

Editorial

HIV and primary health care: disclosure and discrimination

In 2007 nearly 80,000 people were living with HIV in the UK of whom around a quarter were unaware of their infection (Health Protection Agency, 2008a). Most people in the UK who have been diagnosed with HIV attend an NHS specialist outpatient clinic for their treatment and care (British HIV Association, 2007). As a consequence, in the UK, nearly all patients with HIV currently receive their HIV care in a hospital rather than in a primary health care setting. This may change in the future (British HIV Association, 2009). In the meantime, what is the role of primary health care in supporting people with HIV? And what are the key research questions concerning the care of people with HIV in primary health care?

While this editorial focuses on HIV in the UK, it has relevance for service delivery and research in other countries too. The two groups most affected by HIV in the UK are gay men (mostly white) and black African heterosexual men and women. Together, they account for 80% of people currently diagnosed with HIV in this country. Many of the black African heterosexual men and women acquired HIV in Africa while the majority of gay men acquired their infection in the UK. About 10% of gay men with HIV are from an ethnic minority background. White and black Caribbean heterosexual men and women account for a further 10% of people living with HIV in the UK (Health Protection Agency, 2008b; 2008c).

In the UK, the overwhelming majority of HIV-positive patients attending specialist NHS outpatient clinics are also registered with a general practice – around 80–90% (Elford *et al.*, 2007; Burns *et al.*, 2008). In addition, the majority of those who are registered say they have told their GP about their HIV diagnosis – again, around 80% (Elford *et al.*, 2007; Ian Williams, personal communication). So the primary health care team

is usually aware of the patients on its list who have been diagnosed with HIV. What they may not be aware of is that for many patients “HIV is only one of many problems and...not (necessarily) the most important” (Flowers *et al.*, 2006).

While most people with HIV infection appear to have told their GP about their diagnosis, disclosure to other people is much more variable. In a study conducted in North East London in 2004–2005 among nearly 1700 people living with HIV, we found that only one in five respondents had disclosed their HIV status to their employer (Elford *et al.*, 2006; 2008a). There were striking differences by ethnicity in the extent to which people had disclosed their infection. Nearly a third of white gay men had told their employer they were HIV positive compared with <20% of ethnic minority gay men and around 10% of black African heterosexual men and women. Fear of discrimination at work and anxiety about losing their job are almost certainly the main reasons why someone with HIV would conceal their HIV status from their employer (Simoni *et al.*, 1997). Yet, paradoxically, by not telling their employer about their infection people with HIV may be denying themselves their rights under the Disability Discrimination Act 2005 (National AIDS Trust, 2007a; 2007b).

Compared to white gay men, black African heterosexual men and women were less likely to have disclosed their HIV status not only to their employer but also to their current partner, family, friends or colleagues. Ethnic minority gay men were also less likely to have told their friends or parents about their HIV status than white gay men (Elford *et al.*, 2008a). These differentials highlight the continuing challenge HIV disclosure presents particularly for black African heterosexual men and women, a group that reports high

levels of HIV-related stigma (Dodds *et al.*, 2004; Doyal and Anderson, 2005).

But the stigma surrounding HIV is not just confined to family, friends, employers or colleagues. Among the people living with HIV whom we surveyed in North East London, nearly one third said they had been discriminated against because of their HIV infection at some time since diagnosis (Elford *et al.*, 2008b). Of those who experienced HIV-related discrimination ($n = 403$), almost a half ($n = 200$) said this had involved a health care worker including their dentist ($n = 102$) or general practitioner ($n = 70$). People with a stigmatised condition such as HIV may try and conceal their condition to avoid discrimination (Goffman, 1963). Since the general practitioner is more likely to know about someone's HIV status than an employer, for example, this increases the chances of discrimination occurring in a primary health care setting. Our findings highlight the need for the Department of Health to implement an effective action plan to combat HIV-related discrimination in the UK, both inside and outside the NHS (Department of Health, 2006).

In our study of people living with HIV, a substantial number faced social and economic hardship, particularly black African and other ethnic minority respondents (Ibrahim *et al.*, 2008). Forty percent of black African heterosexual men and women, nearly a quarter of ethnic minority gay men and 10% of white gay men said they did not have enough money to cover their basic needs. Black African heterosexual men and women consistently reported more difficulties than any other group in relation to employment, income and housing.

Overall, just under half the respondents were employed at the time of the survey (2004–2005); gay men were more likely to be employed than black African heterosexual men or women. Levels of employment were highest for those who were diagnosed only 1 or 2 years before the survey but then declined steadily with the passage of time after diagnosis (Ibrahim *et al.*, 2008). Even in the era of highly-active antiretroviral therapy (HAART), it seems that people with HIV drop out of the labour force the longer they live with the infection.

Taken together these findings provide further evidence that, in the UK, HIV is associated with poverty particularly among migrant and ethnic minority populations (Crusaid and NAT, 2006).

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Another point to consider is the opportunity primary health care presents for diagnosing HIV at an early stage. At present over a quarter of people with HIV in the UK remain unaware of their infection (Health Protection Agency, 2008a). A study conducted among newly diagnosed HIV positive Africans in London found that in the year before their diagnosis three quarters had seen their GP (Burns *et al.*, 2008). Yet only one in five said that HIV testing had been raised by the GP during that consultation. With the remainder, four out of five, the GP had not discussed HIV testing. This represents a missed opportunity for early HIV diagnosis and for reducing the number of people who are unaware of their HIV status.

What are the implications of these findings for research and practice in primary health care? First of all, it is important to recognise that for many people living with HIV their medical treatment is just one of the things they have to think about while juggling their day to day concerns about housing, immigration status and having enough money to buy food and clothes. People with HIV are not alone in having to juggle their daily concerns while living with a long-term condition. The same applies to people with diabetes, heart disease or chronic respiratory disease, for example. The challenge for primary health care research is to find the most effective ways of providing clinical care for patients with HIV while being sensitive to the many other issues that shape their lives.

Secondly, people living with HIV experience stigma and discrimination not just in the workplace, in the family, among friends or colleagues but also in the NHS. As researchers we need to consider what are the views and concerns of primary health care practitioners about providing care for people with HIV? Research which focuses on the perceptions, misconceptions, skills and knowledge of the primary health care team may provide answers to this question. Answers which will help members of the primary health care team put in place policies and practices to ensure that patients with HIV are treated in the same way as all other patients.

Finally, there seem to be missed opportunities in primary health care for discussing HIV testing with people who may have been exposed to the infection. Primary health care is well placed not

only to provide support for people diagnosed with HIV but to also promote HIV testing among those who may have been at risk of infection.

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