afflictions since in most societies there are no structural features to ensure that identity is formed or maintained in line with type of group. Despite, this SIT attempts to explain group identity.

Another explanation for the representation of the 'other' may be a religious one. According to Joffe (1999) the link between disaster and sexuality stretches back way beyond modernity. It is a strong theme in the Bible. Christianity had and has a strong influence on society's norms and values. Thus, the ideas of the Bible then become integrated into society and become part of lay thinking. The Old Testament in the Bible sees natural catastrophes such as mass diseases, floods and famines through a moral perspective. The salience of the ongoing link between sin particularly sexually related sin and disaster must be emphasized. Thus, the connection to sin, the connection to punishment from God still influences current reactions to mass crises. Previously, before scientists became chief purveyors of information about risks, it was standard practice for representatives of religious establishment (especially the church) to explain catastrophes in terms of the sinfulness of society. It was assumed that God's law was often violated and violations were often presumed to be of a sexual nature.

Control, as opposed to indulgence, is a core norm in Western societies. As one knows Western culture dominates other cultures. Thus, firstly, if a person who does not practice Christianity was considered to be an 'outsider.' Secondly, if this person 'lost' control and gave into sin, then the person is considered to be bad and therefore punished for their sin. Thus, illness was associated with the 'other.'

Thus, one finds that if you call it 'splitting' or optimism biases or attributional errors, these all have the same implication as the representation of the 'other.' In conclusion although the researcher used the Social Representational Theory to explain the findings of the study, other theories may be used. However, these theories all support the 'other' representation. Now let consider the conclusions that this study has arrived at.



#### 4.7. Conclusion

The analysis of the data revealed that AIDS is seen as a mysterious disease because no cure still exists for it. This led scientist, journalists and lay people to compare AIDS to other illnesses such as a leprosy and cancer. The metaphors that emerge from these comparisons were the “death sentence” metaphor.

It was found that counsellors’ experience and perception seems to support that AIDS is seen as a death sentence. Another metaphor that was used to describe other illnesses was also used for AIDS i.e. AIDS was seen as a punishment for some wrongdoing. Further, because AIDS occurred mostly among young people, it was considered a disease of the young.

In the study, the researcher found that counsellors described AIDS in terms of the military metaphor. This metaphor also stems from mental representations of other illnesses. Further, AIDS was also considered as a disease of the “other”. For AIDS the discrimination occurred among the racial lines and outliners. The researcher also considered the stigma and shame that counsellors have to deal with when counselling HIV/AIDS patients.

The next chapter explores these findings and conclusions in more detail. Recommendations are made to address some of the problems in the counselling process and the shortcomings of this study will be explored.

## CHAPTER FIVE

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 Introduction

Counselling is one of the appropriate tools to deal with the psychological aspects of HIV/AIDS. This gave rise to a large quantity of material, which consisted of guidelines, goals, the different stages of HIV/AIDS counselling and the processes involved. However, these publications served to inform the health and social personnel about HIV/AIDS counselling and provide them with some guidelines for practice. Thus, with the 'event' of HIV/AIDS counselling, one found that researchers focussed on health care workers and their attitudes towards AIDS. Most of the studies confirmed that health care workers held negative attitudes towards HIV/AIDS patients irrespective of their knowledge. Therefore, a clearer understanding of these attitudes is needed. It is important to consider if these attitudes exist among counsellors. The implications of these attitudes on the counselling process also need to be addressed. There is a notable lack of research in this area.

The purpose of the study was to investigate the meanings, perceptions and attitudes of AIDS held by lay and professional counsellors. The researcher developed an interview schedule which was 'tested' on five AIDS counsellors, two of whom were lay counsellors while the remainder were professional counsellors. Thereafter, the interview schedule was revised. The researcher interviewed three professional counsellors and three lay counsellors, using the revised interview schedule. The data was then transcribed and analyzed using thematic analysis. A research psychologist assisted with the coding process. This served to increase the inter – reliability in the study.

The analysis of the data revealed that the counsellors identified and used the following metaphors: the mysterious disease metaphor; comparisons to other illnesses; the death sentence metaphor; punishment; the military metaphor and AIDS as a disease of the 'other' and the young. The conclusions, recommendations and shortcomings of the study are considered next.

## **5.2 Conclusions about research goals/questions**

The researcher would now consider the research goals/questions that the study strived to achieve and would try to assess each one as to whether or not these goals were met. The study consisted of four major areas, which forms the research goals or questions. They are the following:

- 1) An exploration of the various attitudes, meanings and perceptions of AIDS that are held by AIDS counsellors

In terms of this study, the researcher found that counsellors held negative attitudes towards AIDS. Some of the counsellors felt that they were immune to HIV/AIDS and that HIV/AIDS occurred to other people and/or other racial groups. Counsellors described AIDS as a mysterious disease because there is no cure available. Two counsellors felt that AIDS patients were being punished for wrong- doing, in that AIDS is a disease that has come to wipe the nation.

The next two goals/research questions will be considered simultaneously because there is a need to compare lay and professional counsellors' meanings and attitudes in terms of each theme.

- 2) To identify , examine and compare the emergent themes or metaphors of AIDS that are held by lay and professional counsellors

There were six emergent themes/metaphors that were evident from this study. They are the following:

**a) The mysterious disease theme/metaphor**

This is a new metaphor that does not seem to be reported in the literature. The majority of the literature seems to define AIDS in terms of the biological aspects and its implications on a person's life. The disease is considered "mysterious" because there is no available cure for AIDS. Both lay and professional counsellors used and referred to this metaphor.

**b) Comparisons to other diseases**

Counsellors compared AIDS to two diseases, namely leprosy and cancer. They reported that AIDS was like the leprosy disease because in both diseases, there is pain and suffering. Both the lay and professional counsellors compared AIDS to the leprosy disease. However, the lay counsellors held more personal and strong views about the comparison. While with cancer, counsellors reported that their patients felt that it was better to tell other people that they have cancer rather than AIDS. It was felt that cancer was more acceptable than AIDS.

**c) AIDS as a death sentence**

Counsellors indicated that this perception was evident among their patients. Counsellors, themselves did not see AIDS as a death sentence but both types of counsellors agreed that this theme existed in society.

**d) AIDS as a punishment**

Some counsellors believed that AIDS was a punishment from God because of some kind of wrong- doing. Both types of counsellors believed that this perception existed in society and they also used this theme. However, the lay counsellors were more verbally expressive or open when they spoke about AIDS as a punishment.

**e) AIDS and the military metaphor**

It was found that counsellors perceived AIDS in terms of the military metaphor. Counsellors defined AIDS as a biological devastation. Both lay and professional counsellors used this metaphor. Linked to this metaphor was the theme that AIDS is a disease of the young. This formed a sub –theme. This is so because when counsellors described AIDS as a biological devastation, they described patients who were young and had a lot going for them. Both lay and professional counsellors used this sub-theme. It was supported by the type of patients the counsellors saw i.e. majority of the counsellors patients were young people.

**f) AIDS as a disease of the ‘other’**

Counsellors believed that this perception exists in society along racial lines, specifically AIDS is seen as a disease affecting the black community. However, a professional counsellor reported feeling the same way as society. She felt she is immune to this disease. In other words, patients, who shared similar racial grouping to herself and was known to the counsellor, were considered to be ‘safe’ and could not be HIV positive.

### 3) Impact on the counselling process

Counsellors reported that patients were stigmatized, rejected and discriminated against which in turn made disclosure an issue in the counselling process. Counsellors also reported feeling scare and afraid of this disease because there are no drugs available to make it a manageable disease. Therefore, because of this situation counsellors felt helpless and hopeless in the counselling process. This may be due to the inadequate tools available to counsellors. Another counsellor also reported becoming emotionally involved with a patient because of the deep level of sharing. However, the counsellor became aware of this and reflected on the process.

The perception that AIDS is a death sentence also impacted on the counselling process. Counsellors did not believe in this theme which in turn helped the counsellor to help their patients to focus on healthy living and to maintain their healthy status. As mentioned earlier, counsellors believed that AIDS is a punishment for wrong – doing and this attitude and/or theme impacted on the counselling process. This was evident when a lay counsellor, who was very religiously orientated, prayed with her patient and spoke to her patient about God. This is because this particular lay counsellor believed that AIDS was a punishment from God. Therefore, she encouraged her patients to pray for forgiveness.

The perception that AIDS is a disease of the young, impacted on the counselling process in that some of the counsellors reported that they found it difficult to deal with young HIV/AIDS patients. This difficulty was linked to the assumption that most of the counsellors were in the parent role and so felt emotionally ‘attached’ to these young patients. Finally, the perception that AIDS is a disease of the ‘other’ also impacted on the counselling process. For example, one of the counsellors failed to do the ‘complete’ pre-test counselling procedure on a patient, whom she know and worked with. This is because she believed that her patient could not be HIV positive. This patient and the counsellor also shared the same racial grouping.

### **5.3 Unique Contributions of the study**

- As mentioned earlier, a new metaphor i.e. AIDS as a mysterious disease emerged from this study.
- The counsellor's religious background impacted on the counselling process.

### **5.4 Implications for Policy and Practice**

Firstly, there is a need to assess or train counsellors' on the importance of personal beliefs because this impacts on the counselling process. It is suggested that all counsellors undergo a 'pre-test' to determine the influence of their religious background on the counselling process.

Secondly, a counsellor reported becoming emotionally involved with their patients. Therefore, it is suggested that the training programmes should include a section where counsellors are trained in peer supervision. This also leads to the implication that the Directors of the various AIDS organizations, should provide counsellors with some time so that they could implement their peer supervision sessions. Furthermore, training programmes should emphasize the need for supervision among AIDS counsellors.

Thirdly, it was found that counsellors reported feeling unprepared for the pain and suffering that an HIV/AIDS patient goes through. Therefore, it is suggested that the training programmes should include more practical exposure to real situations.

### **5.5 Implications for Theory**

The researcher felt that the Social Representational Theory was adequate to explain the emergent themes and metaphors of this study. Although, this study examined the attitudes, perceptions and beliefs of AIDS counsellors within a South African context, it is important to remember that in South Africa (given the Apartheid policy) the 'other'



was emphasized. The ‘other’ forms the core of Social Representational Theory, in that it is used to explain other metaphors and themes that occur in AIDS. Thus, the researcher feels that although South Africa is a unique context, there is no need to develop a unique theory that would explain AIDS and its metaphors in a South African context.

## **5.6 Implications for Research**

Firstly, it is felt that given this study found that a counsellor’s religious background impacts on his/her attitudes, beliefs and perceptions which, in turn impacts on the counselling process, this needs to be examined closer. For example, is it reported among a diverse group of counsellors, what are the implications and how can a counsellor ‘control’ this in the counselling process?

Secondly, the researcher feels that more research around attitudes, perceptions and beliefs is required, especially among counsellors. This is because at the moment, counselling is the only tool to deal with the psychological effects of HIV/AIDS. Therefore, the researcher believes that more research around this topic is required.

## **5.7. Limitations of the Study**

Given the topic of research and the chosen methodology, the study presented some challenges to the researcher. They are as follows:

- (a) The researcher was aware that the sample size was small. Therefore some of the conclusions that were drawn may be biased.
- (b) The sample comprised of female counsellors only. Therefore, some conclusions drawn may not apply to male counsellors.
- (c) The sample was not representative along the racial distribution of the population of South Africa. Majority of the counsellors was white.
- (d) This study only considered counsellors in the Kwa-Zulu Natal region. A cross-country sample would have been better.
- (e) Given that the nature of this study was a qualitative study, the findings of this study can not be generalized to the larger population.

## 5.8 Concluding Comments

For some countries, the spread of HIV/AIDS has become a matter of national security. Researchers attempt to investigate the problem of HIV/AIDS, thus giving rise to an enormous body of research. However, there are many facets of HIV/AIDS such as the medical, the psychological and social aspects. The literature indicates that there is a lack of research in the psychological area.

Counselling is one of appropriate tools used to deal with the psychological aspect of HIV/AIDS. Health care professionals are trained to render this service. However, research suggests that negative attitudes are held by health care professional towards HIV/AIDS patients. Therefore, a clearer understanding of these attitudes is needed, particularly within the South African context.

The purpose of this study was to investigate the meanings, attitudes and perceptions of HIV/AIDS among lay and professional counsellors and to examine how these meanings, attitudes and perceptions impact on the counselling process.

The study concluded that counsellors defined AIDS as a mysterious disease, which rendered them feeling helpless in the counselling process. It was also found that counsellors held negative attitudes and perceptions towards AIDS. These attitudes included the perception that counsellors were immune to the disease and that it was a disease of the 'other'. Further, counsellors perceived AIDS as a punishment for wrong – doing and that it was a disease of the young.

These attitudes and perceptions impacted on the counselling process. It was also found that a counsellor's religious perspective impacted on the counsellor's attitudes and on the counselling process, in that counsellor's spoke to their patients about God and prayed with them. The researcher also considered the implications for theory, research, policy and training. The limitations of the study were also outlined.

However, despite these limitations and problems, of the study, this research was carried out in an effort to gain more understanding about the complex issues in HIV/AIDS counselling. It is hoped that the findings and insights gained from this research will inform and inspire other researchers to investigate this topic further. It is hoped that this research may, in some way impact on the counselling process in South Africa and in general.

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## APPENDIX A

Dear Participant,

My name is Junica Ramsoorooj, and I am currently a Psychology Masters student at the University of Natal (PMB).

This year, as part of the course requirement each student has to submit a research study. As a result I have undertaken to carry out an investigation in the area of AIDS, it's concept, meaning and metaphors used by AIDS/HIV counsellors .

My title thus reads:

*An investigation to examine the construction of meanings, attitudes and perceptions of HIV/AIDS among lay and professional counsellors in KwaZulu Natal.*

This would require you to answer a questionnaire, which may take about approximately 45 to 60 minutes of your time. At this stage I will like to ensure all participants that the information provided will remain highly CONFIDENTIAL throughout the study and will only be used purely for academic purposes. No identifying details would be required.

Your cooperation and support will be much appreciated if you could assist me in my endeavour to complete my research.

Thank you for your time.

Junica Ramsoorooj  
University of Natal, Pietermaritzburg

## INFORMED CONSENT

I \_\_\_\_\_ consent to participate in this study, with full knowledge of its aims and purposes. I am participating in a voluntary capacity and retain the right to withdraw as a participant at any stage during the study without penalty.

The researcher and the University of Natal, Pietermaritzburg cannot be held responsible for any loss or damage as a result of any action arising from the research project.

I consent for the interview to be tape recorded however does not take away my right to full privacy and confidentiality, which will be a high priority at all times.

Thank you,

\_\_\_\_\_  
SIGNATURE

\_\_\_\_\_  
DATE

**APPENDIX B**

**INTERVIEW SCHEDULE**

**Section A: Biological Details**

Name: .....

Age: .....

Gender: .....

Martial Status: .....

Occupation:

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.....

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Working Experience:

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Why AIDS field?

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## Section B: Open –ended Questions

1. From your experience with AIDS, how would you describe AIDS?
  - What are your thoughts and feelings about this disease?
  - Can you think about a case where these descriptions stood out?
2. Can you tell me about the most significant case/patient that you counselled?
  - Why did this case /patient stand out for you?
  - What did you learn from it?
  - How did you feel towards this person/patient?
  - What were some of the patients issues?
3. Can you tell me about the most difficult HIV counselling case that you had/experienced
  - What was the difficulty about?
  - How did you resolve this difficulty?
  - What were your thoughts and feelings regarding this case?
  - Should you have done anything differently?
4. Can you describe a case in which you gave a person a –ve result?
  - What was their reaction?
  - How did their reaction make you feel?
  - What did this case mean for you?
  - What were some of the patient's issues that they raised with you?
5. Tell me about a case/ patient, who was HIV +ve, that emotional touched you?
  - What were some of your thoughts and feelings when you counselled this HIV +ve person?
6. Have you counselled a mother and child who were both HIV +ve? (Can you think about a particular case?)
  - What were your thoughts and feelings at that time?
  - How did you deal with this issue?
  - What were some of the patient's concerns?
7. How do you think society perceives AIDS?
  - Why is it so?
  - How do you see it?
  - How does society's perception of AIDS make you feel?
  - What is your perception of AIDS?