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HIV/AIDS STIGMA: THE LATEST DIRTY SECRET

Jo Stein

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The Administrative Officer
Centre for Social Science Research
University of Cape Town
Private Bag
Rondebosch, 7701
Tel: (021) 650 4656
Fax: (021) 650 4657
Email: kforbes@cssr.uct.ac.za

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CENTRE FOR SOCIAL SCIENCE
RESEARCH

AIDS and Society Research Unit

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THE LATEST DIRTY SECRET**

Jo Stein

CSSR Working Paper No. 46

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Jo Stein is Principal Scientific Officer at the AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town. She has published in the field of HIV/AIDS research since 1992 in the areas of HIV prevention, care and support. She has been co-author of the AIDS Bulletin, a Medical Research Council publication focusing on a wide range of HIV/AIDS related issues, since 1997.

HIV/AIDS Stigma: The Latest Dirty Secret

Abstract

The rejection of HIV/AIDS stigma is based on the understanding that all acts of social exclusion relating to HIV/AIDS are not only morally wrong but also counterproductive to effective HIV/AIDS prevention and treatment. There is some survey evidence suggesting that HIV/AIDS stigma has already diminished substantially over time both in South Africa and worldwide. However, it is arguable that these surveys are failing to measure the changing face of stigma effectively. This paper describes some of the conceptual and methodological challenges that quantitative research measuring stigma needs to address. Foremost amongst these is the fact that HIV/AIDS stigma stems from multiple sources which cannot be conflated if stigma is to be properly identified, measured and most importantly, addressed.

Stigma: How Bad Is It?

People living with HIV/AIDS have been stigmatised and discriminated against worldwide since the epidemic began (Gilmore & Somerville, 1994; Malcolm *et al*, 1998; Mann, 1987; Sontag, 1990). In South Africa, Nkosi Johnson was refused admission to school and Gugu Dlamini was murdered by a mob after publicly revealing her HIV positive status (Finchilescu, 2002). Instances of overt discrimination, including violence, remain common. Indeed, too common, from the perspective of many journalists, to warrant continued reporting in the mass media (Stein, 2002). The stigma surrounding HIV/AIDS is such that, in South Africa's Western Cape Province, HIV/AIDS is just called 'ulwazi' which means 'that thing'. This has been taken to suggest that HIV/AIDS is seen, not only a disease that has no cure, but as one which is so stigmatized, it cannot even be referred to by name (Morgan, 2003).

This problem has not gone unnoticed. As early as 1987, Jonathan Mann, Director of the World Health Organisation's Global Programme on AIDS, identified three distinct epidemics; (1) HIV infection, (2) the AIDS epidemic itself, and (3) HIV/AIDS stigma, which he described as potentially the most explosive of the three epidemics (Mann, 1987). Nearly 15 years later, Peter Piot,

the Executive Director of UNAIDS, the organisation which superseded the WHO's Global AIDS Programme, prioritised stigma as the first on a list of five of the most pressing items on his agenda. This was on the grounds that stigma remained the 'roadblock to concerted action, whether at local community, national or global level, so action against stigma ramifies across every single aspect of HIV work.' (Piot, 2000, cited in Parker & Aggleton, 2002: 6).

There is some international evidence to suggest that HIV/AIDS stigma has diminished substantially over time (France, 2001; Moon, Mitchell & Sukati, 2002). However, much of the published quantitative research measuring stigma, which describes the American public's response, suggests that while support for extreme measures against people living with HIV/AIDS has fallen to very low levels, the American public increasingly blames people living with HIV/AIDS for their illness. Thus, from 1991 to 1997, the number of Americans who agreed that 'people with AIDS have gotten what they deserve' increased by approximately 40%, from 20.5% to 28.8% (Herek & Capitanio, 1999). A British survey comparing stigma before and after the first British AIDS education campaign also showed that while HIV/AIDS related knowledge had increased, blame of those infected had increased (Department of Health and Social Security and the Welsh Office, 1987).

Thus far, South African research regarding HIV/AIDS stigma has been extremely limited, and comparisons of stigma levels over time have been based largely on anecdotal evidence. However, two quantitative HIV/AIDS surveys conducted recently in South Africa, which have included measures of stigma, have identified what appear to be relatively low levels of HIV/AIDS stigma in the general population.

The Nelson Mandela/HSRC Study of HIV/AIDS suggests that the majority of South Africans express attitudes of acceptance towards people living with AIDS, although a small minority have a clear tendency to stigmatise (Shisana & Simbayi, 2002). This survey found that:

- 82.3% of respondents stated that they would sleep in the same room as someone with HIV/AIDS;
- 74.1% of respondents would share a meal with someone who is HIV positive;
- 94.3% of respondents stated that they would talk to someone with HIV/AIDS.

The data from another survey commissioned by the Department of Health has also been taken to suggest "an encouraging degree of openness towards also people with HIV/AIDS" (Parker *et al*, 2002, p14). This is on the grounds that:

- 90% of respondents indicated that they would be interested in talking about HIV/AIDS with an HIV positive person;
- 77% agreed that an HIV positive teacher should continue teaching.

However, it is questionable whether such findings should lead us to conclude that stigma is not the problem in South Africa which conventional wisdom tells us that it is. If stigma of the kind measured in the South African surveys mentioned above is low, this may have more to do with how stigma is being measured than with an overall reduction of HIV/AIDS stigma. As the authors of these studies themselves suggest, the stigma scales used in these surveys are limited.¹ Herek and Capitanio's research, which found much higher levels of stigma in America, used a stigma scale assessing the extent of stigma in a far greater variety of ways than the South African studies under review. This included negative feelings towards people living with HIV/AIDS (PWAs), beliefs that they deserved their illness, and support for punitive AIDS policies, as well as desires to avoid contact with PWAs (Herek, 2002; Herek & Capitanio, 1993).

Studies of stigmatising attitudes and intentional behaviour such as those mentioned above do not attempt to measure actual instances of behavioural discrimination. Needless to say, the relationship between individual beliefs and behaviours is a complex one (Ajzen & Fishbein, 1980). Studies of stigma tend to measure stigma at the level of personal attitudes, beliefs and/or behavioural intentions, regardless of whether these beliefs and intentions result in discriminatory action or not. Crawford's (1996) meta-analysis suggests that greater expressions of stigma were obtained with measures of intended social interaction than with attitudinal measures. Ultimately, it is only the inclusion of behavioural measures which do not rely on self-reporting that would allow for the measurement of enacted stigma or actual discrimination.

South African quantitative studies, like international ones, generally point to one very significant correlation – the correlation between increased levels of HIV/AIDS knowledge and decreased stigma (Parker *et al*, 1992; Shisana & Simbayi, 1993). This suggests that HIV/AIDS stigma can be dealt with through appropriate education regarding the transmission of HIV/AIDS.

However, this correlation could merely indicate that most people in South Africa, as elsewhere, are now aware that discrimination is 'wrong' and want to appear more 'liberal' or accepting of HIV positive people than they actually are.

¹ Shisana and Simbayi (2003) state that, "The measures of stigma used in this study means that someone who registers as showing attitudes of stigma shows a fairly impactful form of stigma."

Research has already shown that national health education campaigns which promote the rights of people living with HIV/AIDS, as well as HIV prevention, have permeated most of South African society (Shisana & Simbayi, 2003). A growing awareness that it is unacceptable to discriminate against people with HIV/AIDS is an important step forward, but it is not quite the same thing as a real reduction in stigmatising attitudes and behaviours. If HIV/AIDS stigma has not in fact diminished but, rather, become another ‘dirty secret’, then the question which arises is how to measure a hidden truth? (UNAIDS/Measure, 2001).

The correlation between increased HIV/AIDS knowledge and decreased stigma may also be accounted for in another way. It is possible, or indeed likely, that those who stigmatise also tend to emphasise or overestimate the risks posed by casual contact. Exposure to public health education does not necessarily mean that individuals will not maintain erroneous beliefs about transmission. Certainly, people may doubt, disregard or disagree with public health information regarding low-risk or non-risk contacts provided to them by public health professionals. This is not to suggest that HIV/AIDS education does not play an important role in decreasing stigma, but rather, that access to information is insufficient to eliminate ‘false’ beliefs regarding transmission or, for that matter, to eradicate stigma.

A quantitative survey conducted in America is illustrative in this regard. In this survey, 19% of heterosexual respondents believed that, ‘a healthy man was almost sure to get AIDS or had a fairly strong chance of doing so if he had sex with an *uninfected* man, even if they used condoms. If the uninfected couple had sex without condoms, nearly half of the sample (47%) believed that one of them was likely to get AIDS’ (*ibid*, 1999: 7). In other words, almost half of the Americans interviewed thought that homosexuals, by virtue of being homosexual, transmit HIV, regardless of whether they are infected with HIV or not. Clearly then, it is not just stigma which is determined by conceptions of moral health and pollution. Even our beliefs about prevention and our assessments of risk have as much to do with moral judgement as with an understanding of physical health and disease. Ross and Levine’s (2002) qualitative study of South African university students in Cape Town also shows how closely ideas about disease transmission are linked with ideas about morality. The idea that stigma is the result of misinformation is, arguably, equivalent to the assumption that safer sex will result from knowledge of the routes of transmission. If only it were that simple. As Ross and Levine (2002: 11) point out, moral ideology is often given more weight as a preventative mechanism than the use of safer sex strategies, such that religious communities often feel ‘immunised by belief’ (cf. also Muyinda *et al*, 1997).

Stigma: What Is It?

When trying to measure something it is generally a good starting point to establish what that something is. One of the most noticeable features of the literature concerning stigma is the variability that exists in the definition of the concept (Link & Phelan, 2003). The term 'stigma' originated with the Greeks and refers to a tattoo mark branded on the skin of an individual as a result of some incriminating action (Crawford, 1996). The physical mark publicly identified the blemished and morally degenerate individual as someone to be avoided. Thus, stigma had nothing to do with illness, and everything to do with behaviour. Later, in Christian times, another layer of metaphor was added to the term, but today the term is used in its original sense, except that it is applied more to the disgrace itself than to bodily evidence of it (Goffman, 1963).

Most discussions of HIV/AIDS stigma take Goffman's work on stigma as their point of departure, and argue that a stigmatised individual is someone who is seen to possess 'an attribute that is deeply discrediting'² (Goffman, 1963: 13). This conception of stigma, which has been taken up in most of the social science research regarding HIV/AIDS stigma, has been criticised in so far as it tends to explain HIV/AIDS stigma in terms of individual psychology rather than in terms of structural social inequality. Parker and Aggleton point out that, as a result, some of the power of the sociological concept of discrimination, which concentrates on patterns of power and privilege, is lost (Parker & Aggleton, 2002). This raises the question of whether HIV/AIDS stigma differs from other forms of prejudice and discrimination and in what ways.

In their work on inter-group relations, Schneiderman and Piazza (1993) argue that the tendency to stereotype and derogate out-groups tends to be consistent so that a racist will also tend to be an anti-Semite and vice versa. We need to ask ourselves whether this is true of HIV/AIDS stigma as well. Is HIV/AIDS stigma any different from racism or sexism or anti-Semitism and in what ways? Will those who tend to derogate out-groups in general derogate PWAs in equal measure?

There are some good reasons why we might expect HIV/AIDS stigma to differ from other forms of prejudice. One of these reasons is that HIV/AIDS is an infectious disease. The line dividing in-group and out-group in the HIV equation (in other words, who is stigmatised and who is not) is porous and, by

² Although Goffman defines stigma as an "attribute", he was concerned to point out that stigma is not in fact a quality of a person, so much as a quality of a relationship. Hence the full quotation from Goffman reads as follows: "The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is needed. (Goffman, 1963, p13)

implication, constantly under threat. HIV/AIDS stigma is therefore different from other forms of bigotry (racism, sexism, etc.) in so far as HIV positive people, once infected, may be stigmatised by those they would previously have considered to be their own group. A stigmatised person is someone who is part of a group, but who has a 'spoiled identity' in relation to that group because, in some respect, s/he has become deviant or abnormal. This is what Goffman appears to suggest when he compares the kinds of stigma, like HIV/AIDS stigma, which attach to 'blemishes of individual character' and to 'abominations of the body', to what he calls the 'tribal stigma' of race, nation, religion, and increasingly, class, 'these being stigma that can be transmitted through lineages and equally contaminate all members of a family' (Goffman, 1963: 14).

Arguably, there is another difference between HIV/AIDS stigma and other forms of bigotry such as racism. Although being black may still, at this point in history, disadvantage a person relative to whites, it seems reasonable to assume that few black people themselves believe that racial discrimination is fair or just or that there is an objective or inherent disadvantage to blackness. By comparison, the disadvantage attached to the differences at stake in HIV/AIDS stigma goes beyond the stigma itself; i.e., beyond having an attribute to which a negative evaluation is attached. Regardless of whether HIV/AIDS is described as a 'terminal or 'chronic' illness, it remains an infectious disease which reduces one's life-chances and impacts negatively on reproductive options, even if stigma does not. Arguably, HIV/AIDS is not just a difference to which negative valuation *may* be attached. It is a very tangible disadvantage, regardless of whether it is stigmatised or not. Perhaps this is what Link & Phelan (2003: 2) are alluding to when they point out that, 'the term "stigma" directs our attention differently than a term like "discrimination" in so far as the stigma or mark is somehow something *in the person* rather than a designation or tag that others affix to the person'.

This may also be why most empirical studies compare and contrast HIV/AIDS stigma to the stigma attached to other terminal or life-threatening illnesses (Fife & Wright, 2000; Finchilescu, 2002). It may nonetheless be instructive to explore the relationship between HIV/AIDS stigma and other forms of bigotry, and to score respondents on social distance measures relating to race, religion and ethnicity as well as HIV/AIDS stigma. This would allow us to see whether HIV/AIDS stigma correlates with these measures of social prejudice and correlates with levels of bigotry across the board.

Certainly, it could be ideologically useful to be able to say that people who stigmatise those with HIV/AIDS also tend to be common or garden-variety bigots who discriminate consistently against all out-groups. This finding could usefully complement stigma research findings in South Africa so far, which

show that black people, poor people and uneducated people tend to stigmatise more than white or Indian people, rich and/or educated people (Shisana & Simbayi, 2002). If we are to stigmatise those who stigmatise, we may do better to identify them as bigots rather than to point to aspects of their group identity such as race or class.

Stigma: What Functions Does It Fulfil?

It is useful to consider the various *causes* or *functions* of HIV/AIDS stigma, because this shed light on what stigma is and therefore, on what it is we want to measure.

The threat of catching an incurable and potentially terminal disease inevitably means that people with HIV/AIDS present a real material threat or ‘risk’ to those who are uninfected. Stigma which is based on fear of the infectivity and the potentially terminal nature of HIV has therefore been called ‘instrumental’ stigma by social scientists such as Herek and Capitanio (1998a) who argue for a distinction between ‘instrumental stigma’, which is seen to arise from utilitarian self-interest, and ‘symbolic’ stigma, which is seen to arise from value-based ideology.³ (cf. also Bishop, Alva, Cantu & Rittiman, 1991; Jelen & Wilcox, 1992). In this regard, it should be noted that instrumental stigma may well decline in relation to the extent to which antiretroviral treatment becomes available and renders HIV/AIDS a chronic, rather than a terminal, disease (Orr & Patient, 2003; Natrass, 2003).

Clearly, however, there is a strong moral or ‘value-based’ component to HIV/AIDS stigma due to its relation to sexual activity, especially promiscuity and homosexuality, not to mention injecting drug-use (Herek & Capitanio, 1998a). Finchilescu’s research (2002) indicates that people living with HIV/AIDS are considered by South African University students to be even more culpable or blameworthy for contracting the disease than people suffering from a smoking-related disease. HIV/AIDS is perceived to be contracted, not only through voluntary behaviours, but also through immoral behaviours (Muyinda et al, 1997; Ross & Levine, 2002).

This moral component of HIV/AIDS stigma is what social scientists often refer to as ‘symbolic’, as opposed to ‘instrumental’, stigma: with the implication that

³ It should be noted that this distinction between different kinds of stigma was originally adopted from the literature regarding competing explanations for racial prejudice (Bobo, 1983; Sniderman & Piazza, 1993).

symbolic stigma is not instrumental. Symbolic stigma, on this model, is the type of stigma based on judgmental attitudes towards those perceived to have put themselves at risk of infection through immoral and/or irresponsible behaviours. Thus, symbolic stigma is manifest when people distinguish between innocent victims of HIV/AIDS, such as babies and hemophiliacs, and those who are infected through so-called 'voluntary' sexual or other behaviour (Crawford, 1996; Schellenberg & Mantler Keil, 1995; Weiner, Perry & Magnusson, 1998).

Apart from fear of infection and moral censure, HIV/AIDS stigma can be seen to stem from other sources as well. Preliminary research indicates growing resentment in sub-Saharan Africa towards people with AIDS because of the resources they expend within the household and the public health and welfare system (Moon et al, 2002). This point is well elaborated in an unpublished paper by Orr and Patient (2003: 6), who emphasize that, 'the withdrawal of support from those who are perceived as no longer able to contribute to the survival of the group' is a basic survival strategy, used throughout human history, which corresponds to the values of utilitarianism. Stigma resulting from the reallocation of resources towards those with HIV/AIDS could therefore also be considered as constituting 'instrumental' stigma as defined by social scientists such as Herek and Capitanio (1998a). This utilitarian aspect of HIV/AIDS stigma is especially pertinent to resource-poor countries with high infection rates like South Africa.

The concept of instrumental stigma is a useful one, especially if we extend it to include a resource dimension. Distinguishing two separate kinds of stigma (instrumental and symbolic), suggests that stigma which results from the concern of the 'uninfected' regarding their own material well being is related to a different set of causal factors from stigma based on adverse social or moral judgment.

But it can be argued that symbolic stigma (i.e., stigma based on moral condemnation regarding sexual behaviour) is also 'instrumental', albeit on a psychological level only. Symbolic stigma is instrumental or useful because it serves to distance the individual or group from the *fear* of infection by facilitating denial of own risk. (It will not happen to me/us because I am a good person/part of a good group of people). In other words, symbolic stigma serves to give us a sense of invulnerability and is a response to imminent threat designed to control anxiety. Clearly, symbolic stigma is counter-productive in so far as it gives us a false sense of security. However, we need to remember that it does nonetheless have a *function*. Its function is to protect us from fear and anxiety, albeit not from infection.

There is substantial research evidence to show that people always underestimate their own risk of misfortune in comparison to others (Heider, 1958). In cognitive psychology, this is called optimistic bias. We also know that people often react with censure to people who experience misfortune and attempt to locate the cause of the event in the actor. Many psychological theories explain this human tendency to believe that people get what they deserve (Walster, 1966; Lerner, 1970; Shaver, 1970). The obvious point, however, is that blame (and stigma) has a function. They make us feel safe or less vulnerable to misfortune because, unlike the victim, we have done nothing to 'deserve' it. In other words, stigma is a psychological defense mechanism which serves to control anxiety in the face of danger (Joffe, 1999). It serves the functional needs of what Finchilescu (2002: 111) calls, 'the observer at risk' by allowing him or her to minimise anxiety without the discomfort of changing his or her behaviour.

Symbolic stigma also has another obvious function. It is a basic device for maintaining social order. Thus Aggleton (2000: 9) argues in a UNAIDS report that, "stigma is a powerful means of social control applied by marginalising, excluding and exercising power over individuals who display certain traits." More specifically, the moral stigma associated with HIV/AIDS functions to reinforce social norms around fidelity and family. Because HIV/AIDS is sexually transmitted, it functions as a marker of promiscuity and other 'deviant' sexual practices which threaten to disrupt family life. The moral imperative against promiscuity in our society is not just some kind of religious remnant; it still has important social functions. Thus it is still constantly argued that promiscuity results in decreased social cohesion, fatherless children and women in poverty. With the same logic, the high incidence of HIV in South Africa may be taken as evidence of the destruction wrought on communities by the Apartheid legacy of migrancy and pass laws *to the extent that family structure was undermined*. Clearly, this argument re-enforces social norms regarding family values by suggesting that it is not just the poverty and inequality which Apartheid facilitated and entrenched, but also the breakdown of family structure, which should be seen to account for high levels of HIV/AIDS in South Africa.

If symbolic HIV/AIDS stigma has a fundamental social function then this may be why the logic of morality in the 'A' and 'B' of the ABC prevention campaign (as in 'Abstain', 'Be Faithful') as a *primary* means of HIV prevention (as opposed to the 'C' for 'Condomise') is so convincing and enticing, not only for religious leaders, but also for community and political leaders whose primary goal is to maintain social order - as opposed to bio-medical scientists and epidemiologists whose primary goal is to maintain public health.

As already noted, Parker and Aggleton (2002) argue that in adopting the psychological term 'stigma' and locating it in relation to the psychological

process of denial – as an individual process or behaviour – the way in which stigma functions like any other form of social prejudice, as a process for establishing relative power, privilege and social control, is occluded or lost from sight. Indeed, there is little doubt that HIV/AIDS stigma plays into virtually all of the key axes of structural inequality present globally: class, gender, sexual orientation, age, race and ethnicity. However, what needs to be recognised is that this function of stigma is operationalised through a manipulation of the psychological defence processes implicated in denial. In other words, it is dependent upon the operation of ‘symbolic’ stigma. It is for this reason ‘symbolic’ stigma is not only just as functional as ‘instrumental’ stigma, but that it appears to have a dual function.

The causes of stigma have been described in some detail to show that if HIV/AIDS stigma persists across time and culture, then this is because it is instrumental and useful for many reasons. It is *not* simply the result of inadequate knowledge or faulty cognitive processing. Stigma cannot be addressed solely by giving people true facts about risk, because people are not motivated by the need for true information about risk alone. We are also motivated by the desire to represent risk in a way that suits and protects us at both an individual and group level.

But, more importantly, the functions of stigma have been outlined because this shows the variety of issues at stake in HIV/AIDS stigma which need to be distinguished if stigma is to be properly conceptualised, let alone identified, measured and, most importantly, addressed.

Stigma: Can We Measure It?

The difficulty of measuring a hidden truth has already alluded to. People are not generally willing to admit to total strangers that they hold discriminatory attitudes. In this regard, education regarding the need for tolerance may not be diminishing stigma but, rather, transforming the forms it takes and/or the willingness to report it. It is extremely difficult to find indicators of stigma which are reliable. Specific examples are useful to show why measuring HIV/AIDS stigma is not as easy as it may seem.

Opposition to government policies which benefit people with HIV/AIDS, such as welfare grants or anti-retroviral therapy for people with AIDS, is not, in itself, proof of stigma. As we know, especially from the current anti-retroviral debate in South Africa, disagreements about how to deal with those who are infected *may* represent a principled difference rather than bad faith or antipathy or discrimination per se (Marseille & Hofman, 2002; Natrass & Geffen, 2003).

This shows that it is only if we know the reasons for a person's answer to many of the questions considered to be indicators of stigma, that we can be sure that it is in fact stigma that we are measuring.

Measuring stigma in the personal realm is also difficult. In many cases, stigma in the (much less easily regulated) sphere of interpersonal relations may not be the result of denial or of devaluing people with HIV/AIDS at all, but rather the result of valid or misguided fears of infection. In cases where fears of infection are simply erroneous (a consequence of ignorance), AIDS education regarding transmission can go a long way to eliminating stigmatising behaviours. However, it must be noted that there are in fact stigmatising behaviours which do *indeed* protect us from infection.

Once again, an example is illustrative in this regard. Most people, including many public health practitioners, do not think that declining a romantic date or refusing to have sex with an HIV positive person *because s/he is HIV positive* is morally wrong. In fact, this is considered to be the only sensible thing to do by many people, *despite* the fact that this is a blatant form of behavioural discrimination. It could be argued that such discrimination, albeit unfair, is not caused by stigma but by a realistic assessment of personal risk, both physical and/or emotional.

This raises the question of what kind of stigma it is that we really want to measure. It seems to include only those activities which are deemed to be *unnecessarily* prejudicial (i.e., irrational), whereas self-protective behaviours which are considered to be rational (in our best interests) are considered to be acceptable and indeed desirable, even to many of those involved in the project of eradicating HIV/AIDS stigma.

This second example (of sexual discrimination) highlights another of the complexities raised by HIV/AIDS stigma. In the private sphere 'personal choice' prevails, and putting oneself and one's needs first *is* acceptable. It is only in the social sphere of public policy, that equality, or the semblance of it, is required to ensure social cooperation. But, while the decision not to sleep with an HIV infected person is a justifiable health-choice from an individual perspective, it is *not* a desirable option from a public health perspective because it mitigates against disclosure of infection, drives HIV infection underground and undermines prevention objectives (Link & Phelan, 2003; Mann, 1987). Clearly, if people are choosing *not* to test, and those who do test are not disclosing, then this is not just because they do not want to get murdered like Gugu Dlamini, or thrown out of school like Nkosi Johnson, but because they also want to enjoy the right to romantic love.

This raises the question of *why* we are measuring stigma and how this influences what we measure.

Stigma: Why Are We Measuring It?

If there is an ongoing global call for research about HIV/AIDS stigma, this is not only because the global public health research community cares about the contravention of human rights principles and the well-being of people with HIV/AIDS. It is also because HIV/AIDS stigma undermines prevention efforts and is therefore counterproductive from a public health perspective. While one can often identify race or disability, an HIV positive person is not visible as such. It is largely for this reason that HIV/AIDS stigma constitutes a public health threat. HIV can be hidden; it has the capacity to go ‘underground’ where it cannot be found (through voluntary testing and counselling), prevented (through safer sex) and controlled (through treatment and containment). The need to measure and address HIV/AIDS stigma is thus commonly expressed by researchers such as Herek *et al* (1998b: 4) in a manner which emphasizes the fact that stigma ‘interferes with effective prevention efforts’:

‘Fears of stigma represent an impediment to disclosure by PWHIVs of their serostatus to others, including sexual partners, which can interfere with effective risk reduction....fears of HIV/AIDS stigma can deter people at risk for HIV from being tested and from seeking information and assistance for risk reduction. Delays in testing increase the likelihood that infected individuals will transmit the virus... Internalized stigma and fear of stigma from others may be associated with adverse responses to receiving a positive HIV test result which, in turn, may increase the likelihood of continuing behaviours that transmit HIV’ (Herek et al, 1998b: 4).

Another dilemma around stigma, from a public health promotion campaign perspective, is the ambivalent position of sexual morality as a HIV/AIDS prevention tool. While sexual morality (as in ‘Abstain’, ‘Be Faithful’) serves prevention goals to some extent, it also undermines this goal because it results in the stigmatisation of those who do become infected (Joffe, 1999). Thus, the ABC prevention campaign (Abstain, Be Faithful, and Condomise *as a last resort*) may have left us with *more* stigmas rather than less, despite increases in risk-related knowledge. As previously mentioned, a survey comparing stigma before and after the first British AIDS education campaign showed that, while knowledge had increased, self-reported behaviour had not changed, and blame of those infected had increased (Department of Health and Social Security and the Welsh Office, 1987).

If society as a whole has a profoundly ambivalent relationship to symbolic (i.e., moral) stigma, then this is because it is and has always been instrumental to social control. We need to ask ourselves why it is that drug-use and commercial sex work remain stigmatised and underground (indeed, criminalized) in most modern societies, despite the fact that – like HIV/AIDS stigma - this is arguably counterproductive to public health. Or from another angle, we could ask ourselves why the stigmatisation of obesity is not a huge public health issue despite the human anguish and suffering *this* causes.

There can be little doubt that we as researchers in the field of HIV/AIDS are being asked to look at HIV/AIDS stigma primarily from a public health (prevention of infection) perspective and that this determines our understanding of what stigma is and of how to go about measuring it, understanding it, and addressing it.

Concluding Remarks

It may well be impossible to overcome all of the conceptual and methodological limitations inherent to quantitative survey research on HIV/AIDS stigma. It seems likely that it is not just HIV/AIDS infection, but HIV/AIDS stigma as well which has become a ‘dirty secret’. However, if it turns out to be true that HIV/AIDS stigma is indeed diminishing, then it will be extremely interesting to see whether this trend continues and if so, how and why – given the very good reasons people have for stigmatising those with HIV/AIDS that have been outlined. Not to mention the obvious difficulties inherent in communicating the necessity for safe sex without implicitly blaming people with HIV/AIDS for their situation. Needless to say, if it turns out to be true that HIV/AIDS stigma is indeed diminishing, then it will also be time for great rejoicing. Hopefully, the increased availability of antiretrovirals, which turns HIV/AIDS into a chronic, rather than a terminal, disease, will contribute substantially to the decrease of stigma in South Africa, as elsewhere.

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The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.
