

WOMEN, HIV/AIDS AND STIGMA : AN ANTHROPOLOGICAL STUDY OF LIFE IN A HOSPICE.

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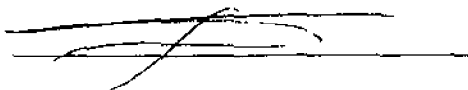
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ABSTRACT

HIV/AIDS is one of the disasters of modern times. The fact that there is no known cure for HIV/AIDS has resulted in religious explanations being sought for the disease. HIV and AIDS have historically been associated with homosexuality and promiscuity, invoking blame, intolerance and stigma. The implication of sex, a life-giving preoccupation, in the spread of the epidemic, further complicates matters as ideas of pollution and contamination are evoked. These attitudes translate into lack of support for infected and affected people. HIV/AIDS eats away at the body, leaving one with a sense of fading away and a negative self-image. The hospice movement humanizes the care of people with AIDS by offering unconditional support in a context where hospitals are overwhelmed and other conventional sources of assistance are threatened by the specter of HIV/AIDS.

Declaration

I declare that that this thesis is my own unaided work. It is submitted for the degree of Master's in Social Anthropology in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other university.



Nokuthula Lucinda Skhosana

This 31st day of October, 2001

Dedication

To the women who are the subjects of this thesis who shared their intimate selves with me.

To the women across the globe who valiantly live with HIV/AIDS.

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Chapter 1

Introduction

One of the greatest disasters of modern times has been the HIV/AIDS epidemic. UNAIDS estimated that, by the year 2000, 36.1 million people were living with HIV or AIDS (UNAIDS 2000:4). The AIDS epidemic has not only had a devastating impact since its appearance 20 years ago, it has also posed a major challenge to previous medical accomplishments. The fact that biomedicine has not been able to come up with a cure for AIDS has undermined its efficacy. The advent of AIDS has challenged the perception that scientific knowledge has surpassed all natural disasters. Although inroads in understanding the nature of the disease and ameliorating its effects have been made, not all affected populations benefit from these developments. In poorer countries and for poor members of rich countries, HIV infection is still tantamount to a death sentence. Among such communities HIV/AIDS is also couched in discourses of sin and punishment, and people remain mystified by the nature and causes of the disease. As a result notions of HIV/AIDS as an infliction of the deviant are pervasive and this provides a false sense of immunity to those who do not consider themselves to be part of the vulnerable 'other group' (Brouard 1993). In South Africa, despite massive media interest and academic research on HIV/AIDS, little is known about how poor people have understood and coped with this disease.

The aim of this study is to disaggregate the socio-cultural factors that bear on the experiences of black women living with HIV/AIDS in Soweto, a township in the Johannesburg area of the Gauteng province. The study seeks to document the impact of the disease on relationships, looking at how the subjects of the study interact with others; how they interpret their illness and how they live with a disease that is so infested with negative socio-cultural meaning. In this study, the opinions of the women interviewed are crucial as the aim is to focus on the lived experience of HIV/AIDS from day to day. Another important aim of the study is to map the women's experiences before they were admitted into the hospice program. An integral component of this study is therefore to trace the process of

transition from township residence with family and friends to living in the hospice. As documented later in this thesis, the transition is not permanent as the subjects of this study move in and out of the hospice depending on their health status. So the hospice experience becomes diluted when they go home and the implications of this is documented in later chapters. The stigmas and taboos that surround the disease have also been major points of concern. The objective of the study is to understand the subjects' experiences of living with HIV/AIDS in a township context characterised by unwarranted fear of contamination and prejudice against people living with HIV/AIDS.

In South Africa, more and more people have been infected with HIV while many others are living with AIDS. Amongst AIDS practitioners and the wider public, there is a general consensus that biomedicine has come to a dead-end as far as AIDS prevention is concerned. Social scientific ways of understanding illness and the research methods thereof are, perhaps, better suited to assess the experiences and to unravel some of the issues that bear on the epidemic. Moreover, the gendered nature of the experience of living with HIV and AIDS has generally been overlooked in medical analysis, despite its importance in the social impact of the disease. This thesis seeks to show how the subjects of the study battle with HIV/AIDS and the difficulties inherent in this struggle. This thesis aims, in addition, to 'give voice' to those people who have been marginalized by their gender, socio-economic status and by the accompanying stigmatisation.

Even though there are several South African anthropologists working on issues of AIDS and sexuality, for example Leclerc-Madlala, Isak Niehaus, Terri Collins, Jonathan Stadler and Eleanor Preston-Whyte, very little has been published. In addition, the hospice phenomenon is a new development in the townships where no anthropological research has been conducted. The significance of studying the care of people living with AIDS (PWAs) and the need to see how the hospice will be shaped by the rising numbers of PWAs in its surrounds, have been overlooked. This research was done in an urban township setting occupied by people of various socio-cultural and economic positions. Local knowledge and constructions of the disease reflect this multiplicity of cultures

merging to form a township point of view (see Chapters Four and Five). Anthropological data on HIV/AIDS has largely been confined to 'groups' where members all have similar socio-cultural backgrounds. Although the township represents a mélange of people from different ethnic groups, many of whom still trace their roots to rural settings, this thesis focuses on a 'township identity' as this has been found to be most salient when dealing with issues of HIV/AIDS. At no stage during my research did informants wish to return to their rural homes in search of healing, ritual or religious salvation.

Literature Review

HIV/AIDS as a social phenomenon

Although AIDS is an epidemic, a disease which theoretically is not confined to a particular category of people or country, the implications of infection with HIV are not the same for the 'haves' and the 'have-nots'. Increasingly, AIDS is becoming the disease of the poor: they are infected most frequently and are most affected by the epidemic because of their life conditions. Altman distinguishes between two AIDS epidemics, that in the world of plenty and that in poor countries (1994). He suggests that the crucial distinction is not one of epidemiology as suggested by the World Health Organization, but rather one of

... political economy, both as it applies to the availability of treatment and vulnerability to infection. In most cases the spread of the virus will be closely correlated to economic conditions, as poverty not only makes effective education and provision of condoms and clean needles more difficult, but also it often deprives people of the choice to make use of these even if they are available. HIV/AIDS will become yet another arena which reproduces already existing dimensions of inequality (Altman 1994: 3).

Economic conditions, however, are one factor in the HIV/AIDS epidemic. Botswana, for example, a relatively wealthy country, has one of the highest rates of HIV infection, indicating that other forces are at play in the spread of HIV.

Shifting the focus from a medical viewpoint to an understanding of the social, economic, political and cultural dimensions of this epidemic highlights the powerful political and economic dimensions of this epidemic. This focus on the HIV/AIDS epidemic renders it a concern of the social sciences. In the

current absence of a cure, it is widely agreed that change in behaviour is the only choice available to control the disease. Despite huge attempts to change behaviour, this has not happened, possibly because behaviour is influenced by a plethora of factors which all need to be addressed.

HIV/AIDS as an anthropological concern

Anthropology is particularly well-positioned to inquire into the multiple factors that bear on the disease both for prevention purposes and in attempting to mitigate the impact for those who are infected and affected. AIDS is a disease that has become loaded with cultural meaning because it is transmitted mainly through sex - an activity which is supposed to be life-giving and/or pleasurable, depending on religious and other convictions. Through AIDS, deviant sexual practices and sex outside of wedlock has come to be linked with sin, deviancy, contamination and death, invoking accusations that individuals have breached various taboos. It is precisely this embeddedness of sex and sexuality that makes anthropological inquiry and understanding particularly suitable to the study of HIV/AIDS. There is an urgent need to understand people's behaviour in the context of social, cultural, political and economic factors. These factors shape and influence behaviour to a greater or lesser extent and in multiplicity of ways. It is through understanding the role that these determinants play in the day-to-day lives of individuals that positive behaviour change may be fostered. Anthropology has the methodological tools to study the social experiences of those who are afflicted by this disease while simultaneously 'keeping' the humanity of those who are infected and affected in the professional discourse on AIDS. As evident in the medical literature on this epidemic, overlooking people's social experiences of living with the disease in favour of medical terminology and statistics does little to assist these people in their day-to-day living.

Blame and counter-blame

Farmer points out that since HIV/AIDS was discovered it has been associated with blame and accusation (1992). Symptoms of what is known now as AIDS were first observed among the gay population in America in the early 1980s. The disease was then dubbed GRID (Gay-Related Immune Deficiency). The perception was formed that AIDS was a gay disease and, therefore, a problem

confined to a particular group with a deviant lifestyle. These perceptions led to 'risk group' notions that had the unfortunate result of providing those outside the 'risk groups' with a false sense of safety. AIDS – identified as a gay disease – also fed into fears and anxieties associated with homophobia (Weeks 1995). Ulin et al. point out that once Haitians were also affected by the disease, the disease came to be known in America not only as a disease of men sleeping with other men, but also as a 'Haitian' or 'African' disease thus further 'othering' the disease (1996). It was popularly agreed that gay men from America contracted the disease from Haiti, a popular tourist destination for them (Farmer 1992). This construction of AIDS as an 'African' disease fed into myths of Africa as a dark continent where moral standards were 'obviously lower' (Brouard 1993). Haiti also did not want to 'own' the disease and responded by blaming its presence on global powers that not only render them underdogs but also seek to lay blame on them. Just as Americans blame Africans for the disease, Africans blame the disease on Americans. Brouard notes that in South Africa, the acronym AIDS is said by many black South Africans to stand for 'American Idea to Destroy Sex' (1993). Ironically, this need to locate the cause and the origin of the disease to foreign sources is influenced by the perception that the disease invades innocent people from the outside. This perception occurs despite the stereotype that AIDS is the disease of the 'deviant' other. Blame, accusation and complacency have characterized public and individual responses to the disease. These reactions have eclipsed the serious nature of the AIDS epidemic and should, possibly, be seen to constitute another epidemic that has impacted negatively on efforts to harness the disease.

The spread of the disease from men to women was blamed on bisexual men (Farmer 1992). However, as more and more women were infected, especially in Africa, there was a growing awareness that AIDS was increasingly becoming a heterosexual disease. In Africa, however AIDS was never a homosexual disease and men and women were infected at the same rate. With time, it came to be predominantly women who were infected in Africa. The American pattern in which the majority of those infected were men came to be known as Pattern 1 of the spread of the disease. The African pattern in

which more women were increasingly infected than men was termed Pattern II. Sobo asserts that the perception that AIDS is a disease of men resulted in women being diagnosed late in the disease process, especially in America where this perception was firmly entrenched (1995).

Towards understanding the origins of HIV/AIDS-related discrimination

Although AIDS is a relatively new disease and its discovery has evoked seemingly unprecedented reactions, McCombie argues that other infectious diseases such as Hepatitis B have prompted the same public reactions (1989). 'Panic, unfounded fear of contagion, social exclusion and blaming the victim for perceived taboo violation all occur with other infectious diseases' (McCombie 1989: 59). The knowledge that HIV is theoretically not an easily transmittable virus tends to be confined to researchers and other 'knowledgeable' people. People on the ground continue to believe that the virus can be contracted through casual contact. Despite the fact that the modes of transmission are known, there is also a 'you never know' attitude which has prompted people to avoid contact with infected individuals (Sobo 1995). These 'risk group' and 'risk behaviour' perceptions exist alongside one another. The 'risk group' perception stems from earlier perceptions of AIDS as a gay men's disease. 'Risk behaviour', however, encapsulates notions of the disease not being confined to a particular group, but spread through specific behaviours such as promiscuity. There is also the perception in the popular imagination that HIV/AIDS is like the flu: easily spread and readily contracted. This idea prompts the unfounded fear that informs the stigma and avoidance invariably associated with the disease. As one informant said to me:

...it attacks in many ways. Let us say I have bed-sores and I go to the toilet, when you sit it invades you. When one urinates on the seat, it invades you.

The fact that the virus remains dormant in the body and can thus be transmitted even without the awareness of the infected person further fuels hysteria. The same interviewee went on to say:

It is also not the fault of the person who infected me. She did not know what was wrong with her. That is why I say anyone – no one should convince themselves that they will not be infected. This thing is like flu. It is in season.

This idea, that AIDS is easily spread and is so contagious as to be 'like flu' is reinforced by the knowledge that there is no way of overcoming the disease. Weeks argues that the failure of medicine to come up with a cure for this disease has revived the need to seek a moral explanation for it (1996). The efficacy of perceiving the AIDS epidemic as a divine retribution could be found in the shift in moral values over time. The AIDS epidemic is a phenomenon of modern lifestyle that tolerates and encourages sexual diversity. This is, at least, true in the secular realm. The advent of this epidemic has brought the relationship between religion and sex into focus again. Homosexuality and promiscuity go against the biblical instructions that sex should be used for reproduction within the family unit. Those who, in their quest for pleasure, get infected are seen as deserving punishment that takes the form of AIDS (Brouard 1993). The AIDS crisis has therefore been used by the church as justification to return to 'biblical values, to family values, to abstinence and monogamy' (Brouard 1993: 17).

This religious perspective is, of course, not pervasive and the medical profession has adopted a different means to address the AIDS challenge. Urquhart posits a clinical construction of AIDS (1995). He argues that in order to 'fight AIDS' it was necessary for the medical profession to present the conditions that are symptomatic of the different diseases that comprise AIDS as one disease.

For that reason there has been a clinical construction of AIDS as developing through time, in defined stages: from seropositivity to the development of 'signs' of AIDS (ARC or AIDS Related Complex) to AIDS as something identifiable and whole in itself. AIDS is thus re-conceptualized to fit the discourse of a disease (Urquhart 1995: 33)

The unfortunate side-effect of this conceptualisation of AIDS as a disease is that the diagnosis of HIV, and later of AIDS, has become equivalent to a death sentence. This is particularly the case where HIV and AIDS are not seen as different stages of the disease. Among a large percentage of the population in South Africa, the diagnosis of HIV continues to mean death (see Chapter Five). As suggested in the following quote, the significance lies, not in the medical condition, but rather in the social death which people experience:

Medicine, in its clinical conception of AIDS, reproduces a specific social construction of AIDS as inevitable and fatal which uses itself, for the medical profession is increasingly concerning itself with future predictions about the disease based on these conceptions. In using these

conceptions, medicine is “creating a class of lifetime pariahs, the future ill ...(and in the process) bringing a social death before a physical one. The result is that medicine, in developing a construction it can understand, abandons the patient as doomed...” (Urquhart 1995: 34).

This means that cultural factors are also important when dealing with PWAs, and as can be seen

in Chapter Four, women living with HIV/AIDS are particularly concerned with covering up their sero-positive status in order to function as ‘normal’ individuals in their cultural setting. This has dire implications for the spread of the virus. According to Urquhart, an HIV-positive diagnosis leads to a fatalism that cannot be overcome, especially where self-efficacy and self-determination have been compromised by other life events (1995). As demonstrated in later chapters of this thesis, this diagnosis compounds an existing and rooted sense of helplessness in the face of other challenges.

Knowledge and behaviour change

Helman asserts that concepts of what constitutes ill-health, of causality and treatment are shared and are embedded in the wider culture (2000). This knowledge is, however, not confined to people with the same cultural background, it may also be shared with others. Moreover, knowledge systems change as new influences come to bear on them. It is therefore difficult to understand and to pinpoint the cultural understandings that inform people’s actions. This is particularly so with HIV/AIDS and other STDs. There is a general consensus that grassroots people know the basic facts about AIDS – how it is spread and can be prevented (Sobo 1995; Crewe 1995). However, as there is not a significant change in people’s behaviour and in the incidence of the disease, it appears that there is a mismatch between what is expected, based on the observation that people are in possession of the knowledge, and the rates of infection. Wilton makes the point that new information about health and ill-health is actively engaged with by individuals and groups and compared to pre-existing beliefs of health (1997). Any information which diverges greatly from these pre-existing beliefs is rejected or modified (Helman 2000; Wilton 1997). Sobo further notes that knowledge does not replace other ways of knowing, it is instead added to knowledge already held (1995). In addition and as mentioned above, knowledge alone will seldom lead to sustained behavioural change as behaviour is rooted in other life-influencing factors.

Traditional perceptions of contagion still influence behaviour as can be seen in the fear of casual contact.

In perfect situations, where there are no mitigating circumstances knowledge directly translates into positive changes in attitudes and behaviour. This has not been the case with HIV and AIDS, precisely because competing beliefs about the disease exist. Sobo isolates the notion of risk perception and argues that although a person's perception of his or her risk plays a significant role in his or her response to that risk, people tend to underestimate their own risk for contracting HIV (1995). This is because the prospect of infection is seldom personalized. Even those people whose behaviour puts them at risk tend to engage in biased comparisons that lead them to believe that others are at higher risk. Biased risk perception is, however, not the only obstacle to behavioural change. Fatalism, unequal power relationships between sexual partners and using sex as a commodity and aid in survival are some factors that might cause individuals not to practice safer sex despite knowing the dangers of unprotected sex. Collins and Stadler make an interesting observation based on their study of youth culture in Bushbuckridge in the Northern Province of South Africa (2000). They posit that what public health practitioners might understand and refer to as 'high risk behaviour' such as condomless sex, the youth in the study understood as play and not 'real sex' which requires some sort of responsibility.

Here jolling [heterosexual relationships before marriage] is associated with recreational sex and other recreational activities such as going out, dancing and drinking. As such, jolling is differentiated from the legitimate sexual relations that take place within marriage. Indeed, in focus group discussions, recreational play was frequently contrasted with romantic, 'true love', relationships, in terms of levels of responsibility and expectations (Collins and Stadler 2000:332).

This points us to Bolton's argument that, in many cases, AIDS researchers do not define sex in the terms of those who are being studied (1995). There is always the assumption that sex is a particular behaviour that has the same basic meanings for everyone. As the above discussion has, however, shown, intervention measures that do not consider emic worldviews are likely to fail.

Public health education on AIDS and behaviour change

Acorn argues that efforts to educate the public about AIDS adopt the stance that individuals need to change their behaviour in order to curb the rate of spread of the disease (1988). This approach is in line with the view that ^{*}the individual has a responsibility for his or her welfare and a social obligation to minimize the risk he or she represents to others (Horn 1994). In response to this Diaz argues, in his study of Latino gay men's experiences, that AIDS reduction interventions and health education programs fail to recognize that sexual behaviour is embedded in social, cultural and economic structures (1998). In other words, sexuality cannot be understood as a different and disjointed aspect of the life of the individual. This also means that ^{*}the risk of HIV infection and the experiences of people living with HIV and AIDS cannot be fully understood unless there is an overt recognition that socio-economic factors leading to poverty and cultural dimensions play a role. AIDS education campaigns that are not sensitive to cultural, as well as economic and political issues in sexual behaviour are not likely to engender positive change. As Sobo points out, the individualistic focus used by AIDS practitioners, who are often white intellectuals, is inappropriate and 'makes little sense' to people in poorer populations and of other cultures who may not prioritise individual needs and desires (1995).

Gender issues pertaining to HIV transmission

It is clear that men and women do not experience HIV and AIDS in the same way. Nonetheless, as Squire points out, the discourse on AIDS has largely ignored the gender dimension of the experience (1993). The politically correct term: 'people living with AIDS' is misleading in that it represents all infected individuals as similar and does not show the importance of gender in the context of AIDS. This thesis counteracts this viewpoint by focusing on women in particular and ^{*}argues that poor, disempowered women are particularly vulnerable to contracting the virus because of their gender and their socio-economic circumstances. In trying to understand AIDS and gender, some insight may be gained by examining other sexually transmitted diseases. Venereal diseases have generally been perceived as the property of the already stigmatised body, namely that of the woman. The male body was thus at risk of being contaminated by the female body. Wilton postulates that at the beginning of

the AIDS epidemic when it was still conceived as a gay disease, the gay male body was used as a substitute for the ills that are said to be embodied in women's bodies (1997). There is an inference of femaleness as a sinful state (Wilton 1997). In addition, and as this thesis goes on to show, the women who are the subjects of this study are further marginalized by their physical condition and they struggle to survive in a cultural environment where women, in particular, are stigmatised for engaging in the types of sexual 'transgressions' that lead to HIV infection. *Where gender has been factored into the AIDS discourse, women's involvement in the epidemic is confined to passing the virus on to men (more so if they are sex workers) and children (thereby becoming AIDS mothers), thus disregarding their own experiences of living with the disease (Squire 1993).

Scholarly efforts pertaining to women and HIV have largely focused on the high risk of infection in sex work (Campbell 1999; Pamela 1997; McKeganey 1994). Such authors have overlooked the many black women in South Africa who are single, unemployed and have children to support. These women do not necessarily think of themselves as sex workers although they may depend on 'gifts' and other favours from a number of lovers for survival. It is thus not only professionals in the sex industry who are at heightened risk of HIV infection. *Most women living in the former townships of South Africa, by virtue of their low socio-economic status vis-à-vis their male counterparts and their dependence on men as providers, are at risk. *This risk is further entrenched through a complex set of relations between men and women which leave women disempowered and unable to negotiate practices of safer sex with their partners (Wilton 1997). The risks associated with *attempts to negotiate safer sex, such as desertion, material deprivation and even physical abuse may discourage women from even broaching the subject. Leclerc Madlala, Stein and Sobo* point out that women's requests that their partners use condoms, for instance are seen as a sign of mistrust or admission of unfaithfulness (2000, 1999, and 1995 respectively). In any circumstances, negotiating condom use in marriage or a stable relationship is problematic because a precedent of not using condoms has been set. In addition it is commonly assumed that the man has unquestionable conjugal rights and may control not only his wife's behaviour

but also the nature of the sexual encounters. Of course, heterosexual relationships are not always characterized by domineering men and submissive women. The interplay is more complicated than this as both parties might have more leverage at different points in the relationship. Morrell highlights the important point that gender does not necessarily prescribe behaviour (1998). The essentialist way of seeing men as intrinsically in control and women as passive, ignores the complex nature of relations between men and women. This has implications for HIV/AIDS prevention as other, not immediately apparent, factors may determine the use or non-use of condoms in heterosexual relationships over and above the conventional argument that 'women cannot negotiate safer sex practices with their domineering male partners'.¹ The conditions that determine condom use are beyond the scope of this thesis. Nonetheless, some discussion on how women, who are already infected with HIV, have changed their perceptions of condoms remains necessary. Other authors have pointed to how rituals such as marriage may serve to transfer women's reproductive capacities from one male-headed family to another. Although it can sometimes be construed as reinforcing the secondary status of women, leaving them with limited choices in their sexual lives (Schapera 1971), a significant number of women do not enter into such contracts and, as shown in this thesis, they should not only be seen as passive victims of their circumstances.

Issues affecting women in the context of HIV/AIDS

Although there are numerous conventions that should protect the rights of all people irrespective of who they are, in most societies, there are many people who do not enjoy these benefits. In South Africa, poverty, illiteracy and lack of economic resources render these rights meaningless. Here, people with AIDS (PWAs) receive inadequate medical and financial assistance and, as shown in Chapter Two, are often subject to extreme harassment by those authorities and medical personnel who are meant to assist them. Notwithstanding all these negative experiences and despite the fatal consequences of AIDS, there has been the positive effect of raising questions about human rights and rights to bodily integrity. The topic of human sexuality and intimacy is steadily taking root in the South African public

agenda. However, in some sectors of society AIDS as a subject still remains taboo, making it difficult for those who are sero-positive to 'come out' and thereby be in better positions to gain the support of others. While it can be assumed that both men and women find it difficult to disclose an HIV positive status to sexual partners, this thesis argues that South African women find this more difficult than men (see Chapter Four). *The blame that invariably accompanies infection does not make disclosure easier.* Women find themselves in a no-win situation whereby hiding infection may cause as many problems as disclosure. Keeping infection a secret increases the risk of infecting one's partner in a context where a woman cannot negotiate the use of a condom without revealing that *she is HIV-positive, and thus opening herself to abuse and stigma.* Even if the woman discloses her status to her sexual partner, studies show that the husband is likely to continue conjugal relations with her while refusing to be tested himself (Leclerc-Madlala 2000:29). Chapter Four examines the question of disclosure in more detail.

The dilemma of whether to disclose an HIV-positive status also feeds into the reproductive choices that women make, bearing in mind, of course, that very few women realize the right to make such choices on their own. Strebel argues that HIV-positive women fear that, should they fall pregnant, their babies may be infected with the virus (1994)¹. This has triggered calls for such women to avoid pregnancy or to undergo abortions if already pregnant. There have also been calls for the mandatory testing of all women who wish to fall pregnant *and the bizarre suggestion that women should be sterilized if they test HIV-positive* (Strebel 1994). These calls are not sensitive to the realities of women's lives. To start with, they assume that women can make autonomous decisions regarding *childbearing. Moreover, these calls place considerable constraints over women who, in many societies, can only gain a positive social valuation through the children they give birth to.* These calls also fail to

¹ Despite some risk of virus transmission through breast milk, women, especially in developing countries are generally encouraged to continue breastfeeding even if HIV-positive because of the benefits to the infant. Such advice confronts women with yet another set of no-win alternatives (Strebel 1994:17).

consider women's religious and moral reservations about abortion and sterilization. Such calls can only serve to support the declaration made by Juhasz that: '[s]omehow AIDS has become just one more systematic oppression of the already oppressed in our society, exaggerating and multiplying the compromised positions under which women live their lives' (1990: 103). Another factor to consider is that the use of condoms may prevent HIV infection but interferes with women's wishes to fall pregnant. There is, as Strebel has commented, a need to develop prevention methods which do not get in the way of conceiving and clear guidelines for safe conception (1994). Female condoms which are believed to give more control to women in HIV prevention are not without problems. They are expensive and thus inaccessible to the majority of women. In addition, using these condoms can produce noises during sexual intercourse thus alerting men who are not supposed to know about their use.

HIV/AIDS in South Africa

UNAIDS estimates that of the 36.1 million people worldwide infected with the virus by the end of 2000 70% are in Sub-Saharan Africa (UNAIDS 2000:4-5). These estimates can be further broken down: 44% of those infected worldwide are women, but in Africa this estimate increases to 55% of total infections, that is 8 out of every 10 women infected worldwide, are resident in Africa. These figures allude to the fact that Africa and women, both with a history of marginalization, carry most of the world's HIV load. Within South Africa there are added complications to bear in mind. South Africa has a renowned legacy of institutionalised racial inequality. For decades resources were concentrated in the so-called white minority group at the expense of the so-called black majority. These inequalities are mirrored in the demographics of HIV/AIDS in the country today. An antenatal survey carried out in 1999 estimates that there are over 4 million people in South Africa living with HIV/AIDS (Meerkotter et al 2000:448). Given the statistical background of the South African population, a significant number of them are black (women), further mirroring the historical inequalities that continue to characterize the nation. As, however, South Africa does not publish HIV figures according to race, this cannot be verified.

The role of the media in the HIV/AIDS dynamics

The media in South Africa has played a large role in portraying AIDS as an issue only in the black population. This can be attributed to the fact that black people are usually the poorer sector and therefore the effects of HIV infection are more readily apparent than amongst their more affluent white counterparts. More significantly, a poor township woman, for example, is more likely to concede to an interview if she thinks that she stands a chance of getting financial and other assistance by participating. Her situation is likely to be more desperate than her white counterpart and so will be the measures she takes to access help. A recent Ministry of Health publication called 'What did you hear about AIDS today' (n.d.) cites the fact that desperation can induce one to partake in ventures that promise money and/or free treatment. The privacy of individuals and rights to informed consent become secondary to perceived benefits in desperate circumstances. The 'Sowetan', a township newspaper that is circulated throughout Gauteng, for instance, is more likely to publish a story of a woman who is ostracized by her community and desperately needs help from the wider community, than a story about rich PWAs and their problems. Parker and Kelly further argue that the media coverage of HIV/AIDS in the country has been characterized by sensationalist headlines that differ markedly from the text in the article (2001). The text itself has tended to be shallow, demonstrating a lack of knowledge of the subject and has been judgemental. Patton notes '[w]hile the media have been instrumental in raising awareness about AIDS, the reportage has consistently misinterpreted the basic concepts of HIV, sensationalized faulty research and selectively reported on conflicting data' (1990:26-27).

The issue of HIV/AIDS has, unfortunately, also been used as a political weapon in South Africa. The recent death of the presidential aide Parks Mankahlana possibly from AIDS-related complications, and the fracas that this particular death caused was, in my opinion, symptomatic of a deeper issue than 'the public deserves to know'. The story was a scoop for the media. Mankahlana had publicly denied the importance of AIDS by saying that an important medical report on AIDS deserved to go into the dustbin. The fact that he was also linked to the president whose stance on AIDS has engendered much outcry, did not help. The president had made a remark that HIV does not cause AIDS. He later

rephrased his statement to say that blind acceptance of conventional wisdom about AIDS would be irresponsible, especially in Africa where the disease manifests itself differently and has not responded well to interventions imported from elsewhere.

Understanding stigma

As already mentioned, South Africa has a history of segregation along racial lines. The tendency to divide into 'us' and 'them' seems to be playing itself out in the dynamics of HIV and AIDS. This propensity gives rise to the stigmatisation that is so pervasive in HIV/AIDS discourse, together with the moral tone that surrounds it. Goffman's (1968) work on stigma and its management is concerned with the everyday interaction of what he calls the 'normals' and the 'deviant'. His work focuses on the management of the self in social situations. Goffman argues that there are conditions, especially those that involve some sort of potential stigmatization, that interfere with rituals of everyday interaction. In keeping with Goffman's theories, PWAs anticipate being judged and stigmatised and will, thus, seek ways to protect themselves. AIDS, as an illness that attacks the body, brings forth stereotypes of how those who are infected look, triggering reactions that interfere with normal social interaction between those who are infected and those who are not. Alcorn concurs that the imagery that surrounds any disease may shed light on how it is constructed in the popular imagination (1988). Moreover, stigmatisation also reflects status and according to Williams, '[a] stigma, then, is really a special kind of relationship between attribute and stereotype' (1987:139), where the stigmatised are assigned an inferior status relative to the rest of the society. The 'known-aboutness' of the stigmatising attribute triggers a chain of secondary consequences, some of which will be discussed in Chapters Four and Five of this thesis. Sontag in *AIDS and Its Metaphors* also examines the nature of stigma through an historical analysis of how illnesses have been perceived (1989). She argues that it is not the mortality rate of the disease that engenders fear in the population and, therefore, stigma, rather it is the impact of the disease on the individual. According to her, it is the diseases that disfigure the face that are prone to being stigmatised. AIDS in Africa manifests itself through the wasting of the individual, disfiguring

and making him or her a shadow of his or her former self. The likely reaction to such a picture is repulsion and fear. Even those who are infected may also exhibit the same reaction when faced with other people bearing the same illness as they share notions of what is normal with the rest of society. This tendency to internalise the negative judgement of others and make it a standard for measuring one's worth is detrimental to the well-being and adjustment of the infected individual (Diaz 1998).

METHODOLOGY

This research project was a logical progression from my previous research on women's reproductive issues, albeit in a rural setting. That research project highlighted the differential power relations between men and women in relationships, although these were not always cut and dried. This research project seeks to unravel urban women's experiences in the context of a stigmatised disease such as AIDS. The methods used to come to grips with these experiences had to be flexible so as to capture the nuances and complexities that characterize individual as well as group experiences of living with HIV/AIDS. This is a difficult topic to research: HIV/AIDS and sexuality remain private and sensitive issues. The methods used, therefore, were dictated by the nature of the question and the personalities of the informants. One of the primary aims of this research was to demystify PWAs by understanding them as people, and not as pariahs who are awaiting a humiliating and painful death. The challenge was to get these women to trust me as someone who was interested in them as human beings, as women and as mothers and not only as PWAs.

This research was undertaken at a hospice in Soweto. The hospice services people with all types of terminal diseases, not only AIDS. Fieldwork was carried out between October 2000 and January 2001 with a two week break at the end of December. After a brief investigation of possible research sites I opted for the hospice. The reasons for this included the fact that the hospice is fairly new in the township and I was interested to find out how it was perceived by those who are involved with it, how it operated and what role it played in the lives of PWAs. Moreover, the hospice presented me with a sample of women with whom I could have close daily interactions. The women also came from different

parts of the township, had different experiences with the common denominator of having been diagnosed with HIV or AIDS and their involvement with the hospice. After some negotiation with the coordinator I was granted access to do my research there. My first impression of the place, formed as I came and went during these negotiations, was that it was gloomy and housed people on the verge of death. I was scared. These feelings surfaced from time to time as I was doing fieldwork. For most of the time, however, I experienced the hospice as a normal place and the impression of perpetual gloom I had initially formulated diminished during fieldwork. At times, I came to enjoy my stay there as I made friends with some of the women who took part in this project. Sadly, some of these women have subsequently died. The fact of death could not be escaped at the hospice but life went on. When I got too involved and depressed, I would take time off and come to the University to do some work and to socialize. At some point I felt desperately in need of debriefing and counselling. Such services were understaffed and I could not justify why I needed them so I would take time away from the hospice and do something different. The hospice, although an NGO and a separate entity, is situated on the grounds of a provincial clinic. Counselling services were only available at the clinic for people who used the hospice. The counsellor from the clinic had close ties with the hospice. However, there was always a long queue of people who had been referred to him.

Although I always tried communicate why I was there, my role at the hospice was baffling to most people, especially those with whom I did not have everyday interaction. The hospice was a busy place with various people coming in and out, people from religious and community organizations brought in prayers, well-wishes and sometimes donations, sick patients and visitors came and went. Invariably someone would ask if I was also sick. There were also volunteers who were like me 'not sick', but they spent most of their time in the kitchen or tending to patients in the admission wards. I spent most of my time 'hanging out' with those who are in the day-care area, although I did a stint in the kitchen every now and then.

There was some resistance to my presence as a researcher. I was not formally introduced to the patients,² and I had to do this myself. On my first day of fieldwork I was mistaken for a volunteer as I helped in the kitchen for most of the day. I decided to come in early on my second day so that I would have the advantage of having made myself feel at home by the time those coming for day-care arrived. This worked to a certain extent, but it was a different group from the one that came in the day before. On the third morning of my fieldwork I still had not said why I was there. I recognized some people from my first day and I felt very uncomfortable. I then decided to approach individuals at strategic points and tell them why I was there. I had come from the kitchen and I had gone out for fresh air (as I had used a different door, I was not aware that other people were also outside), and I stumbled on to a group of younger women. They were seated under a tree and, if I did not wish to appear rude, I had no choice but to go to them. One of them asked why I was at the hospice and I seized this opportunity to clarify my position. I told them that I was a student at Wits and I was doing a research project on women's experiences of being diagnosed HIV-positive. This is not easy to say in Zulu. I did not have adequate words to explain myself. As I was trying to say it I could feel that some listeners were not happy with this. The women voiced some of their unhappiness, asking questions like why did I choose the hospice, did the coordinator give me permission to do this research and what was I going to do with the findings? These were legitimate questions and they gave me the opportunity to explain why I had chosen the hospice as a research site, that I had been granted permission but they were not compelled to participate if they did not wish to and that this would not affect them negatively in any way. I emphasized that I was a student doing this as a requirement for my degree and, therefore, had no power, overt or covert, over them or their relationship with the hospice. I also emphasized that I would

² I have since come to the conclusion that it would have been difficult to for the coordinator to introduce me to everyone as a researcher on issues to do with HIV/AIDS. Although there was an understanding that some people there were HIV positive there was a silence around this issue except for individuals who discussed their status with their respective nurses and friends.

be spending a long time with them and I hoped they would trust me and open up to me. Finally, I said that I understood that this was a sensitive and private issue which was not helped by the fact that I was a stranger to them. The woman who had first asked me what my business was at the hospice said that she understood what I would be doing. I shall call her Carol for the purposes of reporting. Carol was a leader of the other women, she had been at the hospice for longer than the others and was a fighter who protected herself fiercely when the need arose. Apparently she had been involved in a research project conducted at Napwa (National Association of PWAs) by two students from Wits. She appreciated that I gave them the choice to participate as her sense of the other research projects was that she had had to participate.³ The fact that I had indicated that I would be there for a long time also worked in my favour. Carol pointed out that because I was not in a hurry to carry out the research and leave, the women would not feel pressured to talk to me. Although some of the women still felt threatened by my presence, this cleared the air somewhat. I spent the next few days hanging out and joining them when they were sitting in the sun or went to buy fruit at the gates. I would occasionally bring video cassettes for us to watch during the day. I would say when I was not coming in and slowly I gained their trust, although some women would occasionally make remarks such as 'I hate those little professors who tell me that I will get better. What do they know? Have they discovered a cure or

³ During the course of my research some of the women I interviewed also went to these meetings and referred to them during interviews. I wanted to experience them for myself and so I went to Napwa to get permission for this. I was told that they have had a number of researchers and journalists coming to these meetings, undertaking to honour ethical concerns such as not violating the rights and confidentiality of members of the group, only to have stories published without the knowledge and consent of the individuals concerned. They did not specifically say anything about not getting the informed consent of participants in projects, but my sense was that people were not specifically told that they could refuse to participate and that they would not be penalized for this. I was refused permission to sit in the support groups. I suppose I would have had to work harder to gain everyone's trust to have this access.

what?⁴ I did not take such remarks personally although I knew they were directed at me. I understood their anger and frustration. I used some lessons I learnt from my stint in Occupational Therapy, such as not jump to someone's rescue as a way of compensating for their disability. In a nutshell, I observed and participated, sometimes becoming a total observer and sometimes participating more than I observed. I kept a field diary where thoughts and observations were jotted down and later written into notes. In the middle of my research it did not feel so strange to take out my note-book and write things down, as my position as a researcher had become established and accepted.

This technique of participant observation is a conventional method in any anthropological inquiry. Beside the benefit of gaining the trust of those who are being studied so that they might reveal private behaviours in the presence of the researcher without feeling self-conscious (Bernard 1995), this technique affords the researcher first-hand experience of particular activities. For instance, I got to understand why these women felt the need to go collectively to the gates to buy fruit: it was both for companionship and the fact that, as a group, they felt safe from the stares and remarks directed at them.

This research did not seek to isolate and deal only with a particular phenomenon. It is instead, like Urquhart's (1994) study of HIV-positive males in the prison, an attempt to make sense and gain an understanding of the subjects' experiences within a broader societal reaction to AIDS. Other techniques suited and used for this research were the focus group method and in-depth semi-structured interviews. We had two focus groups, the first with eight women at the beginning of the research and the second with seven women at the end of the research. The first focus group was used as an ice-breaker for subsequent one-to-one interviews. I felt that individuals would feel safer to talk in a group, especially because the questions were not personal. I made a 'big thing' of this focus group, I bought refreshments, made appointments with those who were not planning to come on the particular day and

⁴Initially I was lumped into the category of doctors and other medical personnel even though I did not offer diagnosis of or solutions to people's illness

financed their transport to and from the hospice. This worked very well as everyone was anticipating this event, they were curious, in good spirits and all felt included. The focus group lasted almost three hours. I reiterated the choices they had, what the research was for and the confidentiality that we were all supposed to observe. I alerted them to the fact that I might be clumsy in some of my questions and that they should feel free to tell me this. They were asked to introduce themselves. As there were some new women who had just joined the hospice program, this was a good preamble to the whole discussion. We discussed their impressions of the hospice, this led to us talking about the quality of their lives before coming to the hospice. The discussion then moved to the observation that they received unexpected bad treatment from friends, relatives, lovers because they are HIV-positive. At this first focus group meeting, there was a frankness I had not expected. The narratives told that day were punctuated by a lot of crying and the giving of advice by others who had had similar experiences. This focus group, like other interviews was tape-recorded, with the women's permission. I was inclined to turn off the tape recorder as people cried, but I was told not to. This crying continued even in the interviews but when I asked if I was traumatizing them more than they were traumatized by their other experiences, they all said that they appreciated the space to talk and unburden themselves.

The one-to-one interviews that followed the focus group were semi-structured in that I had an interview guide. Questions at the beginning of the guide were general probing, aimed at getting the women to talk about themselves as people with identities other than that of PWAs. Middle questions were probing whether women, in general, were likely to experience the disease in significantly different ways to men and questions towards the end of the interview honed in on participants' particular experiences since a positive diagnosis. Their perceptions on why people react the way they do to PWAs were also asked. Some of the interviews were rich and the interviewees did not need to be encouraged to talk. Others were a bit stilted with participants wanting to be probed. Twelve women were interviewed on one-to-one basis, the interviews lasted between an hour and an hour and a half. Only a few women were targeted because this research project did not set out to discover

representative attitudes and perceptions regarding AIDS. Rather, this project aimed to unravel some of the experiences that particular women living with HIV/AIDS experience because of their medical condition. These experiences were then situated within a broader context of the township and reactions to AIDS. Data that would be representative of all women living with the virus was not sought, rather a description from a small sample of women was aimed for.

At hospice, we had to schedule interviews between meals and other house-matters. Appointments were made beforehand and interviews took place in an office that I borrowed for such purposes. I also went on house-visits with the hospice staff. I only interviewed one family related to the women who participated in this research. In this case I went to the house alone and was expected. In the instances when I went with one of the hospice staff my role as a researcher remained anonymous. I also interviewed one man on a one-to-one basis and two men together. I was trying to understand their understandings of the disease and whether these hinged on ideas that were likely to blame women. I had also interviewed the coordinator of the hospice about the basics of the hospice before my actual fieldwork. I interviewed a pastor who is very involved with the hospice and who runs a feeding scheme for PWAs. I also witnessed the many sermons that were presented at the hospice. Some of the data gathered here was gleaned from parties that were held where people from outside were invited and some from internal rituals such as the giving of toys to children of PWAs by various benefactors. Most of my fieldwork took place on weekdays except for those Saturdays when some donors were coming and the everyday functioning of the hospice was maintained.

Before I finished my fieldwork, I forewarned everyone that I needed to go back to write my findings so that they were not taken by surprise when I left. I also organized a focus group towards the end of my fieldwork so that we could all reflect what being involved in this project meant to us. This time was intended to demonstrate that the women's participation had initiated a process that was now about to be taken further, albeit without their ongoing involvement.

One of the challenges that I experienced during this time was to draw the line between being a researcher and being of assistance to the women in matters such as the intricacies of the welfare system. As I felt that my fieldwork was based on 'a give and take situation', I tried to find the answers to their questions. The social worker at the clinic was a lot of help to this end.

The project was also emotionally demanding. I learnt to come to terms with my fears and prejudices and relate to these people unconditionally. I also learnt to appreciate their struggles and triumphs. Ethical concerns are of primary importance when conducting such research and the women who volunteered to partake in my research constantly guided me. There were times when I felt I was not equipped to deal with the emotional side of this research, but in hindsight I believe that the women were satisfied with their role as participants and my writing of this thesis. I tried, at all times, not to treat people as objects and not to see them only as sources of data. Being aware of power relations that might pose a problem and dealing with them by being upfront about the choices that potential interviewees have levels the playing fields. It was important for this project that the women knew that they could terminate their participation whenever they felt the need and that they did not have to respond to all questions that they were asked. In essence the interviewees were made aware of the power that they had in the research process. I think this put them at ease. The fact that I had disclosed my status as a researcher early in fieldwork also helped address some of the ethical issues that arise with deceiving people in order to get data.

Finally, the wishes of the participants were always honoured, sometimes at the expense of the project. Those who explicitly asked me not to contact their families for follow-up interviews were assured that this would not happen even though these interviews would have helped to balance their stories. Bernard's warning that '[t]he most basic responsibility of the fieldworker is to protect informants from negative consequences' (1995) was noted and heeded. In a research project like this, where disclosure of one's sero-positive status is a significant issue, it is important that confidentiality be promised and observed. As suggested above, this research report uses pseudonyms to safeguard

some of this confidentiality and other information, that may have helped identify the women participants has been deliberately omitted. I am certain that all who participated in this process did so voluntarily. Although I occasionally helped women with money to go to Rissik Street where the process of getting grants begins these gestures were not meant as bribery. The need was there, I was in a position to respond to it and I did so without putting anyone under pressure to participate in the research project. I was also very careful not to promise things that I could not fulfil. During my research I also sought to be accessible to the women I worked with. They could ask me personal questions and I would respond to them as best as I could. I did not try to maintain a façade of a researcher who was there to ask questions and not be asked any in return. To some extent, this worked to my advantage as those women were highly suspicious and would not be manipulated into assisting anyone they did not wish to help.

The lay out of this dissertation is as follows: Chapter two gives biographical details of the interviewees for the research project. The chapter also maps out the disease process of individuals thus making the interviewees subjects rather than objects, in this inquiry and provides an opportunity for the reader to get to know some of the participants. Chapter Three highlights the role played by the township in the care of PWAs, many of whom have been rejected by their families. This chapter also questions the role of the government and business in the care of PWAs. The concept of community based care is introduced in this chapter. Chapter Four explores in detail some of the experiences of the women who were interviewed. The importance of the township as a context that bears on these experiences is emphasized in this chapter. The central themes of stigma and pollution and their effect on the participants' lives are considered. These themes are carried through to Chapter Five. This chapter focuses on death and dying in the context of HIV/AIDS. It argues that just as an HIV positive person is deemed to be polluting while alive her body is also perceived in this light in death. This perception influences how the body is handled prior to burial. The last chapter, Chapter Six, is the conclusion in which central arguments are pulled together and recommendations are made.

Chapter 2

HIV/AIDS: The people behind the statistics

Adams and Sears noted with concern that with an epidemic as big as HIV/AIDS, people's personal experiences are bound to be eclipsed by the statistics that record how many are infected and how many have already died (1998). Keeping statistical records is important to keep track of the epidemic, and indispensable as they provide a measure of the effect interventions have on the incidence and prevalence of the disease. There is, however, an equal need to come to grips with the real, lived experience of HIV/AIDS. *It is, after all, people who are afflicted. They have relations with others, they are not only victims of circumstances, but they are also agents who seek to influence these circumstances.* Weeks asserts that we are all living with HIV/AIDS in various ways (1995). We all know someone who is infected or affected, we read and hear about the devastation caused by AIDS in our daily lives, and some of us write about this devastation. In this thesis, I worked with a handful of individuals who were encouraged to give personalised, subjective accounts of their experiences prior to and after an HIV-positive diagnosis.⁵

This chapter introduces the subjects of this research, although pseudonyms are used to protect identities and particular descriptions that might help identify individuals are omitted. The pattern of disease histories will be highlighted. It will be argued, based on this, that routine voluntary testing is not how most people find out that they carry the HIV virus. This chapter will also examine the various sources of help that are consulted upon a positive HIV diagnosis. *It is hoped that the people who participated in this research will be presented as individuals who creatively seek to influence their lives in particular directions amidst taxing constraints and that the reader will come to appreciate them not so*

⁵ Data saturation was achieved, that is, a situation where no new revelations were made. same anecdotes were told no matter what the data collection technique. Interviews, focus groups, and informal data collecting techniques yielded supporting data

much as people who are dying from HIV/AIDS, but as people who are living with a disease from which they may eventually die.

Chapter One has referred to some of the factors that render HIV/AIDS a mystery and a special challenge to the wider population. These include the fact that there is no known cure for HIV/AIDS, that the methods of prevention pose a challenge to matters taken for granted in everyday living. From her work in Botswana, where the epidemic has extracted a severe toll, Suzette Heald came to the conclusion that 'It is not as easy as ABC' referring to the challenges that plague AIDS prevention interventions (2000). Helman highlights the social and cultural difficulties involved in dealing with disease and says that

[t]he medical perspective assumes that diseases are universal in form, progress and content, and that they have a recurring identity, that is, that the disease is the same in whatever culture or society it appears. However, this perspective does not include the social and psychological dimensions of the disease for the individual patient and for those around him (2000: 67-68).

HIV/AIDS has remained a myth and a mystery. A myth because, for a long time, there were no published stories of PWAs and so it was thought that AIDS did not exist. It was also widely believed that HIV/AIDS was a ploy or a bad joke. As AIDS became more visible as more and more people were infected it became a mystery that it could not be cured scientifically. As such, it resembled other indigenous ailments such as *isidliso* – a Zulu word for the idea that a person has been made to ingest a foreign substance which will result in a slow death if not attended to. In contrast, however, HIV/AIDS would not respond to known treatments. HIV/AIDS unlike other indigenous diseases, was extensively discussed on radio and TV programs. Despite all the publicity, my research findings show that virtually all the participants did not expect to be diagnosed with HIV when they experienced symptoms that, in hindsight indicated HIV infection. They did not believe that HIV/AIDS existed and therefore they thought there was no risk of infection. Public broadcasts about HIV/AIDS were not accompanied by accounts from infected individuals and, therefore, failed to inspire caution in the population. In this regard South Africa is characteristic of 'developing nations' where people find out about an HIV-positive

status long after infection. (Lie and Biswalo 1998) My research findings show that in all cases informants found this out because they were ill from 'something else' and decided to consult a doctor. They did not make a conscious decision and take steps to be tested for HIV. Thus all my informants found out about their HIV-positive status by default. The detailed circumstances of how each informant learnt about their status will be mapped out later in this chapter.

All the women interviewed had, prior to being diagnosed with HIV or AIDS, been in relationships with men who were, in the long run, unable to assist them in times of need. The common thread running through these women's stories is that they were badly treated by men. At the time of the research, not a single woman was involved in a sexual relationship with a man. All of the women, however, had accounts similar to the one presented below. They could recall incidences in which their husbands or partners humiliated them by publicly accepting other women as lovers. When women protested against such behaviour, there were always fights and they risked a beating. As the following case study shows, it was difficult for women to determine who might have infected them with HIV because both men and women did not have steady partners. A general tendency was, however, to believe that men who were 'good' could not be carrying the HIV virus, whereas men who mistreated them were seen as more likely to host the virus.

Case Study 1: Bertha Motha

Bertha was a 27 years old mother of two children, a boy aged 11 and a girl aged 3. Bertha believed that her life had not been easy, it had been characterized by one hardship after another. She recounted her involvement in the political struggle against apartheid while at school and how her parents were also involved. This was a very difficult experience whose significance seemed to be particularly pronounced as she faced the trial of HIV infection. As an adult, she had been living with the father of her first child in a shack in his parents' yard. Although the relationship lasted for about four years, and had been formally recognized through the payment of 'lobola' or bride-price, her residence was not without problems. The man was unemployed, was given to gambling and womanizing. They used to fight a lot, mostly because of his many girlfriends whom he sometimes brought to his parents' house. She also used to fight with these women and she would occasionally leave the man to stay with her own family. But she would soon return to her fiancé.

These experiences, both her involvement in anti-apartheid campaigns and her relationship with this man, were of paramount importance for her and Bertha believed that they had shaped her existence. Although there had been other men in her life, she did not consider them to have been significant. The father of her first child was not part of her story - that had happened when she was young and, according to Bertha, did not have much bearing on her development as a person.

Bertha was not sure who had infected her with HIV although she had narrowed her suspects down to her fiancé and another man she was involved with after the birth of her younger child. This was during one of the many times that she had left her fiancé to go to her parents' house. The fiancé seemed to be the prime suspect since he had sexual relations with a lot of women and also because he had treated her very badly. As the other man was older, married and had been kind to her and her baby, in her mind he was not likely to be the one who had infected her. It was very important to Bertha that this other man had provided for her and the baby when the father of the child had not. She said that having a provider restored her dignity when she had returned home with a child whose father was not showing any responsibility towards them. She finally left her fiancé for good when she became very ill in 1999.

Bertha, in keeping with all the women I spoke to, was afraid to even consider the prospect of having a man in her life. The women in my sample proclaimed that they do not have any feelings for men. This means that they were not attracted to men at all and did not miss being in a romantic relationship. For some of the women the acceptable alternative to celibacy was to meet other sero-positive people. According to Adam and Sears this approach ostensibly took care of two impediments to courtship (1) the danger of infecting someone new and (2) the problem of revealing sero-status and thus facing rejection or incomprehension (1998:46). There was also the need to re-orient oneself amidst a lot of new challenges. Illness and signs of illness also bore negatively on their self-image and sexuality. Only two of the twelve women making up my sample were still married but they were no longer sexually active. Eight of the ten women had never married, one woman was divorced and the other was a widow. All the women had children and this was emphasized as a factor in not actively seeking a relationship with a man. They reasoned that if one already had children there was no need for a sexual partner. These women were fulfilled by the children they had.

Despite the fact that these women no longer had partners, it is worthwhile investigating their experiences before they discovered that they were HIV-positive. In this regard, another common thread concerns their ability to negotiate the practise of safer sex. Here the general wisdom has been that South African women are, on the whole, not able to negotiate condom use with their partners. Olivia Mokoena's story, presented below, shows that there are women who indeed suffer from South Africa's male dominated social structure.

Case Study 2: Olivia Mokoena

Olivia was 35 years old when I met her for an interview, but I had no opportunity to get to know her well as she died in December 2000, leaving behind 2 children. Olivia was not a very talkative person, but she was also not shy to speak her mind when the need arose. She joined the hospice while I was already there and therefore was not part of the first focus group. I had to introduce my project to her as an individual. The first thing she told me was that she was dying because of R8000. She also said that she would tell me all I needed to know, that she was not ashamed because she did not do anything wrong.

Olivia had married a 'very obstinate Zulu man' who did not want to use condoms, despite his many concubines. Olivia was severely beaten every time she brought up the subject of condoms and her husband would say that he paid R8000 'lobola' for her, how dare she even mention condoms to him. They had been cohabiting before his payment of 'lobola', in which time they had two children. Things started changing for the worst after this payment was completed. They went to stay with his family despite the fact that Olivia was not in good terms with her in-laws. She had left the children with her mother, and this became a contentious issue. 'Did she think that they were so poor that they could not take proper care of them?' she was frequently asked. Another problem for Olivia was the money that her husband spent on his mother. Olivia was working at the time and did not do as much housework as was expected of her. She recounted scenes in which she and her in-laws would be shouting at each other and her husband taking their side. Eventually the fights drove Olivia and her husband to relocate to another house where they were lodgers in a garage. On some days when her husband did not come home from work she would go to her parents' house as she was unwilling to sleep alone in the house. If he came back, however, and she was not there, further problems resulted. Finally, one day when she was not at home, Olivia's husband took the furniture that they had purchased together to his mother's house. This act signified the end of their marriage.

Olivia returned home to her parents in September 1999. She had been ill on and off since the year before and in December 1999 she resigned from work. In May 2000 a private doctor diagnosed her as HIV positive. Olivia had some money due to her from her place of work but the process of getting that money had been slow. As she would not go to her place of work because of the way she looked (she had lost weight, was lethargic most of the time, her speech was slurred, had thrush in her mouth and her hair was falling out), she was faxing documents and communicating with relevant people by phone. Olivia's

advised her against returning to his home for formal mourning and sitting on the mattress as is customary because she was also very ill at the time. Instead she showed up on the morning of the funeral in the company of her family and children. Here she was accused of bewitching her husband and she was not allowed to see his body. Her husband's concubines and illegitimate children were given this privilege.⁶ Her in-laws approached her again when ritual cleansing of the family took place. They wanted her children to participate in this but Olivia would not allow them to go.

Olivia had a very supportive family who stood by her. She had three older brothers and she was the only girl in the family. She said that her family had always warned her against marrying her husband. They thought he was inferior to her as he came from a poor family and was not educated. She found out that the bride-price of R8000 had been negotiated down from R12000. The elders in Olivia's family had demanded R12000 in order to discourage the man from marrying Olivia. They did not envisage that he could be able to put together that sum. Olivia believed that the amount demanded for her bride-price remained a sore point for her husband and contributed to why her husband had treated her with contempt, calling her a 'spoilt brat' all the time.

Other women's stories also supported this patriarchal lifestyle and some women indicated that suggesting condom-use would have caused problems with their partners. It is however, more significant that contrary to the general wisdom in South Africa, most of my interviewees felt that they were in a position to bring up the issue of using condoms, although they could not anticipate how their partners would have reacted. What has generally been overlooked here is the fact that these women were simply not interested in protecting themselves and explicitly said that when they had been sexually active, they had not been in favour of using condoms. They did not think it would have been such a problem had they suggested condom use. Nonetheless, and perhaps more significant, there was also a sense that condom-use is not easy to sustain (it was not thought of as a matter of life and death before getting ill) and it would not have been easy to change from not using condoms to insisting

⁶ According to Olivia it was the first time that she knew about some of these children: they were hidden from her. Some were older and others were younger than her own children by the same man. There were four of them and all male.

⁷ One said that she had a general fear for her partner and suggesting condom-use would not have been easy, two other women also stated that their partners were very violent and this would not have been a good idea.

on using them without giving a plausible explanation. Condom-use or the lack thereof have been subjects of much study as shown in the introduction. There is every reason to believe that the women whose experiences are the subject of this thesis were faced with the same challenges associated with condom use as highlighted by other studies. The potential for physical assault by their partners existed as did the affective aspects of condom-use such as the need to trust one's partner. Socio-economic considerations such as not insisting on using a condom because of dependence on the sexual partner for survival were also important for these women. Nonetheless, it is also crucial to recognize that women also endanger themselves. The women studied here consciously chose not to try and use condoms though they could have suggested it to their partners.

The case studies presented thus far have also highlighted the fragile nature of relations between men and women in the township setting. Children were sired by fathers who did not show any responsibility towards their upbringing. Leaving, or being left by the father of your child was accepted as normal. This did not discourage the women from bearing more children by other men with the hope that one of them would prove to be more loving and stay. As this research has however shown, HIV infection has the potential to change this as the women in my sample swore that they did not need men for their lives anymore. They wanted merely to raise their children, and they did this with the help of relatives. They believed that the government should give them grants that would help them raise their children. This may be a passing phase, but like subjects in Sobo's study, the women in my study spoke of betrayal, broken trust and partners who could not have loved them to have infected them (cf. 1995). As demonstrated in the case study material, however, the nature of sexual relationships in the township is such that one is never sure who infected who because there are multiple partnerings as well as rapid change in sexual partners.

Men and women expose themselves to HIV infection when they have multiple and/or rapidly changing sexual partners. Despite this fact, none of the women I came to know had entertained the thought that they might be infected. In the literature on AIDS and AIDS prevention, testing for HIV is a

major issue. The theory is that if more people *volunteered for routine testing*, strides would be made to control the spread of the disease. The reasons cited for not volunteering for such tests include the psychological stress of knowing that one is infected, the fact that no support mechanisms are in place for those who do test positive and the precedence of other day-to-day pressures over knowing about one's HIV status, especially in developing countries. The result, as Lie and Biswalo have noted, is that people find out about their HIV-positive status late in the disease process (1998). This has the danger that those who carry the virus continue to spread the virus to others and the chain continues

It is evident, in both of the following case studies, that testing for HIV was not a prerogative of the women concerned. As suggested at the beginning of this chapter, there is a sense in which HIV/AIDS is believed to be 'not real' in South Africa. People are not seen to die from such infection. This belief exists despite the fact that, throughout South Africa, people are dying from complications related to AIDS. Rather, these women were concerned because they were feeling ill, Mavis was suffering from shingles, and Carol was not feeling well generally. When they sought medical advice, the possibility that they might be infected with HIV had never even occurred to them. They found out, so to speak, by accident, without asking to be tested and without granting permission for the tests to be done.

Case Study 3. Mavis Masilo

Mavis, aged 35 and the mother of 4 children, grew up in a rural village. She had been working as a domestic worker in Gauteng when, in 1997, she took ill and was diagnosed as HIV-positive. She returned with shingles¹ and went to Chris Ham Buthevanath where she was only told to eat lots of fruit and vegetables. When she again took ill she went to a private doctor as she had access to a medical aid through one of her half brothers. Blood was taken from her and she said that she was not worried as she thought that she 'had nothing'. When she returned for the results the nurse there asked whether she should tell her what was wrong with her or whether she had already guessed. She was shattered when the nurse disclosed her status. The nurse asked if she would disclose her status to her family, but she only disclosed three years later when she got very ill. 'I... since then I only disclosed now. I had been ill on and off. I got sick from work finally and was taken to hospital, that's when I realized I had to disclose'. She had not lost weight, or lost hair, and she did not have thrush in the mouth and nerve problems as was the

¹ Shingles is an auto-immune response that affects nerve endings and connective tissue resulting in skin inflammation.

with the other women. *Contrary to her counterparts, she had skin infections which I think were Kaposi's sarcoma³.*

Mavis' children had *three different fathers*. Her youngest child was born in 1995 and the father of the child left them immediately afterwards *for no apparent reason*. She had not been with another man and a child in 1995, my lover left and I have never had another man since then. People say that if you don't meet with a man for some time you get mad and all. But I have survived, close to five years now. I told myself that [there was to be] no other man for me again'.

Mavis had had bad experiences with men and thus *opted to remain single*. Her children were staying with a young relative who had also just had a child and needed a place to stay. They lived in Mavis' RDP house. She wanted to resettle back to her house, taking along all the possessions she had accumulated while she was working, but she had no money to do this. She was very worried about her children back in the rural areas. They lacked adult supervision and did not have any source of income. They relied on relatives and sometimes sold spinach from their garden. Mavis was hopeful that the older one, who was 12 and had 8, would be able to take care of the other ones. Mavis was busy trying to verify the sero-status of her younger child and to get a grant from welfare services when I finished doing fieldwork in January 2001. She was also attending a support group at her local clinic where she was given the produce from the garden that she and others tended. Her family had been supportive and had taken her to various traditional healers. They believed that there is no disease that could not be cured. Mavis was using herbs and traditional medicines she got from the clinic.

Case Study 4: Carol Yende

Carol, aged 30 and the mother of 3 children ended her relationship with the father of her children in 1995. The children lived with their father's parents in a rural village near Durban. Carol had moved from Durban, her place of birth, to Johannesburg where she stayed with her aunt. In 1995 she was diagnosed with HIV. Like many others, Carol did not know what was wrong with her when she was taken to Groote Schuur Hospital. 'We were all in the ward and blood was taken from us, all of us. We were given no choice, blood was drawn from us', she said. Her reaction to a positive-HIV diagnosis is typically that of disbelief and denial. She was tested again during her stay at the hospital and the results were confirmed. When asked if she had received any counselling during this time, she said that it was told by the doctor that since there was no cure for HIV she was going to die. She was discharged from the hospital with those words. She started drinking and smoking compulsively. Carol was reportedly worried because during an earlier casual conversation, her aunt had said that if someone in the house suffered from the disease that was so spoken about (HIV/AIDS), they should know that they would not be tolerated. When Carol returned home from her stay in the hospital, her illness became manifest and she was given separate utensils, blankets and she had to wash outside. She did not have

³ Kaposi's sarcoma is a skin cancer associated with HIV/AIDS, it manifests itself as blotches on the skin. Kaposi's sarcoma is usually found on white/light skin types

and one to discuss matters with and, in 1996, she suffered a breakdown and spent time at Sterkfontein, a mental institution. Recovery was slow as, during this period, her parents' house was burnt down as a result of political strife that was raging in the country. 'I was deeply affected, I had no one to talk to, I was always drunk, in the morning and at night', she said. The counselling that she received at Sterkfontein and later at the Mofolo Psychiatric Clinic and Napwa (National association of people with AIDS) helped her a lot. When the hospice nurse visited her aunt's house to provide the family with counselling, they were told to take Carol away as the family was no longer interested in continuing relations with her. Carol had once been with friends but she spent most of her time at the hospice. Carol had been through a lot and was very cynical. 'I always had the feeling that she dared everyone to judge her so that she could show that she did not care'. Carol did not once shed a tear at the death of a peer or during an interview, as the other women were prone to.

Carol emphasized that she preferred to associate with people who had also been through trying times and aches because those who had not been would never understand the pain and the hurt that she had suffered. Carol's salvation was her new sense of spiritual belonging. She told me that the best thing about the new church and 'family' was the unconditional positive regard and warmth that they gave her. They did not behave as if she was contaminating.

These case studies show that admission into a hospital due to an unidentified illness seems to be the main manner in which people find out that they have HIV. The ethics that govern testing - such as obtaining informed consent from the patient for the test, counselling them before and after the test and respecting their confidentiality - have largely been violated. Ignorance by both the practitioner and the patient about mores that govern HIV testing may have accounted for some of these violations early in the epidemic, but that is certainly not the case today. Sobo gives a different explanation for this '[a]buses of power that result in unsolicited testing can occur and even well-intentioned clinicians - particularly overburdened public servants sometimes cannot find time to carry out testing procedures properly' (1995:151). Unequal power relations between the patient and the medical staff certainly play a role in public hospitals where service delivery is to a large extent subsidized by the government and the patient pays only a negligible fee. The attitude that prevails is that the patient does not have many rights because she or he does not pay for the services. Rights of HIV-positive persons have also been questioned vis-à-vis rights of the general population and those of medical practitioners. Just as the test and/or diagnosis is made without the consent of the patient, the results are communicated whether the

patient wants to know or not. Moreover, communication of such information seems to be confined to the prognosis that since there is no cure for the disease the patient is going to die. In my sample, counselling seemed to be the prerogative of the hospice staff who took over the care of some of the patients diagnosed at Chris Hani Baragwanath Hospital. Although the experience of finding out about one's HIV status was not done to protect the patient and was shattering in many ways, the interviewees of this study seemed to set great store in the fact that at least they knew where they stood, and they were dealing with this knowledge. In general, testing is seen as good for individuals because they can adjust their behaviour and practices accordingly. Those who test negative can strive to stay that way and those who tested positive may take steps to prevent infecting others and re-infection (which increases the viral load in their immune systems and leads to HIV converting to AIDS more quickly). Those who test positive can also strive to take better care of their bodies by taking appropriate medicines, eating well and exercising. This, of course, will be subject to their living conditions. As is shown in the case study material, the women in my study used this time to nurture their spiritual well-being when their physical bodies were failing.

Chris Hani Baragwanath Hospital is known locally as Bara and, as a public hospital, has a reputation for ill-treating patients. Stories abound about the conduct of nurses towards patients. This has prompted the Department of Health to formalize and publicize the Patients' Bill of Rights. Bad treatment of patients by nurses is not confined to HIV-positive persons, though one could surmise that having an HIV-positive status could worsen the situation. Here is what Grace, one of my interviewees said

At Bara they used to uncover me, talk about me as if I am not there, making a show – here's another victim. I lost my things, my clothes etc. People would take my bed-letter and read. The nurses did not make up the bed I slept on. I had not been properly tested by then. What the doctor had said became the basis upon which I was judged. What right did they have to say this [that I am a victim of HIV/AIDS] about me?

Those interviewees who had not been admitted at Bara were terrified of the prospect of ever having to go there and having to submit to abusive treatment that everyone else had described. In fact,

most of the women I interacted with were not admitted to Bara during my fieldwork. In part, this was because they were told at Bara that the hospital could no longer help them in anyway, so they should stay at home. Instead they were admitted at the hospice. Those who did go to Bara, went because they took ill at night and could not come to the hospice.

The following case study illustrates attitudes of the medical personnel to patients. Bertha's experiences, presented below, are not unique. Patients' rights to health care, dignity, privacy and counselling before and after an HIV test were violated. Families also found it difficult to deal with the knowledge that one of them was ailing from complications related to HIV/AIDS. Infected individuals also battle with coming to terms with their status as people with HIV/AIDS. As shown below, the medical staff were unable, or perhaps unwilling to assist their patients with these problems.

Case Study 5: Bertha Motha

When Bertha (already mentioned in Case Study 1) became very ill in 1999, she went to a local clinic where she was sweating a lot and felt lethargic. She thought she had TB as she also had a persistent cough and lost a lot of weight. She said that she got a very bad treatment from the nurses. They kept telling her that her sister who had accompanied her that she should not have brought her to the clinic as there was nothing that they could do for her. Bertha said that she did not understand what this meant. She thought that they were saying that she should have gone to a TB clinic as her TB was very severe. Despite the doctors' comment that nothing could be done for her, a sputum sample was taken. She went to collect the results the following week and these did not confirm TB. Although she got better for a while, she was referred to Chris Hani Baragwanath hospital when her condition worsened and here she learnt that she was HIV-positive. She did not receive any pre- or post-test counselling and she was not formally notified of her status. Instead, one of the doctors asked whether she knew what was wrong with her and she eventually told that she was HIV-positive. She said that she was not alert during most of her initial stay at the hospital and she only remembers different doctors (who were mostly foreigners) poking her and talking to each other about her and the nurses being very harsh to her. At one stage she needed to use the toilet and was very weak. The nurses refused to give her a bedpan or to accompany her to the toilet. She told on her way to the toilet and no one assisted her at all. She was finally able to get herself to and from the toilet. From then on she asked doctors, whom she thought would be sympathetic to help her and the doctors would order the nurses to help her. Bertha seemed to think that this was a positive experience because it taught her to be strong and self-reliant.

Bertha's neighbour who worked as a cook at the hospice referred her to the hospice. Bertha's own family tried to hide Bertha's illness and in an interview, Bertha's mother said 'We did not tell anyone about

her condition, but people can see for themselves'. Although Bertha was initially ashamed to be seen by neighbours and friends (she had lost a lot of weight), she made peace with herself and no longer hid from anyone. "At first when people knocked I would run away and hide but now I am open. People talk but I do not care anymore, I just say to myself, 'you laugh at me, you have not tested you might find that you are also HIV-positive but not yet ill'", she said. She became very spiritual and would recount how she spent the whole night at church praying for salvation and strength to overcome the disease. She did not take any medication and, as is the belief of her church, relied solely on prayer.

As shown by these case studies, public medical health care services leave a lot to be desired with regards to patient care. The unequal power relationships between the patients and the medical staff are particularly evident in patient care. The rights of patients are violated and this affects public perceptions about health care in these institutions. Loss of confidence in the quality of government health care services discourages individuals from visiting them. The hospice has become an alternative to hospitals whose approach to people with HIV/AIDS is not sympathetic. In addition, as shown in Bertha's story, some of my interviewees found strength to survive within themselves and religion proved to be an anchor when all else was disintegrating. Religious belief fostered an acceptance of one's trying situation and became a source of sustenance in the face of relationships strained by a spectre of HIV/AIDS.

All my interviewees had a strong belief that they would overcome this disease. They seemed to believe that a positive attitude would contribute to this and in the same breath they hoped that a cure would be found. When asked, they said they were affected negatively by the deaths of their colleagues at the hospice, nonetheless, they seemed able to divorce their friends' deaths from their own situation. The common answer was that death is untimely for everyone and that they did not believe that people died because of AIDS, rather people died when their time had come irrespective of whether they had AIDS or not. The popular example cited was that of healthy people dying from accidents or simply not waking up in the morning. The fact that HIV/AIDS invariably led to death was also acknowledged in statements such as 'We could see that he or she was going to die, this disease had ravaged him or her'. As, however, this fact was too much to live with from day to day, beliefs that against all odds, one was going to be better had to be sustained in order to keep one sane (discussed further in Chapter Five of

the thesis which deals with ideas and intricacies associated with dying from a terminal illness). Many women continued to use traditional herbs in conjunction with the tablets that they received at the hospice and sometimes from private doctors. There were active attempts to restore health. Although I had expected to find people who blamed their illness on witchcraft and failure to do good by the ancestors, this was not pervasive. In fact, this understanding could be heard more from the men in hospice than from the women. The women largely denied that they were HIV-positive, but they also did not say that they were bewitched. Those women who were in denial about their HIV status either thought they had TB, or that they were losing weight because they are prone to doing that, or that they had some other disease. Perhaps they did not feel confident saying that they were bewitched to me, a university educated person. The use of faith healers, traditional healers and western medicine, all at the same time might be an indication that they were also not sure what they were ailing from and hoped that one of these ways of healing would help. Helman asserts that:

People who become ill and who are not helped by self-treatment make choices about whom to consult in the popular, folk or professional sectors for further help. These choices are influenced by the types of helper who is actually available, whether payment for the services has to be made and the Explanatory Model used by the patient. This model provides explanations for the aetiology, symptoms, physiological changes, natural history and treatment for the illness. On this basis the patient chooses what seems to be the most appropriate source of advice and treatment for the condition (2000:53).

Helman also notes that various modes of treatment can be used simultaneously to attend to different symptoms (2000). In Soweto, many contradictory ideas co-existed simultaneously: AIDS was thought not to exist, to be a variation of a 'traditional' illness and to be a form of sickness that ought to be kept hidden. In addition to the concepts of causality that have already been mentioned, the idea that HIV/AIDS was not new and was a stronger form of other, pre-existing diseases led informants to seek treatment from 'traditional' healers. Despite the widespread belief in the township that AIDS did not exist I got a sense that many of my informants had accepted that they were, indeed, HIV-positive or that they were about to come to that acceptance. They had tried a lot of things that had not helped them much and they were constantly confronted with the evidence of HIV-positive people who had the

same symptoms as them and who had died. Many of them had themselves been at death's door for a considerable length of time and their condition was steadily deteriorating. In complex and perhaps unbreakable ways, these women appeared to both believe that they were not suffering from HIV/AIDS and to know that they were dying from this same disease.

Although faith in overcoming this disease existed, there was a need to share the suspicion of one's HIV status with friends and relatives. There was also a recognition that this disclosure was inevitable in the light of failing health. Disclosing an HIV-positive status is not easy and infected individuals may opt to cling to evidence that disputes this diagnosis as Rita's case, presented below, illustrates. In the same vein, HIV-positive individuals may consult a number of 'knowledgeable' individuals in a bid to get an alternative diagnosis. Disclosing an HIV-positive status is further delayed by fear of losing much-needed support from friends and relatives. The result is that a considerable time normally elapses between the actual diagnosis and disclosure.

Case Study 6. Rita Mhlongo

Rita was 33 and had a daughter aged 16. She did not believe that she was infected with HIV as she was not showing any common symptoms of HIV infection, except for shingles. This affliction was interfering with ordinary activities as she could not dress properly and she had to forgo a temporary job because of this. In December, 1998, Rita got ill and she had a rash which was diagnosed as shingles by a family doctor. The doctor explained that this could mean that she was HIV-positive. In order to be certain, he had to pay R150 for a blood test and she did not have the money. 'I have been to so many other doctors and I am still not sure what is wrong with me', she confessed. This uncertainty was further complicated by the fact that she had a twin brother who had died in Zimbabwe. It was believed that some ritual had to be performed to appease her brother's spirit. The fact that her brother was buried so far away did not help because she could not visit the grave as often as was deemed necessary for her well-being. Rita had also been to faith and traditional healers with the hope of finding someone who would better understand her condition and help her. Rita's two sisters who were present when the doctor suggested that she might be HIV-positive had been instrumental in taking her to churches and traditional healers. Her other sister and brother had not been told about her possible HIV-positive status and neither had the other relatives (her parents had already died, but her daughter knew this). They had not been informed, in part, because no-one wanted to believe this doctor's diagnosis. Like all the women in my sample, Rita said that prior to hearing from doctors that she was infected with the HIV virus, she had not believed that HIV/AIDS was real as she had not seen anyone who was infected.

whereas she was seeing other men on the side. She said 'My boyfriend was not 'stout' (an Afrikaans word meaning silly or naughty), I was sometimes 'stout' and saw other men, I would leave them when he found out'. Moreover, she had once been date raped and had not told anyone about this. She did not know whether the other men she had been with were ill so that she could deduce who had infected her. She had not disclosed to her boyfriend that she might be HIV-positive but they had stopped having sexual relations since she started being ill. They agreed on this since they did not know what was wrong with her and they were worried that it might be infectious. Rita said that she still had a lot of casual friends, although she did not go out with them anymore. She attributed still having friends to the fact that people either thought that she was ailing from something to do with her twin brother or they thought that she had skin cancer because of the way she dressed with her shoulders exposed. She was sure that she would not have as much support from family and friends if they believed or knew that she might be HIV-positive.

Rita's case illustrates some of the dynamics involved in accepting and disclosing an HIV-positive status. It also demonstrates the complex manner in which PWAs both accept and simultaneously reject their medical condition. This acceptance/rejection is also reflected in the behaviour of the people around Rita. Her boyfriend agreed to stop having sexual relations with her, because they did not know the nature of her illness and they were worried about infection – thus confirming that she may have had HIV/AIDS without voicing such thoughts. Similarly, her two sisters knew that she might be carrying the virus but they were not prepared to accept this. Furthermore, Rita was beginning to accept the possibility that she was infected with HIV but could not admit this to her sisters who might respond to this knowledge by withdrawing their support. So, like other women in my sample, Rita continued to seek a second opinion about the cause of her ill-health. This was done in spite of the fact that she was coming to the hospice and had, by implication, acknowledged that she had a terminal illness.

Disclosing an HIV-positive status was not the only challenge related to living with HIV/AIDS. Fear of others' reaction was also not the only factor that contributed to the tendency not to disclose. Denial played a big part and acknowledging the fatality of HIV/AIDS was a major problem as the following case study shows. Several viewpoints co-existed: the need to believe that one would overcome the disease coincided with an urgency to show that one was not infected with HIV. Similarly women strove to conceal the possibility that they might suffer from HIV/AIDS and concurrently believed that the disease

conceal the possibility that they might suffer from HIV/AIDS and concurrently believed that the disease that they were ailing from was not fatal. The impact of HIV/AIDS is so devastating that it produces complex and contradictory beliefs that which both support PWAs in their struggle to survive and hinder their attempts to acknowledge their illness.

The following case study shows that while an HIV-positive status could be concealed from the larger public with varying success, it could not be concealed from peers at the hospice. In fact, this secrecy was not desired as the hospice was regarded as a safe space for infected individuals to let down their guard and gain the understanding of others. This, however, had the negative spin-off of peers at the hospice becoming too involved in the affairs of others. Unsolicited advice was given and relations were adversely affected if it was not heeded. Maria's story, detailed below, is a combination of denial of the gravity of HIV/AIDS and efforts by companions at the hospice to highlight this gravity.

Case Study 7: Maria Mnisi

Maria was 57 years old at the time of the research. She was married and had 3 children. Maria's husband did not feature much in her stories. One could almost believe that her husband did not exist at all. Although Maria had her own house, she was living in a shack in her yard. She did not say that she was evicted from the house because of her status, she just said she preferred to live outside.

When I met Maria she was already very thin. She maintained that she had always been thin; she had ear problems and thrust in the mouth (which prevented her from eating). She always maintained a facade. Although, jokingly, it seemed to me that she was in a constant bid not to face reality. Her favourite rejoinder was that she was going to look for a job and that she was going to grow very old, so those who thought it was doing should just forget this. Despite her bravado and denial, Maria was in and out of the hospice. One day, she came to me and said that she was at Bara the day before and they had told her that she was no longer HIV-positive, she now had full-blown AIDS. She was saddened by this although she seemed finally to have accepted it. She died in December while the hospice day-care section had closed for the festive season.

Maria was not very good with dates. Hers was a general story of what her experiences had been, not defined by dates. Maria's relationship with the older women at the hospice seemed to deteriorate with time. She was advised by them to perform some ritual cleansing ceremony for herself and two of her children. The children had apparently died of AIDS-related complications. Her failure to do this and her apparently care-free attitude were seen as being irresponsible by the older women. They were concerned she would die without having performed this ceremony. Maria, however, argued that she was not

going to die any time soon! Despite her refusal to acknowledge her impending death and perform the rituals others considered necessary, Maria was very concerned about her children. She missed those who had died and was afraid for the future of those who were alive. Maria died before she could perform these rituals.

Maria's story illustrates a paradox. She fervently believed that she was not going to die while her health steadily deteriorated. The people around her were concerned about her declining health and took it upon themselves to caution her against the folly of dying without having performed rituals that are deemed necessary to appease the spirits of her dead children. This concern soured relations between Maria and her peers at the hospice as her seemingly blasé attitude was construed as irresponsible. This case study introduces an additional perspective that needs to be taken into account. It records a scenario where disclosing one's HIV-positive status is not necessary. This status is taken for granted by virtue of being at the hospice and living through the ups and downs of this status in full view of others. Yet the person concerned still refused to acknowledge her medical condition. This gave rise to a situation in which one's affairs became the concern of others without invitation. As such, privacy becomes a non-issue as advice is exchanged with the intention of helping.

As is evident from these case studies, disclosing one's HIV-positive status is one of the most difficult challenges faced by PWAs. Most of the women in my study were prompted to disclose because of failing health or forced to recognise that their status had already become public knowledge through nurses' visits to their homes and through public gossip. Mansergh, Marks and Simon also noted this: '[s]ymptomatic status is important to consider beyond the first few months, because emerging symptoms may heighten anxiety and increase the need for social support, which may motivate disclosure or render it unavoidable (1998:3). My research also showed that people did not always have a choice about disclosure. Others might know because they were present when the diagnosis was made or they may have suspected that the person is infected and spread this information as if it were confirmed. Some individuals would disclose to some people and not to others. The HIV-positive status of the infected, thus, became the knowledge of a privileged few, although in the end others always got to know. Disclosure and/or suspicions that one is HIV-positive is closely tied to the stigmatisation of the

infected and affected individuals and families and may have crucial consequences which, as the following case study will explore, may threaten the lifestyles and survival of these people.

Grace (the subject of the next case study)'s lifestyle had to change – she was forced into a life of a wanderer, moving from one place to another - as she avoided accepting and disclosing that she was HIV-positive. However, Grace's story has to be understood in the context whereby people are just told that they are HIV-positive without an explanation of what this means and how it will impact on their lives. Accepting a sero-positive status depends on knowing some scientific facts about the disease that explain doctors and nurses behaviour and, as explained above, involves a series of contradictory thoughts and behaviours.

Case Study 8: Grace Mthembu

Grace, who was 42 years old, a divorcee and a mother of 5 children, was the only older woman in my sample. I was a bit shy to talk to her, because discussing issues of sexuality with older people is especially difficult¹⁰, but when she came to the first focus group, I felt her need to talk and be understood. There was belief in the hospice that she was in denial about her condition. Although no one spoke about their condition in the day-care area of the hospice, Grace was the only one who would refer to HIV/AIDS (not mentioning her condition specifically) without using euphemisms. She was also very vocal about things she did not like at the hospice. She was especially displeased with the fact that the hospice staff knew about people's HIV status even though this is supposed to be confidential. She believed that any association with the hospice spoilt one's reputation. As the hospice personnel tended to show up at one's house without prior communication, someone who may have been hiding their illness is left with no choice on this matter (see Chapter Three of this thesis in which this is discussed in more detail).

As mentioned above, Grace's biggest concern was being identified as a person with AIDS by the hospice without having any 'proof' of this. 'I felt that I was exposed. I even had a row with the nurses here, asking how did they know about me because what I am being told I do not want to know. I don't have any proof, even computers make mistakes. What if I don't have this thing what if it's a mistake?' she said in an interview.

According to her she was not properly diagnosed, that is, no blood tests were made. The doctor who diagnosed her inserted his fingers between her thighs (to feel for swollen lymph nodes, I suppose) and did other

¹⁰ Discussions about sex and sexuality between different generations, amongst black South Africans, are difficult

These subjects are seen as private and broaching them with one's elder is interpreted as disrespect.

obscure tests. Moreover, the doctor did not disclose this diagnosis to her. She learnt about her status in 1998 at the Chris Hani Baragwanath Hospital when the nurses displayed her as an example of an HIV/AIDS patient to other nurses and doctors. Prior to this, Grace had been living in Natal but when she fell ill, she decided to go to a clinic in Gauteng. This was because of a general belief that services were better here. Grace showed no signs that she was HIV-positive. According to her, this was proof that she was not infected and that there had been a mistake. What was also significant about Grace is that she did not have a permanent address. She moved from one relative to another as soon as she suspected that they might be gossiping about her. Indeed, she was very angry about being associated with HIV/AIDS and felt antagonistic towards those who encouraged disclosure.

The big people in our community say that we should be open and talk about this, they themselves are not disclosing, they are also living with HIV. You only hear after their deaths. Others can disclose. Their positions allow that but I will not because even my children will be negatively affected...I also do not understand how I got this. I am still working it out for myself, I am not ready to disclose. I have 2 years going on to 3 years without a man. We only hear in the Bible that Mary conceived by the Holy Spirit, does it still happen? I am still trying to understand how it happened.

Perhaps because of her refusal to believe that she was seriously ill, Grace gained almost no support from the hospice and I understand that she no longer comes for day-care.

Grace's story highlights that a communication break-down occurs at many levels in the case of HIV/AIDS. It is significant that Grace was not made to understand that an HIV infection has many stages and that she was still at an a-symptomatic stage. Linked to that was her confusion about how she was diagnosed as no blood samples were taken. This confusion also informs her questioning how she could be infected when she had not been with a man in recent years. Another point of communication break-down was within the system of referrals from the hospital to the hospice. As Grace's indignation made evident, inadequate communication between all concerned parties fosters resentment in a situation where confidentiality and privacy are important. Finally, perhaps 'paralysed' by her refusal to acknowledge her condition, Grace was also not able to communicate her plight to her significant others. Instead, she was forced to move from one place to another, constantly running from an illness she did not believe in.

Although the knowledge of an HIV-positive status is shattering in many ways, I did not get a sense that this news always destroyed dreams of a better standard of living. Although many of my interviewees had been hoping for a job before they were diagnosed with HIV, unemployment is so pervasive in the township that it has come to be accepted as inevitable. The most shattering prospect of having HIV was the implications it had for the children. These women had hoped that the quality of their children's adult lives would be much better than theirs, but with this illness they became aware that the patterns of their lives were likely to be repeated in their children. Some of these women had hoped that those children who had progressed further with their schooling stood a better chance of escaping the cycle of poverty, violence and sterility that characterized their own lives.

While the women hoped that their children would have a better life than they did, some had also not given up on themselves. Women like Bertha (introduced in case studies 1 and 5) forged a new lifestyle for themselves in the face of a multitude of challenges. Bertha, for instance, saw a need to reconnect with her former friends in a quest to live a different life. This was a matter of survival for Bertha because she believed that a preoccupation with the past impacted negatively on the future that she envisioned. This attitude was reinforced by her newly-found religious belief that made a clear distinction between evil and good. According to this belief a state of 'holiness' could be achieved on earth and the only way to attain this was to forsake all that feeds worldly desires. The Nazarene Church to which Bertha was a new member, denounced the usage of traditional and Western medicines. Water that had been prayed over and thus made holy was used for medicinal purposes. Candles were another medium used to heal and to ward off evil spirits, including those that manifest themselves through disease. Members of this church also wear different coloured woools that protect them from harm.

Case Study 9 Bertha Motha

Despite Bertha's spiritual growth and inner strength, she passed away early in the year 2001. I was very affected by Bertha's passing away. She was one of the few women who allowed me to go to their homes and interview their care-givers. Bertha and I became very close and although we spent some sunrise hours together I was not able to be with her at her final days. I learnt about her death when I

Case Study 9: Bertha Motha

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This guilt-ridden attitude could have been fostered by her newly-found religious beliefs. The Nazarene church, an African initiated church, preaches holiness and does not tolerate worldly vices.

The many losses that go with a positive HIV diagnosis means that family support becomes vital. As will be demonstrated in Chapter Four, the fear and the lack of knowledge about HIV/AIDS play havoc with familial relations and, in the above case study, Bertha cut her ties with friends and turned to religion to find support and solace. However, the synopsis of my interviewees' lives seems to indicate that there is generally some support for infected individuals. When talking about support, the following considerations are important: the availability of a permanent care-giver, the state of debilitation of the patient and the question of whether care-givers are themselves given support by others. Some incidences may give the impression that an HIV-positive person is *not being cared for or is treated badly* by others. The affected person often feels that he or she has no support and verbalizes these feelings even though this may be an inaccurate reflection of the situation. My research findings show that the support given may not be enough at particular times and may be overwhelming at other times. Support may be totally lacking at times, possibly because of the enormous difficulties encountered by families

the care-givers and patients may mean that things get out of hand with the unfortunate results of hurting others or being hurt beyond repair. That is why counselling for both the infected individual and the affected family and communities is so important. Counselling that seeks to identify potential areas of strife, and offer support to prevent it or to deal with it can make a difference in the quality of life of all concerned. So when a judgement is made that a particular family was supportive of a relative with HIV/AIDS it should not be taken as saying that there were no challenges that threatened the relationship. Instead, it should be taken as saying that despite all odds, the relationship survived.

Secrecy about a possible HIV-positive status remains a major issue for the women I interviewed, in part because they did not wish to challenge good relationships and, in part because of the stigmas associated with the disease. As Grace and Rita's cases, above, and Yvonne's case, below, show the women in my sample went to great lengths to conceal their HIV-positive status. Despite these efforts rumours that they 'have AIDS' were rife in the neighbourhood. These allegations did not only affect the women concerned, they also affected their families, especially children. The choice not to disclose an HIV-positive status is influenced, in part, by the need to protect children from the knowledge that their mother is dying from the dreaded AIDS, as well as shielding them from anticipated negative attitudes of others. Yvonne's case, however, shows that despite mothers' best efforts, children were frequently involved in the care of their sickly mothers and were taunted by others about the nature of their mothers' illness. The responsibility of caring for a sickly mother and the unsupportive attitude of neighbours interfered with the children's schooling and negatively coloured all their daily interactions.

Case Study 10: Yvonne Shilowa

'I wish I did not have children, then I would disclose my status so that people can believe that AIDS is real', were the words of Yvonne. I met her during one of the hospice gatherings, but she did not frequently visit the hospice because she was very busy trying to put things in order for her children. I managed to meet her at her house and I was sternly warned that I should not act like other people and upset her children by my visit. Apparently, people tended to visit and say to her daughters that they should not worry about their mother since she was going to be fine. Yvonne's children, aged 13 and 16, then got worried and started asking what was wrong with her. As a result, our interview was not very comfortable: we had to whisper so that her children would not hear what we were talking about. Yvonne

said that she did not care what happened to her anymore, she was very concerned about the welfare of her daughters.

Yvonne's boyfriend (not the father of either of her children) had died in March 1998 and his family said he died from TB. There were rumours, however, that he had died from AIDS. In September, 1999 Yvonne found out that she was HIV-positive. Like the other women in my sample, Yvonne did not go for voluntary HIV testing. She was diagnosed while admitted at Baragwanath Hospital. At first she did not want to accept this diagnosis, but she was beginning to believe it because she was experiencing symptoms such as lethargy, loss of weight and hair. And like the other women discussed in this chapter, she was ill every now and then. As there was no adult care-giver in her case, her children took care of her and called an ambulance when they became overwhelmed. Yvonne said that she had no relatives nearby who could help. In effect, this meant that her mother who went to the same church as her, was unwilling to assist her.

According to Yvonne, her life had not changed much since the diagnosis. She still did all the things that she had previously done, although she did not have as many friends as before. She was very worried that rumours about her were having a negative effect on her children. Her younger child had refused to go to school as result of people's comments until her teacher had intervened. Yvonne was very angry at the betrayal by friends and at the ignorance that people were showing about HIV/AIDS, but all her energies were focused on ensuring that her children's welfare would be secure after her death. She had made an appointment to see the priest from her church so that she could be assured that her children would be looked after her death. She had also solicited the help of social workers to ensure that her children would inherit her house. She was in the process of changing their surnames and putting everything else in order for her children at the time of the interview. Although Yvonne did not want to disclose why her children's surnames had to be changed, it was likely that the children had different surnames because they had different fathers and that she was therefore changing them to her current surname and the one in which all her assets were registered.

This case study shows how the women's relationships with their children become a point of focus when other relationships with friends and family failed. As demonstrated earlier on in this chapter, the women living with HIV/AIDS also 'replaced' relationships with men with an increased focus of their children. This case study further shows that a tacit recognition and acknowledgement of a possible HIV-positive status and of impending death, hence the efforts made to make a positive difference in the lives of children before it is too late. The secrecy that surrounds HIV/AIDS, however, means that the infected mothers carry this burden alone, without the help of family and friends. The lack of support shown to PWAs and their families is also influenced by prejudice and stigma as an HIV-positive status becomes known despite efforts to keep this a secret.

Conclusion

These personal stories show the impact of living with HIV/AIDS on the infected individual and on relationships with others. One of the common threads running through these stories is that the women have had difficult experiences with men and, as a result, opted to remain celibate. This decision was also influenced by the need not to have to negotiate practices of safer sex and thus to be impelled to reveal their HIV-positive status. Nurturing relationships with their children became more important in the face of declining relations with men. In the same vein, spiritual growth was prioritised when the body was failing.

Furthermore, routine testing was not the manner in which people found out about an HIV-positive status. Instead, people got diagnosed with HIV when they fell ill from an unknown illness and sought medical help. Despite the publicity on HIV/AIDS, the women in this project never expected to be diagnosed with HIV because there is a general sense that HIV/AIDS is not real – that it does not happen to ordinary people. The women in my sample battled to accept that they were infected with HIV and continued to seek a second opinion on the nature and cause of their illness. This resulted in a strange paradox in which many women both believe that they were infected with HIV and that they were not. It was, as the following chapter shows, primarily in hospice that the women were able to come to terms with their illness and start to deal with it.

Chapter 3

Hospice and hospice care.

Hospice is a reaction to the dominant pattern of bureaucratic, technological death. It is a manifestation of a shifting consciousness of death and of shifting ideas that relate death to issues of dignity and human rights. Hospice strikes a responsive chord in people who lament the gradual erosion of the many modes of support once provided by family and community (Munley 1983: 95).

This chapter is concerned with what can be done to mitigate the negative consequences of the epidemic on families and how to enhance the quality of life for those dying from complications related to AIDS. The argument presented in this chapter is that hospice care is the spring-board from which outreach programs can be facilitated. This point of view is informed by the fact that, whilst appropriate education about prevention is necessary, the reality is that millions of South Africans are already infected and affected. The South African government has suggested that home-based care is the most sustainable way to adequately meet the needs of PWAs. The hospice movement has begun, despite the severe lack of governmental support and resources, to offer home-based care for PWAs and other terminal illnesses in Soweto. In this chapter I analyse the extent to which hospice is able to perform these functions through a detailed analysis of the hospice. More importantly, this chapter will focus on how the subjects of this study benefited from the services and care rendered to them by the Soweto Hospice and its staff.

The history of the Hospice and its relevance in South Africa

The hospice movement started in London in 1967 with the opening of an in-patient unit, a community-based service was opened two years later (Clark 1993). Although there is reference to earlier hospice-like care and services early in the 20th century, the modern version of this movement emphasized the holistic care of terminally-ill patients in relation to their families, either at home or in a free-standing unit, and employed the skills of a multidisciplinary team with the overall aim of controlling symptoms and facilitating a pain-free and peaceful death. These services were initially only extended to

cancer patients for whom death was not far off. Hospice care has since been extended to accommodate other terminal diseases.

In South Africa, the hospice movement is a fairly recent development. It is significant that the introduction of this palliative care-oriented service in South Africa and in black townships, in particular, coincided with the prevalence of HIV/AIDS and its accompanying effects on the individual, the family and the broader community. As the previous chapters have demonstrated, the multiple problems that arise in the wake of HIV/AIDS strain relations between those who are infected and other affected South Africans. Hospice services have become very relevant in the context of hospitals ill-equipped to respond adequately and humanely to the needs of PWAs and their families. In the absence of a well-developed welfare system serving as a safety net for those who need both medical and sociological assistance, hospice services are much needed. In South Africa these hospice services play a vital role in the lives of individuals infected and affected by the epidemic. Given the lack of curative medicine, eradication should be the ideal to aim for, but already an estimated 4.2 million people in the country are infected with the virus (Sowetan May 16, 2001). For this reason, care and amelioration of the impact of HIV/AIDS are major issues of concern in South Africa. Poverty, fear of infection, lack of primary caregivers within the family unit, the small size of houses and the stigma associated with HIV infection make hospice care a crucial service. Lucky Mazibuko, a journalist who is HIV positive and an AIDS activist once wrote that for him, as a person who lives with the disease, the significance of the epidemic does not lie in the impact it will have on the economy of the country, but it lies in its impact on the lives of infected individuals and affected relatives. This statement calls our attention to the experiences of PWAs. As argued in Chapter Two, the impact of the epidemic on the economy becomes an abstract, far removed concern to those whose private and personal lives are lived with HIV/AIDS.

Home-based care for PWAs

The South African government also recognizes, albeit in a contradictory manner, the importance of hospice care when it seeks to promote home-based care for the millions of South Africans infected with

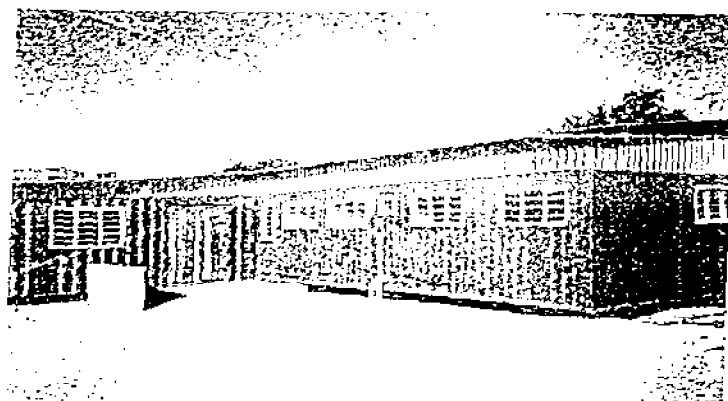
HIV or living with AIDS. Advocating for such care in the absence of homes that can accommodate the sick, of resources to aid such care and of adequate education for those who are supposed to take care of PWAs is tantamount to relinquishing responsibility for nursing infected individuals. Hospice care is therapy within the community with patients and care-givers drawn from the local surroundings. It is characterized by educating care-givers on how to carry out the task of nursing a terminally-ill family member, giving assurance that support is available at all times and the knowledge that the patient will be admitted into the hospice's in-patient facility should the need arise. The hospice nurses emphasized that this is an incentive for care-givers and it helps them to undertake the responsibility of caring for the terminally ill. Hospice services also include modifying the home environment to meet the needs of the sick person. However, because housing still remains a major problem in South Africa, home care may not always be possible. How does one modify a shack that accommodates a whole family to meet the needs of the patient? At the same time, however, admission to the hospice in-patient unit may not yet be appropriate as the patient may live for a long time and need a semi permanent place. In this case the hospice might intervene by seeking such a place for the patient. Home care also means that the sick person will need some equipment to aid everyday living and the hospice lends this out.

Although the hospice contributes only marginally in home-care, there is room for the organization to play a far larger role. When we consider the enormous need for home-care and the deficiency of other resources to carry this out, supporting and enhancing the role the hospice already plays may be one way to extend services to PWAs and their families. The government's pledge to shoulder some responsibility in the care of those already infected, coupled with financial support from the private sector for the services rendered by initiatives such as the hospice, will go a long way in addressing some of the problems associated with the HIV/AIDS pandemic.

The hospice in Soweto

The Soweto hospice is situated on the grounds of the Mofolo Clinic, Gauteng. It is a free-standing unit on these premises and falls under the auspices of the Witwatersrand Hospice Association, which

has its headquarters in Houghton, Gauteng. The Soweto hospice was opened in 1998 with only the day-care section functioning. It has since expanded to include sleeping facilities. This hospice services Soweto and the neighbouring areas such as Noordgesig and Snake Park. The actual building is a shipping container (see figure 1), an indication of the lack of resources for a proper building, that is divided into offices, a kitchen, bathroom facilities, a reception area, a day care and an in-patient section. During severe storms, the rain penetrates the roof and patients who have been admitted are then transferred to the mother hospice in Houghton. Day-care services were suspended until the storm ceases and the problem is taken care of.



The Soweto Hospice: Outside view

Although the Soweto hospice caters for both cancer patients and PWAs¹¹, many PWAs and their families are reluctant to use the hospice. Some PWAs who have been introduced to the hospice no longer come to the hospice. One of their main reasons was their need to terminate the association with the hospice because, according to township gossip, anyone attending the hospice is seen as suffering

¹¹ In general the older people tend to have cancer and the younger ones HIV/AIDS.

from HIV/AIDS. The hospice has come to be associated only with AIDS and cancer patients who attend hospice are automatically judged to be suffering from this disease.

The day-care area is filled with activities designed to keep people busy. There is a table, a number of chairs, a television set, a cupboard where handwork, mainly crocheted blankets, is kept, a heater and many magazines. Patients whose health status still allows them some independence come on rotating basis for day-care. Transport arranged by the hospice collects patients from various places in the morning and takes them back in the afternoon. The day is spent watching TV, doing handwork, browsing through magazines and in conversation with each other. People come and go all day, everyday and they all pass through this area. The day is punctuated with prayer services arranged by various organizations. Some of these people, like preachers, visit more frequently than others and their visits have become part of the routine. Day-care patients are allowed to rest in the admission area, but they are generally reluctant to do this. The younger people tend to go out and sit outside in the shade of an old tree where they sell second-hand clothing on behalf of the hospice to passers-by. The day-care patients receive breakfast, lunch and afternoon tea everyday. This is, according to the people I spoke to, one of the most important benefits of coming to the hospice. As many of these people are poor and unemployed, they need to eat carefully and one of the ways that they can meet this need is by consuming hospice meals. All these patients cited instances when they were not attending hospice, when they needed to take their medication and did not even have bread to take the medication with. The day-care patients also get their medicines replenished during their visits. Although they are encouraged to keep their appointments at their respective clinics where they will get medicine, it is easier for them to get medication from the hospice or from the neighbouring Mofolo clinic. They only need to say they are from the hospice to be attended to.¹² Another benefit afforded by day-care is that

¹² There is a system that allows people to get medical treatment only at their local clinic in the case of non-emergencies. People whose addresses do not fall within the area which the clinic serves are told to go to their local clinic. This practice is supposed to spread the load of patients across clinics.

the patient gets a day out and the caregiver at home gets a day-off and is able to attend to other errands and to have respite from the demands of care. My informants also commented on the advantages of meeting with and spending time with other people who suffered the same plight. I was told that it was a relief for them to attend day-care where it was not necessary to put on a mask to hide pain and heartache as all the patients knew what it meant to be confronted with a terminal illness and, therefore, there was unconditional acceptance of each other. As the following quotes indicate, it was also possible for these women to draw strength from each other, to encourage each other and to make friends. As indicated in the following quotes, coming to the hospice gave the women something to do and, through this, provided reasons to wake up each morning.

Bertha: I did not want to come to the hospice – my mother talked to me and I came. The thing that helped me most is that when I saw Carol and she was open – she told me that she has this illness. That is the thing that helped me because I thought that I was dying. When she stood up and walked I asked myself whether she was lying. Until today I can walk like her. I say thanks because she comforted me and seeing her gave me strength. I said if I can walk like you, I could be so glad. And being in a safe place, I do not have to pretend. We are all ill together and people who are ill understand each other.

Carol: It is nice here, when I am at home I do not get the care that I get here. Another thing, you get to go out and mix with people like you, keeping busy. I no longer want to befriend people who are well because they do not understand. The hospice helped me a lot. When I first got here I could not walk, I was just a thing. Seeing other people and mixing with them helped me.

Phyllis: Hospice helps. We wake up in the morning, groom ourselves [for this outing]. We eat, we sit together and enjoy each other's company. No one is better than the other here.

Maria: It is nice to be at the hospice. All those things that she had just said [this was a focus group] are true. When we are here we laugh, we even use our hands, our muscles sometimes get stiff and we exercise our joints [by doing handwork].

Grace: I like coming to the hospice, I wish to come everyday because at home I am ill-treated. Sometimes I think of killing myself. You know, being a source of ridicule is devastating – people say whatever they like.

These extracts suggest that PWAs at the hospice are motivated by the courage and resilience shown by their peers. Coming to the hospice also offers them reprieve from bad treatment at home,

here they meet people who share their plight and who are able to understand what it means to be a PWA amidst the ill-feeling directed against HIV/AIDS. Unconditional acceptance of each other in an atmosphere that reinforces a positive self-valuation provides a better quality of life that motivates PWAs not to give up.

People get referred to the hospice by hospitals, private doctors or they hear about the hospice from others in their communities. I found that automatic referral by institutions or doctors was extremely problematic as PWAs were not always ready to accept an HIV diagnosis or did not want others to know about their status. I was often asked how, if HIV infection is meant to be confidential, could institutions and doctors provide hospice with the details of victims: how come the people from the hospice came to know about them? This rhetoric question suggests that patients were not consulted about such a referral. Not surprisingly, this sometimes came to be a source of tension between the nurse assigned to such a patient and the patient. The nurses tend to be blamed for knowing about the diagnosis and health condition of the person and for acting on that knowledge by seeking out the person in order to introduce him or her to the services offered by the hospice. The person visited by the hospice staff usually does not expect such a visit as he or she was not consulted on this matter and reacts with hostility to the hospice personnel. Sometimes this hostile attitude changes as the patient starts seeing the relevance of the services rendered in his or her life and establishes a relationship with the nurse. This unrequited association with the hospice could, however, have extremely negative consequences as well and someone, visited once for whatever reason by hospice staff, might never shake off the township gossip that he or she suffered from AIDS.

The Soweto hospice can accommodate nine in-patients, five women and four men at a time. Admission into wards started in May 2000 with a trial number of four patients. All nine beds were opened for use in September 2000. A partition separates men from women while same sex patients are not separated from each other, except during medical examination when curtains are drawn around the

patient. A medical doctor visits these patients every morning and leaves after his rounds. According to Zimmerman:

Once involved in the hospice program, the hospice physician will serve as the personal physician for terminally ill patients in the program, directing his attention at palliation. For new patients and for those considering whether or not to enter the program, it will often be the hospice physician who will provide explanations of the hospice concept. The physician member of the hospice team is obviously responsible for the planning and ordering of the patients' medical care. It is he [sic] who sees the patient in the context of his [sic] prior medical history and who possesses the knowledge of the natural history of the disease process, which is so important to the planning of medical care (1989:99).

At the Soweto hospice consultation with the doctor was arranged through the nurse in charge of the patient. The same doctor came to the hospice every morning. He was always very polite, greeting patients in day-care on his way to the admission area and bidding them good-bye on his way out. This was, however, the extent of his interaction with patients in the day-care area, unless the nurse had arranged a special consultation with him. Patients in the day-care section felt that they were not getting enough personal attention from the doctor but they did not voice this to the hospice personnel. The lack of personal interaction with the doctor was especially frustrating for those patients who were in the process of applying for grants and needed the doctor's input on the application forms. The arrangement was that messages to and from the doctor had to be relayed via the nurse in charge of the patient. Some patients felt that they could plead their case better if they were allowed direct consultation with the doctor but they never said this to the nurses.

The need for medical assistance is the criteria for admission in any of the hospice areas, namely home-care, day-care and in-patient care. Patients' ability to pay is not a consideration. Those who can donate something for the services rendered do, although this is rare. In many cases the hospice is the last resort in the care and treatment of PWAs. Although, the diagnosis is typically made in a hospital, a second opinion is usually sought from traditional, faith healers and diviners. Scarce resources are spent in a bid to get another opinion or a cure. Those friends and family members who know about the HIV diagnosis will also do their best to obtain another opinion. Only after all else has failed, and the person becomes visibly ill, does the hospice become an option. In some cases hospice services are used in

conjunction with alternative medicine or they may be terminated in favour of another promising source of care and treatment. George, a male interviewee, said '...the pain is severe unless one takes pills, but it is the same. Most of the time I use herbs to clean the blood and for pain. The herbs help the pills'. This perspective was not unusual as Rita said 'I have a belief in herbs. I see [positive] change now that I take both herbs and pills'. Inevitably, the hospice is again called upon when the patient is in a critical condition. Now the hospice is perceived to be the most relevant source of care. So, people who were in day-care usually end up admitted in wards and vice versa. Writing about St Christopher's hospice in America, Munley (1983:36) notes that '[p]atients may move from the inpatient program to home care and home-care patients have access to inpatient beds as necessary', which suggests that this happens across the spectrum of hospices.

Despite the fact that the hospice is important to the patients, often only as a penultimate solution before death, many family members and friends avoid hospice altogether. As the following example shows, people only entered the hospice's grounds when there was no other option.

One Saturday morning I went to the hospice for a special function that was being held there. A woman I had never seen before came rushing towards me as I got out of the taxi. She was visiting her brother who had been admitted to the hospice. 'What section of the clinic have I come to?' she enquired. She then asked if I would mind accompanying her to the hospice. I was taken aback by this. Why did she need someone to go to the hospice with her? She said she had heard from her family, who had refused to come with her, that her brother was quite ill and so was everyone else at the hospice. She was afraid of the prospect of going to a place associated with death and dying but felt she had to see her brother before he died. I said that I was also going to the hospice and as we were walking she asked what kind of place it was. I responded to this by saying that she would see for herself. I could tell that she was very apprehensive about her visit.

This anecdote is told to illustrate some of the perceptions that exist about the hospice. Although this was an isolated incident, friends and acquaintances aware of my research continually asked me what kind of place the hospice is. Their questions centred, not on the fact that people were dying in there, but rather that it was AIDS that patients suffered from. There is a widespread perception that the hospice is a sombre place where there is no life and no hope. It is as if people believe that, upon

entering the premises one is confronted with visibly sick people and dead bodies. To conclude the story:

After a few minutes, the woman felt comfortable enough to leave the hospice to buy fruit for her brother and to re-enter the building on her own. She continued to visit her brother thereafter and I saw her a couple of times after that. She later admitted to me that she had not expected the hospice to be what it was, meaning that the evidence of death was not everywhere, crushing the spirit of people who entered it.

There is no denying that the hospice projects a particular atmosphere and emphasizes quietness and stillness. Nonetheless, the atmosphere changed with the mood of the group. While I was there I witnessed lively debates about political issues and other happenings, laughter, song and play and, yes, there was also sadness when there was a need for that. The mood could change from sadness to that of celebration and vice versa in a day. I also witnessed an atmosphere in which one was allowed to do what one felt like doing without being coerced to participate in group activities. People tended to fall asleep on the couches whenever they felt the need to rest, some patients read the bible or magazines and did not feel obliged to partake in group discussions, others just stood up and left the day-care area when they felt that they needed to be alone. Although hospice worked hard to create an atmosphere where everyone could feel at home, this was not always accomplished. Bertha, for example, complained that the only reason she did not want to come to the hospice was that she could not pray on her own when she felt the need. She wanted to be able to pray out loud, to cry and vent her feelings. This presented a real dilemma for her. On the one hand it was important that she attend hospice for the support, companionship and care that it offered. On the other hand, she also desired space in which to express her frustration and anger. It is not that there was a shortage of prayer in the hospice, rather she needed a particular form of prayer that was not accommodated by either the atmosphere or the planning of the hospice.

Home-care: an important part of services offered by the hospice

Home-care is also a large part of the services offered by the hospice. Four senior nurses are responsible for patients at home as well as for those who come for day-care. Each patient is assigned

to a senior nurse upon admission to the hospice program. The nurse sees to the well-being of the patient and should be accessible to the patient 24 hours a day. For this purpose, the nurses carry pagers and can be reached at all times. Although they are obliged to give advice over the phone whenever possible, nurses are not expected to visit the house of the patient after four o'clock in the afternoon. I went on some home visits with the nurses and gained first-hand experience of what these visits entailed. Firstly, there was the risky business of trying to find a patient's house for the first time. In Soweto not all houses display a house number and the numbering of houses does not always follow a logical pattern. This meant that the nurse had to stop and ask the whereabouts of that address. In the townships, where car hijacking is rampant, this was very unsafe.¹³ The nurses hoped that their profession as nurses on duty and community workers would discourage potential high-jackers. The nurses seemed to take this part of their job in stride.

Although with time, these nurses developed close relationships with the patients in home-care and their families, entering someone's house for the first time was always a difficult experience. The nurses did not know what reception to expect, especially when the visit was about something as personal and sensitive as an HIV diagnosis. Of course, the nurse had to seek out the patient before talking to other family members. Indeed, the possibility of talking to other members of the family was negotiated with the patient. This negotiation could, unfortunately, be seen as a farce, because as soon as a hospice nurse visited a house with the express purpose of talking to a particular individual, the neighbourhood and township gossip identified that person as 'having AIDS'.

This home-based care was dubbed 'hospice without walls' by the hospice personnel. It includes seeing to the medical needs of the patient and keeping records of these, facilitating his or her comfort in the home, devising means to adapt the house to accommodate the mobility and other needs of the patient and also responding to the concerns of the primary care-giver at home. Patients who were in

¹³ Nurses use their own cars for home visits except the coordinator of the hospice who uses a car that has been donated to the hospice.

home-care were those whose health status did not allow them to attend the day-care sessions at the hospice. Their needs were such that they could be taken care of at home and not necessarily be admitted into the hospice as full-time patients. Home-care nurses spend most of the day doing home visits. They came early to the hospice and left around mid-morning for visits. The time that they spent in the hospice made them accessible to their day-care patients. They also used this time to do paperwork and replenish their medicine supplies.

The home-care aspect of the hospice and the work done by the nurses during home visits relied heavily on a primary care-giver resident in the home of the patient. The availability of a primary care-giver at home was also important for those who were part of the day-care program. Care-givers did not get remunerated for their services and their emotional ties to the patient were the motivating factor for assuming the responsibility of caring for the person. This is a demanding task in a context fraught with stigma and misconceptions about HIV/AIDS. This task is also exacting as the care-giver has to be sensitive to the patient's needs. The emotional strain of caring for the terminally-ill is particularly pronounced in the case of HIV/AIDS as the care-giver is not supported by the community in this role. This is what Bertha's mother had to say about assuming care for her daughter:

...I could not believe it. Really, I could not believe it [an HIV diagnosis]. I thought of moving from this place. I thought of many other things but I did not think to ostracize her, for who else will take her in if I won't? I am her mother, I must take care of her. I cannot kick her out. It is very difficult to take care of these people (PWAs), they get ill and you must respond to their ups and downs. I also felt that, God, I am tired but my conscience did not allow me to throw her out. The child is mine, why should I treat her badly? I said God I am sorry for having these thoughts, the child is mine. People can talk and say whatever, but we go on.

Care for terminally-ill patients is hard enough under normal circumstances. In Soweto, the difficulty of caring for PWAs was compounded by the stigmatised approach to all PWAs and a general victimization of anyone who associated with them. This was one of the reasons many PWAs tried to hide their status. Such strains and stresses resulted in cases where patients did not have a primary care-giver who felt as committed as Bertha's mother did and who would extend their assistance and concern throughout the terminal illness. I found that the strain that an HIV/AIDS diagnosis puts on

relationships meant that some of the women I interviewed moved from one household to another (as will be discussed in Chapter Five of this thesis). This essentially meant that different people cared for them for varying lengths of time. This posed a problem for hospice in terms of the education of primary caregivers and in terms of ensuring optimal care for the terminally ill. Hospice intervention aimed to curb the need to move from place to place by educating the family and facilitating better relations between the patient and his or her significant others, but this intervention did not always yield desired outcomes and in such cases the hospice has had to find alternative accommodation for the patient. Carol, for example, was kicked out of her aunt's house despite the hospice staff's efforts to educate the family about HIV/AIDS and the hospice had to seek alternative accommodation for her.

The role played by the hospice in terminal illness

Burnell makes the point that the basic purpose of the hospice is to provide patients and families with a comfortable and supportive environment to ease the period of illness before death (1993). Saunders extends the concept of the hospice by saying that "...a hospice should quite simply be 'given to hospitality', that it should welcome those whom no one else wanted to care for and give them the promise that this welcome would last as long as the need existed" (1977:160). This warm and welcoming hospitality was necessary given that the fears and stigma that surround AIDS condemned infected and affected persons to isolated lives without the support ordinarily extended to those in need. It is thus not far-fetched to suggest that the hospice performs a vital role, given that PWAs do not always have people to care for them and hospitality, especially at the very advanced stages of the disease when they are completely dependent on others, is often withdrawn when it is most needed.

One of the basic tenets upon which hospice care is premised is responding to and controlling the symptoms of terminal illness. Zimmerman points out that '[t]erminal illness has both medical and non-medical matters' (1981:2). There comes a time in the progression of a terminal illness when aggressive medical treatment and technology are no longer appropriate (Saunders 1977). Zimmerman also asserts that recognition of this and opting, instead, for the control of symptoms becomes difficult in a hospital

setting where intervention is aimed at curing the disease (1981). Such a situation requires doctors to recognise that although nothing further can be done about the disease itself, there is still something that can be done for the patient. The utilization of aggressive methods of treatment demonstrates a vain attempt 'to do something', however inappropriate that intervention is. This shows confusion between what can be done and what should be done at the particular stage of the disease. This argument may seem irrelevant when we consider that there is a general consensus that AIDS cannot be cured. It does, however, show that whereas nothing can be done to cure the disease, something can be done to make living with the disease more bearable. Controlling symptoms – physical, emotional, spiritual and social – makes a difference to the experience of living with and dying from the disease. 'The interrelationship between the physical and the psychological is recognized' (Zimmerman 1981:29). It is this recognition and the capacity of the multidisciplinary team that make up the hospice staff that enables the hospice to offer holistic care.

The hospice philosophy acknowledges that death does not reflect failure to restore life, however painful and devoid of meaning that life will be, but rather that growth is possible in the face of death (Munley 1983). Saunders claims that hospice care makes it possible for one to be aware of one's impending death and not be afraid of it (1977). This is achieved in several ways, for instance, emphasis is placed on controlling pain by using analgesics throughout the terminal state of the illness. Although painkillers are disbursed, a balance between containing the pain and maintaining alertness in the patient is maintained. Consciousness and awareness in the patient is important as care given in the hospice also seeks to preserve the integrity and identity of the person. It is for this reason that patients are encouraged to surround themselves with familiar belongings even when they have been admitted to the night-care unit of the hospice. Saunders puts it like this:

[w]hen patients enter the hospital, they leave their own community and much of their identity. We are all bound up in our homes and possessions, our work and our hobbies, and we feel stripped and humiliated if our clothes and personal belongings are removed. The emphasis on possessions, clothes and idiosyncrasies in a hospice is a way of maintaining identity...a hospice can be a reaffirmation of his own home and community, even though he [sic] may never return to them (1977:167-168).

Keeping the patient alert and free of pain becomes important in the light of the need to have meaningful interaction with significant others in the short time that he or she has remaining. The hospice staff plays an important role in facilitating the interaction between the dying patient and his or her family and friends (Burnell 1993). My experience of this is the role played by the Soweto hospice nursing staff in helping PWAs disclose their status to their families and the atmosphere that is created in the day-care section of the hospice. This is achieved through the support and education given to both the patient and the family and through the development of the hospice as an 'extended family'.

The hospice 'community' as an extended family

Hospice support does not stop after the patient has disclosed his or her status to family and friends. Rather, Munley introduces the idea of the hospice 'community' acting as an extended family (1963). The nature of the care extended to the patient and his or her family encourages opening up to the hospice personnel. Pent up emotions are explored with the assistance of the hospice staff facilitating an amicable solution for all parties concerned. It is in this regard that the concept of the patient and the family being a 'unit of care' comes into play. There is an explicit recognition that the problems of a dying patient and those of his or her family are inevitably intertwined (Burnell 1993). Moreover, the family is encouraged to take an active part in the care of the patient both in home-care and in the in-patient unit. Some families are more amenable to participate in these interventions than others. The denial that there is a problem and the recognition that the family can benefit from participating in the hospice program were two problems nurses often experienced. This denial often stemmed from the refusal to acknowledge that a member of a family or even in some cases, oneself, was living with HIV/AIDS. During my research I learnt that some families react aggressively to nurses' visits. Other families were open to this intervention but preferred the nurses to visit without displaying any item that identified them as coming from the hospice. For instance, they were asked not to come in the car that displays the hospice sign or to wear nursing uniforms. They should, rather, come as anonymous visitors. Once the problems associated with the first visit were solved and future visits were

permitted, the nurses' main tasks concerned intervention, support and trying to take up family issues for the benefit of both the patient and his or her family. This was not a straightforward undertaking. For instance, the social worker recounted how a client complained about the treatment she had received from her family at home. After discussing the pros and cons of intervention and agreeing with the client that she could visit the family and perhaps intervene on her client's behalf, the social worker arrived to find that her client had gone back on her word and wanted the social worker to say and do nothing. The social worker supposed that this reaction was fostered by the fear that relations with family members would be further strained through her intervention and attempts to provide guidance. My similar experiences would suggest that this was a common reaction. I was often unable to interview affected families because my informants were reluctant to have me speak to them.

It was, perhaps, because of the problems PWAs experienced in their homes, that they came together at the hospice and supported each other so strongly. The idea of the community acting as a surrogate family was further exhibited in the friendships patients formed with each other. Having been treated badly by others, the women I interviewed turned to each other for support and companionship and their friendships extended beyond the hospice setting. They exchanged advice on treatment and took care of each other. They visited each other on weekends and special days, accompanied each other on important business such as applying for disability grants and hospital visits and were generally accessible to each other. Sometimes the patients would organize a get-together at one patient's house and they would meet outside hospice hours to socialize. The fact that the patients in the day-care section of the hospice varied in age, with elderly, mature and young people, made the idea of a family all the more plausible. There was an interdependence characteristic of a functional family unit. The hospice staff was also very involved in the affairs of patients and encouraged them to become part of the extended family. I witnessed several birthday celebrations that reaffirmed the importance of individuals in the overall scheme of the organization. Patients would bring a birthday cake to share with others and the staff would join in the celebrations, soft drinks that would ordinarily not be served would

be made to accompany the cake and photographs would be taken. We celebrated Helen's birthday in November 2000 and she died a few days later. She had been so withdrawn during her last visits to the hospice that people were generally worried about her. Even at her birthday celebration, she did not get involved in conversation and was not looking directly at her peers. *Posthumously* the other women attributed this behaviour to the nearness of her death. The photos of this celebration were displayed along with others of important functions in the hospice. Commenting on the hospice tradition to celebrate life in the face of death Saunders writes:

We cannot take away the whole hard thing that is happening but celebration is an important part of life and each hospice occasion is a salute to this kind of courage. Neither patients, families nor staff are protected from sadness, but in sharing it as they do, they find that living and dying well are linked together and are constantly opening up new and creative possibilities (1977:176).

The celebration of Helen's birthday was very touching. Everyone went out of his or her way to make it a special occasion. It represented a victory, the triumph of life in the face of death. It was considered a great feat that she was able to hang on to life and celebrate her birthday when she was so sick. In the midst of a lonely struggle against HIV/AIDS the surrogate extended family role allowed patients to reach out to one another and to shield the patient from the pain of experiencing social death prior to physical death.

Death at the hospice

The reality of the hospice is that the death rate is high. Twenty-eight people associated with the hospice died between September, 2000 and January, 2001 thirteen of whom died in the hospice. Immediately after a death, a curtain is drawn around the dead person until the family sends an undertaker that will remove the body. The coming of an undertaker to the hospice signalled to the patients in day-care that someone had died in the wards. The corpse was removed through the back door to shield the other patients from coming face to face with death. There was usually no group effort to attend the funeral of someone who had been part of the hospice, although individuals sometimes went on their own. Family members returned to the hospice to collect the belongings of the deceased

and have relevant forms filled. The hospice nurse who was in charge of the patient would make bereavement visits to the family soon after burial. Zimmerman highlights the following as the purposes served by these visits (1981:137):

- To assess the coping ability of the survivors
- To encourage and facilitate the expression of feelings regarding the loss
- To reassure survivors that bereavement, although painful is normal
- To identify disturbed delayed or pathological patterns of grief and make appropriate referrals for long-term follow-up.
- To give opportunity for the bereaved to examine the process of their increased growth and maturity through the death experience.
- To provide opportunity for feedback about program effectiveness.

Amongst other things, these visits were intended to ensure that the family was coping with their loss, to ensure them that their grief was normal and to provide opportunity for feedback about the effectiveness of the hospice. This follow-up intervention is important to the well-being of survivors as they come to terms with a death associated with AIDS in the family. Of course the success and effectiveness of these visits depends on the nature of the relationship the nurse had with the family before the patient's death. Such intervention may be more appreciated when the services rendered by the hospice are perceived to have helped in one way or another. Munley suggests that a common cultural background between those cared for and the caregiver facilitates a more empathetic approach to support as practices and beliefs are understood and/or shared (1983). As pointed out earlier, hospice care seeks to use local expertise to address the needs of the local communities and this assists in the grieving process. Death and dying in the context of HIV/AIDS is discussed in more detail in Chapter Five.

Death, dying and hospice care

The protracted terminal nature of HIV infection and its associated complications bring to the fore the powerlessness of those who are infected. Moreover, problems associated with HIV/AIDS, especially among the poor, mean that those living with the disease go through a difficult and alienating dying process. As suggested by the work done by the hospice and as discussed above, the advent of HIV/AIDS and the fact that there is no cure for the disease may necessitate a shift in how death and dying are perceived and dealt with by both the lay community and the medical profession. The traditional medical goal of prolonging life may need to be revisited and reviewed in the context of HIV/AIDS. Burnell comments that 'soon a new goal for physicians and nurses will be to sharpen their skills in reducing patients' fears of dying and in providing them with adequate pain relief and comfort' (1993:315). It may be that the concern with death becomes primarily about dying a painless and dignified death. The holistic care and support offered by the hospice is guided by the needs of the dying person and his or her family, and ultimately aimed at easing the period of illness before death. In this regard, Saunders highlights the hospice's effort to understand patients in the context of their lives so that social and emotional needs can be addressed (1977). At first glance the concept of death with dignity seems like a dubious one, for dignity is surely subject to individual interpretation and may be culturally specific. However, understandings of making a 'good' or 'bad' death are shared within a cultural group and will influence the nature of the services delivered by the hospice to the local community. Clark notes with concern that hospices often appear as white middle class Christian institutions (1993). Zimmerman, in contrast, points to the diversity of form and style of hospice services and their ability to adapt and respond to local needs (1981). For instance, the hospice in Soweto services more HIV patients than cancer patients, perhaps not because there are more PWAs in Soweto than patients with cancer, but because the introduction of the program coincided with the prevalence of HIV/AIDS in South Africa. Local need shapes and defines the services offered, although not surprisingly I found that the subjects of my study preferred that the hospice be known by the wider population as a place that serves cancer patients. The hospice responded to this concern by stressing,

in media and other public reports, that they not only treated people with particular diseases, but sought to assist anyone who had a terminal disease.

The idea of achieving a dignified death is central to the philosophy of the hospice movement. There is a recognition that some forms of death can be more alienating than others. In the framework of the impersonal and technological approach of modern medicine, the patient and his or her family are not afforded the support that is needed in the face of impending death. In fact, death is undesirable from the modern medicine perspective. Where death is inevitable, the process of dying should not be protracted because nurses and doctors are not skilled to deal with this process (Zimmerman 1981). In modern medicine, death is seen as separate to other factors in the person's life. Relations to others only matter in so far as the signing of documents and other administrative and bureaucratic concerns. In hospice, the relief of pain and other symptoms of illness is of primary importance so that the patient can continue to live in meaningful relationship with those around him or her. Burnell summarizes this idea thus: '[t]he focus is on the quality of life and on helping families optimise the time remaining with the dying member' (1993:279). The period before death is crucial for addressing important issues that could not be dealt with during other times. The notion of dying in peace becomes especially relevant at hospice where an environment which facilitated meaningful communication with significant others is made possible. Experiencing a terminal illness free of pain also lends a sense of mastery over the disease such that the individual's integrity is preserved. This aim is not always achieved by hospice as each individual has his or her own particular problems and antagonisms that frustrate a peaceful death.

Saunders asserts that the hospice is a community which provides limited medical technology and which emphasizes more personal care (1977). Not making an effort to treat the disease more aggressively using modern technology can be seen as tantamount to 'passive euthanasia' (Saunders 1977). The decision to discontinue aggressive treatment in a bid to prolong life should be taken in consultation with the dying patient and his family. This decision to resort to palliative care should be an informed one and should be taken with the understanding that it can be reversed. At the hospice in

Soweto this is difficult as patients come and go without much accountability and they finally stay only when death is inevitable. Anti-retroviral drugs, which are not available in public services and certainly not in NGO services such as the hospice because of their cost, remain the only option in halting or slowing the disease process in the case of HIV. Where such drugs are not accessible and HIV has progressed to AIDS, palliative care is the only option available. Technology is then used in controlling pain and symptoms in conjunction with human warmth, understanding and interpersonal support (Munley 1983). The modern hospice thus sets an ideology that, if properly implemented, can humanize and reform existing patterns of terminal care (Munley 1983).

Poss argues that death and dying can be sources of emotional and spiritual growth (1981). Such growth can culminate in achieving a dignified death, even though the defining features of this dignity may differ from individual to individual and for those who are involved in his or her care.

The effort involved in such growth may be referred to synonymously as 'dying work', 'death work' or 'terminal crisis work'. These terms denote the mental, emotional, social and spiritual work required of the patient in order to come to terms with dying and death, and so to die with dignity. The term 'work' is used in order to indicate that a great deal of energy and effort are required to resolve the crisis involved in dying. Hence the patient cannot master the terminal crisis i.e. he [sic] cannot die with dignity, until his [sic] dying work has been completed (Poss 1981: 3).

The hospice provides an atmosphere that is conducive to dying with dignity. Problem areas in the patient's life that might get in the way of achieving a peaceful ending are identified and attempts are made to deal with them. Of course, this is easier in some cases than in others. Questions about life and death are brought to the fore when facing a terminal illness. Such an illness underlines the certainty of death and may invoke the need for spirituality. Belief in a divine plan that dictates life and death becomes a source of sustenance and acceptance of death and dying, as was shown by some of my interviewees (see Chapter Two). The hospice's philosophy is not to induce spiritual growth in the dying patient but to respond to this tendency. Although the Soweto hospice is not a religious institution *per se*, a focus on spirituality has developed in response to the patients' tendency to want some form of spirituality. The hospice personnel uses this spiritual inclination as a means to counsel individual

patients. Formal sessions of counselling were not part of the services that the hospice provided for the patients during the time I was doing fieldwork. There is, nonetheless, a need for some counselling and religious beliefs played an important part in responding to this need. Munley makes the point that spiritual maturity is one of the criteria used to select the hospice staff. 'The hospice approach to terminal care recognizes and respects the diverse needs terminally ill patients have for spiritual solace and fulfilment. Spiritual care is a basic component of hospice philosophy and practice' (1983:64).

Other members of the hospice team

As mentioned above, the doctor and home care nurses spend only part of the morning in the hospice. Patients in wards and in day-care were left in the care of nurses in training. There were four of them when I was doing research. They came on a rotational basis. Two nurses did the morning shift and the other two came for the night shift. Although they interact with patients in the day care area, they spent most of their time in the wards. In addition to the nurses, volunteers were an integral part of the care offered in the hospice. They were mainly students who were being trained for a diploma in home care. The volunteers were expected to do some practical work at the hospice as part of their training. A number of the volunteers had finished their training but had stayed on to help at the hospice. Some of the volunteers who underwent this training did not do their practical work at the hospice but in associated community based organizations. In fact, individuals who were already in community projects were given preference in the subsidized course because they had already demonstrated an interest and devotion to the care of the terminally-ill. There was only one male student in the home care course that took place when I was doing fieldwork. All other volunteers were women. The volunteers at the hospice were fairly young, especially those who had gone through the course and displayed a commitment much needed in the care of PWAs. A small number of volunteers had not been trained in the care of the terminally ill and were not registered for the diploma, but were interested in assisting hospice for other, more personal reasons. The skills of this latter group were used mainly in the kitchen as opposed to the other volunteers who were involved in the actual handling of the patients.

Zimmerman believes that the use of volunteers in hospice care makes it possible for the nursing staff to extend services to patients that would otherwise not be available (1981). The presence of volunteers also allows hospice care more flexibility in meeting the needs of the patient. Taking meals and baths, for example, can be postponed to the time most convenient for the patient with the help of a volunteer. The volunteer is not constrained by other duties, making her available to listen and talk to the patient when the patient wants to talk. Moreover, the volunteer is seen as outside of the formal health care delivery system and patients and their families tend to open up more to them than to the professional care givers. This may help bridge the gap between the two parties. The involvement of volunteers in the hospice also brings in the outside world to the patients who are confined in bed. Physical contact with non-professional people who are not obliged to handle the patient in delivering care can be important to PWAs who have been denied such contact because of the fear of contagion associated with the disease. The Soweto hospice has also started training volunteers, called community care workers, to give care in the home. This does not only mean that the more PWAs will benefit from hospice services, it also means that the example of ordinary people getting involved in the care of such patients in the privacy of the home might encourage others to take better care of infected family members. The stigma that is partly influenced by the fear of contamination might be reduced. This move to involve individuals in caring for terminally-ill people at home might be a stepping-stone to building a community ethos that will underpin community-based care. This approach does not assume that there is a community that exists naturally out there that will and can take care of each other in times of need. Instead, this approach seeks to educate by example showing that community-based care is needed, can be made possible and improves the quality of life for all involved. Such community-driven initiatives are necessary to increase the capacity to care for others and may be more sustainable than other approaches. As such increased government and private sector support of such initiatives may prove more rewarding than the continued, and now somewhat unsuccessful, campaigns to educate people about HIV/AIDS and to increase condom-use.

Despite the nurses, the nurses-in-training and the volunteers, there was also a desperate need for social work services at the hospice. Although the nurses performed some of the roles that would have been done by a social worker, their time was limited and the need for social work services remained. Shortly after I finished fieldwork a social worker was employed specifically to work with the hospice patients. Before her appointment, patients were referred to a lay counsellor who was based at the Mofolo clinic upon admission to the program. Here problems had arisen as the counsellor was not always readily available and accessible to patients from the hospice. The services of a social worker from the clinic had been used in desperate cases, but as with the counsellor, her workload was heavy and could, therefore, not be available at all times. Moreover, using the services of people whose time is not solely devoted to problems arising from the terminal illness characteristic of patients in the hospice meant that patients received disjointed care that had limited potential to adequately fulfil their needs. The void that was left by the lack of social work services could be felt particularly around the issue of accessing disability grants. Even for South Africans with minor disabilities, the process is long and complicated, leaving a lot of applicants frustrated and in despair. I was frequently asked how to go about applying for this grant by the women at the hospice. I did not have this knowledge and I somehow felt that I was failing them as they were dependent on getting this money to survive and to gain some independence, but clearly could not wait for the usual slow bureaucratic procedure to be completed. This was one of the first areas that the newly-employed social worker sought to deal with. Apart from trying to secure the grants for the patients and their children, the social worker was also able to explain how the system works. There was also the possibility that if the applications were handled by a professional, using the hospice as a source of reference, they would be treated with the urgency that they deserve. It was a real struggle for the women to understand how the system worked as they were sent from pillar to post by different people. It was not unusual for them to expect to get paid on a particular day only to be told that they had not gone through the whole process or had not fulfilled some requirement. Lack of money and ill-health also prevented them from pursuing this goal. Facilitating this

process was not the only important task that the social worker does. During one of my more recent visits to the hospice, I learnt that she was also involved in providing more structured counselling for the patients and their families. This involves disseminating a lot of education about HIV/AIDS as well as facilitating a more meaningful interaction between the patients and significant others. The social worker also offered pre-death counselling for the patient and the family and post-death counselling for the family. According to her, the intense involvement in matters of death and dying was very strenuous, but necessary. She said that she was lucky because she and other social workers involved in the hospice program received debriefing from psychologists on a regular and structured basis. They (social workers) also met to air opinions amongst themselves and this proves to be helpful in relieving stress. The other hospice staff members did not have as much access to such services. Support for them was organized as the need arose.

Conclusion

The multidisciplinary approach of hospice afforded patients and their families well-rounded and integrated care that was tailored to their needs. The recognition that life was still worth living despite having a terminal illness and of the plethora of problems that arose in the wake of death, especially in the new context of HIV/AIDS, proved invaluable in informing intervention. Hospice care extended much needed support amidst confusion, helplessness and the disintegration of other more familiar networks of support and care. I believe that treating the family and the patient as a unit of care has never been more relevant than now when family relations are strained by the threat of HIV/AIDS and when the South African medical system is overburdened and cannot cope. Education for both the family and the patient may lead to better understanding and acceptance of HIV/AIDS. The fact that hospice care is delivered in a number of settings, depending on the needs of the patient, adds value to the hospice concept.

Burnell (1993) puts it concisely when he writes that the hospice tries to answer the question: What does each individual (in this case infected and affected) need? Responding to these needs becomes all-important because the time left to live is limited in a terminal illness.

For the staff, the hospice creates a unique situation in a highly mobile, fast pace society. Where patients are defined as 'terminal', staff literally have the opportunity to know them for the 'rest of their lives'. Hospice espouses an ideology directed at providing patients with fully lived time. Staff members realize this goal by a 'do it now' attitude toward patient and family needs (Munley 1983:106).

Patients are afforded maximum capacity to live in relation with others through the control of pain and other symptoms. A balance is sought between this objective and that of keeping the patient alert and aware of his or her surroundings. The hospice also offers a tranquillity that is not present in hospitals. Hospice care is tailored towards meeting needs that arise in a terminal crisis. The care given and the atmosphere are geared towards a peaceful and easier passage from life to death. Care that is intimate and unconditional is extended so that the dying know that they matter right up until their deaths. Again, this is especially poignant in the context of HIV/AIDS in South Africa where rejection and avoidance seem to be the norm.

The hospice philosophy is also that support should be extended to the bereaved family. Ties that were forged between the hospice personnel and the affected family in the dying process of the patient are carried over into bereavement. Because hospice care is therapy in the community by people with similar cultural backgrounds, empathetic understanding of practices and beliefs becomes easier. Through training volunteers and home-care specialists, the hospice movement has the potential for a rippling effect that can help change the mindset of people about AIDS and caring for those who are infected and affected. Showing by example that care is possible and does not pose danger to caregivers may help reduce the stigma associated with HIV/AIDS. In this manner, the hospice could be a catalyst for social change. Issues of unconditional care and human dignity are brought to the fore. In addition the hospice provides a setting whereby people with similar problems meet and share problems and solutions. It is too early to predict the future of hospice care in South Africa, but the expertise and

services offered by the hospice will be urgently needed and highly sought after as more people become infected and many present with the symptoms of AIDS. In this context, community and home-based care seem more viable and sustainable and the hospice program is equipped with the skills needed for this. Despite everything that the hospice does for its patients, these men and women have to come to terms with their illness themselves and Chapter Four of this thesis highlights the experiences of living with HIV/AIDS amidst the ignorance, prejudice and discrimination exhibited by the South African population.

Chapter 4

Perceptions, understanding and living with HIV/AIDS.

Virtually all studies point out that talking about Aids involves talking about the fear that AIDS brings to mind. It is like a frightening shadow - the materialization of the old, spiritual or psychological contamination that comes from 'impure' and 'dangerous' people (Paiva 1995: 102)

The advent and impact of HIV/AIDS has summarily been likened to an earthquake that hits indiscriminately and catastrophically by my interviewees. Having explored the hospice experience in the previous chapter, this chapter adopts a wider focus and presents existing ideas about HIV/AIDS in the township of Soweto, and examine how these ideas influence reactions towards those who are afflicted. In so doing, it also details the impact of living with HIV/AIDS on the individual and on his or her relations with others. Obbo has argued that public health programmes on AIDS in Africa have tended to emphasize the need to change sexual behaviour and using condoms as a safer sex practice (1995). While behaviour change and condom-use have been stressed in AIDS education campaigns in South Africa, this has not produced any significant transformation in people's sexual behaviour. My research shows that this message has filtered down to 'the people', but with it are other factors that influence behaviour and need to be taken into consideration. Obbo continues to say that these programs will not be effective in the African context because they do not consider the primacy of traditional sexual practices of African people in the transmission and control of HIV (1995). While it is true that emphasis on individual decision making and motivation will not effectively harness the spread of HIV/AIDS because, in some contexts, there may be barriers to exercising individual autonomy, it is not true that all Africans practice and adhere to 'exotic' sexual mores. This chapter will show how cultural or more broadly attitudinal orientations regarding HIV/AIDS have emerged and how they impact on the experience of living with HIV/AIDS in the township of Soweto. These cultural or attitudinal factors are not, as suggested by Obbo, bound by 'tradition' in the sense that they are timeless and specific to a culture. The importance of these factors will be considered in so far as it is understood that they are

products of wider influences across time. In addition to this, this chapter will emphasize the agency of individuals, what information they listen to, how they adopt and apply knowledge to their particular circumstances and what information is *rejected or modified* as individuals try to come to terms with the reality of living with HIV/AIDS.

When HIV/AIDS is the subject of study, it is necessary to explore the sexual relationships between men and women since HIV infection is primarily spread through heterosexual sex in Africa. It is also important to bear in mind that sexual behaviour is embedded in social, political and economic structures of a society. Both Schneider and Head point out that the South African migrant labour system is one of the root causes of STDs, including HIV (1998, 1992 respectively). According to Schneider migrant labour leads to an imbalance in the male/female population of the urban areas, giving rise to a demand for prostitution. 'Prostitutes' and their clients, then, become a 'core' of 'disease transmitters'. Preston-Whyte has, however, problematized this concept of prostitution (1992). She highlights the widespread nature of sexual exchange in urban life. She suggests that, rather than a particular group perpetually engaging in transactional sex, many urban women are unable to find paid work, and thus support themselves by offering sexual favours to a series of lovers in return for material support. My research findings support this observation, and Chapter Two of this thesis has demonstrated the precarious nature of relationships between men and women in the township. In addition, it is not prostitution but serial monogamy – the monogamous but weak unions that lead to one child but last little longer than a year or so, that appear to dominate in the townships. After such unions have dissolved, the woman finds herself with a new dependant and even more in need of a reliable partner. Women are not passive in these arrangements. They actively seek to maximize the returns that they get from the relationship. They can terminate a relationship if it has exhausted any economic possibilities (Schneider 1998).

Sexual behaviour and its propensity to change

Clatts cautions that a narrow analytic framework of factors that influence sexual and other behaviour does not provide an effective understanding of causes that contribute to the spread of HIV/AIDS (1995). He further argues that

[t]he use of [narrow and rigid] categories [to define and give substance to sexual behaviour] makes it impossible to identify and map changes in concepts of self over the course of an individual's life span, or to locate an ever-emergent self within social, cultural and economic institutions that are themselves dynamic in character (Clatts 1995:246).

By portraying sexual behaviour and practice as traditional and exotic, and therefore, bestowing it with properties of being closed to other influences and resistant to change, one undermines the interconnectedness of cultures and their propensity to change when the need arises. This is not to deny the existence of cultural specificity but rather, these points are made to highlight the danger of understanding some cultures as totally isolated and unchanging. In my view the threat of HIV/AIDS is reason enough to question and change historically-rooted practices if they contribute to the spread of the epidemic, but it is not a foregone conclusion that 'cultural traditions' about sexual behaviour are responsible for the spread of HIV/AIDS. Moreover, and more pertinent to the study of HIV/AIDS is the need to recognize that although responses and meanings may be influenced by local viewpoints, some room exists to consider what impact 'outside' influences have had on local perceptions and responses and what ways might this be used to advance anti-AIDS campaigns. Anti-AIDS campaigns have to consider existing ways of knowing about this epidemic and proceed in a manner that is not alienating to the targeted groups. The melange of cultural, social, economic and political factors and its impact on both behaviour and meaning should shape the paradigms that inform interventions.

Paiva asserts that '[e]veryone knows about AIDS and knows that sexual intercourse can cause infection' (1995:102). This may be true, but it also needs to be said that the knowledge of facts does not always lead to behaviour change (Stein 1999). Also, other competing sets of knowledge may be held simultaneously with the understanding that penetrative sex can lead to infection. Chapter One of this thesis has shown that the HIV/AIDS complex, by its very nature, is prone to multiple interpretations.

Suggestions of witchcraft, that AIDS is an old disease, similar to leprosy, which is returning and religious interpretations have been put forward in a bid to understand this phenomenon. In some situations the attitude that 'AIDS or no AIDS, life must go on and damn the consequences' might prevail (Agadzi 1989:144). Schoepf argues that this fatalistic attitude or denial of personal risk can be summarised as: [p]owerlessness in the face of a dreaded disease leads many women to deny their risk' (1995:31). My research findings are that denial of one's risk exists alongside a sense of helplessness against an all-consuming epidemic. Attitudes of denial and helplessness do not encourage positive changes in behaviour and this has dire implications for the spread of the HIV/AIDS pandemic.

The experience of living with the illness has been described as the hardest thing that informants were forced to deal with –as mentioned above, it is a catastrophe against which individuals feel helpless. Busse contends that

[p]eople who are HIV-positive, or who have AIDS have first hand experience that the word AIDS is not merely a neutral label for a disease caused by a virus. They are aware through personal experience, that people's perception and understanding of AIDS is informed by words and language and through visual images and representations (1995:22).

Societal perceptions and experiences are influenced by a number of factors all of which in turn affect a society's potential for behavioural change. This chapter will unravel some of the myths that abound regarding HIV/AIDS, the actual experience of living with the illness, the effects of other people's stereotypes and stigmas and the coping mechanisms enlisted to deal with the experience. The importance of fear in the lived experience of people with HIV/AIDS and the lack of understanding of the disease will be shown. It is these fears, stereotypes and stigmas which induce people to hide their illness, rather than to challenge people's beliefs and through this challenge, to attempt to bring about behavioural change. National debates about HIV/AIDS may also influence local behaviours and perceptions.

National level debates and behavioural change

Weeks postulates that we fear most those diseases that we know least about and that these epidemics trigger irrational responses (1998). Furthermore, sex-related diseases carry moral overtones

and become symbolic of sin, deviancy and moral decay (Crewe 1995; Sontag 1989). Despite earlier evidence of the epidemic, the real extent of HIV/ AIDS in South Africa became apparent at the same time as democratic transformation and promises for a better life for all. The advent of HIV/AIDS all but destroyed these hopes and dreams, especially for those who fell victim to the epidemic and for their families. Amongst the poorest of the poor in South Africa, from whence the sample for this research was drawn, hopes for a better life for infected individuals were hopelessly crushed. These individuals, in addition, bear the brunt of the confusion generated as politicking around HIV/AIDS rages at national level. It is my contention that the discourse about HIV/AIDS at national level hampers the evolution of the illness from being a mysterious and abnormal illness to being 'just another' illness. Such a development can go a long way in alleviating some of the stresses that people with AIDS shoulder from day to day. The full significance of the national dialogue around HIV/AIDS may not be apparent to the majority of those infected and affected, but its impact on the wider population trickles down to affect them negatively. The stoning to death of Gugu Dlamini after she had publicly disclosed that she was HIV-positive is one example that illustrates that HIV/AIDS is still not perceived as an ordinary disease. Instead those who are infected are seen as polluting and as having brought shame to their communities. As the following example shows, the wishes of individuals and family members may coincide with those of the Government on the issue of disclosure.

The print media has, for some time now, been calling upon prominent citizens in the country to disclose their HIV-status, especially those who are sero-positive so that AIDS as an illness can gain some semblance of normality. The argument is that if respected citizens disclose such a status the wide population will come to view HIV/AIDS not as confined to a particular tier of society, but as an epidemic that does not discriminate on the basis of social or economic standing. The media hoped that such acts of public HIV status disclosure will encourage more people to declare their sero-positive status and, therefore, to live openly with the illness and be in a position to obtain resources and support. This call for public acknowledgement of AIDS was taken to its height when the former presidential aide

Mr Parks Mankahlana died of what were popularly believed to be AIDS-related causes. Opposition parties called for the government to use his death as a means of educating the population about the disease and to make a political statement that HIV leads to AIDS which, in turn, is fatal. The government refused to do this and instead insisted that he had died of pneumonia. The president's response to these calls was that Mr Mankahlana's family deserves the privacy not to disclose the cause of his death. What right, therefore, did anyone else have to question this intensely private matter?

This is one example of the nature of HIV/AIDS' impact on national politics, local communities and affected individuals and families. It shows that the government, high-ranking political figures can collude to keep HIV and AIDS out of the media. In so doing, the disease remains abnormal, secretive and opportunities to present this as 'just another illness' are forsaken. The example also demonstrates the extreme concern, and one in which the entire country is involved, over whether one should disclose one's HIV-positive status or not. Let us examine some of the factors that may hinder this.

Fear of contamination

As shown in the previous chapters, casual contact with people with AIDS may be seen as potentially contaminating because of widespread irrational fear in South Africa. Furthermore, those who are affected fear the reactions of others and the impact of the disease on their lives. Those who are not affected fear that they will also be the victims of the epidemic, either through their actions or the actions of infected individuals, hence the prejudice against PWAs. Weeks defines these unfounded fears of contamination and contagion as AIDS-related anxieties (1985:46). These anxieties tend to be disproportional to the chances of infection and can only serve to propagate stigma. For example, Phyllis said in a focus group:

I was very hurt. People treated me badly. I had to wonder if this thing is really only transmitted sexually. Is it like TB that is contagious? When I am here [at the hospice], it is like I am at home. Sometimes when you get home you will get so hurt. The other day they gave me a bucket saying that I should wash in it. I should no longer use the things that other people use. [We all experienced this, it is normal (said someone in the background)]. They tell me so and so died – she was affected by sharing a bucket [with an HIV infected person]. I

am so confused as to how this thing is transmitted. It is as if I had TB. I cannot go to my mother, my aunt or anyone [for understanding and unconditional acceptance].

This quote illustrates the challenges that PWAs face from day-to-day due to other people's unfounded fears that they will contaminate them. The informant refers to Tuberculosis (TB) twice in the extract and likens herself to a TB patient who should be isolated from society. She also seems to suggest that 'AIDS-related anxieties' are unfounded and should, instead be directed to people with TB which is easily spread. Phyllis, however, found herself in a quandary as to what to believe: on the one hand, people treated her as though her illness was highly contagious. On the other hand, medical advice and knowledge said that this was not the case. In the above quotation, she questioned why it was that people behaved towards her in this extreme manner – not allowing her to bath as normal people did or acting as though her presence was contagious. This led to some uncertainty as to whose understanding of the disease was correct – the medical experts or the people who seemed sure of themselves and of her illness?

Noting the pervasive nature of the stigma against PWAs, Crewe was prompted to write

... [t]his is a problem *intrinsic* to AIDS. But side-by-side we find the problems *extrinsic* to AIDS – those not found in the disease itself, which have their origins in the social meanings surrounding it. A person with AIDS confronts not only bodily disease but powerful social diseases as well. AIDS has become as much a symbol as a disease. And whilst the disease might result in tragic death, the symbol often results in tragic life (1995:16) (emphasis original).

The pattern of infection that unfolds in the township generates an understanding that this disease strikes indiscriminately. The following extract from an interview with Bertha's mother shows that although there is a realization that HIV/AIDS is a sweeping catastrophe, there is also a perception that one can prevent contracting it.

'This thing has fallen [like rain], people should know and behave well. I was not a progressive mother. I did not like to talk about such things. But now I tell them [her children] to use condoms'.

The risk categories that existed in the township popular imagination included people who worked in and around the gold mines because these people were believed to be more promiscuous and to use sex as a commodity to a greater extent than other social groups. This group was – in the minds of

Sowetans - made up of immigrants from neighbouring countries and South Africans, whose nationality had become secondary to their being mineworkers. Truck drivers also constituted a risk group because their travelling presented them with opportunities to engage in sexual activities with many different women from different towns. Foreigners, to a lesser extent were identified as forming a risk category because of their perceived deviant sexual behaviour. Despite the identifying of risk categories, there was a growing understanding that everyone was vulnerable, unless they changed their sexual behaviour. Why, then, does this understanding not encourage disclosure and living openly with the disease?

HIV/AIDS and deviancy

In addition to fear of contagion, both Brouard and Sontag argue that AIDS engenders a panic that leads to the polar division of society, with those who are infected being separated from those who are not (1993, 1989 respectively). The former are seen to have done something wrong and they therefore deserve the punishment that HIV/AIDS is sometimes believed to be. The disease is thus thought to 'belong' to this 'other' group whose behaviour is deviant. This allows the rest of society to believe that its members are immune. Notions of deviancy did not, however, feature prominently in the perceptions and dynamics of HIV/AIDS in the sample I interviewed. This is largely because HIV/AIDS was heterosexually transmitted in Africa and there was no pervasive use of intravenous drug usage in the townships. Even those South Africans who practice homosexuality were not the most affected category and, therefore, were not seen to be more at risk. Ideas of deviant sex were confined to sex during menstruation and sex with a widow. These ideas were not shared by all my interviewees, the men in my sample adhered to these beliefs far more than women did. One male interviewee said:

Sex during menstruation is not good. It brings about many problems. It is like crossing a robot when it is red. What do you think will happen when this happens? Obviously, danger. Children must be taught that this is not right, so that they know and refrain from it. It is also the case with sex with a widow, the person should still be in mourning, she is in the 'dark'. What do you expect, heh? These are the practices that cause all these strange diseases, together with the contraceptives that women use.

This extract highlights ideas about both dangerous, deviant sex and blame. In the extract women are blamed for the existence of HIV/AIDS and are said to be party to dangerous sex: sex during menstruation and when in mourning. These ideas stem from 'traditional' or 'cultural' notions, for example, Schapera writing about the Kgatla in the late-1960s, says that:

Widows and widowers are also 'hot' for about a year after their bereavement. A woman is 'hot' during her menstrual periods, during pregnancy (especially in the early stages), and immediately after childbirth...In most cases of 'hotness', especially those resulting from sexual behaviour itself, it is believed that if the person affected indulges in coitus before 'cooling down', his partner in the act will be stricken down with disease and may even die. This belief rests upon the idea that during intercourse the woman's vaginal secretions, which is identified with her 'blood', enters the man's body through his urethra... (1971:173-174).

The prescription of restricting sexual intercourse was associated with the belief that at certain times a person's blood becomes 'hot' and thus he or she becomes dangerous to those he or she comes into close contact with. Women's bodily secretions were deemed to be particularly dangerous because of their potential to enter a man's body and cause him harm. The affliction caused by breaching the restrictions on sex was in the case of Schapera's Kgatla informants, *gonorrhoea*. However, the above quote from one of my male interviewees clearly supports Schapera's (1971) observations, suggesting that such ideas are still widespread and also supports Squire's argument that the discourse on AIDS has resurrected the cultural representation of women's bodies as dangerous, diseased and contaminating (1993). This conceptualisation of women's bodies has perpetuated the understanding that women's role in the epidemic was confined to transmitting the virus to men and children. Women's own experiences have been disregarded. Some parallels can however be drawn by looking at Wilton's historical analysis of syphilis (1997).

Wilton points out that a shift occurred, in the late fifteenth century with the appearance of syphilis in Europe, from viewing the syphilitic as a victim of the disease to viewing *him* as dangerous (1997). Yet another shift took place during the Enlightenment, when the image of the syphilitic changed from male victim to female perpetrator. The construction of syphilis as part of the already contaminated female body gave it the paradoxical properties of desirability and danger. This portrayal of women as

hazardous to men's well-being was reinforced by medical discourse and by the Judaeo-Christian constitution of femaleness as a sinful state (Wilton 1997).¹⁴

The image of women - as embodying possible risk to men has continued in South Africa. Menstrual blood was still believed to be dangerous to men's health. Sex with menstruating women should be avoided. A widow-in-mourning also symbolizes danger and sex with her should be avoided. The men I interviewed also believed that the continuous use of contraceptives rendered a woman's body dangerous to men, especially if the method used interferes with the menstrual cycle. In such cases, blood was thought to be retained in the woman's body instead of flowing out, and this blood was said to be dirty. Hence, where such beliefs existed, women were blamed for men's infection with HIV. Some of the men I interviewed likened HIV/AIDS to cancer or leprosy. The following quotes from interviews with men in Soweto capture some of these ideas:

[they] always go to the clinic, especially girls. The pills [contraceptives] that they eat are dangerous. They cause this disease. It comes from women this thing [HIV/AIDS]

We had leprosy in Soweto. This disease [HIV/AIDS] is like it and cancer. It is an old disease - a combination of cholera, TB and cancer. With this disease that we had in the 1970s in Soweto, the diseased became dark in complexion, shiny dark, they had fluffy hair and they lost a lot of weight. It [HIV/AIDS] is a mixture of sicknesses and the same signs.

Although the women in my sample were aware of explanations for HIV/AIDS that blamed them as women, they did not adhere to them nor did they report that these explanations informed their experiences. Nonetheless, it was clear that 'coming out' would, in such a context, only endanger them more and subject these women to greater stereotyping and ostracism. In a context where even famous public figures were reluctant to express their HIV or AIDS status, for fear of possible ramifications, it was

¹⁴ The biblical construction of women as reservoirs of infection can be found in the story of Moses. When Moses led the Israelites in war against the Midianites, the victorious Israelites captured and raped the Midianite women. Their sexual conquests resulted in a plague that has since been identified as gonorrhoea. The men were cleansed, but as the women were seen as representing a source of infection, they were killed.

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obviously not possible for these women to envisage a way of doing this and still remain 'acceptable' members of society.

The 'problem' of HIV/AIDS

HIV/AIDS has thus far eluded definition in a way that makes sense to the wider population. Like any other disease, HIV/AIDS has had multiple concepts of causation that exist alongside each other. Anthropological research has shown that there are shared beliefs about health and disease in any cultural context. These are a reflection of a marriage between lay persons' understanding and interpretation of bio-scientific data and a pre-existing repertoire of beliefs about health and disease. Any information that is not consistent with already-held beliefs is likely to be rejected or modified (Helman 2000). The HIV/AIDS complex is 'problematic' because it does not exhibit symptoms that are peculiar to it as a medical condition, instead a number of already well-known symptoms present during the illness. The idea that a virus which can inhabit the body without any effects or with minor effects, but will eventually, cause a lethal syndrome, is not easy to understand. Furthermore, the remnants of the initial portrayal of HIV/AIDS as a gay disease, and therefore, a disease of deviant behaviour, still remain in the popular imagination. Both Altman and Weeks observe that AIDS has historically been associated with two controversial issues; homosexuality and promiscuity, hence the denial of one's own risk and stigmatization of those who are infected (1994, 1985 respectively). As mentioned above, the categories of risk were perceived differently in Soweto where mine workers, truck drivers, foreign nationals and menstruating or widowed women were seen to be both responsible for the epidemic and the most likely victims. Such understandings competed with the awareness that 'ordinary' people are also infected. This latter understanding resulted from the everyday experiences of witnessing the death of kin and friends, but unfortunately did not generate sympathetic attitudes towards infected and affected people. The case, therefore, is that HIV/AIDS is understood in a variety of ways by people at different times. My work shows that where HIV is understood to be transmitted through sexual intercourse, promiscuous

behaviour is blamed. As mentioned above, HIV infection is also attributed to 'dangerous' sex. Chapter Two of this thesis also mentioned ideas about *isidliso* – the ingestion of foreign harmful substances – and to links between AIDS and other traditional beliefs. This reinforces the idea that new beliefs are fitted into old worldviews.

It should be clear from previous chapters that there were many competing explanations for HIV and AIDS present in South Africa. Associating HIV infection with sexual activities was one understanding of AIDS that was prevalent in Soweto. Another competing interpretation was that AIDS was a form of divine retribution that signalled the imminent end of the universe. Such metaphors facilitate stigmatisation. Those who are afflicted with this disease were perceived to have gained the *wrath of God through their devious deeds* and were seen as deserving the punishment that AIDS was believed to be. If they themselves did not deserve to be punished, they were seen as examples of what was coming to everyone on earth if the wrath of God is not appeased. Ironically, given hospice's concern to assist PWAs, this discourse about sinning and punishment was regularly preached to patients and was on offer daily by different church people visiting the hospice. The message was *repent for you have sinned, that is why you are ill with this particular disease*. The women at the hospice showed mixed reactions to this message. The majority of them, however, did not believe that *they had gained the wrath of God* and that they were being punished by contracting AIDS. Some of the women would show their contempt for messages that sought to blame them for their misfortune by leaving the room during the sermon or by refusing to remain whenever a preacher associated with such messages prepared to deliver a sermon. Those who stayed would preoccupy themselves with knitting or sewing, thus ignoring what was being said. Those few patients who identified with this thinking paid attention and would sometimes ask for prayers. Their desire to see themselves as responsible and as deserving of punishment can be understood in relation to Sontag's work. She suggests that people ill from stigmatised diseases feel very unfortunate, not merely because they are ill, but because they are ill *from a particular disease that invokes shame* (1989). Diaz and Coffman discuss the propensity of the

stigmatised to identify with and to internalise the views of those who victimize them (1998, 1968 respectively). The women I interviewed, however, showed considerable resistance to understanding themselves as more promiscuous than their counterparts or as deserving of punishment. Nonetheless, they clearly perceived their bodies to have changed and to be in a process of decay. More generally, within Sowetan society, it was widely believed that PWAs have a particular odour that resembled that of a dead body.

Feelings of disgrace and shame, in my informants' case, were however tied to their current HIV status rather than to their previous behaviour. Such feelings forced these women to hide their HIV-positive status. The women I interviewed also see themselves as victims of social expectations that allow men to have multiple partners and yet expect monogamy from women. They admitted to not always being faithful to their partners, but in their perceptions, not nearly to the extent that their partners were unfaithful to them. They strongly believed that they were infected by their unfaithful sexual partners. The constraints on the part of women, especially, to negotiating safe sex even when they were aware that their partners were not faithful exacerbated the women's feelings that they were victims of circumstances.

Although, the women I interviewed occasionally spoke of having 'dirty blood', they denied that this disease was a 'dirty disease' that affected only a certain segment of the population. They maintained that everyone was vulnerable to infection and they were only 'dirty' now that they had the deadly virus and could transmit it to others. They were neither 'dirty' nor 'deviant' before, but they were now understood to be both and, more importantly they had taken this message to heart and had come to understand themselves as such. This 'taking abroad and internalising' of stigmatism by PWAs makes it necessary to investigate the nature of this stigma and its potential management.

Stigma and its management

Goffman defines stigma as an attribute that is seen as inappropriate within a particular social setting (1968). The stigma may be an abomination of the body, a flaw of character or may carry

connotations of deviancy. All these factors come into play in the discourse around HIV/AIDS. The effects of AIDS-related illnesses leave the body wasted and repulsive. A person with full-blown AIDS conjures up images of 'a living skeleton'. This popular imagery of the disease was also shared by my informants. The women were very worried that by the time they had AIDS, they would look like 'living skeletons'. They dreaded this stage of the disease and believed that a person with full-blown AIDS could not escape looking repulsive. At this stage, the body is no longer subservient to cultural protocol regarding sanitation and basic hygiene, leaving the individual dependant on others. This means that PWAs become vulnerable to all sorts of additional abuse and a further lack of support.

In township lingo, AIDS was called *amagama* (*amathatu*), meaning the three words, *Z3* or *phamokate*. *Amagama*, or the three words, was derived from HIV which has three letters. This use of HIV for AIDS signified confusion between HIV and AIDS. People were said to have 'the three words' when they showed signs of full-blown AIDS and people were also said to have died from the 'three words'. Sometimes, it was not even necessary to say 'the three words', a hand signal of three may suffice to carry the meaning through. *Z3* is a coveted model of a car, its surprising linkage with HIV/AIDS may refer to the number three in *Z3* or it may be its small stature that signifies the effects of AIDS due to physical wasting. The last name *phamokate* was derived from a TV program on HIV/AIDS where the main character had HIV and subsequently died of AIDS. I was told of experiences whereby whole conversations about PWAs went on in the township using this language and signs. PWAs were not meant to understand these 'conversations' but they could follow very well what was being 'said'. This constitutes a form of emotional violence that PWAs could do little about. Other forms of emotional violence could also be seen in the segregation of PWAs who were made to feel less than human by such practices. Actions such as these, both within their households and in the streets, sometimes became too much to ignore and some women reported being involved in fights because of them.

Although the women I spoke to had not formed an integrated group identity around their disease, there was a shared understanding of 'people like us' or 'us' as compared to 'them'. This identity did not

derive from the understanding of previous lifestyles that they might have had in common but from their current situation. The caregivers I spoke to mentioned 'people like them' when referring to PWAs who experience the same needs and illness pattern. Goffman's characteristic of stigma, which is about connotations of 'abnormality', relates to HIV/AIDS in this manner. More significant though, is Polunin's argument that the imagery that surrounds any disease may shed light on how it is constructed in the popular imagination (1997). 'From a cultural point of view we might consider a disease as a recognizable pattern of characteristics considered to involve deviations from health which are sufficiently distinctive to be thought of as an entity' (Polunin 1997:89). As shown by the experiences of my informants detailed in Chapter Two, *signs of wasting, successive episodes of illness and other signs believed to go with HIV were constantly looked for by people in Soweto and, if found, the obvious conclusion was that the person suffered from AIDS.*

Sontag in *Aids and Its Metaphors* gives an historical analysis of how illnesses have been perceived throughout time and how these perceptions may be associated with existing perceptions about AIDS (1989). Like syphilis and other STDs, AIDS invokes the use of metaphors that give the epidemic a significance that it does not merit. AIDS is no longer just AIDS, it is also something else – it is a metaphor for sin, deviancy and punishment. Sontag also argues that it is not the mortality rate of a disease that engenders fear in the population and therefore, stigma, rather it is the effect of the disease on the individual (1989). According to her, those diseases that do not affect people's faces - such as polio - have not been stigmatised. *The disfiguring of the face engenders the fear and repulsion that is so characteristic around AIDS. Those who are stigmatised may also exhibit the same reaction when faced with their 'own kind' as they may still have notions of what is normal that are shared by the rest of society.* The women in my study were visibly shaken by other PWAs whose condition had deteriorated so much that their appearance had changed. They avoided the sleeping area of the hospice where visibly ill patients were admitted. But, as the day-care area was used as the main entrance, the women in day-care could not avoid seeing their visibly-ill counterparts as they were brought to the hospice.

It is Goffman's assertion that within any historically situated social category there are rituals that govern human interaction (1968). The interaction becomes stilted and difficult for both parties if these are interfered with. Moreover, in every such category there are stereotypes of what a person ought to be or look like. This is the gist of the issues with HIV/AIDS. As an illness, AIDS is loaded with socio-cultural meaning because it is associated with anti-social attributes – the person becomes a 'living corpse' and people have no way of relating to him (or her)—he (or she) belongs elsewhere – he (or she) signifies death, a fundamental anxiety. Also, because AIDS is primarily an STD, it has come to symbolize the antithesis of sex, a life-giving preoccupation. Pierret, says: '[o]wing to its transmissibility and the cognitive representations surrounding it, AIDS turned out to be an illness that threatens the person's relationships' (2000:1590). In the same vein, Goldin noted that: '[i]n recent years the stigma has tended to define the bearer, rather than the sign carried by the bearer, and the bearer becomes known by the disease carried' (1994: 1360). This becomes what Goffman calls the 'total identity' of the individual. The concept of the 'known-aboutness' of a disease links closely to questions of disclosure. A person's condition may be known about without them having disclosed it. In Goffman's terms an individual whose stigmatising attribute is not yet known is potentially discreditable to others. In such a situation, the individual may devise means to control the information about their condition.

Goffman's work is devoted to the everyday interaction between what he calls the 'normals' and the 'deviant' (1968). His insights are indispensable to the understanding of the everyday challenges that the 'deviant' PWAs face. Central to these challenges was the preoccupation with protecting one's identity as a 'normal' person, as one who did not have a deadly disease. All efforts and energy would become focused on protecting this knowledge and any changes in the behaviour of others would be looked for. Relief would ensue only if it becomes apparent that they did not know about this condition. For example, the woman introduced as Grace in Chapter Two had not disclosed her status to her children. As a result, she was very vigilant in looking for signs that showed that they might know about her medical condition. She would listen carefully to their conversations, steer these conversations to areas

that might reveal whether they knew or not and would then breath a sigh of relief when such signs were not there. Grace had become very paranoid about people finding out about her HIV status. This is what she said:

As long as I have not told them [about my HIV-positive status], I will not allow them to talk to me about it. They [her children] are now fighting against other people about this [allegations that she was HIV-positive].

In this instance, Grace was talking about her children. This attitude was, however, generalized to other people. I pointed out in Chapter Two that Grace did not stay at the same place for a long time. She moved on as soon as she thought the people she was staying with suspected that she was HIV-positive. In an attempt to hide her association with hospice, she organized that the transport from hospice fetched her from a bus stop. She was anxious that, if seen to be visiting hospice, people would have more reason to suspect that she was, indeed, HIV-positive. Although Grace was determined to hide her medical status from her friends and family, her behaviour may also, ironically, have contributed towards their realization that she was HIV-positive. Her tendency to move frequently and to closely observe those around her, would not have gone unnoticed in the vigilant township gossip system. As suggested above, some people were already suspecting that she was HIV-positive and, despite all her attempts, this was bound to become common knowledge.

In a quest to safeguard an HIV/AIDS status, the individual may avoid contact with others lest his secret was discovered. This means that he or she would effectively experience a social death before the physical one, withdrawing from social contact with others as a self-protecting mechanism or as a reaction to the responses of others. I am reminded here of one incident when I was doing home visits with one of the hospice nurses. We were looking for a particular address and stopped to ask for directions there. While the nurse was trying to look through her files for the surname of the person we were to visit, the woman we were asking said that it was not necessary to look up the surname, she knew which house we were looking for. Despite the fact that I had previously spoken to Olivia (see Chapter Two) and had understood from her that neighbours did not know of her condition, clearly

knew which house we were looking for. Despite the fact that I had previously spoken to Olivia (see Chapter Two) and had understood from her that neighbours did not know of her condition, clearly people knew who was likely to be visited by a nurse. She, like Grace, may have genuinely believed that people did not know that she was living with HIV/AIDS because she had become a recluse since her illness. Instead, she believed that people thought she was staying at her own house some distance from her mother's house where we were visiting her. In both instances, it was patently obvious to friends, family, neighbours and other affected persons that something was clearly wrong and that the person was behaving strangely. The obvious conclusion for them to draw, given the context described above, was that the particular individual had HIV/AIDS.

Another strategy that was employed to hide an HIV status was that of disclosing a false diagnosis with similar symptoms. This was usually the case in my sample. People related how very difficult it was to withdraw from one's network of friends without giving a plausible reason. Rather than disclose their HIV-positive status, they would give another condition such as cancer that would gain them the sympathy of others. The woman who was introduced as Rita in Chapter Two had a ready way out of this situation because it was known that her twin brother had died and it was expected that she experience complications, either emotional or physical because of this. Her condition was, therefore, interpreted as this. The propagation of such knowledge depended on others who shared the secret of an HIV status to say the same thing when asked. This secret was usually shared with some family members and kept secret from others. Another factor that forced people to lie about their diagnosis, instead of hiding or relocating, was that they had been visibly ill and as they continued to be ill, some explanation for this was necessary. Women were also selective in the amount of information they disclosed. For example, some women told me things about themselves that they had not told those close to them and who have been giving them support. These women feared that, if they did not withhold information, they would be judged and any help or support would be withdrawn. Rita, for instance, suspected that she contracted the virus when she was raped by an acquaintance at a party.

More on disclosure

An individual can feel obligated to disclose their status to three different sets of people. One may disclose to his or her partner/s, to significant others – generally family members – such as parents, relatives and children and lastly to neighbours, colleagues at work and other social acquaintances. Clearly the dynamics involved in such disclosure differ. The question of disclosing one's sero-positive status to one's partner has been a source of interest to researchers and there seems to be consensus that women will find this more difficult than their partners. In general in Soweto, men were expected and were accepted to be more vocal on sexual issues. Moreover, the negative connotations and blame that accompany HIV infection made it difficult for women to disclose. Added to the fact that broaching sexual issues for women was a difficult task, was the already-discussed fact that women might open themselves up to abuse and victimization. In addition, many women did not have the skill to adequately explain their diagnosis and its implications in such a way as to sustain the relationship. Rather than contend with these issues, the women in my sample simply withdrew from relationships with men.

Disclosing to one's parents and children can also be daunting. My interviewees stressed, especially, their fear in telling their children. Although they were aware of the gains of telling their children, such as planning the future together and sharing their experiences, these women preferred that their children should not know. The negative connotations that surround HIV/AIDS also played a part in this reluctance to inform children. Some women felt that their children were not old enough to be told and those who felt that their children should know, did not feel equipped to tell them. The help of counsellors or that of the hospice staff was felt to be necessary in this regard. It is important to point out, though, that the fact that the mothers had not told their children of their HIV status did not mean that the children did not know. Some mothers recognized that some of their children might know and that these children were not revealing this in order to protect them. We discussed what effect this might have on the children and what being told might achieve. The mothers were worried about the possible negative effects on the children's schooling and on their relations with others. There was also the recognition that not being told formally and not being allowed to deal with the situation in a structured

manner might be detrimental to the well being of the children. Some mothers acknowledged that their children were already having problems at school that might be related to their mothers' illness and the rumours about this. Despite all these concerns, relations with children were not always adversely affected by the HIV-positive status of the parent. For instance, Rita's daughter was a volunteer in the local clinic and was aware of her mother's status. Rita described her as conscientious and that was why she was involved in this manner. The knowledge of Rita's HIV status has not affected their relationship adversely, instead the mother admitted to learning more about the disease from her daughter. The acceptance that the daughter showed was also a source of relief for the mother and strengthened their relationship. Although the women kept their status from their children in order to protect them, the children were also denied the right to work through the problem. Two women in the group, Bertha and Mavis, who had young children (three and five years old respectively) were worried about the possibility that their children might also be infected. Mavis said that she could detect some signs, such as lack of growth in her five year old, which might signal HIV infection. Again, we see signs of HIV infection being looked for in those who are suspected to carry the virus. In this case, the reaction was not to try and hide the signs in order to preserve a 'normal' identity as the children were too young to understand the implications of this. Mavis had started the process of finding out the HIV status of her son by the time I finished my fieldwork. She was receiving counselling at a support group at her local clinic at this stage. Bertha was also very worried about her daughter but she had not yet tried to verify her status. As she was already very ill, she probably did not have any energy to do this.

I was repeatedly told that the experience of living with HIV and AIDS could also be all-encompassing in that the sufferer could no longer think of other unrelated things. Thoughts centred around the implications of an HIV-positive status in one's life, in the lives of loved ones and around the constant exploration of possible options. The experience seemed to block all other positive things in a person's life. The women spoke of how they were looking for a job before they were diagnosed with HIV and how they no longer bothered because, 'what's the use?' Bertha, for example, had been

operating a small business selling cooked food in the Johannesburg Central Business District with a friend when she got ill. Her friend's attitude towards her changed when rumours about her HIV status started circulating. Bertha was very hurt by this behaviour as she had expected that her business partner and friend would stand by her: *Bertha saw no point in looking for other work and said: 'It is pointless to look for a job now. I will lose it as soon as it is known that I am a carrier'.* This attitude was fairly common and Rita similarly said: *'I will not be able to hold on to a job because I will be ill most of the time'.* Although Rita could still perform most of the tasks expected of her, she could not dress properly. She has particularly severe shingles on the right shoulder that made dressing properly impossible. She has to leave the affected shoulder bare. Obviously this affected her chances of finding a job. This tendency to stop looking for work also reflected a draining of the women's energy and a loss of enthusiasm to continue to strive for a normal life. It was, in effect, a tacit acceptance of their illness and its terminal nature.

The role of the media and the medical profession in attitudes towards HIV/AIDS

Earlier in this chapter it was suggested that the media, with the support of government and other public figures, could play a role in changing attitudes about HIV/AIDS. If public figures who projected a healthy lifestyle and a family orientation, were to 'come out' and publicly declare their HIV-positive status it might help other South Africans to deal with their illness. To date this has not happened and Crewe, taking this issue further, contends that the media has played a major role in perpetuating problems extrinsic to AIDS – those not found in the disease itself, but which have their origins in the social meanings surrounding it (1995). Horror words such as 'the killer disease, the plague, the deadly virus, the scourge, a sinister sign' still characterize some AIDS reporting. These have propagated fear about AIDS that is disproportionate to the risk of contraction. Further, Busse states that no real distinction has been made between HIV and AIDS in media reports (1995). This could be responsible for the public imagining HIV as being synonymous with AIDS. My informants had come to understand that the two are not synonymous, but that there is a causal link between them. *They communicated this to me with*

the understanding that HIV was 'better' than AIDS. Better in the sense that one still has control over one's body, one could still perform the daily hygienic and other chores that were expected of one.

In addition to the media, Busse asserts that the medical profession and health care setting are not without blame when it comes to how the general population has responded to PWAs (1995). 'Full barrier procedures, refusal to treat, isolation of patients, testing without consent or counselling and breaches of confidentiality, have all determined exaggerated pre-conceptions of the disease in the mind of the public (Busse 1995: 22; also see Chapter One). These practices, together with those that many of my informants mentioned such as being barred from using utensils, baths and other things that they ordinarily would share with other members of the household, have been collectively been called 'practices of decontamination' by Sontag (cited in Weeks 1985). It is clear that even those persons who are meant to assist PWAs and to facilitate their coming to terms with the disease are antagonistic and prejudiced towards them. Such behaviour on the part of medical personnel confirms, for HIV or AIDS patients, the futility of announcing one's status to the broader public.

The impact of living with HIV/AIDS on intimate relationships

AIDS, as a primarily sexually transmitted disease has the potential to have a negative bearing on intimacy. Self-esteem and self-image which form a sizeable part of the sexual experience are possible areas of immediate vulnerability (Isaacs 1993). AIDS brings about many losses, including the destruction of physical attractiveness, leaving one both disfigured and with an image of decaying, and thereby eroding sources of self-esteem. Macks asserts that while sexuality and intimacy may generally invoke feelings of contamination in some individuals, this is especially true for people who face life-threatening illnesses (1987). The feelings of contamination may be heightened in people living with HIV/AIDS because of the sexual transmissibility of the virus that causes the disease. All the women I spoke to indicated that they were no longer sexually active. None of them were in sexual relationships. There were several reasons for this. A small proportion of the women had been rejected by their partners, while others pro-actively severed ties with their former partners upon learning about their

status. The latter reaction was prompted by a need to protect themselves from an anticipated rejection and possible violence. Bertha discussed the difficulty of disclosing one's HIV-positive status to one's sexual partner 'I would not advise anyone to disclose, that would be the end of the relationship. The minute I said that I was ill to the father of my second child, was the last I saw him. He has never been to see me since'. Others said that feelings of shame and anger at being infected led them to this decision. Carol and Olivia said that their partners had died of AIDS-related illnesses and this had influenced their status. Because of their association with infected men and because, by implication, they were seen to have the deadly virus, they had been avoided by other men. The fact that the women no longer socialized with friends and relatives also minimized their chances of meeting new men. Furthermore, the women demonstrated a new phobia for men and intimacy, largely because they blamed the men in their lives for their infection. They were also concerned about the possibility that they might have infected others while they were unaware of their condition. Now, acutely ware of their infection, they feared that they would infect others if they were to engage in acts of sexual intimacy. Sex had become taboo to them. The loss of sexual partners and the prospect of not getting other, new, partners impacted negatively on these women's images of themselves as desirable women. Even if, under exceptional circumstances, one of these women was to meet a man who was interested in her, feelings of guilt and blame would weigh heavily on an intimate relationship. This was one of the losses of living with HIV/AIDS that is likely to be gendered as women were generally not able to make the first advances on men and, unlike men, they could not push themselves onto potential sexual encounters.

Conclusion

This chapter has examined the lived experience of HIV/AIDS in the township. It has argued that this experience was influenced by how those who are affected and infected perceive the disease. These perceptions were influenced by competing concepts of HIV/AIDS causation. Fear and poor understanding of how the disease is caused and how it spreads led people to treat people with HIV/AIDS as contagious. This extreme ostracism led, in turn, to infected individuals questioning the

validity of the medical explanation of AIDS. This chapter has further shown that PWAs were not passive in the dynamics that unfold because of their HIV status and AIDS illness. They sought to control information about their condition so that they could retain some of their 'normal' identity.

More importantly, this chapter has shown that HIV/AIDS is not a physiological phenomenon devoid of socio-cultural meaning. Such meaning has been argued to be salient in the lived experience of HIV/AIDS. Some of the experiences more pertinent to women have also been discussed. Structural and cultural barriers got in the way of negotiating safer sex practices, leaving women vulnerable to infection and infecting others. The moral tone that surrounded the epidemic invariably translated into the discrimination and stigmatisation of those who were infected. Finally, media, and other avenues of social expression such as the national debate on HIV/AIDS, has played a role in perpetuating some of the stereotypes of HIV/AIDS, and has, at times, made it more difficult for ordinary people to cope with their infection. This prejudice and stigmatization also played a role in the final stages of the disease and, in the following chapter, I explore the difficulties associated with the dying process of PWAs.

Chapter 5

Death and dying in the time of AIDS.

Our attitudes toward death and dying are embedded in our social values. Our values affect the way we conceptualize death. Do we see it as a tragedy or as a release from earthly woes? Is it any longer a moral matter or has it become a technological one. Values also affect our behaviour in relation to death because values underlie the guidelines on which we base our behaviour. Do we avoid contact with death or the things and people associated with death? More specifically values affect the way we treat the dying (Kamerman, 1988:21).

Our conceptions of reality are influenced by our values and beliefs. These will, in turn, have a bearing on how we behave and structure our world. Just as our value and belief systems are subject to change, so is our behaviour. As evident in Chapter Four, behaviours associated with HIV/AIDS tend to be stigmatised and individuals are excluded from society, such that infected persons may suffer a 'living death'. This chapter will explore how values and beliefs influence our attitude to death and dying in the time of HIV/AIDS. The argument that will be pursued is that death and dying cannot be understood as separate from other aspects of people's lives. The way we understand, respond to and organize death and dying is a function of our cultural background. Moreover, death is not only a physical demise but is an act that has particular socio-cultural meaning in different contexts. The township of Soweto, where the ethnographic material for this thesis was collected, will be used as a particular context in which ideas about death and dying developed new meaning as HIV/AIDS became an everyday reality.

Kamerman argues that in Victorian times when mortality rates were high, people were in frequent encounters with death and as a result, death was central to social discourse (1988). Children and adults were socialized to deal with death. In contrast to this, as life expectancy increased, death was increasingly banished to the fringes of social life. 'Talking about death came to be regarded as impolite, and when it was considered absolutely necessary, it was disguised by euphemisms' (Kamerman 1988:2). Kamerman also notes that in contemporary society the dying do so outside their communities, in hospitals and hospices (1988). This protection from death leads to an unwarranted fear of death and dying, leaving the dying to experience an isolated and lonely death. This relegation of death to

institutions outside the community has not, however, completely discouraged public discussions of death. This is particularly so with the advent of HIV/AIDS where PWAs may be banished from mainstream social activities or, as discussed in Chapters Three and Four, will voluntarily withdraw from society. In the case of HIV/AIDS death has progressively become a topic of public discussion. HIV/AIDS has brought the reality of death and dying closer to home. Whereas Kamerman argues that acts of removing the dying and the dead from everyday social life may lead to an avoidance of the topic (1988), everyday encounters with death and dying, as is the case with HIV/AIDS, may foster an acceptance of death. In such cases denial of regular death – as something that happens outside everyday life – and acceptance of death resulting from HIV/AIDS may exist together.

This chapter demonstrates that our perceptions of death and dying are in the process of being re-shaped with the advent of HIV/AIDS. As discussed in Chapter Four, this epidemic has fostered public ostracism. Coupled with a fear that those dying and grieving from its effects are polluting, this results in hospice patients and other infected persons seldom being accorded the support that might ordinarily be forthcoming. In addition, their fear of death is often not mediated by the religious conviction that death is a natural procession from one life to another and not an end in itself (Kamerman 1988). In general, PWAs undergo the process of dying unsupported by society and moral values because of the secularization of death. Where religious explanations for death are employed, an AIDS death is often viewed as punishment for one's sins. Those PWAs who turn to religion do so in the hope that their transgressions will be forgiven and that they will be granted a haven in the here-after and as discussed in Chapter Two, some women have managed to find salvation here. AIDS-related deaths are also shocking because it is young people who are dying almost invariably as a result of sexual activities, experiences that should have been a celebration of their youth and that symbolized their ability to procreate. In South Africa, HIV infection has come to be synonymous with death where life-extending medicines are not readily available to the majority of PWAs. As discussed in Chapter Four, infection with this virus has been stigmatised, subjecting people who are infected to a steady decline both

physically and emotionally as they are not in positions to receive unconditional support from others. In addition, AIDS-related deaths are popularly thought of as ugly and undignified because the experience is drawn-out, causing the dying to become more and more dependant on others as the disease process progresses.

Kammerman argues that death in itself is regarded as polluting (1988). An AIDS-related death is even more polluting because it is perceived to be linked to contamination and immorality. The idea that a distinction can be drawn between a 'good' and 'bad' death has been made by both Bradbury (2000) and Prior (1989). The demonstration of mastery over the biological infirmity of the body is the defining factor. Those deaths that do not demonstrate some control over the body are understood as 'bad' deaths. Such deaths are bad for the individuals as well as for the group from which he or she comes. Bradbury notes that "[b]ad' deaths preclude the chance of regeneration, both for the individual and for the group" (2000:59). In this light AIDS-related deaths, especially amongst the poor, falls under the auspices of a 'bad' death. In addition, 'the extent to which a particular death is perceived as tragic seems to vary as a function of age, the sex and the kind of death involved' (Kalish and Reynolds 1981:41). AIDS kills people who are in the prime of their lives, who are likely to have young children and who are often the breadwinners in the household. AIDS kills more women than men (Gilbert and Walker 2000:31), depriving children of care-givers and homemakers and AIDS means a long and painful death which strips victims of dignity and integrity.

In the same way that our understanding of death is mediated by a particular view of reality, the body is not understood solely through its anatomical and physiological features. Our perception of the body is influenced by particular forms of knowledge. Any discussion about death and dying is incomplete if it ignores some reference to the body and how it is understood in different cultures and historical periods (Prior 1989). Indeed, ideas about death and the body are inevitably intertwined. Prior says that

The signs of death are normally discovered 'on' or 'in' the body, the causes of death are invariably located deep inside the body, the registration of death is contingent on the

production of a body, the bereaved weep over the body, the funeral director prepares the body and the clergy eulogise over an encoffined corpse. In fact without the body, the social processes which are contingent on death are severely and irreparably disrupted (1989:13).

The body has physical properties and is endowed with social attributes that give it meaning in sickness and in health. There are stereotypes that define what an HIV/AIDS 'victim' looks like (discussed in Chapter Four) and these images have significance for how an AIDS-related death will be perceived. Moral judgement is extended both to the 'dying body' and to its owner. The infected body is often deemed contagious and repulsive and the relevant person is regarded as a sinner and deserving of the punishment meted out to him or her. Moreover, as Prior notes '[c]ause and mode of death are the twin pivots around which the public discourses on death circulates...' (1989:67). An 'AIDS death' gains much informal publicity in the form of township gossip and rumour. It is this relationship between the dying person and the broader community to which we now turn.

The dying person in relation to his or her community

According to Munley one's dying is a private matter that is difficult to share even with one's own sector (1983). This may indeed be so, but a dying person also needs to talk about his or her fears and, through talking, draw support from others. My research suggests that PWAs in Soweto were neither afforded the privacy to deal with their deaths, nor were they given emotional and other support. The literature points out that such people die isolated from others, but I found that the concept of isolation does not adequately describe the experience of PWAs in the township. A PWA may have lived his or her dying days secluded from others, but curiosity about his or her condition made people talk and he or she may have heard what others said about him or her. The person may have been physically isolated but her social self became part of township gossip. People whispered about him or her, the rumour spread and the 'secret' became public knowledge. My findings, discussed in Chapter Four, show that PWAs withdrew from social circles for fear of their secret being discovered. Some of the women told stories of how they would run and hide when someone appeared at their door and of how they never responded to knocks during the day when there was no one else in the house. They felt that visitors called only with the ulterior motive of updating themselves about their condition. In other cases, the

women spoke about how the decision of who should or should not see them was taken out of their hands. They were banished to a 'death room' from which they were not allowed to venture out. Nor were visitors allowed to see them. One woman, who was introduced as Olivia in Chapters Two and Three, had chosen not to be seen and, unlike others, her family did not coerce her to stay indoors. She and her family gave others the impression that she was living in her own house in another township. Olivia was, however, confined to bed in her parents' house. This meant that neighbours never visited her. Olivia was allocated a room that faced onto the street and from here she could see who was talking to who, who was going to work, to town or to visit. In this way she had access to township happenings, albeit on a restricted scale. As I have argued that such isolations were never complete, people also knew that she was in the house and was ailing from HIV/AIDS.

The curiosity that was shown about an AIDS illness was also shown when a death related to AIDS occurred. Kamerman argues that death is a literal summing up of one's life and that who you are at the hour of death has salience as there is no opportunity to rectify this (1988). PWAs are condemned by their societies and shunned by their families. The script of who they are at the end of life is a stigmatized one and, as demonstrated in earlier chapters, they may have come to internalize the identity given to them by those who judge them. The dying process of most PWAs is, thus, made difficult not only by the awareness of the impending death, but also by the perception that one is dying from a morally questionable disease. This is likely to have a bearing on how they deal with dying.

Discussions in the hospice's day care section inevitably led to talk about death. Both the old and the young would table their wishes about their funerals. It was not uncommon to hear someone say 'when I die, I want this and this to be observed'. People spoke about how they did or did not want a big funeral, what clothes they wanted to be buried in, who should or should not give a testimony about them, whether they wanted a night vigil or not. The discussion would get so lively that someone would admonish the group, pointing out that it is bad practice to talk about death so much. The discussion would immediately lose its intensity but would continue if someone argued against the belief that talking

about death or one's death speeds up the event. I particularly noted that many people were against the normal practice of buying expensive clothing or blankets to drape the corpse or the coffin. This was justified by the observation that many kin failed to take good care of their dying relatives and, instead, lavish their corpses with expensive trappings. It was, in other words, merely a way to appease the consciences of the living. In the case of these women, this was often a personal reaction to precisely such neglect and their reasoning was as follows: 'what is the use of doing that because I am no longer alive to witness and enjoy this'. Those women who were in favour of these practices responded that it was traditional to drape a coffin with a blanket so that the deceased may not feel cold. The implication of the former stance was clearly that the women attending hospice would rather be taken care of whilst they were alive (and in many cases they believed that were not). Bertha's mother said,

People should accept [that AIDS is everyone's problem]. Why should a person be cast out whilst they are still alive, why do well by them when they are dead? When they are dead you want to do well by them. This is wrong, do well by a person when they are still alive so that when they go to sleep [die] they can sleep well.

This emphasis on the fact that when people were dead they would not be in a position to appreciate gestures such as draping their coffins with expensive blankets may be seen as indicative of not believing in the hereafter. However, even where this belief was present, there was an understanding that worldly trappings had no place in the hereafter. There was much talk about the possibility of there being a hereafter, especially because of the preaching aimed to prepare the patients for the Christian idea of heaven. Not everyone adhered to this belief although many sat in for these sermons. Often the preachings were dismissed as nonsensical as soon as the preacher left the room, especially because these teachings implied that the patients were sinners being punished for their sins. Talk about ancestor worship was more repressed and those who proclaimed such beliefs did not denounce their Christianity.

Ironically when I asked the same people who were involved in the group discussion to talk to me about their thoughts about their death, they would say that although they thought about death, they also believed that they would live for a while longer. Yvonne, a mother of two, had this to say on this matter:

When I see others [PWAs at the hospice], I start thinking that I will be like them one day. I think that I will die and leave my children'. In the same breath Yvonne said: 'I believe strongly that I will get well'. At the time of the interview, Yvonne was not going to the hospice because she was very involved in the process of changing the surnames of her daughters, arranging that they should have ownership of the house and talking to social workers so that her children could be taken of 'in case something happens to her'. Yvonne, like others had accepted her impending death but she also believed that she would live for a long time. The men and the women at hospice often expressed the hope that a cure might be found and they would be saved. Bertha's mother gave the following explanation for the paradox of living with a terminal illness and still denying the near-certainty of one's death:

If you always believe that you will die from whatever illness then, sure, you will die. It is like when one dreams at night – the dreams are a reflection of one's thoughts. She [Bertha] always tells me that 'mother, I am still going to live' and I say 'yes my child you are going to live'.

Sadly Bertha died at the beginning of this year. Perhaps once the health of my interviewees had declined so much that death was inevitable, the answer might have been different. I did not make an effort to interview them again when they were very sick. Some of my interviewees were admitted into the sleeping-over section of the hospice, by which time they were very sick. Even though they could talk, I did not feel that it would be right to interview them at that stage. In addition, I did not feel equipped to handle interviews with them. I observed that those in the day-care section of the hospice avoided their friends who were admitted on the other side, although there was much talk about how they'd be visited and spoken to. I also fell into this pattern and, like my informants, I had also come to associate this 'other side' with death.

Kamerman argues that hoping for a cure for a terminal illness creates a problem in facing death because the cure is seldom found (1988). There is, however, another way of making sense of the tendency to be obsessed by death and simultaneously to deny one's death in the face of a terminal illness. Kubler-Ross argues that terminally ill people constantly think about their death, but they also need to deny it in order to cope with the business of living (1970). I would go further to say that talking

about death in a group made the topic more general and allowed the women to share emotions that they all faced. The fact that a discussion about death was taking place in a group shielded the individuals from confronting the reality of their own impending death head on. In one-to-one interviews, people were forced to confront their own specific deaths and they inevitably employed denial as a defence mechanism. My interviewees also emphasized that even in the event of a sudden death, they would not have died of AIDS – of 'this illness' or 'this thing' – as they were prone to call it. They were at pains to point out that if and when they died, it would be their time, God would have willed it and it would not be because of AIDS. They emphasized that no one knew when and how they would die, citing for example, fatal road accidents. These women explained that even a healthy person or a person who was not infected with HIV might die before them. In this way they divorced the incident of death from the condition of their health and emphasized that they still had a moral claim on life despite their condition. The woman whom I have named Bertha spoke about how she bargained with the virus. 'If you favour me and destroy me and I die, you will also die. So be good to me and I will also be good to you and in this way we both live'. This extract indicates that thoughts about the impending death were not removed from AIDS. Rather, the extract points to an understanding that one can exert control over the disease. Bertha's religious beliefs did not allow her to take any medication and she believed that prayer – coupled with the fact that she had neutralized the virus by befriending it - kept her safe from death. The ability of these women to cling to life showed that even though society had given up on them, they were willing to fight.

Stein et al in their study entitled *Nurse-Counsellors' Perceptions Regarding HIV/AIDS Counselling Objectives at Baragwanath Hospital, Soweto*, point out that nurse-counsellors suppress both the causes and the consequences of HIV/AIDS in an attempt to alleviate distress in their clients (1997). HIV infection is likened to hypertension and nurses tell patients that it can happen to anyone. Such a statement is accompanied by the observation that we are all going to die anyway and God will decide when and how each of us dies. Although these findings may not be generalized and, as seen in

previous chapters, medical staff was not especially concerned about the welfare of HIV-positive patients, they lead one to question whether counselling may play a role in divorcing death from HIV infection. Carol, whose experiences had been so bad that she ended up at a psychiatric hospital and was as a result, undergoing constant counselling, also said that her counsellor stressed that death is God's will. She was deeply affected when both her previous partners died of alleged AIDS-related causes. The idea, reiterated by her counsellor, that it was not AIDS that had killed them but rather that God had willed their death, sustained her.

I was deeply affected when the two men I was involved with died. I had nowhere to hide, I knew that I was going to die too. This pulled me down a lot, I could not function. It was my counsellor who helped me. She said that I should not take other people's misfortunes and make them mine. 'God has a plan for everyone, He knows why those who die do so when they do. He also has a plan for you. You will die when God wills it and not before'. This helped me a lot and I have started to put my life in God's hands.

Finding a place to die: HIV/AIDS and health care in SA

It is all very well to suggest, as Kammerman does, that those who are dying are likely to spend their final days in hospitals and old-aged homes (1988). This may be the case where such facilities are available and are equipped to deal with protracted deaths. But such facilities are already overcrowded and under-resourced in the townships such that people who are infected with HIV or are dying from AIDS are often told to go home to die there. Many of my interviewees had a story to tell about the bad treatment they had received at provincial hospitals. Nonetheless, they would most probably be taken to a hospital in the very final stages of their lives when they got very ill, some against their will. It is, as Kubler-Ross notes, an instinctive reaction to take sick people to some institution and thereby neglect to honour their wishes to remain at home (1970). The reluctance to be taken to a hospital was sometimes fostered by fear of the ill-treatment that they may have already experienced or that so many others had told about and by the superstitious belief that going to hospital would hasten their death. Hospital personnel were reported to have said that the beds they occupied and the medicine they consumed could be better used for people who had a chance to live and who did not have a terminal disease. Thus, PWAs found themselves taken to hospital by their kin and then when they got to the hospital, they

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were told to go home. As shown in Chapter Three, it was at this stage of their lives that the hospice became important.

These terrible experiences could, however, have positive outcomes. Carol said that the shocking treatment she received at the local hospital was the catalyst that strengthened her resolve to survive. It was compounded by her doctor's prediction that she did not have long to live. These factors influenced her attitude and became a turning point in her life. She said that the appalling treatment made her realize that she had to be self-reliant and brave. She then religiously attended all her counselling sessions, attended the support group meetings and took the medication that was given to her. She turned more and more to prayer and found solace in religion. She carried a bible (which was a gift from one of the schools to which she had disclosed her status) with her everywhere in case of an 'emergency'. This meant that if she suddenly took ill, she would have a bible handy for someone to read to her. She wished that this act be prioritised over taking her to the hospital. Prayer and reading the scripts had become a pillar of support for some of the women. Most women said they identified with the story of Job who was persecuted by the devil. Job lost all his worldly possessions and friends but the Lord protected his soul. Feeding the soul had become important in the face of bodily decline. The one positive thing that the women identified from this illness was the chance to nurture their relationship with God. A belief in divine deliverance gave them hope when friends and kin had spurned them. These women's religious beliefs went beyond the punitive moral tone that accompanied HIV-infection, instead they focused on the salvation and hope offered by religion.

HIV infection is accompanied by many losses. The stigma that surrounds infection deprives those who are infected and those who are affected from coming to terms with the disease with the support of others. Instead, they are forced to hide their anguish and to cope, as best as possible, in isolation. As death from AIDS is also denied or kept a secret, families and individuals are forced to grieve in isolation and, again to, forfeit social support. My research suggests that grief that is associated with AIDS is particularly pronounced: not only is the death mourned but also the cause of death. Another factor

peculiar to AIDS-related illnesses is that one's death is anticipated with near certainty and grieving starts long before the death. Kamerman labelled this phenomenon 'anticipatory grieving' (1988). This process may create a guilt-ridden rift between the sick person and the family long before the actual death of the individual. The sick person's source of guilt may stem from his or her consumption of scarce resources, which deprive other members of the family. Family members and relatives may, meanwhile, feel that they are not doing the best they can for the sick person. The awareness by both the family and the sick person of the impending death may facilitate a better preparation for the death but can also strain already fragile relations. As suggested above, the women I interviewed were conscious of a lack of support from loved ones and appeared unaware that their families were also suffering and were, perhaps, unable to offer the sustenance they so desperately needed. Blame for bringing shame to the family weighed heavily on already-stressed relationships. Anticipatory grief also preempted the emotions that were ordinarily felt at the death of the loved one. Bereavement, then, was not always accompanied by grief and this might have fostered feelings of guilt.

Dealing with death in the townships

In South African townships, it used to be customary to paint windows with ash to signal a death in the family. This custom is now seldom practiced and news of a death is usually spread by word of mouth. The curiosity that surrounds an AIDS-related death in the township means that the news of such a death will be made known far and wide in a short space of time. Kammerman's observation that the tendency to remove the dead and the dying from mainstream society results in death being of little consequence is not true in the townships (1988). He qualifies this observation by the statement: '[a]s our life is of little consequence to our community, so too is our death' (Kamerman: 9). As is already evident, general interest in HIV/AIDS victims was sustained through township gossip and people went to extreme lengths to try to hide themselves from public scrutiny. Despite the physical segregation of PWAs from mainstream society, AIDS-related illnesses and deaths continued to attract much public interest.

So intense is community interest in AIDS-related deaths that Grace, one of my interviewees, told of the following experience: some neighbouring women came to her place to mourn her 'death', only to meet her as they were coming through the gate. These women quickly retreated in embarrassment. She said:

According to my neighbours I died on the 4th of July, that was the rumour that was spread. I am still waiting for one of those women to come to me and say something because now none of them can look me in the eye and talk to me. I have become a living ghost to them.

This example shows the power of rumour and how PWAs are anticipated to die sooner than other people, such that people seldom checked the facts before they believed that a PWA had died. Another woman, Juliet, said when she was taken to the hospital by ambulance the rumour spread that she had died. In her case no one came to mourn her death but it was believed that she would soon be buried. People were tongue-tied when they met her, they could not believe that she was flesh and blood and, amazingly, people were even willing to say this to her, thus confirming her belief that she no longer belonged to society.

Already discussed is the tendency among some families to reject those who are infected. The infected person may have left and die way from their family of origin. The family was, however, forced to acknowledge the death of their relative and to 'do right' with their bodies. In Soweto the shame of acknowledging a relative who has died from AIDS-related causes was minimal when compared to the shame of not treating your dead correctly. The blood ties that bound family members together may have been severed under the strain of an AIDS illness but these had to be reaffirmed at death. So, even those who were forced into a life of exile while they were dying were invariably brought home to be given a 'proper' burial. Those relatives and friends who looked after the dying person could not assume the responsibility to bury her or him without the permission of close relatives. This permission was seldom granted as tradition dictated that the dead must return home to be buried. Death is sacred and everything else becomes trivial in its wake. Bertman writes that '[t]he moment of death sets into motion a sort of life review for all participants in the event. It is a time for insight and forgiveness, the last

chance to say the unsaid' (1991:80). *This opportunity is lost to those who die away from their families.*

The separation was likely to have been bad and part of the funerary rites may involve the reaffirming of family bonds by burying the dead at home.

Funerary rites in the township

Much has been said, in general discussions, about the lack of respect shown to the dead, while funerals and wakes continue to attract attention. People came to pay their respects to the dead and the bereaved. They also came to see and to be seen. There was a joke in the township, that might have some truth to it that people browsed through the Friday edition of the local newspaper to check who in their neighbourhood had died and was being buried that weekend. It was important that the house of the bereaved was within walking distance so that the interested parties should not spend money on transport. The whole point of this exercise was that one found a place where one was fed and offered free beer. In a similar vein, many a concerned citizen lamented the new trend of wearing bright and expensive clothing at funerals to ensure the attention of others, and thus making a mockery of the plight of the bereaved. Associated with this was a tendency to make judgments about the coffin and about the quality and quantity of the food. This practice was condemned because it pressurized the bereaved family to spend more money than was necessary and sometimes more than they could afford. The content of the speeches that would be delivered at the funeral was also of much interest. "Would the priest tell the 'truth' about the dead person or would he only emphasize the good in the deceased at the behest of the family"?

In addition to this merry-making that denies the gravity of a death, Prior comments on the widespread practice of making the dead look like they are alive by, for instance, moulding a smile into their expression (1989). However, some bodies cannot be given a lively appearance. The signs of death are too prominent for this and in such cases the bodies are not open for viewing. 'Death, therefore, is only put on display when it is in accord with an acceptable image. Ugly, brutal death is still hidden from view...' (Prior 1989:161). In the townships a murdered person was not open for public

viewing. Older members of the family viewed the body at the morgue and there the coffin was sealed never to be re-opened. This practice was also seen with AIDS-related deaths. Like death from homicide, the bodies of people who have died from AIDS-related causes were not brought home on the night before the funeral. Sometimes the bodies did not even enter the yard at all as people believed that this would bring bad luck to the family. In such cases, a service was held at the home where the deceased used to live without the body being present. Sometimes the body was transported home while the service was taking place and was acknowledged while it was still in the hearse. This was because such deaths were due to 'unnatural' causes and were believed to be polluting in the sense that they would cause more deaths of this nature in the family. This shows that the body of a person who has died from AIDS-related causes is also enveloped by the same discourse that defined the PWA. Taking the cue from Prior who argues that it is important to inquire into how the human body is perceived and constructed at the hour of death, as well as to highlight how this might impact on the funeral process (1989), this chapter will go on to show that an 'AIDS death body' was treated differently from a 'normal' body.

During my research, I interviewed pastor Maphike who was very involved with the hospice. He was a member of the board of the hospice, he ran a community-based scheme that cared for PWAs by providing them with vegetables and other basic supplies¹⁵. Pastor Maphike was called on many occasions to minister over the funerals of people who died from AIDS-related causes. He told me that some funeral homes had special quarters where families could perform the ritual cleansing of bodies. These quarters were used where a death was believed to have been caused by witchcraft. In such instances, the body was doctored so that the curse may return from whence it came. The body was similarly doctored if the death resulted from a homicide. In this case the 'dark cloud of death' was

¹⁵ These goods were donated regularly by certain business concerns. Youngsters were the driving force behind this scheme, they packaged and delivered the supplies to PWAs known to the pastor. These youngsters had undergone a six-month course on palliative care offered in conjunction with the hospice.

reversed to the murderer. Although some AIDS deaths were believed to be brought about by witchcraft, this belief was not widespread. AIDS-related deaths were associated with the pollution of sin and moral decay and as a result ritual cleansing was emphasized. Depending on the beliefs of the family, people from the church or traditional healers would be taken with the older members of the family to the funeral parlour on the day before the funeral. Here prayers for forgiveness were said on behalf of the deceased or some form of ritual cleansing was performed. The coffin was then sealed and not opened again.

Van Gennep analysed the rites of passage that help individuals through major life crises (1960). According to him, such rites have a tripartite structure that can be divided into separation, transition and incorporation. Although Van Gennep's scheme applies to the living and not the dead, a parallel can be read in how the dead are handled. The subject of the rite, in this case, the deceased is removed from everyday life into the mortuary where she or he will remain in a liminal state to both the former life and the one that she or he is being prepared for. The funeral is a ceremony to incorporate the deceased to another life, it is an event to mark a transition from one life to the hereafter. The fact that a person who died from AIDS was not brought into the house before being incorporated into a new life was symbolic of the defilement that AIDS was associated with. A step is skipped in the proceedings in order to prevent pollution. The fact that the body of Mr Parks Mankahlana, whose story is detailed in Chapter One, was only brought home on the morning of the funeral and did not stay overnight as befits a family man, was generally interpreted as a confirmation that he had died from complications related to AIDS. Proor asserts that as the deceased simultaneously assumes the identity of a corpse, a soul and a social being, the funeral is organized to focus on each of these aspects (1989). As a corpse, the deceased is seen to be polluting, as a soul, he or she has been judged to be tainted and as a social being notions of promiscuity are brought to bear on his or her character. In Soweto, the 'AIDS body' was, thus, found wanting at all these levels and did not merit an overnight stay in the house. Although bringing the body of an exiled relative home for proper burial was important and was seen as a means of reaffirming severed bonds, the understanding that such a death was polluting remained. In addition, ritual

cleansing was extended to the home of the deceased during the funeral. Here those who did not go to the cemetery would clean the windows, sweep the yard and place baths of water outside the yard for those returning from the graveyard to symbolically wash the shadow of death from their hands as they prepare to partake in the feast¹⁶. In both homicide death and death from AIDS-related causes an animal may not be slaughtered as both were thought of as unnatural deaths and blood to appease the ancestors may not be shed as they were blamed for allowing such deaths. Although the women I knew were concerned about ritual cleansing, they did not expect to undergo such a process after their own deaths. They did not believe that their status called for ritual cleansing.

We spoke at length about the question of ritual cleansing. There was a consensus among the women that certain circumstances merited ritual cleansing. Examples of such circumstances included the death of a sexual partner or that of one's children. It was cause for concern that Maria's children had died and she had not been ritually cleansed. This concern became pressing as her condition worsened. The other women advised her, at least, to buy a chicken as a medium to fulfil the purpose of ritual cleansing if she could not afford a bigger animal. It was considered a mishap if she should die without being cleansed of the bad fortune associated with losing her children. Maria was not the only woman who had experienced the death of a partner or family member. Lack of family support meant that those women whose partners had died also did not fulfil this obligation. However, this was not discussed so much as Maria's case. I would hypothesize that this was because Maria's relationship to her children was publicly known and was socially sanctioned. They were her children, she was their mother and she had to be ritually cleansed in the event of their death. Most of the women whose sexual partners had died were not married to them and their relationship was thus not socially recognized and

¹⁶ Not eating the food that was prepared by the family was generally seen as a slight against the family. Attending the funeral was not enough, one also had to be seen to be eating with the rest of the mourners. Certain churches did not allow non-members to eat at funerals, such people were caught between being neighbourly (and eating) and adhering to the tradition of their religion.

acknowledged as a marriage. Although ordinarily a woman's family would help her undergo some sort of ritual cleansing in the event of the loss of a sexual partner who was not recognized as a husband, the advent of HIV/AIDS and the tensions that accompanied it meant that surviving partners were not afforded this assistance. Kamerman calls such people who are affected by a death and feel grief, but have no acceptable right to mourn the 'unidentified bereaved' (1988:68). I think that the advent of AIDS, which extracts the severest toll on young people who are likely to be unmarried and whose relationships are not socially recognized, means that the number of such unidentified bereaved will increase. These cases show that it is not only the dead who are deemed to need ritual cleansing, survivors are also seen to need such cleansing.

Kamerman notes that in many societies the ritual destruction of the deceased's possessions is a cultural practice that affords the bereaved an opportunity to express their grief (1988). With the advent of HIV/AIDS, there have been few changes in this practice. Two women complained that their clothes were being worn by other members of their families while they were in hospital. They believed that, in addition to the possibility that family members liked these particular clothes and wanted to wear them, this wearing of their private apparel was in anticipation of their death when these clothes would be burnt. The long trajectory of an AIDS death meant that victims were in a progressive state of pollution as they approached their death. Their possessions, especially the clothes that they wore in their last few months, would be considered polluted and would have to be burnt. Individuals therefore chose clothes and other items belonging to the sick person before this happened. Family members, in anticipation of a person's impending death, were laying claim to the person's clothes before they could be 'polluted'. No healing attribute was bestowed on the personal possessions of the deceased, their capacity to cultivate a feeling of closeness to the deceased and bridge the rift caused by death was non-existent. So, it was not only the fact that death is polluting because the corpse is 'betwixt and between' two distinct life situations as Turner (1967:93) argued, it was also that some deaths and, thus, some

corpses were regarded as more polluting than others. The fear of contagion that characterized relationships while the deceased was alive continued to concern the living after his or her death.

The advent of HIV/AIDS and death following from AIDS-related complications have led to old rituals gaining new meaning as people try to deal with this reality. The ritual destruction of the dead person's clothes is one example of this. Whereas Kamerman notes that '[t]here are usually periods during which old rituals are questioned and no new rituals have yet become acceptable substitutes' (1988: 33). In this case old rituals are given new meanings in the face of a new threat. Pastor Maphike pointed out that township was a melting pot of different cultures and much experimenting was taking place as people borrowed and adapted rituals from other cultures. Contemporary funerary rites exhibited both elements of continuity and of change and, as demonstrated above, much of this change related to the particular circumstances of HIV/AIDS deaths. It should, however, also be emphasized that deaths resulting from AIDS-related causes were often hidden and alternative explanations were concocted. This further influenced the rituals that were carried out. If the extended family, who also partook in the ritual performance, believed that the death was due to some other cause, then 'normal' rituals would be executed. Thus, where the denial was more prominent than the acceptance of such a death, 'normal' rituals would be performed.

A further consideration was the fact that life insurances seldom paid when 'AIDS' was the cause of death in death certificates. Moreover, doctors believed that even where the patient had no insurance, it was easier for the family if the cause of death was not explicitly said to be AIDS (ethics debate on HIV/AIDS held at the University of the Witwatersrand, September 2000). The family was believed to cling to what was written on the death certificate and to ignore other possible explanations for the death. It would be difficult, in any case, to cite the actual cause of death because as Kamerman points out, a number of pathological conditions may be present at the moment of death (1988). There may also be several complications that together cause death rather than any single affliction. In this way, the cause of death would be diagnosed to mask those particular aspects that might indicate AIDS-related

symptoms. This tendency is not confined to the South African situation for Prior also noted this in Belfast, Ireland (1989). She sums this up by writing: '[t]hus, it is sometimes the case that certifying practitioners deliberately seek to suppress clinical data on the ground of social sensitivity... (Prior 1989:91).

The impact of an 'AIDS death' on the family

It is not to be doubted that the family is also affected by the death and dying of one of them. This is especially true for family members who share the same living space as the dying person. Losses that the infected person experiences - such as isolation and lack of social support - may also be felt by members of the household, hence they are spoken of as 'the affected' in this thesis and in AIDS discourse. The grief of experiencing the dying trajectory of a loved one takes its toll on relations, fuelling the resentment that is so characteristic of the HIV/AIDS ordeal. The fear of the disease, of being contaminated, of the unknown and of how others will react are also real to families of PWAs. The treatment and caring for PWAs digs deep into the resources of the family, depriving others of their share and this may breed resentment. The dying person might be blamed for bringing such shame in the family and might be treated badly – or believe him/herself to have been treated poorly. The slow death of a loved one is difficult to witness and with HIV/AIDS families are also forced to experience it. There is substantial literature demonstrating that families, partners, spouses and communities react in inhumane ways to PWAs, but there is also a need to recognize the enormous difficulties that need to be overcome when accommodating an AIDS patient. The challenges of coming to terms with a family member dying from AIDS-related causes are likely to continue long after the death of the individual as the family rearrange their lives without the deceased, but perhaps still with the spectre of AIDS hanging over their heads. The threat of AIDS does not only impact heavily on the affected family, it also impacts profoundly on the emotions of the infected individual during their final moments.

Terminal illness, emotions and final moments

Kubler-Ross has delineated the stages that terminally ill people go through (1970). The stages are denial, isolation, anger, bargaining, depression and acceptance. Although this model of a procession

from one stage to another has been criticized, some light about the challenges of living with the knowledge of one's imminent death can be gleaned from it. The model is also useful if there is a recognition that some people may become stuck at one stage, or regress to 'earlier' stages and may not experience all stages. A problem with this model is that it does not give guidelines on how the manifestation of these stages can be observed by another person. The expression of the emotions associated with particular stages will differ from person to person and from culture to culture. I have already shown that denial was exhibited by many of my respondents and what form it took. Isolation is also a major experience of PWAs. The model has, however, no scope to show the complex, contradictory emotions demonstrated in previous chapters to be a fundamental part of the AIDS experience. For example, I have also come across bargaining with the virus. Earlier chapters have shown that isolation is a major experience of these PWAs. But, how, for example, does one know if another person is depressed? What behaviour accompanies this state and is it universal? Depression and acceptance are trickier states of being and like the other stages they may be fleeting and contingent on other circumstances. Perhaps, understanding these emotions as stages that follow one another is limiting. A better understanding might be that they are emotions that the terminally-ill are likely to experience at some points during their illness, possibly even experiencing contradictory emotions simultaneously. Some of these emotions might be experienced more than others depending on the temperament of the individual, his or her worldview, support systems, evaluation of their life, who they are leaving behind and their socio-economic circumstances. I found that blame, a condition ignored in Kubler-Ross' stages, is also a prominent emotion in PWAs – they blame themselves for contracting the virus, they blame those who infected them, they blame supernatural powers for allowing them to be infected, they blame their families for not taking proper care of them, they blame the government for not doing enough for them and they blame the hospice staff for having 'exposed' them to their communities (As Grace's story in the previous chapter demonstrates). Helplessness in the face of death and other challenges might also come into the picture and this is not equivalent of Kubler-Ross' acceptance stage.

Feelings of worthlessness and self-loathing have also been expressed. But despite all these, PWAs live their lives with a forbearance that some inner quality makes possible in the face of all the losses and adversity. Like everyone else they love, they hope, they appreciate the funny side of things and they laugh. Remarking on the courage that living with HIV/AIDS demands of the individual, Corr et al postulate that although

[d]eath is still perceived to be an enemy, an unwanted intruder but compared to the dying that is sometimes associated with the last stages of AIDS, it is almost welcome. AIDS may reinforce the belief that death is not the worst thing that can happen to humans... (1994:446).

Hine points out that there is always an assumption that in a life and death situation the struggle is for life and against death (1977, cited in Bertman 1991:70). However, there comes a point where struggling to live is useless and no longer desired by the dying. Aisop puts it thus '[a] dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong as well as useless to resist' (1973, cited in Bertman 1991: 70). According to Kubler-Ross people who have been given room to express their anger and frustration on being diagnosed with a terminal illness are more likely to reach the stage of acceptance (which should of course not be mistaken for a happy stage) where the struggle is over and the dying person is more preoccupied by the hereafter than with things of this life (1970). But the silence that surrounds AIDS deprives affected and infected people the environment to voice their fears and frustrations. In a video recording called *The Dying Game* by the British Broadcasting Corporation, people who had been diagnosed with HIV mentioned how their first instinct upon hearing the diagnosis was to shout 'I HAVE HIV'. The reality of this knowledge was too much, they felt that they could not keep it inside them, they needed to share its load with others. In the township, where being infected with HIV was regarded as the worst thing that could happen to an individual, secrecy was the norm and few avenues existed that supplied infected individuals with the support they needed. Instead, their condition was viewed with contempt, forcing them to hide their status in order to remain 'normal' in the eyes of their communities. This social denial interferes with the 'normal' processes of mourning and ritual observances of death.

Kubler-Ross' (1970) observations about terminally-ill individuals reaching a stage of acceptance can be applied to the lives of some of the women in the hospice who, although they were physically present, one could discern that they were not interested in the goings-on around them. I am reluctant to say that invariably they died soon after exhibiting such disinterest, but I can recall a few who actually did. I noticed this because I needed to interview one woman whom I was particularly interested in. She was part of the focus group I formed but was taken ill shortly thereafter. She recuperated at home. She came back and we celebrated her birthday with her but she was taken ill again and this time went to hospital. She was so withdrawn on her return that I had a sense that she was literally fading away. She used to sleep on the sofa as she did not want to sleep in the sleep-over section of the hospice.¹⁷ I wanted to arrange an interview with her to talk about her experiences of celebrating her birthday, of being sick at home and of her time at the hospital. I felt, however, that an interview at that stage of her life must be very trivial. I could not come up with an adequate way to broach this subject with her. Finally because I felt that she had become preoccupied with other important things that did not relate to her present life, I finally summoned enough courage, on the third day that I saw her since her return to say can we talk tomorrow and she said yes. I could not find her for the next few days and I never saw her again. We learnt later that she had died.

Death at the hospice

Death at the hospice was such a common happening that the women made an agreement not to ask when someone did not appear at day-care. It was known when they were either in hospital or were being taken care of at home. In the event of death the family would inform the hospice and transport

¹⁷ There was a shared belief amongst the patients at the hospice that the beds in this section were 'spooky', anyone who slept there was likely to die soon after. So, although they were allowed to rest on the beds during the day, many opted to sleep on the sofas which were more uncomfortable. Some patients, especially the 'newer' ones did go to sleep on the beds as they had not heard the stories about the beds. Most of the 'older' patients 'knew' someone who had died after sitting on one of the beds and never slept on them.

would no longer be arranged. In many cases the hospice personnel failed to inform patients of a friend's death. This was much discussed during my fieldwork and while some patients argued that this denied them a chance to go to the funerals of their friends, others said they would rather not know because it was detrimental to efforts to overcome their own fear of death. This soon changed and, during my fieldwork period, the hospice personnel made a policy decision to inform patients of their peers' deaths. My sense is that knowledge of this sort was easier to accept when the deceased was one of the older women or if her condition had deteriorated so much that the others already anticipated their death. Those who died at the hospice were taken out through the back door so that the patients in the day-care section of the hospice would not see them although they always saw the undertaker come and knew that his business was to collect the deceased. In addition, those patients who were in the sleep-over section of the hospice when the death occurred would invariably tell the news to their friends. So, a death was never completely concealed from others.

It is important to pursue the question of how the death of others affected the survivors of the hospice group because their relationship was based on sharing the common fate of having a terminal illness. It was upsetting to the group who remained at the hospice when it became known that one of them had died. Some consolation could be had from having expected the death when it happened. There was also some consolation in the belief that the deceased has been released from a painful ending. This was spoken of as the person having been granted rest after much suffering. Nevertheless, Carol who had been at the hospice for some time and had, therefore, witnessed many such deaths said that these experiences pulled her down. In other words, she was depressed by these experiences and was sometimes so overwhelmed that she felt she could not face her own life. This and other experiences related to her HIV-positive status became so difficult for her that she had to go for intensive counselling. She said that although she was still adversely affected by the death of her friends and age group, she found solace in what the counsellor said had about God having a plan for everyone.

This viewpoint was reinforced by her belief in the scriptures, she constantly carried a bible and sometimes went outside and sat alone to read and pray.

At hospice, the dead were remembered and often spoken about. Some of those who died were remembered in the day-care section for specific reasons: because they had a favourite chair, or a favourite song, or were very sick or were not perceived to be very sick at the time of their death. After the death of a hospice patient, the hospice transport, that collects and delivers patients, would change its route as certain patients no longer had to be picked up or returned home. So when someone wanted others to remember a certain place they would make an example about where so and so used to be pick up. The families of the deceased also used to come to the hospice for some or other reason and they would sometimes mention the deceased. It was not taboo to talk about the dead but occasionally tears would be shed because of the thoughts of lost friends and the others would stop that particular conversation. The dead were, thus, mourned and their memories celebrated when something positive about them was remembered

Conclusion

Kubler-Ross asserts that death is associated with a bad act, a frightening happening, something that in itself calls for retribution and punishment (1970:2). Mims similarly argues that death is frightening in that it leads one to the unknown (1999). He, however, observes that death is not feared as much as the dying process. This chapter has shown that the protracted trajectory of HIV/AIDS added to the challenges that one's death brings about. The fact that HIV infection was popularly understood as polluting affected the dying process. Dealing with the reality of a terminal illness had become all the more challenging in the face of the HIV/AIDS epidemic, leaving individuals to deal with their situation as best as they could and many of my informants turned to religion. This chapter has argued that death associated with HIV/AIDS was seen as particularly polluting because of the connotations of sin and punishment. Moreover, the advent of HIV/AIDS affected how the dead were dealt with. Just as a

person who was dying from HIV/AIDS was deemed polluted and polluting, so was his or her dead body.

This perception led to particular rituals being performed to cleanse the bodies of the dead.

The argument that the removal of the dying from society into hospitals and hospices fosters a denial of the reality of death is challenged in this chapter. . The high rate of AIDS-related deaths in the township fostered public discussion about death. Progress in medical knowledge has generally meant that death is associated with old age and is not seen as affecting the younger population. Such progress has not been made in combating the incidence and the prevalence of HIV/AIDS amongst the young and the poor. That AIDS kills the young is shocking and that medicine can do little about this adds to the shock, resulting in religious explanations for the epidemic being sought. These factors influenced how the dead and dying were treated. In addition, hospitals in the townships were not equipped to deal with HIV/AIDS patients who were regularly sent home to die. The concept of the hospice was still new in Soweto with the result that only a select handful of people from the township had made use of it. Many of Soweto's people living with HIV/AIDS still died at home, albeit a different home to the one they lived in before their infection. Death in the townships meant that the deceased would have to be brought back to their original home and be given what the family deemed to be a 'proper' burial. Even those who used the hospice were not isolated from the community as they went home at the end of the day. Those who did die at the hospice spent only a short period there before they died.

Finally, and most fundamentally, HIV/AIDS and its association with death has not only shown the weaker side of human nature. I was amazed by the courage that was shown by the women who are the subject of this study. Despite all the challenges that they faced or maybe because of them they had faith and hope that kept them going from day to day.

Chapter 6

Conclusion

This research portrays the lives of black women from the township of Soweto who were living with HIV/AIDS and its many challenges. The research was conducted in a hospice, a new phenomenon in the township of Soweto, and, as such, considers the significance of hospice care in alleviating some of the negative effects of affliction. Moreover, this research seeks to disaggregate experiences that are pertinent to women thus, 'giving voice' to a category of people that has been often relegated to the fringes of important issues. While the subjects of this study have had different experiences as individuals, there were also experiences that they held in common as women living with HIV/AIDS in a township setting. Lack of adequate knowledge about HIV, fear of infection, the moral tone that invariably accompanies the disease, blame and counter-blame were some of the factors that further exacerbated the stigma of HIV/AIDS. These factors also proved to be obstacles in making HIV/AIDS an ordinary disease that warrants social support and empathy.

This thesis has argued that negative attitudes towards PWAs discouraged disclosure and forced infected and affected individuals to keep secret an HIV/AIDS diagnosis. In South Africa PWAs lacked positive role models as even prominent citizens who were living with the virus kept their status hidden. The national controversy on whether HIV causes AIDS, in which the is deeply embroiled, has not helped the case of PWAs for whom the resolution of such matters is of personal significance. The confusion sparked by such discussions contributes to the perception that HIV/AIDS is mysterious, it eludes definition and thus cannot be a 'normal' affliction. Such a context results in PWAs and their families not getting much needed support.

Amongst AIDS practitioners, there is a general understanding that women are particularly vulnerable to infection and that their experiences of living with HIV differ from those of their male-counterparts. This research has shown that women, whatever their circumstances, were active players in the sexual dynamics between them and their men. It is true that women were disadvantaged in many

ways vis-à-vis their male counterparts, but they were not completely lacking in ability to influence the nature of their sexual relations with men. The advent of an HIV infection further complicated matters. Rather than try to negotiate new ways of sexual expression, the women in my study opted to refrain from any sexual relations. This decision was based on their experiences: most of these women had been in precarious relationships characterized by violence, infidelity and a lack of mutual respect. Their decision to turn away from men and to concentrate their efforts on fulfilling their and their children's needs reflect these past experiences. At this point in their lives, they saw themselves as having nothing to offer men, but even more importantly, as having nothing to gain from relations with men.

This research also examined the impact of the virus on the women's bodies and their changing body images. The idea that their bodies were in a progressive state of decay was repeatedly expressed as normal bodily functions were disrupted and declined. The women conjured up an image of a disease that eats away at the body, leaving the body devoid of any fluids. The odour of death that they said was characteristic of PWAs was attributed to the physical erosion of their bodies. Hence, they came to think of themselves as having 'dirty blood' and had an overall sense of being 'lesser women'. Female endowments such as breasts and curves shrunk away, stripping one of assets that were once sources of self-esteem. This, for the women in my sample, was a factor that contributed to the lack of interest in sexual matters.

Another factor concerned the fragile relationships between men and women. Whereas men blamed the HIV/AIDS pandemic on women's use of contraceptives, especially those that disrupted the menstrual cycle¹⁹, none of the women accepted this understanding. When probed, they did not believe that they should be blamed for HIV, although they had all heard this theory. They blamed the men in their lives for their infection, although ironically many could not pinpoint exactly which man was responsible. There was a general consensus that men slept around and that they were the ones spreading the disease, despite the fact that women too have had numerous partners in the course of

¹⁹ The blood that is said to be retained in the body is perceived to be dirty and thus defiling.

their lives. Extra-marital liaisons among men and women were very common, as was cohabitation in the townships. Both men and women could have – and often would - have more than one sexual relationship at a time, although this tendency was not encouraged in women and often remained clandestine. Although the HIV epidemic does not seem to have significantly influenced men's and women's sexual relations, judging by the incidence and prevalence of HIV infection, it is my contention that this may change and that both men and women will, in the future, be more careful in their interactions.

Women living with HIV/AIDS curtailed their involvement with men and focused their attention on their children. The women's children featured as the most important people in their lives, at the time of the research, and about whom they were most worried in the light of their own infection. This worry stemmed from several factors. At an immediate level the women were worried that their children would find out that they were living with the deadly virus. This had become a major preoccupation with some of the women and often extended to other people as well. The women were also worried about the possibility that their children had become infected with HIV and their future would be bleak without their mothers' support.

In an attempt to go beyond mere description of events and processes, this research seeks to understand the phenomenon of HIV/AIDS as a lived experience in the township and in the hospice. This thesis has shown that families were hard hit by the event of one of them being infected with HIV, hence some of the extreme reactions such as ostracizing the infected individual, chasing them away and behaving harshly and unsympathetically. This, in Soweto, occurred in a context where the family itself was not accorded support by others and was not above moralizing about HIV infection. The financial and emotional resources required by the drawn-out nature of HIV-related complications weigh heavily on all concerned and providing assistance for such affected persons is an enormous challenge to the South African government. The extensive provision of counselling and all-round support for the family would make a difference to the assistance extended to PWAs. The hospice initiative and training

of lay personnel as community workers in the home-care of PWAs might alleviate some of the pressures borne by affected families. Government contributions towards this program could mean that support is extended to more families, and this also has the potential to alleviate some of the fear of contagion that informs attitudes towards PWAs.

Another challenge facing South Africa is finding a means to encourage people to volunteer for regular HIV testing. This research project has shown, however, that the ethics governing such testing were usually violated. This had implications for those who were being tested – often against their will - and for the rest of society who may decide not to test for HIV because they do not wish to be violated in the same manner. The challenges that face the country with regards to testing do not end with the process of testing itself. Support is needed for those who test HIV-positive so that they can make positive decisions about their lives and about their relationships with others. If testing for HIV could become ordinary and routine in the minds of the populace, a great feat would have been achieved in combating the spread of the epidemic. The fact that everyone is at risk would have filtered through. HIV/AIDS would be everyone's problem, not only that of already infected individuals. Feelings of shame and disgrace for being infected would diminish with the acceptance that everyone is at risk. This is especially true where the proportion of the infected population is high, such that every sexual encounter becomes that much more likely to be infectious.

The acceptance of the idea that everyone is at risk might also make it easier for infected individuals and affected families to disclose an HIV-positive status, thus allowing them to gain moral and other support from others. As shown in this thesis, HIV/AIDS was highly stigmatised and any display of associated conditions had the potential to discredit the individual and the affected family. Life experiences before an HIV diagnosis became different to those after the diagnosis. This was not because of the disease itself but because of the meaning that had been brought to the disease. As a result, those who were infected and affected would rather take the secret to the grave than let it be known that they were afflicted by this morally-stigmatised disease. Non-disclosure condemned infected

individuals to a life of trying to cover-up their infection so that others did not have the opportunity to judge them. HIV/AIDS had also, however, become a source of contemporary interest in the township. Signs of HIV infection were looked for, or rather HIV infection was perceived to present with certain common symptoms, which if found the 'obvious' conclusion was drawn. Non-disclosure, covering up and withdrawal from the public sphere was, therefore, no guarantee that one's HIV-positive status would remain the exclusive knowledge of few people.

Disclosure was also linked to whether an HIV-positive diagnosis had been accepted by the infected person in the first place. This acceptance was made difficult by the natural tendency to deny carrying a life-threatening disease as well as by the fact that HIV/AIDS presents with symptoms of diseases that are well-known in their own right. As shown in this thesis, it was often easier for one to present oneself as suffering from TB when coughing and losing weight. This signals a very important point that HIV/AIDS, perhaps more than other diseases, is by its very nature liable to being construed in a multiplicity of competing ways that inform the steps taken to deal with it. In Soweto, scarce resources were used in a bid to attain a second opinion. Coming to grips with an HIV diagnosis was further complicated by the relationship between HIV and AIDS, the former manifesting itself in bouts of illness which may be perceived as 'ordinary' spells of sickness and the latter being a signal of imminent death. Acceptance of the fatal nature of HIV/AIDS was brought by the realization that the body was steadily failing despite all the efforts of the patient and the despite the different healers consulted. This realization weighed heavily on the individual and counselling can play a significant role in changing the individual's attitude for the better. The time devoted to understand the plight of the individual and talking to him or her in a non-judgemental way distributes the burden of living with HIV/AIDS.

The general public still needs to be extensively educated about HIV/AIDS, or perhaps to be re-educated. This education should go beyond the basic facts about the disease on which the general public is already well informed. The rote learning of basic facts – such as the public has received to date - provides inadequate assistance when one has to deal with decisions about sex from day-to-day.

Scare tactics have also failed to assist men and women in making life-saving decisions about the nature of sexual interaction. Instead, these tactics are perhaps to blame for the irrational fear of contracting HIV that was shown by the public. Both men and women at grassroots level need to be consulted about the details of their sexual lives and these should be considered when policy is formulated. This is, indeed, a tall order considering that sex is not an easy subject to talk about and the vocabulary used by people on the street may be different from that used by researchers and policy makers. There is also the fact that the resources needed to carry out such consultation are scarce. Nonetheless, the necessity of understanding sexuality in context and in relation to cultural norms, in order for education and social policy to be informed by this, remains. The context of poverty, dependence, superstition, illiteracy, unemployment, violence and an overall sense of doom plays a role in sexuality and sexual interplay amongst the poor, shaping their responses and, as shown in this thesis, their inability to protect themselves in the face of this epidemic. In the light of this knowledge, it becomes clear that sex workers and their clients should not be isolated as the core transmitters of HIV, as is the thrust of many interventions, as the conditions that prevail in the lives of sex workers are widespread in society. An overt recognition of these factors has to be made in policy regarding HIV/AIDS. Efforts to educate must be accompanied by efforts to engender positive change in the lives of people so that they may come to value their lives and strive to uproot themselves from the cycle of doom that they perceive their lives to be.

This thesis has argued that, for poor residents of Soweto, South Africa, an HIV diagnosis was tantamount to a death sentence. They had no access to the anti-retrovirals and resources that help PWAs lead a healthier lifestyle. This highlights the fact that HIV/AIDS is a different reality for the rich and the poor. The advent of this epidemic has made a mockery of the promise of 'A better life for all', the election ticket of the ruling ANC government in 1998. Hospitals are ill-equipped to meet the needs of PWAs whose numbers increase everyday. Appropriate accommodation has become an urgent problem. The number of orphans resulting from this epidemic is high, and there is only an inadequate

welfare system to fall back on. The overall care of the infected and affected leaves a lot to be desired. The government has indicated that the bulk of caring for the sick would fall onto the shoulders of families and communities. At best, this is an unrealistic suggestion judging from the state of the families and communities who are already under-resourced without this added responsibility. At worst, it is unlikely that families and communities will undertake this responsibility for, as shown throughout this thesis, HIV and AIDS have become so highly stigmatised that everyone, including those who are infected, deny any association with this epidemic.

HIV and AIDS have also impacted on how death was perceived. It is the young who are most affected and who are casualties in this epidemic. Although in modern societies the dying usually die outside their communities, in hospitals and old-aged homes, this was not the case with HIV casualties who were sent home by hospitals. AIDS deaths caused a public stir. Notions of pollution and contamination influenced the handling of the dying and the dead. It was in this context that services rendered by the hospice became invaluable. Through intervention by the hospice personnel, both the infected individual and the affected family were given the support needed to try to come to grips with this disease and to deal with it to the best of their ability. The hospice gave the support to work through the tensions that came with this disease. Efforts were made by the hospice staff to restore relations between the patients and their families and to ensure that the death was not over-shadowed by tensions.

My research at the hospice showed the real need for the services offered by this initiative. HIV infection is a traumatic experience that needs to be managed, but is often too overwhelming for patients, families and friends to overcome. Nonetheless, the association of HIV/AIDS with ideas of pollution and with death has not only shown the weaker side of human nature, and I was amazed by the courage exhibited by the women who are the subjects of this study. They had faith and resilience that kept them going from day to day despite, or because of, all the challenges that they faced. I would like to pay tribute to all these women.

Recommendations

Based on the findings of this research project, the following recommendations can be made:

There has to be a recognition that sexuality is an intrinsic part of other life situations and as such will be influenced by them. The ABC strategy has thus far not yielded the desired outcome of prevention, precisely because sex does not take place in a vacuum. Prevention strategies should be informed by this insight as well as by the recognition that halting the spread of the disease cannot be divorced from improving the quality of life.

Gender dynamics are complex and play a significant role in the shape and prevalence of the disease. These need to be understood in their complexity and responded to accordingly. Both men and women should be made to understand that they can make a difference in this epidemic by assuming responsibility for their sexual behaviour. Men and women have to adopt a culture of openness about sexuality. This should be coupled with respect for the rights and dignity of others.

Counselling and sustained moral support is vital for the well-being of infected and affected individuals. This is one of the goals that can be achieved in the short-term with minimal resources. A system of referrals from lay counsellors to professional counsellors has to be established and maintained for the benefit of the affected persons. It is vital that the tact with which these situations are handled be stressed and that counsellors do not, through good intentioned home visits, unwittingly disclose someone's HIV-positive status to the public.

The government and the private sector have to make a concerted contribution to the care of the infected and the affected. It is suggested that this could be achieved by funding initiatives, such as the hospice, that are already involved in HIV/AIDS initiatives and have the expertise to implement programs on care and mitigation of secondary effects of HIV/AIDS.

Efforts to transform the image of HIV/AIDS from that of an abnormal affliction to that with which everyone can identify will have to be made. The media can contribute to this by highlighting some of the positive aspects of this disease, such as its potential as a catalyst for a positive lifestyle and not always focus on the negative effects of the disease. A balance needs to be struck between highlighting the

gravity of the HIV/AIDS epidemic and the ingenuity of the human spirit to overcome this challenge. It would also help transform perceptions about HIV/AIDS if respected public figures who are living with the virus disclose their status and thus act as role models. This gesture would emphasize that HIV-infection is not confined to a certain sector of society.

The Department of Health has to sustain and accelerate efforts to sensitise South Africans about the importance of regular HIV testing. These efforts should be coupled with publicizing the Patients' Bill of Rights, which is already widely publicized. It is also important that patients should know what recourse they have against medical personnel who violate their rights. The assurance that patients' rights will be respected and protected at all times and that, if they are not, they can take the matter further can encourage individuals to volunteer for HIV tests and discourage the medical personnel from behaving unprofessionally towards patients.

The fears that abound regarding AIDS have to be addressed so that the stigma that surrounds this disease can be minimized. The fact that HIV is not easily transmittable should be communicated in such a way that will not diminish the reality of its existence.

INTERVIEW GUIDE

Biographical Information

Age group: 15-25, 25-35, 35-45, 45-55

Marital status

Number of children and their ages

Level of education: junior primary, senior primary, secondary, tertiary

General information

What was your relationship with AIDS before? (Ever thought about it, know plwa, believe that it existed and how did you think about it –what did it represent to you)

what precautions did you take, could you have engaged in safer sex sexual practices (feelings and thoughts around condom use (what imagery surround condoms) / fewer sexual partners...do you think this would have made a difference how/ why? (WHAT WERE BARRIERS TO PRACTICING SAFER SEX?) and in what situations would this have been easier?. FEMALE CONDOM?

How did you find out about your HIV status and what (behaviour, person, practice) do you attribute your infection to. Can you describe how you felt after diagnosis and how you are feeling now. (EXPLORE NOTIONS OF BLAME AND VICTIMHOOD). Do you think you might have unintentionally infected another person and what were the circumstances?

Who did you disclose your HIV status to and why? How did they react and how did you in turn react to their reactions? Why do you think they reacted the way they did?

What help did you seek/get (just after diagnosis, on your own, at the hospice, church) and how did this impact on your life? What made you decide to come to the hospice?

What does living with AIDS mean to you- how has this affected your life (loss of friends, employment opportunities, place to stay, intimacy and sexual behaviour) WHAT CHANGES HAVE YOU MADE TO COPE or how do you cope?

What have people been saying about you as a carrier and about AIDS in general? (what are people's beliefs about AIDS?) Did you share these beliefs before and do you still share them? (Why do you think plwa. are stigmatized, do you think that this is justified?)

What does being a woman mean to you and do you think that men and women experience living with AIDS in similar ways? (care giving, body image (has it changed?), child bearing – are you open to conceiving in your condition- . stigma, gender relations, support systems)

Do you find that you are more informed since your positive diagnosis or being involved with the hospice? Are there aspects about AIDS that you still feel confused about?

What help has the hospice been to you and your family? What has coming into contact with PLWA done for you? Do you find you can communicate your inner most thoughts and feelings about your condition with others with a similar condition more than those who are not as affected?

What concerns you most about your future? What thoughts are upper-most in your mind about being HIV- positive? Can the hospice help in some way?

What help do you think the govt., communities, relatives and govt. institutions can be to plwa.

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