

Nurses have vital roles in challenging prejudice and tackling the stigma associated with HIV – one that can be exacerbated by well-meaning campaigns and wider prejudices

Stamping out stigma in HIV

This article...

- The prevalence of HIV infection
- Why HIV is associated with stigma
- How nurses can help tackle stigma and prevent HIV infection

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Abstract Lewis R (2011) Stamping out stigma in HIV. *Nursing Times*; 107: 11, 16-17. Despite significant developments in the treatment of HIV infection, it is still heavily stigmatised. This article discusses why this is so, what can be done to help change negative attitudes towards people with HIV, and how nurses can help reduce stigma.

In 1998, Gugu Dhlamini was stoned and beaten to death in South Africa by people from her township after speaking openly about her HIV status. Her death was largely due to ignorance and prejudice, and the stigma attached to HIV infection. While the idea that this could happen in the UK may seem unthinkable, ignorance and prejudice around HIV is very much alive – although treatment has been widely available in the western world for the past decade, stigma still surrounds HIV.

Nurses have an important role to play in helping to reduce stigma associated with HIV – specialist HIV nurses by acting as role models and raising awareness, and general nurses by providing non-judgmental care, advising the use of universal precautions and challenging prejudice.

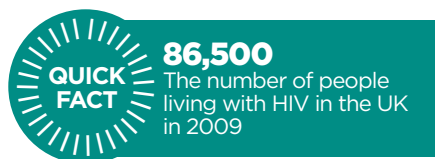
Stigma and HIV

The National AIDS Manual (2008) says: “People who are stigmatised are marked out as being different, and stigma is often attached to things which are seen as embarrassing or a danger. Stigma can be used as a way of denying dignity, respect

and rights to some members of society, and can result in people being isolated or abused. It can lead to discrimination, where people are treated less well because of a characteristic they have.”

HIV stigma is complex, fuelled by racial, homophobic and drug-related prejudice and discriminatory behaviour. It is also a way for people to cope with irrational fears of being infected (Kelly, 2006).

HIV is also a self-stigmatising condition. People with the virus often report feelings of guilt and self-loathing, internalising society’s views that they are at fault or deserve retribution for risk taking and “immoral behaviours” (NAM, 2008).



Public messages

Messages from public health campaigns in the 1980s and 1990s were stark: if you are infected with HIV, you will die. According to international HIV and AIDS charity Avert (2011) the language and imagery in these campaigns contributed to subliminal messages, with HIV seen as:

- » A punishment for immoral behaviour;
- » A crime with innocent and guilty victims;
- » A war on a virus that must be fought;
- » A horror in which infected people are demonised and feared;
- » “Otherness”, with the disease afflicting those set apart.

This approach was designed to frighten people into recognising the risk associated with HIV infection, but it also sowed the seeds of irrational fear. People did not fully accept the additional message that the infection could not be passed on through day-to-day contact, a message that continues to be poorly understood.

Myths surrounding HIV can contribute to the stigma. According to the NAM (2008): “The stigma associated with HIV is used to maintain some of the inequalities that already exist in society.”

Targeted prevention messages

HIV has been specifically associated with certain “risky” lifestyles and behaviours, such as homosexuality, drug addiction and prostitution.

The reported higher prevalence of HIV in some groups – such as black Africans and men who have sex with men (MSM) – means they need particular attention. The National Institute for Health and Clinical Excellence has issued draft guidance on increasing the uptake of HIV testing among these groups (NICE, 2010a; 2010b); the final guidance is due to be published this month.

Although this is well intentioned and while it may be necessary to prioritise prevention messages for those considered to be at high risk, messages that target only specific groups can cause problems. They can add to the stigmatisation of people in these groups and make them reluctant to admit risk or reveal their HIV status.

This targeting may also give people outside these groups a false sense that they are not at risk of HIV, provided they avoid those in targeted groups.

Tackling stigma

Tackling the stigma associated with HIV is vital because it can undermine attempts to stem the epidemic of HIV and AIDS worldwide.

United Nations’ secretary-general Ban

5 key points

1 The stigmatisation of people with HIV can be fuelled by racial, homophobic and drug-related prejudice

2 Prioritising prevention messages for those considered at high risk of HIV infection can add to the stigmatising effect

3 Nurses can reduce stigma by acting as role models, providing non-judgmental care, and challenging prejudice

4 People diagnosed with HIV are at risk of mental health problems

5 It is unrealistic to rely on antidiscrimination legislation to counter the stigmatisation of people with HIV



Former health minister Norman Fowler launched the Don't Die of Ignorance campaign in the mid-1980s

BOX 1. HIV FACTS AND FIGURES

- Around 86,500 people were living with HIV in the UK in 2009;
- Around a quarter of those were thought to be unaware of their diagnosis;
- More than half of those diagnosed with HIV and accessing care in 2009 were infected via heterosexual sex;
- 41% of the estimated total and an estimated 42% of new

infections in 2009 were acquired through sex between men;

- In heterosexuals, females aged 15-24 and males aged 25-34 have the highest rates of recent infections;
- Half of adults diagnosed with HIV in 2009 were at a late stage of infection.

Source: Health Protection Agency (2010)

take precautions only with those known to be HIV positive, as a quarter of people who are HIV positive do not know they have the virus.

» **Opt-out HIV testing:** a major success of recent years has been in the shift towards opt-out testing in maternity services, leading to greater uptake and allowing HIV status to be known before delivery. This has resulted in major reductions in vertical transmission (mother to child). Wider opt-out testing could reduce the proportion of people who do not know they are HIV positive, and assist in reducing onward transmission.

Conclusion

Although it is unrealistic to think the stigma associated with HIV can be eliminated, we can reduce its effects by challenging misconceptions and judgmental attitudes. This will improve the quality of life of those living with HIV, and is likely to increase the uptake of both screening and treatment. In addition, people with HIV will be more likely to receive and act on information about preventing onward transmission. This has both human and financial benefits as the cost of preventing HIV transmission is considerably less than the cost of treating the condition. The message must be “less blame, less shame, less stigma, less HIV”.

Nurses can only help to reduce HIV stigma if they are well informed. Specialist HIV nurses have increasing workloads but, in collaboration with other agencies involved with the communities where they work, could contribute to training. Well informed, compassionate nurses could do much to educate the public and counter self-stigma in patients. **NT**

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Ki-Moon (2008) has described stigma as the most important barrier to public action and a main reason why many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment. If people fear being shunned by family, peers and the wider community, they are unlikely to request testing, or may hide the condition and avoid seeking support.

Preventing HIV

Denial often goes hand in hand with discrimination, and many people deny HIV exists in their community.

Community inclusion projects should focus on changing attitudes to combat ignorance, with the message that everyone is equally valuable to society. A national campaign, emphasising whole-society compliance with prevention is needed. The following areas also need to be addressed:

» **Religious groups:** HIV is often associated with allegedly “morally unacceptable practices” leading to fear of judgement and exclusion. Working

with religious leaders can help them to understand HIV and related issues.

» **School and workplace education:**

regular reinforcement of health promotion messages about HIV will prevent “collective amnesia” about it.

» **HIV champions:** highly visible, HIV-positive role models can help break down stigma, yet there are very few in the UK. Involving people living with HIV in combating stigma could lead to a greater understanding of their needs and of the negative effect of stigma.

» **Clinical education:** this should keep staff knowledge up to date and change negative attitudes. If people with HIV think they will be treated as “unclean”, they will avoid seeking help, so they will not receive treatment or education to prevent onward transmission.

» **Universal precautions:** the importance of practising universal precautions to prevent infection with HIV or any other bloodborne virus must be re-emphasised. It makes no sense to