

HIV in the UK

Poul Rohleder, Tomás Campbell, Audrey Matthews and Jenny Petrak consider the ongoing challenges

Over the past 30 years of the HIV epidemic, many advances have been made in HIV treatment and care, and HIV is now considered to be a chronic medical condition rather than the fatal illness it once was. People living with HIV are able to live longer, healthier lives. However, stigma remains a significant problem. The stigma of HIV also intersects with other traits, behaviours and identities that are considered undesirable.

This article takes a brief look at some of the more significant issues here in the UK, focusing specifically on stigma and its impact on mental health. Research has shown that mental health is an important component in HIV care, and greater attention to this is needed, at this time of great economic uncertainty. HIV requires a multidisciplinary response, and psychologists from a variety of subdisciplines have much to contribute.

question

What challenges do psychologists face in delivering services to people living with HIV in the UK?

resources

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www.bps.org.uk/standards-psychological-support-adults-living-hiv

There may be some of you that are thinking that HIV is not a big issue here in the UK; that the much-feared plague of death that people were expecting in the very early 1980s did not happen, and that everything is pretty much under medical control. While on the surface this may seem true, this obscures the many considerable challenges that people living with HIV in the UK continue to face.

It was evident from the very early days of the discovery of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) that they were associated with considerable psychological, social and political challenges. Since the start of the HIV epidemic, the disease was associated with groups of people already stigmatised, even denigrated, by society. Susan Sontag (1991), writing about the metaphors associated with HIV and AIDS, observed how these were often associated with notions of sin and punishment. Before HIV was identified, the syndrome later known as AIDS was first referred to as the 'gay cancer' or gay-related immune deficiency (GRID). It was constructed as the 'gay plague' come to punish the immorality of 'gays' as well as prostitutes and drug addicts.

We have certainly come a long way since then (see 'Milestones'). There is a greater level of knowledge and understanding about HIV, its transmission and prevention, and improved care and treatments. With improved medical treatments, HIV has become, for many, a chronic, manageable illness, rather than the death sentence that it was seen to be.

While some people may still think of

HIV as a 'gay disease', HIV and AIDS has gradually come to be decoupled from men who have sex with men ('gay AIDS'). However, while the HIV epidemic grew exponentially in poorer regions of the world, particularly in sub-Saharan Africa, HIV and AIDS has come to be associated with Africa ('African AIDS'). The HIV epidemic is perhaps the biggest global public health crisis facing us today, particularly in sub-Saharan Africa, with 34 million HIV-positive individuals worldwide at the end of 2011 (UNAIDS, 2012).

After three decades of the HIV epidemic and advances in medical treatment and care, we may think that all is OK, certainly here in the UK. While statistically the HIV epidemic in the UK is small, it is still a significant problem, and, unfortunately, has continued to grow. At the end of 2011, approximately 96,000 people were living with HIV in the UK, of whom an estimated 24 per cent were not aware of their infection (Health Protection Agency, 2012). Challenges certainly remain: biological, psychological and social. Challenges to which psychologists can make a valuable contribution towards facing.

Stigma – continuing the othering

HIV continues to be a highly stigmatised disease. Goffman (1963) provided a seminal conceptualisation of health-related stigma in which he considered it to be 'an attribute that is deeply discrediting' (p.13) and one which creates, what he termed, a 'spoiled identity'. The mechanism for this process is a societal one by which difference (that which is undesirable) is identified and located in an individual or group. While there has been considerable investment in addressing the medical and behavioural aspects of HIV prevention, stigma prevention efforts are on the most part not as much of a priority. Because stigma may operate at the level of the individual and also at organisational and societal levels and may be affected by different cultural or national settings, it has been

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difficult to measure the extent and impact of stigma, both on individuals living with HIV and wider healthcare and societal structures (Sengupta et al., 2011).

Parker and Aggleton (2003) further argue that stigma is not a static process but rather one that is constantly changing and is fundamentally underpinned by power. In this conceptualisation power can be economic, social or political, but the purpose of stigma is to enhance and reinforce social inequality and to marginalise those who are identified as different and undesirable.

The effects of stigma may also be a layered experience. This idea refers to HIV being particularly prevalent in certain groups or associated with sexual behaviours or drug-using behaviours, all of which are already stigmatised. In this way HIV stigma also becomes attached to other 'traits or behaviours that are undesirable' (Swendeman et al., 2006, p.502). This interaction of HIV and personal characteristics that may already have stigma attached to them provides a context in which the importance of the individual factors become blurred and stigma is experienced at many levels.

From the start HIV has been associated

with gay men, an already stigmatised group. In recent years, there has been a gradual shift to associating HIV with Africa, and, in the UK, African men and women. According to official statistics, there has been an increase in HIV prevalence acquired through 'heterosexual' transmission. Research suggests that the majority of HIV infections in the UK that were acquired through heterosexual sex were probably acquired in African countries, particularly the high-prevalence countries of sub-Saharan Africa (Sinka et al., 2003). The reporting of ethnicity in such statistics is controversial, and may lead to easy stereotyping. Social discourses prevail about 'health tourism': the notion that certain migrants are understood as coming to the UK in order to access free health care, and in so doing, abusing the British

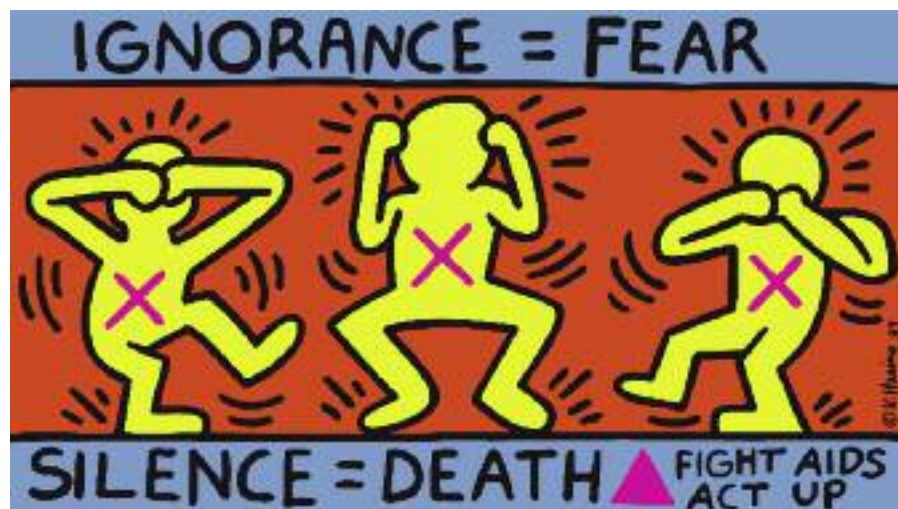
Milestones

- 1981 USA reports first AIDS cases in gay men
- 1983 HIV virus identified
- 1987 UK government 'Don't Die of Ignorance' campaign
- 1988 World AIDS Day established
- 1991 Freddie Mercury dies of AIDS-related illness
- 1992 First combination therapies introduced
- 1995 AIDS diagnoses in the UK exceed 10,000 and >25,000 living with HIV
- 1997 Deaths amongst PLWHA fall with introduction of anti-retroviral therapy (ART)
- 2000 Routine antenatal HIV testing introduced across UK
- 2000 >30 million PLWHA worldwide
- 2001 First criminal trial for reckless transmission of HIV held in Scotland
- 2002 Global fund is established to boost response to HIV, TB and malaria worldwide
- 2010 US HIV travel ban ends
- 2011 HIV 'treatment as prevention' hailed as major breakthrough

healthcare system. Thus many members of the general public might think that HIV-positive migrants arrive in the UK knowing their status, and with the intention of accessing free health care. However, these myths of HIV-related 'health tourism' are not supported by data, which suggests that the majority of migrants only learnt of their HIV status some time after arriving in the UK (National AIDS Trust, 2008).

Furthermore, HIV anti-retroviral medication may have side-effects that result in physical stigmas. One such side-effect is lipodystrophy, where there are changes in body fat. An individual may lose body fat, such as in the face, leading to a gaunt appearance. An individual may also gain body fat in certain areas, such as in the neck and shoulders. This results in visible stigmata for individuals, and is a considerable body-image concern for people living with HIV.

Much of the stigma research to date has focused on changing negative attitudes towards people living with HIV or AIDS (PLWHA), and HIV-positive adults' perceptions of stigma and its impact on their physical and psychological well-



Ignorance = Fear, 1989. HIV continues to be a highly stigmatised disease

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Working with people living with HIV

I began my qualified career as a clinical psychologist in a Sexual Health and HIV Service in Scotland in early 2009, having worked with a variety of long-term conditions prior to and throughout my extended doctoral training. I was reassured by colleagues that I had many transferable skills (e.g. biopsychosocial assessment, formulation, working with health beliefs, adherence issues, individual and systemic responses to a diagnosis, etc.) to put to good use in my first post and that the progressive nature of the specialist field I was launching my career in would keep me enthused for some time. After four and a half years, these words still hold true and my diverse role continues to captivate me daily.

Referrals include adults and older adults who are HIV positive from a multitude of backgrounds and cultures. Presenting difficulties (often unrelated to HIV) cover such a broad spectrum of issues that formulation is a truly fascinating process. Many patients have a mental health history (sometimes unrecognised) and experiences of social discrimination long pre-dating their HIV diagnosis, whilst the emotional struggle of other patients can be a very new experience. Individual therapy

may focus on issues such as adjustment to HIV, adherence to anti-retroviral therapy, disclosure and stigma worries, sexual health and sexual-risk-taking concerns. However, at times, the focus instead relates to difficulties such as anxiety, depression, self-esteem, substance misuse and/or trauma, just as in any other mental health setting. Having helped to deliver various self-management groups for patients with other long-term conditions in the past, I had not quite anticipated the complexities that setting up group work in an HIV service might entail, given disclosure concerns for many who remain intensely private about their condition.

Another hugely fulfilling part of my role is consultancy with colleagues. This can involve sharing the key, relevant themes of a formulation and the context of an individual's HIV diagnosis with those most involved in their care or, when appropriate, consulting with the wider healthcare system to inform patient understanding and management. Being based and embedded within the service with easy access to colleagues certainly facilitates this important part of my job. In addition, I work closely with colleagues from a variety of voluntary sector agencies that provide invaluable

services, such as advocacy, employment advice and peer support to many of our patients.

It has been really interesting coming into an area where science is progressing at speed and the meaning of a diagnosis has so quickly changed from one of a terminal illness to a long-term condition with a more or less normal life expectancy. Although the rapid developments from HIV research have undoubtedly benefited the lives of HIV patients hugely, it has been striking to observe some of the trickier issues that have accompanied such changes. Long-term survivors of HIV, who were diagnosed before anti-retroviral treatment was available, have shared with me how difficult it has been for them to adjust to the changing nature of care offered. Having previously received intensive support from well-resourced services set up in response to the HIV epidemic, progress in treating the condition coupled with the current economic climate has meant that such concentrated input is now generally deemed unnecessary and no longer possible. For some of these patients, this new, more time-limited, self-management approach can therefore be extremely difficult to engage with. Interestingly, some healthcare providers working in the field

since the earlier days of HIV have also found this a difficult transition.

The changing economic climate, resulting in a dramatic overhaul of the benefits system, has also had other knock-on effects on my work, and benefits worries are increasingly a topic high on my patients' agendas. Many HIV patients, who were previously led to expect financial support for years (and sometimes for life), are now being ushered to work. Whilst in countless cases, employment seems to be in patients' best interests, it is unsurprisingly an exceptionally daunting prospect for those who have not worked for years during which the employment landscape has changed dramatically.

My experiences to date have shown me firsthand the value of a close working relationship with my medical colleagues as part of effective HIV treatment. When patients' mental health issues are identified and effectively treated, their ability to adhere better to their anti-retroviral medication, reduce their high-risk behaviours and/or engage fully with society again can be remarkable. It is these kinds of improvements in patients' quality of life that attracted me to our profession and this specialty in the first place.

Dr Audrey Matthews

being. Interventions have sought to change negative perceptions of people with HIV through mass media campaigns, education about transmission and enactment of laws to prevent discrimination. However, UK-based research suggests HIV-stigma is stubbornly resistant to change. The National AIDS Trust reported that in their 2010 survey of 1944 adults, 64 per cent of respondents agreed that there is still a lot of HIV stigma in the UK (NAT, 2011).

While there is some evidence that psychosocial interventions may reduce stigmatising attitudes and behaviours towards PLWHA (Sengupta et al., 2011), surprisingly little is known about the efficacy of such interventions in demonstrating a public health benefit (such as increasing access to testing and treatment, improved mental and physical health outcomes or increased social support for PLWHA). Psychological interventions to address or counter the negative effects of stigma amongst PLWHA are even rarer and suggest that this is an area in which psychologists have expertise, given the extensive literature about interventions to help other populations (e.g. people with intellectual disabilities, those with psychosis) cope more effectively with others' prejudices and negative attitudes toward them.

Living with a 'spoiled' identity

There is increasing acceptance that HIV stigma has complex and mostly negative effects on people living with HIV. Stigma can be a barrier to accessing HIV testing and HIV-related health care, and may result in poorer social support and poorer mental health in people living with HIV. Additionally, fear of disclosure of status to others may affect adherence to anti-retroviral therapy (ART).

From the start of the epidemic, mental health problems have been associated with HIV and AIDS. Mental health problems were traditionally understood as associated with the various risk factors (e.g. drug use) for HIV infection. It was also recognised that receiving a diagnosis was psychologically traumatic, in that there were severe consequences of having HIV, including the resulting denigration and exclusion from a broader society. AIDS-associated dementia was also a significant problem for patients with AIDS in the early days. With the arrival of anti-retroviral treatment, the profile of mental health problems associated with HIV has shifted to those associated with living with chronic illnesses (Williams & Catalan, 2009). Organic problems associated with AIDS have declined as fewer people progress on to AIDS, and other mental

disorders such as depression and anxiety have increased.

In our clinical work with people living with HIV (see 'Working with people living with HIV'), stigma remains a central concern for HIV-positive individuals. Fear of rejection and actual rejection leave many feelings isolated and lonely. A further central concern for many is the damage to their sexual identity and sex lives. Many of the clients we see may want to have sex, but find it very difficult to find opportunities with potential sexual partners. They have either experienced rejection from potential partners, or fear rejection if they disclose their HIV status. This is a particularly salient concern for adolescents living with HIV transitioning into adulthood (Hogwood et al., 2012). Some people living with HIV also struggle with feelings of shame, as a consequence of having become infected with HIV, which many in their family and social environment may continue to view as 'punishment' for immorality. As a consequence, receiving an HIV diagnosis, and living with HIV, has a number of adverse psychological and social consequences. Recent reviews of the international literature suggest that HIV-positive individuals have higher rates of depression, anxiety and suicidality than HIV-negative individuals (e.g. Sherr et al., 2011).

No HIV health without mental health

Mental health has an impact on HIV-prevention efforts for people living with HIV/AIDS. People living with HIV as a chronic illness on ART live longer and healthier lives, but may require support with regard to their long-term psychosocial needs and maintaining safer sexual behaviours. Studies have shown that where an individual has HIV and a co-occurring mental illness, their physical health suffers (Cook et al., 2004). Depression has also been shown to be a major barrier to HIV medication adherence (Lampe et al., 2012). Thus, meeting the mental health needs of people living with HIV has increasingly been recognised as a necessary component of HIV treatment and care.

Recently, the British Psychological Society, together with the British HIV Association and the Medical Foundation for AIDS & Sexual Health have published *Standards for Psychological Support for Adults Living with HIV* (2011), which highlights the importance of identifying psychological difficulties among people living with HIV and providing interventions to promote mental health

and well-being. The specific standards are:

- | Standard 1: Promotion of mental health and psychological well-being
- | Standard 2: Comprehensive psychological support services
- | Standard 3: Engagement of people living with HIV
- | Standard 4: Support at time of diagnosis
- | Standard 5: Identifying psychological support needs
- | Standard 6: Competence to provide psychological support
- | Standard 7: Coordination of psychological support
- | Standard 8: Evidence-based practice

This comes at a time of considerable uncertainty around HIV care in the NHS. There have been recent discussions in the UK about mainstreaming healthcare services for HIV, which has been critiqued as offering less specialised care to deal with the complex needs of persons with HIV (Weatherburn et al., 2007). Many symptoms of depression may resemble those of chronic HIV infection, and so may not be recognised by healthcare workers and GPs who may not be trained to detect mental health issues. The NHS is also witnessing significant budget cuts in these current times of austerity, which impact on the delivery of HIV prevention, care and treatment, including psychology.

However, the HIV epidemic continues to be far from over, and its psychological impact also continues to be particularly felt in terms of concerns such as stigmatisation and depression. In the current climate, it is important that we do not lose the impetus of three decades of developing, promoting and delivering biopsychosocial models of care in HIV.



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