

Stigma and HIV – Time for a New Paradigm?

Ian Hodgson, PhD*

Independent Consultant in Global Health, UK

Abstract

Stigmatizing people with certain illnesses is a constant and damaging social behaviour. In particular, people living with HIV have experienced discrimination and ostracism since the beginning of the epidemic in the 1980s. Its prevalence has led, in the HIV sector, to a plethora of literature, toolkits, reports, and conferences to the point where the demarcation between those who do not stigmatize (the good – people who work in the HIV sector) and those who do (the bad – everyone else) is clearly established. This paper proposes an alternative view (the ugly?), that stigma is a generic characteristic of the human condition, and to truly understand the phenomenon, we should look to ourselves and deconstruct our own tendencies to stigmatize. We may have more in common as a society than we like to admit.

Keywords: culture, history, society, stigma

Background

Reinforcing the fear of disease was a prejudice against strangers and all their strange ways.

George Stewart, *Earth Abides* (1949, p. 277).

Stigma is predicated on the identification of ‘them’ and ‘us,’ and is, for good or bad, part of the human condition. The stigmatization of people living with HIV, often accompanied by discrimination, has been a common feature of public responses to the virus since the early 1980s. Reactions range from simple avoidance, to violence, and murder. Programmes supporting people living with HIV in both developed and developing countries are chock-full of initiatives to address stigma and mitigate its outcomes, reported to include lack of healthcare access (affected people are too scared to attend for testing and treatment), poor employment prospects (employers are too scared to hire people they perceive as dangerous, or in poor health), and community rejection (friends and neighbours are too scared to be in close proximity to what is thought a highly contagious disease).

*Corresponding author: Dr. Ian Hodgson, 2 Angel Place, Bingley BD16 4TT, UK.
E-mail: ian@ijhodgson.co.uk

People working in the HIV sector exhibit constant surprise and outrage that others, through their ‘ignorance,’ stigmatize people living with HIV. Ironically, the very separation between those who do not stigmatize, and those that do, illustrates a core characteristic of stigma – constructed social space. Narrow definitions of stigma, as a product of limited understanding, poor empathy, and lack of imagination, are flawed. This paper argues that it is only by deconstructing our own tendency to stigmatize that we can understand its true nature. An alternative view is proposed; that the proximity between liberal and reactionary tendencies could be closer than we think.

Away with Them: They Infect the State

We naturally generate our social world along a continuum, between people similar to us and those whom are different. In many instances, this is a helpful method of creating a rapid mental picture of our networks. At other times, or when we cluster in groups to construct a collective continuum, there is potential for harm. This is the basis of stereotyping, another common tool for arranging our social world, but one that leads to prejudice.

Running a workshop on stigma recently, for HIV support workers associated with NGOs, this writer suggested an exercise (part of a toolkit designed by

Ross & Clay, 2007), where participants share an experience of being stigmatized. Delegates reeled off a range of unpleasant scenarios. The second part of the exercise asked participants to share a situation where they stigmatized someone else. This was not so easy, and many seemed shocked at the very idea – workers in this field are, by tradition, politically and socially liberal. Gradually, there came a slow realization. Yes, they had stigmatized someone – marked them as different, tagged with attributes that may or may not have been accurate. It could have been someone unsympathetic to their cause, or in a different social class, or simply representing a social group with whom they had limited experience.

Recognizing their tendency to stigmatize was a Damascene moment for many delegates. They now understood some of the mechanisms underpinning negative responses to topics they, as HIV specialists, considered sacred, such as sexual harm reduction, accepting uncommon sexual activities, and rational approaches to HIV transmission. Much learning took place.

For Sontag (1991, p. 42), *[all] societies need to have one illness which becomes identified with evil, and attaches blame to its victims*, and the fact some diseases are seen more negatively than others is certainly not new. Many narratives – ancient and modern, fact and fiction – describe the casting out of lepers, incarceration of the mentally ill, unease when interacting with hospice workers (they carry death), or distrust of immigrants because of their alleged transport of infections. Indeed, the notion of attributing ‘dirt’ and ‘contagion’ to unpopular social groups is an early predictor of discrimination, and sometimes genocide, as shown with Jewish communities in Europe during the 1930s (Kershaw, 1998), and the *Hutu* referring to *Tutsis* as cockroaches (*inyenzi*), prior to the Rwandan genocide of 1994 (Gourevitch, 1995).

This conflation of social and physical attributes is a powerful part of our cultural architecture; disease is often used as a way of evaluating adherence to collective morality. Certain ailments, such as syphilis in Ibsen’s *Ghosts* for example, represent not just pathology but moral corruption as infectious as the disease itself. The sins of the fathers are visited on the sons.

Reasons to be Fearful

Whilst there is no doubt that people living with HIV face significant stigma, the root of this – the nature of the continuum generating distance – can be explained readily. Stigma, like HIV, is not especially complicated, though its cluster of causes can lead to misunderstanding. First,

negative responses can be from fear of being infected. General understanding of how HIV spreads is poor at best (it is actually hard to catch). Most people accept the sexual route, but HIV’s association with other bodily fluids adds a frisson of confusion. This narrative is complicated through news about saliva tests to detect the virus (so it is in our mouths!), risk of transmission between injection drug users from infected blood left in a shared needle, the long lists of ‘banned’ activities excluding certain users from blood donation, or reports – in the early days at least – of the recipients of transplanted organs being infected through poor screening. People tend to have imprecise knowledge of HIV transmission, and overestimate risk when it may be low, and vice versa. Mosquito bites for example pose no risk; a single needle shared with an HIV-infected injection drug user carries a 30% chance of transmission.

Deserving Pathologies

If HIV stigma was simply the product of a lack of information, then a series of teaching programmes in affected regions would soon solve the problem. However, though cognitively we may believe in methods of disease transmission, emotionally there are other factors that shape responses. This is where the second factor driving HIV stigma is found – the social construction of illness. Medical anthropologists confirm that disease and illness are discrete entities. Disease is diagnosed by the ‘expert’, and illness by the ‘lay person,’ who adds fundamental questions: why me? Where did this come from? Am I bewitched? What will happen? Will I die? Importantly, there are personal characteristics associated with illness – people, through *moral attribution*, attribute blame for the misfortune of others, a form of *schadenfreude*. This provides a conveniently protective mechanism to reduce any fear that *we* may succumb in future to the same illness. Here, we see again a social process generating distance, and in regions with a focused HIV epidemic (where the virus manifests within specific social groups), stigma is used as an additional weapon against already unpopular groups. We see evidence in early negative reactions to Western gay communities.

If there is no immediate, visible category (sex worker, gay, or drug user for example), then a new one is created. There is desperation to find some reason that *they* were ‘chosen’ to have this virus. In communities with generalised epidemics (where all groups are equally affected, the extant model in most developing countries), this manifests in a focussing much more on behaviour – they must have done *something* wrong. We are back to moral attribution. Creating difference and space, between others and us, is the greatest challenge

to effective public health. If people think they are essentially different from those with HIV, how can the notion of generalised risk through sexual activity be promoted? Should I use a condom? No, because I am not like *them*.

Story-Ville

Arbitrary interpretations of illness are 'lay explanatory models', underpinned by stories – cultural narratives – reinforcing social constructions not just about illness, but also cultural identity. For example, narratives of distance are common to many civilisations and some (though not all) scholars regard the strict regulations on food throughout the Old Testament as not simply a response to hygiene needs. Instead, they provide a framework defining membership of what was, at that time, a fragmenting population in the midst of diaspora. The 'holy' (literally, 'separate') race of Jews, with strict regulations defining activities down to the last hour, were by default distinct from their pursuers, lacking such a regulated lifestyle.

An interesting tangential narrative is that of the changeling – someone who may look like us, but in reality is from the other camp. From Ovid's *Metamorphoses*, through Stoker's *Dracula*, the film *Invasion of the Body Snatchers* and the popular *Harry Potter* series, we see a selection of stories that include characters who shapeshift. The motive is usually insurgency, and once 'victims' discover their enemy's skill, the resulting paranoia creates an intriguing plot strand, with protagonists trying desperately to work out who are the friends and enemies – they all look the same! In the real world, we see similar manifestations – in Joseph McCarthy's communist witch hunts in 1950s North America, for example, which led, incidentally, to initial plot ideas for *Invasion of the Body Snatchers*.

We can see parallels in health. The need to categorise illness, accompanied by poorly developed skills in making sense of what is really going on, leads to fears of malicious, infiltrating agency. Immigrants to the UK for example, are tarnished as disease carriers, and the myth of incursion by disease is reinforced through articles published regularly in the UK media – the *Daily Mail* in 2005 for example, included the headline 'Our NHS, not the world health service'.

In the context of HIV, the virus' lack of symptoms – its cleverest trick – is also the most socially intimidating. We cannot 'see' it in action; and we are very bad at evaluating the intangible. This leads either to a complete denial of risk, or an unreasonable, and unfounded overreaction, drawing on flawed lay models of illness.

This is shown in studies (e.g., Hennessy, Fishbein *et al.*, 2007) that confirm we are very poor in judging whether or not, in a particular situation this or that person poses a threat of HIV or sexually transmitted infection. There are too many other attributes we use to make our decision – how clean is he or she? How intelligent? How articulate? How attractive? How similar to us? This dependence on physical appearance, basing our evaluations on simply what we see, is the central heuristic driving many people into situations which may, or may not, be safe. We rarely actually know beforehand, and find it difficult to conceptualise the notion of invisible risk. We draw on our own interpretations, and it is this fluidity in decision-making which paves the way for stigma. We construct a landscape in which it is easy to move people around, placed according to acceptability, attractiveness, similarity, perceived threat, or simply where we are told.

Looking to Ourselves and Closing the Gap

This discussion's golden thread is that stigma is generated through individual or group processing. It is also a construct borne from our desire to make sense of the world. Constructed phenomena are by definition arbitrary, and in practical terms, this means that for those of us working in the HIV sector, our judgement of those holding alternative views should be based not on considering them 'ignorant,' but rather acknowledging their constructs; which to them make perfect sense. As illustrated in the exercise described at the opening of this discussion, one way to better understand this process is to consider our own reactions.

Many years ago, undertaking research on an HIV unit, I had my own Damascene experience. One morning, wandering around the corridors, I spoke briefly to a patient on his way to the day room. I shook his hand and chatted some more, and then recalled that the day before he'd been diagnosed with shingles (herpes zoster), a common ailment of people living with HIV in the early days of the epidemic when antiretroviral treatment was unrefined (or unavailable). All of a sudden, I panicked. How does shingles spread? Was I at risk? Why did he shake my hand knowing he could give me an infection? It must be his fault he has it anyway – he is infected with HIV – but why should I suffer because of that?

These irrational thoughts whirled for a few seconds, before rationality – based on what I then recalled about shingles – stamped them down. I was at low risk; my immune system was strong; his infection was unavoidable (and certainly not by choice); I had chickenpox as a child. The strength of that initial two second response – a phase described in some depth by Gladwell (2005)

– gave me a profound insight into how others fear HIV. And why, in certain circumstances shaped by lay interpretations, it may seem so convenient to mentally (and physically) separate the infected from uninfected – to blame and avoid.

Reducing stigma must be predicated on reducing this social separation. Identifying with the ‘outgroup’ – not ‘them’ and ‘us’, but rather ‘we’ – has been shown as a key predictor of effective engagement with people living with HIV in the health care setting (Hodgson, 2006).

Concluding Comments

The prevalence of HIV stigma, and the harm it causes, cannot be ignored. Indeed, the prevalence of our

tendency to stigmatize *anyone* in an out-group should be of concern to us all. The HIV sector rightly works to reduce the stigmatization of people living with HIV, and enhance their quality of life. But to understand responses to HIV, we should look to ourselves and our own tendency to stigmatize. We may have more in common with the ‘ignorant’ than we like to admit. The notion of a ‘global soul’, discussed from a traveller’s perspective by Iyer (2000) is tarnished, sadly, with a hint of new-age fripperies, but it does encourage an approach recognizing *similarities* more than difference. Acknowledging these will help our understanding of other people, and provide a sure footing to developing a new paradigm to reduce stigma.

Our social continuum may be shorter than we think.

References

- Gladwell, M. (2005). *Blink: The power of thinking without thinking*. New York: Little, Brown.
- Gourevitch, P. (1995). *Letter from Rwanda: After the Genocide*. New Yorker (December 18).
- Hennessy, M., Fishbein, M., Curtis, B., & Barrett, D.W. (2007). Evaluating the risk and attractiveness of romantic partners when confronted with contradictory cues. *AIDS and Behavior*, 11(3), 479–490. <http://dx.doi.org/10.1007/s10461-006-9156-9>.
- Hodgson, I. (2006). Empathy, inclusion and enclaves: the culture of care of people with HIV/AIDS and nursing implications. *Journal of Advanced Nursing*, 55(3), 283–290. <http://dx.doi.org/10.1111/j.1365-2648.2006.03913.x>.
- Iyer, P. (2000). *The Global Soul: Jet Lag, Shopping Malls, and the Search for Home*. New York: Vintage.
- Kershaw, I. (1998). *Hitler, 1889–1936: Hubris*. Harmondsworth: Penguin.
- Ross, K., & Clay, S. (2007). Understanding and challenging HIV stigma: a toolkit for action. Academy for Educational Development, International Council of Research on Women, International HIV/AIDS Alliance.
- Sontag, S. (1991). *AIDS and its metaphors*. Harmondsworth: Penguin.