Internal Stigma and AIDS

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Introduction

1. It is a pleasure to be with you this evening, and a particular honour to be asked to deliver the keynote address at this distinguished conference.

2. This evening I want to talk about one of the most perplexing and elusive phenomena in the HIV epidemic. It is the concept of internalized stigma.

3. HIV was first reported in the morbidity and mortality weekly reports (MMWR) of the US Centers for Disease Control in May 1981 – just over 31 years ago.¹

4. From its very inception the chief feature of the political, social and medical response to the disease has been stigma.

5. President Ronald Reagan, who held office in the US as the epidemic became a deathly nightmare in the gay male communities of the east and west coasts, refused even to mention the word “AIDS” until 1987.² His silence was seen as a judgment – one condemning the gay men, who were falling sick and dying in their tens of thousands, because they deserved it.

6. In our own country, the stigma has also stalked the political management of the disease.

7. President Nelson Mandela – though for reasons very different from those of President Reagan – also remained mute about the disease, as its toll rose under his presidency. He first mentioned the word “AIDS” in February 1997, nearly three years after he had taken office. And he did so in a speech outside SA – at the World Economic Forum in Davos, Switzerland.

8. His successor, President Thabo Mbeki, refused to accept that AIDS was a disease caused by a virus that was sexually transmitted. He castigated western medical scientists, doctors and epidemiologists for propounding that a mass, heterosexually-transmitted, epidemic of AIDS existed on the African continent, alone.

9. But President Mbeki’s disastrous and tragic misconceptions themselves rested on stigma – the idea that it was shameful to have a disease with sexual vectors in Africa. He even told opposition leader Tony Leon in July 2000 that the assertion that AIDS originated in Africa was “insulting”.

The Phenomenon of Stigma and AIDS

10. The phenomenon of stigma is well understood and lavishly described in the AIDS literature.

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3 Offeiba Quist-Arcton, “South Africa, Mandela Deluged with Tributes as he turns 85”, AllAfrica, 19th July 2003
4 President Nelson Mandela, Address at the World Economic Forum Session on AIDS, Davos, Switzerland, 3rd February 1997
5 Dr V Murphy, ‘Mbeki stirs up AIDS Controversy’, BBC News Online, 23rd September 2003
6 President Thabo Mbeki, ‘Lies have short legs’, ANC Today, May/June 2005
8 Mahajan et al, “Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward”, AIDS. 2008 August; 22 (Suppl 2): S67 – S79 at p.5, citing Link and Phelan: “stigma exists when the following four interrelated components converge: 1) individuals distinguish and label human differences, 2) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes), 3) labelled persons are placed in distinct categories to accomplish some degree of separation of “us” from “them”, and 4) labelled persons experience status loss and discrimination that lead to unequal outcomes.”
11. Classically, stigma is a mark of disgrace placed upon a member of society because of an unacceptable feature or trait or behaviour. Stigma is disapproval, condemnation, judgment, rejection, ostracism and abandonment. It is an attitude of devaluation that manifests in a social process, and is exacerbated by class, gender, sexual and racial differences.

12. In its enacted manifestation, stigma is discrimination and ostracism.

13. Its external manifestations are widely documented. This is because their effect is so real – they can be easily perceived and easily described.

14. In addition, enacted or external stigma can be socially countered. One can enact laws and pass resolutions and adopt policies against discrimination and ostracism.

15. What is far more insidious, and much more difficult to describe, is the internalized dimension of stigma.

16. In all the vast literature that has arisen in the AIDS epidemic, relatively little attention is given to internal stigma, and some of that attention exhibits basic misunderstanding of its nature and operation.

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9 Parker & Aggleton, “A conceptual framework and basis for action: HIV/AIDS stigma and discrimination”, UNAIDS, World AIDS Campaign, 2002-203 at p.8: “Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatization therefore describes a process of devaluation rather than a thing.”

10 Parker & Aggleton, “HIV/AIDS-related Stigma”, Horizons Program, Population Council in Collaboration with the International Center for Research on Women, International HIV/AIDS Alliance, Program for Appropriate Technology in Health, University of Alabama and Tulane University, 2002 at p.9: “Social and political theory can help us to understand that stigmatization and discrimination are not isolated phenomena or the expression of individual attitudes, but are social processes used to create and maintain social control and challenged by social action” [emphasis added]

11 Roura et al, “Just like fever: a qualitative study on the impact of antiretroviral provision on the normalisation of HIV in rural Tanzania and its implications for prevention”, BMC International Health and Human Rights, 9th September 2009 at p.2: “Drawing from the conceptual work of Deacon, we understand stigma as a culturally constructed and constantly changing social process, through which people project blame onto “out groups” in an emotional response to perceived danger”; see also Edwin Cameron, ‘Moving from Promises to Actions”, XVII International AIDS Conference, 6th August 2008 at [20]

12 Greeff et al, “Experiences of HIV/AIDS Stigma of Persons Living with HIV/AIDS and Nurses Involved in their Care from Five African Countries”, Afr J Nurs Midwifery, 2008; 10(1): 78-108 see pp.79-81 and itemization of: (i) internal stigma, (ii) received stigma and (iii) associated stigma.

13 For example, in the article at fn.11 it is stated that: “Malcolm, Aggleton and Bronfman (1998) stated that perceived or “felt” stigma often precedes rather than results from the experience of stigma. They claim that many individuals reduce the opportunity for “enacted” stigma in order to protect themselves from discriminatory actions”. This must be wrong. There can be no internalization of a non-existent phenomenon.
17. The result is a gaping omission – internalized stigma forms virtually no part of individual, professional or programmatic responses to AIDS.

What is Internal Stigma? 14

18. Internal stigma is the individual’s internal appropriation of the fear, rejection and condemnation with which many react to AIDS. In some of the literature, it is wrongly grouped together, or confused with, perceived, experienced, anticipated or “felt” stigma 15.

19. Internal stigma is not the same as apprehended stigma. It is not the fear of others’ condemnation – but the appropriation, internalization and self-enactment of that condemnation. 16

20. It is therefore more revealing of the motive dynamic of internal stigma to speak of “internalized” stigma.

21. Internalized stigma are self-disabling inner feelings of contamination, shame, self-rejection and self-loathing experienced by people with HIV, and those who fear they have HIV, even when there is no objective reason to fear rejection or discrimination, and even when there is good objective reason to believe that they will receive external support, protection, treatment and acceptance.

22. Internalized stigma has its most pernicious operation when the subject knows, cognitively, that he or she will receive support and acceptance. 17

The source of internal stigma must be external discrimination and prejudice, though this is later appropriated and directed inwards. To say that one feels anticipated stigma, rather looks like blaming the victim. And, one might ask – “anticipation of what?” The answer must be external prejudice. Therefore, whilst an individual may fall into internal turmoil before being the direct subject of a comment or injurious remark – that is not the same as saying that felt stigma precedes external stigma. One cannot deny the source of internal stigma is the external prejudices expounded and manipulated by a society. 14

15 Greef et al; Hasan; Sengupta; MacPherson; see also Parker & Aggleton (May 2002) who refer to internalized stigma as “fear of HIV/AIDS-related stigma and discrimination”
17 Ibid at [31]
23. It is not merely external, or enacted, stigma that constitutes an impediment to the effective management of the AIDS epidemic. It is also internalized stigma.

24. Many people with HIV, or at risk of it, feel overwhelming dread at discovering that they are infected with a socially reviled virus.

25. This dread is often stronger than a cognitive appreciation that friends, family and colleagues will support and accept them. It is stronger than the knowledge that life-saving treatment is now available. And it may even be stronger than the individual’s capacity to make life-saving choices.

26. Internalized stigma is a dread of HIV that may have its origin externally – but it is located not in others, but within the self.

27. It is the most intractable part of stigma. It is more insidious, and more destructive, than external stigma for it eludes the direct, politically-conscious confrontation with which we rightly respond to overt discrimination.

28. In my memoir, *Witness to AIDS*, I try to grapple with this internal dimension of stigma. I speak of my own horror and dismay when in 1986 I discovered I had HIV. Although working at a human rights public interest law centre, surrounded by rights-defending comrades, so deep was my sense of self-revulsion that I felt entirely incapable of accessing their solidarity and support. It was impossible to say a word to them – or to anyone else.

29. I write of how the external stigma of AIDS – the fear of others’ often-real adverse reactions – all too often finds an ally within: an ally that rejects health-affirming choices in favour of paralysed inaction, postponement, delay, denial and death. I suggest that we fail to understand stigma fully if we concentrate solely on its external manifestations and causes, and neglect the inner dimension that may be altogether more deadly.

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18 [www.witnessstoaid.org](http://www.witnessstoaid.org)
30. I write, also, of a man from Zimbabwe who worked for me as a gardener: a quiet, gentle man, who knew full well that I had HIV, and that I had survived AIDS because ARV treatment had saved me – and who knew, also, that if he had HIV I would secure treatment for him.

31. Despite this knowledge, my gardener, while visibly wasting away from what everyone ‘knew’ was AIDS, repeatedly denied that he had HIV or that he was sick with anything more than TB. He ultimately returned to Zimbabwe to die what must have been a lonely and medically-untended death.

32. The story in my book is told in self-reproach. The point I make is that I should have been more pro-active in helping my gardener ascertain his HIV status; that I should not have left him to the isolation and loneliness of his own fears. I should have done more to insist that he be tested and diagnosed and treated. I should, through my external actions, have created a bridge for him to cross over the perilous rapids within that were preventing him from accessing medical diagnosis, care and treatment.

33. But the point of the story is broader. It is that our failure to grapple with and understand the internalization of stigma is impeding our understanding of the epidemic. It is costing us lives.

34. We are now in what epidemiologists call “a mature epidemic”.19 This means an epidemic in which everyone knows someone who has died of HIV. The consequence is that stigma abates.

35. Despite this, the story of my gardener is still being replicated today.

36. Although South Africa has the world’s biggest publicly-provided ARV treatment programme, Statistics SA estimates that there were still more than 281,404 AIDS deaths in 201020 (this is down from the UNAIDS estimate of 310,000 AIDS related-deaths in 2009).21

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37. Some of these deaths would have been due to inaccessibility of medical care or the unavailability of treatment.  

38. But too, too many of them are also due to fear. Fear not outside – but fear appropriated and enacted inside. Fear, propelled from within, that avoids diagnosis, testing, disclosure and treatment. Fear that eludes loving and supportive colleagues, friends, neighbours and family. Fear unto death.

The Puzzle of Internalized Stigma

39. The non-description, or mis-description, of internalized stigma in the literature of AIDS is the more puzzling because the phenomenon is well-known in other settings.

40. The “self-hating Jew”, the “self-loathing gay man” are readily recognisable constructs of the psychological and other literature.

41. In South Africa’s vile past of racial hatred, Steven Bantu Biko recognised that the stigma of racial subordination had an internal impact that had to be eradicated first, if notions of white superiority and black subordination were to be effectively overcome.

42. Indeed, the founding analysis of stigma, that by Erving Goffmann in 1963, itself recognises that “the social label of deviance compels stigmatised individuals to view themselves...as discredited or undesirable”.

43. Why has internalized stigma been so hard to see and to understand in the AIDS epidemic – when its effects are so profound? I think there are a number of reasons.

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22 Ibid statistics show that in 2008, there were 524,000 people in need of treatment who did not receive any
23 Lessing, Der Jüdische Selbsthaß, Berlin 1930, Jüdischer Verlag
24 In a statement attributed to him in the Boston Globe of 25th October 1977, after his death, black consciousness activist Steven Bantu Biko said, “We know that all interracial groups in South Africa are relationships in which whites are superior, blacks inferior. So as a prelude whites must be made to realize that they are only human, not superior. Same with blacks. They must be made to realize that they are also human, not inferior.”
44. First, it is easy to condemn the condemner, the discriminator, the excluder. With external stigma we have a perpetrator and we have a victim. The villain is easy to see.

45. By contrast, with internalized stigma, we have only a victim. A search for a perpetrator seems, unsettlingly, to lead to blaming the victim.26

46. And, indeed, blaming the victim of internalized stigma would replicate the very experience of self-condemnation, self-disentitlement and self-disablement that are its operational effects.

47. A second reason may be that it is harder to detect and discern. The operation of internalized stigma consists in self-disablement, and therefore in inaction or omission (avoidance of testing, care, treatment).

48. Hence it is harder to detect. It is an internal phenomenon and deeply elusive.

49. A third reason may be that we shy away from internalized stigma because we wouldn’t know what to do with it when we found it. It is so intractably difficult to address that we run away from it.

How Internalized Stigma Operates

50. Internalized stigma is deadly because it incapacitates health-seeking choices. Even when diagnosis, care and treatment are available, they become not only unattractive, but unpalatable, because they require an embrace, by the self, of a condition that is internally reviled.

51. What is the practical significance of all of this? I think it is three-fold.

52. First, we need to speak up for internalised stigma. It has been a poor, neglected and shabbily treated player in the drama of AIDS. We need to accept that it exists to understand its psychological operation and to appreciate its impact on volition.

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53. Second, understanding internal stigma has a dramatic impact on the management of the individual patient/health-carer relation.

54. To understand this, we must understand the history of the AIDS epidemic and the inextricable role of stigma in it.

55. Because AIDS affected largely the vulnerable, the marginalised and the dispossessed (gay men; sex-workers; the poor of Africa), and because those with HIV in these groups were blamed for their own condition, it became imperative for the effective public management of the disease to introduce special measures. These included special anti-discrimination measures for those with HIV. They also included special measures inhibiting ordinary physician-patient protocols and procedures.

56. Thus, it became unacceptable to test a patient for HIV without obtaining consent that had to be both express and specific.

57. It became impossible to recount to others that someone had HIV because the stigmatising fall-out was almost invariably so high.

58. The necessity for human rights protections for those with and at risk of HIV was called “the AIDS paradox” – the recognition that protecting the rights of those with the disease was not inimical, but complementary to, effectively containing the epidemic.

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27 Turan et al. “The Role of HIV-Related Stigma in Utilization of Skilled Childbirth Services in Rural Kenya: A Prospective Mixed-Methods Study”, *PloS Medicine*, August 2012 at p.11: “…women of low socio-economic status fear bad treatment at health facilities. For example, pregnant women explained that health workers often treated impoverished patients harshly and that facility-based delivery was more appropriate for richer, educated women.”

28 Turan, *ibid*, at p.10: Account of Pregnant Woman 9: “[Women] don’t want anyone to find out that they are sick. Instead they want to be known as good people. If people find out that she has that disease then they will say that she was a prostitute, the kind of person who will have sex with someone whenever she goes to the market or goes to run an errand.”


30 Michael Kirby, “Law and HIV: A Paradoxical Relationship of Mutual Interest”, *Law and Justice Foundation of New South Wales*, speaking at the IUDVT World STD/AIDS Congress, 22nd March 1995: “By a paradox, one of the most effective laws we can offer to combat the spread of HIV which causes AIDS is the protection of persons living with AIDS, and those about them, from discrimination. This is a paradox because the community expects laws to protect the uninfected from the infected. Yet, at least at this stage of this epidemic, we must protect the infected too. We must do so because of reasons of basic human rights. But if they do not convince, we must do so for the sake of the whole community which has a common cause in the containment of the spread of HIV”
59. Coercive measures were recognised as not just needlessly punitive; they put the very public they were designed to protect at unnecessary risk of further infection by driving those with HIV away from diagnosis, counselling and behaviour change.

60. But this paradox led to a further paradox. The protections in the health care setting for those with or at risk of HIV were designed to protect. They were designed for a world in which there was only temporary palliation for AIDS, and in which nothing could be done to halt inevitable decline and death.\(^{31}\) The pre-dated treatment.

61. But that has all changed. Treatment is now available. And it works. It is relatively easy to administer, side effects are being minimised, and the number of tablets and the frequency with which they have to be taken are being reduced.

62. My own life has given me joyous opportunity to celebrate this. Fifteen years ago, to this month, in September 1997, eleven years after my diagnosis with HIV, I was dying of AIDS. I would, had treatment not been available, surely have been dead by mid-2000.

63. Instead, I started on ARV treatment in November 1997. Within weeks I knew that the medication was working. My energy, my life force and my vitality returned. My appetite became ravenous. My will to work and to exercise were resurgent. I have not looked back.

64. The last time I had a detectable viral load was in October 2000 – 12 years ago. For more than a decade, no instrument of science or medicine has been able to detect the virus itself in my body. All this while I feel privileged to lead a bountifully full, energetic and productive life.

65. Now, rather than protecting the patient against inevitable stigma and discrimination, inhibitions on diagnosis and treatment have the opposite effect. They can only increase suffering and hasten death.

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66. It is for this reason that I have become convinced that, in the Southern African epidemic conditions, the medical community must step far outside the traditional boundaries of HIV testing. It must be actively **directive, interventive and prescriptive** in urging patients to test for HIV and to obtain treatment.

67. In the setting of our epidemic, it has become the physician’s duty to assert his or her hierarchical power and authoritative command in exercise of the duty of beneficence.

68. This is because without direct external intervention, all too many people with or at risk of HIV are too scared to be tested and diagnosed.

69. The physician in these circumstances becomes duty-bound to help overcome the patient’s internalization of self-disabling condemnation and stigma.

70. This has two implications – one for the patient and one for the physician.

71. For the patient, it implies an invocation of and reliance upon medical beneficence when diagnosis is overwhelmingly likely to lead to life-saving treatment.

72. For the physician, it implies a caring conquering of his or her own fears, misconceptions and condemnations in relation to HIV and AIDS. It means that health-carers must actively recognise, address and overcome their own stigmatising conceptions of HIV and AIDS in dealing with their patients.

73. At present, what is happening is that all too often a collusive resonance arises between the patient’s internalised condemnatory fear of diagnosis,

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and the physician’s partly-stigmatising fear of overcoming it and thus encountering HIV.  

74. For the doctor/patient management of the epidemic, recognising and understanding internalised stigma therefore entails a revolution.

75. It has been one that some of my human rights comrades have been slow to embrace.

76. Too many have clung to outmoded and inappropriate inhibition on physician-initiated or encouraged testing.

77. Too many have fought against medical technology, like rapid tests, or self-testing kits, that would help disseminate HIV diagnosis rapidly and widely – and empoweringly – in the hands of patients themselves.

78. But, third, and lastly, recognising internalized stigma should entail also a revolution in the public management of the disease.

79. It is not enough for the public management of the epidemic to recognise and seek to counter external manifestations of stigma. The self-disabling internal workings of it must also be recognised and countered.

80. This means that public messaging should address the fact that people blame themselves for HIV and incapacitate themselves from seeking help and health.

81. This task can partly be undertaken by diminishing the external sources of stigma that are the source of internalized stigma. There has been

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34 See Gillon, “Refusal to treat AIDS and HIV positive patients” Br Med J (Clin Res Ed). 1987 May 23; 294(6583): 1332–1333: “Doctors are occasionally to be heard arguing that drink-drivers should not be treated, and that smokers should not be treated, and that attempted suicides should be left to die...The norms of withholding medical treatment simply do not include moral disapproval by the doctor of his patient’s lifestyle or actions.”

35 See Brazier and Lobjoit, “AIDS, ethics and the respiratory physician” Thorax: An International Journal of Respiratory Medicine. 1990 April; 45(4): at p.286: “Testing without counseling, unless done anonymously with the patient’s consent and knowledge, is a clear breach of the duty of care...Patients with AIDS today bear burdens not shared with any other sick members of the community. Their autonomy is threatened in the name of safeguarding that community”

significant progress in addressing the external manifestations of stigma by way of training, advocacy and community out-reach programmes.

82. In addition, the fact that we are in what I called earlier a “mature” epidemic, together with the widespread availability of treatment, and the increasing knowledge that it words, have helped diminish stigma.

83. But still the effects of internalized stigma operate. An attorney who is a close friend recently told me the tragic story of his sister who died of AIDS in a remote village in KwaZulu-Natal, even though he encouraged her to seek and take treatment, and offered her unqualified love and support in doing so.

84. Hence the reduction of external stigma is not enough. The public management of the disease must recognise that, uniquely, AIDS inflicts an internal burden that is costing lives and causing immense suffering.

85. The public message should be, not only that you can live healthily with HIV, but that those with and at risk of HIV are not alone; that their internal fears are real and can operate brutally; but also that they can be overcome.

86. I do not pretend that this is an easy message to proliferate – or even to articulate.

87. One of the difficulties is that the perils of blame and exceptionalism do not lie far from our good intent. However, the correct articulation of the phenomenon the patient faces, in conjunction with the reassurance that this is a common and understandable feeling, which can be addressed and treated, is of urgent significance.

88. The message – “You are not alone” is pivotal because the patient feels a self-disabling assortment of feelings “loneliness”, “shame”, “isolation” and “stigmatisation”.

89. But we must beware of a risk – the risk that to articulate those notions to the patient could serve to augment and intensify those very emotions. To
tell the person with or at risk of HIV – “you feel isolated”, “you feel ashamed” – may only give external definition to a tacit internal turmoil.

90. The message should therefore not over-dramatise the feelings the patient experiences, but must seek to reassure and counsel against those feelings.

91. Learned members of the medical profession should give medical and academic credence to the particularities of internal stigma.

Conclusion

92. The story of stigma in AIDS is a story of human fear and fallibility. And the role of stigma in that story is the same as with any form of irrational blame, rejection or condemnation.

93. It can be fearsome and intractable. It was stigma that led to the gas chambers of Auschwitz, and to the Rwandan genocide of 1994.

94. But what is hopeful about ignorance, fear, prejudice and hatred is that they are conditions of the mind. And all conditions of the mind can be made subject to change – immediately.

95. Internalised stigma is more difficult to address not only because it is less visible but because its object, and therefore its victim, is the self.

96. We do ourselves a disservice, however, when we fail, in addressing any of the complex social burdens we carry that are exacerbated by externally or internally directed fear or hatred, to recognise them and to tackle them.

97. Your profession concerns itself with agonies of the mind. You, assembled here, have probably seen more human anguish and suffering than lawyers in my position see. Medication and prescription drugs have an important role to play in relieving human distress.

98. But understanding the complexity of our own external and internalised thought-processes is an indispensable part of the remedy.