

**A 'GOOD DEATH'?**  
**RUSTENBURG MINERS DYING FROM HIV/AIDS**

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A mini-dissertation submitted to the Faculty of Arts, Rand Afrikaans University, in partial fulfilment of the requirements for the degree of Master of Arts in Industrial Sociology.



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## **ABSTRACT**

This dissertation examines the fear that surrounds death as a consequence of AIDS. It focuses on the relationship that exists between two kinds of deaths, namely the ‘good death’ and the ‘wild death’. The aim of this dissertation is two-fold. It specifically investigates the existence of a ‘good death’, posing the question whether dying ‘wildly’ is necessarily inhumane or unnatural. Secondly, it seeks to emphasise the fact that the stigma surrounding AIDS increases the fears of dying and death.

In this dissertation, investigation is confined to workers on the Impala Platinum Mines on the western limb of the bushveld complex, near the towns of Phokeng and Rustenburg in South Africa’s North West Province. The dissertation focuses on mineworkers, among whom – as a consequence of an excessive use of prostitution, single sex hostels, strenuous working conditions, and a lack of knowledge – there is a high level of HIV infection.

The dissertation consists of two critical parts. The first aims at understanding the ideas of the fears of dying and death, with a specific focus on the theory of good and wild death, while the second analyses these fears in relation to HIV-positive miners. My methods of data collection, analysis and interpretation were ethnographic, providing a description of death and AIDS in concrete circumstances, rather than an abstract and hypothetical analysis of the phenomenon of dying and death. Information was acquired from 25 selected HIV-positive mine respondents during the period November 2002 to March 2003.

This dissertation deals with a topic on which little has been written in relation to AIDS sufferers in South Africa. Its objectives are to clarify the meaning of a ‘good death’ by drawing on the South African approach of a ‘good death’ and to also examine what would be required in trying to help people living with HIV/AIDS (PLWHAs) to achieve this ‘good death’.

## OPSOMMING

Hierdie verhandeling ondersoek die vrees vir die dood by mense wat aan VIGS ly. Daar word gefokus op die verband tussen twee moontlike ‘tipes’ dood, naamlik ‘n vreedsame- en/of ‘n gewelddadige dood. Daar word spesifiek ondersoek ingestel na die realiteit van ‘n vreedsame dood – en die vraag word gestel of ‘n gewelddadige dood noodwendig onmenslik of onnatuurlik is. Tweedens word gepoog om te bewys dat die stigma rondom VIGS, mense se vrees vir die dood vererger.

Vir hierdie doel is die ondersoek beperk tot werkers by die Impala Platinum Myn in die westelike Bosveld-gebied, naby Phokeng en Rustenburg in die Noordwes provinsie. Die verhandeling fokus op mynwerkers wat as gevolg van buitensporige seksuele eskapades, promiskuïteit en ‘n gebrek aan kennis rondom die realiteite van VIGS, ‘n hoë VIGS-syfer toon.

Die verhandeling bestaan uit twee kritiese dele: Die eerste poog om die idee *van* en vrees *vir* die dood te begryp, met spesifieke klem op die teorie van ‘n vreedsame- en/of gewelddadige dood. Die tweede deel analiseer hierdie vrese *viz-a-viz* ‘n groep mynwerkers wat HIV-positief is. Die metodes vir data insameling, analise en interpretasie is etnies van aard en weergee ‘n beskrywing van dood en VIGS onder realistiese omstandighede – eerder as ‘n abstrakte en hipotetiese analise van sterwe en die dood. Inligting is verkry van 25 uitgesoekte HIV-positiewe mynwerkers/respondente en strek gedurende die tydperk November 2002 tot Maart 2003.

Hierdie verhandeling spreek ‘n onderwerp aan waaroor weinig nog geskryf is. Die doelwit is om sover moontlik duidelikheid te verkry aangaande die betekenis van ‘n vreedsame- en/of gewelddadige dood - gesien vanuit ‘n Suid-Afrikaanse perspektief/benadering aangaande hierdie ‘tipes’ dood. Verder word ondersoek ingestel na hulpverlening aan diegene wat met VIGS leef, sodat hulle uiteindelik vreedsaam en waardig sterwe.

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I hope my readers will experience an appreciation for life as they begin to understand, both intellectually and emotionally, the social-psychological processes of dying and death from AIDS. Indeed, this mini-dissertation concerns dying and death, but it is really about living with AIDS. May reading this mini-dissertation help make life more meaningful for you.

Finally I declare that this mini-dissertation, submitted in partial fulfilment of the Degree of Master of Arts in Sociology, is my own original work, that all sources of reference and assistance have been acknowledged; and that it has not previously been submitted to any other university.

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## ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-retroviral treatment
CSW	Commercial sex worker
DNA	Deoxyribonucleic acid
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
PGM	Platinum group metals
PLWHA	Person living with HIV/AIDS
RBN	Royal Bafokeng Nation
RNA	Ribonucleic acid
SIV	Simian Immunodeficiency Virus
STD	Sexually transmitted disease



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# CHAPTER 1

## INTRODUCTION

South Africa probably has more HIV-infected people than any country in the world. HIV is a generalised epidemic in this country that extends to all race groups, age groups and geographic areas. The Nelson Mandela/Human Sciences Research Council (HSRC) study of HIV/AIDS estimates that the HIV prevalence in the population is 11.4 percent and that 15.2 percent of persons in the 15-49 age groups are HIV positive. The study further indicates that Gauteng, Free State and Mpumalanga provinces have the highest prevalence rates. There is also a clear evidence of a high incidence of HIV in people living in urban settlements, informal and formal, compared to those living in tribal areas and on farms (Shisana and Simbayi, 2002: 1-6). Shisana and Simbayi (2002: 7-9) also found HIV prevalence among children aged 2-14 years to be higher than expected, with a rate of 5.6 percent. Their study further showed that women were more at risk of contracting the disease than men. There was also a substantial variation in prevalence among different race groups with prevalence rates respectively being higher for Africans, lower and the same for whites and coloureds, and lowest for Indians (Shisana and Simbayi, 2002: 8-9).

According to Campbell (2003:13) 'one in five adults, or a total of about five million South Africans, are living with HIV or AIDS, and 1700 more are being infected every day'. Under normal circumstances, national life expectancy would have reached 64 by 2010; instead, due to AIDS, it will regress to 47, with mortality rates increasing dramatically in the age group 15-39 (Nattrass, 2004: 24). Looking at the numbers gives us an idea of how enormous the problem is. The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO) estimates that '37 million adults and 2.5 million children were living with HIV at the end of 2003, which is more than 50 percent higher than the figures projected by WHO in 1991 on the basis of the data then available' (Forbes, 2004a: 1).

In the changing and developing climate of care for PLWHAs, we still have so much to learn. As the epidemic spreads in the heterosexual community, and more women and children are affected, we must continue to address issues relating to their special needs. In this dissertation the idea of dying and death as a consequence of

AIDS is investigated. The dissertation approaches this problem using the concept of a 'good death'. This is because, apart from rare exceptions, there is no hope for a cure for HIV-positive people, but then there is no cure for the mortality of any of us. Although we try not to believe it, we are all dying. What makes this study more appealing is the fact that HIV/AIDS is completely unique, differing from other terminal illnesses in that it 'constitutes a public health crisis and a threat to economic livelihood akin to no other illness' and it can devastate the entire society, widening the gulf between rich and poor nations (Nattress, 2004: 23). These two concepts, HIV/AIDS and 'good death' go hand in hand; people who are diagnosed with this disease are in a way given notice of death.

There is no one best way of defining a 'good death'. Its definition changes with time and sometimes depends on an individual. To avoid repetition, I am just going to give a summary on the arguments provided in the next chapter, in relation to a 'good death'.

When reviewing the literature on 'good death', it was found that the meaning and definition of a 'good death' depends on culture and that it changes over time. It was also established that it is impossible to study the concept of a 'good death' without firstly constructing its meaning. There are also different notions and characteristics of a 'good death', especially in multicultural societies. More importantly, though, religion and secularism influence ideas about the 'good death'. The general argument in the literature is that life-saving treatments may and may not be appropriate to achieve a 'good death' in terminally ill patients, and that the emotional and psychological needs of the patients, the family, and carers have to be considered alongside medical issues in order for a 'good death' to exist. The challenge for today, according to the literature, is how to die well from the slow, dehumanised, highly stigmatised and degenerative conditions that accompany AIDS.

This dissertation endeavours to explore the development of the concept of a 'good death', and to highlight its limitation with regards to HIV/AIDS. One research question central to this exploration is: *can people who are dying from AIDS have a 'good death'?* Therefore, the main concern here was to try to investigate problems of people dying of AIDS and how these problems may limit the possibility of a 'good death'.

In order to answer the above question, I selected the HIV-positive Impalaminers as a case study, because of the strong correlation that exists between

mineworkers and HIV/AIDS. The fact that the Impala Mines has its own mine hospital with an independent HIV/AIDS department, assured me that I could gather appropriate information. Because my study was completely qualitative, it used the non-probability snowball sampling method. Twenty-five respondents were interviewed face-to-face with the help of my research assistant, Mr Webster Diale. Some ethical considerations were dealt with before, during and after the research project. Verbal voluntary consent was achieved prior to undertaking interviews. In order to protect their anonymity pseudonyms are used for all my respondents. Data collection, analysis and interpretation were my responsibility as the researcher. Data was collected in the forms of tape recordings, notes, and informal interviews. The data was analysed by grouping the information under specific themes. To interpret the data, differences and limitations were discussed to allow the researcher to write an appropriate qualitative report.

The uniqueness of this study is also signalled by the fact that the research conducted here, was one of a kind. The concept of a 'good death' comes from the 'North' and is US-centric; the literature around this concept does not discuss issues around HIV/AIDS in depth. I, therefore, hope that my research, which draws on an African context and AIDS-related deaths, will make a contribution to the way in which the concept of a 'good death' is understood. So then, my research has two specific aims: one, to clarify the meaning of a 'good death', and two, to examine what would be required to assist PLWHAs to move closer towards having a 'good death'.

Chapter 2 reviews some recent relevant literature on the issue of dying and death. Its focus is twofold. Firstly, it attempts to define good and 'wild' deaths, considering, in particular, the characteristics of a 'good death'. Secondly, it tries to understand this 'good death' by analysing issues relating to death as a result of AIDS. The limitation of the theoretical literature on 'good death' in a South African context makes this research an interesting investigation. Chapter 3 deals with the research paradigms and research methods used in this study. The chapter relates the ways in which respondents were selected to the way in which the data was analysed. Ethical issues are also discussed in this chapter. Chapter 4 provides the research findings, which are based on the themes presented in Chapter 2 and on new themes that were developed during the course of the research. Key findings are supported by quotes taken from the interviews. The final chapter, Chapter 5, analyses the contributions made by this research to the study of dying and death. All in all, though, this research

has shown that much still needs to be done to ensure that every single individual facing death, especially those dying from AIDS, can achieve a good death.



## CHAPTER 2

### UNDERSTANDING A 'GOOD DEATH'

#### 2.1. Introduction

The purpose of this chapter is firstly, to clarify my understanding of what, in a general sense, is meant by a 'good death'. Secondly, it provides a critical review of the theory of 'good' and 'wild' death by analysing the characteristics that are usually associated with a 'good death'. Thirdly, it explores this theory of 'good death' in alliance with the disease of AIDS.

For more than three decades, interest in improving the care of the dying patients has progressed from being the concept of a few health care professionals to a widespread social concern. Emanuel and Emanuel (1998: 116) show that more than 35 years ago Saunders founded the hospice movement in Britain. Nearly 30 years ago Kübler-Ross published on death and dying and the 'living will' was first proposed. More than 20 years ago, the Quinlan decision made clear that it was legal and ethical to terminate life-sustaining treatments in the United States (US), and California became the first state to enact a living will statute. They further showed that 15 years ago US states began recognising the legal authority of families to decide whether to terminate life-sustaining care, and the medical system, which provides health insurance for the elderly and disabled (Emanuel and Emanuel, 1998: 116). More recently, though, there has been intense interest in euthanasia and physician-assisted suicide in developed countries. Despite all this attention, a 'good death' remains more a hope than standard medical practice for almost all patients. In part, this is because the contemporary re-examination of how we approach dying and death coexists within a persistent social attitude that denies death (Emanuel and Emanuel, 1998: 116).

Debates over whether people are dying wildly or well obviously depend on the definition of a 'good death'. As difficult as it might be to define this 'good death', it can only, however, be achieved if physical, psychological and cognitive symptoms are removed, economic demands of the dying are met, where the dying enjoy both social and professional support, existential beliefs are discussed, and finally, where the



hopes and expectations of the dying are being satisfied. The section below, which discusses the different meanings of a 'good death', will provide a better and broader understanding of this topic.

## **2.2. What is a 'Good Death'?**

In order to understand the concept of a 'good death' its development must be traced from the work of Phillippe Aries, the French historian, through the influential writings of the Swiss-born American psychiatrist and physician, Elizabeth Kübler-Ross, to the contemporary contributions within the sociology of dying and death. 'Good death' now has a diversity of definitions and meanings that 'unify around the ideal of dying with dignity, peacefulness, preparedness, awareness, adjustment and acceptance' (Hart, Sainsbury and Short, 1998: 1).

The idea of a 'good death' began in the Middle Ages and persisted up to the mid-twentieth century. When Aries first developed this idea he defined a 'good death' as one in which the dying person 'acted as a manager of ceremonies, presiding over his/her last days of life, conducting farewells, giving blessings and seeking pardons, and approaching the end of life in ways he/she has witnessed since childhood' (Aries, 1981: 28). This 'good death' was a public event, taking place at the dying person's home with family, fellow workers and members of the community present. Aries (1981: 30) described this as a death known but not feared, 'when the rituals of dying and death were practised in ceremonial manner'. This he termed the 'tame death'. The way this tame death was named was in a form of a contrast to the 'wild death' of modern society, 'hidden within institutions and managed by the doctor and the hospital team who strive to obtain from their patients an acceptable style of living while dying' (Hart *et al*, 1998: 2).

It is also of the utmost importance to note two of the significant sociological studies that marked the beginnings of the sociology of dying and death. Dying and death within the hospital context were firstly described by two US sociological studies: Glaser and Strauss's *Awareness of Dying* (1965) and Sudnow's *Passing on: The Social Organisation of Dying* (1967). The concept of the dying trajectory was introduced by Glaser and Strauss (1965), who depicted the good or appropriate death. This 'good death' described the modern medical management of dying and death, characterised by bureaucratised control of death, which minimised the disruptive

possibilities of human mortality (Blauner, 1966: 384). The lives of dying people in hospital context were characterised by ‘experiences of meaninglessness, isolation, powerlessness, and loss of control. The dying person’s autonomy and opportunities were overridden by the hospital staff and the organisation of work’ (Hart *et al*, 1998: 2). This dying and death was what Aries (1981) called the ‘wild death’.

Elizabeth Kübler-Ross in *Death and Dying* (1969) concentrated on five stages of dying, with the last stage of acceptance being the most important phase to achieving a ‘good death’. She did not, however, conclude that this final stage of dying was in fact a happy death. It was in fact a state and a final stage wherein the ‘denial, anger, depression and emotional struggle to resist the ending of life was resolved, unfinished business attended to, all necessary words spoken, preparations and farewells made, after which peaceful death followed’ (Hart *et al*, 1998: 3).

But what about a ‘good death’ in the contemporary hospital context? Kellehear (1990: 25) here defined a ‘good death’ as characterised by the following five features: awareness of dying, adjustment to and preparation for death, relinquishing of roles, responsibilities and duties, and the making of farewells with others. The ‘good death’, he concludes, is good in two senses: ‘it is good at the individual level in a psychological sense as it gives the dying person opportunities for order and control’, and ‘it is good at the social level as it provides a series of rites for appropriate disengagement and the exercise of professional power and expertise, and thereby the creation of private profit’ (Hart *et al*, 1998: 5).

In order to define a ‘good death’ Berfman (1991: 95) addresses the significance of socialisation in the life of a dying person. The way in which we relate to others will shape the way in which we die. Whether a person dies a ‘good death’ or a ‘wild death’ depends largely on the social life of that person.

Social support is an essential aspect of the dying person’s life. It can be conceptualised as ‘the functions performed for an ill or distressed individual by persons in the social network, most commonly family members, friends, co-workers, and neighbours’ (Celentano and Sonnega, 1992: 111). House (1981, quoted in Celentano and Sonnega, 1992: 111) categorised those functions to include instrumental aid (assisting with the normal daily functions of life), socio-emotional aid (sympathy, affection and affiliation) and informational aid (provision of advice, opinion and facts). There is an extensive range of literature demonstrating the social support, and particularly the existence of confidants, in reducing the impact of adverse

stress producing events. The argument surrounding the literature is that the more isolated a person becomes, the greater the chances of that person dying a 'wild death'. Regardless of cultural backgrounds, people face death with a variety of beliefs, attitudes, superstitions, fears, and hopes. Furthermore, in many writings on dying and death, death is presented in a pessimistic way, as something to be feared. Not much has been written on the concept of 'good death', especially for those relating to AIDS.

The 'good death' is commonly understood to have two rather different meanings. These, according to Howarth and Leaman, are derived from two divergent Greek etymological sources. The first is *eu thanatos*, meaning 'to die well'; this is the 'good death' linked to the debates around the medical quality of the physical end of life, namely euthanasia. The second meaning, *kalos thanatos*, is 'to die nobly', to be prepared to meet death, which is the social meaning of being prepared for death (2001: 209). The sociological and anthropological literature has focused on this second meaning of the 'good death', while the ethical, legal and medical literature has focused on the first meaning.

In everyday practice, though, the idea of physically dying well and dying socially well tend to converge. Howarth and Leaman (2001: 210) indicate that, in general, there have been two perspectives on how well prepared people have been in meeting their death – the dying person's perspective and the caregiver's viewpoint. Unfortunately, most of the social science and palliative care literature has concentrated on caregiver's realities – the needs of the dying as assessed by family or health care professionals. This is partly why this study emphasises the need to understand the elements of both 'good' and 'wild' deaths from the perspectives of the AIDS sufferers; in these specific cases, miners living with AIDS.

Different periods in history have had differing views of what constitutes a 'good death'. For example, the late twentieth century idea of dying unaware in one's sleep would have been deemed the worst of deaths in previous eras. For the Greeks, a 'good death' took place at home where the dying person was closely surrounded by friends and family, allowing time to make his/her farewells. Dying in battle would also be good, especially if it brought honour that would live on in memory. Having a proper burial was also an essential part of dying well, as 'it lets the soul pass to Hades'. For the Romans, the physical contact between the dying and the bereaved was close, with a relative kissing the deceased to catch the departing soul (Howarth and Leaman, 2001: 210-211).

In the Middle Ages 'the concept of judgement was central to a 'good death'. The deathbed was the setting for a cosmic battle between the fears of good and evil for the departing soul. The sins of a lifetime could be overcome by a 'good death' (Howarth and Leaman, 2001: 210). They further indicated that the Protestant 'good death' differed in that 'the role of the clergy was reduced or even dispensed with altogether ... deathbed speeches were a major aspect of dying well' (2001: 211). By the early years of the eighteenth century, death began to take more of a medical aspect through the use of laudanum, containing opium, to ease the pain of dying. This, according to Howarth and Leaman (2001: 211), undermined spiritual preparations, as did doctors' increasing unwillingness to declare that death was imminent. Only in the mid-twentieth century did the medical focus on cure lead to death being seen as failure, 'a view which the hospice movement has sought to dispel, encouraging, once again, and the idea that death can indeed be good' (Howarth and Leaman, 2001: 211).

It, then, becomes obvious that a 'good death' is one we might all choose, had we a choice. It is not necessarily an ideal death as has been indicated in the previous arguments by Corr, Habe & Corr (1997) and Hart, Sainsbury & Short (1998). Just what is a 'good death'? It can be described as an appropriate death, a correct death, a healthy death, a peaceful death, or even a happy death (Clinton, 1999: 100). Hart, Sainsbury and Short (1998: 2) define a 'good death' as the kind of death that takes place in a public event (for example, in a dying person's home) and where family, friends, co-workers and even some members of the community surround the dying person. A more formal definition is one provided by Feifel (1977: 119) when he states that:

A 'good death' means an absence of suffering, preservation of important relationships, an interval for anticipatory grief, relief of remaining conflicts, belief in timeliness, exercise of feasible options and activities, and consistency with physical limitations, all within the scope of one's ego ideal ... a dying person will die with dignity, perhaps with greater self-esteem than was possible during life.

The major difference between a good and a wild way of dying is that, in a 'good death', death is always known but not feared, and in a 'wild death' death is always feared and hidden. According to Seymour (2001: 128) a 'good death' is 'characterised predominantly by reference to ideas about the facilitation of awareness

of dying, development of conscious self identity, and social and psychological preparations for death'. Many writings argue that our excessive use of technology may be a threat to the development of a 'good death'. The debates surrounding the relationship between 'good death' and technology are, mostly, drawn from the literature that discusses palliative care and/or hospice movements.

Authors who are against the use of technology in analysing a 'good death' argue that to die peacefully means to be surrounded by people who care for you (ideally family, friends, co-workers, neighbours etc.) and not to be jailed (isolated) in some hospital in the middle of nowhere, surrounded by strangers (doctors and nurses), with life supporting machines, and waiting to die. For them, hospices or palliative care increase the fears of death. Their argument stresses that there are patients presently dying in hospices and hospitals who are not benefiting from the services provided. They argue that this is usually because 'facilities do not exist in the immediate area or because local medical practitioners lack the training and skills necessary to manage terminally ill patients properly' (Olivier, 1998: 99).

Those authors who encourage the use of palliative care report that virtually all-unpleasant symptoms experienced during terminal illness can either be relieved or substantially alleviated by techniques already available. By spreading this message, they are suggesting that the process of dying must not be viewed as an inevitably frightening ordeal. According to them, since the suffering of terminal patients can largely be alleviated by proper treatment, the national effort should be focused on palliative care, which would then 'support (rather than destroy) the dignity of the human person, protect (rather than attack) life and promote (rather than negate) the value of humanity' (Olivier, 1998: 98-99).

Whereas a 'good death' is natural, a 'wild death' is unnatural, inhumane, shameful and solitary. External factors such as advanced technology or incurable diseases such as AIDS may bring on a 'wild death'. O'Gorman (1999: 4) termed this 'wild death' a clinical death. A clinical death occurs when the doctor's role is placed at the centre stage of a dying person. A doctor here takes over the life of another person. This is so because of the myth that doctors have power over death. A person dying a 'wild death' is mostly isolated in a particular institution waiting to die, asserts O'Gorman (1999: 4). A person in this kind of a death has no social support and his process of socialisation is prematurely terminated. This brings about stress, fears and

anxieties in the dying person, which is a reason why a ‘wild death’ is considered an unhealthy way of dying.

The concern with the sociology of dying and death is to try to bring a ‘good death’ back into the picture. A ‘good death’ is regarded as a thing of the past, principally because of the use of technology.

In days gone by, death was a family experience . . . people usually died at homes attended by family members and friends of long acquaintance. At the moment of death, these intimate associates were often present, providing comforting care, exchanging meaningful words and then observing the termination of breathing and the total relaxation of the body. In striking contrast, death in the contemporary urban setting now occurs primarily in hospitals and other medical facilities. Only rarely are family members and friends present during the final moments of life (Lofland, 1975: 15).

Any literature that discusses issues of death and dying provides different characteristics that help to identify both ‘wild’ and ‘good death’. This study is an investigation of a ‘good death’, therefore, only the characteristics of a ‘good death’ will be dealt with. The next discussion explores these characteristics with the hope of giving us a better understanding of the theory of good and wild death in analysing the fears surrounding death and dying.

### **2.3. Characteristics of ‘Good Death’**

#### **2.3.1. Introduction**

There are many characteristics of a ‘good death’ explained by different authors. For the purposes of my study, I shall only concentrate on five of them: openness and communication, dignified death, place of death, death and the afterlife, and the cause of death. Attention was only given to these five characteristics because they appeared to be the most important and intensively studied ones. In the literature it is argued that all these influence the kind of death that will be experienced by the dying person. The characteristics will be discussed individually in the next section and they form the foundation of this study. The themes and questions that were used in the field were drawn from these characteristics.

### 2.3.2. Openness and Communication

Having the support of those you care about (friends and family) may lead to a 'good death'. It is important to note that 'dying is a social process guided by expectations of appropriate behaviours which delimit a range of dying trajectories, thus defining normal and abnormal dying' (Curtis, 2003: 223-224). It is the case, as Donne indicated, that 'no man is an island, that everyone is a part of the main, and that every man's death diminishes us' (quoted in Barnard, 1980: 3). Emotional support provided by both family members and friends of the dying is an essential aspect of achieving a 'good death'. The dying should have someone to talk to, someone to share their hopes and fears with, and someone to have a good time with, etc. (Emanuel and Emanuel, 1998: 116-131).

As a terminal illness progresses, family members become increasingly crucial contributors to the quality of life of the dying. This is because 'emotional support and the less technical expressions of caring assume a more important role in providing comfort and consolation' (Gonda and Raurk, 1984: 108). Even though this emotional support may not change the symptoms of illness, or may not lessen the pain, the dying will be sure to find some comfort in knowing that even in the worst times, their family and friends held their hand to the very last, and this will help them to be at peace and experience a good exit (Shane, 1998: 42-43).

Clinton also argued that in order to achieve a 'good death', the dying must be able to resolve residual conflicts and to satisfy any remaining wishes. Achieving a 'good death' in this sense means completing any 'unfinished business and making personal and social preparations to ready themselves for their final moment' (Clinton, 1999: 103). Emanuel and Emanuel tend to agree with the fact that unfinished family business may influence decisions and experiences of the dying and might even postpone death. They further indicated that 'death tends to occur after important family events, such as birthdays, or major holidays' (1998: 116-131). This is so because the dying may want to say their last words, blessing or supporting their family members and friends.

When Jim Jordan was interviewed and asked about things that would make his death a positive and a hope-filled experience, he answered by saying: 'knowing that my wife and children know how much I love them and that my life has somehow made theirs better would help' (quoted in Garry, 2003: 21-24). Cynthia Astle, one of Garry's respondents, gave the following procedures as the best for preparing oneself



to meet a 'good death': 'I am preparing for death everyday . . . I have written plans for my memorial. I have an advance directive to physicians, a medical power of attorney, and a will' (2003: 21-24).

Authors also seem to agree that having an awareness of dying is an essential step in achieving a 'good death' because 'acceptance of one's mortality is a prerequisite of one's departure if one is to die with the sense of inner freedom and without narcissism'. This means that being mentally aware involves being open about death. The dying person in a 'good death' has to resolve the unresolved socio-emotional and mental concerns prior to death (Clinton, 1999: 101). The dying needs to accept death and be able to share his or her fears, dreams, last hopes and wishes with those most loved. It should be openly known by all those surrounding the dying that the person is truly dying and probably needs their help. It is in this sense that Metcalf and Hungtington (1991) have pointed out that 'the death awareness movement have popularised the notion of openness as an element of a 'good death'' (quoted in Clinton, 1999: 101).

The idea of being open about death as a way of achieving a good death was validated by a study that was conducted in Korea that tested nurses' attitudes towards good and wild deaths. In the study, 88.5 percent of nurses interviewed believed this to be true, stating that most of their patients always felt better with themselves after discussing their terminal illness and the fact that they are dying with their family and friends (Kim and Lee, 2003: 624-637).

The above discussion clearly points out that, as far as this characteristic is concerned, a 'good death' can be attained by going through four kinds of experiences: emotional support from family members, resolution of residual conflicts, awareness and acceptance of death and by being open about one's death.

### 2.3.3. Dignified Death

Dignity is not a proxy measure along the way to a good death; it is one of its constitutive components. Dignity in this context may be divided into two parts, with both clinical and psychological problems that may be a threat to achieving a good death. By clinical problems we mean those issues relating to physical pain that causes dehumanising death (Jackson and Youngner, 1980: 331-340). Emanuel (2002: 199-200) suggests that the primary reason for promoting hospice and palliative care, dying



at home rather than in a hospital, and improving symptoms at the end of life is the believe that this will promote dignity.

Dignity may also be explained in a psychological sense. Psychological symptoms are common and a major problem for dying patients. 'More than a third of dying patients may be depressed and more than half of patients with advanced cancer feel sad, anxious, and irritable' (Emanuel and Emanuel, 1998: 116-131). Healthy people may view these individuals as being incapable of cognitive thinking, unable to make their own decisions. Because physically they are being sedated and are using life-supporting machines with tubes, and because mentally they are exhausted, they are, therefore, being robbed of their dignity. The dying process is, therefore, just another stage of life, through which each person has to live. To die with dignity, thus, means to live with dignity.

Olivier strongly illustrates this point when he suggests that 'for many people with AIDS their deaths lack the dignity which they may have had in life. Human dignity should be protected up to the moment of death' (1998: 101). Because death is 'visualised as part of the transformative process', the principle of respect for human dignity of people demands that the economy of terminally ill and the dying patients should be respected (Bloch, 1988: 11).

Syed (2003: 1047) argues that a good life is always followed by a good death. She further reports that even though a good death follows a good life, 'a good life also looks forward to a death that hopefully will be good. We need to live in light of our mortality'. It is irrelevant whether our concept of an afterlife includes a heaven with a golden gate, reincarnation, or a land of the dead. What is relevant in achieving a good and peaceful death is 'how we have lived, how we have loved, and how much trust and faith we have had in our lifetime' (Williams, 1974: 155). When Shneidman (1980: 11) argues that the most obvious way of achieving a 'good death' is by making certain of enjoying life before death snatches it from us, he does not suggest that the joy of living is bound up with beautiful houses, up-to-date cars, or even an opportunity to listen to a good string quartet. The quality of life does not mean material riches. It refers entirely to 'the moment in our lives when we were at peace with ourselves and the world we lived in' (Williams, 1974: 158). This might be the reason why bitter, resentful, money-hungry and greedy people have more difficulty in accepting death. Material things lose their value gradually as we reflect on the deeper meaning of life and death. Therefore, Williams (1974: 159) is right when he suggests

that ‘if we could stop our pursuit of more and more material things, if we could reflect for a while on what really counts, if we had the courage to think and reflect about life and death, . . . we would then be able to raise a generation that would say with peace, “I have lived and therefore I will be able to die”’.

Dhammananda (2004:1) argues that living a good life as a means of achieving a ‘good death’ may be enhanced by the way we contemplate death. His argument stems from the fact that the more we think about death, the more we contemplate it or reflect on it in a regular basis, the more we boost our ability to approach and face death in the right and peaceful way. In his article, the contemplation of death helps to relieve fear (bringing a new quality to our lives, enabling us to live our lives with higher values), enables us to die in dignity and encourages us to live a good life and die a good death (2004: 1). If we can, in life, ‘transform ourselves into completely wise and loving beings’ we can, therefore, at the moment of death, ‘work with our pure nature and become enlightened’ (Leonard, 2002: 1). Meaning that we die as we have lived.

This is what is meant by achieving a ‘good death’ through living a good life? In this context, a good and peaceful death can be defined as ‘the irreversible deterioration of the quality of life that precedes the death of a particular individual’ (Barnard, 1980: 8). People who do not follow the principle of a good life often feel guilt and remorse before death. They grieve not only for their impending death, but also for the irreversible loss of opportunity for love, faith and true living. They start living through their dying moments wishing for the impossible: ‘if only we could slip back to yesterday and craft the seasons all over again’ (Shane, 1998: 30). Their death, instead of being a peaceful experience, becomes an experience compounded by guilt, remorse and regret.

#### 2.3.4. Place of Death

A ‘good death’ may also be the one in which the dying person is given an opportunity to choose the place of death. People should not be judged according to their location of death. If the dying person chooses to die in a hospital, hospice or at home, then we should let it be.

A “good death” is a “great passing on”, which does not happen but is achieved if one can let go or renounce the “life-birth” in full consciousness, at the time and place of one’s choosing. With such things achieved, one dies in a state of dignity (Clinton, 1999: 103).

The idea of dying in a hospital or hospice in a dependent and undignified state is a very distressing thought for the dying. The dying do not wish to be a financial or physical burden on anyone, yet the options of care may be limited. Relocating the dying is a very sensitive issue, with some in favour and others being totally opposed to it. The decision to relocate should, nonetheless, rest with the person facing death. Even though the majority of the dying wish to die at home, they, however, continue to die in hospitals and hospices. When trying to explain this issue, Leming and Dickinson indicate that ‘to die at home requires substantial resources, including money, space and time, thus, the well to do are sometimes allowed to die at home because of their private control’ (1998: 132).

Many people simply cannot afford the luxury of dying at home. There are, however, advantages to dying in hospital. Not only are these better equipped to handle dying people but they also save the family from the considerable strain of having to care for a dying family member at home. Leming and Dickinson (1998: 132) showed that even with these advantages of dying at a hospital more and more of the dying still opt to be at home. In their view, terminally ill patients are usually afraid to die in hospital because they are more concerned with ‘the fears of pain, indignity, and dependency in the dying process, the fear of leaving loved ones, and the fear of not accomplishing their goals’ (1998: 132).

It is, therefore, clear that ‘the proportion of all deaths in the United States occurring in institutions has been rising steadily, at least for the last two decades and probably for much longer than that. It may now be as high as, or higher than, two-thirds of all deaths’ (Lerner, 1980: 89). It was recognised that only by facing the problems honestly could fear of death be relieved and the problems of the dying be overcome, that by controlling pain, relieving unpleasant symptoms and providing strong emotional support, death could be natural and dignified, instead of a daunting and dehumanising process (Young, 1981: 1).

In most cases, people choose hospitals because they believe that a person will die a ‘good death’ only if he is relieved from pain. This creates confusion between the meanings of a ‘good death’ and of euthanasia. The most important thing here is the

removal of anything that may expose a dying person to pain. It is believed that a dying person should be in a comfortable, alert and pain-free stage prior to death. The World Health Organisation (WHO) connects the concepts of freedom from pain and alertness by stating that:

One of the essential elements of a 'good death' is freedom from pain that dominates consciousness and [which leaves] the patient physically and mentally capable of reaching whatever goals he or she may want to achieve before death (1990: 52).

The argument is that any medical intervention given to a dying person takes away the person's right to die naturally. Therefore, medical intervention used as a way of prolonging life is rejected. Nonetheless, 'a 'good death' is one where the only medical intervention that takes place is that of pain relief, which highlights once again the importance of being free from pain and suffering' (Clinton, 1999: 101).

This may then mean that at present most patients have pain free deaths. Even so, Riley (2003: 235) argues that a significant minority do not enjoy such a death and that it is for these patients that research is needed. Therefore, Riley's hope, based on her own personal experience, is that 'a good, pain free death can be the right of everyone, so that other people do not have to go through the extreme distress suffered by my late sister-in-law, brother and their boys' (2003: 235). Syed (2003: 1047) summarises this argument very clearly when she said that 'a painless exit is an index of how moral and helpful your earthly life has been'.

It is then true that of all the aspects of dying, pain is the most studied. Validated and reliable pain assessment measures exist. Treatments such as extensive anaesthetic, pharmacological and neuroablative ensure adequate pain relief in 95 percent of cases. However, 'among dying patients, pain remains inadequately treated, with a reported frequency ranging from 20 percent to over 70 percent' (Emanuel and Emanuel, 1998: 118). Therefore, providing adequate pain control to the vast majority of patients requires better implementation of existing therapies through training of clinicians, use of guidelines, education of patients, redesign of health care systems and changes in regulations (Emanuel and Emanuel, 1998: 118). It is because of these painful stimuli that most people opt to die in a hospital rather than at their own homes.

### 2.3.5. Death and the Afterlife

‘Dying a ‘good death’ also means being spiritually prepared’ (Berfman, 1991: 17). In practical terms being spiritually prepared may be presented in two ways – firstly, from a Western or Christian perspective (fear of God, and especially of heaven and hell) and, secondly, from an African perspective (fear of ancestral powers). For the Christian, death is viewed as ‘an entrance to eternal life and, therefore, preferable to physical life. There is a strong belief in the immortality of the soul, the resurrection of the body, and a divine judgement of one’s early life after death, resulting in the eternal rewards of heaven or the punishment of hell’ (Leming and Dickinson, 1998: 151). For most authors, a ‘good death’ is one in which the dying has accepted God as his or her saviour (Bailey, 1981: 19). The argument is that it does not really matter whether a person dies of AIDS, cancer, violence, or in a car accident, for as long as they die Christians they die a ‘good death’, and obtain entry into heaven.

Hall (1915, quoted in Barnard, 1995: 14) describes religion as the greatest answer to the fears of death. It was Hall’s contention that ‘the fear of death is completely removed by religion which is observed as the most mastery of all psychotherapies’. Similarly, Burling found this to be true, as all her respondents in her study asserted that religion decreases their fears of death (1988: 37). This, of course, has been heavily criticised because the issue of the afterlife is completely subjective. There are no underlying facts that can be used to prove its existence. This might mean that the fear of the afterlife may not be a necessary prerequisite to determine the death of a person. Even so, Mashinini (1997: 56) argues that:

The involvement of the church in the healing process of AIDS suffers should not be narrowly defined as being a politically correct act of the church for it be seen as doing something constructive and beneficial to those affected by AIDS. Instead, the church should be involved in the ministry of healing because it believes that God desires for all mankind to live in its abundance.

It is true that sometimes Christians do fear death, but the whole idea of becoming a Christian, as far as dying is concerned, is to achieve a ‘good death’. Christian faith teaches people to accept death with all its devastation to earthly hopes and values, and by so doing, affirms the ultimate victory gained in Christ. The hope for Christians is the hope of the resurrection. ‘As Christ affirms his own death, so can we our death. Christ’s victory over death makes our death the climax of life, an end to

which we have been continually moving' (The American Lutheran Church, 1977: 7). Therefore, to the Christians, dying can be the summit from which one can view the totality of one's life. It doesn't necessarily have to be a fearful act.

In a more African perspective, the fear of death presents the fear of the ancestral powers. Those who do not fear the afterlife in relation to God, fear the afterlife in relation to ancestors. Ancestors are 'dead kinsfolk who are viewed as being either inactive or active in their descendants' lives. In many traditional societies active ancestors receive identity with responsibilities over various political, economic, moral and religious aspects of life, capable of blessing or cursing the living' (Howarth and Leaman, 2001: 15). Many members of African societies believe that having a good and pure relationship with their ancestors would help them to perhaps achieve a 'good death', as they will be blessed during their last days of life.

Ancestor worship (such as slaughtering of a goat for the ancestors) may then be, in African culture, a way of ensuring a strong relationship between the dead and the living, a way of eliminating ancestral curses, or a way of ensuring a peaceful departure to the next life. Howarth and Leaman further report that many traditional African societies feel the need to gather together to pay respects to their ancestors, 'one important social consequence of which was the need for harmony' (2001: 16).

In many societies, one particular world religion is the religion of that society and it is expected that members of the society adhere to that religion. Religion is in part what glues such societies together. 'The death of any one member undermines the family, the community and even (for individuals of high social status) the entire society, so it is important that death is managed according to the required religious rites, for it is these rites that glue the group together at precisely the time that it is most threatened' (Walter, 2003: 219).

Nevertheless, Emanuel and Emanuel (1998: 120) argue that these effects have been separate from the central concern of medical care, doctors have not been trained to explore spiritual and existential issues and they rarely inquire about, discuss, or address them with their patients. Consequently, despite this importance of spiritual and existential issues, there are few data on them and their relation to a 'good death'. 'It is not known what proportion of dying individuals become more religious or conversely alienated from spirituality, or what proportion receive comfort from their faith, whether this comfort is from formal interaction with a religious mentor or a more informal spirituality' (Emanuel and Emanuel, 1998: 120). As a result, there is

little information on what interventions might improve the spiritual condition of the dying.

It is also important to note that there are those who do not fear the afterlife, who do not believe in its existence, and who thus believe that they will one day die a 'good death', as they have nothing to fear. The entire issue of the afterlife, therefore, is 'a master of faith, to be adjudicated on none other than psychological or spiritual grounds, where the appropriate concern is the purpose served by one's faith as applied to particular spheres of life' (Walker, 1974: 168).

### 2.3.6. The Cause of Death

As for this theme, authors believed that a good way of dying depends on the cause of death. It is sometimes believed that a long and lingering death is more likely to be wild as compared to the one that comes suddenly. The most important thing that is argued in this connection is the difficulty of living with a terminal illness. It is often very difficult for such a person to determine the time to start dealing with death related issues. The line that separates life and death becomes very blurred for the terminally ill. 'When an individual has a life threatening illness like cancer or AIDS it is often hard for all concerned to tell when the person has made the transition from living with his/her illness to starting to die of it' (Shernoff, 1999: 45).

The other problem with a terminal illness, such as AIDS, as Machanic in *The Encyclopedia of AIDS* (1998) argues, is that the diagnosis of such diseases brings with it a social stigma. Those who are diagnosed with them face not only the typical end-of-life issues surrounding the degenerative illnesses and impending death, but also issues specific to social aspects of the disease. In addition, these issues also 'affect the grieving processes of their loved ones, who must face the impending decline and death of a partner, child, parent, or friend who also has become a person with AIDS' (Machanic, 1998: 15).

Therefore, the kind of death that will be experienced through terminal illness will be different from the one that comes suddenly. Shernoff (1999: 46) argues that, with a terminal illness, an individual might go through four processes of dying. First is the psychic process, which is death acceptance. Second, comes the sociological process, which involves the withdrawal from people and activities. Thirdly, the biological process involves the loss of those characteristics that constitute being 'human', for example, personality. Finally there is the physiological process, which



represents the failure of the body's organs. As people develop symptoms of cancer/AIDS, they increasingly lose control over their bodies and lives. They sometimes lose the respect and love of their families and friends; this is especially true for persons with AIDS, and is why AIDS patients are being hidden or isolated. Their families and friends view them as a shame to an extent that 'they wouldn't even recognise AIDS on death certificates, they would put things like "died of pneumonia or hepatitis"' (Thomas, 2000: 6).

All of these are the arguments used when analysing the cause of death as influencing the existence of a 'good death'. The question that is mostly asked is: can a person suffering from a terminal illness achieve a 'good death'? If not, are we, the public, to be blamed for that? Dixon in his book *The Truth About AIDS* (1994) attempts to answer this question. He comments:

Dying people tend to be marginalised anyway. We kid ourselves that we are caring but we are in fact rejecting. This . . . is especially so of AIDS . . . There are all the intense fears of catching a plague related to AIDS.

When you don't know what to say, the results may be either ludicrous conversation or oppressive awkward silence. Because both are uncomfortable, many people shy away from visiting someone who is near death or has been bereaved. If they do visit, the conversation is stilted and often meaningless to the ill person who finds entertaining visitors exhausting. Visiting times can become nightmares (Dixon, 1994: 61).

Does this then mean that if a 'wild death' was to occur in a terminally ill person that the community is partly to be blamed for it? As difficult as it is to answer this question, some authors, Dixon (1994), Machanic (1998), Shernoff (1999) and Thomas (2000), argue that the following, in a terminal situation, determines the kind of death to be experienced: the kind of the terminal illness, the symptoms of illness, the length of the disease, the patient's psychological being and/or the community's perceptions of that particular disease.



### 2.3.7. Conclusion

From the above discussion on the characteristics of a 'good death', it seems as if not being a burden (physically, mentally and financially) to our loved ones at the time of death is a good way to die. Being physically and mentally completely independent almost to the time of death is a wish only a few could hope to achieve. A non-lingering and quick death can also be accepted as a 'good death'. Others would certainly have applauded it for having saved them from experiencing the prolonged mental trauma of the inevitable death of someone they loved, liked or revered. Deshpande (2003: 226) asserts that not only how one dies but also when one dies is important. She further indicates that people would definitely like to see certain tasks completed before leaving this world for good. Of course, this varies according to the person's cultural and religious background. Also, being HIV positive does not help; it increases the fear of death.

However, the issue of these characteristics as being influential to a 'good death' is not as simple as it has been stated above. In some of the characteristics there exist so many contradictions. Let us take the issue of location as an example; one can see that there exist differing views. Some dying patients preferred hospital while other opted for the comforts of their own homes. There is the minority who are confused and want both. Similarly, while some dying patients believe in the existence of a 'good death' through Christianity, others, in turn, favour the ancestral world. Of course there were those who practise both spiritual beliefs because they have no idea which to choose and which is real. These are some of those differences that my empirical data is trying to resolve. Chapter 4 analyses these differing views and tries to answer the question of why they exist.

It was very difficult to do that just by analysing and reviewing the literature because as good as it might be, it is, nonetheless, US-centric and does not deal with South African issues. It was, however, useful to use it as a foundation for discussions because my study is using this 'good death' as an ideal to help to understand the real world, as we have come to know it, and because the literature provides some insight into the ongoing debates around issues of a 'good death'. Thus, the US literature reviewed for this study, is used as a base or a beginning point from which to, firstly, explain why things are the way they are in the South African context, and secondly, to try to fill in the missing gaps and, thirdly, to attempt to clarify the existing contradictions in peoples' views.

Moreover, to do all of that the study used patients who are either HIV positive or have full-blown AIDS. Why? Because for many people with HIV/AIDS, death is inherently undignified. Patients with HIV/AIDS are connected to tubes and machines; they experience pain, shortness of breath, and other excruciating symptoms. They are mostly cared for in impersonal institutions. In such circumstances, there is no way to maintain dignity in the dying process. This loss of dignity is a major concern to patients dying from AIDS and constitutes ‘one of the main motives behind efforts to improve palliative care and promote the goal of a ‘good death’’ (Emanuel, 2002: 199). Yet, one of the biggest hurdles in improving care at the end of one’s life is the vagueness surrounding the definition of the concept of a ‘good death’. It is for that reason that this dissertation concentrates on studying a ‘good death’ as a consequence of AIDS. Therefore, the section below is a discussion on ‘good’ and ‘wild death’ in relation to HIV/AIDS.

## **2.4. AIDS in South Africa: Relevant Issues**

### **2.4.1. Introduction**

AIDS is the disease that has taken South Africa by storm. There is no recent historical example of any infectious disease threatening to take so many lives as the HIV/AIDS pandemic, which is the most devastating in the history of modern civilisation. Even though there is no place on earth that is untouched by this problem, the epidemic is not the same all over the world. Crewe shows that since 1990, the number of HIV infections has increased from six million to 60 million and that out of all continents, Africa has been the most affected (2002: 446). In a research report published by the Bureau of Market Research it is estimated that ‘by 2010 to 2015 there will be more deaths in the age group 15 to 34 years than there would have been in the absence of HIV/AIDS’ (2002: xiii).

In South Africa all the underlying pre-conditions exist for being amongst the worst hit countries in the world and the available evidence is already pointing in that direction. Figures released lately have shown that ‘sub-Saharan Africa has more than two-thirds of the world’s 33.4 million people who are HIV positive’, noting that South Africa is second only to India in numbers of people living with HIV/AIDS (National Population Unit, 2000: 61). To indicate just how high South Africa’s *per capita* HIV prevalence is, a report by the Bureau of Market Research indicates that by

the year 2000, adult HIV prevalence was below 25 percent while the HIV prevalence for the whole population was estimated to be 11 percent. Put differently, it estimates that 4.7 million were HIV positive in 2001 with about 5.3 million people being HIV positive by 2002 (2002: xiii).

Forbes (2004b: 1) argues that AIDS is worse in sub-Saharan Africa than anywhere else in the world partly because 'of denial', partly because 'the virus almost certainly originated here, giving it more time to spread', but also because 'Africa was weakened by 500 years of slavery and colonialism and now has many corrupt and autocratic governments, which hoard resources that could fight the epidemic'.

It is important to analyse the above given incidence and prevalence rates with a critical eye. To calculate the country's infection rate, South Africa has, in the past, relied on two records: AIDS case data and HIV data. This is where the above discussed infection rates comes from. We cannot objectively rely on information drawn from these data sets. The problem with AIDS case data is that we have to wait for a case to be reported before recording it and including it in the country's infection rate. The problem is that most AIDS cases are not officially recorded. Sometimes reporting may be very slow, or data may be inaccurate, and sometimes AIDS may not be the condition diagnosed (Whiteside and Sunter, 2000: 30). Relying on HIV data is also problematic in South Africa because information is drawn from surveys of specific groups. In the early years of the epidemic they included blood donors, sexually transmitted disease (STD) clinic attendees, people with tuberculosis (TB) and women attending antenatal clinics. Today, the most consistent data comes from the antenatal clinic surveys. An obvious drawback of this method is that 'it applies solely to women attending antenatal clinics. It does not cover the general population' (Whiteside and Sunter, 2000: 34).

Clearly, in South Africa a better method of assessing the HIV status of the general population would be to sample it directly. This is why Shisana and Simbayi's study (2002) can be viewed as the most important social research on AIDS to date, as it is the first systematically sampled national community-based survey of the prevalence of HIV in the country. Even so, the study has its own flaws. It raises concerns relating to representivity and response rate (see Alexander and Uys, 2002). Before discussing HIV/AIDS in relation to 'good death', it is important to try to understand its origins, the way it works and the reasons why the disease is so stigmatised.

#### 2.4.2. Defining HIV, AIDS, and Stigma

The diseases pneumocystis carmine pneumonia and Kaposi's sarcoma both have common biological and social factors. They are both opportunistic infections and they both appear to have manifested in young gay or bisexual men. The shared condition was hypothesised and was first known as gay related immunodeficiency syndrome (Howarth and Leaman, 2001: 5). After this condition appeared in haemophiliacs, recipients of blood transfusion, donated organs, and injected drug users, it was modified to acquired immunodeficiency syndrome (AIDS). The first two cases in South Africa were diagnosed in 1982 (Shell, 2000: 10). By 1984, Luc Montagnier of the Pasteur Institute in France and Robert Gallo of the National Institute of Health in the US had identified a virus responsible for the immunodeficiency. The first recorded South African death occurred in 1985. This virus was finally named human immunodeficiency virus (HIV) in 1986 (Howarth and Leaman, 2001: 5).

Understanding how HIV and AIDS works is very important in any AIDS discussion. It is very difficult to trace the origin of the human immunodeficiency virus because it changes its form. HIV will attach itself to the CD4 cells of the human body. When it enters the CD4 cells, it copies the structure of ribonucleic acid (RNA) so as to gain access into the cells nucleus. When the virus enters the nucleus, it changes its form and becomes a deoxyribonucleic acid (DNA). Because HIV ends up looking like a DNA, it becomes impossible to trace (Zeller and Swanson, 2000: 75-86). This is the reason why it cannot be detected immediately in human blood, and why a window period (where a person is tested twice to ensure infection) in HIV testing is very necessary.

A debate around the origin of AIDS has sparked considerable interest and controversy since the beginning of the epidemic. The most dominant debate around the origin of AIDS states that HIV-1 and HIV-2 are basically identical to a group of simian immunodeficiency viruses (SIVs) found in Africa. According to this theory, HIV is a disease that has crossed the animal species (specifically Sooty Mangabey monkeys), meaning that SIV is naturally a chimpanzees' disease that was transmitted into the human species. Among animals, the virus does no harm, but when it enters the human blood, it becomes a killer disease (Whiteside and Sunter, 2000: 4-7). This theory suggests that a certain hunter in Africa was butchering monkeys, became infected with the virus and travelled around the world infecting other people. Even though the theory is very popular and is used in almost all research, it is nevertheless,

untrue. This theory was, however, validated by the fact that ‘Sooty Mangabeys are resident in the same region of West Africa in which HIV-2 is most prevalent’ (Forbes, 2004c: 1). The fact of the matter is that we do not know the origin of HIV and all the other suggested origins including this one are nothing but myths.

AIDS is a different stage to HIV which is why it is always a mistake to combine the two stages (for example: HIV/AIDS). AIDS can be seen as an advanced stage of HIV, where the immunodeficiency syndrome has become acquired. To define AIDS it helps to break it down into small pieces. Whiteside and Sunter (2000: 1) give a very good explanation. In their view, ‘A’ standing for acquired, means that the virus is not spread through casual contact; a person has to do something or have something done to them in order to be infected. ‘I’ and ‘D’ standing for Immunodeficiency, mean that the virus attacks the immune system of the person making it deficient in its ability to fight disease. ‘S’ standing for syndrome means that AIDS is not one disease but a number of different diseases. People who die of AIDS do not die of AIDS itself, but die of HIV plus opportunistic infections (such as TB, Kaposi’s sarcoma, pneumonia etc) plus stress. In an HIV stage, a person suffers no physical illness and the lifespan is usually five to ten years. In an AIDS stage there is physical evidence of illness and the lifespan is, in most cases, two to four years, especially in developing countries.

People living with HIV/AIDS (PLWHAs) go through four phases of illness. The first is commonly known as the window phase, where there are no symptoms and where a person, if tested for HIV, may show a false negative due to the fact that the antibodies against HIV have not yet been developed. This period may last from four to six months. The second phase is known as the latent phase, where a person tests positive for HIV, but shows no symptoms. This period lasts for about five to ten years. The third phase is the symptomatic period where an HIV-positive person starts suffering from opportunistic infections and here hospitalisation is possible. The person may still be able to perform both mental and physical work. The phase may last from two to four years depending on the health and treatment of the person. The final phase is known as the phase of full-blown AIDS. In this phase a person will experience opportunistic infections, one or more of which may ultimately be the direct cause of death. A person here may suffer for about two years before death (Ngwena, 2000: 98 - 99).

Usually, a normal (HIV negative) person will have 800-1,000 CD4 cells, which drops to 300-500 if the person becomes infected with HIV, and to 100-300 on entering the AIDS stage. Managing the viral load and stress gives an HIV-positive person a better chance of surviving. If the CD4 count is higher, the viral load and stress of an HIV-positive person will be lower. Reducing stress is very important for an infected person (Zeller and Swanson, 2000: 75-86).

The world's response to AIDS is structured by the politics of inequality, poverty and oppression. However, it is an epidemic that also engages with the nature of expertise, the capacities of science and the responsibilities of the individual. Howarth and Leaman suggest that AIDS in sub-Saharan Africa is about social as well as individual survival. Overall, it is an epidemic that allows us to interrogate how we could and sometimes do – but often do not – take responsibility for ourselves and for our neighbours (2001: 7).

HIV/AIDS is the most highly stigmatised disease of all times. Loneliness and depression are already recognised as the twin companions of PLWHAs. The history of this epidemic is a history of 'exclusions, panics, fears and denials' (Silin, 1995: 13). Because of its stigma, people do not want to discuss it. This silence is fueled by 'fear of being sick and unable to work and of ridicule and isolation from an already desperate and unstable community' (Meeson, 2000: 44). There is also the problem of other people in the community talking. People are afraid of gossip, of being the joke of the town, and of being isolated. AIDS, due to its modes of transmission and undesirable symptoms of illness, is viewed as a sin. HIV negative individuals do not want to be associated with those infected. Because they view AIDS as an enemy they automatically view the carrier as such. Even some of the doctors, nurses and caregivers do not want to be associated with the disease. One nurse who has cared for an AIDS patient reported that: 'I don't think we should have bothered in the first place. He deserved what he got. It's not one's fault but his. And I don't see why we should have to take care of him' (Nicolson, 1996: 26). This powerfully illustrates the level of stigma on this disease. The next section will try to analyse this disease in association with the concept of a 'good death'.

### 2.4.3. Death Due to AIDS

It is very difficult to associate AIDS with a 'good death' due to its association with many things that oppose everything a 'good death' stands for. Teguis and Ahmed report that AIDS deaths cannot be viewed as good because of the numerous major losses that are associated with the disease (ranging from the loss of financial security to loss of former lifestyles) (1992: 12-15). Sims and Moss also argued that with the diagnosis of AIDS comes loss of control, dignity, body image and future, 'rejection, isolation and guilt may compound the feeling that the person is useless, hence their self-esteem is lost' (1991: 12).

Howarth and Leaman argue that the fear of AIDS is further increased by the unpleasant and disturbing 'insidious pathological process of the body's own cells turning against it, expanding and eating away at normal structures'. They further argue that the side effects of AIDS treatment, such as nausea and vomiting, are widely known and feared (2001: 72). But most of all it is the fear of pain and symptoms, suffering and death, which have given AIDS such a bad name. Thus, AIDS, loss and death are strongly linked. The word AIDS strikes fear into the hearts of people and HIV diagnosis is widely regarded as a death sentence, despite advances in both detection and treatment.

It may also be argued that an AIDS death can be explained as wild because of the disease's social consequences, such as stigmatisation and avoidance. This disease is one of the many stigmatised diseases that result in multiple problems upon diagnosis. According to Sellin, Faltz and Davis the first set of difficulties is 'the physical and emotional sequelae resulting from HIV infection'. Additionally, 'trauma often strikes patients because of societal attitudes towards behaviours correlated with risk for HIV infection' (1992: 19). These attitudes can result in discrimination in housing, employment and access to health care. As Shaw (1992: 99) puts it, 'AIDS seems to be equated with sin requiring retribution and punishment'.

The fear that is also generated by death from AIDS is also due to the fact that PLWHAs are not viewed as human beings but rather as statistics. McCarroll (quoted in Teguis and Ahmed, 1992: 12) points out the importance of not viewing PLWHAs as statistics, but as persons deserving of compassion and love. To illustrate his point, he uses the example of a one-year-old boy named Aaron, who died of AIDS at that tender age, stating that:



Aaron was not a statistic. He was recognised and respected as a unique human being. In learning to live and to die, Aaron was encouraged by a loving extended family . . . Aaron was not defined as a pitiful product of a dirty IV drug needle. He was a person. He lived; he died, and will be remembered as a person. Until his death, we did not see clearly that our function, perhaps our assignment, in a war against AIDS is to see that as many babies as possible are given a chance to be people instead of a statistic (1992: 12).

Because we view AIDS as an enemy in a war that seems incapable of being won, our rage against this epidemic is, then, directed to those people suffering from it. Teguis asserts that the ‘danger in addressing any threat to our sense of inner security as a “war” is that we tend to blur distinctions between our rage at the disease or the epidemic or our displaced anger at those who suffer from it, ultimately regarding them as “the enemy”’ (1992: 161).

Coming to terms with death must be painful even for those who have lived a full life, but it must be so much more difficult for the many young and not-so-old people with AIDS. A ‘good death’ stresses the fact that patients need freedom from isolation, rejection, guilt, pain and fear. The isolation felt by people with AIDS is probably something that makes it difficult for these people to achieve a ‘good death’. Because AIDS seem to be conflicting with every characteristic of a ‘good death’, it makes for an interesting investigation. What makes this research unique is the fact that it does not study just anyone who is afflicted with this condition, but concentrates only on mineworkers who are HIV positive or have full-blown AIDS. The reasons for this are discussed below.

#### 2.4.4. Mineworkers and HIV/AIDS

Mineworkers were selected for this case study because of the strong correlation that exists between them and HIV infections in South Africa. This correlation is not a South African problem alone but a global issue. Decosas and Kane (1995: 2), for example, studied migration in Uganda and their data analysis indicates this strong correlation between HIV and migrant labourers. Similarly, Manuel and Aditi (2001: 4) report a high correlation between migrant labourers, STDs (sexually transmitted diseases) and HIV in European countries such as Belgium, Sweden and Germany. There are many different reasons given by many different writers for the escalating



rate of HIV infections among mineworkers, but only a few will be briefly discussed in order to give the reader some idea.

The use of the single sex hostel in the mines is one of the contributing factors in the high and escalating rate of HIV infections among mineworkers. Even though there were married quarters in the past, Lurie (2000: 344) indicates that 'in 1993, 89% of miners still lived in single sex hostels and only 2.1 percent occupied housing for married couples'. Sexual intercourse is the main mode of HIV transmission among mineworkers. A single sex hostel forces miners to live on their own, spending about six months at a time without seeing their families; thus access to sex becomes a major problem (Fassil, 1998: 3 and Moodie and Ndatshe, 1994: 119). The majority of miners in single sex hostels will complain about the high levels of boredom and loneliness. They crave female company and intimacy. As one miner puts it, 'you cannot call yourself a man if there is no woman involved' (Macheke and Campbell, 1998: 8).

Lack of knowledge that exists among mineworkers is viewed as one of the contributing factors in increasing HIV infections. Macheke and Campbell (1998: 4) indicate that in the gold mines 90 percent of miners believe that AIDS does exist, showing that there is great awareness of AIDS. The problem is with knowledge, the knowledge to protect one's self against AIDS. This lack of knowledge amongst the mineworkers also brings problems regarding available treatment. In the last year (2003) there has been a great growing commitment, by the Chamber of Mines, to providing anti-retroviral treatment (ART) to workers with HIV/AIDS. This commitment will 'ensure that miners continue to be treated after they have left the company's employ and it will also guarantee that the dependants of infected miners are treated' (Spicer, 2003: 22). A pilot study is already about to be implemented. To date, only 39 platinum miners are on the treatment. However, because of the lack of knowledge that exists amongst the mineworkers, clinicians have reported that 'poor education would lead to poor compliance which would, in turn, lead to drug resistance' (Spicer, 2003: 22). Even so, Dr Petra Kruger, Anglo Gold HIV/AIDS Manager, believes that this problem can and has been reduced by adequate counselling and training of mineworkers (quoted in Spicer, 2003: 22).

The working and living conditions of mineworkers are both physically unhealthy and psychologically stressful. They operate under very strenuous working conditions – extreme heat, long working hours, dangerous conditions, etc. In this

extremely strenuous working environment, mine workers will always be vulnerable to HIV infections, as their conditions force them to be more pleasure than safety orientated. According to mineworkers, HIV is nothing compared to the dangers they face in a day-to-day working life. They justify sleeping around with different women as being a positive payment for all the hard work they perform underground (Macheke and Campbell, 1998: 10).

The other problem with high HIV infection rates on the mines is related to prostitution. We cannot avoid prostitution today because an increasing number of women are slowly but surely being driven towards it, not because they want to but because they use this act as 'a means of earning a living for themselves and their children' (Cruz-Grote, 1996: 3). The majority of the mineworkers who reside in the mine hostels use the services provided by commercial sex workers (CSWs). This is not ideal and it increases HIV infections in the mines, with both groups viewed as highly vulnerable and with a very low level of education. One researcher found that 'average completed school level was less than standard seven for both central city and suburban sex workers' (Varga, 2001: 354).

It is, however, important to note that prostitution and promiscuity as such do not spread HIV; unsafe intercourse (that is unprotected sexual intercourse) does. Knoll (1995: 78) argues that 'by concentrating on high risk groups rather than high risk behaviour, persons who practice safe sex are at risk of being hit by coercive measures while those from the ordinary heterosexual majority who do not, go scot-free'. Knoll maintains that 'critics of the present position propose that criminal sanctions aimed at sexual acts between members of the same sex and at commercial sex workers should be abolished' (1995: 78).

Even though there have been efforts in trying to extend the educational level of both CSWs and mineworkers through peer education programmes (Campbell and Mozaidume, 2001: 1-18), it is nonetheless important to note that the problem with high HIV infection rates on the mines has not lessened. Bernard Swanepoel calculates that last year (2003), in the hostels alone, there was a 30% infection rate among the mineworkers, which means that about 15,000 of the 50,000 employees were infected (quoted in Spicer, 2003: 23).

Finally, mineworkers are very fond of traditional healers. The majority do not trust western doctors and their modern medication. Most of them, experiencing sexually related diseases, such as chlamydia, or STDs, do not seek treatment from

western doctors, but approach traditional healers for treatment. This can be clearly seen from the study that was conducted by Catherine Campbell among mineworkers. The quote below, taken from Campbell's study, demonstrates mineworkers' strong belief in traditional healers:

The doctor's role is that he will give you instant relief with his injection. Thereafter the *inyanga's* procedure must take place over a longer period. Firstly, you have to vomit after taking the emetic, then the healer will administer an enema, then you will take a steaming session to produce excessive sweat, and finally the healer will make incisions in your pubic area. All this process is some kind of cleansing of your reproductive system, and this gets rid of the 'eggs' that have caused the problem (Campbell, 2003: 27).

Not to say that there is something wrong with receiving treatment from traditional healers, but most of these healers are illiterate and cannot successfully deal with HIV/AIDS related matters. Even though the South African government has now started a project of bringing traditional healers and western doctors together, we cannot, however, overlook the fact that the project is still at its initial stage and we cannot be too certain of how knowledgeable these traditional healers have become as a result. Besides, not all traditional healers are part of this project and we do not know which traditional healers these mineworkers visit.

The discussion here generally indicates that mineworkers, as in Campbell's case study, prove to be an important group in investigating the phenomenon of 'good death' in relation to HIV/AIDS. Reviewing this discussion was important as it prepared this researcher for empirical research and it gave her a better understanding of the working conditions and lives of mineworkers.

There have, however, been some authors that tried to deal with the existing gap in South African literature on issues of death and AIDS, but most of them did not concentrate on AIDS and death in the mines. Even Dworzanowski's research on 'Caring for People Dying of AIDS: Lessons Learned from Hospices' did not specifically concentrate on mineworkers dying of AIDS (Dworzanowski, 2002: 420-431). This is the gap my research is trying to bridge, analysing death and dying ('good death' to be more precise) from the mineworkers' perspective. This will, in a unique way, illustrate a South African viewpoint of a 'good death' as a consequence of AIDS, and it will also show how this view differs from that of the North.

## 2.5. Conclusion

In conclusion, one can see that the concept of a ‘good death’ has undergone lots of debates over the years. Defining a ‘good death’ has been a tricky task for all the authors. Its definition has depended on the place and time of death. Thus, the definition of this concept of a ‘good death’ is not a stable one. It changes with time. Nowadays, ‘good death’ seems to be explained in terms of hospital and hospice care. Some authors say that the use of hospitals and hospices is a threat to the existence of the ‘good death’, while others argue the opposite (that hospitals and hospices lead to a ‘good death’).

The main reason why this dissertation focuses on reviewing this topic in relation to HIV/AIDS is because of the argument that to achieve a ‘good death’ one needs to be free of pain and suffering. With this kind of disease it is very difficult to reach this ‘pain-free’ state of death. The dissertation mainly seeks to highlight the difficulties suffered by AIDS patients and to determine whether these patients can ever be able to achieve a ‘good death’.

The next chapter, then, will try to explain how miners with HIV/AIDS were selected for this research. The investigation of this phenomenon was done in a form of developing themes that needed to be explored in the fieldwork. The themes were based on information that was gathered from these discussions on ‘good death’, more specifically, from the characteristics of a ‘good death’. These characteristics are the most important part of this research and were used as a base from which to judge the reality. The characteristics were not only used to construct themes but they were also developed to build research questions that were used to gather information in the field. As indicated in the introduction, the themes mainly tried to answer the main research question of this study, i.e. can people who are dying from AIDS have a ‘good death’?

## CHAPTER 3

### METHODOLOGY

#### 3.1. Introduction

This chapter provides a detailed exposition of the research design utilised in this study. It begins by explaining the reasons why this study was conducted in the form of a case study. It goes on to discuss the sampling methods used, the ways in which data was collected and analysed, the place where the interviews took place, and the ethical procedures that were followed.

#### 3.2. Case Study

As indicated in the previous chapter, the methodology used for this research project was the case study. Case studies are an important strand in social research. For numerous researchers, case studies are employed in the analysis of quantitative and, more commonly, qualitative data. They can be used at a number of different levels or scales of social life, varying from individuals through families, workplaces, occupations and formal organisations (such as schools and hospitals) to nations and states. With a case study, one can connect the actions of individual people to large-scale social structures and processes, and can demonstrate an argument about how general social forces shape and produce results in particular settings. Case studies are ‘likely to produce the best theory’ (Neuman, 2000: 33). Welman and Kruger (1999: 21) formally define a case study as ‘an empirical enquiry that investigates a contemporary phenomenon within its real life context, especially if the boundaries between phenomenon and context are not clearly evident. A case study is, then, an intensive study of a specific individual or specific context’.

A group of HIV-positive mineworkers on the Rustenburg platinum mines is used as a case study in this research. There are many mines in Rustenburg that produce platinum; but this research focused only on Impala Platinum Mines. This mine has its primary operations concentrated on the Impala lease area on the western limb of the bushveld complex, near the towns of Phokeng and Rustenburg in South

Africa's North West Province. It is reported that in the past decade Impala transformed itself from one of the highest to one of the lowest cost primary platinum group metals (PGM) producers in the world. These PGMs are composed of palladium, rhodium, iridium and ruthenium (Ralushai, 2003: 29). All in all, Impala holds mining leases covering approximately 25,000 hectares to the north west of Rustenburg (Implats, 2002a: 1).

The Royal Bafokeng Nation (RBN) owns mineral rights within the lease area. A landmark agreement, which secures Impala's access to these mineral rights, was signed with the RBN in February 1999. In terms of the agreement, the RBN not only enjoys royalties from metals obtained from areas over which they hold the mineral rights, but has also become a major shareholder in the company, with board representation by the head of the nation, Kgosi Leruo Molotlegi (Implats, 2002a: 1). The RBN is a vital part of the Impala Platinum Mines, which is one of the reasons why the majority of my respondents were not hostel dwellers but residents of Phokeng village.

I have already, at the beginning of the dissertation, indicated the challenging working and living conditions of mineworkers that exposes them to HIV infections. Impala Platinum Mines acknowledged those challenging conditions, part of the reason why they prioritise safety in the mines. In Impala, external safety experts have been employed to assist with the implementation of a behaviour-based safety management system that is aimed at ensuring the constant monitoring of conditions and equipment by employees (Implats, 2002a: 2). In line with this, a set of safety rules, called the Five Platinum Rules, have been introduced for each operating division, along with a programme of behavioural monitoring for both management and employees.

In addition to all this, the Impala mine has its own HIV/AIDS Department, which is overseen by a collaborative union/management committee that has two principle aims – to prevent the transmission of HIV among employees and to manage the effects of HIV/AIDS on infected employees and on the company (Implats, 2002b: 1). The HIV/AIDS committee, which meets monthly, is guided by an agreed policy based on the principles of the World Health Organisation and the International Labour Organisation. The policy provides for:

HIV testing, the confidentiality and privacy of those who are HIV positive, HIV/AIDS education programmes, the management care and counselling for employees with HIV/AIDS, Allied employee benefits, ensure the rights of employees with HIV are protected and respected, and provide guidelines on managing the disease in the workplace (Implats, 2002b: 1).

Impala has been conducting extensive HIV/AIDS education programmes among its employees since the early 1990s. Research conducted by an independent company has shown that current employees have a high level of awareness and understanding of HIV/AIDS and the means of transmission, and have mostly modified their behaviour as a result. The emphasis has, thus, shifted to the education of new employees. In addition, Impala has extended its HIV/AIDS programme to include neighbouring communities in informal settlements. This is being done in partnership with other companies, the Department of Health, youths, community groups, and local churches (Implats, 2002b: 1-2). Also, traditional healers practising in communities surrounding Impala's operations have become an integral part of the education and wellness management programme, as have commercial sex workers who are provided with education, condoms and access to treatment for sexually transmitted diseases (Implats, 2002b: 2).

Impala has implemented a wellness programme to manage the effects of the disease on infected employees and to provide them with care and counselling to extend their healthy, comfortable and productive lives. Medical care is provided by Impala's medical services. The programmes available to infected employees are provided on a completely confidential basis (Implats, 2002b: 2).

Impala has also conducted an anonymous survey of employees that confirmed existing medical statistics indicating a prevalence rate of 16 percent. This, together with statistics gathered at an operational level over the past 18 months, 'confirms a leveling off of infection levels at 16 percent, which is much lower than was originally expected and is also significantly lower than both the national prevalence rate of 24 percent and the reported industry rate of 30 percent' (Implats, 2002b: 3). All this information shows how important and relevant it was to select the HIV-positive mineworkers of Impala Mine as case study. The next section will explain how these mineworkers were selected to be a part of the study.

### **3.3. Sampling Methods**

My methods here were ethnographic as they gave description of death and AIDS, in concrete circumstances. My research was purely qualitative and I used the snowball sampling technique. I used a strictly qualitative approach because, firstly, I wanted to be able to record and understand people in their own terms, and secondly, because ‘data tend to be collected in the field by people engaging in and observing natural, ordinary, everyday behaviour’. Lastly, qualitative methods helped me generate richly detailed data about the group that was studied and also assisted me to provide a contextual understanding (Baumgartner and Strong, 1994: 177).

It was impossible for me to list all the HIV-positive miners and sample randomly from the list. This is the main reason for choosing the snowball technique. When I went to the mines to conduct my research, I knew no HIV-positive mineworker. I had to rely on my informant, who is an employee of the Impala Mines, to supply me with respondents. He selected respondents using his own judgment and I interviewed some while he interviewed others. The snowball technique began when the already selected respondents that were drawn by relying on the informant’s judgment were asked to nominate others. Some nominated two or three people, while others refused, claiming that the people they knew preferred to keep their status confidential. Each of the later nominees, who responded positively, was also asked to identify others and in this way my sample size rapidly expanded. The sensitive nature of this research topic also directed me to use the snowball technique; as Goldenberg argues, snowballs are best used for sensitive research topics (1992: 162-163).

### **3.4. Data Collection, Analysis and Interpretation**

Data collection was conducted through a system of one-on-one and group interviews. One-on-one interviews offer important advantages. Because the interviewer has the ability to ‘notice and correct the respondents’ misunderstandings, to probe inadequate or vague responses and to answer questions and allay concerns’, complete and meaningful data can be obtained (Judd, Smith and Kidder, 1991: 218). In a group interview, the researcher can get different opinions from different people at precisely the same time. When I conducted my group interview, to which I did not set any time limit, I underestimated the length which such an interview could take. This interview



lasted from 10:30 am to 12:40 pm (lunchtime). This additional length permitted my extensive in-depth questioning about complex and multifaceted issues. It is important to note that none of my interviews, either one-on-one or in the form of a group interview, had a time limit. Respondents could express themselves at length.

For the majority of my respondents, a semi-structured interview guide was followed. An example of my questions can be viewed in Appendix A. Burns (2000: 424) defines semi-structured interviews as ‘repeated face-to-face encounters between the researcher and respondents directed towards understanding informants’ perspectives on their lives, experiences or situations as expressed in their own words’. Questions about sexual practices pose serious problems and were viewed as threatening by some respondents. The basis on which valid responses to all sensitive questions depend is, however, the interviewer’s rapport with respondents. For example, I spent half an hour with my group interview trying to explain the purpose of my research and trying to answer their questions as fully and in as detailed a manner as possible. My interview with the group was programmed to start at 10:00 am, but because of the necessary explanations, the actual interviewing only began at 10:30 am.

Where possible, a tape recorder was used, with permission from respondents, together with a notebook for helping me to record non-verbal communication. For some respondents, both approaches were unacceptable. These respondents claimed that the use of a tape recorder and a notebook were too intimidating for them. To respect their wishes, I only talked to them without noting things down or saving information on a tape recorder. I was afraid that if I forced the issue of tape recording or note taking, respondents might not be open or totally truthful with me. After all, ‘a sufficiently experienced or skilled interviewer should be able to just talk to people, and then write everything after the interview is over and the subject is no longer present’ (Baumgartner and Strong, 1994: 137).

Twenty-five respondents were interviewed. Twelve of these agreed to use both the tape recorder and a notebook, five refused to use a tape recorder but allowed me to take notes, and three of these 25 respondents were involved in informal interviewing where no tape recorder, notebook and semi-structured interview guide were used. For these three, notes were written immediately after the informal interview was over and the respondents were no longer present. The last five were brought together to form a

group interview where a tape recorder, notebook and a semi-structured interview guide were used.

Where it appeared as if a certain question did not obtain any reaction from a respondent, an improved formulation was sought. If the question still failed to evoke a response, that question was discarded. The questions were formulated in a non-suggestive manner. Non-verbal communications were registered on the spot, so as to prevent any distortion by a later notation.

Collecting data from respondents was not my responsibility alone. It was shared with my research assistant, Mr Webster Diale, head of the HIV/AIDS Department of Impala. Diale was a gatekeeper as well as my key informant and research assistant. He has worked for several years with these respondents and is trusted by them. He is in his early 40s and he can speak all three languages that the respondents used. Diale is also in touch with the surrounding traditional healers, which seems to please those he works with. It was not only advisable and informative to use him as a key informant and research assistant, but it was also necessary. Without Diale I would never have gained access to mineworkers with HIV/AIDS. Below is a photograph of him with the researcher (myself), taken during one of the field visits to the Impala Mine clinic.

**Photograph 1. Mr Webster Diale and Ms Prudence Makhura**



*Source: Makhura, 2004*

There were no significant differences in the research data that was collected by me and the data collected by Diale. After the collection of data, the five themes that were discussed in the theory chapter and used as an entry into the fieldwork, were reconstructed for the purpose of analysis. The new, improved formulation of these themes is indicated in the next chapter, Chapter 4, and they were the ones that were used for analysis. The interpretation of this data is dealt with in Chapter 5. Therefore, the process entailed the formulation of themes based on the literature that was reviewed, the development of research questions that were used in the form of an interview guide, the collection of data from the field, the sorting of information into different, new, and improved themes (data analysis), the development of patterns by searching for similarities and differences (data interpretation), and lastly the writing of a report.

### **3.5. Interview Setting**

The group interviews I conducted took place at the Impala Mine hospital in the HIV/AIDS Department. Diale's interviews took place at the Impala Mine in his own office and some he conducted in the mine hostels. Impala has both the clinic and a hospital for its workers and their families. Impala miners who fall sick are not treated anywhere else in Rustenburg except at the mine hospital or clinic. The Impala hospital is very big. Each ward consists of six beds. Their wards are very hygienic and clean. The photographs below show an example of a ward and of one of the bathrooms found in each.

**Photograph 2. Impala Mine, hospital ward**



*Source: Makhura, 2004*

**Photograph 3. Impala Mine, hospital bathroom**



*Source: Makhura, 2004*

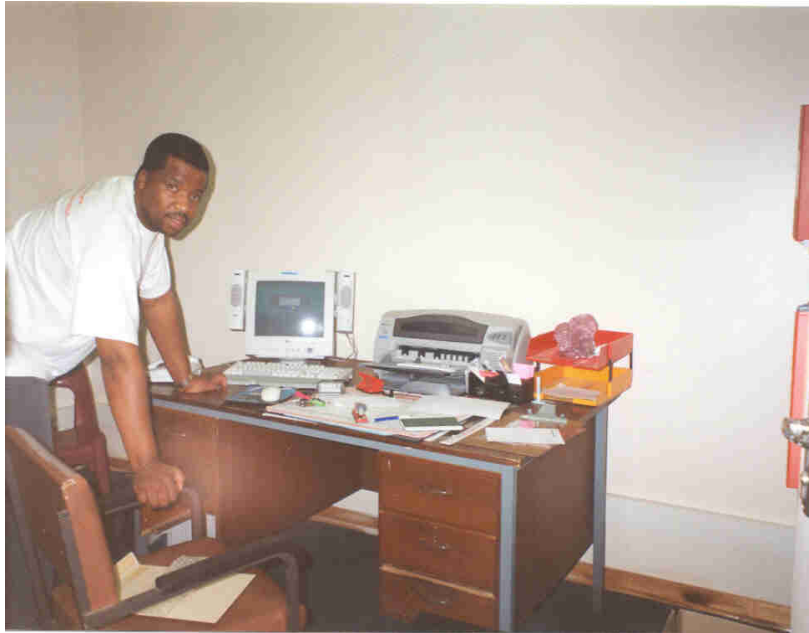
The HIV/AIDS department of Impala is also very big. Each HIV/AIDS counsellor, coordinator or peer educator has his/her own office with electricity, computers, telephones and everything else that is needed to run the office. They are located just between the hospital and the mine's human resource department. Diale's office, where some of the interviews took place, is also situated in these offices. See the photographs below.

**Photograph 4. Impala's HIV/AIDS department**



*Source: Makhura, 2004*

**Photograph 5. Mr Diale's office**



*Source: Makhura, 2004*

Diale interviewed some of the respondents in the mine hostel. Below is a photograph that shows the outside of Number 2 Hostel and the inside of one of the hostel rooms in which one of my participants was interviewed.

**Photograph 6. The outside of Number 2 Hostel**





*Source: Makhura, 2004*

**Photograph 7. The inside of one of the hostel rooms**



*Source: Makhura, 2004*

My remaining respondents preferred to be interviewed at their private homes. These were located at Phokeng, Luka, Lefaragatla and Freedom Park. Members of the Bafokeng, a Batswana ethnic group, mainly populate Phokeng. It is one of the richest villages to be found in Rustenburg. Its wealth is principally due to the fact that the Bafokeng nation is a major shareholder in the platinum mines. Phokeng has its own schools, police stations, clinics, churches, a large shopping complex and a very big stadium (named the Royal Bafokeng Stadium). See the photographs below for examples of some of these buildings.

**Photograph 8. Phokeng Shopping Complex**



*Source: Makhura, 2004*

**Photograph 9. The Royal Bafokeng Stadium**



*Source: Makhura, 2004*

Luka is also composed of Bafokeng people. The only major difference between Phokeng and Luka is that the residents of the latter do not have an area where they hold mineral rights. Seen from a distance, Phokeng looks much richer, more civilised and prettier than Luka.

Lefaragattha is completely different from these two villages. The village is poor, isolated, and the residents struggle to obtain different services (e.g. a police station). It does, however, have strong houses, built with bricks. The residents' basic needs are being catered for. They enjoy the benefits of electricity, running water, and convenient roads. The village is also composed of the Bafokeng, even though some ethnic groups, such as the Bakgattha, are beginning to settle there. It is situated 14 km south of the Impala mines (see photograph below).

**Photograph 10. A house in Lefaragattha village**



*Source: Makhura, 2004*

Freedom Park is an informal settlement situated 8 km east of the Impala mines. The only existing relationship between this informal settlement and Impala is that some of the mineworkers stay at the settlement with their families. The settlement is mostly populated by Tswana, Pedi, Sotho and Nguni speakers. It is composed mainly of shacks. It does not have running water or sanitation, let alone schools, convenient roads and clinics. Below is a photograph showing Freedom Park.

**Photograph 11. One of the shacks in Freedom Park**



*Source: Makhura, 2004*

### **3.6. Ethical Considerations**

One of the main lessons learned from this project was that researchers must be honest and open about their intentions, and must be constantly alert to the feelings of the respondents. Being trusted by the gatekeeper did not ensure acceptance by the respondents. Again and again people challenged my presence and tested my intentions to 'see if I was for real'. As this study is on human beings, their consciousness and actions in relation to the phenomenon of AIDS, some ethical issues were considered before, during and after the research. Voluntary verbal consent to participation was secured from the participants prior to the interviews. Sensitivity to, and empathy with



HIV-positive mineworkers' rights, privacy, self-esteem, emotions, beliefs, values and actions were maintained.

No matter how much I emphasised the issue of confidentiality, there were still those respondents who were sceptical about giving me their real names. They believed that there was a possibility of someone, reading my dissertation, tracing their names and finding out whom they were. In a way they were trying to ensure their protection, even though I presented no harm to them. They were probably not worried about me as a researcher, but about anyone who might read the dissertation. One has to understand that, except for those respondents who were part of the group interview, these respondents had never been exposed to research. They had never had someone visiting them and wanting to write about their opinions. Therefore, in the case of those respondents who wished to remain nameless, such anonymity was fully respected. To ensure full anonymity pseudonyms were used for all respondents.

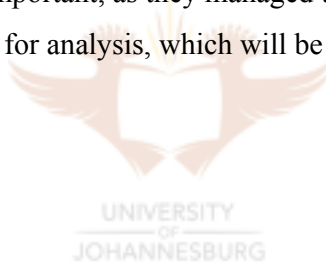
In order to secure ethical issues, I provided respondents with information concerning the following:

1. the nature and purpose of my research;
2. all procedures to be used with my respondents;
3. procedures (including methods to ensure confidentiality) for protecting against, or minimising potential risks;
4. any benefit to the respondent for taking part in the research, such as incentives in the form of food; for example, I had to bring lunch to one or two of my respondents. Thus, in most of the cases where an incentive was provided, food was used;
5. an indication of what information will accrue to science or to society in general as a result of the research; and
6. provision of my contact details and signature along with the name and location of my institution and the names and contact details of both my supervisors.

To put it briefly, the nature of this research topic calls upon any researcher to take precautionary measures with a view to protecting the people studied.

### **3.7. Conclusion**

The qualitative nature of this research allowed me to draw fruitful results at the end. The fact that I used a case study composed of HIV-positive mineworkers, a group that has not been studied in relation to ‘good death’, also helped me to gather new perspectives and fill in some of the missing gaps in the literature. The snowballing method that was also used here helped in obtaining a reasonable amount of respondents for a limited project such as this. The collection of data with the help of a research assistant further ensured its success. Without the help of my research assistant, who was also a gatekeeper and an informant, this research would have never started in the first place. Separating data collection, analysis and interpretation helped in clarifying confusions and in shaping the main argument of the study. The set of themes that were reviewed in Chapter 2, i.e. the literature review, were the same that were used for data collection and for developing the interview questions. These themes and questions were important, as they managed to retrieve information that led to new and improved themes for analysis, which will be discussed in the next chapter.



## CHAPTER 4

### RESEARCH FINDINGS

#### 4.1. Introduction

This chapter discusses, in detail, the information acquired during the fieldwork. The information is presented in accordance with the themes outlined in the previous chapter, together with some new themes that developed during the research. As has already been indicated, the theory reviewed in Chapter 2 was merely used as a guide to the formulation of themes, and interview questions, which shaped the presentation of the interview data. In order to accurately answer the research question, the interview data was grouped by specific themes. The themes used in this chapter are the original themes, based on the literature review, and the new themes based on the information collected during the fieldwork.

Data was collected in three South African languages, Setswana, Sepedi and Sesotho, and later translated into English. The original versions of all the quotes used here are presented in Appendix C. This chapter is composed of two sections. The first discusses the profiles of the respondents. This section is very important as it familiarises the reader with their personalities and characteristics, telling the reader about the kinds of people that were interviewed. The second section addresses eight main themes, five of which are based on the literature reviews, with three new ones based on respondents' answers. This section will lead to the concluding part of the chapter. Data interpretation will be dealt with in the following chapter, Chapter 5.

#### 4.2. Profile of the Sample

The main purpose of this section is to try to provide the reader with a clear picture of the different characteristics of my respondents, to try to familiarise the reader with them, by providing the respondents' personal traits. A summary of this information is presented in Appendix B. This section will only address the following characteristics of the respondents: occupation, gender, HIV status, religious affiliation (Christians and ancestral believers), marital status, age, and the respondents' present residence.

#### 4.2.1. Occupation

For the purpose of this research a distinction was made between the ordinary mineworkers and those considered to be professional workers. Trying to concentrate on respondents' actual work titles brought a lot of confusion. To eliminate this, workers were strictly categorised into two groups. The mineworkers' group consisted mainly of stopeworkers, and the professional workers' group involved those employees who occupied white-collar jobs, such as counsellors, peer educators and AIDS coordinators. My sample consisted of five professional workers and 20 ordinary mineworkers. All of my professional workers were males and during the fieldwork they were grouped together to form an interview group. Their names are Diphoko, Mosupi, Meletlo, Thato and Tshepo. Diphoko and Mosupi described themselves as AIDS coordinators, Meletlo and Tshepo explained themselves as peer educators while Thato introduced himself as an AIDS counsellor. They all seemed pleased with the kind of jobs they were doing at the mines. They believed that these jobs had changed their lives for the better. All five of these professional workers were HIV positive and they were all living openly with the illness. They all agreed that if it was not for their jobs they did not think that they could have been able to face the world. Diphoko indicated this when he said: I love my job . . . it helped me a lot. I was able to come to terms with my disease because of it . . . and I'm helping others who are also infected (Quote 1, Setswana).

#### 4.2.2. Gender

Unfortunately, only two women participated in my research. The two women' names are Mmatladi and Nkadimeng. These two women indicated that legally and professionally women have been accepted in the mines. But they argued that socially an improvement is needed. Nkadimeng reports that: Sometimes it feels like we are invading in their world . . . and they used to say things like a woman can never be a true stoneworker (Quote 2, Setswana).

They do not, of course, say that this is a major problem; they view it as a mere minor hiccup. All the men that I interviewed had no problems with women working on the mines. It is some years now since women workers were first introduced in the mines. Mineworkers of both sexes are getting used to the idea.

#### 4.2.3. HIV Status

To avoid confusion during data analysis terms such as ‘HIV-positive’ or ‘full-blown AIDS’ were not used. The main reason for this was that those individuals who were HIV positive indicated they were going through different levels of HIV. These levels were confusing, as some of them were similar to those of a full-blown AIDS person. Therefore, it became difficult to classify respondents into distinctive groups for analysis purposes. Thus, being HIV positive and having full-blown AIDS were redefined. Two titles were developed: the non-symptomatic, which were the HIV-positive respondents and the symptomatic, which were the full-blown AIDS ones. The sample consisted of three symptomatic respondents and 22 non-symptomatic ones. The names of the symptomatic respondents were Ditse, Lenyora, and Mataboge. This symptomatic group was living openly and positively with HIV/AIDS. They seem to have accepted the disease as a part of their lives. Lenyora placed this clearly into perspective when he said: Sometimes people come in here to look at me . . . I let them because I want them to see the realities of HIV/AIDS (Quote 3, Setswana).

Not only are they open and positive towards AIDS but they are also trying to educate others. None of the professional workers and none of the women were symptomatic.

#### 4.2.5. Respondents’ Present Residence

As far as the residence goes, respondents were grouped under two groups: a group of those workers who presently reside in the mine hostels and a group of those who reside in settlements near the mines. This can be easily classified as follows:

❖ Group A: Hostel dwellers

- South Africans = 6
- Lesotho resident = 1
- Mozambican resident = 1
- Total = 8

❖ Group B: Those who reside in settlements closer to the mines

- Phokeng residents = 6
- Luka residents = 7
- Lefaragatlha residents = 3

- Freedom Park resident = 1
- Total = 17

The names of the two respondents who are from outside South Africa were Mosupi and Thato. These two respondents, particularly Thato, who came from Mozambique, complained about xenophobia on the mines. They said that other workers gave them an attitude problem. This was part of the reason why they did not prefer to rent a room in the nearby villages but opted for residing in hostels. Thato expressed his concern by stating that: Is better in the hostels because it is weak group cohesion, but in the villages, villagers know each other, they belong to distinguished groups . . . one can easily identify a foreigner (Quote 4, Stswana).

Thato further indicated that they even see it in the day jobs when some of the HIV-positive miners refuse to be counselled by a ‘lekwerekwere’ and preferred their own ‘homeboys and girls’. Both foreigners were professional workers and they were both non-symptomatic.

#### 4.2.5. Christians and Ancestral Believers

The concern here was with respondents’ religious beliefs or lack thereof. It was irrelevant to try to determine which respondent affiliated with which church because the focus was really on the extent of their religion. In this regard, respondents were grouped into three categories: Christians, ancestor worshippers, and those who affiliate to both religious beliefs. The table below shows the distribution of religious beliefs.

**Table 1. Religious Affiliation**

	<b>Christians</b>	<b>Ancestor worshippers</b>	<b>Those affiliating to both religious beliefs</b>	<b>Total</b>
Professional workers	2	0	3	5
Women	2	0	0	2
Symptomatic	2	0	1	3
From outside SA	0	0	2	2

#### 4.2.6. Marital Status and Age

For my sample, the average age in years was 37, the youngest respondent was 26 years old, and the oldest respondent was 51 years old. Meletlo, one of the professional male respondents, was the youngest respondent while Mokgatlisi and Maropeng, both non-symptomatic South African male workers, were the oldest. Respondents who were younger were single, while older respondents appeared to be married. The sample consisted of twelve single respondents and thirteen married ones. The table below gives a clear picture:

**Table 2. Marital Status**

	Marital Status	
	Single	Married
Professionals	2	3
Women	1	1
Symptomatic	1	2
From outside South Africa	0	2

#### 4.2.7. Conclusion

This section briefly illustrates the profile of the sample of respondents. A more detailed analysis is presented in Appendix B. Generally, in practice, the respondents could only be divided into six main groups: professionals and non-professionals, women and men, symptomatic and non-symptomatic, Christians, ancestor worshippers and any other traditional religious believers, South Africans and foreigners, and marital status. The next section discusses the fieldwork results, in the form of themes, in order to answer the research question posed at the beginning of this dissertation.

### 4.3. Fieldwork Results

#### 4.3.1. Introduction

This section reports on what the respondents said about a good death. The responses were recorded in the form of themes. Some of the themes are the same as the ones discussed in the previous chapter while others are those that were developed during the fieldwork. With all of this, I ended up with eight themes. All of them helped in trying to analyse the kind of deaths that exist among the HIV-positive mineworkers at Impala mines. The themes are as follows: communications breakdown, dignified death, place of death, death and the afterlife, the cause of death, stigma, material conditions and gender.

#### 4.3.2. Openness and Communication

As has already been indicated in the previous chapter, the main motive behind this theme was to try to find out the extent to which HIV-positive mineworkers receive social support from their doctors and family members; whether these miners view their socialisation process, after being diagnosed with HIV, as normal and whether they are satisfied with the particular support they receive. Sebina (33 years old, married man from Phokeng) states his views as follows:

My relationship with my doctors is good. I trust them. I think they are doing their job properly. Yes, I am free to talk to my doctors and nurses about my illness. They did arrange counselling for me because I was counselled by nurses and caregivers at my home. When it comes to my family the relationship is now better. They accused me at first, of ill treated behaviour, but I think they eventually accepted my status. I told only my closest friend. He too did not just accept me, but I think with understanding he is becoming supportive. Before the diagnosis I had a good relationship with my family and friends. There were normal family problems as with every family . . . I suspect they feel I am the one to blame for the destruction in our family, but they don't show it . . . Well, under the circumstances that I am in, I believe they are as supportive as they can be. I can't really expect much from them. I am the one who is sick not them (Quote 5, Setswana).

The next question asked was based on the respondents' relationship with their family members and friends. The question tried to analyse the state of this relationship before and after the HIV diagnosis. This, as Wasi (2004: 1) argues, is because it is not only the microbes that end the lives of HIV-positive people and their families, but



also the lethal attitudes and feelings of a wide range of persons or groups such as ‘HIV positive people themselves, their family members and people in the community, the ministry of public health, the media’ – in other words, the attitudes of the whole society. Therefore, the main aim of this question was to try to evaluate the extent to which these HIV-positive respondents receive their social support from their loved ones. The respondents’ answers varied according to whether they have or have not publicly disclosed their HIV-positive status. Amongst those who have disclosed is Tshepo (28 years old, single man from Luka):

Tshepo: No, I am not married but I have a child with my girlfriend. I don’t know whether my child is HIV negative or not because my girlfriend refuses to take her for testing . . . when I was first diagnosed I told my family before anyone else. I knew they would support me.

Interviewer: How is that?

Tshepo: First of all my family knows a lot about HIV/AIDS, because my sister is a nurse. My sister has talked a lot about AIDS. There are HIV/AIDS pamphlets lying around at home. They support me completely. They were shocked at first but they never stopped supporting me.

Interviewer: So, the level of AIDS awareness in your family, in a way, helped you?

Tshepo: Oh yes, if it wasn’t for my sister being a nurse I don’t know (Quote 6, Setswana).

Mothusi (38 years old, married man from Phokeng) agreed, stating that:

The truth is my family members told me that I am going to die. They keep on saying that everyday. At this stage it appears as if they accept me simply because they have to. I am family too. So, I now realise that I have to take care of my life and myself if their attitude is like this. I only feel people I can trust are people like you [referring to Mr Diale, Head of the HIV/AIDS department of Impala]. Before the diagnosis things were all right. We respected each other, but I will continue to respect them. I was blamed for not listening to those who loved and cared for me, but chose to listen to friends who misled me. Now I have to live with the results. If it wasn’t for the doctors and nurses who give me support, I don’t know how things would have been (Quote 7, Setswana).

Family support also reduces the fears of death. It makes death seem less traumatic. Mataboge (48 years old, married man from Phokeng) and Ditse (52 years old, married man from Luka) agreed with each other's personal experiences. They responded to the question of emotional support as one way of achieving a good death:

Mataboge: I've got full-blown AIDS and there's nothing funny about it. I'm a Christian, but sometimes I do really wonder what will happen to me . . . Sometimes the priest does visit me from time to time, but when I'm alone my conscience speaks to me . . . You will never know how scary this disease is until you experience it for yourself . . . Yes, yes of course, I knew that death was scary, but combined with AIDS [*he gives a very sad sigh and frowns a little*] it becomes something out of the ordinary . . . At least I've my family's support unlike some people who are completely alone (Quote 8, Sepedi).

Ditse: People who don't have AIDS don't really understand how scary it is to die from this disease. It is really impossible to go through it on your own. You need people who understand you, who love you more than anyone, to take a good care of you. The fact that my family has accepted this disease says a lot about them . . . when you have AIDS you do not really care about what people will think of you. All you care about is making certain that those around you understand how important they've been in your life (Quote 9, Setswana).

It was generally agreed among all my respondents that everyone needed someone to talk to, someone to confide in. Being open does not necessarily mean going around telling people that you are dying. It simply means being able to talk about it, without judgment, when the need to talk arises. For my respondents, the secrecy of death makes things harder for a 'good death' to occur. By keeping it a secret, the dying suffer alone, and their fears are slowly being increased. Selabi (38 years old, married man from Luka) spoke of the problem of not being open about one's death:

In this society, it is a shame to live positively with HIV. You stand to lose a lot by declaring your status. My wife is a strong woman and I know that she can handle this, but not now. I'm not ready to lose her respect as yet. I'm not ready to break her heart. Do you understand this? I'm in a difficult position. I'm torn between doing the right thing, which is telling the truth and risking, not only my life, but my family's (Quote 10, Setswana).

Setlogelo (41 years old, married man from Luka) expressed similar views:

Setlogelo: my wife and I love each other very much. We respect each other and we understand each other's weaknesses. We have four children together. All in all we have a happy family. Why would I want to destroy that by telling her that I'm HIV positive? It doesn't make sense to me, does it to you?

Interviewer: How is telling the truth about your HIV-positive status destroying your family?

Setlogelo: Oh! Come on. Don't tell me that you haven't realised that HIV is a taboo disease. It is full of stigma, disgust and all of that. I am not about to let my family go through the humiliation unnecessarily. What they do not know cannot hurt them, right? In fact, they should be grateful that I love them enough to jeopardise my own happiness by putting theirs first (Quote 11, Setswana).

Even though my respondents know how important being open about one's dying situation is, some of them were still afraid to talk to people, including their closest family members. They said that things could have been better if they were dying from any other disease, and not AIDS. AIDS makes it difficult for them to be open. This is how Boikgatlho (34 years old, single man from Luka) framed his answer in this regard:

The only one who knows about my status is my sister. My parents don't know yet. I am still afraid to tell them because I think that it will change, hamper or do badly to our relationship. I told my HIV-positive friend and we both help and support each other. Right now my family treats me well because they are unaware of my HIV-positive status. I do rely on them when I feel down, but I don't tell them what the problem is (Quote 12, Setswana).

They did, however, agree that no matter how difficult being open about dying from AIDS might be, it still needs to be done. Respondent were quite determined to reveal everything to their families and friends because they believed that this will help them be at peace with their death. This is how Kopano (36 years old, single man from the hostel) showed his determination:

I did not yet get a chance of going home to reveal to my family members. I work far away from home and I am determined to break the news to my family as soon as I get home. The two friends I disclosed to, who stay with me in the hostel, have been motivating me.

I'm a little scared myself. It has not been long since my diagnosis. I'm still getting used to the news myself. I need to get used to the idea before I can tell any one else. I am honestly thankful and satisfied with the support that my two friends in the hostel are giving me. They are good people (Quote 13, Setswana).

Mosupi (36 years old, married man from Lesotho) argued that no matter how angry your family might be when you tell them about your dying position, because they love you, they will have to get over their anger and deal with the reality. This is how he expressed his point:

When I told my wife, back home, that I am HIV positive she was shocked, angry, irritated and she didn't even want to talk to me. But she is my wife. I showed her reason. I made sure that I explained everything to her, including ways in which HIV can be contracted, how to protect one's self and how to live a happy and healthy life with HIV. We love and respect each other deeply . . . the love we have for each other and the education I gave her opened her eyes to realities of AIDS (Quote 14, Sesotho).

Being open about one's illness also seemed to depend on how long since the diagnosis, and the marital status of the diagnosed. In my analysis, respondents who have known their HIV-positive status for a longer period were more likely to have told their loved ones, compared to those who have just been diagnosed. Also, the unmarried respondents were more likely to keep their status secret, compared to the married ones, and in most cases the chances of a married respondent infecting his or her spouse were higher when compared to those of the single ones. It was highly unlikely that the spouses of married respondents, who had known their status for a longer period, were HIV negative. Therefore, for the married respondents the issue of openness, as illustrated by Mothusi (38 years old, married man from Phokeng), was viewed differently, compared to single respondents:

When I was diagnosed, I knew that my wife was also positive, it was obvious, I've never used any condoms with her and by the time I got diagnosed I had already been treated for different sexually transmitted diseases in the past . . . I knew I had infected her . . . I disclosed to her because I knew that she was also positive and I knew that she had to start living positively with HIV (Quote 15, Setswana)

Respondents also reported that the nice thing about knowing about the time of one's death is the fact that one can make prior preparations. With this kind of death the dying does not leave the family members unprepared, unblessed or leave conflicts unresolved. This not only makes family members and friends of the dying feel better but also helps the dying die at peace with him or herself. Maropeng (51 years old, married man from Lefaragattha) strongly supported this view:

I want to be able to say goodbye to all my children. I want to tell my family how much I love and care for them. I want them to know how important they have been in my life . . . There are some things that are hard to say in an everyday life, things that you always postpone because you always thought that you've got enough time to say them. But when you know that you haven't got enough time then you are able to say those things before you die. Unlike when you've got a traumatic accident and you die on the spot. With this kind of death all those important and beautiful things will be left unsaid, and it is really a shame . . . I truly want to prepare my family for my death. I don't want them to go on mourning for me forever and feeling responsible or guilty for my death . . . I want them to remember me as their loving, happy and caring father and husband . . . I want them to have a good memory of me. I want to mean something good to them not something bad. With such things achieved I can look forward to a peaceful and stress-free death (Quote 16, Sepedi).

From Maropeng's comment it is clear that it is not only about the material things that you leave behind but it is also about the emotions that you leave behind. The important question that the dying asks him or herself is 'how did my life on earth affect those I love the most, either materially or emotionally?' If the dying can answer this question positively, then they might be able to achieve some form of a 'good death'.

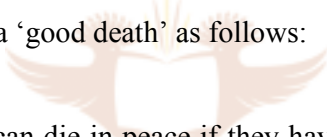
It is clear that social support is very important in dealing with issues around dying and death. If the lines of communication are opened between the dying and their social structures, issues such as being open about one's death can be promoted. The dying can then be able to say their last words and farewells and can bless those they want to bless. With such things achieved, a person can look forward to a good death.

My findings, in this regard, clearly support those of the literature reviewed in Chapter 2. Making a connection through healing relationships and 'letting go' help to ensure the attainment of a 'good death'. When Khadro made this argument, his

emphasis was also on the relationships with family members and friends, more than any other social groups. In his book *Preparing for Death and Helping the Dying* (2003), the main points that he thought were important for the dying person in healing relationships and 'letting go' in peace, were firstly, to learn to communicate honestly, compassionately and unselfishly, and, secondly, to resolve any unresolved problems the dying might have with others (Khadro, 2003: 11). As far as communication is concerned, the findings of this research have shown that even an HIV-positive mineworker in South Africa goes through the same communication issues that any other dying person, elsewhere in the world, goes through.

#### 4.3.3. Dignified Death

Almost all my respondents agreed that having lived a good life might help one have a 'good death'. The response from Thabo (29 years old, single man from the hostel) made this point clear. This is not to say that the others did not agree with him, it is just that his point of view was more precise in this regard. In his own words he expressed the notion of a good life and a 'good death' as follows:



I think that a person can die in peace if they have satisfied themselves with their life on earth, if they have lived a comfortable lifestyle. I mean that if you know that you have done all the major things that you know you've always wanted to do, why would you complain? When your time comes, you'll accept it with an open heart . . . I even think with HIV is better . . . I'm 29 years old and I've been diagnosed with HIV not so long ago. I know that I still have about 5-10 years of my life. Because I know the time for the ending of my life, I can start really living a day as if it were my last. I can start to really appreciate thing around me. I don't want to complain and be grumpy at the end . . . Having done everything that I've always wanted to do during my remaining time, I can peacefully look forward to my last hours with no regrets (Quote 17, Setswana).

The argument may be that the more an HIV-positive person relies on others for financial support, the more he or she feels like a burden. PLWHAs need to feel in control of their lives in order to die peacefully. They do not want to die knowing that they were a burden to someone else. They need to take good care of themselves up until their moment of death. When asked questions relating to this theme, Mogomotsi (44 years old, married man from Luka) and Moeti (45 years old, single man from Phokeng) indicated:

Mogomotsi: I am independent because I use my own earnings. No one is paying anything for me, especially for my illness. Because I am financially independent I think that I am also in full control of my life. I do not need anyone to tell me what to do (Quote 18, Setswana).

Moeti: Because I can also make decisions for myself, I don't need people to tell me what to do. Mostly, all I need from others is just their support or their advice and tips on how to handle things but they don't control my life. I control my life . . . Yes I do think that I definitely have my personal dignity because I am not a burden to anyone. People respect me because I can support myself. I don't go around asking money from anyone, especially for maintaining my illness (Quote 19, Sepedi).

Mmatladi (37 years old, single woman from Freedom Park) shared these views to a large extent. Here is how she explained her predicament:

I am now unemployed and dependent [she was once an employee of Impala mines]. I live on handouts and keep on asking from a friend and someone I know from home . . . It worries me because I am normally not used to being a dependent. I would like to do my old job and get some money to feed my children and myself. Sometimes I engage in risky behaviour like sleeping with men to get some money for my children. Where is the dignity in that? Where is the respect? (Quote 20, Sepedi).

Sometimes the income level of an HIV-positive person determines the sense of suffering and level of dignity. In this context, respondents explained dignity as a sense of worthiness brought by different characteristics, such as material possessions, ability to have children, leading a healthy lifestyle, having a respectable, well-paying job, and others. Those who consider themselves as living a middle-class life tend to think that because they have money their life problems, such as HIV, can be reduced. The more money you have the better the chances of survival. Nonetheless, some of the respondents who have money felt that AIDS is too powerful for them. They believed that you could have all the money in the world but for as long as you have HIV/AIDS you do not have a life. They say that AIDS takes over their life by robbing their dignity and respect. They feel so helpless, to the point that the fact that they are working makes no difference to them. Setlogelo (41 years old, married from Luka) is one of those people. He does not believe that a person with HIV can be respected and can have self-esteem or dignity. He reports that:



I want to be in total control, but we are told this AIDS can defeat you one day. I think AIDS will always own our bodies and the way we think. Do you understand? My body is an AIDS body now . . . Yes, I can make decisions for myself but they are always shaped by the fact that I am HIV positive.

Interviewer: And is that such a bad thing?

Setlogelo: Yes it is. Nowadays I do things that I would have never done if I were still negative. Even people look and talk to me differently now that I am HIV positive (Quote 21, Setswana).

When questioned on this issue, Meletlo (26 years old, single man from Lefaragattha) replied by saying:

I think that it is really possible for a person to die a good death provided that they are not suffering from HIV/AIDS. It is very difficult to accept death by this disease because we are not used to it. When you have AIDS people rebuke you, you become the laughing stock of the society. You lose your human side and you become a very interesting species for scientists and researchers to study. That's why you are here isn't it? To study us. To you I'm just a statistic not a human being isn't it? (Quote 22, Sepedi).

For my respondents dignity took many forms. Some explain it as a form of psychological suffering (not being able to mentally make one's own decisions), some explain it as emotional suffering (being rebuked and laughed at by one's own peers), and some see it as financial problems (being a burden on others and relying on them for money). They might all explain it differently but they all, nevertheless, agree that it is important and leads to a 'good death'. In a more general sense, though, having achieved dignity means that a person has lived a good life. Thus, living a good, respectable life leads to a good and respectable death.

This is the same argument that was made by Khadro (2003: 13-14). He believes that a person can have a peaceful exit if they have lived ethically, refrained from negative actions such as stealing, sexual misconduct, killing, slander etc. The fact of the matter is that there is no way of knowing when death will happen, to ourselves or to another. Therefore, according to the literature and the findings of this research, living a good life and making certain that we purify ourselves on a daily basis can lead to a 'good death'.



#### 4.3.4. Place of Death

The literature reviewed indicated that the place of death is important in a 'good death'. It is argued that the dying needs to be responsible for selecting their place of death if they are to die peacefully. This theme tries to establish the best place for a 'good death' to occur. The choice given was between two major locations: the hospital and one's home. There were a lot of opinions regarding this issue. Some of the respondents argued in favour of the use of hospitals and hospices, whilst others were completely against it. Some of the respondents were undecided. They could not choose between the two, as they believed that the combination of both is very important. Boikgatlho (34 years old, single man from the hostel) argued against the use of hospitals and emphasised his view by stating that:

When my moment of death comes, when I'm too weak to continue working, I would like to be taken home. I want to be around those who care for me. I don't want to lose contact with my family. If I stay in a hospital I'll die of loneliness. Besides, I don't particularly envy the idea of having strangers around me all the time. A good family is the one that looks after each other through times ... Anyway, I know my family would love to have me around (Quote 24, Setswana).

To some of the respondents the hospital was not really a bad idea. They believe that the help of the doctors and nurses was more important than the help that they would receive at home. They said that family members have no idea of medical issues. If they start relying on them, nothing good could come of it. They indicated that the family members would be there for them only for emotional support, which is a good thing, but there is still the issue of the physical pain. They would rather live without the support of their families instead of enduring the physical pain. Mosupi (36 years old, married man from Lesotho) supported this view:

Mosupi: I want to be hospitalised here in our hospital.

Interviewer: Do you mind telling me why?

Mosupi: Because in a hospital you can easily get help if you need it. If I experience some difficulties the doctors will know what to do. I won't have to suffer. Back at home, there is no help. All the family can do is boil water and use a cloth to try and ease the pains in your body or to try and straighten your muscles, water cannot ease pain. You'll need real medicine for that (Quote 25, Sesotho).

Meletlo (26 years old, single man from Lefaragatlha) also agreed:

I want to be hospitalised first. If there is still hope for me I want to be near my doctors and nurses. They can only transfer me home when the doctors are sure that there is no longer hope for me, when they are sure that there is absolutely nothing they can do for me. I know my family can't help me and the medicines from the doctors can no longer help me, so, I would go home and wait for my time there (Quote 26, Sepedi).

When these questions of location of death as a way of achieving a 'good death' were expanded further, those who came from outside South Africa argued differently to those who were South African. Thato (39 years old, married man from Mozambique) answered the question in the following manner:

Thato: When my moment comes I want to go back home. I don't want to die among strangers. I want to be surrounded by love and those people I know I can trust. I'm from a royal family in Mozambique and I would like to be buried in our royal graveyard. I want my spirit to go where others have gone.

Interviewer: But to achieve that you don't necessarily have to spend your last days at home, after your death they can just transfer your corpse back to Mozambique and you'll be buried there, right?

Thato: You don't get it do you? It is not only about spending the last days there; it is also about the last faces you see when you die. I don't want to die where my soul will never have peace. I want to see my family by my side, I want to be able to say my last goodbyes, be able to bless those that I want to bless . . . This will help my soul rest in peace, the knowledge that my family loved me until the last moment of my life . . . In the hospital I'll be so lonely and scared . . . Imagine how scary death is, and imagine going through it all on your own. It's not human (Quote 27, Setswana).

Tshepo (28 years old, single man from Luka) is one of the local South Africans who argued that:

Tshepo: I think the hospital would be best for me. I trust my doctors and nurses.

Interviewer: But what about those dear to you? Don't you want to be surrounded by your family?

Tshepo: Of course I do. They can always visit. It is not like I will be miles away. I will be just a few kilometres away from them. They can always catch a taxi and visit me during hospital visitation hours. And again I don't really want to be their burden. It is better to be in a hospital. Then you can avoid a lot of gossip and unnecessary expenses. If you go home, you'll have to think about many things such as food, medication, check ups by your doctor, someone to take care of you day and night. It is too much. On top of everything people will be coming in and out of your home to take a look at how an HIV-positive person looks like. And what if something happens and the doctor or nurse is not there. My family won't know what to do. They can only give you support, but you also need proper medicines. I think it is important to die in a hospital. Your family can visit you always, but you cannot expect them to be your doctors. They also have their own lives to live (Quote 28, Setswana).

The selection of one's place of dying seemed to be influenced by the extent of HIV in the respondent's blood. During the analysis, it became clear that those respondents who were still in the HIV stage and who have not yet disclosed their status, were more prone to choose dying at the mine hospitals rather than at their homes. When asked why, ten of them indicated that when they fall helplessly ill, they would like to hide from society at large. They are still afraid of the stigma surrounding AIDS. Those with full-blown AIDS seem to have thrown in the towel. They seem not to care about the views of the public. The evidence below will give a deeper understanding of these two views. Mogomotsi (44 years old, married man from Luka) is one of those respondents who are HIV-positive and who believe in the use of mine hospitals in achieving a 'good death':

Mogomotsi: Imagine all those people at home knowing that I've got AIDS. I couldn't take it, not even for one second.

Interviewer: Why is that sir?

Mogomotsi: You know how people are. They would start putting pressure on my family and me. They would start saying horrible things about me, visiting non-stop trying to see for themselves what AIDS looked like. I don't want to be the talk of the town. I could not put my family through all that humiliation ... The best thing is to hide myself in some institution where only my family members would have a chance of seeing me ... At least in that manner my family would be able to come up with an acceptable story concerning my disappearance. Dealing with death and AIDS it's enough to give a person stress without having to add people's gossip to it (Quote 29, Setswana).

Lenyora (37 years old, single man from Luka) is one of those respondents with full-blown AIDS who believe that a ‘good death’ is one in which the dying are surrounded by their loved ones in the comforts of their own homes.

My family is the most important part of my life. From now onwards I want to make sure that I spend every second of my life with them. To hell with the rest of the society. What do they know anyway about true love and care? They are just there to gossip and make our lives a misery . . . People will never stop talking, whether you are at the hospital or at your house they will keep on gossiping about you . . . whether you are sick or healthy they will keep on gossiping. So, then, what is the point of trying to run away from them . . . with AIDS there is nowhere to hide . . . I’ll rather stay in at home with the people who matter the most to me (Quote 30, Setswana).

There are a lot of differing views among respondents with this theme. Some want the hospital, others want the comforts of their private homes, while others preferred both places, for a ‘good death’ to occur. These conflicting opinions together with others from other themes will be discussed in the following chapter, when focusing on data interpretation.

An important point that also emerged during the research is that those respondents who viewed a peaceful death as the one that occurs at their homes were more open to traditional medicines. Respondents who wanted to die at the hospital or hospice trusted modern medication, if not the combination of both. Thato (39 years old, married man from Mozambique) discussed these cultural beliefs as follows:

Thato: If I go home, I’ll be able to use my traditional medicines. I cannot say that I honestly believe that they do work, but they have been used for centuries and in my family I don’t really have a choice.

Interviewer: If you were given that choice would you then choose western or traditional medicines?

Thato: Well, at the moment when I feel sick, I do use western medicines. I take treatment from our wellness programme. They say it will boost my immune system. I am not complaining. But you have to understand that our traditional medicines help to clean our blood, not necessarily to cure AIDS. I think I’m stronger because I use both (Quote 31, Setswana).

Seruwe (35 years old, single man from Lefaragatlha) who also believed in the use of hospitals said the following about traditional medicines:

Seruwe: I would like to spend my last days at the hospital nearer to home. I don't really think my family can help me much when I'm really sick. They are good people but sometimes they can give me stress. The truth is they don't really want to know a lot about this disease. They say the disease is not part of their lives but part of mine. But what can I say? They are family and they are important to me . . . I want them to visit me.

Interviewer: If they don't care why is it important that they visit?

Seruwe: Because I love them and they are a part of who I am . . . I also need them to sneak in *muti* to the hospital. I would still like to use *muti*. I actually want to use both medicines. I think when combined they are strong. I know of people who got help from *muti* as well.

Interviewer: What kind of help – to cure AIDS?

Seruwe: No, of course not, just to help them be strong and to release pains (Quote 32, Setswana).

Moeti (45 years old, single man from Phokeng) agreed with Seruwe, saying:

Moeti: I only use the treatment from our wellness programme; my doctor advised me. I don't know if they are working. The doctors say they are working and I trust them. I use the traditional medicines for something I was bewitched with called *sejeso* [a Setswana word meaning some sickness that a witch gives to another person due to jealousy]. Before I was bewitched with *sejeso*, I was clean; my blood was clean. After this *sejeso* they told me I had HIV. I think the person who bewitched me with *sejeso* did something again to give me HIV.

Interviewer: Was it a man or a woman who gave you this *sejeso*?

Moeti: We don't know who is a witch and who is not, but because they say you get HIV from sex, it must have been a woman. I cannot really tell who it was.

Interviewer: Are you saying *sejeso* and HIV is the same thing?

Moeti: I honestly don't know, all I know is that I got sick and I visited my traditional healer who told me I've been bewitched by *sejeso*, and she gave me *muti* and showed me how to use it. My other friend advised me to visit one of our doctors here at the hospital. The doctor just said I've got HIV. It was a shock. Before I had no *sejeso* and no

HIV. Right now they tell me I have them both. I really don't know. What I know is that there is witchcraft and there is AIDS (Quote 33, Sepedi).

In the literature reviewed in Chapter 2, authors saw a place of death as important in determining the kind of death experienced. Even though most authors believed that for this 'good death' to occur, the dying should be the one responsible for selecting that particular place, they nonetheless stressed the importance of dying in a hospital or hospice. For them, the hospital or hospice serves one most important purpose for the dying: dealing with the physical aspects of care, which involves medication and proper nutrition (Dworzanowski, 2002: 424-426). Therefore, in this regard, respondents for this research study agreed with the literature. But, then again, selecting a place for a 'good death' to occur depended on various aspects, as far as my respondents were concerned. These included their cultural beliefs, the level of the disease, physical pain, the presence of the loved ones, and access to traditional medicines.

#### 4.3.5. Death and the Afterlife

Under this theme, authors argue that for anyone to die peacefully they need to prepare themselves for the afterlife. They described the afterlife in two ways, in a form of Christianity where people believed in the existence of God or heaven and hell, and in an African tradition, the belief is directed towards the ancestors. It is believed that the dying, no matter what their race might be, will have to deal with issues of the afterlife before they can even think of a good death. Authors agreed that everyone fears the afterlife, whether it is God or ancestors. Miners interviewed also emphasised the importance of preparing one's self before death for the afterlife. Some believed in God, others believed in ancestors while others argued that both approaches are important. Only few of the respondents, four of them to be precise, argued in favour of witchcraft.


Those who believed in God stressed that it is only through God that one can ever be able to achieve a good death. For them, a good death is one in which the Lord Almighty has blessed the dying soul and has made a place for it in heaven. Kabelo (32 years old, single man from hostel) emphasised his point of view by saying:

I strongly believe in God. I believe in the bible even though we don't have proof. I believe that if you are not a Christian, you will definitely go to hell. Christians will go to heaven. The sinners will suffer forever while Christians will live in harmony under his care forever . . . for a person to die peacefully he needs care, support, and protection of the Holy Spirit (Quote 34, Sepedi).

Setlogelo (41 years old, married man from Luka) supported Kabelo's view, saying:

I do believe in God, He brought me to this planet, He is my creator . . . I believe that the Christian does not fear death. He remains hopeful and leaves everything to God, the Saviour. I think that non-Christians do not even believe the existence of AIDS, that is why they spread the virus ...To die peacefully you need the truth. To get the real thing unlike when lied to and living a false life. The truth can help you survive for a long time. This is why my motto in life is 'the truth shall set you free' (Quote 35, Setswana).

On the other hand, Thabo (29 years old, single man from the hostel), as one of those respondents who believed in ancestors, argued that:



Ancestors are an important part of anyone's life. I do believe that they exist. I sometimes slaughter for my ancestors. When you slaughter for them, they will give you good luck. They did assist me to avoid some illnesses. I may have this [*referring to HIV*] because I took some time without remembering them (Quote 36, Setswana).

Moeti (45 years old, single man from Phokeng) supported this argument:

I strongly believe in ancestors, I even have a way of communicating with them. Sometimes I slaughter for them or I talk to them by visiting their graveyards. They do need a share of your efforts here on earth to bless you. You don't have to give much, just a little that you have. If you think about it, in every situation, you do have to give something in order to get something in return (Quote 37, Sepedi).

Others combined the two approaches when asked questions regarding their belief in the afterlife. They believed that you need both the ancestors and God to die peacefully. Thato (39 years old, single man from Mozambique) asserted that:

Thato: Well, my family and I believe in God and heaven and hell. We go to church every Sunday and all my children were baptised in a church. As I have already told you, I'm from the royal family and originally we practice traditional methods. We slaughter for ancestors to pay them our respects. When I am with my family I practice life as a Christian and when I go home to Mozambique I pay my respects to my ancestors and I follow what they follow.

Interviewer: What do you, personally, believe in?

Thato: Well, both I guess, I mean God does exist that I know for a fact; and, as for ancestors, they've helped my royal family to survive all these years, so I guess they exist as well and have the power to curse or bless a person. To be on a safe side, I support them both (Quote 38, Setswana).

Meletlo (26 years old, single man from Lefaragatlha) agreed with Thato, reporting that:

God and ancestors work hand in hand. As an African man I believe in ancestors but I also believe in God the almighty. Our bodies are not important, what is important is our spirits, our souls. There has to be a place where our spirits are stored. I mean we know that when we die our bodies are buried six feet under, but what about the spirit? (Quote 39, Sepedi).

Mootli (37 years old, single man from the hostel) said:

I believe that when I die, when my time comes, I will die in peace. I have lots of support and God is watching over me and there is nothing more comforting than that. AIDS or no AIDS God loves us all (Quote 40, Sepedi).

Nkadimeng (28 years old, married woman from Phokeng) agreed with Mootli, indicating that:

Death my child is death. It is simply air out of your flesh nothing more. Death itself is not important because all men die . . . What is of importance is how you die. Accepting God as your Saviour is the right way to die. But just because you have accepted God does not mean that you'll automatically stop fearing death. The fact that you have God on your side will help you relax and be at peace . . . I don't let the fact that I have AIDS bother me too much. God loves us all, otherwise He would have never sent His beloved son to die for our sins. We are all God's children (Quote 41, Setswana).



This theme also presents a lot of conflicting views that will be dealt with as part of the data interpretation. But, all in all, respondents here agreed with a lot of things that other authors, in Chapter 2, discussed. They all agreed on the importance of the afterlife in achieving a ‘good death’. This is validated by Giles’s argument when he said that ‘people are essentially spiritual beings’ (1984: 14). What is also interesting to note here, is that those respondents who believed in ancestors did not believe in hell. They argued that every person, after death, becomes an ancestor, that an ancestor is the mediator between God and human beings. For them, an ancestor is equivalent to an angel. Therefore, both groups (western and traditional) believe in God. It is just their worship that is different. Traditionally, ancestors are used as mediators between God and humans, and in western culture angels are used as such. Therefore, these two groups believed in the power above all powers and in the importance of preparing one’s self for the afterlife, in order to achieve a ‘good death’.

#### 4.3.6. The Cause of Death

The cause of death plays a significant role in discussing a ‘good death’. Death in itself is a fearful act. There is no denying that. For my respondents, dying of a terminal illness in general presented fears and anxieties. All my respondents felt that dying from a terminal illness caused by AIDS is the worst kind of death ever. The comments below taken from Maropeng (36 years old, married man from Lefaragatlha), Boikgatlho (34 years old, single man from the Hostel), Diphoko (43 years old, married man from Phokeng), Nkadimeng (28 years old, married woman from Phokeng) and Setlogelo (41 years old, married man from Luka) strongly illustrate this point:

Maropeng: It is not easy dying from this disease. You know, I think I can handle my dying process better if I was dying of something else and not AIDS . . . I’m not coping at all, it’s difficult . . . Not only the way people look at you, but is also about what you see when you look in the mirror . . . Have you seen a full-blown AIDS patients? . . . I have . . . they are so very thin, they say that if you take their finger and pinch them what comes out won’t be blood, but water . . . serious, eh! It is not human. AIDS will make you suffer like you have never suffered before. As difficult as it is to live with HIV, it is ten times more when you have to die from AIDS (Quote 42, Sepedi).

Boikgatlho: The nightmares, the thinking . . . you know you lie there looking at the ceiling, thinking and rethinking all kinds of things. You over-exhaust your mind thinking about AIDS. All those ‘only if’s’ you make. Is psychological trauma, it’s stress . . . it’s pain. Sure they can give you the most expensive and lengthy counselling there is, your family can be there day and night to support you, but there comes a moment when you are alone. And those few seconds you are alone, those few minutes lying there looking at the ceiling, fighting with your own demons, can erase all the years of good counselling you’ve had . . . Dying from AIDS really is not an easy thing, take it from me, I know (Quote 43, Setswana).

Diphoko: No amount of death acceptance can erase the pain of dying from AIDS . . . Yes, death is fearful but AIDS is worse than death itself (Quote 44, Setswana).

Nkadimeng: My dear, AIDS can frustrate you . . . Why do you think HIV-positive people commit suicide rather than die of AIDS. Eh? Why? People with AIDS would rather shoot themselves, hang themselves, even poison themselves, instead of letting AIDS claim their lives, doesn’t that tell you something? . . . The difficulty of it all is unbearable (Quote 45, Setswana).

Setlogelo: AIDS makes death more difficult. I really don’t see how your good death can be achieved with AIDS (Quote 46, Setswana).

Respondents, therefore, support the arguments made earlier in the literature, that terminal illness increases the fear of death and thus limits the possibility of a ‘good death’. This is argued by Dixton (1994) who says that suffering from a terminal illness increases the chances of a wild death, especially if stigma is attached to that particular terminal illness.

#### 4.3.7. Stigma

For my respondents the problem of finding it difficult to be at peace with oneself at the moment of death comes from the stigma of AIDS. Kabelo (32 years old, single man from the hostel) added his view here, asserting that:

Yes, yes, of course AIDS increases the fears of death . . . And I strongly believe that to achieve this good death of yours is to come together as a community and try to eliminate the stigma attached to AIDS (Quote 47, Sepedi).

All of my respondents agreed with what Kabelo indicated. It was not a shared view among some of them but, rather, among all of them. They all agreed on the same

definition of stigma and they all stressed its role in achieving a 'good death'. Because each topic with each respondent was automatically related to stigma, stigma then became an important aspect of 'good death' for this research. This will be discussed in more detail in the next chapter, in the section that deals with data interpretation.

Respondents also believe that the level of the disease right at the time of death can also be an important determinant of a 'good death'. They hypothesised that the more symptomatic (full-blown AIDS) a person becomes the more likely a wild death will occur and *vice versa*. They believed that if a person dies before becoming extremely ill (experiencing AIDS symptoms) then that person might die a 'good death'. Avoiding physical pain may lead to a 'good death'. They indicated that to die a 'good death' is to die as a human being, and not to die as some helpless thing sleeping on the bed waiting to be fed and cleaned. Ditse (52 years old, married man from Luka) is one of those respondents who believed this to be true. In his analysis of the subject he reported that:

I've got full-blown AIDS. I wish I could just die right now before I become a burden to anyone . . . I truly wish I could have died earlier but I'm still here. I know that I'm deteriorating. I can feel it. It really does hurt knowing that I can never get better but continue to get worse. What then is the point of continuing? Nothing can help me now. No medication they give me can help. I still have a little strength to do some things on my own, I'm still human and I wish to die as one. Why doesn't my time come now? I'm ready, I really wouldn't mind if I die now (Quote 48, Setswana).

This does not necessarily mean that they have given up or that they are weak. It simply means that determining the time of one's death, in this case, can lead to the achievement of a 'good death'.

Of course, none of my respondents has ever used the term 'good death' to describe the right way to die. A 'good death' for them meant being at peace with themselves and their surroundings at the time of their death. Thus, respondents described a 'good death' as death that comes at the point where the dying is peaceful. They have never really used the word 'good death', instead they have used 'being at peace' to describe the same thing. Botlhe (27 years old, single man from the hostel) showed how being at peace could lead to a 'good death'. In his report Botlhe indicated that:

I'm not afraid of death. I'm more peaceful towards it. With or without HIV/AIDS I was going to die anyway. It is not like being negative you have avoided death. Death is going to visit all of us. Good death depends on one's attitude when it comes. I'm at peace with the fact that I'm mortal. All living things have to have an end, one way or another, and I'm not going to let that fact stop me from living my life to the fullest and the way I see fit. I've come to terms with the fact that I'm dying. I'm at peace with it so should everyone else for that matter (Quote 49, Setswana).

All in all, though, respondents agreed that the stigma surrounding HIV/AIDS contributes a lot to making death unbearable. They argued that a 'good death' could be possible for a terminal illness, which does not carry a stigma, like cancer. Death by AIDS, as my respondents and Thongsa-aad (2004: 1) argue, is made unbearable by the fact that people with HIV/AIDS are refused love, understanding, generosity and thoughtfulness, by other people in the society, despite the fact that HIV-positive people have done nothing wrong, except that they have the HI virus in their bodies. Thongsa-aad further indicates how unfair it is for society to reject HIV-positive people, since every human being passes through birth, old age, sickness and death, and that HIV/AIDS is simply one kind of disease. Because society regards HIV-positive people as having something terrible, something hateful, their chances for a 'good death' are limited, as they cannot enjoy their life here on earth (Thongsa-aad, 2004: 1).

#### 4.3.8. Material Conditions

This theme is related to the second theme that was discussed earlier in this section, dying with dignity, especially when the theme concerns issues around a 'good life' as leading to a 'good death'. My respondents agreed that to die a 'good death' a person must have had a good and acceptable occupational stance in society. In this regard, Thato (39 years old, married man from Mozambique) reported that:

I occupy a good job, thus, others respect me. My job as Impala's AIDS coordinator gives me a great social stance. Because of what I do people tend to respect me . . . So, because of my job, I live a fairly good life and because I'm respected, I've got my personal dignity and with all of these, I truly look forward to a peaceful death (Quote 50, Setswana).

Not all my respondents saw this theme as important, but because more than half (16 respondents) talked about their jobs as being important I then decided to

make this theme one of the bases of analysis for a ‘good death’. This, of course, has not been discussed in the literature. It is just what my respondents have added as one of the most important characteristics of achieving a ‘good death’.

#### 4.3.9. Gender

Two women interviewed saw it important to discuss how gender (relating to HIV/AIDS) affects the outcome of death. They believed that, compared to men, women do not receive the same kind of emotional support that they deserve. When Nkadimeng (28 years old, married from Phokeng) was questioned regarding the social support she receives from her family members, she responded by saying:

Don't get me wrong, my husband is a good man, but that is just the problem. He is a man. Sometimes when I take my medication, I can see in his eyes that he is irritated. He hasn't chased me out so that must mean that he still cares for me. I cannot ask too much from the poor man because I'm the one who is wrong. He is doing all he can. To some extent, when he does not help me out when I need him, I do understand his position. It is not because he does not care or love me but he is just being a man. After all, men are God's images and we, women, are His emotions and together we make the totality of God. It is just the way life works. When they [referring to men] are sick, it is our task to see to them but when we are sick, it is like we've committed a sin to them (Quote 51, Setswana).

Mmatladi (37 years old, single woman from Freedom Park) agreed with Nkadimeng by saying:

Men are just dogs. When they want something from you they expect to get it, but when we ask for the same favour in return they look the other way. I think a woman who's got the support of her man will be able to die in peace. But I think that it is rare to find such a man as a woman . . . Men don't have emotions and they don't have feelings. Women are really suffering, and what's worse? We've got good hearts (Quote 52, Sepedi).

These two women believed that it is highly unlikely for a woman to achieve a ‘good death’, as compared to her male partner, due to many social circumstances that are based on stereotypes.

An interesting and unique finding of this research, is one relating to the ability to have children. Most of the HIV-positive people interviewed in this study felt that

HIV/AIDS has taken away their right to reproduce. For the single men, they believed that being a respectable man means being able to have children and raising them properly. This is how they defined manhood. They argued that a man needs to have children to carry their names and legacy that a man needs to leave a mark showing that they once existed on this earth. This, they believed, will give their lives some form of meaning, unlike being alone. The fact that because of AIDS they can't have healthy children, and even if they do have healthy children with the help of Nevirapine, they can never stick around long enough to make certain that they are raised properly, takes away their manhood. This, in turn, strips away their dignity, and for this reason, a 'good death' becomes highly unlikely. This argument did not appear anywhere in the literature that I reviewed, it was raised only by my respondents. Thabo (29 year old, single man from the hostel) is one of those respondents.

How can I call myself a man? I can't have kids . . . I came alone on this earth and I guess I'll leave like that too. I'll never be remembered. I don't have any evidence indicating my existence . . . my name will die with me (Quote 23, Setswana).

This issue of gender was not part of the original model seen in the literature, in Chapter 2, and thus can be seen as a major contribution to this study of 'good death'.

#### **4.4. Conclusion**

This chapter has tried to familiarise the reader with respondents interviewed for this research. This was done by concentrating on six characteristics: occupation, gender, HIV status, religious affiliation, marital status and age, and respondents' present residence.

It also discussed different themes used to answer the research question. Some of the themes were drawn from the literature review and used for data collection. The other three themes developed during the course of the research. All in all the research ended up with eight themes: openness and communication, dignified death, place of death, death and the afterlife, the cause of death, stigma, material conditions and gender. Together, these themes began to point towards a 'good death,' in the South African context, for miners living with HIV/AIDS, can be achieved.

The next and final chapter, Chapter 5, will deal with data interpretation by looking at the how the respondents differed in their responses and by concentrating on the reasons as to why the responses differed. The chapter will go on to discuss how HIV/AIDS limits the existence of a 'good death'. This is where the research question - can people with HIV/AIDS have a 'good death'? - will be answered. The contributions that my research has made to the study of dying and death will also be discussed in this chapter.



## CHAPTER 5

### CONCLUSION AND RECOMMENDATIONS

#### 5.1. Introduction

This dissertation concentrated on the most sensitive issue around HIV/AIDS, the issue of dying and death. When reviewing the literature on ‘good death’, we have seen how different authors agree on the five most important characteristics of determining the existence of a ‘good death’, namely: communications breakdown, dignified death, place of death, death and the afterlife and the cause of death.

After reviewing these characteristics, I then developed a research problem that I wanted to investigate. The research question for this study was drawn from a South Africa’s contemporary problem, HIV/AIDS, and was combined with unexplained issues surrounding the concept of ‘good death’. The research question read thus: *can people who are dying from AIDS have a ‘good death’?* With this research question, two specific aims/objectives emerged. Firstly, I sought to clarify the meaning of a ‘good death’, and secondly, to examine what would be required to assist PLWHAs to move closer towards having a ‘good death’.

To answer the question, I developed a case study consisting of HIV-positive mineworkers. These mineworkers were asked questions based on five themes, which were drawn from the above-mentioned characteristics of a ‘good death’. During the course of the research, new themes or new characteristics of a ‘good death’ were developed and these were based on the respondents’ responses. The five characteristics that were used for data collection then expanded to form eight characteristics.

The three new characteristics state that a ‘good death’ depends on the level of stigma surrounding the terminal illness, the gender of the terminally ill and the material conditions owned by the dying. I then interpreted the results as follows:



## **5.2. HIV-positive Mineworkers' Perceptions of a 'Good Death' in Relation to the Literature Review**

This section will deal with the interpretation of data collected from the respondents. It will discuss the themes independently to see how they support or contradict the literature that was reviewed. During data analysis there were those other characteristics, which presented a lot of contradictions. There were two themes in particular that featured these contradictions, place of death and issues around fears of the afterlife. These contradictions will be discussed below, in their own specific themes.

### **5.2.1. Openness and Communication**

As far as communication goes, respondents were quite happy with the relationship they have with their doctors and nurses. The only problem they had was with their loved ones. Respondents for this study supported the views found in the literature on the importance of having family and friends around before death. They said that it is difficult to survive death anxieties without their help.

### **5.2.2. Dignified Death**

Respondents also supported the views found in the literature on dignified death. They believed that to die a good death involves living a good life, being able to support one's self materially and being able to support one's family. No one wants to be a burden and having money (which does not necessarily mean being rich, just being able to put food on the table everyday) given a person a sense of pride. This is what the respondents were arguing, that even if you gets sick (by contacting HIV/AIDS), for as long as you do not bother anyone you might be able to live with yourself.

### **5.2.3. Place of Death**

Some of the respondents believed that to die a 'good death' means to be hospitalised, while some believed a 'good death' could occur when one dies in the comfort of one's home. There were those who believed that a 'good death' could be achieved by using both locations. I think the conflicting opinions in this group are mainly due to issues of physical distance, the distance between the hospital and one's home. The further from the hospital, the more the dying would opt for the comforts of one's home.

Respondents wanted to be free from pain and suffering during their last days and this can be easily achieved through a hospital. At the same time, they wanted to be surrounded by their loved ones during their last moments, which can be easily achieved if one is to die at home. Thus, those who are closer to the hospital would enjoy the benefits of both worlds. They would be hospitalised to avoid pain, and have their family members visit them from time to time, and thus gain emotional support.

Under this same theme, the use of medication aroused and presented confusions. Some respondents believed in the use of modern medication, others believed in using traditional medicines, while others wanted to use both. This latter group claimed that they felt better knowing that they are doing what the doctors instructed them to do and at the same time they are satisfying their traditional needs. None of them could say for certain that the traditional medications were working or not. They were just using them because the medications have been used over a period of time without hurting anyone. Some of those respondents who wanted to spend their last days at their homes wanted to have easy access to *muti*. Even those who opted for a hospital said that when their families or friends visit they would like them to sneak *muti* in the hospital for them.

#### 5.2.4. Death and the Afterlife

There emerged a conflict in opinions regarding spiritual beliefs, where respondents believed that satisfying both God and ancestors would lead to a 'good death'. They could not choose between being either Christians or ancestral worshippers but claimed to follow both approaches. Some really and honestly believed in the ancestors but also prayed God just in case He does exist and *vice versa*. Respondents would go to church on Sundays and visit the ancestors on any other day of the week. They feared selecting just one belief and sticking by it, because they were not certain that the other does not really exist. One belief was used as a back-up plan, a 'just in case the other does not work out'.

The following three sub-sections will try to interpret this data in more detail by trying to answer the research question mentioned earlier. Thus, this section consists of three critical sub-sections, which indicate the existence or the non-existence of a 'good death' among HIV-positive miners as outlined by themselves.

### 5.2.5. Causes of Death

There is general agreement both for my respondents and expressed in the literature reviewed. The fear of death is influenced by the cause of death; the more sudden the death the lesser the anxiety. Death, as a consequence of AIDS brings fears and anxieties, which limit the attainment of a good death.

## 5.3. HIV-Positive Mineworkers' Contributions to the Study of a 'Good Death'

Respondents believed that a 'good death' does exist in the South African context. They agreed with the characteristics of a 'good death' that were drawn from the literature, but due to their responses I was able to add new characteristics to explain this 'good death'. As a result of this study, I concluded that it is highly unlikely for this group of people to achieve a 'good death' when dying from AIDS. The following three factors were mentioned as limiting the achievement of a 'good death'.

### 5.3.1. Stigma

All respondents argued that the stigma associated with AIDS makes it impossible for a 'good death' to exist for an HIV-positive person. They further indicated that this stigma of AIDS limits the characteristics of a 'good death' in the following manner:

**Stigma limits openness** about AIDS, as it presents problems with disclosure of HIV-positive status. By doing so it hinders HIV-positive people from being open about the fact that they are dying. In this way, it becomes difficult for this group of people to accept death as a consequence of their illness. Therefore, people suffering from AIDS find it difficult to enjoy this characteristic of a 'good death'.

**Stigma also limits a good life** by making an HIV-positive person feel guilty about having contracted the virus. Because HIV is spread mostly by promiscuous sex, HIV-positive people feel responsible for their bad behaviour and also guilty for having behaved in such a manner. This guilt, caused by the stigma attached to AIDS, makes it difficult for those living with HIV to achieve a perceived high quality of life.

**It further limits the dignity** of an HIV-positive person by, firstly, pressurising the person to die at a hospital, using it as a hideaway for a person cannot face society. This is because of fear of rejection. Secondly, it is a dehumanised way of dying, with excessive levels of physical pain, accompanied by visible symptoms of illness such as weight loss, hair loss, skin rashes, etc.

**Stigma may also limit the emotional support** provided by the family and friends of the dying, as they might reject their dying relatives in order to avoid unnecessary humiliation. Besides, these people suffering from AIDS do not want to put their family through all those headaches, therefore, as a last resort, they themselves terminate contact with their loved ones in order to protect them.

**Stigma presents AIDS as a sin.** Those who are or want to become Christians fear that they might not be spiritually prepared to meet death, as they believe that they might have committed a deadly sin in front of God. Those who worship ancestors feel that they might never forgive them for committing such a horrible sin.

Therefore, because of this stigma, it is then concluded that it might be very difficult, but not impossible, for an HIV-positive person to achieve a ‘good death’ as some of the characteristics of this ‘good death’ can never exist, in such a situation

### 5.3.2. Material Conditions

Lack of resources, or poverty for that matter, limits a ‘good death’ in an AIDS patient by diminishing the following:

**Lack of resources, limiting choices in medication.** Some respondents would only use traditional medicines because they cannot afford to spend money on modern ones or *vice versa*. Thus, being poor limits an AIDS patient’s chances of selecting the medication of his or her choice and not taking the medicine of one’s choosing means not dying a ‘good death’.

**They also limit the choice in location.** Sometimes those respondents who would like to spend their last days at a hospital cannot do so, as these institutions are often unaffordable for them. Sometimes those who want to die at their homes would easily do so, if they could afford to pay doctors and nurses who are willing to make house calls.

**Access to healthy food is also limited,** especially in the case of mineworkers. Respondents indicated that being a stopeworker (mineworker) means that they occupy low jobs. These low jobs mean low pay, and low pay results in patients being unable to afford to follow a healthy diet. Even so, respondents were quite pleased that they did at least have jobs. This was relating to the fact that with a job, they do have a sense of self-worth. Nonetheless, they were still saddened by the fact that this was not

enough to provide them with very single need aroused by their disease, especially when it came to maintaining a health lifestyle.

**The level of the illness also plays a major role in limiting a ‘good death’.**

With poverty, this will always mean a lack of maintenance for those with serious symptoms.

### 5.3.3. Gender

Respondents also agreed that gender stereotypes limit the achievement of a ‘good death’ by AIDS patients. In their view, gender stereotypes limit a ‘good death’ in the following ways:

**Gender stereotypes limit communication lines.** When women are sick, they are seen as disrupting the family unit. They do not get as much support as do their male partners. Therefore, women find it difficult to express their last wishes, as they were not expected to get sick in the first place. The social gender stereotype for men is that they are not supposed to cry, meaning that men end up not saying what they really feel like saying at the moment of their death, as they do not want to feel ashamed of not being ‘man enough’. The other problem that men experience is feeling that their manhood is limited by their inability to have children. Men believe that in order to die a ‘good death’ one must be able to leave something important behind, something of value, and something that they can be remembered by. For these men, that something is their child. The fact that with AIDS they can never have healthy babies and even if they do (with the help of Nevirapine), they can never live long enough to make certain that their babies are being taken care of properly, limit the attainment of a ‘good death’.

The characteristics that were discussed during data analysis in the previous chapter show that respondents agree that a ‘good death’ does exist in the real world, that it is not an unattainable ideal. The problem is that this ‘good death’ seems only to exist for the limited few. Unfortunately, the answer to the research question of this study has to be a negative one. ***It is not completely impossible, but rather highly unlikely for an HIV-positive person to die a ‘good death’.*** Therefore, these characteristics can be seen as the contributions made by my respondents to the study of death and dying from AIDS.

### **5.3. Policy Implications**

This section shows how the second aim of this research, which was to examine what would be required to assist PLWHAs to move closer to having a ‘good death’, was successfully met. Respondents indicated that the experience of a ‘good death’ by PLWHAs might be possible if the stigma attached to AIDS is removed. By reducing the stigma, those suffering from the disease might be given the chance to experience a ‘good death’. Gender stereotypes in communities should be reduced by treating both men and women as equals. It is through this equality that we might start to treat each other with a little more compassion and understanding. Lastly, policy can be improved by trying to give HIV-positive patients the resources that they need, such as increasing the number of healthcare givers. Moreover, since some of the people cannot afford the services rendered by the healthcare givers, programmes, such as home or community-based care programmes should be promoted, to encourage people to volunteer as healthcare givers. The number of volunteers may allow for better home-based care services for HIV-positive patients. With all of this achieved, the characteristics of a ‘good death’ might be strengthened for those suffering from AIDS.

### **5.4. Implications for Scholarship**

The problem with the literature on ‘good death’ is that it is US-centric. Of course, the literature has its merits as it provided helpful debates on this particular issue. The problem was with linking all the issues to the South African context. Because of that, it then became difficult to judge some of the things based on this literature. To try to bridge this gap in the literature, I made certain that I treated the literature as an ideal type that I used to judge the reality. Using the literature in this sense was useful, as it gave me a starting point in my search for answers and it gave me a foundation on which to build my argument. More South African scholars are needed who would focus on this topic and I hope that my dissertation has highlighted the importance of this. It might also be helpful for future researchers, who are interested in undertaking a similar study, do so on a larger scale.

## 5.5. Research Contributions to the Field of Study

Not only did this research contribute by adding three new themes to the study of ‘good death’ but it also indicated ways in which South Africans understand and define a good way of dying. According to my respondents, a ‘good death’, in relation to a terminal illness, in this case HIV/AIDS, is the kind of death where the terminally ill person:

- 1) Is in control of his or her surroundings;
- 2) Is afforded dignity and privacy;
- 3) Is has lived a considerably good life prior to death;
- 4) Is in control of pain relief and other symptoms;
- 5) Is in control of the choice over where death occurs;
- 6) Is has access to any emotional support required;
- 7) Is able to issue advance directives which ensure wishes are respected; and
- 8) Is in control of the resources needed to ensure a peaceful and pain-free exit

Therefore, the first aim of my research, which was to clarify the meaning of a ‘good death’, was successfully met. I have managed to get a glimpse of what some of the HIV-positive mineworkers think a ‘good death’ is.

## 5.6. Conclusion

High levels of AIDS infections pose a serious threat, not only to individuals themselves, but also to South Africa’s emerging democracy. AIDS leads to a tragic loss of life. It casts fears into the hearts of South Africans from all walks of life and prevents them from taking their rightful place in the development and growth of the country. Therefore, in relation to this, there is a need for a special focus:

- To emphasise the fact that the stigma surrounding AIDS may increase the fears of dying and death, at the same time threatening the possibility of a ‘good death’.
- To address the issue of gender stereotypes and eliminate them, as they limit the achievement of a ‘good death’.
- To also stress the point that the lack of health and care facilities serves as a threat to a ‘good death’.

Therefore, this study has not been conducted in vain. It points out the importance of a 'good death' for those living and dying from AIDS. It has also highlighted areas that still need investigation in the South African literature on this topic.





# APPENDICES

## APPENDIX A: INTERVIEW SCHEDULE

### 1. Biographical Details

1. Your name
2. Your age in years
3. Your level of education
4. Your home language
5. Your marital status
6. If you are married, are you presently living with your spouse?
7. Do you have children? How many?
8. Are you a South African citizen or a migrant from outside South Africa?  
(From where?)
9. Where do you live at present? (Hospital, Village, Township, Informal settlement etc)
10. Whom do you live with? (Family, Friends, Roommate)

### 2. Medical History

1. HIV-positive or full-blown AIDS?
2. HIV-positive
  - How long have you been living with HIV?
  - Have you ever been hospitalized and where?
  - Are you using the Wellness Program that is offered by your hospital?
  - If yes, why do you use it?
  - Are you open about your status?
  - If no, who knows about your disease? And why did you choose to disclose to that particular person? Do you ever plan to live openly with HIV? When?

- If you live openly with HIV, tell me how it is like?

### 3. Full-blown AIDS

- How long have you been living with AIDS?
- If not in hospital, have you ever been hospitalized and where? Why are you not hospitalized now?
- If in hospital, was it your choice to be hospitalized and why?
- What is it like to live openly with AIDS?

### **3. Theme 1: Communications Breakdown**

1. Tell me about your relationship with your doctors and nurses
2. Do you feel free to talk to your doctors and nurses about your illness?
3. Do your doctors and nurses offer or arrange counselling sessions for you?
4. Tell me about your relationship with your friends and family
5. How was your relationship with your family members and friends before they knew that you were diagnosed with HIV/AIDS?
6. In what way has the relationship changed after the diagnosis?
7. Do you sometimes discuss your illness with your friends or family members?
8. Do you feel as if your family members or your doctors are giving you enough support?
9. If no, does that give you a sense of suffering? Explain
10. How often is there someone to confide in and talk about yourself or your illness?
11. How often is there someone to have a good time with?
12. During the past month, how much of the time have you felt downhearted and blue?
13. Do you know what is bothering you?
14. Would you like to see someone to talk about your feelings?

#### **4. Theme 2: Dignified Death**

1. How do you define dignity?
2. What does 'dying with dignity' mean?
3. What do you need in order to have dignity?
4. Do you think you have self-dignity?
5. Do you think that you will one day die with dignity?
6. Are you independent in terms of buying things for maintaining yourself in your illness? For example: medicines or following a healthy diet.
7. Whom do you depend on?
8. How do you feel about depending on others? (For example: childlike, helpless, ashamed, happy etc) Please elaborate
9. Do you feel in control of your life?
10. Are you able to make decisions for yourself?
11. Does that give you a sense of personal dignity?
12. Does it also give you a sense of self-esteem?
13. Do you feel as if you have lost your personal dignity?
14. Do you feel like you have lost your sense of self-esteem?
15. How much help do you need with personal care, such as helping with bathing or eating?
16. How much help have you needed from someone on your family?
17. How much additional help do you need with personal care?
18. Would having a home health aid be of help?

#### **5. Theme 3: Location of Death**

1. When your time comes, where would you like to spend your last days? (e.g. hospital/ home)
2. Your reasons being?
3. What symptoms bother you most? Aside from everyday pains like minor headaches, sprains or toothaches.
4. How much pain have you had during the past month?
5. Do you take medicines from the hospital for your illness or do you use traditional ones?

6. What are your reasons for using the kind of medicines that you use?
7. Would you like more treatment for your pain, have the same treatment, or have less treatment for your pain?

#### **6. Theme 4: Death and the Afterlife**

1. Do you believe in God?
2. Do you believe in the afterlife, that is heaven and hell?
3. Do you think that there is a difference between dying a Christian and dying a non-Christian?
4. If yes, what is the difference?
5. What do you think a person needs in order to die peacefully?
6. Do you believe in ancestors?
7. According to you what is an ancestor?
8. What are ancestral powers?
9. Do you believe in making sacrifices as a way of talking to the ancestors?
10. If yes, what is the purpose of these sacrifices?
11. What is the relationship between God, angels and ancestors?
12. Do you think an HIV-positive person also has a good relationship with his/her ancestors? Explain
13. Since your illness, have you become more spiritual or religious?
14. Do you pray?
15. What have you been praying for?
16. Do you have a spiritual or religious community that helps in your personal spiritual journey?

#### **7. Theme 5: Causes of Death**

1. Have you filled out a living will stating your preference for medical care in case of a life-threatening situation?
2. Have you talked to your family about your plans regarding your medical care at the end of your life?
3. Do you believe that you are going to die in peace?

4. If no, does the fact that you are living with HIV/AIDS have anything to do with your negativity towards death? Explain in detail
5. As far as you are concerned what is peaceful dying?



**APPENDIX B: PROFILE OF THE RESPONDENTS**

<i>Pseudonym and language of transaction</i>	<i>Gender</i>	<i>Age</i>	<i>Marital Status</i>	<i>Respondents' Present Residence</i>	<i>Religious and/or Spiritual Beliefs</i>	<i>Occupation</i>	<i>No. of children</i>	<i>Level of Illness</i>	<i>Description of interview and location of interviews</i>
Boikgatlho (Setswana)	Male	34	Single	Impala Hostel	Ancestral	Mineworker	2	Non-symptomatic	Makhura/ one-on-one interview/ note taking/ home
Botlhe (Setswana)	Male	27	Single	Impala Hostel	Christian	Mineworker	0	Non-symptomatic	Makhura/ one-on-one interview/ note taking/ home
Diphoko (Setswana)	Male	43	Married	Phokeng Village	Ancestral & Christian	Professional	4	Non-symptomatic	Makhura/ group interview/ taped/ hospital
Ditse (Setswana)	Male	52	Married	Luka Village	Christian	Mineworker	3	Symptomatic	Makhura/ one-on-one interview/ note taking/ home
Kabelo (Sepedi)	Male	32	Single	Impala Hostel	Christian	Mineworker	0	Non-symptomatic	Makhura/ one-on-one interview/ note taking/ home
Kopano (Setswana)	Male	36	Single	Impala Hostel	Christian	Mineworker	2	Non-symptomatic	Makhura/ one-on-one interview/ note taking/ home
Lenyora (Setswana)	Male	37	Single	Luka Village	Christian	Mineworker	1	Symptomatic	Makhura/ one-on-one interview/ note taking/ home

Maropeng (Sepedi)	Male	36	Married	Lefaragatlha Village	Ancestral & Christian	Mineworker	3	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Mataboge (Sepedi)	Male	48	Married	Phokeng Village	Ancestral & Christian	Mineworker	4	Symptomatic	Makhura/ one-on-one interview/ note taking/ home
Meletlo (Sepedi)	Male	26	Single	Lefaragatlha Village	Ancestral & Christian	Professional	0	Non- symptomatic	Makhura/ group interview/ taped/ hospital
Mmatladi (Sepedi)	Female	37	Single	Freedom Park	Christian	Mineworker	2	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Moeti (Sepedi)	Male	45	Single	Phokeng Village	Ancestral & Christian	Mineworker	2	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Mogomotsi (Setswana)	Male	44	Married	Luka Village	Ancestral & Christian	Mineworker	4	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Mokgatlisi (Setswana)	Male	51	Married	Luka Village	Ancestral	Mineworker	4	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Mootli (Sepedi)	Male	37	Single	Impala Hostel	Christian	Mineworker	0	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Mosupi (Sesotho)	Male	36	Married	Lesotho	Ancestral & Christian	Professional	3	Non- symptomatic	Makhura/ group interview/ taped/ hospital
Mothusi	Male	38	Married	Phokeng	Christian	Mineworker	4	Non-	Diale/ one-on-one interview/

(Setswana)				Village				symptomatic	taped/ hospital
Nkadimeng (Setswana)	Female	28	Married	Phokeng Village	Christian	Mineworker	2	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Sebina (Setswana)	Male	33	Married	Phokeng Village	Christian	Mineworker	2	Non- symptomatic	Diale/ one-on-one interviews/ taped/ hospital
Selabi (Setswana)	Male	38	Married	Luka Village	Ancestral & Christian	Mineworker	3	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Seruwe (Setswana)	Male	35	Single	Lefaragatlha Village	Christian	Mineworker	2	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Setlogelo Setswana)	Male	41	Married	Luka Village	Ancestral & Christian	Mineworker	5	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Thabo (Setswana)	Male	29	Single	Impala Hostel	Ancestral & Christian	Mineworker	0	Non- symptomatic	Diale/ one-on-one interview/ taped/ hospital
Thato (Setswana)	Male	39	Married	Maputo	Ancestral & Christian	Professional	3	Non- symptomatic	Makhura/ group interview/ taped/ hospital
Tshepo (Setswana)	Male	28	Single	Luka Village	Christian	Professional	1	Non- symptomatic	Makhura/ group interview/ taped/ hospital



## APPENDIX C: ORIGINALS OF THE TRANSLATIONS

### Quote 1: Setswana

Ke rata mmereko wa ka . . . O nthusitsi go utlwala. O ile wa dira gore ke kgone go lebegana le bolwetse jwa me . . . E bile ke kgona go thusa ba bangwe ba ba tshwaetsegileng.

### Quote 2: Setswana

Ka dinako dingwe o kare re ba kgoreletsa lefatsheng la bona . . . E bile ba na le go bua gore mosadi a ka se tsogile a bile moepi wa boammaruri.

### Quote 3: Setswana

Ka dinako dingwe batho ba tla mo ba tla go ntekola. Ke a ba letla ka gonne ke batla gore ba ipone gore HIV/AIDS e lebega jang.

### Quote 4: Setswana

Go botoka mo dihosteleng, ke “mix masala”. Kwa metseng ba a itsane, ba na le ditlhongwana tsa bona. Go bonolo go bona gore ke mang lekwerekwere le gore ke mang yo e seng lona.



### Quote 5: Setswana

Botsalano jwa me le dingaka tsa me ke bo bo siameng e le ruri. Ke a ba tshepa. Ke nagana gore be dira tiro ya bone ka matsetseseleko. Ee, ke lokologile go bua ka bolwetsi jwa me le dingaka tsa me. Ba ile ba mpha le counselling ka ga ke ile ka etelwa ke ma-nurse le di-caregivers kwa lapeng. Botsalano ba le le ba lelapa bo botoka. Ba simolotse ba mpona molato e bile ba mapteletsa gore ke ne ke sa itshwara ka tshwanelo, mme jaanong ba acceptile. Ke ile ka bolelela tsala ya me pele, le ena o ile a nna le bothathanyana mara ka morago ga gore a tlhaloganye o ile a mpha sapoto. Pele ke diagnosiwa ke ne ke na le botsalano bo bo siameng le ba lelapa la me. Mathatha ona a ne a le teng fela jaaka mo lapeng lengwe le lengwe . . . Ke nagana gore ba mblama for go disrupta family ya rona ke fela gore ga ba mpontshetse kwa ntle. Mo maemong a ke leng mo go ona ke nagana gore ba mpha sapoto ka moo ba ka kgonang ka teng. Tota ruri nka se solofele go le gontsi go tswa mo go bona. Ke nna ke lwalang e seng bone.

### **Quote 6: Setswana**

Tshepo: Nnya ga ke a nyala mara ke na le ngwana le lekgarebe la me. Ana ngwanake ona le HIV kgotsa nnya, nka seke ka itse ka fa kgarebe yaka e gana go mo isa testeng . . . Ka ke ne ke diagnosiwa ke ile ka bolelela ba lelapa laka pele ka batho botlhe. Ke itsitse gore ba tlile go mpha sapoto.

Interviewer: O raya jang?

Tshepo: Sa ntlha ke gore ausi wa ka o itsi go le gontsi ka HIV ka fa e le nurse, o tlhola a bua go le gontsi ka yona. Di HIV pamphlets ke tse dintsi gore ko lapeng. Go bua nnete fela bona ba mpha sapoto, ke fela gore ne ba makatse ka lantlha mara gone jaanong ba siame fela.

Interviewer: So, go raya gore kitso ya AIDS mo lapeng la gago e go thusitsi, akere?

Tshepo: Ee, fa e ka bo e se ka gore ausi wa ka ke nurse ga ke itse gore go ka bo go ile ga direga eng.

### **Quote 7: Setswana**

Nnete ke gore ba lelapa la me ba ile ba mpolelela gore ke tlile go tlhokofala. Ba phela ba mpolelela seno tsatsi le tsatsi. Gone jaanong be nkamogetse ka gore ba tlamegile ba dire jalo. Le nna ke leloko la family. Ke itemogetse gore ke tlamegile ke itlhokomele if ba mpha attitude e e so. Batho ba ba tshwanang le wena ke bone fela ba nka ba tshepang [o raya Mr Diale, moemedi wa HIV/AIDS Department ya ko Impala]. Pele ga kokonatlhoko e dilo di ne di siame magareng ga rona, re ne re tlhomphana, fela nna kna se stope, ke tlile go tswalela pele ke ba tlhompha. Ba ile ba mblama fo go reetsa ditsala tse di ileng tsa ntatla gona le gore nkabo ke reeditse bona. Ga e ka bo e se ka dingaka le di-nurse tse di mphang sapoto tota riru ga ke itse gore dilo di ka bo di ile tsa nna jang for nna.

### **Quote 8: Sepedi**

Gape ke na le full-blown AIDS ene ga se selo sa go kgatlisa sana soe. Ke modumedi efela ke na le go ipujisa gore go tlile go dialang ka nna. Moruti o fela a etla ka dinako . . . Gape o ka se tsogile o tsibile gore kokonatlhoko e e šhišhimisa bwang go fitlhela e go tsena . . . Ee, ke ne ke dutse ke tseba gore leso le a shishimisa mara gape ga o le tswakantšha le AIDS le napa le feteletse . . . Gape nna ke thuswa ke sapoto ya ba lelapa la ka, ga ke tshwane le bao ba seng yona.

**Quote 9: Setswana**

Batho bao ba senang AIDS ga ba tlhologanye gore go swa ka AIDS go a tshosa. Tota ruri ga go kgonege gore o kgone go e feketsa o le mongwe. O tlhoka bao ba go ratang, e bile ba go tlhologanya gore ba kgone go go tlhokomela. Taba ya gore ba lelapa lame ba amogetse bolwetsi jo, e bua go le gontsi ka ga bone . . . Ga o na le AIDS ga o sa tlhola o kgathala gore batho ba reng ka wena. Se o se batlang ke fela ke gore bao ba leng gaufi le wena ba tlhologanye gore ba ne ba le bothlokwa go le kae mo bophelong ba gago.

**Quote 10: Setswana**

Mo sechabeng se sa rong, go tsenwa ke AIDS ke matlhabisaditlhong. Ga o ka bolelela batho gore o na le AIDS o tlile go latlhegelwa e le tota. Mosadi wa me o tiile, ke a itsi gore a ka kgona go kgotlhelela seno, empa e seng jaanong. Ga ke ise ke batle go latlhegelwa ke tlhompho eo a mphang youna. Ga ke ise ke batle go utlwise pelo ya gagwe botlhoko. A o a tlhologanya? Ke mo matsapeng. Ga ke itse gore ke direng, ga nka bua nnete ke tlile go tlhakatlhakanya bophelo jwa me le ba lelapa la me.

**Quote 11: Setswana**

Setlogelo: Nna le mosadi wa me re a ratana, re a tlhomphana e bile re tlhologanya makoa a rona. Re na le bana ba le four. Re lelapa le le itumetseng. Ke lebaka lefe le le ka etsang gore ke senye seo ka go bolelela mmosadi wa me gore ke HIV positive? Seo ga se mphe tlhologanyo, wena o bona jang?

Interviewer: Go bua nnete ka status sa gago go thusa lelapa la gago jang?

Setlogelo: OH! tloga fa, o batla go nthaya o re ga o ise o lemoge gore HIV ke taboo. E A sisimogiwa, e na le stigma. Ga ke batla gore ba lelapa lame ba tlhabiwe ke dotlhong go sa tlhokege. Se ba sa se itseng se ka se ba utlwise botlhoko, akere? Go bua nnete ba tshwanetse go nteboga gore ke ba rata mo e leng gore ke tlisa lethabo la bone pele ga la me.

**Quote 12: Setswana**

Ausi wa ka ke ene a itsing ka status sa me. Batsadi ba me ga ba itse. Ke sa tshaba go ba bolelela ga gonne ke nagana gore se se tlile go senya botsalano ba rona. Ke ile ka bolelela tsala nngwe ya me e e HIV positive, mme re a thusana, re a sapotana. Gone jaanong ba lelapa lame ba ntshwere sentle ka gonne ga ba ise ba itse ka status sa ka se

se positive. Ga ke sa ikutlwi sentle ke leba bona gore ba nthusa efela ga ke ba bolele gore bothata ke eng.

**Quote 13: Setswana**

Ga ke ise ke thole chono ya go bolelela ba lelapa lame kwa gae. Ke dira kgole le legae mme ke ipopleletse gore ke tla ba bolelela motlhang ke yang gae. Ditsala tsa me tse pedi tseo ke nnang le tsona mo hostel, tseo ke ileng ka di bolelela, di ntse di mpha sapoto. Ke a tshaba le nna. Ga se kgale ke diagnositswe. Ke sa ntse ke batla go tlwaela pele. Ke tshwanetse ke tlwaele pele ke bolelela batho ka kwa ntle. Go bua nnete ke kgotsafoaletse e bile ke itumelela sapota e ditsala tsa me tsa mo hostel di mphang yona. Ke batho ba ba siameng.

**Quote 14: Sesotho**

Mosadi wa ka ko lapeng o ile a tshoga thata ga ke ne ke mmolelela gore ke HIV positive. O ne a sa batle le go bua le nna. Ke ile ka mmontsh mabaka, ke mosadi wa me. Ke ile ka totobatsa gore ke tlhalosa sengwe le sengwe kwa go ena. Ditsela tse motho a ka bonang HIV ka tsona le gore motho a ka itshireletsa jang kgatlhanong le bolwetse jo. Le ka go phela bophelo bo bo monate e bile bo sireletsegile. Re a ratana e bile re a tlhomphana. Lerato la rona le thuto e ke mo fileng yona ka HIV e dirile gore a bule matlho mme a lemoge dilo di se kae ka AIDS.

**Quote 15: Setswana**

Ga ke ne ke diagnosiwa ke ne ke itse gore mosadi wa me o positive, go ne go le mo pepeneneng, ga ke ise ke tsamaye ka dirisa di-condom le ene, e bile gape ka nako e ke neng ke diagnosiwa ka yona ke ne ke setse ke kile ka tretiwa for di-sexual transmitted diseases mo nakong e e fitileng. Ke itsitse gore ke mo tshwaeditse. Ke ile ka mmolelela gonne ke ne ke itse gore ke setse ke mo tshwaeditse, le gone ke ne ke tswanetse ke mofe chono ya gore a simolole go phela bophelo jo bo nepagetseng.

**Quote 16: Sepedi**

Ke nyaka gore ke kgone go sadile banake gabotse kwa mafelelong. Ke nyaka gore lelapa laka le tsebe gore ke ba rata kakudu. Ke nyaka ba tsebe gore ba botlhokwa bophelong bwa ka . . . Gona le dilwana tseo di loeng boima gore motho a di bolele go sa re sepe. Ka nako dingwe ga re di bolele gobane re nagana gore nako e sale e ntshi.

Fela ga o itse gore ga o sana nako e kalo dilwana tseo o di bolela o sa phela. Ga go tshwane le ge o thutswi ke mmotoro, o tlile go palelwa ke go bolela dilo tseo . . . Ke nyaka gore ba lelapa laka ba kgone go itukisetsa leho la ka. Ga ke nyake gore ba nagane gore ke hwile ka baka sa bone. Ke nyaka gore ba nkgopole bwale ka ntate wa lelapa, o rategileng. Ke nyaka ba nkgopole ga botsana. Ke nyaka gore ke tlise ntho ya botsana go bona. Ge ke gumane tše, ke tla kona go hwa ka kagiso, e bile ke sena stress.

**Quote 17: Setswana**

Ke nagana gore motho a ka swa ka kagiso ga a kgonne go phela bophelo bo bo mo siametseng. Ke raya gore ga o direle tsotlhe tse o neng o batla go di dira o tla bo o setse o ngongoregela eng? Ga nako ya gago e tla o tla e amogela ka pelo e e phuthulugileng . . . E bile ke nagana gore ka HIV bo botoka . . . Ke na le dilemo di le 29 ene ke ile ka tsenwa ke HIV mo nakong e e fetileng. Ke a itse gore ke santse ke na le 5-10 years ya go phela. Ka gonne ke itse bokhutlo ba me ke ka kgona go simolola go phela bophelo ba me ka tolamo. Ke tla kgona go simolola go lebogela seo ke nang le sona. Ga ke batle go ngongoregela ruri kwa bofelong . . . Ga ke ka kgona go dira sengwe le sengwe se ke neng ke batlile go se dira kwa bofelong ke ka kgona gore ke seke ka itshola ko bofelong.



**Quote 18: Setswana**

Ke ikemetse ka gonne ke dirisa letlotlo lame. Ga go motho you o mpatelelang sepe, bogolosegolo mo go tlhokomeleng bolwetsi jwa me. Ke nagana gore ke kgona go itaola jaanong ka gonne ke kgona go ikemela ka fa cheleteng. Ga ke tlhoke ope gore a mpolelele gore ke direng.

**Quote 19: Sepedi**

Ke kgona go ikakanyetsa, ga ke tlhoke batho ba go mpotsa gore ke direng. Se ke se nyakago gagolo ke dikakanyo le maele a bone gore ke direng ga se le sele efela ga ba diye selo ka go laola bophele baka. Ke a itaola . . . Ee, ke nagana gore ke a tlhomphega ka ge ke sa laolwe ke motho e bile ke sa kope motho selo. Ke a tlhomphega ka gonne ga ke kope ope selo, ga ke tlhwe ke kopile dichelete tsa go itlhokomela.

**Quote 20: Sepedi**

Ga ke sa shoma gana bwale, ke phela ka go kopa digwera kapa mongwe wa lelapa . . . Taba e e ya ntena ka ge ke sa tlwaela dilwana tše. Ke eletše ge nka humane mošhomo waka wa pele mme ka kgona go sapota ba getsho. Ka dinako dingwe ke dia tsa go sa tsebalege like thobalano gore ke kgone go fepa lapa laka. Tlhomphe e kae gana moo?

**Quote 21: Setswana**

Setlogelo: Ke batla go laola tsotlhe tse di ntibileng e fela ba na le go re bolelela gore AIDS e ka go fekeetsa ka dinako dingwe. Ke nagana gore AIDS e tla dula e laola mebele ya rona le ka mokgwa oo re naganang ka ona. A o a tlhaloganya? Mmele waka ke wa AIDS . . . Ee, ke kgona go ikakanyetse e fela dikakanyo tsaka di ya le gore ke HIV positive kgotsa nyaa

Interviewer: A seo ke selo se se maswe?

Setlogelo: Ee, matsatsi a gompieno ke dira dilo tseo ke neng ke ka se di dire ga nkabo ke le negative. Le batho ba nteba ka mokgwa o mongwe ka gore ke HIV positive.

**Quote 22: Sepedi**

Ke nagana gore go a kgonega gore motho a hwe leho le le botse ge a sena HIV/AIDS. Go tla go le bothatanyana gore motho a amogeleitse leho la AIDS ka ge re sa e tlwaela. Ge o na le kokonatlhoko e batho ba go nyonya, o thoba goba setshego sechabeng. Ga o sa le motho, o nna selo fela sa gore di-scientists le di-researchers di ithutele mo go sona. Ke ka fao o leng fa, go tla go ithutela mo go nna. Mo go wena ke nomoro fela, ga go motho, akere?

**Quote 23: Setswana**

Ke tla ipitsa monna yang? Nka se tsogile ke kgonne go nna le bana . . . Ke tlile ke le mongwe mo lefatsheng e bile go raya gore ke tlile go boela morago ke le jwalo. Ba ka se tsogile ba nkgopotse. Ga go sepe se se supang gore ke kile kabo ke phela mono lefatsheng . . . Leina laka le tlile go swa le nna.

**Quote 24: Setswana**

Ga nake yaka e tla, ke sa tlhola ke kgona go bereka, ke batla gore ke isiwe gae. Ke batla go nna le ba ba nthatang. Ga ke batle go latlhegelwa ke ba lelapa lame. Ga nka nna mo hospitala mo ke tlile go bolawa ke bodutu. Le gone ga ke rate go tlhola ke

kgobakanetswe ke batho bao ke sa ba itseng. Lelapa le le siameng ke le le tlhokomelanang ka nako tsotlhe . . . Le gone ke a itse gore ba lelapa laka ba batla gore ke nne ntse ke bapile le bone.

**Quote 25: Sesotho**

Mosupi: Ke batla go hospitalisiwa mo sepetleleng se sa rona

Interviewer: A o ka mpolelela gore goreng o batla seo?

Mosupi: Ka gonne mo sepetleleng o ka fumana thuso ga o e tlhoka. Ga ke ka bona mathata dingaka di tla itse gore di direng. Nka se sotlege. Ko lapeng ga gona thuso, seo ba ka se etsang, ke go futhumatsa metsi mme ba go thobe mo mmeleng go fokotsa ditlhabi le go futhumatsa mesifa. Metsi a ka se fodise ditlhabi. O tla tlhoka meriana ya nnete.

**Quote 26: Sepedi**

Ke nyaka go dula mo sepetleleng pele, ge e le gore go sana le tsheponyana. Ba ka njeya ba nkisa gae ge e le gore dingaka dire ga go sana tshepo. Ga ba tseba gore ga go se ba ka ntirelang sona. Ke tlabo ke tseba gore ba lelapa laka ba ka se nthusi ka sepe, le dingaka ga di sa kgona, ka byale ke tla ya gae, ke ye go hwela ntshe.

**Quote 27: Setswana**

Thato: Ke batla go swela gae ga nako yake e fitlhile. Ga ke batle go swela dikgweng. Ke batla go dikologwa ke lerato, le batho bao ke itseng gore ba a nthata e bile ke a ba tshepa. Ke tswa lapeng la bogosi kwa Mozambique, e bile ke batla go bolokelwa mo mabitleng a segosi. Ke batla mowa wa ka o ye ko emengwe e ileng teng.

Interviewer: Go fumana seo ga go tlhokege gore ba go romele gae, morago ga lesa la gagwe ba ka nna ba tsaya setopo sa gago ba se romela gae akere?

Thato: Ga o tlhaloganye, akere. Ka se fela ka gonne ke batla go bolokwa teng, ke ka gore o bona sefatlhego sa mang pele o ineela. Ga ke batle go swela mo moweng waka o tlileng go tlhoka kagiso gone. Ke batla go laela sentle, ke tshegofatse bao ke ba tshegofatsang . . . Se se tla dira gore ke swe ka kagiso, go itse gore ba lelapa laka ba ne ba na le nna go fitlha kwa bofelong . . . Kwa sepetlele ke tlile go nna ke le mongwe le gone ke tlile go boifa . . . Nagana fela gore lesa le tshosa yang, jaanong nagana ga o le lebile o le mongwe. Ga se botho.

**Quote 28: Setswana**

Tshepo: Ke nagana gore nna ke siametswe kesepetlele. Ke tshepa dingaka le mannese a me.

Interviewer: Jaanong o reng ka ba lelapa la gago, a ga o battle gore ba nne le wena ka matsatsi a gago a bofelo?

Tshepo: Ee, ke a batla. Ba ka nna ba phela ba nketela. Ga se gore ke tla boke le kgakala le bone, ke tla boke le dikilometara di se kae fela. Ba ka nna ba tshwara taxi mmeba nketela ka nako tsa baeti. Le gona ga ke battle go ba imele. Go botoka ga kele mo sepetlele mo. Ke tla ba ka kgona le go tshaba ditshebo tsa batho, ebile ke tla kgona go fokotsa dikoloto. Ga o ya gae o tlamegilego nagana ka dilodi se kae, dijo, ditlhare, di check-up, motho yoo ka go tlhokomelang tsatsi lengwe le lengwe. Gogontsi. Mogodimo ga seobatho ba tlile gophela ba tletse ka ntlu ya gago ba batla gobona gore motho yo o tshwereng ke AIDS o lebega yang. Le gona go tlile go diregang ga nka gatelelwa ke bolwetsi dingaka di se mo gaufi. Ba lelapalaka ba ka se itse gore ba direng. Se ba ka se dirang ke gore ba mphe sapoto ene ka nako eo ke tla bo ke tlhoka ditlhare. Ke nagana gore go botlhokwa go swela sepetleleng. Ba lelapalaka gaeno ba tla phelaba go etela empa o ka se solofele gore ba nne ngaka ya gago. Le bone ba na lemaphelo a bona.

**Quote 29: Setswana**

Mogomotsi: Nagana fela gore batho bao kaofe ba itse gore ke HIV positive. Nka se kgone go di emela tsona tseo.

Interviewer: Ele gore why?

Mogomotsi: O a itse gore batho ba yang. Ba ka simolola go tsenya ba lelapalaka pressure. Ba bue dilo tsa go tsa tsebalege, ba phele ba etile ba tla go bona gore motho wa AIDS o lebega yang. Ga ke batle go nna motho o ba tlholang ba mo sebile letsatsi lotlhe. Nka se tlabise lapalaka ditlhong tse di kalo . . . Se se botoka ke go iphitlha mo sepetleleng, mo e leng gore ke tla bonwa ke ba lelapa laka fela . . . Ka mokgwa o ba tla kgona go tshamela botho story sa gore why ke timeletse. Go dila ka dilo tsa lesa tsa AIDS gogontsi, ga go tlhokege gore le tlhakanye le go seba sa batho.



**Quote 30: Setswana**

Ba lelapa laka ke batho ba ba botlhokwa mo bophelong ba me. Go simolola gompiano ke batla gore ba itse gore ba botlhokwa jang mo bophelong ba me. Batho ba sechaba ka nna ba ya diheleng. Legone ba itse eng ka lerato la nnete. Sa bone ke ditshebo le go tlhakatlhakanya maphelo a rona . . . Batho ba tlile go nna ba seba, go sa kgathalesege gore o ko sepetleleng or okwa lapeng,ba tlile gophela ba seba, go sa kgathalesege gore a o alwala khotsa ga o lwale,ba tlilego phela ba seba. So, use ya go tshaba ke eng? Ka AIDS ga gona mo nka iphitlang teng. Go botoka gore ke nne le batho bao ba nthatang.

**Quote 31: Setswana**

Thato: Ga ke ya gae,ke tlile gokgona go dirisa ditlhare tsa me tsa setswana.Ga se gore tsona di a dira ke fela gore ga di bolo go dirisiwa,seo se raya gore di a bereka. Le gone ba lelapa laka ga ba bologo di dirisa so,ga ke na choice.

Interviewer:Ga o ka bo o le choice o ne o tla tsaya dife? Tsa setswana kgotsa tsa sekgoa?

Thato: Gona jaanong ge ke lwala ke dirisa tsa sekgoa. Ka dirisa Treatment ya rona ya Wellness Programme. Ba re e thusa immune system. Ga ke nyonyorege. O tshwanetse go tlhaloganya gore ditlhare tsa rona tsa setswana di tlhatswa madi,e seng go fodisa AIDS mara go re thusa gore re nne strong.

**Quote 32: Setswana**

Seruwe: Ke batla go nna sepetlelengse se gaufile ko gae. Ga ke nagane gore ba lelalame ba tla nthusa ga ke setse ke lwala,ke batho ba ba siameng ke felagore ka dinako tse dingwe ba na legompha stress. Go bua nnete,ga ba battle go itse gole gontsi ka bolwetsi jo. Ba re bolwetsi bo ke leloka lakae seng la bona. E felake tla reng? Ke ba lelapa la ka, ba botlhokwa mo bophelong ba ka.

Interviewer: Ga ba se go kgathalele ke ka lebaka la eng go le botlhokwa gore ba go etele?

Seruwe: Ka gone ke a ba rata, ke leloko la me . . . le gone ke battle gore ba kgone go sukunyetsa muti mo sepetlele. Ke batla go dirisa muti. Sentle ntle ke battle go dirisa ditlhare tsotlhe. Ga di tlhakane di na le matla. Go na le batho bao ke ba itseng ba ba thusitsweng ke muti.

Interviewer: Thusa ya mothale ofe? Go fodisa AIDS?

Seruwe: Nyaa, e seng jalo, fela gore ba nne le matlale gore ba fokotse ditlhabi.

**Quote 33: Sepedi**

Moeti: Ke dirisa treatent ya wellness program ya rona. Dinyaka di boletsa gore ke dirise yona. Ga ke tsebe gore di a šhoma nna. Dongaka tsa ka dire e a šhoma e bile ke a ba tshepa. Ke shomisa tse tsa rena tsa sesotho go fodisa sejeso. Pele ga sejeso kene ke sena mathatale madi ame a ne a le clean. Morago ga sejeso ba ile ba mpotsa gore ke na le HIV. Ke nagana gore motho yo o mphileng sejeso o ile a mpha le HIV.

Interviewer: E ne e le motho wa monna kgotsa wa mosadi?

Moeti: Ga re itse goremoloi ke mang, le gore ke mang yo e seng moloi. Ka gore ba rere bona AIDS ka sex, go raya gore e be e le motho wa mosadi. Ga ke itse sentle gore e ne elemang

Interviewer: A o raya gore sejeso le HIV ke selo se le sengwe?

Moeti: Tota ruri ga ke itse, se ke se itseng ke gore ke ile ngakeng ya rona ya setswana ya mpolelela gore ke na le sejeso ya be ya mpha muti o nka o dirisang. Tsala nngwe ya ke e ile ya nkopa gore ke ye go bona ngaka ya rona ya sekgoa, eeileng ya ntlhatlhoba ya ba ya mpolelela gore ke na le HIV. Go raya gore ke na le tsona tsothle. Go bua nnete ga ke itse. Se ke se itseng ke gore boloi boteng le gore AIDS e teng.



**Quote 34: Sepedi**

Ke dumela go Modimo. Ke dume go bebelelege re sena bopaki. Ke dumelagore ga o semokeresete o tlile go ya diheleng. Bakeresete ba ya legodimong. Badiradibe ba tlilegosotlega goya goilemme bakeresete ba tlile go nnamo tlhokomelong ya gagwe goya go ile . . . Gore motho a hwe leho le la kagiso ke gore a bone sapoto le tshireletsoya mowa o o tlhohonolofaditsweng.

**Quote 35: Setswana**

Kedumelago Modimo. Ontlitsitsemo lefatshengle, ke ena a mpupileng. Ke dumelagore mokeresete ga a tshabe lesa. Sagagwe ke gore a beye tshepoya gagwe moreneng. Ke nagana gore badiradibe ga ba tshabe lesa e bile ba dumela gore AIDS ga e yoke ka mokgwa oo ba phatthalatsang AIDS ka teng . . . Goswa ka kagiso o tlhoka nnete. E gore o phele o bolelelwa maaka. Nnete e ke go thusa, keka mokgwa oo motho wa ka wa bophelo eleng gore “the truth shall set you free”.

**Quote 36: Setswana**

Badimo ba botlhokwa maphelong a rona.Kedumelagobona. Ka dinako dingwe ke ba etsatsa ditlhabelo. Ga o ba etsetsa ditlhabelo ba tla go tshegofatsa.Ba ile ba nthusa gore ke se tsenwe ke malwetsi mangwe. Motlhomongwe ke na le senwe ka gore ke kgale ke sa ba tlhabele.

**Quote 37: Sepedi**

Ke dumelagobadimo. Ebileke na le mokgwa oo ke buang le bona ka ona. Ka dinako dingwe ke a ba tlhabela, ka tse dingwe ke na le go etela mabitla a bona. Gore ba kgone go go tshegofatsa o tlamegilegore o ba fe sengwe sa dilo tseo di kgobokantseng molefatsheng. Ga o a tlamegagore o ba fe gole gontsi, bonnye bo o nang le bona bo ntse bo lokile. Ga o nagana ka yona,gonwele gongwe kwa o yang teng o tlamegile go fa sengwe gore o fumane sengwe.

**Quote 38: Setswana**

Thato: Nnale ba lelapa la ka re dumela go Modimo. Re ya kerekeng sontaga sengwe le sengwe. Le bana ba ka ba ile ba kolobediwa kwa kerekeng. Jaaka ke setse ke kile ka gobolelela,ke tswa lapeng la segosi,ko e leng gore re dirisa badimo,re a ba tlhabela go supa tlhompho. Ga ke le lapeng laka ke mokeresete,ga ke ya gae kwa Mozambique ke rapela badimo.

Interviewer: Wena personally o dumela mo go eng?

Thato: Tsotlhe, Modimo o a phela,ke na le bopaki ba seo.Badimoba seleba nna teng since ka na ko tsele tsa kgale. Se se raya gore ba a phelale gore ba na lematla a go thusa kgotsa go sulafaletsa motho bophelo. Go nna ke bolokegile,ke di sapoto tseo bobedi.

**Quote 39: Sepedi**

Modimo le badimo ba a dirisana. Jaaka monna wamoAfrika kedumelamo badimong,ebile ke dumelagoModimo segolo. Mebele ya rone ga e botlhokwa se se botlhokwa ke mewa ya rona. Go tshwanetse gwa be go na le lefele le mewa ya rona e yang gona. Ke raya gore fa re tlhokofala re a itse gore mebele ya rona e ya 6 feet ka mo tlase ga lefatshe,mewa ya rona yane?

**Quote 40: Sepedi**

Ke dumela gore ga ke swa,ga nako ya ka etla ketla swa ka kagiso. Ke na le sapoto,leModimoo phelaa ntshegofaditse ka nako tsotlhe. Ga gona se se itumedisang go feta seo. Ana AIDS e teng, ana ga e teng,Modimo o re rata kaofela.

**Quote 41: Setswana**

Leso ke lesa ngwanaka. Ke mowa o tswang mmele ga go fete moo. Leso ka bo lona ga le botlhokwa. Re tlile go swa rotlho. Se se botlhokwa ke gore, re tlile go swa yang. Go amogela Modimo, ke yona fela tsela. Ga o amogetse Modimo ga go reye gore o ka se boife lesa. Go amogela Modimo go thusa ka gore o tlile go kgona go iketla . . . Ga ke dumelele taba e ya gore ke na le kokonatlhoko ya AIDS e ntshwenye thata. Modimo o re rata rotlho, ke ka moo a ileng a romela morwa wa gagwe a e esi go tla go re swela dibe. Rotlho re bana ba Modimo.

**Quote 42: Sepedi**

Ga go bonolo go swa lesa la AIDS. Ke nagana gore ke ne ke ka kgona go itshokela lesa ga nkabo ke ile go bolawa ke sengwe fela e seng AIDS . . . Ga ke sa kgona, go boima . . . Ga se fela ka mokgwa o batho ba go lebang ka teng, o tshoswa gape ke se o se boning fa o leba seipone . . . A o kile wa bona motho o o nang le full-blown AIDS? . . . Nna nkile ka mmona . . . Ba basesane bo bo tseneletseng. Gatwe ga o ka ba phunya monwana ga go tswe madi, go tswa metsi . . . Ka boammaruri . . . Ga se botho seo. AIDS e tla go sotla mokgwa o e leng gore ga o ise o ke o sotlege ka ona. Go boima go phela ka HIV empa go napa go feta lesa go swa ka AIDS.

**Quote 43: Setswana**

Ditoro tse di masisi le go phela o nagana . . . O phela o robotse o labile marulelo o nagana masana a kokometse. O lapisa tlhaloganyo ka go phela o nagana. Le gona o nagana ka bo “ga nkabo ke sale ka”. Selo seo sefa stress, se botlhoko. Ba ka nna ba go fa tsona di-counselling tseo tsa bona tsa go tura, le ba lelapa la gago ba ka leka go go sapota ka mokgwa oo ba ka kgonang ka teng, efela go a tle go tle nako, mo mothong o mongwe le o mongwe, gore o iphitlhela a le esi metsotsonyana. Metsotsonyana eo o leng mongwe ka yona o labile marulelo, o lwa le madimone a gago, e ka tlosa dimgwaga tsotlhe tse o kileng wa di tsamaya tsa counselling . . . Go swa lesa la AIDS ga se motshameko, ntumela, ke itse seo ke buang ka sona.

**Quote 44: Setswana**

Le ga o ka amogela leso jang kappa jang o ka se tsogile o tloitse botlho jwa go swa leso la AIDS . . . Ee, leso le a boitshega, efela AIDS yona e worse.

**Quote 45: Setswana**

My dear, AIDS e tla go tlhakanya tlhogo . . . Wena o nagana gore gore lebaka la gore batho ba ba nang le AIDS ba bone go le botoka gore ba ipolaye gona le gore ba bolawe ke AIDS ke lef? Batho ba ba nang le AIDS ba bona go le botoka gore ba ithuntshe, kappa ba ikgwagetse, kgotsa ba dirise poison go na le gore AIDS e ba bolaye. A seo ga se go bolelele sengwe? . . . Matsapa a a tlišwang ke AIDS ga se a a ka itshokelwang.

**Quote 46: Setswana**

AIDS e etsa gore leso le be boima, tota ruri ga ke bone gore leso le la gago la kagiso le ka kgonega yang ka matsapa a AIDS.



**Quote 47: Sepedi**

Ee, Ee, AIDS e oketsa poifo ya leso . . . E bile ke nagana go totobetse gore gore motho a bone leso le la gago la kagiso ke fela fa re ka tla mmogo re le sechaba mme ra lwantsha stigma sa AIDS.

**Quote 48: Setswana**

Ke na le full-blown AIDS. Ke rapela gore nka itshwela gona jaanong pele ke imela batho . . . Ke ne ke lakaditse gore nkabo e le kgale ke sule gone jaanong efela ke sa le mo. Ke a itse gore ke a felelela. Ke a ikutlwa. Tota ruri go utlwiswa botlhoko go itse gore ga gona gore nka tsoga ke ikutlwa botoka, go itse gore go simolola jaanong jaana dilo di tlile go nna worse. Lebaka la go tswela pele ke lefe? Ga gona se se ks nthusang, le ditlhare di ka se nthuse. Ke na le matlanyana a go dira dilwana dingwe ka bonna. Ke sa le motho, e bile ke batla gore ke swe ke le ena. Ke eng nako ya ka e sa tle gona fela jaanong. Nka se utlwi botlhoko ga nka itshwela gona jaanong.

**Quote 49: Setswana**

Ga ke tshabe lesa. Ana ke na le AIDS ana ga ke na yona ke ne ke ntse ke tlile go swa. Ga go reye gore ga o le HIV negative o ka se swe. Lesa le tlile go re etela rotlhe. Lesa la kagiso le ikaegile ka maikutlo le maitshwara a motho ka nako ya lesa. Ke amogetse ntlha ya gore ke motho, nka se phelele ruri. Sengwe le sengwe se se phelang se na le bokhutlo. Nka se letle ntlha eo e nkgoreletsa go phela bophelo ba ka ka mokgwa oo ke ratang ka teng. Ke amogetse ntlha ya gore ke a swa, mongwe le mongwe o tshwanela ke go dira jalo.

**Quote 50: Setswana**

Ke na le mmereko o o kgotsofatsang e bile ke a tlhomphega. Go nna AIDS co-ordinator ya mo Impala go mpha maemonyana mo sechabeng ke ka moo batho ba nang le go ntlhompha . . . Mmereko o wa ka o dira gore batho ba ntlhompe, e bile o mpha maemo, ene ke nagana gore ke tla kgona le go swa lesa la kagiso ka seno.

**Quote 51: Setswana**

Ke batla gore o ntlhaloganye sentle. Monna wa me ke motho o o siameng. Bothata ke fela gore ke monna. Ka dinako dingwe ga ke tsaya meriana yake ke kgona go bona gore o a tenega. Gona ga a ise a nkobe, seo se raya gore o santse a nkgathalla. Nka se solofele go le gontsi go tswa mo go ena ka gonne ke nna ke leng molato. O dira seo a ka se kgonang. Ka dinako dingwe ge a sa nthuse ge ke mo tlhoka ke kgona go tlhaloganya gore lebaka ke lefe. Ga se gore o dira jalo ka letlhoo, ke fela gore o a bo leka go nna monna. Le gona banna ke popego ya Modimo, ro na basadi re maikutlo a gagwe. Ke ka mokgwa o dilo di leng ka teng. Ga ba lwala ke tiro ya rona gore re ba tlhokomele empa ge rona re ka lwala okare re dira sebe se se ka se itshwarelweng.

**Quote 52: Sepedi**

Banna ba tswana le dinja. Ga ba nyaka ntho go rena re a ba fa, ge re nyaka ntho mo go bona ga ba nyake go kwa selo. Ke nagana gore mosadi o manna wa gagwe a mo tlhokomelang e bile a mo fago sapoto a ka kgona go hwa ka kagiso. Go napa go le boima go bona monna wa mothale oo o le mosadi . . . Banna ga ba na maikutlo. Basadi ba a sotlega, se se kwesang botlhoko le go feta ke gore re na le pelo tsa go loka.

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