Dying and Death From AIDS: A Mineworker’s Perspective

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Seminar 2003/15

Paper to be presented at 16:00 on Friday, 18 July 2003, in Anthropology and Development Studies Seminar Room (D Ring 506)
Introduction

This paper deals with the issues surrounding the fears of dying and death as a consequence of AIDS. The concern of this paper is on death that does not occur suddenly but rather eventually with time and gives an individual a chance to speak last words and receive responsive farewells. It does not focus on immediate death but analysis a prolonged death, hence the reference to AIDS.

Furthermore, the paper analyses these fears by concentrating on two kinds of deaths, a “good death” and a “wild death”. The good death, which is the focal point of this paper, is commonly understood to have two rather different meanings. These meanings, according to Howarth and Leaman (2001: 209) are derived from two divergent Greek Etymological sources. The first is “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 is “to die nobly”, to be prepared to meet death, which is the social meaning of being prepared for death.

In everyday practice, though, the idea of physically dying well and dying socially well tend to converge. Howarth and Leaman (2001: 210) indicated 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 the caregiver’s realities – the needs of the dying as assessed by family or health care professionals. Part of the reason why this study emphasises the need to understand the elements of both good and wild death from the perspectives of the AIDS sufferers, in specific cases, miners living with AIDS.

Nowadays, a good death seems to be a theoretical concept or a myth, separated from reality. This theory of good and wild death, especially among people dying from AIDS, raises a number of questions for this paper: can we really achieve a good death in real life or is it just a myth? If it is real, how can we help people suffering from AIDS to achieve it? Is it possible that fearing death is part of a natural process of dying? And lastly, do HIV positive miners or miners suffering from AIDS related diseases fear death at all and
if they do what causes their fear of death? What do they fear the most about dying and death? Is it the afterlife they fear, the indignity of dying from AIDS, or the actual death itself.

Though this paper is in no way meant to be judgmental, it is clear that whatever the answers may be to these questions, AIDS patients are suffering more – not physically, perhaps, but emotionally. This paper does not provide full or sufficient answers to the above-mentioned questions. Its purpose is far more modest, as an explanatory effort to open up what is hopefully a fruitful line of inquiry.

Therefore, the aim of this study is to investigate the existence of a good death. Different authors (such as Clinton 1999, Corr et al 2000, Hart et al 1998, Seymour 2001, WHO 1990) on dying and death argue that a good way of dying does exist in the real world and they provide different characteristics of this good death to support their argument. These authors, furthermore, argue that this good death must be promoted at all costs. The aim is specifically to investigate the argument that dying wildly is neither inhumane nor unnatural.

To analyse this problem statement the paper will be divided into five sections. The first section deals with the relationship between good death and wild death. It also analyses the different possible reasons as to why people fear death by AIDS. This section will give us a better understanding of the Sociology of dying and death. The second section explains the different themes used in the fieldwork to explore the kind of death that exist amongst the mineworkers of Impala. Section three will, therefore, deal with the research design of the paper and the research results will be discussed on the following sections i.e. section four. The last section will give an overall conclusion.

**Understanding the relationship between dying, death and AIDS**

Since the purpose of this paper is to explore the fears of dying and death caused by AIDS, the nature of AIDS deaths, whether they are good or wild, one may then ask the following question: “Why study mineworkers alone?” Well, the answer to this question is very simple. Male labour migration has been and it is still the strongest mode of getting
employment in South Africa and some other countries. Lurie (2000: 343) shows that ‘more than 2.5 million legal, and many more illegal, migrants are drawn to work in South Africa’s mines, factories and farms from rural areas within South Africa and from neighbouring countries’. The emphasis in this discussion is on mineworkers as a form of migrant labourers simply because ‘gold mines have drawn large numbers of workers from all over the sub continent... more than 800 000 men were employed on these mines’ (Lurie, 2000: 344).

There is a strong correlation that exists between HIV infections and the mineworkers in South Africa. This correlation is not a South African problem alone but a global issue. Decosas and Kane (1995: 2), for example, did a study on migration in Uganda and their data analysis indicated this strong correlation between HIV and migrant labourers. Similarly, Manuel and Aditi (2001: 4) reported a high correlation between migrant labourers, STD and HIV in EU countries such as Belgium, Sweden and Germany. There are many different reasons given by many different literatures on the escalating rate of HIV infections among the mineworkers. Such as the excessive use of single sex hostels, the existing lack of knowledge, strenuous working conditions and prostitution, among others.

The concern with the Sociology of dying and death is to try to bring back a good death, that is, if it has ever existed. A good death is regarded as a thing of the past profoundly because of the use of advanced technology. The next discussion, which explores the debates around the good and the wild death, gives a much deeper understanding of the topic.

Whereas a good death is natural, a wild death is unnatural, inhumane, shameful and solitary. In our society today, a good death has been replaced by a wild death. This may be due to external factors such as advanced technology or incurable diseases such as AIDS. O’Gorman (1998: 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, asserted O’Gorman (1998: 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 as an unhealthy way of dying.

In a good death social support is a very important aspect in 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 & Sonnega, 1992: 111). House (1981, quoted in Celentano & Sonnega, 1992: 111) categorised those functions to include instrumental (assisting with the normal daily functions of life), socio-emotional (sympathy, affection and affiliation) and informational aid (provision of advise, 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 adversed 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.

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. 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 surrounds 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.
In a good death the dying person ‘acts as a manager of ceremonies, presiding over his or her last days of life, conducting farewells, giving blessings and seeking pardons and approaching the end of life in ways he/she has witnessed in childhood’ (Hart et al, 1998: 2). 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.

There is no best way to cope with death. There is only the way that, each person, develops as a manner of coming to terms within their capacity at any given moment. Even so, by ensuring that the dying person, during their terminal illness, are relieved from pain and suffering, are able to talk openly about death, have enough control and autonomy over their life, have prepared for their departure, dealt with their fears of the afterlife, and that they were responsible for selecting their location of death, we can be certain to eliminate, to some degree, their existing fears of dying and death (Clinton, 1999: 101-103). In this manner, they might have a chance of experiencing a peaceful death.

Because the paper is on death caused by AIDS, it then becomes vital to review the ways in which the fears associated with the disease, contribute to the existence of a wild death.

The world response to AIDS is structured by the politics of inequality, poverty and oppression. But 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 (2001: 7) 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.

This paper focuses on HIV/AIDS because of the reported negative attitudes surrounding the epidemic. Due to the high level of stigma and fears surrounding AIDS, the tendency to view People Living With AIDS (PLWAs) as statistics and not as human beings, numerous governmental scandals in relation to uncertainties about AIDS, major loses; ranging from loss of financial security to loss of former lifestyles; that are associated with
the disease, it becomes very difficult for people to accept death as a consequence of this epidemic.

When you hear the word AIDS, it probably sounds frightening. Any discussion of the disease brings about a variety of responses. Fears about death and disease are among the most common reactions (Puentes, 1992: 199).

The fear of AIDS is generated through its social consequences such as stigmatisation and avoidance. Howarth and Leaman (2001: 72) 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. 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 is strongly linked to loss and death. The word AIDS strikes fear into the hearts of people and HIV diagnosis is wildly regarded as a death sentence, despite advances in both detection and treatment.

AIDS is one of the many stigmatised diseases that result in multiple problems with diagnosis. According to Sellin, Faltz and Davis (1992: 19) 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’. These attitudes can results in discrimination in housing, employment and access to health care.

High levels of AIDS infections pose a serious threat not only to individuals themselves but also to South Africa’s emergent democracy. AIDS leads to a tragic loss of life. It cast fears into the hearts of the 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. Thus, the future of this country, with regards to AIDS, may be shaped by the decisions and actions of the individuals in choosing to die a good death.
The fear generated by the death of AIDS is also due to the fact that PLWAs are not viewed as human beings but rather as a statistic. McCarroll (Quoted in Teguis & Ahmed, 1992: 12) points out the importance of not viewing PLWAs as a statistic, but as persons deserving of compassion and love. To illustrate his point, he used the example of a one-year-old boy named Aaron who died of AIDS at the tender age, by 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 statistic.

People also fear death as a consequence of this epidemic because they feel that AIDS will, in the long run, bury South Africa before poverty can even be alleviated and the tragedy is that our government seems to be doing nothing about the matter. Instead, the government has targeted poverty as the nation’s most urgent problem. The government’s confusion in dealing with the epidemic, and its reported scandals, increases the civilians’ fear of dying and death. Firstly, as an example, a few years earlier, in 1992, a National AIDS Co-ordinated Committee of South Africa (NACOSA) was set up. Its intention being to convene a national strategy to deal with the problem of HIV/AIDS. NACOSA consisted of consultations amongst a host of NGOs, churches, trade unions, government departments and political parties. In 1994, the NACOSA strategy was officially adopted as a governmental National AIDS Plan. But ‘by 1996, on the eve of the World Conference on AIDS, the plan was deemed to have been a failure’ (Posel, 2003: 26).

Secondly, the health education initiative headed by the Department of Health was in turn ‘severely compromised by a corruption scandal (the so-called Sarafina affair) which hit
national and international headlines’ (Posel, 2003: 26). Thirdly, in 1997, an inter-ministerial Cabinet Committee on AIDS was constituted, with Thabo Mbeki as chair. Its aim was to broaden and deepen the state’s response to the worsening epidemic. This time, another political scandal, ‘the virodene affair, achieved national and international prominence, along with continuing accusations from NGOs, doctors and others, of government ineptitude and lethargy in tackling the epidemic’ (Posel, 2003: 27). Fourthly, things changed rapidly when our President, Thabo Mbeki, stood on national television announcing that “HIV does not cause AIDS” which, according to him, is due to some scientific explanations. Fifthly, the following year, 1998, South Africa took a turn for the worst when the Department of Health announced that it would no longer provide AZT to pregnant women because of its toxicity and cost implications (Soal, 2001: 24).

Teguis and Ahmed (1992: 12-15) reports that AIDS deaths are also feared because of the numerous major losses (ranging from the loss of financial security up until the loss of former lifestyles) that are associated with the disease. The following table was created as a way of explaining these losses in a simpler term.

**TABLE 4: Major Losses Associated With HIV/AIDS and their Explanations**

<table>
<thead>
<tr>
<th>Loss due to AIDS</th>
<th>Explanation of the Loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of financial, job or health care security</td>
<td>Many adults due to single or childless status have never taken on life insurance or adequate health insurance policies. One in five PLWAs has no medical insurance.</td>
</tr>
<tr>
<td>Stigmatisation and social ostracism</td>
<td>People are denied entrance to schools, restaurants, and the like.</td>
</tr>
<tr>
<td>Loss of physical contact, touching</td>
<td>Some health professionals enforce unnecessary precautions and infection control practices, further isolating the patient.</td>
</tr>
<tr>
<td>Isolation</td>
<td>Some dentists, physicians, and hospitals transfer PLWAs out or refuse to treat them so that “real” patients will not be driven away.</td>
</tr>
<tr>
<td>Loss of future, hopes,</td>
<td>Sometimes the pain of knowing that one will never attain</td>
</tr>
</tbody>
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dreams and goals | something is deeper than the pain of having attained something and lost it.
---|---
Loss of youth | PLWAs losses vigour, energy, physical appearance, particularly with Cytomegalovirus or Kaposi’s Sarcoma.
Loss of privacy | Loss of privacy is entailed in having to reveal one’s most private life.
Loss of support of family of origin | In contrast to Cancer patients where the family often rallies and become re-involved, PLWAs often need to lie and tell their family they have Cancer. PLWAs have also experienced rejection due to AIDS phobia.

There were about five main themes that I explored in the field in an attempt to answer the already mentioned research questions in the beginning of the paper. The themes, to a greater extend, helped in determining the kind of death that exists amongst the HIV positive miners of the Impala mines.

**Theme 1: Communication Breakdown (Socialisation)**

With this theme, the paper, explored the fears of dying and death by concentrating on the possible communication difficulties that may exist between the HIV positive mineworkers and their families and friends and between these miners and the medical staff. This is because the theory on good and wild deaths suggests that in order for a person to die peacefully they must be able to talk openly about their illness and their fears of death. The argument is that for the so-called good death to exist, the patients must be given an opportunity to express their feeling (Teguis, 1992: 165). It is further argued that this can be achieved only if the lines of communication between patients and their medical staff or their family members are opened.
Theme 2: Dignified Death

The paper explored the fears of dying in relation to uncomfortable psychological responses such as feelings of loneliness, vulnerability, alienation and mutilation that, when repressed, provide deep sense of suffering in the HIV positive mineworker. It has been shown that the lonelier a dying person becomes the more likely the wild death to occur (Bloch, 1988: 11). Isolation is not recommended in a good death. Therefore, this theme explores the extent of support the patient receives, whether the support is good enough to determine the kind of death that will be experienced.

The concern was also on the level of dependency on others, which may cause an HIV positive miner to feel childlike and helpless, ashamed and resentful. The argument here is that peaceful dying involves full control of one’s self. In a good death, a dying person must not depend on others for many things, especially financial support. This dependency will make the dying feel depressed by making him feel like he is a burden to others. The research studied the fears of death in relation to a sense of loss of control over events in one’s environment, which lead to a diminished sense of personal dignity and self-esteem.

Theme 3: Advanced Technology

During the fieldwork, questions were asked about the respondents’ location of death, which lead to the achievement of some sort of control over one’s life. It has been indicated that people should not be judged according to their location of death. Dying at a place of one’s choosing means dying with dignity (Seymour, 2001: 131). In other words, this argument states that if the HIV positive mineworker chooses to be hospitalised in a mine hospital, they will be at peace with themselves.

Theme 4: Death and the Afterlife

In relation to this theme, the research project addressed the fears of death by focusing on the concern with one’s relationship to God and the hereafter, or one’s relationship to ancestors and with existential issues such as the moaning and purpose of one’s life. This
Theme was divided into two parts. The first is only relevant to those respondents who believe in the existence of God and heaven and hell. Those who follow a more religious route will fear the afterlife and believe that by accepting God, as their saviour, will allow them an entry into heaven. The second part addresses fear of death by concentrating on the belief of ancestral powers. According to Howarth & Leaman (2001: 16) this belief is more African and will be more applicable to African/black respondents.

**Theme 5: Causes of Death**

The aim of this theme was to try to evaluate the extent to which the cause of death influences the fears of dying. The argument here is that since AIDS is characterised by fear and stigma it is therefore reasonable to assume that its death will be feared the most.

The next section explains the research methodology that was used to explore this topic in the fieldwork.

**Research Design**

The research was conducted at the Rustenburg Platinum Mines. There are many mines in Rustenburg that produce platinum but this research focused only on the Impala Platinum Mine. The methods used here were ethnographic as they gave description of death and AIDS, in concrete circumstances, rather than an abstract and hypothetical analysis of the phenomenon of dying and death. Because my research was qualitative, a combination of two sampling techniques were used, quota sampling technique and the snowball sampling technique.

I specifically chose quota sampling because I knew some of the parameters of the target population. I knew that I wanted to interview mineworkers, who are HIV positive, they can either be male or female, black or white, between the ages of 25 and 45. In this manner, the sample collected resulted in a data base that has some overall characteristics as the target population even though no random sampling strategy was used. As Goldenberg (1992: 162-163) suggests, because there is no control over biases in such a strategy, my data collection, then, fell into the trap of taking a route of least resistance, in
so doing, I ended up interviewing only those respondents who were accessible and amenable, and failing to seek out those who were not.

By using the above-mentioned method my sample could not reach the desired sample size. More respondents were required in order to make sense of the results. And because of that, I then introduced a snowball technique in my research. The aim was to expand my sample size with the respondents who have the same qualities in question. The already selected respondents that were drawn by using a quota sampling technique were then asked to nominate others who have the same qualities as theirs. Some nominated two or three people while others refused claiming that the people they knew preferred to keep their status confidential.

A face-to-face interview style was used to acquire information from the selected respondents. To the majority of my respondents, a semi-structured interview guide was followed. A tape recorder was used, with permission from other respondents, together with a notebook for helping me record non-verbal communication. To some respondents, both approaches were unacceptable. These respondents claimed that the use of a tape recorder and a notebook were too intimidating to them. To respect their wishes, I only talked to them without noting things down or saving information on a tape recorder.

Only twenty-two respondents were interviewed. Nine 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, three of these twenty-two respondents were involved in informal interviewing where no tape recorder, notebook and semi-structures 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 grouped together to form a focus group where a tape recorder, notebook and a semi-structured interview guide were used.

This means that my research project consisted of 17 face-to-face interviews. All 17 respondents were HIV positive, Impala employees, between the ages of 25 and 45 only two of the 17 were female. All the 17 respondents were blacks and some were hostel dwellers while others were residents of nearby villages, namely, Phokeng and Luka. Two
respondents were not South Africans, of which, one was originally from Mozambique and the other from Lesotho. The majority of the interviews for these 17 respondents took place in the Impala hospital at the HIV/AIDS department and were conducted, mostly, by Mr. Webster Diale [Head of the HIV/AIDS Department of Impala].

Only one focus group was conducted. This focus group consisted of 5 male AIDS co-ordinators, counselors, and peer educators of the Impala mines, who are, themselves, HIV positive.

In the next section is a summary of the research findings. These findings are discussed according to their specific themes. The findings clearly indicated those results that contradict the already stated theory and those that support it.

Research Findings

Theme 1: Communication Breakdown (Socialisation)

The main motive behind this theme was to try to find out the extent to which HIV positive miners receive both social and professional support from both their doctors (and nurses) and their family members (and friends). The purpose was also to determine whether these miners view their socialisation process, after being diagnosed with HIV, as normal and whether they are satisfied with that particular social and professional support they receive. Teguis (1992: 165) is one of the writers who argued that being in the presence of others can ensure a degree of acceptance. The more HIV positive miners are surrounded by their loved ones, the more they are to accept their disease and the death thereof. This acceptance will ensure, to some degree that miners with HIV die a good death. They first need to recognise and feel the support of those around them.

During the analysis of this theme it appeared as if the majority of my respondents had no complaints with regard to their doctors and nurses. Almost all respondents were quite pleased with the treatment and support they receive from their medical staff. ‘My relationship with my doctors is good. I trust them, I think that they are doing their job properly because they did arrange counseling for me’ (Mr. Sebina, 41, Phokeng). The
problem of social support is not, mostly, professional. The problem is experienced between family members and friends. According to these miners, family members and friends are not quick to accept their HIV positive status. Even when they accept it, it is mostly with great difficulty.

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 . . . It appears as if they accept me only because they have to. I am family too [Mr. Moagi, 39, Phokeng].

In most cases, the difference in social support between the doctors and family members is that doctors and nurses have in-depth knowledge of the disease while family members and friends rely on the information they receive from the media and on what is said on the streets. Usually this information that is said on the streets is misleading and full of misconceptions (myths). And because of that family members and friends of HIV positive people tend to fear this disease and anyone associated with it. This lack of information on HIV/AIDS makes it difficult for them to accept the fact that one of them is suffering from the disease.

Lack of knowledge and education is not only a problem for friends and the family members of HIV positive people but is also a big problem for PLWAs. When these people are firstly diagnosed with HIV, they prefer to share the news with their loved ones. But they are usually afraid to do so because they don’t know how other family members would perceive them. ‘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’ (Setlogelo, 24, Luka). They are afraid of being rejected by their own blood relatives. To them it is better to keep the news to themselves. What the family members do not know can not hurt them. Lying about their HIV positive status is perceived as a good lie. They are, in a way, protecting their family members from unnecessary hurt and humiliation. Besides, they do not want to lose the love, friendship and support they receive from them. If they
confess to their families that they’ve got Cancer or TB instead of AIDS, they are sure they will get support and love instead of rejection and hatred.

Therefore, the findings of these interviews totally supports the arguments brought forward by different authors, earlier in the dissertation. For people to die peacefully they need to be able to talk openly, without fear of rejection, to their doctors, nurses, relatives, and friends about their illness and they should be able to share their fears of death with others. They need to know that they can rely on their loved ones for any kind of problem they might face in life, including HIV/AIDS. These PLWAs believe that with constant education come understanding and then acceptance and lastly support. Thus, without a doubt, socialisation plays a major role in the dying process of any person, including those dying from AIDS related diseases.

**Theme 2: Dignified Death**

In this theme, questions were asked in relation to the financial position of PLWAs and their capacity to have children. The theoretical argument here is that the more an HIV positive person relies on others for financial support, the more he/she is to feel like a burden. PLWAs need to feel in control of their lives in order to die peacefully. They don’t want to die knowing that they were a burden to someone else. They need to be able to take a good care of themselves up until their moment of death. According to Olivier (1998:101) to die with dignity means to live with one and human dignity should be protected up until the moment of death. Many respondents agreed that being able to maintain their HIV positive status gave them a sense of self-control. By being able to buy medicines for themselves, to be able to follow a healthy diet without help from anyone gave them a greater sense of self-esteem and person dignity (Clinton, 1999: 103).

To the majority, the nice thing about being in control of your finances is that you can do whatever you wanted. No one can tell you what to do. You are absolutely free to make your own decisions. ‘I feel I have 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’ (Thapelo, 29, Lefaragatlha). Relying on
others gives them power to control your life by dictating what you must eat and why, places you should visit, even selecting people suitable to talk to you. For them, being in control of one’s finances meant being in control of one’s mind. They seem to be pleased with the fact that they are able to make up their own minds and receive respect for that.

One female respondent reported the difficulties of relying on others for financial support. For Mmatladi, lack of finances reduced her level of self-worth and as a result she felt like she had no dignity. She did not feel like people respected her, especially for what she often engages in for survival. She explained her situation as follows:

I am now unemployed and dependent [she was once an employee of Impala mines]. I live on hand outs 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 [Mmatladi, 37, Freedom Park].

Some of the respondents who have money felt that AIDS is too ‘powerful’ for them. They believed that you can 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 lives. They feel so helpless to the point that, working makes no difference to them. ‘I want to be in total control but as we are told this AIDS can defeat you one day. I think AIDS will always own our bodies and the way we think. . . My body is AIDS body now.’ (Mr. Mokgatlhe, 43, Phokeng).

The issue of having children, as an HIV positive person, was not viewed as a major problem for these miners. This was especially true for the married ones with children. Those who are single argued that they might still have children, thanks to Nevirapine. They do not think that AIDS reduces their manhood by taking away their ability to reproduce. This was a shared feeling amongst those respondents who took part in the focus group.
Dignity is defined in a form of material possession. Respondents agreed that money speaks all languages. They argued that a rich HIV positive person stands a better chance of having the support of his family and friends as compared to a poor one. If you are HIV positive and poor, you are no longer viewed as a part of the family but your family members and relatives see you as another mouth to feed. Siblings seemed to be more open minded if HIV positive relatives can clearly take care of themselves. Some respondents reported that if you were the breadwinner, your family members would totally support you and go to the extent that they even help you hide your HIV positive status. This is simply because they rely on you for financial assistance. Therefore, money plays a major role in the lives of those facing death as a consequence of AIDS. The more financially independent they are the more at peace they will be.

The issue of reproduction in assessing manhood of HIV positive miners was totally discarded. They argued that even some of those people who are HIV negative have problems with having children. They believed in the help of Anti-retroviral Treatment (ART) especially Nevirapine. It is important to note that this was especially true for those married miners who already have kids. Some of those who are still single were a bit unclear on the issue.

Dignity plays a major role in peaceful death. These miners believed in earning people’s respect in order to die peacefully. They further believed that they, themselves, would never rest in peace until they know that at least they lived with pride.

**Theme 3: Advanced Technology**

Lofland (1975: 15) states that the place of death is important in a good death. It is argued that the dying needs to be responsible for choosing their place of death if they wish to die peacefully. This argument is brought about by our excessive use of advanced technology. Seymour (2001: 131) believes that today’s technology deprives people the chances of experiencing a good death. Being hospitalised with life supporting machines is not viewed as good for the dying. The fact that you are surrounded by doctors and nurses everyday and not by your loved ones injects fear into the hearts of those dying. A
good death is explained as one in which the dying is surrounded by those he loves the most in the comforts of his own house (Lofland, 1975: 15).

The other side of the coin, relating to this argument, is that hospitals and hospices lead to a good death. For anyone to die peacefully they must be relieved of anything that can cause pain and suffering. The hospital medicines and machines reduce pain and, as a result, they are not viewed as detrimental to the existence of a good death. Clinton (1999: 101) believed that medical intervention should be used as a way of relieving pain and not as a means of prolonging life.

For that reason, technology, for the dying person, may be viewed in two ways, as a disruption to a good death. The unexpected recovery of a person, due to medical intervention, is regarded as technological failure rather than success. Technology, therefore, became an intervention in a natural cause of the dying process (Seymour, 2001: 131). Secondly technology can, be viewed as a good thing because it can eliminate painful stimuli in the dying person. The fact that the dying person died in a comfortable, pain free zone, where help, if needed, was readily available, makes death somewhat peaceful (WHO, 1990: 52).

Thato (39, Mozambique) agreed with Lofland (1975: 15) when he said, ‘When my moment of death comes, when I’m too weak to continue working, I would like to be taken back home. I would like my family to take care of me. I don’t want to die among strangers. I want to be surrounded by love and those people I know I can trust . . . I want my spirit to go where others have gone.’

Tshepo on the other hand stating that:

I think the hospital would be best for me. I trust my doctors and nurses. 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 [Tshepo, 28, Luka]

For this theme, the results of the interviews agreed with the theory reviewed on two specific basis but they also contradicted it on one particular case. The results seem to support the theory on the issue of pain reduction. Respondents agreed that it is important to eliminate pain and suffering if one is to die without fear. Eliminating pain also helps the dying to accept his death. They, secondly, pointed out that respondents need to be given an opportunity to choose their location of death. The actual place where death takes place is not important. What is of the utmost importance is the fact that an individual chose the place and feel comfortable with that particular place. What is best for the dying is what they, themselves, say is best and not what the doctors and members of their family think is best.

There is, however, a part of this theme that greatly contradicts the theory. According to theory, technology is a disruption to a good death (Seymour, 2001: 131). A good death is one in which death is viewed as a family experience, where the dying is surrounded by their loved ones (Lofland, 1975: 15). O’Gorman added to this by saying that a good death does not exist today and that it is replaced by a wild death, which he calls a clinical death. Isolating the dying in a hospital and placing the doctor’s role at the centre stage of the life of the dying is considered, by O’Gorman (1998: 4), as unnatural, inhumane, and wild. The argument was found not to be the case for the respondents who were interviewed in this research. Actually, respondents preferred to be hospitalised, as they believed that it would reduce their existing anxieties about death. They believed that in hospitals the doctors can help them, not only by eliminating pain and suffering, but by also making certain that the departure is as smooth and as peaceful as possible.
Theme 4: Death and the Afterlife

Authors, under this theme, argue that for anyone to die peacefully they need to prepare themselves for the afterlife. They described the afterlife in two ways, as a western religion where people would fear God or heaven and hell, and as an African tradition, where the fear of death would be directed towards the ancestors. It is believed that the dying, no matter what their race might be, will have to deal with their 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. Even Kubler-Ross (1969: 74) suggested that every dying person has to go through the process of bargaining, where they negotiate, mostly, with God to exchange their health with something else.

Miners interviewed also emphasised the importance of preparing one’s self for the afterlife before death. Some believed in God, others believed in ancestors while others argued that both approaches are important. Those who believed in God stressed their point of view by saying:

I strongly believe in God. I believe in the bible even though we don’t have prove. 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 holly spirit [Kabelo, 32, Impala hotel].

On the other hand, those who believe in ancestors argue 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 because I took some time without remembering them [Thabo, 29, Impala hostels].

Others combine the two approaches, as they believe that you need both the ancestors and God in order to die peacefully. They addressed the issue by saying:
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.

There may not be proof for the existence of the afterlife but all respondents believed that when we die our souls and spirits have to go somewhere. They may differ in ways that they express their fears of the afterlife but they all agree that there is life after death. They all stressed the importance of having a good relationship with the hereafter. In this way, the research findings then agree completely with the theory. Respondents argued that they would be able to die in peace and without fear if they know that they have prepared themselves well for the afterlife. They further argued that even if they did not believe in the existence of the hereafter they would still prepare themselves for it, in case it does exist. After all, no one knows for certain.

Theme 5: The Cause of Death

When questions were asked under this theme the aim was to try to specifically evaluate the role that AIDS plays in increasing the fears of dying and death. The argument simply states that since AIDS is characterised by fear and stigma it is then reasonable to conclude or assume that its death would be feared. When respondents were asked questions in regards to this issue, most of them indicated that death will always be feared with or without AIDS. They argued that it does not really matter what the cause of death is. We, as humans, can never get used to it, no matter how often it occurs. The trick is not to reduce the fear of death because it is impossible, what is important is to help the dying to die in peace with him/herself. Dying at peace or dying a good death does not necessarily mean that you no longer fear death. Fearing death is a natural process of dying. Fear is part and parcel of death.
Of all the respondents I talked to on this issue, one particular female respondent from Rustenburg Township called Tlhabane, was able to show the intensity of her fear. She also believed that it does not really matter what a person dies from, he/she will fear death just as well as an HIV positive person. She reported that death was, and it is still, and will probably always be fearful to her. She expressed her feelings clearly when she said:

Death is simply air out of your flesh, nothing more. Death itself is not important because all man dies … 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 love us all otherwise He would have never sent His beloved son to die for our sins. We are all God’s children.

Rape, car accidents, violence, or AIDS does not make a difference. Death in itself will always be a fearful act. All my subjects confessed that they fear death and they indicated that their fear is not necessarily due to the fact that they are HIV positive. They said that even an HIV negative person will also fear death.

Conclusion

The results of this research showed the importance of social groups in the life of a dying person. A human being is a social being. Most respondents indicated that the support that is usually needed is not the one received from doctors and nurses. Professional support did not play a major role in the lives of those facing death. What was important to them was the social support. They needed to know that they could rely on their relatives and friends for moral support. For the dying, the support of doctors and nurses was not important because it came from strangers not from those dear to them. The doctor’s support will always be there. It is a doctor’s duty to support his patients. Doctors do not, usually, give their support with love and care; they only do it out of professional obligations.
The dignity of the dying also played an important role in determining the kind of death that might be experienced. The argument was that, to achieve a good death people need to die with dignity. This was not only a theoretical argument. Respondents of this research agreed completely with this statement. They explained their dignity in a form of material possession. They said that in order for the dying to be respected, they must be able to take a good care of themselves. They believed that the family members and friends wouldn’t easily reject a person if he/she were rich, especially if that person appeared to be the breadwinner of the house. For these miners, money is everything; it speaks all languages.

The fact that a good death is one that takes place at home where the dying is surrounded by the loved ones was completely discarded. For my respondents, a good death is one without pain and suffering. This means that in order to die peacefully you will need to be surrounded by doctors and nurses in a hospital or hospice. The advanced technology provided by medicines and machines (hospital equipments) is greatly accepted. This is, however, not to suggest that dying at home is considered as wild. If the dying chose to die at home, he would then die peacefully because that is what he wanted. Therefore, the place of death itself is not important. What is important is that the dying was given an opportunity to select the place of death. Deaths that takes place at hospitals, hospices or at the comforts of one’s home are all considered good depending, of course, on the fact that the dying was responsible for selecting the place.

The results also showed that with or without the necessary prove, the afterlife does exist. Respondents argued that if our bodies get buried six feet under, then, our souls must also have a special place where they can all be buried. The only way they could explain it was with the belief that there has to be a place higher than the one we live in. That there has to be a place where all our souls meet and this place was named the afterlife. The afterlife took different forms. Some believed that heaven and hell represent the afterlife while others argued that the life after death is a place where our ancestors live. For these reasons, respondents, then, concluded by saying that for anyone to die peacefully they must prepare the departure of their souls or spirits.
For all my respondents, the causes of death did not determine the kind of death that will be experienced. Many of them believed that with or without AIDS they will die a peaceful death. They maintain that no one can get rid of the fears of death because they are natural. We can only reduce them in order to find peace with ourselves.

The results of the study, then, conclude that a good death does exist in the real world. It is not a myth. This good death then becomes one in which the dying is supported by the family members and friends, where the personal dignity of the dying is highly protected, where the dying is given an opportunity to select their place of death, and where the dying prepares for the hereafter.

References


