

# Stigma and HIV: the current situation

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## Abstract

People living with HIV (PLWH) present to us in our clinical areas with numerous issues. Health problems are identified, diagnostic testing and regular monitoring takes place. As health professionals we aim to do the best we can for our patients by attempting to address these problems and providing working solutions for them. But do we always address one of the main challenges faced by those living with HIV: stigma. Long-standing evidence proves that stigma poses a major issue in HIV care and not only

affects those living with HIV but the people around them, as well as those who are most at risk of contracting the virus. The aim of this article is to highlight the issues of HIV-related stigma that are present to this day, despite the fact that HIV is now considered a chronic, manageable condition with improved outcomes. Current situations will be presented with ideas of solutions that could be developed to address stigma and provide support to those who have been victims of its effects.

## Introduction

In 2014 an estimated 103,000 people were living with HIV in the UK with 18% of them unaware of their HIV status [1]. Since the beginning of the HIV epidemic in the 1980s, stigma surrounding HIV has been present that has resulted in numerous issues and effects on the psychological and physical well-being of PLWH [2].

Stigma is defined as 'a mark of disgrace associated with a particular circumstance, quality, or person' [3]. Elsewhere, stigma has been thought to be derived from a number of factors such as a deviation from social norms, the structure of power within societies and stereotypical views as to what may be right or wrong within specific populations [4]. It is important to recognise that stigma and the act of discrimination differ but are often intertwined into behaviours that produce negative effects, thoughts, feelings and outcomes for those who are recipients of such behaviours [5]. Therefore, it is essential for us as healthcare professionals to tackle and address stigma in order to facilitate more positive outcomes on the health and well-being of those affected by stigma regarding their health inequalities [6].

## The current situation with HIV and stigma

The populations most affected by HIV are men who have sex with men (MSM) and African men and women [7]. With advanced treatments in the form of highly active antiretroviral therapy (HAART), outcomes have improved on a large scale with 95% of those being treated showing viral suppression [8]. However, it should be pointed out that in the UK, significant numbers of all newly diagnosed HIV patients tested positive after the recommended point

of starting treatment due to late diagnosis [9]. Globally, as of 2015, 36.7 million people are living with the virus with variable outcomes for populations in different parts of the world [10]. Recent studies completed by Ipsos MORI on behalf of the National Aids Trust (NAT) have found a prevalent lack of knowledge on HIV transmission, living with the virus and the overall outcomes of those infected [11]. For example, only two-thirds of the study participants correctly identified the correct routes of HIV transmission and around seven in ten participants still believe that there are poor outcomes for mother-to-child transmission [11]. Poor knowledge of HIV has been found to be a major precursor of stigma and it has been identified that despite positive support for its inclusion within the learning curriculum, there is a lack of education on HIV. Therefore, it is essential that education is provided not only about HIV as a condition but also the stigma that surrounds it, and the effect it has on PLWH.

Despite ongoing research, improved treatments and the development of sound clinical knowledge within the HIV arena, stigma surrounding HIV is still present in large proportions locally and around the globe. This poses continuing problems, not only for those with HIV but also their carers and those within the pre-testing stage [8]. In addition to the lack of education and knowledge, it is suggested that stigma exists around HIV for numerous reasons such as:

- the potential link with illegal activity such as drug use and sex work;
- issues of sex and sexuality that people often feel uncomfortable discussing;
- religious beliefs and the perceptions of what may be wrong such as homosexuality and sex outside marriage;

- beliefs surrounding race and gender issues; and
- incorrect beliefs about HIV that may cause fear and irrationality surrounding the virus itself [12].

Research conducted by Public Health England in partnership with the HIV Stigma Index UK found that high numbers of PLWH disclosed both self- and social-stigma [1]. People reported being excluded and excluding themselves from social situations as well as sexual rejection; in addition they reported a fear of being spoken about and a feeling of self-guilt and shame with regard to their HIV status and how they were exposed to the virus. Feelings such as these have contributed towards high levels of depression in PLWH [13]. Further research conducted by Grov *et al.* supports this by stating that HIV stigma exacerbates depressive symptoms by up to 80% [14]. This in turn can cause PLWH to go on a 'downward spiral' in terms of the maintenance of their physical health and compliance with HIV treatment [15]. Attending HIV appointments and taking daily antiretroviral medication can be a constant reminder of their HIV status and how they were exposed to the virus, and has been found to affect compliance with their care and long-term health outcomes [16,17].

While HIV stigma affects those infected by the virus, uninfected individuals are also significantly affected [8]. The lack of education, fear of the virus, social perceptions and individual thoughts and feelings about HIV affect this group's attitudes towards themselves and others being tested, as well as their relationships with those who are positive and how they would feel if they, or someone they knew, were to become infected in the future [1]. Overall, through research conducted by Ipsos MORI and NAT [11] it has been found that there has been an increase in positive attitudes towards HIV, but there still remains a significant number of people with negative attitudes and feelings towards HIV [8]. One of the main issues identified here is a fear of being tested due to a lack of HIV knowledge and the perceived implications of being HIV positive [18]. Medical evidence suggests that people who are diagnosed with HIV at a late stage, after primary infection, have poorer outcomes with relation to their general health with a 10-fold risk of death within the first year of diagnosis [7]. However, it has been reported that a significant number of people at risk of HIV do not test themselves due to the stigma towards HIV and a fear of being diagnosed positive [19,20].

## Healthcare and HIV-related stigma

An interesting finding surrounding HIV stigma is the stigma that lies within the community of

### Case study 1

#### Background

- Patient referred to the clinical area having received a positive diagnosis during routine antenatal testing. Most recent negative HIV test two years previous in local GU service during routine testing.
- Two other children from previous relationship.
- Partner tested during partner notification process – never had a sexual health screen as didn't perceive himself to be at risk despite reporting a history of high-risk sexual activity.
- Ongoing disclosure to family members and friends at time of visit to the clinical area.
- Mother currently on anti-retroviral treatment (ART) in order to prevent mother-to-child transmission of HIV.

#### Presenting issues

The patient described herself to be in 'shock' at her diagnosis. She constantly thought of her death which she perceived to be close due to her HIV status. It was clear that the patient had limited knowledge of HIV, management and prognosis with current treatment. She stated that she had done some independent research via online websites, journals and blogs but explained that it was fuelling her anxieties around the situation as she found a lot of the material to be negative and provided mixed information.

She couldn't understand why she had been infected – she perceived it to be an infection associated with the MSM population and questioned the trust and sexuality of her partner. She felt dirty and ashamed and disclosed that she, and her family, were worried to share regular household items with relatives through the fear of infecting them with the virus.

Due to her emotional reaction to the diagnosis, the patient had disclosed her status to a number of friends and family with mixed reactions: some supportive, but others showing negative perceptions of the situation – becoming distant and avoiding contact with her. Her partnership remained intact and she felt that amidst her trust issues around his fidelity, they were providing support to each other in regards to both of them being newly diagnosed.

Despite her fears and worries, she remained positive in regards to the situation of her unborn baby. She had actively listened to the advice and support from the HIV antenatal team and felt confident that if she adhered to treatment she would deliver a baby free of the infection.

#### What was done to address these issues?

- Presented and educated with trusted literature on HIV as a chronic manageable condition.
- Verbal education to patient and presenting relatives on HIV risk factors and transmission.
- Guidance on seeking support from local HIV organisations that provide advice and support.
- Regular follow-up in line with national HIV management.

It is apparent from Case study 1 that Pre- and post- diagnosis the patient held particular thoughts, beliefs and perceptions about HIV as a condition, who it affects and the outcomes for the people who live with the virus.

**Case study 2****Background**

- A 45-year-old male patient attended the local GUM clinic with urethral discharge.
- Tested positive for gonorrhoea on this clinical attendance.
- Last known HIV test 9 years previously to this attendance (no other sexual health screen in this time).
- End of long-term relationship (non-monogamous) around 6 months before presentation to this clinic.
- Met up with most recent sexual partners via the use of online dating apps.
- History of 'high-risk' sexual activity both throughout duration of long-term relationship and after relationship breakup (numerous accounts of unprotected anal intercourse with casual male partners).
- Recently started using mephadrone and cocaine during sex as he felt that it increased the pleasure that he received.

**Presenting issues**

During the initial clinical visit, the patient was offered an opportunistic HIV test that he refused. He stated that he didn't want to take the test as he was scared of what the result may be and at the time would rather not have known his HIV status. Due to his sexual history a rational was presented to him as to why it would be within his best interests to have a HIV test.

He explained that he was fearful of testing due to his perceptions of what it would be like to live with HIV. He remembers the 'Don't die of ignorance campaign' during the 1980s where he developed the perception that being diagnosed positive would be the cause of his death. He explained that this had happened to his friends and stated that if he became HIV positive he felt that he would lose friends and have strained relationships with family members as they had previously expressed negative views and attitudes towards PLWH. He continued to refuse the offer of a test.

When the patient attended the service at a later date for his test of cure appointment the offer of a HIV test was again given to the patient. He was again presented with the rational of testing for HIV. During this consultation, he agreed to test. Overall, his HIV result was negative.

**What was done to address these issues?**

- Verbally educated with literature on facts about HIV, HIV transmission and living with the virus.
- Educated on disclosure of sexually transmitted infections.
- Referred to a local 'gay man's' organisation where could receive ongoing peer support on beliefs surrounding HIV as well as support for his drug use.
- Educated on the importance of protection against sexually transmitted infections and the benefits of regular testing in line with current guidance.

healthcare professionals and its effect on PLWH who access healthcare. Professional codes of conduct dictate that health professionals have a duty to provide health and social care to the best of their ability through the use of standardised procedures

regardless of any differences in the health or personal circumstances of the individual. However, it has been reported by PLWH that they have been subject to stigma and discrimination when attending a healthcare setting due to their HIV status, which has in turn made them less likely to access needed healthcare [18]. Research findings produced by Weatherburn *et al.* have shown a noticeable discrimination and stigma towards HIV-positive patients from healthcare providers in areas that did not specialise in HIV care, with some patients reporting that at times they were refused certain aspects of care owing to their HIV status [21]. Nurses working with PLWH need to be self-aware with regards to their own prejudices in order for this not to impact on patient care. From the above, it is clear that there is work to be done in educating healthcare professionals. A survey conducted by Veeramah *et al.* of final-year student nurses and midwives (with qualification imminent) found a positive response from participants in answers to their overall decision as to whether they would feel comfortable in caring for an individual living with HIV [22]. However, it was identified that there was a significant lack of education on HIV and its issues on their curriculum, which in turn meant that to increase their knowledge of the subject they had to self-source the information.

## Addressing HIV stigma

As stated, stigma surrounding HIV is an ongoing issue, but the question has to be asked: what can be done about it? Despite the issues presented with HIV stigma, there is recognition that it can cause a decline in the well-being of individuals. Various means of reducing stigma have been implemented but it must be asked how more of a social movement could be created to have a shift in thinking with regards to HIV?

Tackling stigma isn't something that can be done with immediate results. It is an ongoing process that takes time, effort and many different approaches to effect a reduction [23]. Under the Equality Act 2010 HIV is registered as a known disability and this grants protection under laws of discrimination [24]. Despite awareness that discrimination often occurs due to underlying stigma, there are limited clear national developments in tackling stigma for PLWH [19].

Despite the lack of guidance on tackling stigma, there is official recognition of its existence. Stigma surrounding HIV is highlighted in various articles regarding sexual health issues. The Framework for Sexual Health Improvement in England states that one of the desired outcomes of ongoing sexual health targets is 'tackling the stigma, discrimination and prejudice often associated with sexual health



matters'; as well as 'reducing inequalities and improving sexual health outcomes' [20]. Further recognition came from the offices of the Chief Medical Officer of the UK in 2013 [25], who suggested that people are reluctant to be tested due to stigma surrounding HIV, which resulted in known incidents of late diagnosis and poorer health-related outcomes.

As suggested by UNAIDS [26], to effectively tackle stigma a collaborative and united approach should be implemented by each nation to tackle the root causes. These include the ongoing fear of contracting HIV, different personal beliefs and thoughts surrounding HIV and a neglectful attitude towards the effects of stigma. With the use of intervention-based community focus groups, influential people within those communities, peer support and the measurement of such interventions, it is thought that these causes could be investigated in depth. Measures could then be implemented and monitored to continually address new and ongoing issues within HIV-related stigma. Furthermore, an effective way of tackling stigma surrounding HIV could be by using HIV-positive people within stigma interventions [8]. Evidence has shown that the audience for such campaigns is able to make a connection to other HIV-positive people. It has been found that people are more likely to possess prejudices and be judgemental when they do not have relationships with anyone who is HIV positive. This is actively supported by research conducted in Nigeria, where it was found that the use of people who were known to be HIV positive within the stigma interventions provided a positive increase in the change of attitudes towards HIV [27].

Within today's society, with technological advancements there are numerous ways messages can be relayed to different audiences throughout the world [8]. The use of mass media including TV campaigns and social media can be beneficial in educating the population, dispelling myths and allowing people to develop thoughts, feelings and beliefs on chronic illnesses such as HIV [27]. In the UK, one of the most noticeable mass media HIV campaigns was the 'Don't Die of Ignorance Campaign' [28]. This was a campaign that encouraged HIV prevention through images of tombstones and the portrayal of death as an outcome of testing positive for HIV, which had a large impact and shocked the audience. Still widely remembered, it could be argued that this campaign could have been a cause of the stigma surrounding HIV to this day.

Since the development of successful HAART there have been no national campaigns in the UK regarding HIV on such a large scale [28]. However, media presentations targeting HIV and stigma have been carried out in other countries. The USA, France,

Scotland and Italy have all used mass media; utilising celebrities, members of the general public and influential figures to relay the message that they are still the same person despite their HIV status and to relay facts about HIV transmission, treatment and outcomes [8]. Unfortunately, there has been limited research into the effectiveness of these campaigns on attitudes towards HIV. However, there is evidence to suggest that media campaigns do work in tackling other areas of health-related stigma. The 'Time to Change' campaign was used to address attitudes and stigma towards mental health [29]. Ongoing today, the campaign uses different forms of media to relay facts and messages regarding a range of issues in mental health and recent evaluations have shown an increase in more positive attitudes towards mental health [30]. With this in mind, it could be argued that now is an ideal time to use the force of the media to produce a national campaign to address the population with solid facts about the different aspects of HIV infection in order to address the stigma associated with it and encourage its reduction.

As well as stigma interventions within the context of relaying messages and education to communities and wider populations, stigma interventions could also be carried out on a more personal level directly with those individuals who are affected by it [8]. Doing this on a personal level can help educate individuals, dispel myths and develop more positive attitudes towards HIV. A clear example of this is the use of peer support for those already infected with HIV. Information gathered by Positively UK [31] proves how such an intervention is beneficial to those directly affected by the issues of HIV including stigma. Significant numbers of participants reported an increase in their knowledge of HIV with a positive change in their emotional well-being.

Despite the use of HIV stigma interventions over time, it should be noted that measurement of the effectiveness of stigma intervention and stigma reduction is commonly neglected on stigma intervention within larger scales [19]. It can be argued that a cause of this lies within a lack of a united approach to producing guidance and gathering data on tackling stigma. Furthermore, it is understood that stigma is a complex problem and elements of it can be deemed to be more specific to certain cultures, making it more difficult to tailor and measure within individual communities [32]. It is therefore recommended that a united approach to stigma intervention should be developed by the government and relevant health-related bodies by producing official guidance on tackling the causes of stigma and providing support to those who have fallen victim to it. In addition, there should be a notion of working towards eradicating

policies and guidance that provoke negative attitudes towards HIV.

## Conclusion

Stigma associated with HIV still remains one of the largest barriers for those infected, those at risk and those who may come into forms of contact with PLWH. Despite HIV stigma being relatively well reported and easy to measure, it is more difficult to address, tackle and find measurable solutions that work to reduce it, not just here in the UK but globally. Stigma surrounding HIV is complex and comprises a significant number of issues, which present as a larger problem and impact people in many different ways. Addressing such issues shows that positive outcomes can be derived for the social, physical and mental outcomes for PLWH [14]. It is important to address the lack of education on HIV, how it is transmitted and how it affects the lives of PLWH. A significant drive for the inclusion of HIV educational curriculums in general education as well as other curriculums such as nursing, midwifery, health and social care-related subjects is required. It would be hoped that specialists caring for PLWH would not have any stigma or thoughts that impede judgement during the delivery of care. Furthermore, they should be able to share knowledge, promote good practice and educate those who may require it. It is the duty of the healthcare professionals to tackle and work towards eliminating the stigma of HIV in order to improve the quality of life of those affected by it.

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