

**SITUATIONAL ANALYSIS OF STIGMA ASSOCIATED WITH HIV/AIDS: A
PILOT PROJECT.**

By

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DECLARATION.

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ABSTRACT

Stigma and discrimination play significant roles in the development and maintenance of the HIV epidemic. It is well documented that people living with HIV and AIDS experience stigma and discrimination on an ongoing basis. This impact goes beyond individuals infected with HIV to reach broadly into society, both disrupting the functioning of communities and complicating prevention and treatment of HIV. This paper reviews the available scientific literature on HIV/AIDS and stigma in South Africa, as well as press reports on the same subject over a period of 3 years. Analysis of this material indicates that stigma drives HIV out of the public sight, so reducing the pressure for behaviour change. Stigma also introduces a desire not to know one's own status, thus delaying testing and accessing treatment. At an individual level stigma undermines the person's identity and capacity to cope with the disease. Fear of discrimination limits the possibility of disclosure even to potential important sources of support such as family and friends. Finally, stigma impacts on behaviour change as it limits the possibility of using certain safer sexual practices. Behaviour such as wanting to use condoms could be seen as a marker of HIV, leading to rejection and stigma. All interventions need to address stigma as part of their focus. However, the difficulty of the task should not be underestimated, as has been shown by the persistence of discrimination based on factors such as race, gender and sexual orientation.

Keywords: HIV, AIDS, stigma, South Africa, discrimination.

Opsomming

Stigma en diskriminasie speel 'n betekenisvolle rolle in die ontwikkeling and handhawing in die HIV epidemie. Dit is duidelik gedokumenteer dat mense wat leef met HIV en AIDS deurlopend gebrandmerk (stigma) en diskriminasie beleef. Die impak hiervan oorskry die grense wat persone wat ge-infekteerd is met HIV en AIDS maak dit moeilik vir die persone om in die samelewing opgeneem te word en dus die funksionering in die gemeenskap heeltemal ontwrig wat die voorkoming van HIV EN AIDS kompliseer. Hierdie paper beoordeel die wetenskaplike literatuur oor HIV en AIDS en die stigma in Suid Afrika sowel as die media verslae oor dieselfde onderwerp oor 'n tydperk van 3 jaar. Analise van die studies dui daarop dat die stigma verbonde aan HIV en AIDS dwing HIV uit die openbare oog, en sodoende die druk vir gedrags verandering. Die stigma bring mee dat die individu ook nie hulle eie status wil weet nie, dus is daar 'n overtrading om te laat toets en om behandeling te verkry. Op 'n individu se persoonlike vlak ondermyn die stigma die individu as persoon nie opgewasse om die siekte te hanteer nie... Vrees vir diskriminasie belemmer die moontlikheid om status bekend te maak, selfs aan moontlik ondersteunings bronne soos familie en vriende.. Tenslotte, stigmata beïnvloed gedrags verandering, aangesien dit die moontlikheid om veiliger seksuele praktyke inperk.

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CHAPTER: 1. INTRODUCTION AND BACKGROUND TO THE STUDY

‘If we are to address stigma, we must first understand it. We should focus our attention on understanding what causes us as a society to react in this way to people living with HIV/AIDS — people who are suffering enough, either physically or mentally to be challenged yet again by the judgment of others, by the very people who yesterday were their neighbours and who should be reaching out to them today. Only when we understand the cause can we hope to help our fellow men and women react in a more compassionate and human way.’

The potential impact of stigma and discrimination has been of ongoing concern to those involved in addressing the HIV/AIDS epidemic. Jonathan Mann spoke of a hard epidemic of discrimination that would follow the HIV and then AIDS epidemics. He asserted that this third phase would be as central to the global AIDS challenge as the disease itself (Mann, 1987, quoted in Parker, Aggleton, Attawell, Pulerwits and Brown, 2001). Sabatier (1988) predicted discrimination at individual, community and national levels, which would have major implications for the epidemic. Divides would be created between those who are vulnerable to infection and those who are more distant. That the HIV epidemic has followed in many respects the trajectory of those who are most victimised by discrimination anyway has heightened that divide (Crewe, 1992). Stigma is common when societies face problems that seem inexplicable or outside of their control, such as the HIV epidemic (Panos Institute, 1990). The direct experience of stigma is terrible when you consider how it impacts on those who feel the discrimination. However this paper will argue that the implications of stigma go even deeper to impact on multiple aspects of the lives of people living with HIV/AIDS and more broadly on members of society, creating disruptions in social functioning, increasing people's vulnerability to infection and reducing the overall caring capacity of communities.

Stigma has had particular implications for South Africa (SA) given our history of racism and their stigmatising beliefs. Goffman (1963) defined stigma as a deeply discrediting attribute that reduces a person to someone who is in some way tainted and can therefore be denigrated. It is a pervasive problem that health globally, threatening an individual's psychological and physical well-being (Cabe & Sorkin, 2002). Enacted stigma refers to the real experience of discrimination (Brown, Macintyre & Trujillo, 2003). Discrimination constitutes acts or omissions in which the content of the stigma is applied, either at an individual or

social/community level. Four components have been identified as being part of the stigma concept. These include distinguishing and labelling differences, associating human differences with negative attributes, separating 'us' from 'them', and status loss.

Ultimately stigma is entirely dependent on social, economic and political power, as power is required to be able to introduce stigmatisation. Stigma removes power from the stigmatised person, enhancing differences and reducing the stigmatised group or person's social status and self worth (Link & Phelan, 2002). Stigma and discrimination have a shameful history internationally. In South Africa they took a particularly horrendous form in the apartheid system. A major role that stigma plays in society is to create 'difference' and social hierarchy, and then in turn legitimising and perpetuating this social inequality (Parker, Aggleton, Attawell, *et al.*, 2001). Discrimination arises out of any point of difference that can be consistently labelled: for example physical deformity or disfigurement, racial or any other factors that set up the person as different to the perceived norm. In this case the norm is generally defined in terms of who is powerful in the community (Goffman, 1963).

Major focuses for discrimination have been on race, gender, sexual orientation, handicap, religion and age, amongst others. The attachment of discrimination to illness has a long history, with it impacting on people with mental illness and physical disorders such as cancer, TB, STDs and leprosy (Sontag, 1988). The nature of stigma and discrimination is complex, varying across time, person and context, making analysis and especially intervention very difficult.

Stigma and discrimination are cruel social processes that offer some feeling of protection to the powerful, while increasing the load on the individual or group who is victimised in the process. Stigma can be seen as a tool used by more powerful groups to protect themselves as people. It is in turn constructed as only impacting on directed recipients who are seen to be at blame anyway, so deserve this discrimination (Douglas, 1995). The argument can be challenged immediately at a human rights level. However, this paper argues that stigma has a far more insidious influence, going well beyond the individual and potentially impacting on all sectors of society.

1.1. Objectives of the study

This study is a pilot project, which should pave the way for a major study in the subject area of stigmatisation and discrimination related to HIV/AIDS. Its broad objective is to lay the ground work for a multi-district study, with the aim of comprehensively assessing the nature and prevalence of stigma and discrimination associated with HIV/AIDS in Aspen Pharmcare, South Africa. It constitute an exploratory stage to the major study during which tentative knowledge (hypotheses) will be developed for testing by, and to guide the major study of my PhD after my MPhil (HIV/AIDS). More specifically, the pilot study aims to:

- Documentation information on the perception, attitude and beliefs of PLWHA, caregivers, the affected, community leaders, including community group, pertaining to the aetiology, transmission and prevention of HIV.
- Identify the factors that seem to contribute to the stigmatization of HIV/AIDS itself and of people living with HIV/AIDS and those caring for them.
- Describe the nature and forms in which stigma and stigmatisation are expressed behaviourally and communicated both verbally and non-verbally by PLWHA, caregivers, the affected as well as by community groups.
- Determine the factors that lead to discrimination against those living with HIV/AIDS and their caregivers.
- Assess the extent of the actual discrimination against people living with HIV/AIDS, the affected and their caregivers.

1.2. The rationale for the study

South Africa is committed to the prevention of HIV infection and the mitigation of the impact on individual, family and the community. Prevention, Behaviour Change and Support and Care Strategies have been put in place (2007 -2011 HIV/AIDS Strategic Plan). Similarly, the Government, Non-Governmental Organisations (NGOs), Community Based Organisations (CBOs), the Private Sector and International Partnerships have joined hands to develop, manage and implement multi-sectoral programmes on HIV infection, prevention, care, support and counselling. These efforts are not likely to bring about desired results if the individuals and community groups do not demonstrate an openness and transparency about the prevalence and impact of HIV and AIDS at individual, family, community and societal levels.

There are, however, strong indications of the prevalence of denial, HIV/AIDS-related stigma as well as discriminatory practices against people living with HIV and AIDS. The combinations of all these factors are bound to impede the effective prevention, care, counselling and support strategies, including community-based initiatives.

The psychological and social responses and behaviours are usually discernible and can be described in both qualitative and, in other instances, quantifiable form. However, stigma and discrimination are much more intricate, subtle and less evident and observable from time to time, and it is difficult to target them with interventions likely to bring about change. South Africa has adopted behaviour change as one of its main strategies for turning the epidemic around. Behaviour change touches individuals, families and community groups on a personal, interpersonal and social level. Similarly, stigma and discrimination and, in other instances, discrimination occur at all level.

The need to profile and understand stigma and discrimination in South Africa cannot be overemphasised, thus the undertaking of the pilot project on stigma and discrimination. It will be observed from the study design and the explanatory methodologies that the 'centre of the study's analysis' is the people and their perceptions, interpretation, the experiencing, of stigma and discrimination, their attitudes and beliefs about stigma and, in some instances, discrimination against PLWHA. A large study subsequent to the pilot should create a better understanding of stigma. Consequently a refinement and consolidation of current approaches to prevention and behaviour change will be achieved.

1.3. The significance of the study

Broadly speaking, this study is important in two ways. First, it will contribute to the existing body of knowledge in an area that, although central to the effective prevention of HIV/AIDS pandemic, remains under-researched. As indicated earlier, the existing literature does not provide an elaborate documentation of the nature and extent of, and the factors that contribute to stigma, stigmatisation, and discrimination within the context of the HIV/AIDS epidemic in South Africa. The knowledge gained through the study will constitute the framework for the major study on HIV/AIDS-related stigmatisation and discrimination, mentioned earlier.

Secondly, the study will contribute knowledge that will strengthen government, non-governmental and private sector policy for the prevention of HIV infection. Studying stigmatisation and discrimination associated with HIV/AIDS will realise information that can be utilised to combat, if not eliminate, such practices. Elimination of stigma and discrimination will create a supportive environment and encourage personal and protective behaviour (UNAIDS, 2000). The data generated by the study will create a better understanding of the nature and the extent of stigmatisation and discrimination and the factors that are responsible for their existence. This should constitute an important step towards making workable the multi-sectoral approach espoused by South African Health Department, National AIDS Council for the stemming out of the HIV pandemic in the country.

CHAPTER 2: LITERATURE REVIEW

Stigma, discrimination, denial and even blame characterise both developed and developing countries grappling the HIV/AIDS menace. People infected with HIV/AIDS may experience felt stigma or anticipated discrimination as well as actual arbitrary discrimination. Denial, on the other hand, can occur at the national and individual levels. For instance, when the first case of HIV/AIDS was diagnosed, the disease was dismissed as one that affected homosexuals. In South Africa, the initial response was that AIDS was a disease of Africans, foreigners, sex-workers, and promiscuous gay white males.

Stigma is a negative social label that disgrace or shame someone not because his or her behaviour runs counter to the expectations of society but because he or she has personal or social attributes that lead others to exclude him or her (Johnson, 1995). This is true of people who are infected with HIV or who may be related to, or associated with someone who is infected. These are often stigmatised by the rest of the community. Although stigma is hard to measure, the World Health Organisation and UNAIDS Joint Programmes on HIV/AIDS in 1998 identified the following indicators as some of those that signify stigma:

- A scornful look in the market place.
- Refusal of family and friends to visit, social isolation and abandonment by family and friends.
- Refusal of family to care for or even touch someone who has HIV/AIDS.
- Loss of jobs on ground of being HIV positive.
- Maltreatment of the children of those who are infected.

2.1. AIDS and stigma in South Africa

HIV-related stigma has its own unique qualities, and is 'heightened as it is layered upon other stigmas associated with race, gender, homosexuality, drug use, promiscuity etc.' (Lee, Kochman & Sikkema, 2002, p. 310) Discrimination is perpetrated against communities which are perceived to be more affected by HIV, be these physical criteria, such as skin colour (Erwin & Peters, 1999; Parker, Aggleton, Attawell *et al.*, 2002); gender (Gollub, 1999; Parker, Aggleton, Attawell, *et al.*, 2002); sexual orientation (Crewe, 1991; Walpin, 1997); type of work, such as prostitution (Wojcicki & Malala, 2001); or geography, and even an entire continent, such as Africa (Sabatier 1988; van der Vliet, 1996). So stigma not only

affects the individual who is carrying the virus, but also increases the exclusion of already stigmatised groups associated with HIV, such as gay men and black people (Aggleton, Hart & Davies, 1989; Sabatier, 1988). In the early period of the AIDS epidemic in the USA the apparent connection of the epidemic solely to the gay community lead to fears of the isolation of this community being extended and the hard-won battles against discrimination turned around (Shilts, 1987).

Attempts were made to dismiss HIV as a gay-only disease, and thus not requiring a large-scale intervention (Parker, Aggleton, Attawell, *et al.*, 2002; Shilts, 1987). By extension, in the case of AIDS the threat of multiple stigmatisations exists. A person could fall into more than one category of stigma and so feel multiple burdens (Gilmore & Somerville, 1994). Examples would be of a black gay HIV-positive man, or a physically handicapped HIV-positive woman. Each of these would feel stigma in all areas of difference from the norm, with each point of stigma isolating them from different sectors of their community. So work against HIV-based stigmatisation should interact with other stigmas that people experience (Hospers & Blom, 1998).

Anger and fear contribute to the development of discrimination both in those who are HIV positive or HIV-negative (Kok, Kolker, de Vroome & Dijker, 1998). Morality had also become a key factor in the development of stigma in AIDS (Das, 2002; Golden, 1994). A judgemental discourse has distinguished sharply between those 'innocents' who contract HIV via organ or blood transfusions, the children of women with HIV, and women whose partners are unfaithful; and those who are considered guilty and almost 'deserve it' (Schellenberg, Keil & Bem, 1995). Religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgements against those who are infected with HIV (Paterson, 1996). Attempts to label the epidemic as God's punishment for sinners, especially gays, prostitutes and drug users, have often been documented (Crawrod, Allison, Robinson, Hughes & Samaryk, 1992; Johnson, 1995).

To be able to blame others is psychologically reassuring as it divides the society into 'us' and 'them'. 'Others' are guilty as a result of their behaviour. They are guilty not only of getting themselves ill, but also of infecting 'innocents'. This increases the stigma load borne by those groups seen as responsible (Crewe, 1992). The attachment of gender discrimination to HIV stigma has led to women being blamed for spreading the epidemic. Thus women are contradictorily expected to provide sexual services to men generally, be chaste and pure, and take on the responsibility of preventing pregnancy and disease (Crewe, 1992; Leclerc-

Madlala, 2002). A further difficulty is not knowing how to relate to someone with HIV (Kok, Kolker, de Vroome & Dijker, 1998).

There are many examples at a national level of discrimination introduced by socially conservative governments, including policies of restriction of admissions, deportation of foreigners, mandatory testing for those seeking work permits or tourist visas (Parker, Aggleton, Attawell, *et al.*, 2002), and Cuba with its policy of restricting those with HIV to sanatoria (Hansen & Groce, 2001; Scheper-Hughes, 1993).

2.2. Discrimination in South Africa

As with most other countries worldwide, South Africa has reported a large number of incidents of stigma. These include the murder of Gugu Dlamini in December 1998 for openly stating that she was HIV positive (Baleta, 1999; Kortjaas & Msomo 1998; Nicodemus 1999; Rusnak 1998); the murder of Mpho Mtloung together with her mother by her husband, who then also committed suicide (TAC, 2000); not allowing HIV-positive children into schools (Sapa, 2002; Streak, 2001a); exclusions or attempted exclusions from the work place (Ngqalaza, 2000a; Viol, 2000), within the military services (Ngqalaza, 2000b), and in home communities (Gosling, 2000; Smetheram, 2001); and rejection from families (Altenroxel, 2000). A recent case, in 2004, is that of Lorna Mlofane who was raped and later murdered after her three rapists had learned that she was HIV positive (Mbamato & Huisman, 2004). These and many other scenarios are well known and have been covered in the mass media.

Many published papers also document stigma as an aspect of their findings, for example among university students (Strebel & Perkel, 1991), school pupils (Mathews, Kuhn, Metcalf, Joubert & Cameron, 1990), youth (Leclerc-Madlala, 1997; Skinner 2001), in the workplace (Miller & Mastrantonis, 1992) and in couples and families (Strebel, 1993). The connection of stigma around HIV to historical racism and gender has developed a particular form of discrimination. Blame is often assigned to black people or to women. Men blame women for infecting them and spreading the virus (Leclerc-Madlala, 1997, 2002; Shefer, 1999). In couples, it can lead to violence against the woman or her exclusion from the household (Strebel, 1993). Stigma around disease often attaches itself to existing stigmatising frameworks (Sontag, 1988; van der Vliet, 1996), for example in South Africa AIDS has been associated mainly with black people and women.

Many research studies have found a significant number of respondents who want people living with HIV (PLWH) to be clearly identifiable, to be separated from the rest of the population, or excluded from contact in schools, work and social institutions (Mathews, Kuhn, Metcalf, *et al.*, 1990; Strebel & Perkel, 1991). Conflicting views around people living with HIV are sometimes found. For example in a workplace study it was found that there was enormous compassion for colleagues who were HIV-positive, together with a wish to know who did have HIV, implying a need to keep separate from those who were infected (Miller & Mastrantonis, 1992). It appears that knowing the person who is HIV-positive encourages greater feelings of compassion, but fear remains both of the disease and the associated stigma.

Reports of stigma are pervasive, extending even to the health professions. The AIDS Law Project reported that the Health Professions Council of SA did not act against 28 doctors who breached patient confidentiality. The patients were mostly domestic workers whose employers had been told of their diagnosis and many of whom were subsequently dismissed (Altenroxel, 2001). Some health professionals have refused to treat people with AIDS, on the grounds of possible risk of infection (Krautkramer, 2000). Children orphaned or rendered vulnerable by AIDS are likely to experience increasing stigmatisation. They faced verbal and physical discrimination at schools and in the community (Streak, 2001b). Orphans have also been identified as a major security threat for the future (Schönteich, 2002). While this may be a rational call for resources and intervention; it does also lay the basis for them to be identified as a special group for discrimination. Stigma would clearly worsen the situation of orphaned and vulnerable children, excluding them even further from resources and support.

2.3. Implications of discrimination

The extensive nature of the stigma against people with AIDS is well established. This has significant impacts on those immediately affected, but also has a number of implications for the epidemic and broader society. These insidious impacts must be acknowledged, if the work to eradicate stigma is to be taken seriously.

2.4. Making the Epidemic invisible

A prime impact of discrimination is that it pushes the epidemic underground, forcing people who have contracted HIV, and anything else associated with the disease, into hiding. An acknowledgement of HIV becomes difficult if not impossible. Likewise any association with the disease or people with HIV can be a basis for that person being excluded from their community, so is denied. The disease itself then remains hidden so its perceived threat is reduced. It also makes the disease someone else's problem. The stigmatising beliefs then facilitate the use by individuals and communities of denial and distancing as defensive processes against the epidemic, again reducing the need to adapt (Skinner, 2001).

Distancing or creating barriers between those infected and the rest of the population consumes considerable energy that could be more profitably used, and robs the intervention of some of the best advocates for behaviour change, namely those who are directly affected. Thus the epidemic disappears, or at least has few public faces, leaving the space open for scape-goating of any person or group associated with the disease. These scape-goating processes can be dangerous, as they pin the blame on a small section of the population, leaving the rest with the mistaken belief that they are safe (Douglas, 1995; van der Vliet, 1996).

A greater problem arises when those with the power to construct interventions use discrimination as a basis for not implementing such programmes. For communities as a whole, or for those responsible for structuring interventions, blaming infected people can be a substitute for tackling the problem itself. So even when interventions are developed from this basis, they are constructed in such a way as to discriminate against those in affected groups and to reinforce a false sense of safety in the majority of the population.

2.5. Limiting access to treatment

Discrimination has significant impacts on diagnosis and treatment. For the individual it can delay diagnosis and therefore also delay entry into treatment and adoption of a healthy lifestyle. There is no motivation to be tested, as the person sees no benefit when the diagnosis of HIV is seen as equivalent to death, and they are likely to experience discrimination (Abdool Karim, Tarantola, Sy & Moodie, 1992). In certain contexts research respondents have been shown to be more fearful of the stigma than of the disease itself, so even with treatment, stigma may be a block to access (Lie & Biswalo, 1994). This has already been shown to be a problem in the case of PMTCT, where women have expressed fear of being tested (Grange, Story & Zumla, 2001). In the same way the use of formula feeding rather than breastfeeding can become a problem. Many women feel restricted from being able to breastfeed for fear of family observation and questions.

Even for those who are aware of their status, discrimination can limit access to care and treatment (Grange, Story & Zumla, 2001; Rehm & Franck, 2000). Many are not able to acknowledge even to their families that they are infected, so are denied that level of care (Wiener, Battles, Heilman, Sigelman & Pizzo, 1996; Yoshika & Schustack, 2001). If some level of general acceptance and support can be obtained for the person who is HIV-positive, this can facilitate better results (Aranda-Naranjo & Davis, 2000). The benefits of testing need to be openly acknowledged. Even minor modifications of behaviour can improve life (Department of Health, 2001; Feinberg & Maenza, 2000), and the introduction of ARVs can considerably extend a person's life, even in resource-poor settings (Cheever, 2000).

2.6. Impact on identity and coping of the person with HIV

Stigma impacts on the PLWH themselves, as it is internalised into their self-perception and sense of identity, impacting on the person's perceptions and how they interact in the world. Research has found that people with HIV feel isolated, guilty, dirty and full of shame, which is then often incorporated into identity (Kalichman, 2004). General participation in the activities of life is therefore restricted by stigmatisation (Sowell, Seals, Moneyham, Demi, Cohen & Brake, 1997). Isaacs (1993) found that among gay men the rejection experienced by the person who was HIV-positive fed into their sense of self, causing them to feel compromised and to blame for their situation. Similar results were found with a sample of

HIV positive women (Strebel, 1993). When this stigma is internalised it might influence the ways affected individuals look at themselves and how they interact with others, including health care providers (Lee, Kochman & Sikkema, 2002). This again impacts on a person with AIDS coming to terms with their illness. Examples of exclusion in South Africa have been described in the incidents of stigma outlined in an earlier part of this paper.

2.7. Disclosure, support and protection of those close to the infected person

In all relationships discrimination counteracts trust. This often leaves those infected alone and distanced from the rest of their communities, colleagues and even family. The fear of discrimination has been shown to create problems for disclosure, since disclosure has the common reaction of rejection, leaving the person living with HIV alone (Maman, Mbwambo, Hogan, Kilonza, Sweat & Weiss, 2001). This also increases the risk of infection for the sexual partner of the HIV-positive person. Studies focusing on disclosure have also begun to explore the processes of dealing with negative reactions and the empowerment of the person who is disclosing their status (Maman, Mbwambo, Hogan, *et al.*, 2001). Social contacts and family members may also resist being informed, as they too may become vulnerable to exclusion, by being associated with a person with HIV. This in turn can lead to breakdown in the social commitments to care as there is a fear of asking for care and a fear of offering care, both regarding the fear of disease and of association.

2.8. Impact on behaviour change

Discrimination and stigma have implications for the implementation of prevention efforts and have reduced the possible impact of these interventions (Grundlingh, 1999). Certain behaviours such as the use of condoms have become signifiers of the epidemic, leading to the possible rejection of those who initiate their use (Link & Phelan, 2002). Thus many youth in South Africa are scared to use condoms due to the felt implications (Leclerc- Madlala, 1997). Even the option of being faithful can be stigmatised. In a community where multiple partners are seen as an indicator of success or manhood, a person who has one partner may be marginalised.

The intersection of these different points of discrimination can become a vicious circle of stigma with sex workers, gay men, the poor, black women etc. being seen as responsible for HIV/AIDS. However these are also the groups most vulnerable to infection, so they are more likely to contract the disease and thus increase the stigma again (Parker, Aggleton, Attawell, *et al.*, 2002). Stigmatisation of 'at risk groups' or other stigmatisation based on race, gender, class, occupation or sexual preference also puts people at greater risk of infection (Zierler & Krieger, 1997).

There is pressure to deny being part of these groups in order to reduce the felt stigma, including refusing to use safer sexual practices that act as markers for HIV (Leclerc-Madlala, 1997). People who can define themselves outside of these groups are also able to reject the need for safer sexual practices (Crewe, 1992; Ross & Levine, 2002).

In South Africa the attachment of AIDS to the poor, especially poor black women, has created additional risk-associated beliefs. Thus a sample of students at the University of Cape Town believed that their educated status protected them and that it was others who were at risk (Ross & Levine, 2002). In research done in Natal, youth stated that they did not want to know whether they were infected. This was felt so strongly that medical personnel were seen as the worst culprits in the HIV epidemic, as they gave out the diagnoses. At the same time, many infected teenagers were stating that since they would be facing rejection, they would try to spread the infection as far as possible so that they would not die alone (Leclerc-Madlala, 1997).

Stigma and associated beliefs can also impact on how people receive educational inputs. At the level of providing education and getting people to listen, there are many taboos about sex from traditional culture, religion, morality, as well as the hidden nature and sensitive role sex plays in interpersonal relationships.

The addition of information on a stigmatised disease like AIDS makes intervention all the more complicated (Crewe, 1992). It can also paralyse educational efforts. Moreover, while AIDS remains a stigmatised disease it is more difficult for the government to take up the issue. This is particularly so when battles for power are being fought both on a national basis and within the party (Taitz, 2000).

CHAPTER 3: METHODOLOGY

The study was conducted between October and December 2008. It was carried out in three villages in Limpopo. In light of the fact that this study is a pilot for my future PhD, the three sites were selected by the HIV/AIDS/STI Unit of the Limpopo Department of Health, for their dual convenience. First, they all house Home Based Care Programmes for people living with AIDS. As such, they provided the combo of respondents that is, HIV/AIDS patients, carers of people living with HIV/AIDS and community members who have been in close contact with people living with HIV/AIDS. This was considered necessary for the realisation of quality data on stigmatisation and discrimination. A second consideration was the logistical convenience in terms of distance.

Based on information provided by health workers, the three villages had a total of hundred and seven (107) officially reported cases of HIV/AIDS. These included fifty-eight (58) adult females, twenty-three (23) adults' males and six (6) children below the age of ten. The first village housed thirty-five (35) of the hundred and seven (107) cases; that is seventeen (17) adult females and eighteen (18) adults male. The second village, on the other hand, had fifty (50) cases consisting of twenty-nine (29) adults females, seven (7) adult males, and four (4) children under ten years, while the third village has twenty-seven (27) recorded cases which included twenty-two (22) adult females, three (3) adult males and two (2) children aged below ten years.

3.1. Sample and selection procedures

Two broad categories of respondents, individual interviewees and focus group discussants were utilised for this study. Individual respondents comprised of persons infected with HIV, AIDS patients' carers, health workers and community members. Each segment of individual respondents was considered important to the total understanding of the subject matter under study. While patients and carers represented those living directly with HIV/AIDS, health workers constituted the immediate contact with the health care system for HIV/AIDS patients and their carers. The perceptions of health workers about HIV/AIDS are thus important, not only with reference to health interventions, but also with respect to how the general public views the disease. On the other hand, the inclusion of community members as individual respondents facilitated the acquisitions of views from those indirectly living with HIV/AIDS.

Focus group discussants were all members of Home Based Care Programmes in their respective villages.

In all, forty-seven (47) individual respondents and thirty-nine (39) focus group discussants (FGD) were interviewed for the study. Both categories of respondents were selected using purposive (or judgmental) sampling. This is a non-probability sampling method in which the researcher uses his or her own judgement about which respondents to choose and picks only those who satisfy the purpose of the study (Bailey, 1994). This being a pilot study, the selection of the study sample, utilising a non-probability sampling technique, was considered appropriate. The study did not aim to generalise its findings to the population and as such, sampling representation was not a key concern.

To gain access to the two categories of respondents, the good will of the HIV/AIDS/STI Unit was relied on. The Unit linked the researcher with health workers operating in each village, some of whom also serve as members of the Home Based Care Programme. The health workers and other HBC committee members therefore identified potential respondents to be included in the study; particularly people infected with HIV and had developed AIDS symptoms and those caring for the sick. The community members were selected randomly by the researcher who travelled the village and requested to interview those who were available. With respect to focus groups, these were made up of members of the HBC committees in each village studied.

From each village, discussions were conducted with one focus group comprising members of the HBC committee who had volunteered to care for patients suffering from both HIV/AIDS and other diseases. Committee members comprised who had been serving in them since their inception in the mid-2004 and those who had joined as recently as 2007. The majority (30 of 39) of the focus group members were females. The sex composition of focus groups across villages was as:

- Village I – seven females and eight males.
- Village II – all (10) females.
- Village III – thirteen (13) female and one (1) male.

Most of these fell within the 40 – 60 year age bracket with very few of them aged below 30 years. The majority of them had no education or had only attained primary education. Only two of the thirty-nine (39) discussants indicated that they were employed.

The individual respondents included twelve (12) people living with HIV/AIDS, ten (10) individuals caring for those infected with HIV/AIDS, nine (9) health care workers and

sixteen(16) community members. The majority of (81 percent) of those respondents were females. Virtually all the caregivers of people living with AIDS were female relatives of the patients. This is consistent with a study carried out in Molepolole, (HIV/AIDS/STI Unit, 1998). Their ages ranged from 20 to over 70 years, with the majority (68 percent) being over 40 years. Concerning education, only 23.4 percent of the individual respondents had attained Junior Certificate and above levels of education. The rest either had no education at all or were primary school leavers. About 55.4 percent of the individual respondents were either married or cohabiting and 63.8 percent of these respondents were unemployed at the time of study.

3.2. Data collection and analysis procedure

Data was collected on two major areas, namely Perception, Attitudes and Beliefs about HIV/AIDS and HIV/AIDS Related Stigmatisation.

a) Perceptions, attitudes and beliefs about HIV/AIDS

To capture the stigma and stigmatisation related to perceptions, attitudes and beliefs about HIV/AIDS, the study focused on the respondents' understanding of what HIV/AIDS is, who they consider to be vulnerable to infection and their views about knowing one's HIV status, voluntary testing and mandatory testing.

b) HIV/AIDS related stigmatisation and discrimination

This data focused on the assessment of the level of stigmatisation and actual discrimination due to HIV/AIDS. To analyse this, the study looked at other key indications, in addition to perception, attitudes and beliefs about HIV/AIDS, namely support of HIV/AIDS patients relative to other types of patients, support of other (non-patients) living with HIV/AIDS and the obsession with secrecy and confidentiality.

Data from individual respondents were collected using semi-structured questionnaires, blending both closed and open-ended questions. The researcher conducted face-to-face interviews with all respondents. The questionnaire gathered information specific to the study objectives and on the demographic and socio-economic characteristics of the respondents.

To collect the information required from the focus groups, semi-structured interviews were utilised. This involved using topics selected in advance and tailored to fit the subject under study. The major strength of the focus interview is that it goes one step beyond the open-ended questions utilised in a structured interview, thus allowing for flexibility in terms of the

questions asked (Bailey, 1994). The questions are not written in advance and this allows for a chain of probes that could yield information relevant for the hypothesis or topic being studied. Focus group discussions also allow the researcher to get diverse views from a single sitting, compared to the individual interview which gives only one view. In all cases both individual interviews and focus groups the research explained the purpose of the study to the respondents before the actual data collection commenced.

The data realised through this study were analysed in two stages. The first stage involved the analysis of the data realised from individual respondents. The second stage entailed a descriptive compilation of information received from focus group discussions to constitute a coherent knowledge base.

CHAPTER 4

FINDINGS

The core findings of the study are grouped under four major sections:

- 4.1. Perceptions, attitudes and beliefs about HIV/AIDS**
- 4.2. Support of HIV/AIDS Patients**
- 4.3. Support of caregivers and relatives of people living with HIV/AIDS**
- 4.4. Secrecy**

Information related to these two key areas was gathered from patients, caregivers, community member and HBC committee members.

4.1. Perceptions, attitudes and beliefs about HIV/AIDS

4.1.1. Patients

Patients perceived HIV/AIDS as a dangerous, incurable disease. Whether this perception was inspired by the information they had got through the awareness campaigns was not easy to discern as they provided divergent information pertaining to what they perceived, included the following:

- A scary disease that brings fear to you
- An incurable disease that waste the body
- A complicated disease with no cure.
- A disease of the genitals that give diarrhoea and general body pains.

Patients considered HIV/AIDS as a disease that was different from others, which they regarded as being scary. It would seem that their perceptions, attitudes and beliefs about HIV/AIDS were linked to what they had seen in terms of the symptoms, the disease process, its impact on those infected and the prognosis. There seemed to be a relationship between their understanding of the basic facts on HIV/AIDS and their attitude, beliefs and perception of the disease. Of significance is how they viewed susceptibility and vulnerability of various groups to HIV and AIDS.

From the patients' perceptions about what HIV is and who is at risk of infection, one can conclude that HIV/AIDS is stigmatised only in terms of what it is by even those who have it. This is reflected in the way patients departed from the conventional conception of the disease which considers it to be like any other disease to label it as scary, a killer and incurable without mentioning that it is preventable. But the identification of vulnerable groups reflects

no stigmatisation. The groups identified by patients do not present a negative construction of infection.

As may be seen from these findings, patients seem to have attitudes, beliefs and perceptions about HIV/AIDS disease and seem to have drawn a clear line between these, and the feelings towards those who control the disease. The seriousness and consequences of the disease as perceived by the patients can be gleaned from the following statement that the researcher constructed from their responses. *“All patients who responded understood the gravity of being HIV positive mainly in terms of the effect of the disease. Some clients felt that being HIV positive is like being sentenced to death. They indicated that they were confronted with the apprehension of death on a daily basis.”*

It should be noted that patients' frame of reference about HIV/AIDS was largely influenced by what they saw around them and what they had been told about the fatal disease. They had seen PLWHA die in hospitals and homes. Most, if not all, of these respondents had never heard of ARV therapy and other treatment options. Even those who may have heard of ARV therapy and their effect had been told that such drugs were not affordable and the hope of accessing ARV therapy had never crossed their minds. The terminology used to describe HIV/AIDS was consistent with its effects and proven prognosis.

4.1.2. Caregivers

Overall, the caregivers demonstrated a high understanding of what HIV/AIDS was. They had acquired their knowledge through awareness campaigns and through shared confidentiality with their patients. However, two demonstrated some measure of ignorance about the disease. While one of them said AIDS was birth constriction which resulted in a child developing rashes and pneumonia or food poisoning. Some of the most commonly held perceptions about HIV/AIDS by caregivers included the following:

- An infectious killer disease; once you have it, you are dead.
- A mysterious and complicated disease; no one understand it, not even the doctors.

Like patients, caregivers felt that everyone was at risk of contracting HIV infection. To illustrate this, one caregiver used the example of her brothers who had since died of AIDS-

related illnesses. She pointed out that her brothers were ‘good’ people compared to her, she used to be outgoing and a real woman of the world, yet they had died but she remained HIV negative.

Consistent with patients, the only stigmatisation of HIV/AIDS evident from the perceptions of caregivers is related to what the disease itself was rather than to those considered at risk of contracting HIV. In particular, it was the mystification of the disease, evident through its being labelled as mysterious and complicated, which pointed to its stigmatisation. The association of HIV/AIDS with death also seemed to indicate the stigmatisation of the disease.

4.1.3. Community members

Community members like the clients and caregivers described HIV/AIDS in terms of the aetiology, disease process, symptoms and prognosis. Community members also understood what HIV/AIDS was and derived most of their knowledge from awareness campaigns. It should be observed that community members had observed the morbidity and mortality trends of HIV/AIDS. They also expressed negative attitudes towards condom use, and seemed to link the use of condoms with both the incidence of HIV/AIDS and the promotion of indiscriminate sexual behaviours. Communities indicated that caregivers who were not aware of the positive sero-status of the patient they were looking after were at risk of contracting HIV/AIDS. The community members also addressed the gender related aspect including the effect of gender-based power relations in HIV/AIDS prevalence. They also brought out issues related to the economic factors that contribute to intergenerational sex between young girls and older men. They were fully aware of the high prevalence of HIV infection among women.

Everyone is at risk of being infected with HIV. Even older women are believed not be sexually active could get infected while nursing those who are infected without wearing protective clothing. Consistent with patients and caregivers, the community members seemed to stigmatise HIV/AIDS in terms of their perception of the disease itself. There are several indications of stigmatisation evident from the way they perceive the disease. These included the perception that, unlike other diseases, AIDS is a complicated, dangerous and killer disease and that the disease is caused by sexual promiscuity and the breaching of cultural sex taboos. In addition, community members tended to ‘feminise’ the disease; women were considered to be more infected and affected. This view constructs AIDS as a disease of women.

4.1.4. Home based care committee members

Focus group discussions comprising HBC committee members expressed the same perceptions, beliefs and attitudes with respect to HIV/AIDS as patients, caregivers and community members. The consequences of the disease, its transmission and prognosis were viewed with the same seriousness as other groups. Like all individual respondents, they reported being quite conversant with the disease. According to HBC committee members, although everyone was at risk of being infected with HIV, the groups that were most at risk included individuals who practised unsafe (unprotected) sex and those who were promiscuous and had multiple sex partners.

Given the above perception, it may be concluded that members of HBC committees do not appear to stigmatise HIV/AIDS very much. This might be a reflection of their exposure to those infected and the sensitisation workshops they have participated in as preparation for their work. Besides relating it to God, their perceptions bordered on the conventional knowledge disseminated through campaign messages for the control of the spread of infection. Unlike other categories of respondents, HBC committee members' perceptions about vulnerable groups manifested some measure of stigmatisation.

4.2. Support of HIV/AIDS patients

The way community members relate to those infected with HIV/AIDS is another pointer to the existence or absence of stigma and stigmatisation. Broadly speaking, this can be reflected through attitudes towards HIV/AIDS patients. Such attitudes could manifest themselves through a variety of behaviours and practices. To capture these, the study focused on the respondents' feeling about being infected with HIV/AIDS, the social isolation of patients and the use of protective clothing when caring for the sick.

4.2.1. Feelings about those infected with HIV/AIDS

To assess the respondents' feelings about those infected with HIV/AIDS, the study asked them to indicate their reaction if they learned that someone they knew was HIV positive or had AIDS.

4.2.1.1. Patients

Most patients reported that, although what they would actually feel was beyond verbal description, they would generally be sympathetic. The feeling of isolation experienced by patients, coupled with the consolation that would accompany knowing that there were other people in a similar situation, point to the stigmatisation of HIV/AIDS. The association of ridicule and laughter with HIV/AIDS by one of the patients could also point to the existence of such behaviour in the community and thus to the stigmatisation of the disease.

4.2.1.2. Community members

The first reaction from most of the community members whenever they learned that someone they knew had been diagnosed HIV positive or had developed AIDS was one of disbelief. They indicated that they were sympathetic to such a person because 'it is happening to a fellow human being and being infected with HIV/AIDS was a death sentence'. According to those respondents, those infected experience endless health problems and tremendous suffering before they finally die. Furthermore, HIV/AIDS affects even those who are aware about its dangers (such as doctors and nurses). It is not possible to tell who has or does not have the disease and the disease is widespread, particularly among young people.

The above views reflect sympathetic and caring attitudes towards those who are infected as opposed to stigmatisation and discrimination among community members. However, the reaction of disbelief points to a special fear of HIV/AIDS and the wish among community members not to associate it with one closely related to them. This has implications for stigmatisation of the disease.

4.2.1.3. Home based community committee members

According to information obtained from focus group discussions, health workers at times relate to AIDS patients with indifference and keep reminding them of their HIV status. The health workers allegedly say "you know your condition", therefore such ailments are to be expected. The respondents expressed the need for more awareness lectures on how to deal with the infected not only in clinics but also at home and at the workplace. With specific reference to the workplace, they believe that employees who are infected with HIV/AIDS should be allowed to continue working depending on the type of job they held. 'Only those who held jobs that risked them infecting others e.g. those handling food, should have their

jobs terminated'. Arguing that the provision of support to the infected was essential for their well-being, these respondents advocated that such support be availed to patients at the workplace by colleagues and at home by spouses, relatives and friends.

4.2.2. The Social isolation of patients

The social isolation of patients spans practices such as the creation of separate health institutions to care for the infected; the use of separate accommodation, bathing, cooking and eating facilities and the shunning of patients (e.g. refusal to shake hands). In extreme cases, social isolation could take the form of total abandonment of patients by relatives (family) and friends.

4.2.2.1. Patients

The patients interviewed for this study were opposed to the isolation of those infected with HIV/AIDS. They did not consider it necessary to confine HIV/AIDS patients to separate institutions and facilities. With respect to treatment in clinics, they felt that they were well treated. They attributed this type of treatment to HBC committee which facilitated their transportation to and from the clinic. The cordial relationship between the HBC committee and the clinic made it possible for the committee members to collect medication and other supplies for those patients who were not able to go to the clinic. However, a few patients reported suffering intimidation at the hands of clinic staff. Some of these complained that, at times, when they go to the clinic, health workers remind them of their HIV status. Concerning abandonment, four of the twelve patients reported that their spouses had abandoned them as soon as they fell ill. One completely by her spouse and relatives, including her own children.

4.2.2.2. Caregivers

Although most caregivers were opposed to the social isolation of patients, some favoured separate facilities such as utensils and toilet facilities for patients. According to one carer, the government should reconsider the near universal sharing of pit latrines between patients and non-patients because this promotes the spread of infection particularly where these could not be disinfected properly. Those who supported separation of facilities, however, argued that this should be done not as a sign of discrimination but for the good of the patients. With specific reference to the use of separate utensils, one of the caregivers whose patient observed the practice intimated that there was nothing wrong with doing so. After all, during the 1970s

when she suffered from TB, the rest of the family used separate utensils from her. As such she did not see any reason why her patient would misconstrue such a practice as representing stigmatisation.

The information adduced from caregivers does not explicitly point to the existence of HIV/AIDS based stigmatisation and discrimination. However, the support for the separation of certain facilities while deliberately struggling to paint this as normal practice under the guise of 'for the good of the patient' manifests an element of discrimination grounded on the stigma associated with the disease. In other words, the signal these individuals are passing is that HIV/AIDS is a dangerous disease and those who are not suffering from it need to be protected from those who are infected.

4.2.2.3. Community members

Among the community members for example, only five of the sixteen interviewed were opposed to both shaking hands and sharing bathing and toilet facilities with infected individuals while three others preferred not to share utensils and four preferred not to share accommodation. Those who supported the shaking of hands nevertheless argued that it should depend on the health status of the patient. If the patient has sores on his or her hands, shaking hands with HIV/AIDS patients, they would be silently praying for protection from God. Some of those who supported the sharing of utensils, however, pointed out that they would disinfect them immediately using jik. Others reported that they would dig a very deep hole and bury the utensils used by the patient. Those opposed to the sharing of utensils argued that, traditionally, someone who is ill and is being nursed at home is supposed to have separate utensils; this also applied to a woman who was in confinement after giving birth. This was done for hygienic purposes and out of love for the patient rather than to stigmatised or scorns them. The same applied to the sharing of toilet facilities; they would clean it thoroughly after use to stop the spread of the infection. Some of those opposed to the social isolation of patients, particularly focus group discussants, felt that it would have adverse effects on the infected. According to them, patients who are isolated become depressed as they feel that are not human.

Some community members supported the social isolation of AIDS patients from the rest of the community, mainly on grounds of fear of infection. They argued that the initial reaction to AIDS should have been to isolate those infected from the rest of society. This would have curbed the spread of the disease by limiting the exposure of too many people. Some of these

respondents argued that, to contain the spread of the disease, the South African Government should have treated HIV/AIDS the way it had treated leprosy in the past and the cattle lung disease in the 1990s. Those respondents who favoured the social isolation of patients included some who made it clear that they would not want their whole household infected and also because they would want to share it with a dying person. According to them, the disease was highly infectious and interacting with infected persons contributed to its spread.

4.2.2.4. Health workers

All health workers were opposed to the social isolation of HIV/AIDS patients. For instance, they felt that there was no need to use separate health institutions to treat these. According to them, with the publicity that HIV/AIDS was getting, if patients were treated in separate health facilities, it would worsen their insecurity and stigmatisation. In addition, they reported that in light of the large numbers of HIV positive persons whose status is not known, it would be difficult to enforce the separation of facilities effectively. The health workers further stated that when the HIV virus had completely incapacitated the patient it became too much for them to queue for treatment at the same institution as people who are relatively healthy. It was also too much to handle for the caregivers who had not been trained to look after patients who were very ill and helpless; such patients had to be fed and re-hydrated intravenously and needed around the clock care, a responsibility that a single carer cannot provide in the home. When the patients reached this stage, the health workers felt that they should be institutionalised where they would receive extensive professional care and support.

Basically, the health workers' point of view about the social isolation of patients did not reflect stigmatisation of or the discrimination against HIV/AIDS patients. Instead, they seemed to suggest a desire on the part of the health workers to protect the patients. This, however, tends to run counter to some of the complaints and allegations reported earlier by some patients and HBC committee members that patients were usually maltreated by health workers in institutions.

4.2.3. The use of protective clothing

Only patients and their caregivers were directly interviewed concerning the use of protective clothing. Some community members did touch on this subject during their discussion of

social isolation of patients. They were unanimous that those who look after AIDS patients should wear protective clothing as directed by health authorities. But while doing so, they should show love and compassion to their patients and look after them in every way possible including bathing and feeding them.

Most of the patients, including those whose caregivers were not currently using protective clothing, had a positive image about its use. They considered such a practice to be a necessary health precaution for the avoidance of infection. According to them, when looking after the infected, the caregivers should protect both the patients and themselves. Otherwise they may also infect the patients who are even more vulnerable to infections. Some patients, however, did attach a negative interpretation to the practice of using protective clothing. One patient who was being looked after by her 70 years older mother from whom she had concealed her HIV status reported that “if my mother uses protective clothing when taking care of me, I would give up on myself”.

Half (5) of the ten carers interviewed used protective clothing when handling their patients. They indicated that they had discussed the practice with their patients. The caregivers who did not use protective clothing, despite being provided with it and taught how to use it, indicated that they did not see the need. Information received from some carers did reveal some negative interpretation of the practice of using protective clothing. One caregiver reported that, even though she thinks about using protective clothing, she does not know how to bring up the subject. When the researcher pointed out that the use of protective clothing is for protecting both patients and caregivers, she replied that she wished the patient could hear for herself since it would be easier for the patient to accept it if the idea came from others and not her own mother.

This study is of the view that the use of protective clothing may not necessarily signify stigmatisation or discrimination. However, the possibility of this practice being misconstrued thus, particularly on the part of patients, remains a reality. The community members and caregivers appear to have been sensitive to this fact. This is evident from the emphasis by community members that as caregivers use protective clothing they should remember to show love and compassion to their patients. In addition, some caregivers emphasised the need to protect patients from opportunistic infections, as opposed to protecting themselves, as the main reason for using such clothing. Otherwise the patients would have developed a negative outlook about the practice. Indeed, there are indications that some patients would have actually believed that they were being stigmatised had their caregivers used protective

clothing. The patient who indicated that she would give up on herself if her mother who cared for her used such clothing is a case in point. At the same time one may argue that the use of protective clothing manifests stigmatisation because there are other more infectious or even airborne diseases such as TB and yet those living with individuals infected with these are not necessarily advised to use protective clothing. This is probably an issue for further clarification and discussion.

4.3. Support of caregivers and relatives of HIV/AIDS patients

For the purpose of this study, those living with HIV/AIDS include both patients and those others who associate or are related to them. It is the latter, particularly caregivers and members of HBC committees, who are the focus of this section of the research project. The emphasis on their relationship with other community members and how the community receives them given that they are involved with HIV/AIDS patients. Data was sought from caregivers themselves, community members and from members of HBC committees.

4.3.1. Caregivers

Results from interviews with caregivers showed that most of them received support from the community, relatives and friends. Only four of the ten caregivers studied reported that their relatives were not supportive. One of these narrated an incident during which she wished to borrow a mopping broom from her sister-in-law (brother's wife) only to be completely turned down on grounds that her house was infectious. This care also reported that the rest of the family fear coming to her house. Another caregiver indicated that at the onset of the illness relatives used to visit but once the illness became prolonged, they stopped. The third carer, who was looking after her sister, reported that she did not receive much support from family and friends. Only one aunt and her husband were supportive; all other relatives scorned both her and the patient. Indeed, it was her husband who insisted that the patient moved in with them because there was no one to look after her at her own house. The four carers, who complained of lack of support from relatives, however were of the view that AIDS may not have been the major reason behind this trend. This is particularly so in light of the fact that most relatives did not know with certainty what the patients were suffering from. However, the level of clinical suspicion with respect to HIV/AIDS among community members and caregivers has increased.

The information received from caregivers was consistent with that provided by individual community member respondents and focus group discussants. Most of these have a positive attitude about caregivers. They emphasised the need to extend love and compassion, not only to the patients but also to the caregivers. The support could be social (e.g. feeding and bathing the ill), financial and other material support. The support group discussants in particular were unanimous that caregivers should also be treated with love and compassion. They argued that there are times when the caregiver needed care and all round material and moral support from members of the community in general and from HBC committees in particular. The respondents were also opposed to the social isolation of carers. They felt that the carers should be allowed to continue mixing freely with other members of the community as they are part and parcel of the community. Being a carer did not necessarily mean that one also had the virus and may infect others.

The information presented above points to some existence of the stigmatisation of and discrimination against some of those caring for patients living with HIV/AIDS, particularly by relatives and friends. This is evident from the four caregivers reported being shunned by their relatives. Furthermore, the suggestion by community members and HBC committee members that caregivers should be shown love and compassion points to the potential for the stigmatisation of and discrimination against them.

4.3.2. Home based community committee Members

Stigmatisation and discrimination due to HIV/AIDS could also be evidenced in the way the community relates to members who have joined HBC committees. According to information gathered from HBC committee members, the HBC programme provided an essential service. HBC committees in the three villages studied were treated with mixed feelings. For instance, there existed a perception that the CHBC programme only deals with HIV/AIDS-related diseases and, as such, some patients and community members did not want to be associated with them. Indeed, this view was not only entertained by some community members but also by some caregivers and patients who dislike being openly associated with HBC committees.

To those individuals, the presents of HBC committee members in one's home was synonymous with telling the world that oneself or someone in one's household had HIV/AIDS; a disease which most people feared and dreaded. Whenever the HBC vehicle arrived at their homes, non-supportive community members tended to show signs of

annoyance and irritation. However, some sectors of the community, particularly those who had terminally ill patients, did receive committee members very warmly, and showed appreciation.

There are clear indications of the stigmatisation of HIV/AIDS itself in the information presented above. This takes the form of the desire to disassociate oneself from HBC committee members and the interpretation of the presence in a particular household to mean that someone in the household has HIV/AIDS.

4.4. Secrecy

The existence of secrecy related to HIV/AIDS can manifest itself through attitudes to knowing one's HIV status and to voluntary testing for HIV. All individual respondents, except two patients and three community members, emphasised the importance of knowing one's HIV status and approved of voluntary HIV testing for everyone living in South Africa. Those who supported voluntary testing argued that it is important for individuals to know their HIV status in order to lead a healthy life. They also argued that knowing one's HIV status decreased the chances of infecting others.

The study also addressed the subject of secrecy directly by asking patients and carers whether they had ever revealed the HIV status of the patients to others such as spouses, other family members and friends. Most community members and focus group discussants supported the revelation of patients' HIV status to others. They felt that, if carers and family members are to care for the patient effectively and ensure the protection of both the patients and themselves, they should be told what the patient is suffering from. They felt that this should occur regardless of whether the patient insists on keeping it a secret or not. Information provided by health workers indicated that all the patients knew that they were HIV positive or had AIDS. However, only nine (seven females and two males) of the twelve patients interviewed revealed their HIV status to the researcher. All nine had learnt about their status through illness and subsequent testing. The nine included six of seven patients who were under direct Home-Based Care. Of these six, only three had confided their HIV status to their caregivers. They felt that it was only proper and ethical for them to reveal their HIV status to the caregivers considering their diligence in caring for them.

As implied earlier, three of the twelve patients studied concealed their HIV status from the researcher. They were emphatic that they did not know what they were suffering from despite the fact that their health history was punctuated with indications that they could be HIV

positive or suffering from AIDS. To illustrate this, one patient was bed-ridden at the time of the interview as her sickness was on and off. When not bed-ridden, she was well and was able to do all household chores. This patient was staying with a spouse and was reportedly at pains to conceal her HIV status from the spouse. The second patient had two children, aged two and five years, and was in an advanced stage of pregnancy. Although the five year old child was reportedly HIV positive, the patient's attitude was one of defiance. There are three possible explanations for this. Firstly, she had gone against medical advice not to become pregnant after the first child was diagnosed HIV positive. Secondly, she had had a child who was reportedly not HIV positive. Thirdly, she was expecting her third child, meaning she was practising unprotected sex, and she was still in good health and may have felt that she had proved the health workers, who had advised against getting pregnant, wrong. Third patient had not revealed her HIV status and was very unwilling to do so from the beginning. She perceived herself to be a 'star' in the community and did not wish anybody to know about her HIV status as this would reduce her status. This brings in the dimension of 'image and the nature of the disease.

The stigmatisation of HIV/AIDS was reflected through respondents' attitudes towards knowing one's HIV status and voluntary testing. Despite the near unanimous support for the importance of knowing one's HIV status, only three of the current caregivers reported that they knew what their patients were suffering from. Yet virtually all patients knew that they were either HIV positive or suffering from HIV/AIDS-related illness. The fact that individuals wish to know their status, but at the same time prefer to conceal such information from others, points to a possible fear of stigmatisation. On the other hand, the near unanimous support for voluntary testing may signify, not just the fear associated with HIV/AIDS, but its stigmatisation too. A basic question that one cannot extricate is why HIV/AIDS should be singled out for mandatory testing and not other life threatening diseases. In addition, the fact that most respondents questioned the possible benefits they would derive from such testing shows that they wanted HIV/AIDS to be regarded as any other disease.

CHAPTER 5 : CONCLUSIONS

Stigma impacts beyond the individual infected with HIV, to affect all those associated with the disease. It can also impact on society more generally, by extending the epidemic and undermining whatever behaviour and treatment interventions are already in place. Thus interventions need to be introduced to reduce stigma and encourage acceptance. There are different political and social forces that come to bear when considering interventions against stigma, and there needs to be openness by leadership figures to such issues. Working to reduce or end stigma is also not a short-term undertaking. As has been shown in attempts to end racism, stigma can be highly resistant to change (Foster, 1991). The popular notion that provision of information is sufficient to change stigma is clearly insufficient (Deacon, Prosalendis & Stephney, 2004). The link of information to beliefs and behaviour has been shown to be insufficient in changing sexual behaviour in relation to HIV, and has also proved insufficient in addressing racism and sexism.

Several conclusions derived from the results of this study. First the level of awareness and understanding of HIV/AIDS in all three villages studied is relatively high. The respondents understood what HIV/AIDS is, how it is contracted and the complexity of the disease and the seriousness of the pandemic in general. Nearly everyone had experienced some sensitisation about HIV/AIDS. Secondly, there existed potentially stigmatisation attitudes, beliefs and practices among the communities studied. However, the majority of the patients and caregivers interviewed did not consider themselves to be experiencing stigmatisation or even discrimination. Attitudes, beliefs and practices amounting to stigmatisation and discrimination were evident, but very few respondents perceived actual stigmatisation and discriminated against patients and other living with HIV/AIDS. For instance, most of the patients did not consider practices such as the separate use of utensils and bathing facilities or the use of protective clothing to be stigmatisation or discriminative. According to the patient respondents, what AIDS patients experienced was segregation rather than stigmatisation.

Stigma towards people with AIDS is related to the incidence of all other kinds of stigma. So campaigns need to address or make space for changes of attitudes and beliefs about stigma based on race, gender, sexual orientation, physical illness or disability and class, amongst others. This was supported by a call from Kofi Annan, UN Secretary General, at the World

Conference Against Racism, where he made a combined call to end racism and discrimination against people living with AIDS: racism and HIV stigma support and uphold each other so were in reality part of the same campaign with racism boosting the AIDS epidemic (Tren Grove-Jones, 2001).

A possible explanation for the lack of perceived stigmatisation and discrimination among most of those interviewed is the fact that the study took place within the context of HBC. It can be argued that the HBC programme orients community members to the realities of HIV/AIDS by taking the disease to the people. This way the programme is able to demystify the disease and enable community members to come to terms with it and with its realities. Where such programmes have been in existence for some time, as in the three villages studied, the public is likely to have a better understanding of the disease itself, how it can be contracted and avoided and who is at risk of being infected, among others. As they watch family, neighbours and friends nurse their sick, community members come to terms with the HIV/AIDS pandemic. This helps them to understand that anyone is at risk and consequently waters down the tendency to stigmatise both the disease and those infected by it.

Furthermore, the patient respondents and health workers saw the somewhat differential handling of patients by community members as being occasioned more by the general fear of the disease rather than by the stigma and discrimination associated with it. According to them, people did not fear the death associated with AIDS but rather the disease itself. Some argued that death was even better than the suffering accompanying the disease coupled with its horrifying symptoms, particularly the loss of weight, rampant sores and the general disfiguring of PLWHA. The genesis of the fear associated with HIV/AIDS was the nature of the disease itself. To the respondents, HIV/AIDS is not like other terminal (and sexually transmitted) disease; it is highly infectious, so far has no cure and ultimately culminates in one's death. This makes it a scary disease; one which community members are likely to be fearful of when dealing with. Such fear is aggravated by the lack of understanding of HIV because of its complexity.

In addition, HIV/AIDS is a mysterious, complicated and unpredictable disease; even medical doctors have a limited comprehension of it. The disease is still shrouded in mystery and scientific research is yet to unravel this. For instance, initially HIV positive mothers were

encouraged to breastfeed their babies only for the practice to be discouraged later. Also the disease was said to be transmitted through sex and shared use of needles among drug addicts but currently other modes of transmission have been added to the list. In the words of one patient, “it is difficult to explain exactly what the HIV virus is “Unlike other disease, which is seen as natural, HIV/AIDS is associated with multiple sexual partners, sexual promiscuity and prostitution. There are all morally unacceptable practices. Those who engage in them are often considered to be outcasts. The fear of HIV/AIDS was also associated with some of the preventative messages broadcast by the Ministry of Health. This is particularly true of those that threaten recipients with death unless they change their sexual behaviour. Sometimes the messages send conflicting signals to the members of the community. For instance, one message may urge community members not to fear HIV/AIDS suffers and to treat them like a person suffering from any other disease while another message strongly advises those caring for the sick to use protective clothing.

Despite the low levels of actual stigmatisation and discrimination against patients, their carers and HBC committee members the study found that HIV/AIDS itself is a highly stigmatised disease whether this occurs consciously or unconsciously. This was clearly reflected in the respondents’ perceptions about HIV/AIDS; particularly what it is and who is most vulnerable to infection. The stigmatisation of HIV/AIDS was also evident from some of the practices related to the treatment of patients, their carers and members of HBC committees. HIV/AIDS was associated with excessive sexual activity which is socially and morally wrong in society. Although the official position describes HIV/AIDS as any other disease, most respondents did not treat it thus.

There is a clear need to establish a research agenda that is related to HIV in South Africa. An initial priority is the development of a greater understanding of the nature and practice of stigma against HIV positive people in South Africa. Stigma is a social phenomenon so needs to be understood at both individual and social levels. This work can lay the basis for directed campaigns and interventions against the practice of discrimination. This is a real and centrally important challenge for harnessing the HIV epidemic that needs to be taken seriously.

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