

**ATTERIDGEVILLE PRISONERS' EXPERIENCES OF HIV/AIDS PRE- AND
POSTTEST COUNSELLING**

by

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Declaration

I declare that *Atteridgeville prisoners' experiences of HIV/AIDS pre- and posttest counselling* is my own work. All sources used or quoted have been indicated and acknowledged by means of complete references. I further declare that this dissertation was not previously submitted by me for a degree at another university.

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Summary

Title: Atteridgeville prisoners' experiences of HIV/AIDS pre- and posttest counselling

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This study focuses on prisoners' experiences of HIV/AIDS pre-and posttest counselling. The objective of this study was to explore and report on prisoners' experiences, perceptions and views on HIV/AIDS pre- and posttest counselling. It is a narrative exploratory study which was conducted in the Atteridgeville prison in Pretoria. This work highlights the complexity of the issues involved in HIV/AIDS testing and counselling, and emphasises alternative stories about prison and HIV/AIDS. Such stories include themes like the positive aspects of being HIV-positive and incarcerated; prison as a safe haven; a quest to live despite being an HIV-positive ex-con. The aim was not to interpret the narratives, but rather to share them as they were told. Conclusions suggest that HIV/AIDS testing has a potentially overwhelming psychosocial impact on individuals; it is therefore crucial that proper pre- and posttest counselling accompany the testing procedure.

Key Terms

HIV/AIDS testing

Pretest counselling

Posttest counselling

Prisoners

Prison

Narratives

Experiences

Alternative stories

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CHAPTER 1

INTRODUCTION

The extensive attention that the HIV/AIDS pandemic has been receiving in the media, as well as personal encounters with prisoners infected with or affected by HIV/AIDS, stimulated the initial interest for this research study. The impact that HIV/AIDS has had both on our society and globally is reported in many texts (Barnett & Whiteside, 2002). The far-reaching implications of the problem are reported daily in newspapers and magazines. Various systems, such as politicians, policy makers, health departments, schools, families, and religious bodies are affected by HIV/AIDS, and all are invested in finding the most efficient ways to target the problem and curb its devastating impact.

Before exploring the experiences of those infected or affected by the HIV/AIDS pandemic, this chapter briefly outlines the extent of this pandemic on a national and international scale. In addition, the primary goal of the study is stated, and a brief introduction is given to the key aspects of the study, namely the HIV/AIDS pandemic, pre- and posttest HIV/AIDS counselling, and HIV/AIDS in South African prisons.

Aim of the Research Study

This study focuses on prisoners' experiences of HIV/AIDS testing and counselling. In particular, prisoners' experiences, perceptions and views on HIV/AIDS pre- and posttest counselling are considered. As this is an exploratory study informed by the narratives of the research participants, the primary goal is to explore and report on the narratives of participants concerning HIV/AIDS testing and counselling. Finally, the goal of the research study is to strive to satisfy the researcher's curiosity. This is achieved by gathering diverse responses to questions such as: what perceptions, views and thoughts do prisoners have about HIV/AIDS

counselling? What happens when a person goes for HIV testing? Are prisoners counselled before being tested?

For these and other reasons, a dissertation addressing the experiences of HIV/AIDS counselling is long overdue. This dissertation represents an attempt to fill this gap and might be of interest to both counsellors and counselees seeking a more in-depth understanding of how prisoners experience HIV testing and counselling. The information gathered in this research study could be useful in helping people infected with and/or those affected by HIV/AIDS to become aware of or, obtain clarity on the myths and misconceptions surrounding the HIV/AIDS pandemic as well as counselling for this disease. A further purpose of this research study is to contribute to an exploration of the impact of the HIV/AIDS pandemic in South African prisons. This is particularly relevant as HIV/AIDS in this context is poorly researched (Mckee & Power, 1992).

Key Aspects

The following section briefly introduces the key aspects of the research study. A detailed discussion on each key aspect follows in chapter two.

Concise description of HIV/AIDS

AIDS is a condition in which the body's natural defence mechanisms cannot defend the body against illness. It is caused by a retro virus called HIV and was first reported by a group from the Pasteur Institute in Paris in 1983 (Lewis, 1988). Because of the damage to the immune system, patients develop infections which normal immune systems would be able to ward off. The eventual cause of death is usually traced to these "opportunistic diseases". It is an incurable disease, which has a profound impact on the family and friends of those infected and/or affected by it (Mvoko, 1999).

AIDS has many faces. Its physical face presents through a myriad of symptoms. In its final phases, these symptoms are often frighteningly visible, and the relentless course towards death evokes people's natural fears of this final, unknown

destiny. It also has a social face, which is often fed by the most primitive and irrational fears that underlie modern beliefs and social attitudes. According to Mvoko (1999), even family members of AIDS victims are affected by social stigma because of prejudice, homophobia, and hysteria resulting from an irrational fear of contamination. It is therefore crucial that research studies of this nature are undertaken to gain a greater understanding of HIV/AIDS and HIV counselling. For more on myths and social stigma attached to HIV/AIDS refer to the relevant section in chapter two.

The global impact of HIV/AIDS

Since the first awareness of HIV/AIDS in the world approximately twenty years ago, it has become a major pandemic worldwide and especially on the African continent. During this time, the world has investigated HIV/AIDS more than any other pandemic in the history of humankind. It seems likely that while the medical and scientific research will continue to progress, it is the psychosocial, behavioural and economic research into the pandemic which will become increasingly important (Whiteside & Sunter, 2000).

According to UNAIDS, 2002 (United Nations Programme on HIV/AIDS), more than 60 million people have been infected with the virus since the pandemic was first identified. HIV/AIDS is now by far the leading cause of death in sub-Saharan Africa, and the fourth biggest global killer. In 2001, the pandemic claimed about three million lives. The figure reflecting global estimates of people living with HIV/AIDS show that the total number of adults and children living with the disease is 40 million. Sub-Saharan Africa leads the statistics with a figure of 29 million infected people, followed by South and South-East Asia with an infected population of six million people (UNAIDS, 2002).

HIV/AIDS in Africa

The high occurrence of HIV/AIDS in Africa can be attributed to the fact that most African communities are poor, have underprivileged medical systems and insufficient skilled labour to deal with such a pandemic. This situation is, however, expected to improve since the new South African government and many other African

countries (such as Mozambique, Senegal, Tanzania and Uganda) have implemented strategies to address the pandemic. These include the distribution of free condoms, provision of food to the poor, especially those infected with HIV/AIDS, and the issue of free HIV medication including the Azidothymidines (AZTs) (Education and HIV/AIDS a sourcebook, 2004).

According to UNAIDS (2002), the average life expectancy in sub-Saharan Africa is currently 47 years, whereas without AIDS it would have been 62 years. In South Africa, where the prevalence of HIV/AIDS increased rapidly in the 1990s, the number of HIV/AIDS-related deaths among young adults is expected to reach its highest point between 2010 and 2015. South Africa, with the fourth highest infection rate in Africa, has a death rate in the age group of 15 to 34 that is 17 times higher than it would have been without the pandemic. In the absence of HIV/AIDS, the expected number of deaths in this age group is estimated to have been approximately 100 000 in grouping 2010. However, at the current rate of infection, the expected death rate in this age group is likely to be approximately 1,7 million people in 2010 (UNAIDS, 2002).

HIV/AIDS: Pre- and Posttest Counselling

Researchers are desperately attempting to find a cure for HIV/AIDS. As a result, medical journals are overloaded with case reports, clinical and laboratory research results and discussions on the aetiology of this lethal syndrome. Consequently, the psychosocial aspects are generally confined to the media (Whiteside & Sunter, 2000).

It is important that while the world is actively attempting to find a cure for HIV/AIDS, the psychological aspects that accompany it are not taken for granted. Counselling is one of the fundamental processes required for HIV/AIDS intervention as it helps reduce the psychosocial impact of the pandemic on individuals (Mbuya, 2000; Webb, 1997; van Dyk, 2001). Counselling may assist those people who are affected or infected with HIV/AIDS in coping with and adjusting to the disease, and is especially important for those who will not live to enjoy the benefits of a cure. Part of my motivation for this study was an exploration of counselling as an intervention to

assist those infected and affected by HIV/AIDS to live as harmoniously as possible with the diagnosis. In accordance with Bor, Miller and Goldman (1992), I believe that it is through learning and understanding more about the counselling process that health care officials may provide better counselling services.

HIV/AIDS in South African Prisons

The present research study was conducted in Atteridgeville Prison. The prison is situated in Pretoria and is one of the smallest yet the oldest prisons found in South Africa. It has approximately 1045 sentenced male prisoners. It is referred to as a community correction centre because most, if not all, of its prisoners have less than six months left to complete their sentences. Prisoners are trained to do farming, gardening and other activities related to agricultural sciences. Although considered one of the smallest correctional service facilities, Atteridgeville Prison shows shocking HIV/AIDS statistics (Department of Correctional Services [DCS] Annual report, 2004).

According to the DCS Annual Report (2004), monthly statistics show that in January 2004, there were 138 HIV-positive inmates. Seven HIV-positive inmates were admitted in that month, while three HIV-positive prisoners were released and three were transferred. There was one HIV/AIDS-related death.

When discussing HIV/AIDS in prisons an immediate concern is transmission. According to the DCS annual report (1994), people who are likely to be incarcerated are also those who are likely to be infected with and/or affected by HIV/AIDS. The socio-economic factors that significantly contribute to the prevalence of HIV/AIDS within a specific population are very similar to those that lead to criminal activities and incarceration. In South Africa, HIV/AIDS “flourishes most in the areas that are burdened by unemployment, homelessness, welfare dependency, prostitution, crime, a high school drop-out rate, and social unrest” (Whiteside & Wood 1996, p.1).

Format of the Study

The focus of this study is exploring prisoners' experiences, views, perceptions and thoughts about HIV/AIDS counselling. This inquiry therefore concerns itself with prisoners who have undergone HIV testing in a prison setting. An outline of the organisation and content of the research, as reflected in the respective chapters, is set out below.

- Chapter 2 provides a discussion of the study's key features through a background literature review. The review is based on the literature on the HIV/AIDS pandemic in general, the counselling provided in HIV testing as well as the setting in which the study was conducted.
- The process of inquiry informed by a narrative epistemology is discussed in Chapter 3.
- Chapter 4 outlines presentation of data as collected during the first round of data collection process.
- Chapter 5 provides presentation and discussion of data during second round of data collection.
- Chapter 6 provides an integration of all the identified themes from both the first and second round of data collection.
- Chapter 7 includes reflections on the themes and on the research process, with particular attention to the participants and researcher. It also contains conclusions drawn from the research study. Finally, a discussion on the limitations of the study and suggested recommendations for further research are provided.

Conclusion

This chapter briefly referred to the scale of the HIV/AIDS pandemic, both internationally and nationally, and mentioned the context within which the current study was conducted. Furthermore, the primary goal of the study was stated, and the key aspects of the study, namely the HIV/AIDS pandemic, counselling for HIV/AIDS, and Atteridgeville Prison, were also introduced briefly. Chapter 2 takes

the discussion of the inquiry's key features further through an exploration of the literature.

CHAPTER 2

LITERATURE REVIEW

Introduction

This chapter discusses the research study's key aspects as introduced briefly in the previous chapter. Firstly, some background information on the HIV/AIDS pandemic in general is provided, including its incidence and prevalence. Furthermore, myths, misconceptions and stigmas about the pandemic are stated and discussed. The discussion will then be narrowed down to a consideration of HIV/AIDS in South African prisons. The discussion focuses on the origin and causes of HIV/AIDS in prison, as well as the policies on HIV/AIDS in South African prisons. Lastly, HIV/AIDS counselling is explored, and related concepts defined. This is followed by a discussion of pre- and posttest HIV counselling.

Incidence and Prevalence of HIV/AIDS

While HIV/AIDS is not the only crisis facing the world, it merits serious attention. It is currently estimated that some 40 million individuals are infected globally (Lee, Venter & Bates, 2004). Numerous authors (e.g. Barnett & Whiteside, 2002; Education and HIV/AIDS a sourcebook, 2004; Jones, 2001; Price-Smith, 2001; Whiteside 1999) agree that AIDS is a pandemic that is challenging and changing human history. It has changed and continues to challenge all the rules by which we live.

Two decades have passed since the HI virus was first reported; yet the impact of HIV/AIDS remains a major threat and continues to have a devastating impact on populations worldwide. While no country has been spared the diagnosis of an HIV/AIDS pandemic, the speed of its spread and its extent varies between and within countries (Whiteside, 1999). In South Africa, for example, analysts warn that "AIDS

could have a more devastating impact in this country than apartheid” (Marais, 2000, p.6). HIV/AIDS has taken a terrible human toll on South Africans, and has claimed millions of lives, inflicted pain and grief, and resulted in fear and uncertainty.

According to the Education and HIV/AIDS a sourcebook (2004), South Africa has one of the most extensive AIDS epidemics in the world, with 4.7 million people infected with HIV. It is the major cause of death in South Africa and is the national public health priority.

At this stage nowhere has the impact been more devastating than in sub-Saharan Africa. According to Barnett and Whiteside (2002), most, if not all, of the 25 million people in sub-Saharan Africa who are living with HIV/AIDS will have died by the year 2020, in addition to the 13.7 million Africans already claimed by the pandemic.

The World Health Organisation (WHO) and the UNAIDS estimate that 29.55 million people in Africa are now living with HIV/AIDS (cited in Barnett & Whiteside, 2002). In countries like Botswana and Zimbabwe, more than one in four adults is infected. By the year 2000, a cumulative total of 13 million children had lost their mothers or both parents as a result of AIDS; some 10.4 million of these children were under the age of 15.

HIV/AIDS is also spreading dramatically in Asia. India leads the region in absolute numbers of HIV infections, estimated at 3.5 million. China, too, has a growing HIV/AIDS problem, with approximately 0.5 million AIDS cases and, according to private estimates by Chinese specialists, up to 10 million HIV infections. Barnett and Whiteside (2002) predict that Asia will overtake sub-Saharan Africa in absolute numbers before 2010 and suggest that by 2020, Asia will be the HIV/AIDS epicentre.

HIV/AIDS has changed the lives of millions of individuals worldwide. It has ruined their health, caused their deaths, and left survivors to mourn and some to fear for their lives. Despite several interventions in place to address this pandemic, the national and international impact continues to increase. The following section focuses

on some of the interventions launched to address the spread and prevention of HIV/AIDS.

HIV/AIDS Prevention Programmes in South Africa and Other Countries

According to Stein (2003) being HIV-positive results in a tremendous systemic impact on both the medical, psychological, social, spiritual, educational and economic life of the infected person, his or her affected significant others and the community as a whole. Because there is no cure or vaccine for HIV/AIDS as yet, our only defence against infection is prevention through education and dissemination of information about HIV/AIDS (Huber, 1998; Price-Smith, 2001; Van Dyk, 2001; Visagie, 1999).

When working with HIV/AIDS-related information, it is necessary to consider the relationship between the information creator and the information consumer. Traditionally, it has been the responsibility of the researcher to describe phenomena and disseminate information, while the responsibilities of the policymakers and the health practitioners are to apply this knowledge. The HIV/AIDS crisis challenges this traditional division and forges stronger and more effective working partnerships between the policy makers, health practitioners, and people infected and affected by HIV/AIDS. As a result, a great deal of AIDS-related information has been and continues to be created by people infected and affected by HIV/AIDS. Such information is distributed through international and local media such as Soul Buddyz, Lovelife and Scanto groundbreakers (Huber, 1998).

HIV/AIDS is teaching us the importance of community involvement, of partnerships between governments and nongovernmental organisations and that it is important not to marginalise or discriminate. HIV/AIDS is simply not a problem that can be resolved by medicine alone. HIV/AIDS is a medical, psychological, social, spiritual, educational, economic, cultural and political problem. Therefore the power to defeat the spread of HIV/AIDS lies in our partnership as a South African community (Egan, 2004; Jones, 2001).

In their attempts to combat the spread of HIV/AIDS, various South African organisations (for instance, NGOs, the media, and community organisations) have begun to work together to establish preventative programmes (Jones, 2001).

As a result, the Soul City Institute for Health and Development Communication (SCIHDC) was established in South Africa in 1992. The SCIHDC uses the power of the mass media to broadcast programmes that aim to educate while entertaining at the same time (Education and HIV/AIDS a sourcebook, 2004).

Many other African countries (including Mozambique, Senegal, Tanzania, Uganda) as well as other countries around the world have developed HIV/AIDS programmes. These include medical interventions, such as providing government-issue free condoms and anti-retroviral therapy (ART) to HIV-positive patients. Although medical advances are improving the lives of people living with HIV/AIDS, prevention remains the key to stopping the spread of this devastating pandemic. Prevention through information is one strategy that has been widely implemented. Integrated information delivery systems have been created throughout many parts of the world. On 1 December many countries across the world celebrate the annual World AIDS Day as a means of increasing HIV/AIDS awareness. People can get information on HIV/AIDS by telephone (via AIDS toll-free help lines), mail, and via the Internet, where various websites have been created so that people may educate themselves in an attempt to stop the spread of this pandemic (Freeman, 2004; Huber, 1998; Bos, Visser, Tempert & Schaalma, 2004).

Myths and Stigma Attached to HIV/AIDS

Despite the fact that knowledge about HIV/AIDS has increased dramatically, many people are still haunted by primitive fears that existed at the beginning of the pandemic. People living with HIV/AIDS worldwide have been stigmatised and discriminated against since the discovery of the pandemic (Guest, 2003; Stein, 2001).

In South Africa, instances of overt discrimination, including violence, remain common. The stigma surrounding HIV/AIDS in South Africa is such that in certain provinces it is not even referred to by its name. It is often just called ‘the big A’, ‘high five’, or ‘ulwazi’ which means ‘that thing’ (Stein, 2003; Orr & Patient, 2004; Guest, 2003).

Stigma threatens more than the human rights and well-being of infected individuals; it also threatens public health. Stigma prevents people from being tested and seeking support from family and friends. Stigma prevents infected individuals from disclosing their status to partners or from seeking proper care. People’s fear is often not so much the infection itself as what to tell the neighbours. The social stigma of HIV/AIDS is by far the greatest obstacle that people face (Orr & Patient, 2004; Stein, 2003).

Guest (2003) adds that in South Africa it is common practice for society to discriminate against HIV/AIDS support groups. Volunteers working for such organisations are regarded as HIV positive even if they are not. Most people do not want to be associated with such organisations because they are afraid of the social stigma attached.

Laws against HIV/AIDS-related discrimination in South Africa exist but are of little use in a context where those who are discriminated against find that their situation worsens in the face of further discrimination when they disclose in the course of taking action against the initial injustice. Until the stigma and discrimination suffered by people living with HIV and their families are addressed, the pandemic will continue to grow (Guest, 2003; Orr & Patient, 2004; Stein, 2003).

Attitudes towards HIV/AIDS may have important consequences for social behaviour when HIV-positive and negative individuals are brought together within the same environment, as in prisons. The issue of HIV/AIDS in prisons has been the subject of considerable debate (McKee & Power, 1992). However, remarkably little research has been attempted to determine attitudes of both prisoners and prison staff towards HIV/AIDS issues, including testing and counselling (McKee, Markowa & Power, 1995).

Voluntary Counselling and Testing (VCT) programmes are regarded as an important strategy in the management of the HIV/AIDS pandemic worldwide. Often, however, such programmes have had limited success due to problems such as the existence of negative attitudes, myths and misconceptions about HIV/AIDS and VCT in South Africa. AIDS-related stigmas, myths and misconceptions are pervasive in some segments of South African society and can impede effective efforts to promote VCT and other HIV/AIDS prevention effective efforts (Guest, 2003; Kalichman & Simbayi, 2004; Van Dyk & Van Dyk, 2003).

When a new epidemic occurs, it is inevitable that people will take time to recognise it. This is particularly true of the HIV/AIDS epidemic, because the virus is so slow to cause observable disease. Evian (2000) and Freeman (2004) state that early reports of HIV/AIDS concerned homosexual men in the United States of America. Thus the initial coverage of HIV/AIDS suggested it was not a problem that need personally concern most people in South Africa. Mbuya (2000) adds that when the local media began to report on HIV/AIDS in Africa, there was already a feeling that the problem only affected other people (gay people specifically), and was irrelevant for most people in South Africa.

However, the current reality that this disease can affect anyone, anywhere, has succeeded in joining people around the world in a common consciousness about its threats and implications. It is the only pandemic to have a dedicated United Nations organisation – UNAIDS - charged with the single aim of confronting it (Barnett & Whiteside, 2002; Gibney, DiClemente & Vermund, 1999; Visagie, 1999).

However, a large number of people still deny the existence of HIV/AIDS. This seems to occur especially when people have not been personally confronted with the evidence of the pandemic. Denial can take many forms. According to Mbuya (2000) these can be broadly categorised into three groups, namely denial relating to the existence or non-existence of AIDS, denial of its seriousness and relevance, and a fatalistic view that it cannot be avoided.

Various authors (e.g. Egan, 2004; Mbuya, 2000; Van Dyk, 2001) note some alarming myths that are circulating in some communities about how to avoid HIV infection and AIDS. These myths are extremely dangerous and should be counteracted in our society by means of intensive public education. An example of such a myth is that people will not get AIDS or that AIDS can be cured if they have sex with very fat women, with virgins, with girls younger than twelve years of age, or with very young boys. Beliefs like these can be the abhorrent cause of criminal behaviour and can cause HIV infection to spread like wildfire.

Some people take a fatalistic approach, believing that there is no way to avoid AIDS, and that there is therefore little point in taking preventive action. This form of denial is seen in such views as:

- There is nothing we can do about it because there is no cure, so we might as well enjoy life while it lasts.
- If AIDS is so widespread anyway I've probably already got it, so there is no point in taking precautions now.
- It is God's will if you get HIV/AIDS, so there is no point in fighting it (Kalichman & Simbayi, 2004; Peltzer, 2003).

Rugalema (as cited in Barnett & Whiteside, 2002) argues that the perception that families affected by HIV/AIDS manage to cope with the diagnosis is a myth. Many families affected by HIV/AIDS do not cope. On the contrary, they break up and their members - orphans, widows and the elderly - join other families. In most instances it is not families that cope, rather it is individuals within them that manage to survive (Whiteside, 1999).

Although there has been a substantial body of research exploring the attitudes toward HIV/AIDS issues, there have been relatively few satisfactory attempts to explore the dimensions underlying such attitudes (Mckee et al., 1995). The literature reports three main dimensions in attitudes to AIDS. These include social distance and prejudice, provision of care and research, sympathy and victimisation (Heaven, Connors & Kellehear, 1990).

HIV/AIDS in South African Prisons

Between 2002 and 2003 approximately 188 000 prisoners were incarcerated in South African prisons. Over 40% of prisoners are incarcerated for two years; only 2% are serving life sentences. On average, more than 30 000 people are released from South African prisons each month (Goyer, 2001).

During the years 2002/2003 nearly 400 000 former prisoners were released from South African prisons on medical grounds (HIV/AIDS being the dominating medical reason). If their illnesses are not properly treated while in prison, the prisoners are returned to their communities and may constitute a health risk. The greatest concern should not only be the risk of HIV transmission inside prison, but also the potential impact of former prisoners living with HIV outside prison (Goyer, 2002). People who are more likely to be incarcerated are also those who are more likely to have HIV/AIDS. The socio-economic factors that significantly contribute to the prevalence of HIV/AIDS within a specific population are very similar to those that lead to criminal activity and incarceration (Goyer, 2001).

Origins and Causes of HIV/AIDS in Prison

In addition to environmental factors, several aspects of pre-incarceration behaviour place prisoners at risk for HIV infection. High-risk behaviour for contracting HIV includes unprotected sex and drug use, especially if needles are used for intravenous drug use. Furthermore, age appears to be another significant predictor of HIV infection rates. Since people between the ages of 18 and 35 are less likely to be in monogamous relationships and have a wider sexual network, young people are more likely to contact HIV as well as other sexually transmitted diseases (STIs) (UNAIDS, 2002).

The conditions inside prison such as overcrowding, poor nutrition and gang activities can contribute, in varying degrees, to the risk for HIV transmission, the progression of HIV, and the deterioration in health of an inmate with full-blown

AIDS. According to Moriarty and Fields (1999), prisoners infected with HIV/AIDS die earlier than people infected with HIV/AIDS outside prisons.

Policies Concerning HIV/AIDS in Prison

Many governments, with the assistance of international organisations such as the WHO and UNAIDS, have attempted to devise policies to appropriately respond to HIV/AIDS in prison. In no other field is the role of law and ethics as crucial as in the field of HIV/AIDS. The most well known rule of medical ethics is ‘do no harm’ (Klinck, 2004).

The first policy to address HIV/AIDS in the South African prison system was formulated by the DCS in 1992, and aimed to segregate prisoners living with HIV/AIDS. The policy was not implemented until 1995, and was criticised as being based on fear, lack of knowledge and prejudice (Achmat & Heywood, 1996).

By the mid 1990s, the DCS policy came under scrutiny in the light of the WHO guidelines on HIV infection and AIDS in prisons, which condemned segregation policies. The primary changes included the desegregation of prisoners infected by HIV/AIDS and the distribution of condoms to all prisoners. During the second half of 1996, a policy amendment paper was distributed to prison officials, which ended the practice of segregating HIV-positive prisoners. Instead of recommending prisoners for HIV testing upon admission, prisoners were only to be tested when they requested a test or were tested upon recommendation by the District Surgeon. In either case, the prisoners’ written consent was required before the test could be administered (DCS annual report, 1996).

Despite the prison policy of testing of prisoners only with informed consent, there was minimal pretest and posttest counselling and prisoners were given little time to decide whether or not to have the test administered. In such cases some prisoners took legal action against the DCS for violating their right to privacy (DCS annual report, 1996). In October 2002, the DCS again updated its policies for HIV/AIDS in prisons. The most significant policy was that condoms were easily accessible and available at

all times. HIV testing would still only be done on medical grounds or when the prisoner requested it. Such requests are restricted only by cost constraints.

In spite of the lack of resources, psychologists, health and social workers have succeeded in implementing successful programmes for addressing HIV/AIDS in various prisons. For example, the multidisciplinary team in the Pretoria prison management area has organised various support groups for the four prisons in this management area, namely, the Pretoria Central, Local, C-max and Female prisons. Although these groups differ according to their size, facilitators and nature (i.e. closed or open), their main function is to cater for the needs of people infected and affected by HIV/AIDS.

From the above discussion, and in line with Skoler and Dargan (1990), it is clear that early approaches to HIV/AIDS infections in prisons were less well informed and somewhat more alarmist than the current concepts of progressive custody. More recently, and despite the fact that certain prisons have implemented dynamic programmes for addressing HIV/AIDS, Goyer (2002) finds the current policies for addressing HIV/AIDS in the DCS generally problematic. These include a deeply flawed condom distribution policy, a weakly implemented HIV testing policy, and inconsistent, if not entirely inadequate, treatment and health care. The conclusion reached by Thon (2003) regarding testing in institutionalised settings is that national policy guidelines and other general ethical guidelines should be followed as far as possible. Therefore, testing should be voluntary with full informed consent. The indications for testing without the consent of the client are limited to emergency situations, or where there is a clinical indication for testing and the person concerned is incapable of giving informed consent. Furthermore, it is acknowledged that HIV counselling plays a major role in preventing the spread of HIV/AIDS.

HIV/AIDS Counselling Defined

Counselling is a term that connotes many different activities. The word has been applied to the activities of attorneys, insurance advisers and even cosmetologists. It is often defined as advice-giving, which assumes an expert who tells others what

they ought to be doing (Patterson & Welfel, 2000).

In this dissertation, the term counselling refers to a process of communication and interaction between a counsellor and a client, which aims to empower the client with choices. The process of empowerment is facilitated by promoting a change in attitude, perceptions and behaviour, and where necessary, suggests realistic action. Counselling helps the client to accept disturbing information as well as adapt to its implications (Anderson & Wilkie, 1992; Gibney et al., 1999; Hough, 2003; Jones, 2003).

Counselling helps patients to deal with various problems such as fear of rejection, social stigma, and many uncertainties associated with the management of HIV/AIDS. Counselling provides support at times of crisis. It helps patients to communicate better with those they are emotionally involved with. Emotions that are difficult to deal with can be confronted in the counselling session. In counselling, HIV-positive patients can get all the information they need about the pandemic. The process further helps patients cope with discrimination that typically follows the HIV-positive diagnosis (Adler, 2001; Hetherington, 2001; Jones, 2003).

HIV/AIDS Counselling

The HIV/AIDS test is different from all other medical tests. It has huge emotional, psychological, practical and social implications for the person. HIV testing should therefore never be done without thorough pretest counselling (Carballo & Miller as cited in Bor et al., 1992; Gibney et al., 1999).

Mbuya (2000), Klinck (2004) and Webb (1997) remark that when done properly and comprehensively, pretest counselling prepares the client and counsellor for more effective posttest counselling. Furthermore, these authors believe that pretest counselling forms an integral part of the process of obtaining consent from the person taking the test. Not only does it show respect for the physical integrity and human dignity of the person, it also prepares the person for the potential outcome of a test and issues that may arise from such an outcome. It is recommended that health care

professionals make use of pretest counselling to educate and give information to the client, because it is often difficult to do so in the posttest counselling.

According to Peltzer (2003) and Freeman (2004), the majority of people are not willing to take the HIV/AIDS test. While no systematic studies have been conducted in South Africa on how many people have been voluntarily counselled and tested for HIV/AIDS, it is estimated that only around five percent of the population have been tested (Van Rooyen, Solomon & Gray as cited in Freeman, 2004). This situation exists despite the fact that Van Dyk and Van Dyk (as cited in Freeman, 2004) found that 87.3% of their sample of South Africans believed that every person should know their status.

Peltzer (2003) reports that the reluctance some people show to take an HIV test is due to their belief that they would not be able to cope with living with an HIV-positive result, so they would rather just not know. Other people fear the social attitudes and stigmatisation of their communities. Still others feel that it is meaningless to be tested when there is no cure for the disease. For others the major fear is the reaction of their churches. This fear is realistic in light of Peltzer' findings that indicate that some churches stigmatise people infected with HIV/AIDS, instead of giving them support.

In practice at present, health workers are in the front line of working with people with HIV/AIDS. At the point of advising people about testing, giving test results, advising on medical treatment and monitoring progress, doctors and nurses are likely to be the main people involved. Yet, many of the problems facing HIV-infected people are not only medical. They also include sexual and cultural issues, personal adjustment, dealing with the reactions of family members, and so on (Mbuya, 2000; Van Dyk, 2001; Webb, 1997). Non-medical counsellors are therefore an important addition at many different stages of HIV/AIDS counselling, right from the first contact. These professionals include social workers, psychologists, teachers, religious workers and legal workers who use counselling and helping skills as part of their work (Jones, 2003).

These various counsellors have been proclaimed the “champions” of the social functioning of individuals. Mbuya (2000), Van Dyk (2001), and Webb (1997) note that the role of these professionals may be to demystify the medical jargon and give simple explanations about the disease, thus enabling individuals to understand their diagnosis.

Pre- and posttest counselling is likely to be more effective if the counsellor is clear about the aims of the session, and if the discussion is focused and time limited. A number of authors (e.g. Bor et al., 1992; Mbuya, 2000; Van Dyk, 2001; Webb, 1997) agree that the purpose of pretest counselling is to provide information to individuals who are considering being tested.

A typical pretest counselling session could include what the test is, how it is done, the advantages and disadvantages of being tested and knowing the results, what a positive and negative result means, the chances and implications of an incorrect result and appropriate support structures available (Bor et al., 1992; Klinck, 2004).

Guidelines for Pretest Counselling

For the purpose of this dissertation the reasons for pretest counselling are discussed in the form of guidelines. In practice, however, the counselling sessions does not always follow such a neat format due to the individual style of each counsellor and the unique interaction between client and counsellor. It is crucial, however, for the counsellor to ensure that all areas of concern are addressed.

Reasons for Testing

The decision to take an HIV test is one that few people take lightly. For many people, taking the test is an act of enormous courage. Counsellors have an important role to play in assisting individuals in making the decision to test or not (Anderson & Wilkie, 1992; Gibney et al., 1999).

An individual’s motivation for being tested is important because it sets the scene for the rest of the pretest counselling session. There are various motives for getting tested. Some people are tested for insurance purposes; some are forced by

their significant others to take the test. Some people want to be tested before getting married; some plan to become pregnant and want to check their HIV status before they do. Others are simply curious (Anderson & Wilkie, 1992; Peltzer, 2003).

Confidentiality

According to Van Dyk and Van Dyk (2003), it is often found that clients are not against VCT in principle, but they have serious doubts and anxieties about the confidentiality of HIV test results. The counsellor should therefore stress the confidentiality of test results and assure the person that his or her confidentiality will be respected at all times. If the person chooses not to disclose his or her status, he or she must be reassured that no information will be communicated to anyone without his or her prior permission.

Consent

There are many ethical issues in HIV testing and counselling. Before being tested a person must give verbal or written consent. Although HIV counselling and testing is often seen as an important public health tool in the primary prevention of HIV/AIDS, nobody can be coerced to take the test (O’Leary & Jemmot, 1996; Orr & Patient, 2004).

People have the right to know their status. It is also a human right to choose not to know one’s HIV status and consequently a person can refuse to give consent to undertake an HIV test. In all circumstances, the emphasis should be placed on providing individuals with enough information to allow them to make a free and informed choice about being told their HIV status (Gibney et al., 1999).

Exploring Knowledge about HIV/AIDS

The counsellor should make a concerted effort to find out what the person understands about the HIV test. It is also crucial to determine what the person believes and knows about HIV infection and AIDS, and correct inaccuracies by providing accurate information about transmission and prevention.

Identifying the Perceived HIV Risk

The information that is provided about HIV/AIDS and its transmission, and the correction of any misconceptions that the client has about HIV/AIDS, will enable clients to make a realistic assessment of whether it is possible that there is a risk that they may have been exposed to HIV infection (Anderson & Wilkie, 1992).

Presenting Information About Risk Reduction

Pretest counselling also provides an opportunity to provide information about safer sex, and possibly how to use drugs in a way that removes the risk of transmission of HIV (Anderson & Wilkie, 1992).

Discussion of Treatment Options

Some people who present themselves for pretest counselling may wish to review in detail particular treatment options which may be available to them should they take the test and receive a positive result (Anderson & Wilkie, 1992).

Implications of Testing

The possible personal, medical, psychological, ethical and legal implications of a positive test result should be discussed with individuals before being tested. The person's concerns should first be identified and discussed.

Coping with the Waiting Period

Clients who decide to take the HIV test may wait a few hours or at most a few days before they receive their test results. Although this is an improvement on the longer waiting period of the past, these few hours or days may seem like an eternity to the person who is waiting. A counsellor can assist clients to plan how they are going to cope with this period of waiting. Such planning may include leisure activities to help occupy the person's time, and consideration may be given to how the person can best find emotional support (Anderson & Wilkie, 1992).

Psychosocial Support

Supportive counselling may be offered to individuals and their families in an attempt to reduce the psychological and social effects of HIV/AIDS (Gibney et al., 1999).

Preparation for the Result

It is important for the counsellor to anticipate the result and to talk about how the client can deal with the result. Clients should be prepared for both a negative and a positive result. No pretest is either adequate or complete until a person has been prepared for the results. Preparing clients for the possibility of a positive result paves the way for more effective posttest counselling (Bor et al., 1992).

There are several stages in pretest counselling. The order in which these stages occurs will probably differ from person to person. However, it is always important to be consistent and ensure that all the necessary areas have been addressed (Patterson & Welfel, 2000).

HIV Posttest Counselling

Although pre- and post-HIV test counselling sessions are carried out separately, they are nonetheless interrelated. Pretest counselling gives the counsellee an indication of what to expect in posttest counselling. If possible, the same counsellor should carry out both the pre- and posttest sessions. This will facilitate the continuation of the established rapport between the client and the counsellor and it will also provide the client with a sense of continuity. The counsellor's experience of the pretest counselling session will also give him or her a better idea of how to approach the posttest session (Bor et al., 1992; Van Dyk, 2001).

Posttest counselling should revisit the points discussed during the pretest counselling. It also serves to facilitate an individual's decision making on future health care. Thus, Klinck (2004) recommends that the health care options and the ongoing and/or longer-term health care planning of the person need to be discussed.

The exact procedure for giving a test result will vary from counsellor to counsellor. There are a few basic guidelines, however. HIV results should be given simply, and in person. For HIV-negative people this may be a time where information about risk reduction can be further reinforced. The window period should be checked again and the decision taken about whether further tests are needed or not. HIV-positive people should be allowed time to adjust to their diagnosis. Coping procedures

rehearsed at pretest discussion stage will need to be reviewed in the context of the here and now; and include questions such as: what plans does the person have for today, and who can they be with this evening? Direct questions should be answered although the focus remains on plans for the immediate few days, when further review by the counsellor should then take place. Practical arrangements including medical follow-up should be written down. Overloading the person with information about HIV should be avoided at the result giving stage. Information overload sometimes represents counsellors' way of managing their own anxiety rather than focusing on the client's needs (Adler, 2001; Anderson & Wilkie, 1992).

HIV/AIDS Testing

There are some people who strongly support the idea of testing for HIV and knowing their status. They may have different reasons for the decisions they make, for example, they may wish to know if they have negative result so that they can relax and stop worrying. Other people may want to know if they have a positive result, however depressing and upsetting this is, so that they can avoid further infections and/or infecting other sexual partners, and so that they can practise safer sex. Such information can assist them in making important decisions in life (for instance, whether or not to have children). It provides an opportunity to re-evaluate their life, make the most of the time they have left; re-think relationships, work, leisure activities, religious or spiritual convictions, and many other things (Mbuya, 2000; Van Dyk, 2001).

There are also many people who are against the idea of being tested for different reasons. Firstly, if the test confirms a positive result, people have to live with this knowledge for the rest of the lives. They cannot change their minds about knowing. Some people will be permanently anxious and afraid if they have a positive result, fearing that every sore throat means that they are dying. Some people are afraid that the news of their positive results will leak out and many people may react negatively to them (Mbuya, 2000; Van Dyk, 2001).

Responses to an HIV-positive Result

The impact of the diagnosis and the possibility of facing death may be profound for individuals who have been informed that they are HIV-positive. Many reactions to an HIV-positive diagnosis are part of the normal and expected range of responses to news of a chronic, potentially life-threatening, medical condition. Adler (2001) and Eloff (1988) report the following common problems people experience upon hearing the results of the tests:

- Fear of infecting others, particularly lovers
- Utter frustration at not being able to adjust to their circumstances
- Anxiety about the reaction of the outside world, possible desertion by friends and relatives, declining health
- Fear of loss of confidentiality and exposure of sexual orientation
- Depressive symptoms: feelings of sadness, helplessness, worthlessness, anticipatory grief and suicidal thoughts
- Anger: being suspicious of the attitude of others
- Sense of isolation and reduced support.

Conclusion

The implications of the HIV/AIDS pandemic extend far beyond the individual bodies it destroys. It has social, psychological, and economic causes and consequences. It is very important that while the search for the cure of HIV/AIDS continues, we do not neglect the psychosocial consequences of living with the illness, as well as the dysfunction that it imposes on the individual. The importance of HIV counselling must therefore be emphasised. This emphasis represents one of the goals of this dissertation. Chapter 3 discusses the research methodology employed in the present research study.

CHAPTER 3

RESEARCH PROCESS

Introduction

Since a cure for HIV/AIDS is not yet a medical reality, attention needs to be given to the psychological aspects of the pandemic (van Dyk & van Dyk, 2003). Attending to the psychological sequelae of the disease allows those infected and affected by HIV/AIDS to live more harmonious lives. This goal provided part of the impetus for this study.

Through learning and understanding more about counselling, health care officials may provide better counselling services. Although aspects of the present research might relate to the population at large, the specific area of focus in this study is HIV/AIDS testing and counselling, specifically in a prison context. Since this is a hitherto neglected area of research, it is hoped that this dissertation may contribute both in the areas of education about the disease as well as furthering an understanding of the HIV counselling process.

This chapter clarifies the exploratory approach followed in collecting and analysing the data. In so doing, my role as a researcher will also be explained. Lastly, a description of the ethical considerations of the research study is presented.

Research Method

A qualitative research design was deemed appropriate for the purposes of this study. Methods used in qualitative research provide a deeper and richer understanding of social processes than would be obtainable from methods employed in quantitative designs (Miles & Huberman, 1984). The deeper and

richer understanding of social processes obtainable from qualitative methods complements the narrative exploratory method employed in the present research study. A qualitative research design provides the researcher with an opportunity to gain insight into and understanding of words and images rather than numbers. It furthermore allows for the observation of natural occurrences by means of unstructured interviews and observation, where science is not viewed as a model and understanding is aimed at meaning rather than behaviour, from the perspective of the person being studied (Silverman, 2001).

The aim of exploratory studies is not to provide definitive answers or solutions to research problems, but rather intends to generate and clarify ideas as well as formulate questions and hypotheses for more precise investigation at a later stage. It intends to broaden the understanding of issues revolving around the research questions. Hence, it is defined as “research into an area that has not been studied and in which the researcher wants to develop initial ideas” (Neuman as cited in Struwig & Stead, 2001, p.510).

In the following section the research questions are stated and elaborated on. The setting in which the research study was executed is described, and the motive for choosing the qualitative research design is explained. Furthermore, the tools used to gather information are stated and the reasons for using the selected research tools are explained. Finally, the thematic data analysis process is outlined.

Research Question

I embarked on this research study mainly because I was keen to find out how the research participants experienced HIV testing and counselling. I was interested in what they had to say about the HIV pre- and posttest and their experiences thereof. My question was: what thoughts/perceptions do the prison inmates have concerning HIV testing and counselling?

Research Setting

The study was conducted in Atteridgeville prison.

Study Population and Sample

The study population in this research study comprised the identified prisoners and key informants (officials) at Atteridgeville prison. In definitions used by various authors (e.g. Babbie 1992; Breakwell, Hammond & Fife-Shaw, 2002; Goddard & Melville, 2001; Wilson 1989 as cited in Brink, 2002), a study population is the entire group of persons or objects that is of interest to the researcher and from which a sample is selected. This may include all units which may be included under the delineation of the research study.

Samples consist of individual participants selected from target populations. To compile a sample the researcher selects participants assumed to be representative of and capable of speaking reliably and validly for the larger population (Breakwell et al, 2002; Goddard & Melville, 2001; Holstein & Gubrium, 1995). Patton (2002) and Maykut and Morehouse (1995) contend that in order to gain a deeper understanding of some phenomenon experienced by a group of people, it is necessary to purposefully select individuals, thereby acknowledging the complexity that characterises human and social phenomena. For this reason, purposive sampling was used in this study. This kind of a sample consists of elements which contain most of the characteristics or attributes typical of the population (Singleton, Straits, Straits & MacAllister, 1993). The research sample consisted of seven people, three of whom were interviewed for the purpose of a pilot study. Four participants participated in the first round of semi-structured interviews, and two were re-interviewed in the second round of semi-structured interviews.

Research Procedure

This section provides a summary of the course of action taken to initiate and conduct this explorative inquiry. The process of obtaining permission from

the DCS, as well as the process of gaining entry into the research field, is noted, and my role as a researcher is also discussed.

Authorisation to Execute Research

Singleton et al. (1993) notes that the researcher's first step in conducting a study in a formal setting is to seek permission from those in charge. In addition, Taylor and Bogdan (as cited in Singleton et al., 1993) describe the ideal setting as one that is directly related to the researcher's interests, easily accessible, and allows for the development of immediate rapport with informants. I applied to the DCS in writing to obtain permission to conduct research in a Pretoria prison. The choice of Pretoria was informed by practical and logistical considerations.

It took some time and effort for my application to be approved. I received a fax confirming the success of my application to execute a research study at Atteridgeville prison. The HIV/AIDS coordinator from DCS Head Office contacted me telephonically, and provided me with the names and contact numbers of officials delegated by the DCS Head Office to offer me administrative assistance in terms of security and accessibility matters at Atteridgeville prison. I started to make telephonic arrangements to locate Atteridgeville prison, as well as to meet the research participants and obtain their informed consent.

Obtaining Entry

My primary motive for conducting this study at a prison was that I was already an employee of the DCS and I therefore assumed that gaining entry to a prison setting would be simple. However, I was not prepared for the bureaucratic procedures that turned what I thought would be an easy and simple process into a complicated, difficult and frustrating red-tape ordeal.

I learnt that to achieve what I needed for my study, the best practice was to seek the cooperation of those who were likely to question what I was doing. Despite the fact that I had received written permission for the study from the DCS Head Office, I had to continuously seek permission from those in charge, referred

to as gatekeepers by field researchers (Taylor & Bogdan, as cited in Singleton et al., 1993). In the course of my investigation, I encountered numerous people in charge of subdivisions and subsections whose cooperation and permission I was obliged to seek at every turn.

This was a tedious but fruitful exercise. According to Punch (1998), the process of data collection in the field requires, among other things, time, a deep personal involvement and commitment and the ability to withstand tedious situations. I also began to understand as I read more of the literature that entering and staying in the field is not a straightforward, easy procedure – a discovery corroborated by authors such as Berg (1995) and Taylor and Bodgan (1984).

My Role as Researcher

As a researcher my role was that of multiple engagement and collaboration. Such a role required me to both facilitate and participate in the process of change through conversations. This role requires creating a space for and facilitating a conversation such that it remains in the domain of dialogue. The opportunity for communication of problems is maximised, new descriptions arise, new meanings are generated and therefore new social organisations expanded.

My role as the researcher was that of collaboration. This implies mutuality, modesty and respect for and about people and their ideas. The participants' ideas and stories are the only tools to keep both the participants and myself open and flexible to the development of meaning and understanding (Real as quoted in Anderson & Goolishian, 1988).

Penn (1991) argues that in the space provided, people must perceive themselves as being heard, and in finding their own voice, discover that they have been living their life less by their own experiences than according to other people's descriptions of these experiences. The space referred to here is that of reflection and introspection. In being heard, people find validation in a new story to replace the invalidation of their experiences implied in other people's descriptions of them.

As researcher, facilitator and participant, I was fully involved, and it therefore became difficult for me to observe the interactionist rule. However, Penn (1991) states that neutrality in qualitative research is probably not a legitimate way of achieving the researcher's goal. In other words, the researcher cannot ask for openness from the participants without being open, free and sincere herself. The researcher believes that the stories as told by her or to her by the participants serve as a window through which she sees herself, in much the same way as White (1995) sees the interaction between researcher and participants as having a reciprocal influence on one another.

White (1995) argues further that this storytelling process can initiate a reverse process whereby people might rescue themselves in understanding their roles. They may do this by providing a platform of healing that was previously construed as a formal self-misunderstanding and self mis-representation. Through these tellings and retellings, many alternative themes or counterplots of people's lives are thickened, and the stories of people's lives become linked through these themes, and through the values, purposes and commitments expressed in them.

Creswell (1994) and Locke, Spirduso and Silverman, (2000) suggest that the terminology of the qualitative researcher differs from that of the quantitative researcher. Words such as "understanding", "discover" and "meaning" are important terms which invite a sustained and intensive experience with the participants. These authors indicate that this introduces a range of strategic, ethical, and personal issues into the qualitative process.

Ethical Considerations

The following ethical considerations, outlined by Breakwell et al. (2002) and Silverman (2001), were addressed:

- Protection and welfare of participants
- The principles of informed consent
- The use of deception
- The debriefing of participants

- Confidentiality and anonymity of data
- Participants' right to withdraw from an investigation

The above considerations were addressed during the course of the research and negotiated with each research participant. The nature of the study did not pose any mental or physical harm to any participant. Informed consent was obtained by establishing voluntary participation and providing background information about the research concerning the aims and objectives, the reasons for the research as well as a description of the whole process.

Participants were informed of their right to withdraw at any stage of the research. The nature of the study did not require the use of deception; on the contrary, the participants' understanding of the research aim, methodology, and so on, added to their ability to contribute positively to the research study. I furthermore hoped that the participants would gain from their participation in the research by gaining more information about HIV/AIDS, participating in free counselling as well as engaging in a process of self-reflection. Confidentiality was addressed by assuring participants of anonymity and allowing input into related issues, including using fictional names in all reports where necessary. For more information on confidentiality and consent refer to Appendix A.

Research Design

A small sample consisting of seven participants was used. Quantitative researchers might see this as the weakness of the study, but according to qualitative inquiry, intended focus is to obtain the rich descriptions of individuals, thus necessitating a more thorough consideration of a smaller sample. In focusing on a few individuals as opposed to large group of representatives of the population, Wills (as cited in Holstein & Gubrium, 1995) suggests that individuals, in principle, are equally worthy despite individual differences and their stories are therefore worthwhile to tell.

Research Tools

For the purpose of the first round of individual interviews, I designed a semi-structured research schedule based on the information obtained in the pilot study. An attempt was made to carefully omit questions which were double-barrelled; which introduced assumption before posing the question, which included complex wording; or which were leading, included double negatives or acted as catch-alls (Breakwell et al., 2002). As I worked through the transcribed interviews and my researcher's notes, however, I realised that some of the questions were closed-ended and not always clear. As a result, the data collected during the first round was thinly described and this constituted a major limitation to the research study. For this reason I decided to return to the research field for a second round of interviews with an improved interview schedule. For more information on the interview schedule refer to Appendix B.

According to Creswell (1998), multiple sources of information may include observations, interviews and documents which situate the study within a context. Although interviews were the main tool of data collection, I included multiple sources of information which were considered rich in context. The pilot study, the first round of semi-structured interviews, personal contact as well as telephone conversations, my own experiences and accessible literature comprised these various sources. The abovementioned data collection tools are discussed in the following subsection.

Data Collection Process

The data gathering part of the process of inquiry involved four phases. The first phase consisted of unstructured conversations with the DCS officials, the second phase involved the pilot study, the third phase consisted of the individual interviews and finally, the fourth phase entailed the second round of semi-structured interviews. Following Silverman (2001), the phase approach allowed for a fuller exploration of the HIV testing experiences of participants and provided a space for reflections upon the process.

First Phase: Introductory Conversations

According to Creswell (1998), data collection often demands that researchers ask questions and follow hunches, if not in direct conversation with respondents, then in the observers' notes on what to look for. In this study, much time was used discussing the proposed research with various correctional officials. At first, these conversations comprised an inquiry into the correct procedures that I needed to follow to execute the research. It was during these inquiries that I was enlightened about some crucial facts related to my study. I was informed about the difficulties that health care workers encounter in terms of resources and work force, and I was also told about the increasing numbers of HIV-related illnesses inside the prison.

It seemed apparent that HIV/AIDS is escalating in the prisons. It was also clear that there was a growing need for HIV/AIDS counselling among inmates. The prison officials were pleased to hear that I wanted to explore the issue of HIV counselling amongst prisoners. They told me that they had not been trained in providing HIV counselling but were nevertheless expected to provide the services to the prisoners. They were therefore not sure as to whether the counselling that they had been providing to date was working or not. The results of the present study may therefore give these officials some feedback from the prisoners about the counselling provided thus far.

During these conversations we discussed ways in which the research participants (the prisoners) would be selected. The intention was to find cooperative participants who would be willing to share their HIV/AIDS testing and counselling experiences with me. I also provided the officials with the background information about the research, including the purpose of the research as well as the interview process, discussing when and how many prisoners would be interviewed. It was also during this initial phase that I briefly discussed the ethical considerations with the DCS officials.

Second Phase: Pilot Study

Numerous authors (e.g. Barker, Pistrang & Elliot, 2001; Brink, 2002; De Vos, 1998) define a pilot study as a small-scale try-out that is conducted before the main study on a limited number of participants from the same population as that intended for the eventual research study. The importance of piloting cannot be stressed enough. It is rarely possible to design a study and then translate it straight into action. De Vos (1998) and Denzin and Lincoln (1994) add that a pilot study gives the researcher a clear indication whether the selected procedure is most suitable for the purposes of the investigation.

Breakwell et al. (2002) explain that the pilot study represents the first-hand, direct involvement of the researcher with the social environment where the study will take place. The pilot study is therefore one way in which researchers can orientate themselves to the research study they have in mind. It is during the pilot study that the researcher should acquire practical experience of the relevant research context and should take into consideration the complexity and dynamics of the particular research field (Strydom as cited in De Vos, 1998).

According to Barker et al. (2001), Breakwell et al. (2002) and De Vos (1998), a pilot study is valuable for refining the wording, ordering and layout filtering of the interview schedule. The purpose of the pilot study is to explore the practicability of the planned study and to expose possible deficiencies in the research method employed.

Although I had visited Atteridgeville prison before and I had encountered the prisoners in their orange uniforms, it was during the pilot study that I had the opportunity to communicate directly with prisoners for the first time. It was during the pilot study sessions that I familiarised myself with the setting and with the rules and regulations that govern the prison. Embarking on a pilot study helped me to get administrative procedures roughly right. I became attentive to the protocol in the prison, and learnt that I had to continuously seek permission from the gatekeepers.

Furthermore, the pilot study offered me an opportunity to test the interview schedule and make necessary modifications before embarking on the semi-structured interviews. The prisoners behaved differently to what I expected. They were well-behaved and willing to share their stories with me. These conditions were, however, still not enough for me to access participants' rich descriptions. I was very concerned about my own protection and security issues, and thus found it difficult to relax and concentrate on the interviews.

Before commencing with the interviews, I arranged an information session with each selected participant during which I explained the research procedures and the participant's rights, and obtained informed consent from each participant. During these sessions I made it clear that participation was voluntary and that they had the right to withdraw from the study at any time if they felt uncomfortable. The purpose of the study was also explained so that the participants could get a clear picture of their role. I made an effort during these sessions to answer questions relating to the research study, including my working relationship with the DCS. More information on the consent forms may be found in Appendix A.

The pilot study interviews were conducted in a nurse's office. The room was spacious, well-ventilated and comfortable. Despite these conditions I continued to feel threatened and uncomfortable. I was afraid of the prisoners, and did not want to be left alone with them. However, because of the ethical aspects of the research, the nurse could not stay with us throughout the interview process. The nurse and I therefore agreed that he would occasionally enter the room under the pretence of fetching something. Although this agreement helped calm my nervousness, it was very disruptive because every time he came in the whole conversation was interrupted.

Before I started with the first interview, I was concerned about the reactions of the prisoners to the interview questions and to my approach. I believed that prisoners were cruel and dangerous and that I could not have a civil conversation with them because they might hit or harm me in some way. I thought that being alone in an office with a prisoner was taking a huge risk.

During the pilot study, these qualms proved to be gross misconceptions, and I realised that there was nothing to fear. Once I started talking with each of the participants individually, I realised that prisoners are “normal” people who happen to live behind bars for one reason or the other. The pilot study was therefore an eye opener for me; however I continued to feel uneasy.

The pilot study involved interviews with three male prisoners. Each interview lasted between 15 to 30 minutes. I interviewed all the participants in one day. The pilot study interviews were not recorded because I was not allowed to enter the prison with a tape recorder. The questions asked during this session are listed in Appendix B. Most of these questions were closed-ended and as result I collected thin descriptive data.

Third Phase: Semi-Structured Interviews

Interviews are a flexible tool for research and can be used at any stage in the research process. In the present study interviews were used both in the initial stages to identify areas for more detailed exploration (as part of the piloting) and later as the main vehicle of data collection. Interviews yield rich insights into people’s experiences, opinions, aspirations, attitudes and feelings (Denzin & Lincoln, 1994). Researchers have described various kinds of interviews, such as in-depth, unstructured, structured, semi-structured, and standardised (Struwig & Stead, 2001; De Vos, 1998; Denzin & Lincoln, 1994; Marshall & Rossman, 1995; May, 1997).

The data in this study was gathered chiefly through the use of semi-structured interviews. Such interviews are described as a conversation with a purpose (Ely, Azul, Friedman, Garner & Steinmetz, 1991). During semi-structured interviews the researcher explores a few general topics to uncover the participants’ meaning perspective, but otherwise respects the way that the participant frames and structures the responses. The fundamental assumption underlying semi-structured interviews is that the participants’ perspective on the phenomenon of interest should unfold as they (and not the researcher) view it (De Vos, 1998; Ely et al., 1991; Marshall & Rossman, 1995). Furthermore, these

authors agree that the most important aspect of the researcher's approach concerns conveying an attitude of acceptance, and an acknowledgement of the participants' information as being valuable and useful.

In semi-structured interviews, the researcher has a number of topics to cover. However, the precise questions and their order are not fixed but are allowed to develop as a result of the conversation with the respondent. The researcher is permitted to probe and deviate from these questions (Struwig & Stead, 2001). In this study, I adapted, developed and generated questions as the interview progressed. I introduced the pre-planned questions towards the end of the conversation if those questions were not addressed during the course of the interview.

Interviewing has limitations and weaknesses, however. Interviews involve personal interaction; therefore cooperation is essential. The interviewees may be unwilling or uncomfortable to share all that the interviewer hopes to explore. The interviewer may not ask questions that evoke long narratives from participants either because of fatigue, lack of expertise or familiarity with local language (Marshall & Rossman, 1995). For instance, when I interviewed Respondent five I got the feeling that he did not want to talk much about his experiences. I was also feeling exhausted because I had walked for about two hours to get to the prison. Consequently, I had little vigour to ask questions that evoked long narratives from him. This was consequently a short interview and consisted of brief answers.

Four male prisoners were interviewed during the first semi-structured interview round. These individuals comprised both young and middle-aged individuals. All of them had undergone HIV testing. I had previously explained to the official who assisted me with the selection of research participants that I specifically wished to interview prisoners who had been tested for HIV, and I was not concerned about the result (either positive or negative). In the first round I interviewed two HIV-positive and two HIV-negative participants.

The research interviews lasted for about 30 to 45 minutes each. These interviews were spread over six weeks. The lengthy time period was as a result of frequent rescheduling that took place because of clashes of prison activities with my scheduled appointments, or because of my transport problems. On some occasions I had to walk for a few hours to get to Atteridgeville prison. Getting to the prison was difficult due to the lack of public transport to and from the prison. When I did finally arrive there, it was usually to face another bureaucratic battle just to pass through every major and minor gate. The result was that I conducted most of the interviews in a state of fatigue and agitation.

The semi-structured interviews took place at the same venue as the pilot study. The room was free from distractions and inconveniences. There were two armchairs with a small coffee table in between. I placed the tape recorder on the coffee table. Unlike the pilot study interviews, these interviews were tape-recorded.

During the first round semi-structured interviews I was better relaxed and more focused on the interview process than I was during the pilot study interviews. This could be because I did not have to write every uttered word down since the tape recorder was doing that for me. During the interview, I found myself waiting impatiently to ask the next question immediately after the participant had finished responding to my previous one. I did not observe participants' nonverbal cues; subsequently I missed crucial details in the data. I did not follow the process and I was not even aware of what was happening nonverbally. I later realised that I had missed a great deal of information by not asking probing and open-ended questions.

In addition to my inexperience and the challenges I experienced, the language used was probably the main reason that led me to miss much information. Most of the interviews were conducted predominantly in English, with a mixture of Northern and Southern Sotho languages at times. It became clear during the interviews that the majority of the research participants had difficulties in expressing themselves well in English. They struggled to understand the interview questions as I asked them in English. I had to frequently

translate every word for them to be able to answer the question asked. There were times where even after explaining and repeating a question some participants gave me an irrelevant answer.

My preoccupation with what I wanted to hear clouded my judgment. Instead of considering language as a possible barrier, I concluded that the participants did not know what counselling meant. It irritated me whenever they seemed lost or did not understand the question. As I transcribed and attempted to analyse these interviews I became aware of some of the obvious mistakes that I had made, the questions not asked, the lack of thick descriptions and nonverbal information. Upon realising these shortcomings I knew that I would have to do more interviews; but just the thought of it made me nervous.

I remember telling one of my supervisors that I felt that I had not asked enough questions, that my art of asking questions had been poor, and that I had not consulted enough material. I told her that I had realised now what questions I should have asked. I went on and on about what I should and should not have done. My supervisor then responded by saying, “Zengiwe, it sounds like you are telling me that you are ready to do your interviews... is that what you are telling me?” (Prof. T. Bakker, personal communication, October 4, 2004).

From that moment I knew I had to go back to the research field and do more interviews. This time I was not worried about the participants; my main concern was accessing the prison, both in terms of getting transport to take me there as well as negotiating entry to the prison again. The following section tells the story of how I went about executing the second round of interviews.

Fourth Phase: Second Round of Semi-Structured Interviews

I realised that continuing the old pattern of worrying about the possible difficulties of re-entering the research field did nothing to remove the shortcomings of this study. I remained stuck. I had to do something, I had to face the obstacles head-on; they were preventing me from producing a meaningful piece of research.

I telephoned the prison hospital and made an appointment with another nurse, after being told that the previous nurse I worked with had resigned. After careful preparations I was back on my way to the research field. Unlike the previous time when I felt insecure about my role as researcher, this time I felt like a real pro: I was prepared and optimistic. I had all my necessary documents, the improved interview guide, the tape recorder, spare batteries and spare tape cassettes; everything was in order. Most importantly, I felt confident and in charge. This allowed me to be relaxed and focused.

Chase (cited in Holstein & Gubrium, 1995) indicates that the researcher's questions incite responses that reveal the meaning-making process in relation to the research objectives. He asserts that qualitative researchers agree that the questions we ask make a difference to the quality of the information we collect. The second round of interviews was remarkably different from the first round. My newfound confidence allowed participants to take the lead and say whatever they wanted to share. This enabled me to find information that I had never thought about before.

Pool (as cited in Holstein & Gubrium, 1995) states that the participants' stock of knowledge could shift around in the course of the interview in relation to the role taken by the expected responses. He explains that rather than searching for the relevant, best and most authentic point, the aim is to systematically activate different ways of knowing, even if participants reveal diverse and contradictory information. In the second round of interviews, I asked questions and I found myself more interested to hear what the participant had to say (verbally and otherwise) than what I thought they should say. This open-ended approach, free of assumptions and leading questions, made it easy to gather thick descriptions of data. These interviews can be described as having more of a conversational agenda than a procedural directive, and questions were phrased in everyday language with intent to ask participants' about their own experiences, thoughts, and feelings about HIV/AIDS testing and counselling.

Interviews were conducted predominantly in "Ghetto language" which is also known as "*tsotsi taal*", "*loxion lingo*" or "*language ya kasi*". Speaking the

same language, as the participants made them feel comfortable and free to tell their stories. It also gave the interview environment a relaxed and humorous touch. This time around I interviewed only two of the previous four participants. Five other prisoners who had participated initially have been released. I therefore had to make sure that I made the most of these interviews. I chose to be open and honest in explaining to them the reasons why I needed to redo the interviews. They told me that they were a little disappointed to hear that I was returning to redo the interviews because when I left previously I had promised to come back with feedback. However, they were understanding and cooperative once I explained the reason for my long absence and lack of feedback: I had been involved in a serious accident which required hospitalisation and confinement to a wheelchair for several months, and was on disability leave for eight months. Since both the participants were due to leave the prison soon, we agreed that I would send the feedback to the DCS, as it would help improve the services and help other HIV-positive prisoners to cope in the future.

The dialogues that transpired during the individual interviews were tape-recorded. Permission to do so was sought, and given by both the participants, neither of whom expressed any concern about being recorded. Although at an interactional level, some people may find the tape recorder inhibiting and do not wish their conversations to be recorded, tape recording can assist interpretation as it allows interviewers to concentrate on the conversation and record nonverbal gestures of the interviewee during the interview, rather than spending time looking down at their notes to write what is said (May, 1997).

It was again a mutual agreement between the participants and myself to keep their identities anonymous. I assured their confidentiality and anonymity. Some participants even suggested the fictional names to be used. The research participants felt that their participation would benefit them to some extent: they wanted to talk about their coping difficulties and acquire skills in facing their everyday HIV-positive lives. Talking about their experiences was also an opportunity for them to vent their feelings. Flying Squad and Ghetto Guy pointed out that it was exciting for them to have somebody interested in what they had to say for a change, rather than being expected to listen to prison rules and officials

all the time. These were in-depth conversations and each interview lasted for about three to four hours.

Thematic Data Analysis

Creswell (2003) states that the process of data analysis involves making sense out of the text and image data. It involves conducting different analyses, moving deeper and deeper into understanding the data, representing data, and interpreting their larger meaning. Data analysis is an ongoing process involving reflection about the data, asking questions, and writing memos throughout the study.

According to Marshall and Rossman (1995), the analytic process demands an increased awareness of data and focused attention to those data. They state that the most intellectually challenging part of the process is to identify relevant themes, recurring ideas or language, and patterns of belief that link people and setting together. Through questioning the data and reflecting on the conceptual framework, the researcher engages the ideas and the data in significant intellectual work.

The central themes that were covered in the pilot study and individual interviews were extracted from the wealth of tape-recorded dialogues and filed notes taken. Extracting themes from the recorded discussions was an extremely difficult and absorbing task since the interviews were conducted in “*tsotsi taal*” and had to be translated to English – which is not even the researcher’s first or second language.

Once themes had been identified, they were then discussed with reference to the literature review that had preceded the interviews and discussions. Holstein and Gubrium (1995) state that a method that is commonly used in the analysis of data from in-depth interviews is called content analysis method, which involves summarising and classifying data within a thematic framework. This framework

provides a structure for the interpretation of qualitative research data so that it is based on emerging themes and concepts.

The final stage was to make sense of the data collected for the purposes of drawing conclusions that reflect on the interests, ideas and theories that initiated the inquiry. In most instances the results feed back into the initial interest, ideas, and theories. Denzin and Lincoln (1994) note that in practice, this feedback may very well represent the beginning of another cycle of inquiry.

Conclusion

This chapter described the methodology followed in the research study. The procedure, the sources of data collection and the analysis employed were thoroughly discussed. Chapter 4 presents the data collected in the first round of interviews, while Chapter 5 presents the data collected in the second round of interviews.

CHAPTER 4

RESULTS

Introduction

This chapter presents the data as it was collected during the first round of semi-structured interviews. Although interviews were the main tools of data collection, I engaged in an in-depth data collection process involving multiple sources of information which were considered rich in context. These sources included informal face-to-face and telephonic conversations that I had with the DCS officials. The pilot study served as my formal debut in the research field. Drawing on my own knowledge and experiences also played an important role in the data-gathering process.

Presenting Data

Data Collected from Phase One: The Informal Conversations with the DCS Officials

These conversations were not recorded; however I retrieved the information from my researcher's notes and from personal communications I had with the research participants. It was during these conversations that I was enlightened about some crucial facts related to my research study. I was informed about the difficulties that health care workers encounter in terms of resources and staff shortages, and I was also told about the increasing numbers of HIV-related illnesses and deaths inside the prison. It seems that HIV/AIDS is an escalating problem in the prisons. It was also apparent that there was a growing need for HIV/AIDS education and counselling among inmates.

The prison officials were pleased to hear that I wanted to explore the issue of HIV counselling amongst prisoners. They informed me that they had not yet

been trained to offer HIV counselling but were expected to provide this service to the prisoners. One DCS nurse said,

“We have not yet received formal counselling, but we are trying to give them pre- and posttest, even though we are not sure how to go about it exactly”.

The officials further indicated that they were not sure as to whether the counselling that they had been providing thus far was working or not. The results of the present study will therefore give them some feedback from the prisoners about the counselling provided thus far. One social worker said, “The hospital refers HIV-positive prisoners to us for posttest counselling, and it is difficult to get the feedback as to how one’s intervention has helped because these prisoners just come once and they do not come for follow-up sessions. I then worry whether I have chased them away or I have helped them. So it will benefit us if we can get the results of your research to see how everything is going...”.

Data Collected from Phase Two: Pilot Study Interviews

It was during the pilot study sessions that I familiarised myself with the setting, and the rules and regulations that govern the prison. Embarking on a pilot study helped me to get administrative procedures more or less right. I became attentive to the protocol, and became aware of the importance of continuously seeking permission from those in charge (the gatekeepers).

The pilot study participants consisted of three male prisoners, two black and one white. All of them fell in the age category of 27-45 years. One of them was diagnosed HIV-positive.

Participant One

Participant One received both pre- and posttest counselling. He said that he wanted to know his HIV/AIDS status because he was ill on a regular basis. Pretest counselling encouraged him to take the test and it also prepared him for the result.

Participant Two

He said that the pre- and posttest sessions helped him deal with the sad reality of living with HIV. The records confirmed that he was HIV-positive (DCS, 2004).

Participant Three

He is HIV-negative. His view changed radically after being tested and he indicated that he is now more careful and health conscious.

After conducting these interviews I tried hard to convince myself that I had learnt something, but I was still very much in the dark...

Data Collected during Phase Three: Semi-Structured Interviews

In this section each of the four participants is presented individually. After careful reading and re-reading of the interview transcripts, the following themes emerged. In this section, I summarise the themes according to each participant and then substantiate the analysis by including a quote from the interviews.

Respondent One

Respondent One is a 31 year-old black man. He has been sentenced to four years and eight months for bank robbery. He has been diagnosed as HIV-positive.

1. Testing for HIV/AIDS

Respondent One was tested for HIV in February 2003. He could not remember the exact date. He was tested for medical reasons since he had been ill for some time. His leg was sore and he had sores all over his body. The doctor at the prison clinic recommended that he take the HIV test and he agreed. He stated, "It's been a while, I cannot remember the exact date... I went to them because my legs were painful, I couldn't even walk and they said they would draw some blood and make some tests including HIV test to investigate what the problem could be. Because I was suffering from the pain I agreed and they made blood tests. When results came they told me that I am HIV-positive."

2. Receiving pretest counselling

Respondent One did receive counselling but did not seem to understand what counselling means. This is how he responded during the interview:

Zengiwe: Did they counsel you?

Respondent One: They counsel me...*(he said this with a frown in his face that seemed to indicate confusion)*.

Zengiwe: Mm, did they talk to you about the HIV illness? Or did they explain anything? Tell me what happened.

Respondent One: Yes they explained to me, I went to them because my legs were painful. I couldn't even walk and they said they would draw some blood and make test to investigate what the problem could be. Because I was suffering from the pain I agreed and they made blood tests. They said they would give me results. When results came they told me that I am HIV-positive.

3. Views about HIV/AIDS before taking HIV/AIDS test

Respondent One did not clearly described his views about HIV/AIDS. His lack of an explanation could be due to the nature of the question; it is possible that he did not understand the question or maybe the question was closed-ended and it did not allow for a detailed answer. I realised as I was transcribing this interview that I should not have left it but should rather have probed to find out more about his ideas. The conversation was as follows:

Zengiwe: Before you got tested for HIV what did you use to think about this illness?

Respondent One: Well I used to think that it could be witchcraft that my feet were so painful.

Zengiwe: Okay, I hear that but now my question is before you knew where do you stand as far as your HIV status is concerned. What did you use to think about this disease? What were your views?

Respondent One: Well after they told me that I am HIV-positive I accepted. Because I understood that those were the results, trying to refuse, ignore or fight them were not going to help or change anything.

4. Views after HIV/AIDS testing

Respondent One's perception about HIV/AIDS changed. Instead of watching himself getting weaker and weaker from the illness and thinking that he is being bewitched, he shifted his whole attitude and quit smoking, started to be health-conscious and took better care of himself. He discovered spiritual healing and comfort and accepted Christian principles of living.

This is how the interview went:

Respondent One: Well, that time... when I did not know that I am HIV-positive, I felt normal and healthy. But now that they have told me that I am HIV-positive I felt that I should quit smoking and I successfully achieved that. So now people tell me that my body has changed.

Zengiwe: So after you did the tests and you received counselling you realised that you should take more care of yourself. For your health's sake you even gave up smoking?

Respondent One: Yes... I have accepted that and I am also a born-again. I have accepted God in my life. I understand that I must put everything in his hands. Even before we started with this interview I was busy in the church with other members and visitors from other communities outside the prison.

5. The role of posttest counselling

Posttest counselling helped Respondent One to become stronger and more positive about life.

Respondent One: Yes it has really changed my life in a very good way. It helped me stay focused and positive about life in general.

Respondent Two

1. Testing for HIV/AIDS

Respondent Two is a 34 year-old Indian male. He has been in prison for eight years and was charged for theft and robbery. He is HIV-negative.

2. Receiving pretest counselling

He received pretest counselling and it seems from his reply that it was a very extensive session.

Zengiwe: When you did your testing - tell me about it. Did they talk to you or counsel you beforehand? Or did they just draw blood from you?

Respondent Two: Yes, when I did the testing they did talk to me. They asked me questions about what I want and why I want to do the test and they also told me that if I feel uncomfortable or not ready yet I should say so. They also told me about the confidentiality of the test and its results. Ja, they gave me pre-counselling.

3. Views about HIV/AIDS before taking HIV/AIDS test

Respondent Two is a very active person in finding information about HIV/AIDS. He attended a course on HIV counselling. During that course he obtained a few basic facts about HIV/AIDS. He was also aware of some of the myths about

HIV/AIDS. He also mentioned that there were few questions that he was wondering about as far as AZT is concerned.

Zengiwe: And before that basic counselling course you attended, what views did you have about HIV/AIDS?

Respondent Two: I am used to reading books and magazines. Well I don't believe in myths, I wanted total understanding of the whole issue.

Zengiwe: You don't believe in...

Respondent Two: Myths about everything that has got to do with AIDS. What people use to say and think about AIDS I didn't believe in that. Actually I validate everything I hear about AIDS. I strive to get the truth about AIDS I went out looking for facts about AIDS in pamphlets, the only question I had before the course was about the AZT and how the mother can infect her unborn baby and why was AZT not supplied to prevent that but that was addressed in the course.

4. The role of pretest counselling

Respondent Two did receive pretest counselling but for him this session did not bring any thing new. All the information discussed during that session he said he had already learnt from the pretest counselling course that he attended in prison a few weeks before taking the test. Attending the first pretest counselling course encouraged him to take the HIV/AIDS test. It also prepared him to receive his result no matter what the outcome might be.

Respondent Two: No I did not see any much contribution of that pretest counselling because I came to do the test long before I have made up my own mind. By attending a course a basic counselling course on HIV/AIDS. It took place here in prison. Well before that I did not see any reason to take the test; I never thought I could be

affected or infected by HIV. But I thought I should do it after that, that course I attended.

Zengiwe: If I understand you correctly, I might be wrong so please correct me if I am wrong, they had pretest counselling with you when you did the test.

Respondent Two: Yes.

Zengiwe: But what helped you most is the basic counselling course.

Respondent Two: Yes, it is the basic counselling course. It set the platform for my decision to take the test. I already knew what I was going to go through, like a written map I had to walk through.

5. Views after HIV/AIDS testing

His view changed positively after undergoing the counselling and testing. He became more cautious, and aware of high risk behaviours.

Respondent Two: Yes, I think it has changed. Now I feel more concerned. I even notice the mistakes that could have led me to be infected and try to realise the scenario that could have led me to be infected. For other people you know we all have groups of companions that we keep. Of people we live with and interact with. I can now have a picture of what [they] we normally used to talk about with regard to this issue. What they really lack now and what I already know.

Zengiwe: Can you give me an example of what they now lack?

Respondent Two: I think they... maybe they've got girlfriends, they don't see a need to maybe use a condom because a girl you know... You know people have got types. And that is wrong because anyone can get AIDS irrespective of their types of status or class. Use of condoms must be emphasised. I didn't even use condoms and that could have been a risk for me because I didn't

know the status of the person I was involved with. Maybe she used to have intercourse with other people but I didn't want to believe it, that AIDS is there and is a reality. I ignored and denied it.

6. The role of posttest counselling

Respondent Two did not undergo posttest counselling. He said he did not see the use because he was diagnosed as being HIV-negative.

Respondent Three

Respondent three is a 38 year-old white male. He was sentenced for ten years and was charged for assault and attempted murder. He is HIV-positive.

1. Testing for HIV/AIDS

Respondent Three had been tested for HIV while in prison.

2. Receiving pretest counselling

Respondent Three seemed hesitant about whether he received pretest counselling or not. At first he said that he had received counselling but he almost immediately changed the answer and said that he had not been counselled. As I probed more into his reply I found that he did receive counselling but that it had been a very brief session and it seemed fairly ineffective in preparing him to receive his result.

Zengiwe: Tell me about the testing when you were tested. Did you receive any counselling?

Respondent Three: Yes, I have received any counselling...
(Silence) No I was not counselled.

Zengiwe: Please tell me what happened.

Respondent Three: The way I was so ill the doctor advised me about the illness and he explained a lot of stuff and my rights as far as HIV testing is concerned.

And I understood him so I agreed with him.

Zengiwe: What did you understand?

Respondent Three: I understood what he was telling me about HIV/AIDS. They was I was so ill and it was soon after my wife died, she was also very ill before she died. He told me that AIDS-related diseases killed my wife. He asked if I had taken HIV tests and I said no not yet. So he explained the importance of doing the tests. So I did the tests. And the result came positive. I got very stressed and I worried a lot. During that time I was on trial, until I got sentenced and I was imprisoned. After that I got even sicker. Yes, now I was suffering from painful ears. Because I found out that I am HIV-positive whilst I was on trial I was not given any treatment. So after I was sentenced I asked to be re-tested. So they did the tests without any counselling.

Zengiwe: They did the tests without any counselling?

Respondent Three: Yes, without any counselling. Results came back positive. And they gave me HIV treatment since then until now I am still continuing with the treatment. But although I am receiving treatment and my ears are getting better although not completely healed. I have a lot on my mind, I worry all the time, I have lots of problems. I was even taken to Kalafong hospital that's where I was helped a lot and my ears were treated successfully there. It's been a month now since I've been discharged from Kalafong. Even there at Kalafong they did some HIV testing with my consent. There at Kalafong they gave me pre-counselling before they even draw blood.

Zengiwe: So you received counselling at Kalafong hospital?

Respondent Three: Yes that's where I understood how everything works. And they explained that just because I am positive it does not mean that I have AIDS already. It does not mean I am going to die tomorrow or the next day. I still have more days to live. I must just look carefully after my well-being and take good care of

myself to avoid further infections. I also started reading more about this disease. After that session my life became better and my worries also decreased, I started to go on with my life and everything became better especially my health. And now I am focusing on finishing up my sentence so that I can get released and go out there and try to make an honest living for my children's sake.

3. Views about HIV/AIDS before taking HIV/AIDS test

Respondent Three had uninformed views about HIV/AIDS. Most of his views were based on uninformed myths and misconceptions.

Respondent Three: I thought when you are diagnosed with HIV positive it meant that it is the end of one's life that one will only have a couple of days to live. I also thought that it makes people to change; that all people will be afraid of me or getting closer to me or still being my friends.

4. Views about HIV/AIDS after HIV/AIDS testing

His views about HIV/AIDS did not change after his first testing. He was very depressed and could not cope with his HIV/AIDS status because he was not properly counselled. However, his views and attitude changed dramatically after receiving extensive counselling at Kalafong hospital.

Respondent Three: After my first HIV testing my views did not change. I think that is why I was so ill and depressed. I thought I was going to die soon. My views only changed after I got tested for the second time and I received counselling. There I was consoled and I learnt the facts about HIV/AIDS. I was happy to know that I can still live long depending on how well I can take care of myself.

Respondent Four

Respondent Four is a 25 year-old black male. He was sentenced for four years. He is HIV-positive.

1. Receiving pretest counselling

Respondent Four did receive pretest counselling.

Respondent Four: Yes, they counselled me and explained a lot of facts concerning HIV/AIDS.

2. Views about HIV/AIDS before taking HIV/AIDS test

He had an idea of the nature of HIV but he did not have many views on the topic. It seems that he did not really think much about HIV/AIDS. For him it was just another serious illness.

3. The role of pretest counselling

The pretest counselling played a significant role in educating Respondent Four about preventative measures.

Zengiwe: Did the counselling prepare you to receive your results?

Respondent Four: Yes.

Zengiwe: How did it prepare you?

Respondent Four: I was told to be careful and protect myself from being re-infected. Importance of using condoms was also addressed.

Zengiwe: So during the counselling process they reminded you of the importance of taking precautionary measures?

Respondent Four: Yes.

4. Views about HIV/AIDS after taking an HIV/AIDS test

The counselling session helped Respondent Four to change his attitude towards HIV/AIDS. He is now more careful and aware of high-risk behaviours.

Zengiwe: The information that you gained during the pretest counselling, how did it help you to change your views about HIV/AIDS?

Respondent Four: I am now more aware of the dangerous situation that can put me at risk.

Conclusion

This chapter provided a sketchy report on the interviews. The identified themes seem more like topics. It was clear that during these interviews I was collecting answers to my specific questions. Data collected is thinly described. There is no biographical data of the participants, and nowhere did the voices of participants or a sense of their stories appear authentic. Most of the questions asked were closed-ended and did not provide the rich descriptions I was hoping for. The questions I asked were leading, presumptuous and not easy for participants to understand. In most instances the questions asked encouraged the participants to act conformingly. As a result they gave me the socially appropriate answers.

I became aware of all these shortcomings and decided to go back to the research field. It is significant that the key words in this study include “pre” and “post” because the way that I see it is that I also went through a pre and post research phase. During the pre-research phase, I battled to understand and follow the research process. The post-research phase is when I faced the research journey the second time around with incredible awareness and improved understanding of the research journey. In the next chapter (Chapter 5) I share the enriched stories of participants’ experiences about HIV pre- and posttest counselling as collected from the fourth phase, namely, second round of interviews.

CHAPTER 5

FOURTH PHASE: SECOND ROUND OF INTERVIEWS

Introduction

This chapter presents the data obtained from the fourth phase, namely, the second round of semi-structured interviews. It would be well beyond the scope and available space of this dissertation to include the complete interviews transcripts and detailed researcher's notes. However, all the field notes and interview transcriptions have been summarised in such a way that they echo clearly the participants' voices.

The Story of Flying Squad

According to prison lingo, a Flying Squad is a promiscuous man who sleeps with different women. A promiscuous woman is referred to as "Jericho", which means a huge dam that can drown anything. For the purpose of this study, and with his permission, I named this participant Flying Squad, though he requested that I keep in mind that he is an ex-Flying Squad because he does not sleep around any more. His story is discussed below.

Getting to Know Flying Squad

Flying Squad is a 32 year-old black South African man. Flying Squad participated in the first round of semi-structured interviews and he was Respondent One. Flying Squad is a Tswana by birth but was raised in a South Sotho-speaking environment and so speaks Southern Sotho fluently in addition to Tswana. He is not yet married, and he has one son aged 13 years. He and the mother of his child separated ten years ago and she passed away two years ago. His son is in Grade 8 and he is doing well at school. Flying Squad attended school up to Grade 9. He was forced

to leave school when his son was born, when he went to work in a mine to be able to financially support his child.

While working on the mine he became aware that there were no possibilities of promotion and he felt that he was underpaid. He started applying for different jobs as advertised in local newspapers, for example, the Sowetan, Sunday Times and City Press. He resigned from the mine when he got a new job at an embassy in Pretoria. He has been working there for seven years now. While in prison the embassy sent him a letter to confirm that he is welcome to return to his job upon his release.

At the moment Flying Squad is in a steady relationship, and before he was diagnosed HIV positive, he was planning to marry his girlfriend. But now things have changed and he has not yet told his parents or his girlfriend about his status and his decision not to marry anymore.

Flying Squad took the HIV test while in prison in February 2003 and was found to be HIV-positive. The Department of Correctional Services is currently supplying him with the necessary HIV medical treatment to maintain and boost his immune system. He is also on the prison's special diet for HIV positive inmates. This diet includes all the basic nutritious food such as fruits, nuts, vegetables, and so on. He has quit smoking and does not drink alcohol any more. He exercises regularly to keep fit. He exercises by cleaning rooms and cells.

Both of Flying Squad's parents are still living. He has a good relationship with them and they manage to visit him and stay in touch via letters and telephone calls. Flying Squad has been in prison for two years now and has to serve four years and eight months.

My Thoughts and Experiences While Working with Flying Squad

Flying Squad is a very warm and caring person, and as a result, I felt comfortable around him and it was easy for me to relax and have a conversation with him. It was easy to ask him questions and he showed a great willingness to open up and spoke freely about his life.

In the following subsection I narrate Flying Squad's life journey. This journey is divided into three parts: his past life, the present and his future life, as he perceives it. In our discussion regarding his past life he shared tales of things he used to do and the reasons why. He also discussed his current way of living, the changes that he has made in his life, and the lessons learnt. Finally, he explained how he wishes to live his life after being in prison. All these facets of Flying Squad's life are discussed in relation to HIV/AIDS testing and counselling. We focused on his story of testing and undergoing counselling and role these processes played throughout his life journey.

Flying Squad's Previous Life

In discussing Flying Squad's past life the interview specifically revealed how he lived his life and the crimes he committed. The company of friends he kept, his attitude/views towards HIV/AIDS testing and counselling thereof were included in this story, as were stories of his high risk behaviours and how he exposed himself to danger and bodily harm.

It was very obvious that before incarceration Flying Squad led a very spontaneous and dangerous life. He used to travel often with his friends; they would drive around every weekend to places as far a field as Messina, Louis Trichardt, Port Elizabeth, Klipgat, Mamelodi, Shoshanguve and so forth. When they reached their destinations the routine was to participate in many drinking sprees, socialise with many girls, and have unsafe casual sex. He said, "When we get to every place we have to get girls to spend the night with, and in every town or city we visited we arrived at the tavern... there was no way we could not get girls..."

Most of the friends he travelled and socialised with resided in Pretoria. Flying Squad had free use of the telephone at the embassy where he worked, and so he would call his friends, they would give him their friends' cellphone numbers and he would call them, and that was how he arranged weekend dates. He lived alone in the apartment he rented in Pretoria and it was there that he had most of his numerous one-night stands and parties.

Flying Squad describes his previous life as mixed-up and dangerous. When he was in Pretoria he was a different person to the one he was when he was back at home with his parents. When he was at home he was well-behaved, and he did not engage himself in any criminal activities. He attended church regularly, though he argues that his promiscuity started at the church. He said, “Our church youth group used to travel around, we played, sang and engaged in a lot of competitions with other churches’ youth groups. In these travelling and competitions we would meet girls and we would have after-parties and stuff...”

Flying Squad recalled a few times when he exposed himself to danger and bodily harm. “I was once stabbed with a knife... I nearly died. The doctors told me that the knife was left with only few inches (*he showed me with his fingers how close the knife was*) to reach the heart, and if that had happened I would have died. I stayed in the hospital for seven days.” As he was telling me what happened I was aware of the intensity of that incident and how it threatened him, but that was not enough to make him quit his dangerous life activities. He also recalled another life-threatening incident: “I remember when we were on our way to Pietersburg, and I became involved in a road rage fight. Without thinking I parked the car aside and we were pointing guns at each other... I could have been shot and killed (*he exhales deeply as he shakes his head*).”

As discussed in chapter 2, large numbers of people still deny the existence of HIV/AIDS. It is easier to continue denying the existence of HIV/AIDS especially when a person has not been personally confronted with evidence of the pandemic (Guest, 2003; Mbuya, 2000). Flying Squad was beyond doubt one of these people. He was not only living recklessly and dangerously, he also had a lethal attitude toward the world’s most feared illness. At the time, he did not feel that HIV/AIDS was a threat at all. He used to hear people talk about it but he and his friends never paid attention to it at all. “Before I got tested, I never practiced safe sex. At those times when I wanted to sleep with a girl and she asked me to use a condom, I would just stop with everything, leave her there, and go to another girl who does not tell me about condoms... that is how I operated... at those times I did not see any danger.”

He and his friends never talked about HIV/AIDS. He said, “We totally ignored it, we heard about it but we did not believe that it existed for sure... We did not take it seriously.” The other reason why they never talked about it, he said, was because “we never had the chance, every time we got together we were already with girls we had to party and sleep with...”

Flying Squad is worried about his friends because he thinks they are continuing with their hectic lives and that they have not realised the seriousness of the illness despite the fact that so many people are dying. Some of their friends have died already but he believes that it still has not sunk into their minds because they are far too busy to care.

To further illustrate how casually he treated HIV/AIDS, before coming to prison Flying Squad once took an HIV test. He saw this as a game, and took the test because the testing station was next to the tavern. He was already drunk when he saw a board saying *free testing, everyone welcomed*, so he went and took the test for the fun of it. He never returned for the results.

Flying Squad was arrested for robbing ABSA bank in Pretoria Central business district. There were six people involved in the robbery, and he was the last to be arrested. His companions were sentenced to thirteen years in prison and he was the only one who received a lighter sentence of four years eight months. The reasons for his lighter sentence were because he was not armed and because he was a first time offender.

Flying Squad's Current Life: Life Behind Bars

At the time of our interview Flying Squad was a changed person, and he describes himself as a different Flying Squad to the person discussed in the previous section. Among other things, he now has a different attitude towards HIV/AIDS. He has accepted the existence of HIV/AIDS and its lethality. In his own words he recalls, “My study buddy here in prison passed away a few months ago, he was HIV positive; I saw him getting weaker and weaker (*he became very sad as he talked about his study buddy, his voice tone became lower and it was trembling because of the*

sadness)”. He has also been told that some of his ex-girlfriends have died too. Presently, Flying Squad is more careful, he is extremely cautious about what he eats, and reports taking very good care of himself. His health is more important to him now than it was before. He has stopped smoking and drinking alcohol. He eats healthily and follows the prison special diet for HIV-positive inmates. He is also taking medication to help maintain and boost his immune system.

Flying Squad's Future Life: Life After Prison

Flying Squad is very hopeful about the future. He is looking forward to making a fresh start. He says that he has learnt from his past mistakes and is willing and prepared to change his life for the better.

Flying Squad intends to go back home to his parents, to live peacefully and to avoid all the recklessness and dangers. He does not want to travel all around the world anymore. He wants to cut off the friends he had before, and because all of them are in Pretoria, he thinks that he can achieve this by going back home.

Soon before Flying Squad was sentenced he had a disagreement with his 13 year-old son. The boy wanted a cellphone and Flying Squad did not want to buy him one. He is now prepared to maintain his child and supply him with all the necessities. He reports that he wants to make up for the time lost. He said, “I want it to be clear that I am back... I don't think he knows how to use a bank ATM, if nobody has taught him yet I am going to teach him... I want to make my son proud... to be the best dad I can be.” He continued to tell me his future plans: “I want to focus on guiding and raising my child. Go to church. Watch my health and get good treatment to keep the HIV at bay.”

When I asked him about girls and dating again he said “I cannot afford to be easily attracted to girls any-more... things are different now... I am positive.” (*I could not help but feel sorry for Flying Squad as he explained how he wants to live. I felt that he is going to be lonely and that his life is going to be tough; but then again maybe I was feeling my own fears should I be in a similar situation... could it be that I was imposing my fears upon him?*)

Flying Squad intends to cut off all his friends and remain with only one good old friend ('friend T') back home. He says that he grew up and went to school together with 'friend T', and they live in the same street. Flying Squad suspects that his 'friend T' might also be HIV-positive. 'Friend T' was shot during one of their expeditions and is now confined to a wheelchair.

Even though Flying Squad's previous employer is willing to take him back, Flying Squad plans to resign and open a small business at home. His motives for resigning are to get away from his dangerous friends and high-risk behaviours. He says that he is well-mannered and lives better when at home.

In the next subsection I integrate the past, present and future reflections on Flying Squad's life with an emphasis on the role HIV/AIDS has played in his life in general. The discussion begins with Flying Squad's first real encounter with HIV/AIDS which is HIV testing. I refer to this as a "real" encounter because although Flying Squad had been aware of HIV/AIDS throughout his life, it had never occurred to him that it was a genuine, lethal illness. There was therefore a defining moment in Flying Squad's life which revealed to him the lethality and seriousness of the pandemic. The following section reports on the circumstances of Flying Squad's being tested and his experience of HIV counselling.

Flying Squad's First Encounter with HIV

Flying Squad was tested for HIV in February 2003. He was experiencing stomach aches and had blisters that appeared and disappeared on his body on a regular basis. As a result the doctor at the prison hospital advised him take the HIV test. He agreed and was diagnosed as HIV-positive. This was a defining moment for Flying Squad; in his own words he describes that testing process as "frightening and emotional". He then began to recognise and accept the lethality of HIV/AIDS. Although this was not the first time that Flying Squad was tested, it was the first time that he received a result.

Flying Squad's Experiences of Counselling

Flying Squad distinguishes between the counselling session he had outside prison and the one he received while inside prison. He refers to the one outside prison as the 'best' counselling he had; and his only regret is that he did not take it seriously. This was when Flying Squad took the test while drunk and did not pay attention to anything he was told then.

He explained the counselling he received outside prison. "That one was a long counselling session," he recalled. During that counselling session they sat him down and gave him time to think about what he was about to do. He said, "The nurse asked me, sir do you really, really want to get tested and know your status? (*He stopped for a moment and then continued*)... That nurse was so warm and she spoke sensitively, she was in no hurry. (*He shook his head and repeated*) No hurry at all. She inquired about my possible reactions should I find that I am HIV-positive. It is a great pity that I was drunk and did not take her seriously," he said. Looking at the floor with his head in his hands, he continued with deep regret in his voice, "I also remember her telling me to always practise safe sex and to use condoms..."

There was a brief moment of silence as I sat there and looked at him as he stared at the floor. He then looked up to me and with some energy in his voice he started to describe the counselling session he received in prison. "I attended an HIV/AIDS counselling course here inside prison before I was tested. The way that I was taught in that course, the counselling that she (*he referred to the nurse that had counselled him the second time*) did was wrong. That is not how you counsel a person. (*I became aware of the anger and bitterness he felt as he was remembering that session. His body posture was also displaying anger; he frowned and was poking vigorously at the armrest of the chair he was sitting on*)".

He continued: "She was supposed to tell me more facts about the pandemic - that it does not have a cure yet, explain how it works... you see? (*He halted for a moment, stared at me and then continued*) She was supposed to advise me about practising safe sex. She... (*He frowns angrily and he throws his hands around in agitation*) was not supposed to tell me that I am going to die... that information was

not helping me in any way, I already knew that AIDS kills, it was not necessary to hear it again and again... Furthermore the session was extremely brief. Within ten minutes she had already finished talking and drawing my blood for the test. She never asked me if I understood or not. I was also not happy that she counselled and tested me. In my previous testing there were two different people, the counsellor and the nurse doing the testing.”

Despite the fact that he was not impressed with the latest counselling he received, Flying Squad strongly believes in the power of counselling. He says he would recommend it for anybody having HIV/AIDS difficulties. He said “I think my friend (‘friend T’) who is now in the wheelchair will benefit, counselling can help him understand the importance of practising safe sex.” Flying Squad is happy that he attended the counselling session after participating in the HIV/AIDS counselling course. He was already armed with the basic counselling skills and he had an idea of how the counsellor should approach the sensitive issues. He learnt in the course that it is helpful to be subtler and less confrontational when communicating a person’s positive result. At the end of the course all prisoners who attended were issued certificates to confirm that they had attained necessary skills to become HIV/AIDS volunteer counsellors.

Prison: A Safe Haven and a Holiday with a Purpose

I was astonished by the way that Flying Squad perceived his life. He has an extraordinary ability to make sense of the things that happen to him. An example of this is when he told me that he was thankful that he came to prison. I could not believe it at first, but it all made sense after I listened to his story.

“I thank God for sending me to prison. I think it was His way of showing me the things that I was not aware of. I do not think I would have taken the HIV test if I were not in prison. That means I would never have accepted HIV/AIDS as part of my life, a very crucial part that needs to be taken seriously. Coming to prison therefore has saved my life. Most of my friends have been killed; I would probably have been shot as well. The prison gave me an opportunity to know my status early enough... The prison gave me a break from my chaotic life... Here in prison it is not as hectic as

it is out there. I have enough time to scrutinise my life... *(He then halted for a moment and repeated these words slowly)* That is why I say the prison saved me... it has really saved my life”.

Flying Squad felt that prison had not only given him a second chance, it had also armed him with valuable information to live his life wisely. The proof of this is, for him, the HIV course that he attended, and the opportunity to review his life and see all the wrongs that he did. For Flying Squad, being in prison has not being time wasted.

Being in Prison: What a Disgrace?

It is said that a coin always has two sides. Flying Squad’s coin is no different. The other reality of being imprisoned is the label and stigma attached to being a convict, which endures long after the sentence has been served. Flying Squad shared with me some of his regrets on being in prison. He said, “On the other side I am embarrassed to be in prison. Being in prison taxes one’s dignity. So when you get released... *(he thinks for a moment)* Like for instance my younger sister’s daughter was born two months after I was incarcerated... I am supposed to be the new baby’s uncle but I have not seen the child at all... that is not good...” He continues, “Another thing... my younger brother got married and I feel embarrassed that I could not attend the wedding”. Flying Squad regrets missing out on family events and growth processes. He says, “Even though being in prison has helped me on one side, on the other side it did not help me at all.”

Being HIV-Positive: Could it be a Blessing in Disguise?

According to Flying Squad, being HIV-positive is not all awful, as it might seem. Being HIV-positive has in some way contributed positively to saving his life. It took a positive diagnosis for him to realise how much danger he was exposing himself to. He sees being positive as serving as an everyday motive for staying out of life-threatening situations such as violent fights including dangerous weapons, knives and guns.

In his own words he says, “HIV/AIDS forbids alcoholism and promiscuity... such lifestyles destroy one’s immune system.”

Harsh Realities of Being HIV-Positive

Being diagnosed with HIV can have a seriously negative impact on an individual, irrespective of whether they are in prison or not. People diagnosed as positive are forced to re-evaluate their lives and dreams and this can be an emotionally taxing ordeal. Flying Squad was supposed to marry his girlfriend upon release. However, his positive status has prompted him to reconsider this decision. This is what he had to say: “So now I don’t know... I have not told anybody about my changes of plans. I cannot marry her anymore... I just can’t”. According to Flying Squad, the most important aspect of marriage is having children, and he says he cannot get married because it would be too challenging to have children while being HIV-positive.

HIV/AIDS Stigmatisation and Social Attitudes

The social stigma around HIV/AIDS is by far the greatest obstacle people face (Guest, 2003; Stein, 2003; Orr & Patient, 2004). Stigma prevents people from getting tested and seeking support from family and friends. For those infected, stigma prevents them from disclosing their status to partners or from seeking proper care. People’s fear is often not so much the infection itself as it is what to tell the neighbours.

The above findings are strongly supported by Flying Squad’s story. He told me that he has not disclosed his status to his girlfriend or anyone in his family. He added, “I do not want to get any medication related to HIV/AIDS from the public government hospital because people will suspect that I am positive”.

Still Afraid to Call a Spade a Spade

As discussed in chapter 2, the stigma surrounding HIV/AIDS in South Africa is such that HIV/AIDS is sometimes not even referred to by name. It is often just called ‘the big A’, ‘high five’, or ‘*ulwazi*’ which means ‘that thing’ (Orr & Patient, 2004; Stein, 2003).

I could not help but notice that throughout the conversations it was only in a very few instances that Flying Squad referred directly to HIV/AIDS by name. In most

instances he referred to it as ‘that thing’. For instance, when I asked him why he and his friends never talked about HIV/AIDS he said, “We never had time to talk about that thing. Furthermore, he said he started taking HIV/AIDS seriously only after he was tested and after he saw his study buddy die. He said, “I then started to notice that that thing is a serious problem. When he talked about disclosing his status he said, ‘You see after you tell one person, that person tells the next one and then they spread around the whole community that so-and-so has that thing.’”

Being HIV-positive in Prison

As stated by Mckee and Power (1992), attitudes held towards HIV/AIDS may have important consequences for social behaviour when HIV-positive and negative individuals are brought together within the same environment, as in prisons. When I asked him about how it is like for him to be HIV-positive in prison he said, “Sometimes it is not so bad, but sometime it is... like me, for instance, many prisoners think that I am not HIV-positive. They think that I have bribed the doctor to give me a letter so that I can be on a special diet.” The other prisoners believe this because Flying Squad appears healthy and fit. A common misconception among the prisoners is that HIV-positive people are thin and weak. Flying Squad further explained how other prisoners treat HIV-positive inmates. He said, “When there is a quarrel between the two prisoners, the HIV-negative one will say to the HIV-positive prisoner, *Wai*, I won’t waste my time quarrelling with you because you are dying, you sleep next to your grave... you have been lucky to have woken up today... talking to you is a waste of time... I do not think that by tomorrow this time you will still be here...”

Being HIV-positive outside Prison

Flying Squad reckoned that it might be easier to be positive outside prison. He argued that the availability to facilities, shops and pharmacies would give him the opportunity to get quality food and medication.

The Role of the Media and Community Programmes

Community-based programmes and the media have played a crucial role in Flying Squad’s journey in learning about HIV/AIDS. Even though at the time that he

went for HIV testing he was drunk and not aware of the seriousness of the illness, the crucial fact is that there was a free testing facility available. He took the test then, but he only realises now the valuable information he learnt there. News on radio and television has not only kept Flying Squad informed about the latest developments on HIV/AIDS treatment, it has also instilled hope for the future. He said, “I heard on the radio that there was a girl who was very sick and she started taking antiretroviral and she became much stronger and now she is about to finish her studies.”

After All is Said and Done, Life Still Goes On

As seen from Flying Squad’s point of view, living a rich HIV-positive life in prison is extremely hard due to the prisoners’ attitude towards fellow positive inmates. Minimal recreational facilities, insufficient medical services and the lack of good nutrition also contribute to the challenges faced by HIV-positive prisoners.

It was striking for me to realise that all these obstacles did not stop Flying Squad from living a fulfilling life. Instead of being discouraged and giving up on his health, he has stopped smoking and drinking alcohol, he supplements for the lack of exercise facilities by committing himself to cleaning cells and hallways inside prison. This is how he exercises and releases stress. He has a zest for life.

When he leaves prison he is determined to take all the necessary precautionary measures to ensure that he stays healthy. He said, “I am not going to give up, I am going to inquire on retroviral and other available medication to help me stay healthy... at least when I am outside I can buy any type of fruits and foods that help fight HIV and keep me strong”. He is looking forward to being a parent to his 13-year-old son. He is also planning to take better care of his own parents than he did previously. He said, “My parents are very old, I do not want them to bury me, I am the one who should bury them.”

The Story of Ghetto Guy

According to township culture, (affectionately referred to as ‘*loxion*’ culture by its dwellers), a ghetto guy is a sleek and streetwise man born and raised in the

township. Such a person is charming, which makes it easier for him to manipulate people or circumstances to his own advantage. For the purposes of this research study and with his permission, I named this participant Ghetto Guy because he had all the characteristics and personality that matched the description of a Ghetto Guy. His story is narrated as follows.

Getting to Know Ghetto Guy

Ghetto Guy is a 26 year-old black, South African man. Ghetto Guy participated in the previous round of semi-structured interviews and he was Respondent Four. Ghetto Guy is single and has one child. He and the mother of his son broke up three years ago. Both of Ghetto Guy's parents have passed away. His mother died six years ago and his father died last year. Since his father's death occurred a few months after he was incarcerated, according to the DCS policy, he was not allowed to attend his father's funeral. He was devastated by this.

Ghetto Guy's parents divorced when he was nine years old. He says his parents' divorce played a huge role in his becoming a criminal. He started engaging in criminal activities around 1989. His father remarried and Ghetto Guy was forced to live with his stepmother. He says although the stepmother treated him well he did not accept her wholeheartedly. He would have preferred his father to live alone with them (he refers to himself and his younger brother), and not bring another woman into the house. Ghetto Guy claims that his father divorced his mother after the local residents in the neighbourhood bewitched her. His mother was bewitched so that she did not care for her family anymore; she gave up her job and all her responsibilities and was an alcoholic. She later died from an alcohol-related illness. Ghetto Guy's father died unexpectedly. He appeared healthy, until he complained of a headache one day, went to sleep, and never woke up. Soon after the funeral Ghetto Guy's stepmother returned to her own family.

Ghetto Guy has one brother who is currently living in their deceased parents' house, which is where Ghetto Guy will reside after being released from prison.

When I met with him, Ghetto Guy had only two more months to finish his sentence. So far he had served 18 months. He was sentenced for four years but had to serve two years in prison before getting a parole release. He will therefore be released during the first week of January 2005.

Ghetto Guy attended school up to Grade 12 when he failed his final examinations. After this, he went to a college to study mathematics and computer literacy for twelve months. Soon afterwards he found employment as a cashier in a fast food shop. He enjoyed working there and was earning R500 wages per fortnight. The shop was sold and the new owner wanted to pay Ghetto Guy half the amount he was given. He found this unacceptable and so he quit.

My Experience and Thoughts While Working with Ghetto Guy

Since I was also born and bred in the township, I greatly enjoyed interviewing Ghetto Guy. I believe the “Ghetto girl” in me connected to Ghetto Guy on a deeper and exciting level. Our interview session flowed naturally and it felt as if we shared an unspoken agreement which allowed us to unreservedly express our emotions. Consequently, the interview session shifted from being a euphoric experience filled with delight, affection, tenderness, joy and laughter to containing despairing moments filled with feelings of sadness, pity, frustration, and disappointments.

Ghetto Guy was very willing to tell his story and share his life experiences with me. His involvement and enthusiasm in sharing his stories was remarkable, and he showed an ability to re-experience overwhelming emotions and deep pain in the telling of his tale. He was open and honest in discussing his story about HIV/AIDS testing and counselling in prison. Even though we had moments of sadness we also had great fun as he taught me some of the “*loxion*” lingo.

When I asked him about his motives for partaking in the research study he said, “Well, I like helping HIV-positive people. So I wanted to tell you (*he nods in my direction*) my problems and struggles as an HIV-positive person so that you can write about them and hopefully another person will read about it and see that he or she is not alone.”

In the following section I narrate Ghetto Guy's life journey following the same approach I used in discussing Flying Squad's life. Hence, the discussion is divided into three parts: Ghetto Guy's past life, his present life and his future life, as he perceived these to be.

Ghetto Guy's Previous Life

Ghetto Guy started with criminal activities at the young age of nine. He first started stealing car radios and other car parts. In his criminal history he seldom worked alone; in most instances he was a team member of a group consisting of six to eight people. The latest group he affiliated with consisted of six people. It was a syndicate which burgled expensive boutiques and cellular phone stores.

Ghetto Guy describes their operation. They did not break into stores haphazardly. Before they launched their attack, they would survey the place. He said, "We were always planning and strategising our next mission. We would first survey the place; check how many security guards are there, if there were any, and locate the position of alarm. Get the feel of the vibe around that place... we would spend a long time just surveying the place."

Ghetto Guy operated in a very professional manner. His criminal work had its own rules and regulations. There was no mixing business with pleasure. The people with whom he stole were not his friends. He referred to them as colleagues and they did not know anything about his personal life, and did not know or care what he did with the money that they shared between them after a successful mission.

His friends were people with whom he lived in the neighbourhood. Such people were very close to him and they would frequently visit each other's homes. They drank and partied together. Even though these people were close to Ghetto Guy, they had no idea about his other life (of stealing and breaking into shops). They only knew that Ghetto Guy held numerous pitch jobs.

When I asked him about his motives for continuing with criminal activities, this is what he had to say: “The way my life was going it was good... I had a lot of cash... I did not lack anything. That is what I told myself... *eish* but...*(he halts briefly and looked me in the eye)* I was lying to myself... *eish*, I was lying to myself. *(He breathes out deeply and then slowly shakes his head.)*”

Despite his smooth operating skills Ghetto Guy was constantly in danger of being shot by police or security guards. Even in his social life the parties he attended were wild and violent. He told me about one incident where his friends became jealous of his successes and the things that he had. They then wanted to destroy him by attacking his home. He explained, “They shot at the house and I shot back... we kept shooting at each other for about an hour or so...” When the police came, he said, “I was already lying on the floor and I had a huge opening on the side of my stomach *(he shows me a big scar on his side)*. They had slashed me open with a very sharp weapon... I was admitted at the hospital for eight weeks.”

Ghetto Guy did not only expose himself to physical harm, he also exposed himself to psychological harm. He told me that he lived recklessly and in most instances he was aware of the danger but he did not care. He said, “I did not care... I did not obey anybody *(he frowns deeply)* or any societal rules and just did not care...*(He throws his hands around impulsively.)*”

Ghetto Guy also took drugs, which he bought from illegal street markets. The drug that he used for over a year was called ‘shabba’. According to him, “In the long run it makes your bones very weak and painful... and you lose a lot of weight because it eats you up from the inside.” I found it unbelievable that he had all this information about the dangers of ‘shabba’ but continued using it anyway. It scared me just to hear about the drug, and I felt extremely disappointed in him.

He said the drug helped him to relax and calm down because he was edgy and fidgety. The constant planning and strategising drove him to the edge because there was always so much risk involved. He said, “I could not relax; the fear of being caught gave me sprinkles”. I asked him what “sprinkles” meant and he said that it was when one is quivering with fear.

During his turbulent life history, Ghetto Guy gave up many life opportunities. He remembers when he was still in school, that officials from South African Defence Force came for selections and recruitments. He was amongst the selected group. In that group he was the only one left out because he did not show up for the final interviews. All the other learners were taken in and are now working in the Navy. He said, regretfully, “I only focused on crime and nothing else mattered at that time.”

Ghetto Guy's Current Life: Life Behind Bars

It was remarkable to see how Ghetto Guy's body posture and his tone of voice changed as he moved from speaking about his past life to his current life. When he spoke about his past life, the “Ghetto Guy” in him came to the fore. He would talk vigorously and rapidly, and immersed himself in the manner of the “Ghetto Guy” persona. His tone of voice was tough, he fidgeted, and he would illustrate his statements with sweeping, vigorous whole body movements. However, when he described his current life his tone of voice was far more peaceful and gentle. He was relaxed and sensible. He kept comparing the present to the past, pointing out what he has learnt. For instance talking slowly and selecting words cautiously, he said: “At this moment I have peace in my life, I can rest and I sleep like a baby... unlike when I was still out there. *(I notice how the energy in his voice and his body posture changes; he leans forward and talks rapidly)* I could not sit still; I was always tense and worried. At night I would sleep but I would jump from the bed all night through... I always had bad dreams, being chased and shot by the police...”

Ghetto Guy's Future Life: Life After Prison

Although Ghetto Guy is excited about getting out of prison he is also very anxious about going back to the community “buzz”. He said, “I do not know how life is going to treat me the second time around, but I am ready to face all the challenges.” His parents left him some life investments and insurance and he is going to receive the money around 2006. While waiting for the money he intends to start a catering business. He has some catering talents such as cooking, and organising parties and weddings, so he is ready to explore his potential and further his abilities by enrolling in the necessary courses.

Ghetto Guy stated that he wants to get rid of his criminal mindset. He aims to learn from people with knowledge and experience. He wants to broaden his way of thinking and improve his life skills. He says that he is going to embark on a quest for improved life and mentality. He is not sure how exactly he is going to attain these goals, but he knows for sure that “I don’t want to be a criminal no more.”

Ghetto Guy’s family hardships and his own life-struggles have made him very cynical of marriage and family life. He says he is still not sure if he will date again because his previous girlfriend infected him with HIV and he trusted and loved her very much. He never thought something like this could happen to him. He realised only much later that his girl was not trustworthy and she was sleeping around. Even though he does not completely rule out dating in the future, he does not plan to marry. His reasons for this are that marriage would render him vulnerable to envy and jealousy from family members because of his success and his happiness. “Not everyone loves and adores you... Some people, the more you succeed the more they want to destroy you... They will bewitch you and you will be surprised to see that you have nothing left... nothing, even your sense of responsibility is gone... *(I became sad as I listened to him talking like this, although it is not surprising that he feels this way after all he has been through. However, I felt that he was very young to be giving up the future hopes and dreams of parts of life, like getting married)*”.

We spoke about how his parents’ misfortune had contributed to the ideas he held at that time and how those ideas could be transformed if he allowed himself to learn about other aspects of family and marriage life. He said, “*Eish, I will see... (he kept silent for a moment and looked down and then he raised his head, faced me and repeated) I will just see. (I kept eye contact as I nonverbally accepted what he had said by nodding my head slowly)*”. I felt that this phrase suggested that Ghetto Guy was allowing himself another chance to observe and teach himself other opportunities.

Ghetto Guy planned to move on with his life despite the fact that he is HIV-positive. He reported that he is going to do everything in his power to stay strong and healthy, including eating well, exercising and taking the necessary medical treatment to strengthen his immune system.

In the next subsection I follow the same approach I used in discussing Flying Squad's life in general. As a result I integrate Ghetto Guy's past, present and his future life, emphasizing the role that HIV/AIDS testing and counselling has played.

Ghetto Guy's First Encounter with HIV

Ghetto Guy took the HIV test in 2001. He was applying for a bank loan and taking the test was one of the prerequisites. He agreed to take the test without any hesitations. He was sure that he was HIV-negative. He said "I had a faithful relationship with the mother of my child and my son was HIV-negative, so I thought there was no way I could be positive. At the bank they told me that they have confirmed my credit history and everything is fine they are just waiting for my HIV results and then they will approve my loan."

He continued, "The doctor phoned me to come for my results. I went and he told me that I am HIV-positive...*(with a raised voice)* I could not believe it. I was convinced that there had been a mix-up or a mistake of some sorts. So I took the tests again and again for about three times after that... *(He shook his head slowly, and then stopped for a moment, covering his mouth with his fingers. He then breaths out deeply)* but they all came back positive. *(It saddened me to see him like that. For a moment I looked at him and felt sorry and tearful.)*"

Being HIV-positive and Incarcerated Saved My Life

Ghetto Guy felt that being HIV-positive had saved his life and given him more time to live. His previous life was already at risk and in danger. His days were numbered: "In everything I did, *ke ne ke pholoha ka lesoba la nale* (each day I survived it was sheer luck)".

He said he did not know what it felt like to be relaxed and live in peace until he was incarcerated. Being in prison gave him the opportunity to review his life and realise that he needs to take good care of himself or else HIV/AIDS will start to take a rapid toll.

He continued, “If I was not in prison I would have been dead. I could have been shot by the police or killed in the car accident as we try to escape... If I had not been diagnosed positive I am sure that I would still be living dangerously. Well, I might have been caught but I would have served my sentence and afterwards continued with my reckless and dangerous life of crime. But now everything has changed. I am going to leave this prison and go out there and live my life peacefully and safely.”

Ghetto Guy's Experiences of Counselling

Ghetto Guy said after being told that he was positive he attended counselling sessions about seven times. It was through counselling that it became possible for him to accept his status and cope better.

If You Thought Being Locked Up in Prison is Horrible, Think Again

For Ghetto Guy, a person who has been on the run for his entire life, being in prison was like being given a break. What he has feared the most has finally happened: he has been caught. When I asked him how it felt to be in prison, he said, “One thing I appreciated about being in prison is that I had wonderful and peaceful sleep. At night when I went to sleep I was not worried about being chased and caught anymore. I did not have the sprinkles anymore. I felt so safe ‘cause I knew that I was all locked up and I had guards watching after me while I sleep”.

Being in Prison: Could it be God's Wake-up Call?

Ghetto Guy thinks that it was not a mistake that he got caught. There were so many times that he could have been caught but was not. He said, “I think God's intention was to bring me here (*prison*), so that He can make me aware of the things that I was not aware of.” He continues, “Inside prison it is easy to communicate with God, sometimes it gets so quiet and peaceful I can actually feel His presence...”

Being in prison has given Ghetto Guy an opportunity to review his life and see that he was putting his life in danger. He also realised that the people he thought were his friends, family and relatives were just using him for his money. Before

incarceration Ghetto Guy used to help these people with all their financial problems by giving or lending them money. But now they do not visit him, phone or send him letters and postcards. He feels that they have abandoned him.

Challenges in Prison

When I asked Ghetto Guy to tell me more about his life in prison, he said, “In here gangsters rule... there are Air Force Four, Big Fives, and Twenty Six (*names of gangster groups*).” If prisoners do not belong to any group they are called “*mpata*”, meaning a stupid person. Ghetto Guy explained that it can be extremely difficult for a newcomer prisoner to survive inside prison if he does not affiliate with any group as soon as possible. If prisoners do not belong to any group, they find themselves fighting with all the groups for survival. Unaffiliated prisoners are at risk for being insulted, mocked or violated, and without a group affiliation, there is no-one to rescue them. Affiliation with a group means that team members support and defend each other.

When Ghetto Guy first arrived in prison he affiliated to the ‘Air Force Four’. He later quit the gang because he found it destructive and did not encourage him to change his criminal mentality, but enriched it even more. He reported that it was difficult for him to quit but he decided to live by his decision and be called and treated as ‘*mpata*’.

Coping Mechanisms

Being HIV-positive for Ghetto Guy has its advantages and disadvantages. The disadvantages are that “it can get very lonely, because there is no one to trust enough to vent emotions and fears with.” When I asked him how he copes and release stress, he said, “Most of the time I ignore the pain, and I would reserve it until I get a safe place to cry. I would cry when I take the shower (*he was tearful as he reported this, and I felt tearful too*). I also released stress when I was inside my blankets, so at some nights I would cry myself to sleep.”

Still Afraid to Call a Spade a Spade

Just like Flying Squad, Ghetto Guy did not refer to HIV/AIDS by name. He referred to it as “daai ding” (that thing). For instance, he explained that, “I was always curious about how do people with *daai ding* survive. I did not know that I would also end up having *daai ding*”.

Being HIV-positive Outside Prison

Ghetto Guy thought that being positive outside prison might make it difficult for people who are struggling financially, because then they would not be able to afford a good diet and necessary medical attention.

After All is Said and Done, Life Still Goes On

Ghetto Guy said, “Life after prison is challenging, but it needs me to boost myself and move forward... In life there is no one who understands and loves me more than I do myself. Therefore I am going to rely on me the most to make things happen for myself.”

Conclusion

In this chapter I reported on the stories of Flying Squad and Ghetto Guy as I heard them told to me. The aim was not to interpret the narratives, but rather to share them as they were shared with me. In the following chapter (chapter 6), I discuss themes that emerged in the research process, and assemble the data obtained into a coherent whole.

CHAPTER 6

SUMMING-UP

Introduction

This chapter integrates the themes identified throughout the process of data collection. In the discussion of central themes, there is a high probability that the dynamics and uniqueness of each participant's retelling of his story might be lost or missed. For this reason, sparing reference will be made to unique aspects to provide a clearer picture of the participants' feelings during the interviews.

Identified Themes

The following central themes emerged as I read and re-read the transcripts as well as comparing themes identified from each participant.

Role of HIV Counselling

Despite the fact that the pilot study and the first round of semi-structured interviews provided sketchy information, it nonetheless emerged that pre-and posttest counselling has an important role to play in helping people come to terms with their HIV status, especially if it is a positive result.

Even though the counselling sessions the participants encountered naturally differed from counsellor to counsellor, there were basic elements of HIV counselling that needed to be addressed in each case, as discussed in chapter 2. The story of Flying Squad indicates that it is often beneficial if the counsellor is subtler and less confrontational in conveying a positive result.

The conditions of counselling that were more beneficial to the research participants matched those discussed in the literature review (chapter 2). As stated by various authors (e.g. Anderson & Wilkie, 1992; Gibney et al., 1999; Hough, 2003;

Jones, 2003), a process of communication and interaction occurred between the counsellor and the client, which aimed to empower the client with choices. Such a process of empowerment was facilitated by promoting a change in attitude, perceptions and behaviour. Where necessary, a realistic action was suggested and the client was helped to accept disturbing information as well as its implications.

After attending such counselling sessions the research participants changed their views and thoughts about HIV/AIDS. They became more cautious and aware of high-risk behaviours. It was after attending a couple of posttest counselling sessions that Ghetto Guy came to the realisation that being HIV-positive could be seen as a positive occurrence. He came to the conclusion that he needed to take good care of his health to stay healthy. He decided that he needed to quit the reckless and dangerous life he had been living. All that mattered to him then was to keep HIV at bay.

The Influence of Social Context

According to Struwig and Stead (2001), human behaviour does not occur in vacuum. It was therefore important that I inquire about the participants' present context (prison) and their previous context (communities in which they lived before). During the course of the inquiry I realised that for most prisoners, their views changed radically at the prison. They learnt more about the pandemic inside the prison than they did while outside. This led them to hold more positive and realistic views than they did before. The prison not only served as rehabilitation for their various criminal behaviours but it also changed their views. This was illustrated by the change of attitude and perception about HIV/AIDS during the interview. As soon as they were incarcerated and exposed to different lifestyles, for instance the calm, safe environment referred to by both Flying Squad and Ghetto Guy, they became aware of the things they had taken for granted.

It can be argued that knowing their status helped Ghetto Guy and Flying Squad to change their views. The question arises: should they not have come to a different living environment (prison), would their views have changed? In pondering this question it must not be forgotten that Flying Squad said that he does not think that he would have taken the test had he not being incarcerated. Ghetto Guy knew his

status before being incarcerated, but only showed determination to live healthily after he was incarcerated.

HIV/AIDS Stigmatisation and Social Attitudes

Despite the fact that knowledge about HIV/AIDS has increased dramatically, many people are still haunted by primitive fears that existed at the beginning of the pandemic. People living with HIV/AIDS have been and continue to be stigmatised and discriminated against worldwide (Stein, 2001).

The social stigma around HIV/AIDS is by far the greatest obstacle people face (Guest, 2003; Orr & Patient, 2004; Stein, 2003). Stigma prevents people from being tested, and from seeking support from family and friends. For those infected stigma prevents them from disclosing their status to partners and from seeking proper care.

Neither Flying Squad nor Ghetto Guy have disclosed their status to anyone close to them. Their major reason for this is their fear of the family's reaction. Flying Squad is even reluctant to collect medication from the government hospital because he does not want people to suspect that he is HIV-positive. It is likely then that the stigma attached to the illness will make it difficult for him to obtain the relevant care.

Still Afraid to Call a Spade a Spade

The stigma surrounding HIV/AIDS in South Africa is such that HIV/AIDS is not even referred to by name, and so has been given nicknames such as 'the big A', 'high five', or 'ulwazi' (that thing) (Stein, 2003; Orr & Patient, 2004). The current research confirmed that HIV/AIDS is not called by name. Most participants referred to HIV as *daai ding*, meaning 'that thing'.

Being HIV-Positive in Prison

As stated by Mckee and Power (1992), attitudes towards HIV/AIDS may have important consequences for social behaviour when HIV-positive and negative individuals are brought together within the same environment, as in prisons. The stories of Flying Squad and Ghetto Guy illustrate how being in prison has both advantages and disadvantages. The disadvantages include the stigmatisation and

negative attitudes of other prisoners. The advantages are that prison affords individuals a chance to review their life; and HIV-positive inmates receive a special diet. For Flying Squad, an additional advantage was being diagnosed at a relatively early stage. He was thankful that he found out that he was positive while he was still healthy, so that he could take steps to prolong his lifespan.

The Role of the Media and Community-based Programmes

As stated by various authors (such as Barnett & Whiteside, 2002; Gibney et al., 1999; Visagie, 1999), the role played by the media in promoting certain perceptions of HIV/AIDS has changed from HIV/AIDS as a problem for certain population groups to a position where HIV/AIDS is a problem that affects us all. While in prison Flying Squad found radio, television and newspapers to be the only reliable sources that had kept him informed about the latest news and developments on HIV/AIDS.

According to Egan (2004) and Jones (2001), community-based programmes also play a major role in creating HIV/AIDS awareness and in assisting people to take HIV tests. Flying Squad confirmed that such programmes exist in our South African communities. Even though he was not sincere when taking the test that day, the important fact is that at that time resources were freely available.

Conclusion

In this chapter the identified themes were discussed and integrated with the literature. Chapter 7 reflects on the research process and makes recommendations for further research.

CHAPTER 7

REFLECTIONS AND RECOMMENDATIONS

Introduction

Creswell (1994) points out that in qualitative research researchers have a responsibility to explicitly state their biases, values and judgments in the research report. Such openness is considered useful and positive. The language of the study may be personal, using the first person and drawing on the researcher's impressions and experiences. My reflections and perceptions on the research study are obviously shaped by my personal experience and subjectivity. In analysing the data I drew on my first-hand experiences with the setting, the informants and the text. As Rubin and Rubin (1995) point out, the researcher's contribution can be very useful and positive. Empathy, sensitivity, humour, and sincerity are necessary qualities of the researcher in qualitative interviewing.

Reflections on the Research Process

As I read through my interview transcriptions the first time around, I became aware of many questions that I should have asked but did not. I could not believe that I had made so many simple mistakes. This happened not only because I am a novice researcher, but also because I was not emotionally prepared to do the interviews and engage myself in the research process. Experiencing emotional insecurities when conducting research is a normal part of the research process. As Ely et al. (1991) put it, "denying our feelings would be to shut out one large chunk of reality" (p.111).

Even though I thought that the pilot study was an opportunity for me to familiarise myself with the setting and the participants, my experiences during the pilot round failed to alleviate all my fears and worries about the setting and the participants. The prisoners intimidated me, and this negatively affected the way I asked the questions. For fear of upsetting the participants, I was afraid to probe and

invite participants to elaborate on their answers. Upon reflection, I wonder to what extent I was protecting the participants or myself from being more uncomfortable than I already was. I was extremely reserved. I was doubtful, hesitant and reluctant to interact with the participants.

Although I realised that I had to redo the interviews, the mere thought of doing this terrified me. I worried about gaining entry to the prison; finding transport to take me there; and finding the prisoners again (most of them should have gone home by then). I was obliged to examine these fears and change my mindset, after which I felt more confident to contact the prison and make another appointment. After tying up all the loose ends I was back on my way to the research field. Unlike the first time when I felt like a little schoolgirl who had no clue what she was doing, the second time around I was determined, prepared, and had all my necessary documents (tape recorder, spare batteries and tape cassettes). Most importantly, I felt confident and in charge, which allowed me to relax and focus.

Flying Squad and Ghetto Guy explained that the interviews brought them a sense of relief. Ghetto Guy said it was a good venting-out session. He said it is not always that one finds a person he trusts completely to discuss his problems with. In this way, the interviews succeeded in the goal of not only gathering information, but also assisting the participants in some way. This assistance seemed to occur through the provision of a space conducive to reflection and the creation of alternative stories that are less problem-saturated.

Problems Encountered During Research

Receiving permission to execute the research study with the DCS was extremely difficult. Following this struggle was the second challenge of gaining physical entry into the prison – a task that at times seemed almost impossible. As a result, I expected that working with the prisoners would be as difficult, and that they might be unwilling to participate since my study focused on a very sensitive illness. To my surprise, the opposite proved to be true: the prisoners as well as the DCS officials at Atteridgeville prison responded very positively to the request.

To gain entry into a formal institution such as the DCS requires the researcher to adhere to all the requirements, no matter how tedious it may seem. In such a setting, arguably the most important quality in a researcher is patience. Another is sensitivity to the idiosyncrasies of the organisation. For example, I was obliged to continually seek permission to enter from the gatekeepers of the system, namely each on-duty official and the guards in charge of each section and subsection at the prison. In the field, my general letter of permission from the DCS Head Office was not sufficient.

Recommendations and Conclusion

The first recommendation concerns the approach of novice researchers to the research process. Beginning researchers wishing to enter research settings such as the one described in this study should take care to read and re-read the available literature and research material to familiarise themselves both with the procedures and processes of research, as well as terms and concepts often used by researchers. There is a fine and yet distinctive differentiation between concepts such as research procedure, research method, research questions and research process, and new researchers can get caught up in the confusion of the process, resulting in the derailment of the research process.

As mentioned in chapter 1, it is essential that while the world is actively attempting to find a cure for HIV, it also takes into account the psychological aspects that accompany this illness. This will assist those people who are affected and infected with HIV/AIDS to adjust to the diagnosis, and cope effectively with it, even though they are unlikely to live long enough to enjoy the benefits of a cure. Counselling may assist such people live as harmoniously as possible. To promote the role of counselling in the fight against HIV/AIDS was one of the motivations for this study.

This study demonstrated that pre-and posttest counselling has an important impact on the person's views and thoughts about HIV/AIDS. No HIV test should

therefore be done without pretest counselling and the results must be communicated during a posttest session. The latter counselling can take place on a regular basis until such time a person is able to cope reasonably with his or her HIV status (Bor et al., 1992).

This inquiry was begun with a clear intention to explore qualitatively the stories of prisoners' experiences of pre- and posttest counselling. What emerged, through the narrative exploratory study, was a rich narrative of seven participants that exceeded the initial scope of the inquiry. It offers the hope, albeit within the limitations of this inquiry, that some prisoners can provide clues to new and alternative ways of relating to this dreaded disease.

Through a process of deconstruction, it seems possible that the disease can be engaged with in a way that empowers us significantly as its combatants. This process of selfhood through the creation of new relational selves holds a promising view of human behaviour, even beyond the conquering of this dreaded disease.

The study has illustrated that HIV/AIDS testing without thorough counselling has the potential to result in psychological distress. It is therefore crucial that every HIV test be accompanied by thorough counselling both before and after testing. Although the quest for effective treatment and a cure for this disease is imperative, the management of the disease and the alleviation of psychosocial suffering that accompanies it is equally essential.

It is clear from the identified themes that HIV/AIDS testing is a sensitive issue. It is my hope that this dissertation, with all its strengths and all its flaws, will contribute to our growing awareness of HIV/AIDS, and will assist us to understand the importance of HIV/AIDS pre- and posttest counselling.

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Appendix A

Consent form

Research title: Attredgeville prisoners' experiences of HIV/AIDS pre-and posttest counselling

Appendix B

INTERVIEW SCHEDULE

- 1 Did you receive HIV/AIDS pre and posttest counselling?
- 2 How do you feel about it?
- 3 What views did you hold about HIV/AIDS before the pretest and posttest counselling?
- 4 Did the information you gained during the pretest help you to change any of these views?
- 5 What different views do you have currently?
- 6 Did the pretest prepare you in any way to receive your results? If the answer is yes, how?
- 7 How did posttest counselling assist you?

Appendix C

IMPROVED INTERVIEW GUIDE

Explain the motive for the second round of interview to the participant.

1. Biographical data:

Gender:

Age:

Ethnic:

Marriage status

Children:

Previous work history:

Qualifications:

Next of kin:

2. Current context: Behind bars

What are your reasons for participating in this research study?

Tell me about your life here in prison.

Is it different or the same to your previous life before incarceration?

How did you get here in the first place?

How long is your sentence?

How long have you been here?

HIV/AIDS inside and outside prison: are attitudes, myths views same or different?

How are HIV-positive prisoners treated in here?

Views about HIV/AIDS before and after incarceration.

Have these changed or remained the same? Why?

AIDS challenges/problems you encounter here in prison.

What is the views attitude of other prisoners as far as HIV/AIDS is concern?

Stigma, misconceptions, social attitudes of prisoners to HIV/AIDS

Views about HIV/AIDS.

3. Previous context: Life in their various communities

Tell me about your life before the prison.

Where you lived? With whom?

How was your life in general?

Did you work?

How was it different from your present life?

Your HIV/AIDS views.

4. Future live: Being free again

Future plans

Ambitions

Second chance to face HIV/AIDS as a free man

5. HIV/AIDS testing

What are your views about testing?

What do you think about knowing or not knowing your status?

6. Pretest counselling

What are your views about that?

Did you receive HIV/AIDS pretest counselling?

How do you feel about it?

7. Views about HIV/AIDS before undergoing testing

What views did you hold about HIV/AIDS before the pretest counselling?

Did the information you gained during the pretest help you to change any of these views?

8. Views about HIV/AIDS after undergoing testing

What different views do you have currently?

9. Preparation to get HIV result

When did you get tested?

Where was it?

Why did you test?

Did the pretest prepare you in any way to receive your results?

If the answer is yes/no, how?

10. Role of posttest counselling

Posttest counselling and future health care

Stories of participants' counselling experiences

Are stories the same or are they different?

Thoughts of the participants

HIV/AIDS cure vs protection

Myths, stigma, discrimination personal/social attitude

HIV in prison

HIV/AIDS programmes in SA: communities/prisons

Stigmatisation and HIV status disclosure

Stigma and fear to seek care

How does being HIV positive affect a person/prisoner?

Attitude towards AIDS now in the 20th century

Attitude towards AIDS in the 80s

Reflections of the participants

How was the interview?

Any comments or clarity seeking questions?

What have you learnt?

What were your expectations?