

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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HIV and Stigma

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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Call for

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

2008

HIV Nursing welcomes all articles, editorial letters, case reports and other contributions of interest to healthcare professionals working in the HIV field.

If you have recently completed a dissertation for a degree, set up a project that has improved the service of care for your patients or done some interesting research, let us know.

As professional nurses, one of the best ways to raise our profile is by demonstrating innovative work that improves the lives of patients, family and staff within the domain of HIV care. HIV Nursing aims to provide a forum for those at the forefront of caring for people affected by HIV and is intended to provide a medium of communication on issues relating to HIV care. Readers' contributions are highly valued.

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HIV and stigma

Ian Hodgson

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Welcome to this edition of *HIV Nursing*. In this issue, we consider a topic that remains a central factor of the HIV epidemic – the stigmatisation of people living with HIV (PLHIV). Studies continue to confirm the reality of stigma for PLHIV, and the articles in this edition have been selected to provide a broad base of material revealing different elements of the phenomenon, from personal and professional perspectives.

The opening article – ‘HIV stigma: a question of morality?’ – returns to some of the specific factors contributing towards HIV stigma, but also broadens the debate. Stigma is clearly an issue of human rights [1,2], but also one of morality – in the normative sense as a ‘right’ behaviour chosen in preference to alternatives by all rational people. To stigmatise must be classified as immoral, and as such is not an ideal code for conduct.

Frustration at stigma is addressed by Simon Corcos writing from his perspective as a Clinical Nurse Specialist in HIV care. He describes the illogical roots of stigma, and the experiences of affected people dealing with its impact. The paper also highlights further topics central to clinical care: confidentiality and the normalisation of HIV, both of which remain areas of contention.

In a moving and very personal reflection, Declan Montgomery paints a vivid picture of stigma in his own life, coming out as a gay man – and then a PLHIV – in Ireland. He focuses in particular on ‘self-loathing’ – self-stigma generated by a PLHIV anticipating negative responses from others – and its impact on social integration. Declan ends his article with a message of hope: it can be possible for affected people to confront stigma and reject

society’s labels, reaching a point of self-advocacy rather than self-condemnation.

The final article in this edition of *HIV Nursing* turns to solutions. Evidence suggests [3] that workshops and training events designed to raise awareness and highlight the antecedents of stigma can have positive results. Information provision, and increased self-awareness are vital in reversing the apparent inevitability of stigma, and David Armitage shares important – and very practical – insights into preparing and running a workshop that can be used as an intervention for HIV stigma.

The lived experience of stigma remains a potent and in many instances damaging manifestation of the HIV epidemic, and the adequate preparation of healthcare workers for the care of PLHIV is vital [4]. We believe this edition of *HIV Nursing* provides a range of insights and information, and will hopefully play its own part in the continuing battle against HIV stigma.

As always, we invite feedback, and if you would like to comment on any of the articles in this edition, send a message to: hivnursing@mediscript.ltd.uk

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HIV stigma: a question of morality?

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Even 25 years after the appearance of HIV, it continues to instil fear, and responses seem little changed over time. Perhaps this is not surprising: HIV remains incurable, continues to spread at an alarming rate, and antiretroviral therapies (ART) are still unavailable in countries where they are most needed. And of course, HIV involves the taboo of sex.

This apparent lack of control undoubtedly drives many negative responses, and the tendency to attribute stigma and blame is especially strong when an illness is mysterious and apparently out of control [1]. Evidence-based local HIV-stigma reduction programmes exist in some areas, though success is patchy (for a useful review see [2]), and the complex nature of the phenomenon is leading to calls for a much more robust application of theory to practice [3,4].

Definitions of stigma have been discussed in this journal before, but the intransigence remains a significant factor in the lives of many people affected by HIV. Only recently, the following posting was sent onto a list forum, serving Ireland, written by a person living with HIV:

My housemate recently gave blood as she regularly does. But this time was different. In the past she's filled in the forms really quickly but this time she focused on the question: 'Does anyone in your household have HIV?' I'd recently informed her of my diagnosis, so she pondered this question for quite some time, and decided honesty was the best policy. She ticked 'Yes', presuming this wouldn't be a problem.

The nurse shockingly looked at her form and told her to be very careful around her housemate. The nurse proceeded to tell her to ensure she washes all of her cups etc. very carefully.

Tears were in her eyes as she was telling me about her afternoon spent giving blood, and I almost felt guilty [5].

That this conversation can still take place in July 2007 must raise concerns for all healthcare workers. It would be too easy to simply castigate the nurse for being ignorant or narrow-minded even though he or she may very well be. Instead, broader questions should be asked: what were the antecedents to this behaviour? Was it simply a lack of knowledge, or representative of a more serious malaise within the culture of healthcare workers, and therefore by default (as they are often more similar than we would like to think) the broader population?

Stigma

Many studies and reports confirm the experience of HIV stigma [6-8]. The impact of stigma on affected people is traumatic, especially with regard to self-stigma - when affected people stigmatise themselves:

...the way I saw myself fundamentally changed in a matter of minutes: I thought I was marked, different from everyone. I felt dirty, ashamed, and guilty [9].

Primary definitions of stigma often refer to Goffman [10], who suggests stigma is an attribute that discredits a person, denies full social acceptance and draws on arbitrary rules of inclusion and exclusion. More recently however, the discourse around stigma has focused less on stigma as a phenomenon in itself, but rather on it as a result of underlying social processes [11]. Most worrying perhaps, is that it is now clear that to stigmatise seems part of the human condition, and, as well as defining inclusion and exclusion, it also articulates society's values and extant cultural mechanisms. According to Sontag [12], societies 'need to have one illness which becomes identified with evil, and attaches blame to its victims' (p. 140).

Recent research highlights some of the finer nuances of HIV stigma. Reidpath *et al.* [13] and Desclaux [14], for example, suggest that loss of social capital and economic inequality feed in to the stigmatising process: communities finding themselves in dire straits quickly arrive at the limits of any 'obligation of solidarity' (p. 4). Farmer [15] proposes that 'structural violence' is instituted against people living with HIV whereby 'fundamental social forces and processes come to be embodied as biological events' (p. 14). The impact of stigma on people living with HIV can never be underestimated, although direct links between stigma and the worsening HIV epidemic are not yet proven, as discussed by Reidpath and Chan [16].

There is no question that stigma is entirely socially constructed, and does not exist until people agree it should. As a collective phenomenon, HIV stigma is therefore based on social collaboration, and the use of powerful inclusion and exclusion rules is at the root of Foucault's argument about the role of established regimes of knowledge and power, dictating what is allowed, and what is true [17,18]. This is most potently illustrated in the context of HIV when the media maintain and reinforce stigma by using pejorative and salacious terminology. Here,

as Fowler [19] suggests, 'deplorable values are openly displayed, pointedly highlighted; [and] even a critical reader can be disarmed by pleasure in the awfulness of the discourse' (p. 45).

Seeing stigma as an inevitable social process, rather than as a mechanism targeting a particular pathology, is an important and relatively recent development. Taking this approach, stigma reduction is not simply the result of information provision – although effective dissemination of knowledge could be part of a broader constellation of interventions – but also demands better consideration of social processes, and the relationship between members of society.

Stigma in healthcare

Is HIV stigma prevalent in healthcare, as the quotation above suggests? According to some studies, stigma is indeed endemic [7, 20], including, surprisingly, in areas of relatively high HIV prevalence such as Nigeria [21]. Lack of confidentiality is often a consequence: anecdotal stories of medical and nursing records being marked as 'HIV positive' are not uncommon.

It seems a range of factors determines the level of stigma: level of experience; knowledge of HIV; access to equipment; and peer pressure. Studies reporting less anxiety about HIV (often a precursor to stigma) suggest a correlation between this and effective occupational support [22]. Healthcare workers who display negative attitudes clearly require some form of intervention, although information-giving is simply the first step. Pressures to conform to societal mores are strong, and unless an appropriate social organisation is available for healthcare workers to engage, then it is unlikely real progress can be made.

Healthcare workers who have chosen to work in the field of HIV, who have extensive experience, are willing to engage with clients and have no problems with 'otherness', display minimal stigma towards affected people according to one study [23]. HIV stigma in healthcare was a recurring theme at the International AIDS Conference in Toronto, 2006, and recommendations [24] emerging from that conference included:

- * The promotion of universal precautions, and sufficient equipment to ensure safety

- * Provision of services that welcome people living with HIV and provide a safe haven for affected people

- * The encouragement of people living with HIV to become involved in the development, management and evaluation of services

- * Encouraging social openness around HIV and maintaining confidentiality

Interventions

How can stigma be addressed? Three specific ways are suggested here.

First, as a human rights issue, the protection of those who are vulnerable can be 'locked in' through legislation, as has been done over the years with, for example, the disabled.

Secondly, because stigma is socially constructed, mechanisms for maintaining collective perceptions, such as the media, must be better informed and disseminate clearer messages about HIV. Salacious copy in the red-tops, epitomised perhaps in the media witch-hunt against Sarah Jane Porter, who in 2006 allegedly intentionally infected other people with HIV, must be redressed. The plasticity of truth is a concept relevant to any discussion about socially constructed beliefs as we can see in the context of social theory [18] and politics [25], and for those of us in civil society (including healthcare), shaping the discourse amounts to a moral imperative. If we see negative comments in any document, we can act.

Lastly, we can dismantle 'otherness'. The writer whose posting opened this article, summarised by saying:

Life with HIV can be as normal as life without HIV. We all have a role to play in spreading the word, so hopefully as time goes on these occurrences of ignorance will become less and less.

The first stage in reducing stigma in many contexts – not just HIV – is connecting and engaging with individuals from an affected group. The consequent realisation that 'they' share the same hopes, fears, dreams, and indeed live in the same world as we do, marks a turning point in alleviating stigma, and accelerates dismantling the 'us and them' paradigm, the most destructive aspect of stigma. This is the foundation on which many stigma-reduction workshops are based.

Morality

As part of the human condition, our tendency to stigmatise will, sadly, be with us in perpetuity. For Thomas Hobbes, our intrinsic drive to 'war against all' [26] can be saved only through adopting a robust and defensible moral position. Perhaps it is only through this that the stigmatisation of HIV (and other socially derided pathologies) can be truly confronted, reversing our entropic drift towards moral decay [27], and social classifications based on arbitrary and arcane rules

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HIV stigma – what is it good for? Absolutely nothing!

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HIV has been in the public domain for at least a generation, so I find it more than a little puzzling that after 25 years it still has a certain 'something' that sets it apart from the other myriad medical conditions. For the purposes of this article I shall try to address only the stigma that HIV can still cause for many individuals infected with it. I will look at what I think are some of the root causes of this, reflect upon some of my experiences and observations having worked in HIV nursing over the last 17 years, and then suggest some approaches that I've found useful in addressing patient needs around stigmatisation.

Trawling through the dictionaries I found the following three definitions of stigma:

Mark or sign of disgrace or discredit;

Mark branded on slave, criminal, etc.;

Imputation, attacking a person's reputation, stain on one's good name.

This is pretty strong stuff and the central problem for me is: why should a person be made to feel this way simply because they acquired an infection by having sex with a partner, a normal and indeed essential act between human beings (and all other mammalian species come to think of it)?

I can still mostly remember 'O' level biology lessons in which the basic functions that each cell must perform to sustain life were established. Among these are respiration, excretion, nutrition and, of course, reproduction. We have a biological imperative to reproduce along with breathing, eating and drinking, and going to the toilet, so I'm saying that sex is a very basic and primal urge that makes people attracted to each other firstly as a means for reproduction. However, we humans have worked out, and not just recently, that sex can be a mutually enjoyable experience for both partners and that at its best can be the pinnacle of intimacy, sensuality and indeed love.

Now, the problem with a primal urge, and I'd venture that the majority of sexually active people can acknowledge this, is that libido/sex is not always rational, or well-timed, or sensible, or perfect, or especially of late, sober – it is normal human behaviour. It also may not be consensual – rape and non-consensual sex in any form is a very ancient phenomenon and, I would contend, stems from the same basic sexual and reproductive urge.

If HIV only affected people who beat up and robbed old people, or who stabbed lollipop ladies, one could understand a stigma being attached to these individuals – so why stigmatise people who have only had sexual intercourse with a partner? Fear of death, and especially premature death, have always been a big factor in the way certain medical conditions are perceived and tolerated by the general population. Cancer, TB, syphilis, epilepsy and leprosy, to name just a few, have all incited fear and stigma in the past and this fear is natural on a psychological level. Along with fear will go ignorance, of course. If one knows nothing about HIV and perhaps has heard only myths and wrong information then this makes for a truly dreadful concoction particularly when visited upon huge numbers of people infected with, and affected by, this virus. It is a huge problem we all know.

If sexual intercourse is mixed along with the fear and ignorance of HIV, this seems to cause an equally big problem in many quarters. My only memorable session from the ENB 276 course in 'Sexual and Reproductive Health' was 'Deconstructing Sex and Gender' (many thanks to Dr Anthony Pryce at City University, London). In a nutshell, he dealt with where and how we get our information about what we think of as 'normal' and 'acceptable' sexual behaviour – it was a fascinating excursion into religious patriarchy and bigotry as well as social policy, family and media influences. All these factors have some bearing on how a person tries to understand their sexual role, identity, function and enjoyment; however, in my view the most pernicious have been the religious doctrines over the past centuries. On their own they have gone a long way to stigmatise sex before or outside marriage, certain types of sexual behaviour between consenting parties, homosexuality, use of contraception/condoms, and termination of pregnancy. I think I will stop there. It is a minefield and a tragic and unhelpful one for a person whose only 'crime' is that they had sex with a partner.

Somehow sex and morality became entangled and people have been suffering for it ever since. It is worth saying that HIV, the tiny virus itself, 'knows' nothing about morality, or religious creed, or who is a good or bad person. As with adaptive bugs of all kinds, it only 'knows' how to transmit between people and then get its act together.

I want just to reflect briefly on a conversation I had with my father many years ago to attempt to

illustrate a common double standard. In discussion around my caseload he casually asserted that their HIV infection must have been self-inflicted, a phrase to which I take great exception. So I asked him whether he had ever had unprotected sex with anyone prior to, and including, my mother, and he replied that he had. When I then suggested that, had he caught HIV in this way, it would have been self-inflicted, the look of revelation and the sound of a large penny dropping were something to behold. Most individuals of basic sexual maturity and experience, including myself, have had unprotected sex with a partner but we happened not to get HIV. Acting in a totally rational and responsible way in every sexual situation is not something we are ever likely to accomplish – it is not really in our nature!

I must apologise if this is meandering a bit but I'm trying to give as broad a perspective as possible because I feel that this is what many patients need to explore to get a better view of what HIV and stigma actually mean. Some people acquire HIV infection outside an established monogamous partnership, marriage for example, and this can be seen as morally wrong due to the breach of trust; however the sex itself, is not.

Patients tend to divide into three groups: HIV-positive individuals who have not disclosed their status to anybody and stigmatise themselves to varying degrees; people who have disclosed to supportive family and friends who still feel stigmatised; and those who have disclosed to unsupportive or prejudiced family/friends who are stigmatised by them. As a nurse, a variety of approaches can be used to address the need of stigmatised patients. If I've learned nothing else in HIV nursing it is to treat people as individuals, to listen to them and to encourage them to ask questions. The core nursing values of kindness, respect, acceptance and support are absolutely crucial to forming relationships with patients, especially as they will be receiving care, on or off antiretroviral treatment, for many years. If patients feel no stigma in the clinic setting, they are much more likely to discuss feelings of stigmatisation from their personal life with nurses and other clinic staff.

Disclosure of HIV status by the infected person can require a lot of support and information from nurses depending on individual circumstances and the dynamics of the patient's relationships. For example, for people who are finding it very hard to disclose but want or need to do so, I can bring together a meeting with their partner or family member and, with their permission, I will disclose their HIV status and then deal with all the issues arising directly. This allows questions to be asked, good information on HIV to be given to all parties and discussed thoroughly, and further plans of action can be made.

HIV-positive patients should be encouraged to continue in sexual relationships. As nurses this may

require attention to detail in discussion of sexually safer, and of course enjoyable, sexual activities as well as regular condom use with provision and demonstration of these. Nurses can also be key in talking about disclosure to new sexual partners, a particularly difficult step for many patients.

Onward referral to counselling services and/or a psychologist can be very useful to explore and address patients' feelings of stigma as can be introduction to peer support groups in the voluntary sector – to feel you're not alone with HIV can work wonders for many patients. After all, what is someone with HIV supposed to look like anyway?

Giving impartial and accurate information on all aspects of HIV allows the individual a much more realistic perspective on their future and prognosis and can greatly reduce the fear and ignorance side of the equation. HIV nurses are lucky to have NAM, i-Base, and the Terrence Higgins Trust providing such great resources.

Some patients successfully find HIV-positive partners on internet dating sites or in lonely hearts columns. A problem shared and accepted may again lead to lessening the feelings of stigma.

Over my years in this continually developing and ever fascinating field of nursing I hope I've tried to normalise HIV treatment and care, which in the last decade has become more of a chronic condition for many patients. Owing to the nature of my two-days-per-week job in Lancaster (the rest of the week, I work in Bradford) our HIV clinics run in parallel with all other medical outpatient clinics in hospital outpatient departments. It is all very low key and some patients have said they find this preferable to attending a 'special' clinic in a GUM setting. I will also just gently say that perhaps the code number required in GUM/HIV settings, unlike any other medical area as far as I'm aware, may have had its day. How can we expect to fully normalise and integrate HIV treatment and care if, as healthcare professionals, we actually collude with stigmatisation of infections transmitted by sexual means?

It is true to say that some HIV-positive patients feel no stigma at all. They refuse to have their lives defined or blighted by a single viral infection and HIV takes very much a back seat in all the other busy and interesting facets of their lives.

As nurses we can do so much to help alleviate stigmatisation in all its forms using the human and professional skills at our disposal. However, only the patients themselves can truly lift and unlearn their own stigma and find a better peace and quality in life.

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The lived experience of stigma

Declan Montgomery

Dublin

It's amazing what you get used to. Walk past lots of things on your way to work; see the same people at the bus stop every day; and both the things and the people become kind of invisible, beneath your normal awareness. You hardly even notice them anymore: the background music of a movie that you hear but don't at the same time.

As a young man I remember writing a short poem about people I saw daily at the train station. I won't bore you with the whole thing, but one line kind of sums up what I want to say: 'Crowds of sullen faces, vague images unseen, question marks each one of you, for nothing do you mean'. You get the point. Strange as it might seem, stigma can pass beneath our notice, our conscious awareness, and form part of the natural backdrop of our lives. And it doesn't have to be a passive phenomenon where we experience stigma of any type inflicted on us. Something done unto us as innocent victims, but not something we do, oh no, not me, not ever. We don't live in splendid isolation. The attitudes and prejudices amongst our own family and friends, our culture, our society become absorbed, running like ink into the fabric of ourselves. We can stigmatise ourselves and others easily because the attitudes and beliefs that underpin stigma are usually commonly held within society, and they can be hard to challenge for that very reason. Firstly, these beliefs and attitudes have become intrinsic to us: we've invested something of ourselves in them; and secondly, to challenge them perhaps means separating ourselves from the herd, and few of us like to do that too much.

As a teenager my first recollection of gay stigma, that negative and shaming attitude towards gay people simply because of their sexuality, was amongst my family and peer group. My father, responding to something on the TV about gay men, said 'They should be all out digging ditches'. It says a lot about the level of stigma prevalent in society at that time that I considered this a remarkably restrained, almost reasonable level of prejudice. My peers were not so kind. 'Queer' and 'puff' were amongst the category of high-level insults, reserved for special occasions when you really wanted to hurt someone. Being gay myself, I hate to admit it, but I too probably called a few people these names. How ironic, a gay teenager who avoided being stigmatised by doing it himself. The message was clear: gay people were queer, strange different, bad, less than, not part of the herd. The herd I so desperately wanted, needed, to be part of. This initial introduction to stigma taught me a very important lesson. I needed to hide the real me,

because the real me was not acceptable to the majority of others in my society. The pain, hurt and isolation I experienced, the sense of being rejected by mainstream society, the state, the family unit, the Church – all the places I needed to get affirmed and supported by and wasn't – warped my life and sent me down dark roads of drinking and out-of-control behaviour. I look back now and see that I was a victim of stigma. I can see clearly as well that I took on the attitudes and beliefs and values others had, to the point that I hated myself for being gay. And yet being gay was not a 'life choice' for me, I wish it had been; it was an immutable fact, just like my blue eyes or brown hair. This sense of self-hatred is the abiding memory of that time, as well as a real need to hide myself.

Several years later, and with hardly any surprise given the risky behaviour my previous drinking and self-loathing had led to, I was diagnosed with HIV following a test in a dingy old part of a major city hospital. The GUM clinic was, and by the way still is, located in an eighteenth-century part of the hospital, well away from today's shiny new hospital with its coffee docks, squeaky-clean floors, phone banks and juice bar. I wonder what message that gives out? The day I was diagnosed, the packed waiting room was filled with prisoners and their accompanying guards, injecting drug users and other gay men. The attitude of the doctors and nurses was extremely friendly and supportive; they did their best to reassure me. But I remember sitting in that dreadful, dreary place and saying to myself in absolute despair, 'Is this what I've been reduced to?' I felt terrified and utterly rejected. The fact that the clinic was at the very back of the hospital grounds and separated from the main hospital felt like yet another rejection, another separation from the herd. It was another very clear reminder, in shabby bricks and dirty mortar, that I was different and unequal. I think I know what lepers must have felt like in their colonies.

The attitude of the media and in society to HIV at that time, and to a lesser extent today, was often sensational. Statements like 'gay plague', 'killer disease' or 'HIV beast' grab the public attention and feed the fear and negative, simplistic judgements that often surround the illness. HIV was placed in a special category in the public mind. You could be blamed for having it. There was a sense that something you did, which was already illicit or on the social margins, like drug use or gay sex, was the cause. You brought this illness on yourself. It was your own fault. Footballers and rugby players break legs all the time; however, few blame them

for playing football because playing football is socially acceptable and is in fact, encouraged, as part of a healthy lifestyle. The real stigma came from society's attitude to groups on the margins such as gay people, drug users and now immigrants, particularly from Africa. This, coupled with fear of catching HIV, causes many in society to stigmatise those living with HIV and sadly, it also causes those people affected to stigmatise themselves.

My personal sense of self-stigma reached deep inside me and became part of my self-image. Self-stigma was borne out of the stigma inflicted on me as a child and an adult. I took on board every subtle and not-so-subtle cue about attitudes and beliefs from those around me, and made them my own. It left me cowed and beaten and brought me close to the edge through alcoholism. Being diagnosed HIV-positive was one more reason to feel marginalised. I remembered that as a teenager I had sat in church and looked at other young people in the choir and I saw myself as evil and corrupt because I was gay. I then remembered realising I was an alcoholic and thinking of myself as different again, and now finally I'm HIV-positive to boot. It felt like each of these steps took me further away from society, deeper into my loneliness. It felt like I was the stranger looking at everyone else around the campfire, while I had to stand outside like a beggar, unwanted and alone. I believe we are fundamentally social animals; we live in social networks that provide the meaning and framework of our lives. I can understand why banishment was such a punishment in the past. Stigmatising people is a form of banishment.

Thankfully, that's not the whole story. If I had accepted what many others, maybe the majority, had thought about me and accepted the labels others placed on me then the outcome of my life might have been quite different - quite sad and tragic in fact. I don't doubt this, because I've seen it happen. Some part of me refused to accept stigma, refused to accept that I was flawed and evil for being gay, weak for being an alcoholic or 'deserving' because I had HIV. Jimmy Somerville puts it well in his song: 'It ain't necessarily so'.

A key part of this process is awareness and challenging myself - my own way of thinking, and my own view of the world. My recipe also involves large dollops of self-understanding and self-compassion. At first I got angry and started the process of questioning and wondering, I was like a child in the 'terrible twos' asking 'why, why, why?' Why did I feel so ashamed; why did I feel such a mistake; where did these beliefs and attitudes come

from; are they valid, credible beliefs? It was, and is, an ongoing, imperfect process. You cannot challenge something until you can see it, and feel it, and question it. The first part of my overcoming stigma is overcoming my own internal stigma. As I said at the beginning, it's amazing what you can get used to, what you can accept as normal. The process is a painful yet rewarding one. I am encouraged by people like Carl Rogers, the founder of person-centred therapy, who believed that human beings seek to grow. He also said the facts are always friendly, meaning that we should not fear ourselves, but meet ourselves and what comes up from within with compassion and acceptance. These have been key supports in helping me face up to stigma and see it for what it is - to challenge it, to change it. I passionately believe that challenging stigma is firstly an inside job.

Mostly, when I encounter stigma in others today, I try to deal with it in the same way I deal with it in myself - to understand it, and to understand that people who stigmatise are as much a product of their own environment as I was of mine. This might sound like a cop-out but I earnestly believe it is not. There is an old saying, 'A man convinced against his will is of the same opinion still'. I get angry about stigma, particularly when I see the harm and hurt it causes, even the lives it has cost. I want laws and regulations and procedures to protect people from it. I want services to HIV-positive people, for example, to be of the same quality and level as those enjoyed by others. I don't want to be treated differently. All these things are possible through legislation and lots of progress has been made. However, you cannot legislate new attitudes into society. That's a job done over the longer term. You can, however, begin the process of raising awareness of stigma, all types of stigma, which I believe often underpin HIV stigma. Deep roots of stigma around gay people or intravenous drug users for example. It always amazes me how much effort and money we put into educating children and yet spend so little of it on helping them become emotionally balanced, self-accepting, and caring individuals. This would go a long way towards challenging attitudes at a formative time in a child's life. I know that this would have greatly helped me. Stigma, like HIV, is often silent and unnoticed, often we just don't see it, and it thrives on this. We need to wake up to it and challenge it in ourselves as well as in society in general if we are to defeat it.

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Considering training as an intervention to reduce HIV stigma

David Armitage

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While few employees hold a sole remit to deliver HIV training, the majority of people working within HIV and sexual health deliver training as a small component of posts that can seem to be ever expanding and complex. Most people working in this area juggle service user or patient needs, administration, planning and many other tasks in a working day. However, despite these growing demands, finding the time to plan and deliver training in relation to HIV-related stigma can reap rewards and can make a real difference.

If you are required to give training in relation to HIV, draw strength from the knowledge that delivering workshops can be a very positive experience. As we develop our training objectives we can hope that in some way we can facilitate the breaking down of HIV-related stigma and have a positive impact on the experiences of people living with HIV.

In addition, whatever your level of experience in relation to HIV, it is important to realise that formal research is not essential to find out how stigma impacts on people living with HIV; it is much more important to communicate and transfer what you learn into your training. Experiences of talking to people living with HIV are very valuable and significantly impact on the ability to deliver training. These experiences can be used as an invaluable tool allowing training to be delivered with added purpose and insight. I say this because however many papers or evidence-gathering exercises we manage to find time for prior to delivering training, personal experience can significantly develop our understanding of what HIV-related stigma is, and allow us to consider the human cost of its effect. These are some of the experiences that perhaps I would utilise in training sessions centred on HIV-related stigma, all of which have been recalled by people living with HIV:

- Very poor experiences within healthcare settings, such as the automatic need for some workers to feel that they have to double-glove or place HIV (both invasive and non-invasive) procedures as end-of-day appointments only;
- The hurt and fear that can often be seen in other people after receiving a positive diagnosis;
- The feeling and the reality that disclosing HIV to anyone will result in a severe personal loss;
- Travel to some countries has been restricted;
- Not applying for a job because there is a requirement to give the name and address of your GP;
- Being told that you cannot disclose your status at work;

- Not taking an HIV test until very late, often after becoming unwell;
- The fear of prosecution in relation to sexual transmission.

Whilst it would be very restrictive for any trainer to deliver a workshop or training event on issues relating to HIV from personal experiences alone, the pain, hurt, guilt, and anger that are often expressed by people during consultations should influence you as a trainer. If your experiences are limited try contacting other practitioners and organisations from both inside and outside the healthcare provision sector. In this way you can quickly start to develop your knowledge.

Fortunately there is also a growing body of research that can help us to better understand what HIV-related stigma means to those living with HIV and to our wider communities. Certainly before delivering any training it is very important that practitioners go beyond their own personal experiences of HIV. Sigma Research for example is a social research group that specialises in HIV with high quality journals and reports that are free to access (www.sigmaresearch.org.uk).

When considering the best approach to delivering workshops that are designed to have a positive impact upon HIV-related stigma, make your objectives clear, achievable and give due consideration to the practical application of the skills that hopefully your participants will have developed. As you are developing your training objectives there are a wide range of possible exercises that you may consider, from sharing personal experiences of working with people living with HIV, video extracts, case perspectives, and research dissemination to drama-based workshops or sessions that involve someone living with an HIV diagnosis. (Put that Powerpoint presentation out of your mind!) Here are five things to consider in preparation for delivering training in order to influence a positive impact.

- Training around HIV should encourage participants to look at their own values and attitudes.
- Always consider the potential impact of your training on people living with HIV and also consider involving people living with HIV, not only in training delivery but when developing services, policy and resources.
- Involving personal insights from people living

with HIV who wish to get involved with training can often go beyond the proposed outcomes of training and develop an impetus for action amongst participants. With more HIV projects offering this opportunity it is worthwhile finding out whether local social support organisations can help. Involving people living with HIV in training delivery allows participants to better understand the actions that support HIV-related stigma and creates an opportunity to understand and work against its foundations, those being fear, discrimination, prejudice and ignorance.

- Whilst it can be an automatic response to collate resources for training such as those that describe transmission routes and the virology of HIV, make sure that you also offer resources like *Positive Nation*, NAM's Living with HIV manual, and Positively Women. Exploring the role of HIV-related stigma goes beyond biology.
- If you regularly work with people living with HIV, if appropriate, ask how living with HIV impacts upon their life. Those issues listed previously are just a few examples that affect many living with HIV and where stigma has played an important part in their experiences or feelings. Your experiences will allow you to delve beyond the basic definitions of stigma that may be found in a dictionary. Such definitions often describe it as something that is created as a sign of social disgrace, a disease or defect. You can then start to unpick how HIV has developed into a condition so associated with stigma and to consider the impact that it may have on us all.

Good luck to anyone planning to deliver training on this topic, HIV-related stigma continues to

significantly inhibit the potential health and well-being of people living with HIV and increasingly restricts how communities engage with the realities of HIV. For many years, HIV has been compared by health professionals to other chronic but often manageable conditions; however, the problem is that those comparisons are based primarily around treatment options and potential physiological health outcomes. A true comparison to other chronic and manageable conditions will require a significant shift in the way HIV is regarded within society. Hopefully a commitment to training can make this shift more likely to happen.

Further reading

Bogart LM, Cowgill BO, Kennedy D *et al.* HIV-related stigma among people with HIV and their families: a qualitative analysis. *AIDS Behav*, 2007, Apr 26 [Epub ahead of print].

Semi-structured interviews looking at the experiences of discrimination and the related stigma within 33 families in which a parent is living with HIV.

Dodds C, Keogh P, Chime O *et al.* Outsider status: stigma and discrimination experienced by gay men and African people with HIV. London, Sigma Research, 2004. Online at: www.sigmaresearch.org (last accessed on 9th October 2007).

A report involving 20 targeted focus groups with heterosexual African men, heterosexual women and gay and bisexual men living with HIV. This report gives a clear overview of the experiences relating to stigma and discrimination.

Peretti-Watel P, Spire B, Obadia Y, Moatti JP. Discrimination against HIV-infected people and the spread of HIV: some evidence from France. Institut National de la Santé et de la Recherche Médicale VESPA group, 2007. *PLoS ONE*, 2007, **2**, e411.

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Book review

The AIDS Pandemic: The Collision of Epidemiology with Political Correctness

By James Chin

248 pp, Radcliffe Publishing, Ltd, Oxford, 2007
ISBN 10-1-84619 11 8 1, £27.50

Reviewed by Ian Hodgson

Part hagiography, part textbook, part political critique, this text is likely to be an interesting, if controversial, read for anyone in the field of HIV. The author, James Chin, has been involved in public health for over 50 years, including a stint in California at the outbreak of the HIV epidemic, and working for the World Health Organization in the department that was to become UNAIDS, the agency now at the forefront of the global fight against HIV and AIDS. More recently, Chin has been working as Professor of Clinical Epidemiology at the University of Berkeley, California, and it is from this academic enclave his controversial text has emerged.

Chin's thesis is that figures estimating HIV prevalence have been consistently overestimated by up to 50% since the earliest days of the epidemic. He suggests reported numbers of affected people are not always based on clinical or epidemiological evidence, but are often the product of agencies and activists drawing on models describing a generic risk of HIV – a risk, which, for the vast majority of people is nowhere near that predicted by these flawed models.

He believes using such models stems from a desire to disseminate a more socially acceptable and politically correct message, avoiding overtly tackling specific social groups and regions, and therefore avoiding the danger of stoking prejudice. This, for Chin, is simply not evidence-based, and he is unequivocal: HIV will only ever significantly affect populations who engage in behaviours with a high risk of transmission. He cites many examples of anomalous discourse, including the dominance of poverty, gender inequality and stigma as drivers of the epidemic. Chin agrees these are no doubt serious issues, but by no means prime factors: HIV is rife in Africa because of African sexual practices, and until this blatant fact is addressed, this is simply bad faith.

He is especially critical, and at his most vituperative, when discussing UNAIDS. He suggests the agency exaggerates the 'carnage' model so as to attract additional funding, and by drawing on the (flawed) paradigm of generic risk, encourages

HIV prevention programmes that address general populations, rather than the much harder to reach, and more HIV-vulnerable, people on a society's periphery. Chin proposes that this approach misses – most people in most regions are not at risk of HIV, and even the threat of 'bridging' between low- and high-risk populations has been exaggerated. He believes that only by focusing on risky behaviours in high-risk groups will HIV incidence be reduced.

Chin's downgrading of broad socio-economic factors around HIV no doubt raises the hackles of many, including patient advocates such as Paul Farmer and pop-economist Jeffrey Sachs, but Chin provides much data to support his argument. To this extent, Chin can appear sanctimonious and even messianic; there are hints in the text that only he sees the elephant in the room. Saying that, Chin is not alone in his views – Godwin *et al.* [1] for example, propose the need for a more rational response to HIV in Asia predicated on the notion that the African AIDS tragedy is not possible elsewhere. However, his attacks on UNAIDS and other 'big beasts' will make him enemies, and place him outside the mainstream. On the basis of this text, I suspect this does not concern him greatly.

In spite of undoubted hubris, Chin's text is compelling, and he is certainly no Duesberg-style AIDS denialist: sections on links between HIV and AIDS, and the possible roots of HIV, are certainly orthodox. He simply asks for a more evidence-based response to HIV, reflecting available data rather than political pragmatism. As he says, the data supports his view that 'sexual HIV epidemics can *only occur* in populations with the highest risk pattern and highest prevalence of sex partner exchanges' (my italics).

As I write this review, a news item on the BBC website catches my eye. New figures implying HIV prevalence in India is likely to be half of previous estimates, down from 5.2 million to 2.5–3.1 million [2], close to Chin's suggested 50% anomaly. The statistics in India are still catastrophic for affected people of course, but if predictions can be that awry, Chin's call for a more careful look at epidemiological data before rapid deployment of what could be inappropriate and expensive interventions does make more sense.

References

1. Godwin P, O'Farrell N, Fylkesnes K and Misra, S. Five myths about the HIV epidemic in Asia. *PLoS Med*, 2006, **10**, e426.
2. BBC (2007). 'Sharp drop' in India Aids. Online at: http://news.bbc.co.uk/1/hi/world/south_asia/6276398.stm (last accessed 7th September 2007).

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National HIV Nurses Association

NHIVNA BIRMINGHAM STUDY DAY

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To understand the use of HIV nursing competencies in practice

Programme

0900-0945	Introduction and overview of competencies
0945-1115	Assessment of health and well-being <i>Applying skills in practice</i>
1115-1135	Refreshments
1135-1300	Health prevention and promotion <i>Identifying and overcoming barriers</i>
1300-1345	Lunch
1345-1515	Management of antiretroviral therapy <i>Applying knowledge to practice</i>
1515-1535	Refreshments
1535-1605	Linking health policy and competencies <i>Managing networks and standards</i>
1605-1620	Evaluation and Close

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NHIVNA update

Well, autumn is here already and planning has begun in earnest for next year's 10th Annual Conference, which will be held in Glasgow on Thursday 26th and Friday 27th June 2008. The programme is coming together and it is already very exciting. The evaluations from this year's London conference were taken into account and we have planned the next programme accordingly. The feedback on the whole was very positive: thank you to all who completed the Conference evaluation form. The First Announcement will be sent out later this year and in the meantime, please start thinking about preparing abstracts for the Conference.

Membership renewal time is coming and renewal forms and information will be sent out soon. This year, we have again managed to hold the membership fee at the same level. When you consider that membership includes *HIV Nursing*, *NHIVNA Newsletter*, free registration for study days, *AIDS Treatment Update* and access to grants and scholarships, we hope you will agree that it is very good value for money.

The final Competency study day to be held this year is in Birmingham on Wednesday 21st November. We have already run well-received study days in London, Stirling and Manchester. Remember study days are free to members. Full details for this study day are given in this issue of *HIV Nursing* and on the NHIVNA website (www.nhivna.org), where information about other NHIVNA events can also be found.

We expect to announce soon the setting-up of a members-only section on the NHIVNA website. In the meantime, we are keen to receive documents for inclusion in this section - if you have nurse-led clinic protocols, guidelines, or any documents concerning your practice that you are happy to share with other NHIVNA members please send them to jacqueline@mediscript.ltd.uk

Sheila Morris, Chair

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'Best of CROI' Feedback Meetings

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14th Annual Conference of the British HIV Association (BHIVA)

23-25 April 2008

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2nd Annual Conference of the Children's HIV Association (CHIVA)

Friday 23 May 2008

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10th Annual Conference of the National HIV Nurses Association (NHIVNA)

26-27 June 2008

Glasgow



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including

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*For further information on these events,
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Miller D. *Living with AIDS and HIV*. Macmillan Press, London. 1987.

Corey L. HIV vaccine: update on science and policy. 14th International AIDS Conference. Barcelona, 2002, Abstr. TuOr143.

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