

Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa

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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, Africa, discrimination.

RÉSUMÉ

La stigmatisation et la discrimination jouent des rôles importants dans le développement et le maintien de l'épidémie de VIH. Il existe beaucoup de travaux écrits sur la stigmatisation et la discrimination que subissent, de manière continue, les personnes vivant avec le VIH/SIDA. Cet impact va au-delà des individus contaminés du VIH et atteint la société en gros. Cet impact, à la fois bouleverse le fonctionnement de communautés et complique la prévention et le traitement du VIH. La présente communication a pour but de passer en revue la littérature scientifique existante sur le VIH/SIDA et la stigmatisation en Afrique du Sud ainsi que les rapports de presse sur le même sujet au cours d'une période de 3 ans. Une analyse de ce matériel indique que la stigmatisation cache le VIH du public, de sorte, la pression de changement du comportement est réduite. La stigmatisation suscite un désir de ne pas vouloir savoir son statut sérologique. De ce fait, le dépistage et l'accès au traitement sont retardés. Au niveau individuel, la stigmatisation sape l'identité de la personne et sa capacité de faire face à la maladie. La peur d'être discriminé réduit la possibilité de dévoiler son état sérologique même auprès des sources de soin importantes comme la famille et des amis. Enfin, la stigmatisation a un impact sur le changement comportemental étant donné qu'elle réduit la possibilité d'avoir des rapports sexuels sans risque. Vouloir utiliser un préservatif peut être considéré comme signe de VIH suivi par le rejet et la stigmatisation. Toutes les interventions doivent mettre l'accent sur la stigmatisation. Toutefois, la difficulté de cette tâche ne doit pas être sous-estimée. Cette difficulté apparaît dans la persistance de discrimination basée sur des facteurs comme la race, le sexe et l'orientation sexuelle.

Mots clés: VIH, SIDA, stigmatisation, Afrique, discrimination.

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Introduction

'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 Prime Minister of Tanzania, Hon. FT Sumaye in the Regional Consultation Report, 2001*).

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 third 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 other 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

affects 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 differences 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

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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.

Information sources

The material for this paper was drawn principally from two literature searches. A formal search was made of Medline, Psychinfo and Anthropological Abstracts, using the keywords HIV/AIDS, stigma, discrimination and Africa. An additional manual review was conducted of newspaper clippings for the period 2002 and 2003, to extract important articles on experiences of stigma as noted in the mass media. Unpublished reports and reports that do not appear on the above databases were identified and incorporated where possible. The list of references covers only those papers cited in the text and not the full collection of papers read and reviewed.

AIDS and stigma

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 (Crawford, 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

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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).

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 (Mbamoto & 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. Recently 90 children affected by HIV/AIDS spoke of their experiences of discrimination. 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.

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.

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

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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 scapegoating of any person or group associated with the disease. These scapegoating 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.

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 & Biswal, 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).

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.

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

In all relationships discrimination counteracts trust.

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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.

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).

Conclusion

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 an 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

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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.

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 (Trengrrove-Jones, 2001).

There is a clear need to establish a research agenda for stigma 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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