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aids treatment update

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in this issue

During the course of researching this special issue of *ATU* on oral health and the dental profession, it became clear that the ongoing crisis within the NHS dental system does appear to have hit HIV-positive people especially hard.

The gradual erosion of free NHS dental care comes, perhaps, as a warning of what could happen when NHS healthcare in general changes to the payment by results system. The business-like, profit-focused attitude of some dentists – which appears to override any ethical responsibility to provide universal care – has led to some blatant cases of discrimination.

The short-term solution is for all HIV clinics to help their patients find good quality, timely, affordable, discrimination-free dental care.

In the mid-term, some guidelines from the British HIV Association would help standardise the quality of dental care available to HIV-positive people.

In the long-term, the government needs to fight HIV-related stigma and discrimination and work harder for equal access to healthcare for all, and in particular those of us who are unable to access private healthcare.

Doesn't it also make sense for NHS dentistry to be made available to all HIV-positive people free of charge, like the rest of our healthcare?

page 3 This month's *Upfront d*iscusses the implications of an important new study which challenges conventional thinking regarding the importance of viral load measurements as a predictor of CD4 cell loss.

page 4 In *Watch Your Mouth*, new *ATU* contributor, Derek Thaczuk, provides us with an overview of why oral and dental health matters to HIV-positive people.

page 8 In *(Trans)mission impossible?* we investigate the complex reasons why dentists appear to discriminate against HIV-positive people more than any other healthcare professional.

page 12 In *News in Brief* we find that CD4 counts don't significantly affect the risk of liver toxicity after switching to nevirapine; what happens to the one-in-six people new to anti-HIV therapy who interrupt their treatment within two years of starting; how to avoid HIV drug errors that can happen in hospital; and find that there's increased risk of HIV disease progression if CD4 counts don't rise despite having an 'undetectable' viral load.

page 14 In *Dentists: the good, the bad and the ugly* two *ATU* readers share their experiences with the dental profession.

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In *Watch your mouth*, we highlighted the importance of good oral health for HIV-positive people. And yet, whilst there are many things that we can do for ourselves to reduce the chances of problems with our teeth or gums, there is one area over which we have a lot less control: accessing good quality, timely, affordable, discrimination-free dental care.

This year, the media has been full of reports describing the extreme difficulties faced by the general public in accessing NHS dental care. But HIV-positive people have been experiencing these difficulties for years, and the problem isn't just limited to NHS dental care. NHS or private, HIV-positive people face a disproportionate amount of discrimination from dentists.

A 2006 survey of patients attending a large HIV clinic in north-east London found that one out of four people who had experienced any kind of discrimination due to their HIV status had been discriminated against by a dentist[1].

Dentists admit that they discriminate, too. A recent survey of dentists in south Cheshire found that only 45% would treat a diagnosed HIV-positive person without hesitation; and 20% said that they would refer an HIV-positive person elsewhere[2].

Why is it, that when we make it our mission to find a good dentist, it can feel like an almost impossible task? What factors make dentists think twice about treating us - or refusing to treat us at all? And why do dentists discriminate against us - more than any other group of healthcare workers - despite the fact that this kind of discrimination is unethical and outlawed under the Disability Discrimination Act?

It's not just us

NHS dentistry is facing a crisis of massive proportions. The rot set in when changes mandated by the Conservative government in 1990 meant that dental care was no longer universally free for people entitled to NHS services, unlike health care. Far from reversing this policy, the Labour government inadvertently made matters worse, culminating in the contract disaster this April which saw dentists leaving the NHS in droves. More than 1,600 of England's 21,000 dentists left the NHS at the start of April after rejecting a new contract that offered "a highly committed NHS dentist, on average, around £80,000 per year, with additional money for practice expenses, guaranteed for three years, along with a 5% reduction in work load."[3]

The result is that many people cannot find a local NHS dentist and those that do may have to pay private charges (which are up to three times higher than NHS fees[4]) and/or travel many miles from home, even in an emergency[5].

Another consequence of the reforms that began in 1990 is that specialised dental services for HIV-positive people lost their funding. Today, there are often long waiting lists for the two types of NHS services that tend not to discriminate against HIV-positive patients - the Community Dental Service or hospital-based Dental Access Centres - and some are only available to people with an AIDS diagnosis, which means that the majority of HIV-positive people are unable to access them.

Although there are no reliable data regarding how many HIV-positive people in the UK currently lack a dentist, it is estimated that only about half of the general population in the UK currently have a dentist[6]. Anecdotal evidence suggests that far fewer HIV-positive people seek regular, preventative dental care. Recently, I invited members of the *ATU* readers' panel to share their experiences with dentists. Many noted how hard it has been to find a dentist in the past, and some don't have one still. One panellist wrote that "[I] currently don't have a dentist (although I am looking for one), and haven't had one for a number of years."

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are dentists' irrational fears making it harder to access dental car

"We don't treat people like you"

According to the National AIDS Trust (NAT), the most common examples of HIV discrimination in a dental setting are:

- refusal to treat;
- inadequate and/or inappropriate counselling;
- inadequate and/or inappropriate treatment;
- breach of confidentiality and privacy; and
- unjustified changes in practice and safety procedure.

Real-life examples provided by NAT include one dentist telling an HIV-positive individual that it was "illegal" for him to treat HIV-positive patients, and another saying, "We don't treat people like you. We would have to close the surgery for an hour afterwards to disinfect it."[7]

A 2002 Terrence Higgins Trust (THT) report[8] chronicling the kind of discrimination HIV-positive people were experiencing at the dentist found:

- outright refusal of service;
- insistence on treating at the end of the day for "extra sterilisation procedures";
- persistently putting people with HIV to the end of operating lists (and thus effectively never operating on them);
- writing "HIV" in large letters on the front of patient records.

And a 2003 investigation by BBC Online[9] found that seven out of 30 dentists contacted by the BBC refused to commit to treating someone who told them they were HIV-positive.

What are the rules?

Discriminating against someone who is HIV-positive, purely because they are HIV-positive, is now against the law, thanks to the Disability Discrimination Act (DDA), which was amended in December 2005 to include HIV-positive people from the moment of diagnosis. Under the DDA, it is unlawful for a dentist not to provide services to an HIV-positive person that they would otherwise provide to members of the general public. To avoid breaking the law, a dentist would need to prove that any discrimination was justified.

In addition, there are two professional bodies that provide ethical and practical guidance to dentists. Specific guidance on discriminating against anyone with a blood-borne infection is provided by the British Dental Association (BDA). However, the BDA guidance is purely voluntary.

Highlights of the BDA's guidance[10] include the following:

> "Dental clinicians have a general obligation to provide care to those in need and this should extend to infected patients who should be offered the same high standard of care available to other patients.
>
> It is unethical to refuse dental care to those patients with a potentially infectious disease on the grounds that it could expose the dental clinician to personal risk. It is also illogical as many undiagnosed carriers of infectious diseases pass undetected through practices and clinics every day.
>
> "If patients are refused treatment because they are known carriers of an infectious disease, they may not report their conditions honestly or abandon seeking treatment; both results are unacceptable. Those who reveal that they are infected are providing privileged information."

n impossible?

? asks Edwin J Bernard

The General Dental Council (GDC) is the organisation that regulates dental professionals in the UK. All dentists, dental hygienists, dental therapists, clinical dental technicians and orthodontic therapists must be registered with the GDC in order to work in the NHS or in private practice. The GDC's regulations do not specifically mention blood-borne infections in their anti-discrimination guidance.

However, a spokesperson for the GDC told *ATU*, "We would take any allegation that a dental professional had discriminated against patients with HIV very seriously. Our guidance[11] makes it clear that dental professionals should not discriminate against patients on any grounds. It states that all dental professionals should: 'Treat patients fairly and in line with the law. Promote equal opportunities for all patients. Do not discriminate against patients or groups of patients because of their sex, age, race, ethnic origin, nationality, special needs or disability, sexuality, health, lifestyle, beliefs or any other irrelevant consideration.'

When the GDC was asked how many cases have come before them for refusal to treat because someone was HIV-positive, they were unable to provide any data. "We do not categorise cases to the level of granularity that would enable us to report on the number of cases involving refusal to treat on the grounds of HIV," said the spokesperson.

But from this December, the DDA requires all public bodies like the GDC to actively promote equality for all disabled people, including everyone with diagnosed HIV infection. What proactive measures is the GDC taking?

"The GDC is committed to promoting and developing equality and diversity in all its work," a spokesperson told *ATU*. "We ensure that our policies and ways of working are fair to all individuals and groups, regardless of their ethnic origin, race, colour, gender, religion, disability, sexual orientation or age. We proactively promote equality by making it clear to dental professionals that this is a key aspect of the professional standards which they are required to uphold in their work."

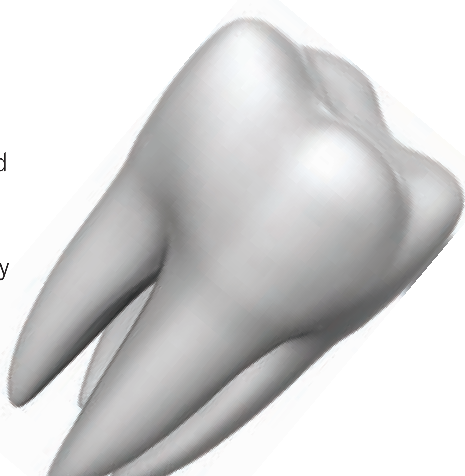
However, many dentists may still not be aware that HIV is a legally-protected disability.

Dentists' transmission fears

In 2004, Professor Michele Crossley, of John Moore's University in Liverpool, undertook a detailed investigation[2] into dentists' knowledge of, and attitudes to, HIV. She identified all 330 dentists who were practising in the South Cheshire region (Chester and the surrounding towns between Liverpool and Manchester) and sent them all a questionnaire. Although only 152 (46%) responded, and these respondents might not represent all dentists, the study's findings provide some fascinating - and surprising - insights.

One of the most worrying findings was that although 99% correctly identified blood as a mode of HIV transmission, only 46% knew that saliva does not transmit HIV. Consequently, the study found that around one-in-three were worried about occupational exposure to HIV infection, although only 3% believed that HIV transmission was "very likely".

According to the Health Protection Agency[12] there have been no reports of a dentist becoming infected with HIV during the course of their work in the UK. Worldwide, no documented case of occupationally-acquired HIV infection has ever occurred in dentistry, and only 3% of all possible global cases of healthcare workers being infected with HIV at work involved dental workers.



Dentists' exposure fears

In a more detailed follow-up study[13], Professor Crossley asked fifteen dentists to talk more about their attitudes to HIV. It transpired that some of the dentists were more concerned about taking post-exposure prophylaxis (PEP; a month-long course of anti-HIV therapy to reduce the risk of becoming HIV-positive after being exposed to HIV) than the risk of acquiring HIV. One dentist had been on an HIV awareness course, which had changed his attitudes significantly, although he still had "mixed feelings" and remained fearful: "What continues to worry me," he said, "[is] the [drug] regime you had to go through [which] was horrendous."

Occupational HIV exposure usually occurs if a healthcare worker accidentally injures themselves with a needle or sharp object that had previously been in contact with HIV-infected blood. There are no data for the UK, but a 2006 review of HIV transmission in dentistry reports that in the United States (with a population five times that of the UK, and an HIV prevalence that is fourteen times greater than the UK) there were only 24 cases reported to the US Centres for Disease control between 1995 and 2001 where a dental worker was accidentally exposed to HIV-infected blood from a diagnosed HIV-positive individual. None of these exposures resulted in HIV infection.[14]

Consequently, not only are the odds of becoming HIV-infected after a needle or sharp instrument injury incredibly low (officially estimated to be 1-in-333 without PEP[15]), but the chances of this kind of accidental exposure happening in the first place are even more remote.

Perhaps the most surprising finding in Professor Crossley's study was that the greatest worry for dentists was dealing with staff fears about HIV: 59% cited this as a concern. Even though there are firm and stringent guidelines from the BDA regarding the importance of good

communication, staff training, and the use of universal infection control procedures, one dentist told Professor Crossley: "Fear isn't rational. It doesn't relate to risk. If people are afraid, as an employer it is my responsibility to make people feel safe."

Public perception

Addressing dentist and staff fears could probably be improved by more training, and by the GDC making HIV-specific training mandatory. But Professor Crossley also identified areas that are harder to tackle, including public perception. One-in-three dentists were worried about losing other patients if it became known that they were treating HIV-positive people. Aside from the extremely important issue of breaching patient confidentiality, this also suggests that HIV remains a highly stigmatised condition, and that a widespread government campaign to inform the public of the real risks of HIV transmission is necessary. Certainly, the results of a recent European Commission survey[16] - which found that many people throughout Europe believe that HIV can transmitted through kissing, giving blood, sharing a glass or using a toilet seat - suggest that widespread ignorance around HIV transmission risks may be fuelling HIV-related stigma and discrimination.

Financial burden

To help deal with this, the BDA recommends that dentists display "an infection control statement. [which may] help allay patient anxiety and gain their confidence." However, one-in-three dentists cited the financial burden of "extra" infection control that they thought was necessary when treating HIV-positive patients.

Universal infection control precautions, as recommended by the BDA, minimise the risk of blood-borne infection transmission between patients, and between dental workers and patients. They include the use of protective barriers (e.g. gloves, gowns or aprons, masks, and protective eye wear); careful handling and disposal of needles or other sharp objects; hand-washing and/or use of alcohol hand rub before and after a procedure; safe disposal of waste contaminated with bodily fluids and blood; proper disinfection of instruments and other potentially contaminated equipment; and the use of disposable, one-use instruments where possible.

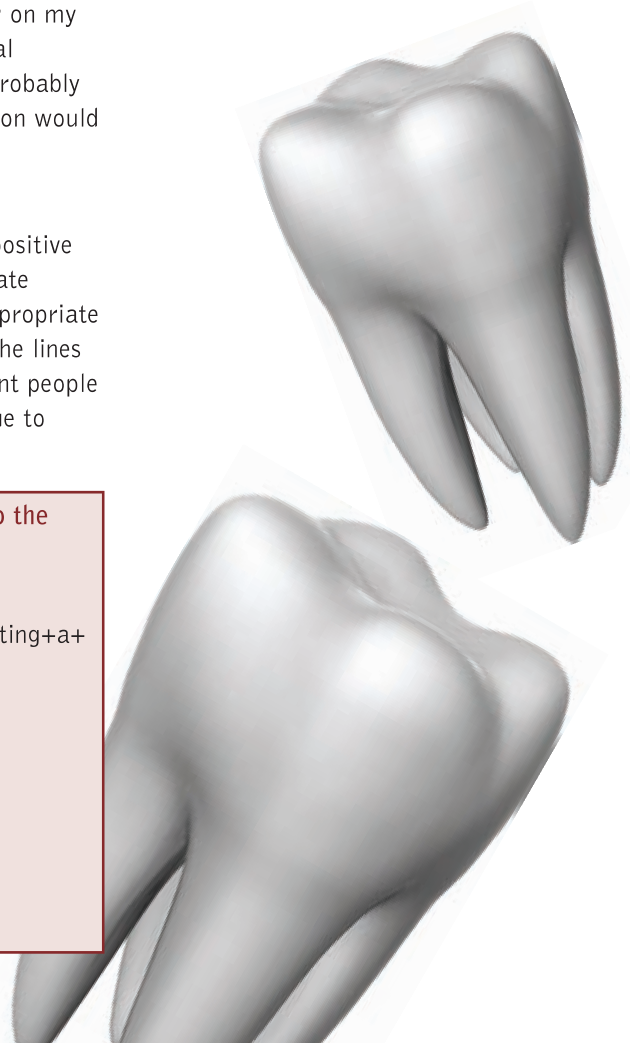
One dentist told Professor Crossley, "Sure, there's the argument that routine [infection control procedures] should be sufficient but I would want to do more - it's probably fear on my part, but there's that additional anxiety. It's a fatal disease - probably patient to patient cross-infection would be less of a worry than patient-dentist."

Many dentists said that HIV-positive patients require disproportionate amounts of time to provide appropriate care, and some argued along the lines that "resistance from intelligent people to treating these patients is due to financial reasons - at the end of the day, we're running businesses."

Double standards?

The same law that protects HIV-positive people from being discriminated against by dentists also provides protection for HIV-positive people in the workplace. Current Department of Health (DH) regulations[17] mean that HIV-positive dentists are not allowed to practice any invasive procedure. This basically means that the only job they can do in a dentist's practice is to work on reception. Yet, the DH Risk Assessment Expert Group estimates that the risk of an HIV-positive healthcare worker infecting a patient is between 1-in-5 million and 1-in-10 million - practically impossible![18]

Is it possible that this double standard - mandated by the DH and regulated by the GDC - is also inadvertently contributing to the ongoing discrimination that some members of the dental profession display towards HIV-positive people?



If you experience discrimination from your dentist, you can complain to the GDC through the following channels.

NHS dentists
www.gdc-uk.org/General+public/Reporting+unfitness+to+practise/Reporting+a+dental+professional.htm

Private dentists
www.dentalcomplaints.org.uk/

Call the **Disability Rights Commission Helpline** (8am-8pm Mon-Fri) if you think you have a case for claiming disability discrimination.

tel 08457 622 633 textPhone 08457 622 644
fax 08457 778 878 web www.drc-gb.org/about_us/helpline.aspx