# 'Just take a tablet and you'll be okay': medicalisation, the growth of stigma and the silencing of HIV

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## Introduction

This article explores the growth and impact of the medicalisation of HIV and HIV-related stigma. Since the early days of the virus when treatments were unavailable, political voices for HIV advocacy were powerful; public discourse reflected these changes with growing public-health campaigns that began to demystify HIV as a concept. However, with the development of antiretroviral therapy (ART) the voices powerfully associated with HIV have largely moved away from the campaign and advocacy groups, having switched to, and accruing dominance from, the biomedical establishment through the medicalisation of HIV. This has led to a parallel system in which people today are living longer with HIV treatment and their standards of living are getting better; however, the once powerful process of demystification and public discourses discussing HIV and its stigma, have become much more muted. HIV in the public realm has become largely 'silenced' outside the work of HIV organisations and biomedical institutions and so has yet to develop into a 'post-HIV' stage of public understanding and acceptance. This article uses the work of Ghaziani and applies his three-stage model of community change, arguing that HIV as a concept has not begun the final stage of acceptance where HIV stigma is tackled through public discourse because of the medicalisation process itself [1].

## What is stigma?

Stigma is wrapped up in sociocultural and historical processes, and alters and changes over time. Stigma is defined as the occurrence of 'labelling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised'. It overlaps with discrimination and racism for example, but it differs from these in some respects [2]. What sets stigma apart from discrimination is that it incorporates other elements such as labelling and stereotyping, shame, status loss and the process of discrimination [2]. Indeed, discrimination only becomes an effect, or manifestation, of stigma when society defends or encourages it [3], and so it is not always an inevitable outcome of stigma [4].

It is vital to recognise that stigmatisation works on many levels, it can be overt and manifest as aversion, avoidance, social rejection, dehumanisation, discounting and turning others into stereotypical characters [5]. However, it can also be subtler than this and arise through non-verbal expressions of discomfort such as a lack of eye contact and creating tense social interactions [6]. Stigma is not a recent concept. The word 'stigma' dates to the ancient Greeks who would brand criminals, slaves and traitors to identify them as tainted or immoral people who should be avoided [7]. This combination of socio-historical attitudes and shifting cultural attitudes in a globalised world has shown stigma to be a global psychosocial phenomenon [8].

In his seminal work, Goffman [7] argued that stigma is an attribute that serves to discredit an individual or group. It operates by tainting and diminishing them, rendering them abject and inferior and he drew on the examples of 'orphan' or 'criminal,' to show how these statuses can engender negative stereotypes [9]. Stigma is associated with 'abominations of the flesh', the soul and the tribe (deviant bodies, deviancy mentally/behaviourally and ethnic/national characteristics). Goffman argues that these are either controllable or uncontrollable, as well as visible and invisible. Individuals with visible deviant characteristics are deemed to have 'discredited' stigma, displaying visible signs of difference and those who have invisible 'discreditable' characteristics can pass as 'normal' but they must manage the risks associated with this. Individuals with discreditable characteristics fear their characteristic being discovered [7,10]. Although stigma is often presented as something that resides within the individual, it is more a language of relationships rather than attributes, and as a result, changes over time, and is salient depending on what is regarded as normal or acceptable in particular social contexts. Goffman termed those who do not have a stigmatic characteristic 'normal' and those who are 'normal' experience their bodies as absent, or unproblematic, and so stigma creates a boundary between 'us' and 'them', confirming a moral superiority of the stigmatising group and reinforcing their claim to normalcy. Importantly, the stigmatising of 'others' is an identity-producing practice. Normal identity, which does not deviate from social expectations, is produced through the enactment of exclusionary practices [11].

In the literature on deviance other authors have clarified links to the process of stigma itself. Mankoff,

for example, made a distinction between 'ascribed' and 'achieved deviance' [12]. Ascribed deviance is a condition attributed to individuals for which they are not held accountable and so no blame is attached. Achieved deviance sets out the notion that the individual is in some way culpable for their condition. Blindness could be regarded as an ascribed deviance and HIV, through its sexual transmission, as achieved deviance. However, Mankoff did not account for the significant overlap between the two. Blindness may be caused by a mishap on the part of a careless individual and so their behaviour is judged irresponsible and thus implicated in their condition. Similarly, children born with HIV may have their deviance ascribed; however, they are not blamed for it. Weiner's 'attribution theory' argues that perceiving a cause as uncontrollable and judging an individual as responsible leads to negative emotions and avoidance behaviours [13,14]; although, perceiving a cause as uncontrollable and de-individualising it, elicits positive emotions and approach behaviours. Part of addressing illness- and disease-related stigma is through campaigns to reduce stigma in the public consciousness; however, the effectiveness of some campaigns is hit and miss. In fact, anti-stigmatising campaigns that emphasised individual biomedical, rather than psychosocial explanations, did not reduce stigma and in some cases increased it [15].

As well as links to deviance and reinforcement of social norms, numerous studies have identified that stigma internalised by individuals has detrimental consequences on the psychological wellbeing of those who are stigmatised [16,17]. 'Self-stigma' results from an acute awareness of a stigmatised person's own social devaluation connected to their condition or illness and, like public stigma, it has cognitive and behavioural components [5]. Self-stigma can be part of a 'felt' process and leads to individuals hiding aspects of their condition (or the condition entirely) from others and being receptive to perceived ideas of shame and guilt for their condition.

Stigma and deviance can be either 'enacted' or 'felt'. Enacted stigma and deviance 'denote discrimination by others, felt stigma and deviance denote: (1) an internalised sense of shame and blame respectively; and (2) a frequently distressing and disruptive fear of being discriminated against' [18]. In terms of 'hidden' illnesses, individuals may manage their illness and information about it with extreme caution in order to pass as normal [10]

Well-established theories on the self, such as symbolic interactionism [19], social comparison theory [20] and social identity theory [21], suggest and predict that public stigma should exert direct influences onto self-stigma. In certain circumstances and contexts, people may gain status (and thus self-status) if they come out about a stigmatised characteristic and so they become legitimate spokespeople for marginalised groups in the process. The stigmatisation can become the foundation of a minority group identity and so establishes the group's legitimacy for lobbying for political change. In doing so, an individual or group's confidence can develop by using their own stigmatised status to gain social progress or reward, which has been seen in the growth of the HIV activist movement that began in the 1980s.

This is not always a straight forward process and as Goffman argued [7], people who choose to 'pass' as 'normal' by hiding their stigma still remain 'discreditable' for as long as the potential for stigma to be revealed persists, which may lead to significant distress amongst those who conceal their condition. When people voluntarily disclose their stigmatised status or when they have a visible stigma (such as an obvious physical disability) they do not face the issues around disclosure, but they must still endure the potential for being discredited in front of others [22]. Stigmatised individuals can attempt to mitigate the negative effects of this by employing coping strategies such as selective disclosure, compensating for the stigma during social interactions (for example, by being particularly outgoing) and through disengagement (avoiding situations where stigmatisation is more likely) [5]. Others may use different coping methods, such as being more politically aligned by seeking or setting up social support, as people living with an invisible stigmatised condition experience a mood lift in the presence of others who share their stigma [2]. This is also seen, in some cases, by alignment with others in social, political or community (or public facing) groups [23].

## What is meant by medicalisation and how is it linked to HIV-related stigma?

Conrad [24] argued that the process of medicalisation is to 'make medical.' Something such as HIV becomes a problem primarily 'defined in medical terms, described using medical language, understood through the adoption of a medical framework, or "treated" with medical intervention'. Stigmatisation is itself an important part of the history of any particular epidemic. It is a social process: a feature of social relations, reflecting the tension, conflict, silence, subterfuge and hypocrisy found in every human society and culture [25]. HIV-related stigma is 'a term that refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated' [26]. This stigma is commonly understood as a process of devaluation that can have many outcomes, for example direct discrimination, also known as 'enacted stigma' [18]. Furthermore, in the context of HIV, stigma can adversely affect how and when someone physically accesses services, including testing, support

and treatment. It also affects how people interact with each other, including friendships, intimate partnerships and professional relationships, and how someone perceives themselves and their self-esteem [27].

Initial government and media-related scare tactics, such as the UK's 'Don't Die of Ignorance' (1987) public-health campaign, and the public fear they triggered, helped to form early HIV-related stigma that has continued throughout the epidemic, particularly towards certain groups. From the moment scientists identified HIV and AIDS, public responses of fear, denial, stigma and discrimination have accompanied it (see www.avert.org [28]). Discrimination spread rapidly, fuelling anxiety and prejudice towards the groups most affected, that is, men who have sex with men (MSM) in general, and those living with HIV or AIDS. HIV and AIDS are, therefore, as much about social phenomena as they are about biological and medical concerns. This is argued by Altman [25] who highlighted that HIV and AIDS mixes sex, death, fear and disease in ways that can be interpreted to suit the prejudices and agendas of those 'controlling particular historical narratives in any specific time or place. Fear of infection all too easily translates into fear of the infected. The disease has been used to stigmatise various out-groups' [25]. The uncertainty and disagreements about the cause, scale and consequences of the virus led to a fracturing of medico-scientific progress as set out under modernity [29].

AIDS was regarded as a 'disease' of lifestyle and 'commentators were quick to moralise about the actions of particular social groups' [29]; some scientists presented 'fast-lane gay lifestyles' as the cause of AIDS. In the early 1980s the disease was even labelled GRID (gay-related immune deficiency) by some scientists. Owing to the confusion of scientific establishments and governments who denied or did not act, consumer activism developed in this space as HIV/AIDS became politicised as 'life politics' [30]. In place of traditional politics from institutions, life politics became something that was more personalised as people pursued issues close to their own lives and would not passively accept authority (from medical establishments or governments, for example). Although these are personal politics, they are also global, as HIV/AIDS saw alliances forged in the global arena.

People diagnosed with HIV/AIDS before 1996 lived in a climate of death and many expected to die. The introduction of ART in 1996 meant that 'patients who had resigned themselves to death, cashed in life insurance policies, and given up employment found themselves granted a new lease of life' [31]. In what became known widely as 'Lazarus syndrome' [25], people who had believed that they were going to die through lack of effective treatment or highly toxic trial drugs, now had a second chance through ART medication. This led to a rapid reclassification of HIV and AIDS by the World Health Organization in terms of severity and HIV is now classified as a chronic illness, along the same lines as diabetes [32]. In the same year in which ART became widely available to people living with HIV (PLWH) and AIDS, post-exposure prophylaxis (PEP) with antiretrovirals was also recommended to healthcare workers exposed to needle-stick injuries and later to the public. Conversely, while biomedical developments have been important for those living with HIV, there has been a shift in cultural beliefs so that HIV/AIDS discourses are now the domain of science through the advancement of medication, and to a lesser extent, (falsely) media-reported 'cures'. This leads away from the social and cultural issues of stigma that still need to be addressed. HIV/AIDS has become a 'problem of the body alone' and is a problem to be solved almost exclusively by medical science, clinical practices, epidemiological knowledge and the behavioural intentions that affect the ways that bodies behave toward each other [25]. The impact of discrimination, this shift from public to scientific discourse (and thus silencing of the discussion as it is left to medical experts) and HIV-related stigma is still prevalent.

HIV-related stigma in contemporary Britain has not abated; it has increased. A *silencing* of public discourse on HIV/AIDS has developed because medical discourse dominates HIV/AIDS. This silencing of HIV/AIDS has become a key point. Knowledge and public awareness of HIV is on the decline and owing to this, older cultural memories of HIV/AIDS have held firm [33]. Biomedical advances have changed the course of HIV for the better, while HIV-related stigma has stayed within early social constructs around it. While early comprehensive policies were put into place at a UK level and had a significant response globally, the emergence of ART significantly changed the social fabric of dealing with HIV/AIDS.

The National AIDS Trust (NAT) published a longitudinal study into 'Public knowledge and attitudes toward HIV' in 2014, in the UK [33]. However, while the report suggested that the public is now more aware that HIV-related stigma exists and believes that more needs to be done about it, it also highlighted social attitudes, for example, one in 10 people do not have much sympathy for PLWH. This increased to three in 10 if a person was infected through unprotected sex. This is a concern because by far the most common form of transmission among people diagnosed with HIV in 2014, just before the survey was undertaken, was through unprotected sex (95%). Other results from the survey highlighted workplace HIV-related stigma: just over two-thirds (67%) of respondents were comfortable working with a colleague living with HIV. The report also showed incorrect transmission knowledge, as one in 10 (10%) respondents incorrectly believed HIV could be transmitted through spitting, almost one-third (28%) believed HIV could be transmitted through biting and

almost half believed HIV could be transmitted by a blood transfusion in the UK (49%). The report went on to state that the sizeable proportion who responded with 'don't know' to these statements indicated that some members of the public were quite aware that their knowledge about HIV was limited [33]. The number of PLWH in the UK trebled between 2003 and 2013 [34] but over the same period, there was a significant decline in public knowledge about how HIV is transmitted. Public attitudes have not kept pace with improvements in treatment.

Many people continue to hold stigmatising attitudes to PLWH [3]. Alongside these attitudes come a range of difficulties and constant challenges in daily life, which include living with noxious symptoms, side effects from treatments, periods of disability, unemployment, isolation from social networks and poverty [35]. HIV-related discrimination and public perceptions of HIV are the largest handicaps to living well with HIV. They extend to all areas of life and many people experiencing double discrimination as a result of their ethnicity or sexuality [36]. In a survey by the Positively UK [37], three-quarters of respondents living with HIV stated that they had suffered from either depression, anxiety or ongoing emotional distress in the past 12 months, with 40% of respondents experiencing discrimination in the past 12 months due to their HIV-positive status. Other results from this survey back up the findings by NAT, revealing that PLWH are least willing to disclose their positive status to work colleagues, with four out of 10 respondents preferring not to disclose their positive status [33]. Whether discrimination did occur at work, the perception was that there was a real danger that they would be discriminated against.

There have been no UK, nationwide government-funded public health campaigns since 1987 and HIV has increased substantially since that time as 'ignorance of how to prevent HIV is still vast and in the absence of public health education campaigns it has increased over the last twenty years' [38]. However, each new generation of individuals needs to be educated to continue to lower the risk of HIV infection [39]. This is increasingly difficult to maintain due to austerity measures and because few resources, other than those from the voluntary sector, are being used to push a large-scale HIV/AIDS-specific prevention and stigma message [40].

Further research has shown that stigma has discouraged or deterred people from being tested for HIV, disclosing their status to others, seeking information and maintaining medical regimens [41], and many education and prevention programmes rarely address HIV-related stigma. Schools have been accused of offering haphazard sex-education classes as 'recent sexual health campaigns – especially those aimed at young people – have made no mention of it at all. Young people rarely learn about HIV in schools' [42] Yet, interestingly, the vast majority (86%) of members of the public agree that all young people should be taught about HIV at secondary school to ensure they have a good understanding of the condition by the time they leave [33,43]. In all, HIV is becoming a silent virus within modern Britain, yet those who are living with it, and increasingly infected by it, have clearer needs other than just medical treatment if the social exclusion and stigma, which has existed from the emergence of the virus, is to be tackled.

## A post-HIV stage?

A fuller picture and model of the nature of medicalisation and the growth of HIV stigma can be analysed using the work of Ghaziani and his exploration of 'gaybourhoods' [1]. While Ghaziani's model focuses on geographical, social and economic gaybourhoods – that is, geographical and social-lived neighbourhoods of LGBT people – his identification of three changing historical characteristics can be transferred to the growth and development of HIV. Ghaziani discusses the following changing stages of sexual history in the West:

(1) Closet: a stage typified by fear, hostility and aggression toward LGBT people. This stage is more insular and fragmented, with some small pockets of resistance to social norms;
(2) Coming out: a shift into geographical gaybourhoods and the movement of LGBT bodies into a political process to fight larger oppressive policies and to bring lived LGBT experiences to light; and
(3) Post gay: due to shifting social forces and attitudes, this stage sees a dispersal of LGBT people into the 'general' population as gaybourhoods begin to transform and/or disappear.

Ghaziani's model becomes a useful framework to discuss the shifting attitudes toward HIV from its appearance on the world stage in 1981 onwards. This is touched on by Flowers [44] who constructs a framework for how 'risk' was managed in relation to UK gay men by the identification of three key stages. Stage one refers to the 1980s as a 'confused' period with a general climate of fear. A second 'somatic' period emerged of risk management, from the mid-1980s to the 1990s, when it was discovered that HIV was associated with AIDS. The 'management of bodies' came to the fore at this point [44], via health promotion programmes asking people to act responsibly and rationally while 'other' discrete bodies – those who were tested and diagnosed as living with HIV and those who were untested and engaging in risky behaviours, were to be avoided. Towards the early 2000s, the third stage emerged as a 'technological period' where the advent of new drug treatments and testing technologies to monitor HIV viral activity, added a new dimension to risk

management. This risk management has been placed in the hands of medical practitioners, which has had the effect of fracturing the HIV community, volunteer support systems and activism that characterised the earlier confused period.

Transposing Ghaziani's model onto the history of HIV, the developments and social shifts of HIV stigma have accomplished the first two stages of this model: a general fear and confused period leading to the activist groups and HIV campaigns that resulted in the survival work of trying new medications, drug trials and the development of technologies. However, this has proved to be a double-edged sword as the forces of medicalisation and medical narratives have taken dominance in the treatment of PLWH (which was to be expected when ART became available), but wider public stigma towards HIV has not tackled. As such, what I call a *post-HIV stage* [45] has not been accomplished. This should have run alongside the technological period of advancement. The post-HIV stage means that there should have been a significant shift in public attitudes to allow PLWH to be less stigmatised as well as an awareness among the general population not living with HIV, about the facts, stigmas and knowledge of what HIV is and how it can be transmitted. The medicalisation of HIV has contributed to a *silencing of HIV* within wider public discourse because of the medical dominance of HIV discussion and treatment as prevention [46]. This ignores the stigma accompanying the virus. All too frequently, in discussions of HIV, a medical model of a 'cure' or a new treatment is highlighted, which leaves little room for the voices of HIV activists and PLWH to be heard away from the medical realm thus blocking progress in dealing with wider stigma around the virus. A direct consequence of this has been the growth of HIV-related stigma and stigmatising attitudes within wider society, the silencing of HIV discussion outside those living with HIV and the medical remit, and the stalling of stigma from entering a post-HIV stage.

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