

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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## Aims and Scope

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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# Past, present and future

Juliet Bennett

Independent Nurse Advisor

Happy **10th Anniversary** *HIV Nursing*  
and welcome to our 11th year of publication

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**N**ow in its third decade, the HIV epidemic has matured, in many ways beyond recognition for those of us who have lived with and/or worked alongside it. Today, HIV presents a whole host of new and different challenges both for those living with the virus and for those coming to work within the speciality for the first time, as well as for us 'old hands'. However, as many of the articles in this issue illustrate, some challenges have remained stubbornly present. Stigma and prejudice, ignorance and inequality remain deeply entrenched.

The fundamental nature of the care we provide has changed over the past two decades from acute to chronic and from inpatient to outpatient/clinic based. Today drug treatment advice, side-effect management and the medical conditions of older age are dominating our time, rather than the diagnosis and treatment of opportunistic infections and palliative care. We have learned so much in the process about providing truly patient-centred and responsive care. Instead of splitting biological and psychosocial services, for example, we have forged many effective ways of working collaboratively with other health and social care professionals and with the voluntary sector, which has allowed these elements of care provision to be accommodated within a holistic and relatively seamless continuum of care. Sharon Wilson and Catriona Bellingham both illustrate how times have changed in clinical practice in their accounts of their changing and developing professional roles.

The articles by Tom Matthews and Robert Fieldhouse give us real insight into the lived

experience of those diagnosed at different time points in the epidemic and show us that, while medical interventions are increasingly successful, high quality and holistic nursing care remain critical to the experience of those living with the virus.

In the UK, specialists will now have to adapt to the changing demands of providing broader primary care, and primary care providers will have to learn aspects of technical speciality care. Both areas must be addressed while at the same time strengthening appreciation of the importance of prevention and reaching those most at risk and most in need. The power of prevention is clear: in the developed world, antiretroviral treatment and safe infant feeding has virtually eliminated paediatric infections. Many believe that this is achievable in the developing world too; however, greater political commitment and continued resources are needed to make this a reality. Equity of access to care and treatment, prevention and reduction of stigma must be all our priorities, as Ian Hodgson writes.

As many of the articles in this edition demonstrate, there is real value in our past experience. We must not forget where we have been, all those who we have lost along the way and who contributed so much to our understanding of nursing in this area. The lessons learned to date will inform our understanding of the future, one that we can look forward to with optimism.

Thank you to all who contributed to this and to all past editions. Your willingness to share your experience and knowledge with others is valued and very much appreciated.

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# The HIV epidemic in the UK: the last 10 years and current priorities

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## Introduction

The HIV pandemic continues to grow and evolve. In the UK, the epidemiology and care of persons living with HIV has dramatically changed since the introduction of highly effective antiretroviral therapies in the late 1990s. This article gives a brief overview of methods used in HIV surveillance in the UK and provides a detailed picture of the HIV epidemic and major trends over the last decade.

## Surveillance systems in the UK

Surveillance data are the key to tracking efforts to curb the epidemic, for setting public health policies and evaluating prevention efforts aimed at those most at risk of the infection. The UK has some of the most comprehensive surveillance of HIV in the world. Important surveillance methods employed to provide a comprehensive picture of the HIV epidemic in the UK are briefly described below. More detailed descriptions of these methods are available at the Health Protection Agency (HPA) HIV website ([www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/](http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/)).

The routine reporting of new cases of HIV and AIDS and deaths in HIV-infected individuals provides the backbone of the surveillance of HIV in most developed countries. In the UK, case reporting is supplemented by laboratory downloads of all CD4 cell counts and an annual survey (biannual in London) of persons in HIV care. The Survey of Prevalent HIV Infections Diagnosed (SOPHID) collects demographic, risk-factor and clinical information, and therefore provides a rich epidemiological snapshot of prevalent cases of HIV. Linked over time, this allows for the monitoring of the quality of HIV care received in over 220 HIV clinics. Surveillance data for Scotland and children are collected separately by Health Protection Scotland and the Institute of Child Health, respectively, and added to the final UK datasets.

In addition, the HPA conducts annual unlinked anonymous (UA) serological surveys in four key adult populations: pregnant women, injecting drug users (IDU), sexual health clinic attendees and men who have sex with men (MSM) recruited through the Gay Men's Sexual Health Survey (in collaboration with University College London). These data provide basic epidemiological and

behaviour data but, more importantly, allow for the calculation of estimates of undiagnosed HIV infections in these groups and settings. Findings from these UA surveys together with data from SOPHID, new diagnoses and other sexual behaviour surveys, are fed into a statistical model, known as a multi-parameter evidence synthesis (MPES) model, to provide national estimates of persons living with HIV in the UK, including both diagnosed and undiagnosed infections.

More recently, laboratory techniques, refined at the HPA and elsewhere, are used to distinguish recently acquired from long-standing infections among newly diagnosed cases of HIV using an aliquot of the original diagnostic sample. Results of the tests are interpreted with clinical and epidemiological information (CD4 cell count, AIDS indicator diseases and antiretroviral treatment) to reduce the likelihood of misclassification and together comprise a recent infection test algorithm (RITA) result. Almost 40% of all newly diagnosed persons had a RITA result in 2010, providing a means of measuring current levels of HIV transmission among most-at-risk groups. At the clinic, RITA results may create an opportunity for focusing partner notification to a recent time frame (within 4–5 months of diagnosis), particularly among those with multiple sexual partners.

## Overall epidemiological trends

Over 86,500 people were estimated to be living with HIV by the end of 2009. This figure includes approximately a quarter (over 22,200) persons who remain unaware of their infection as well as those receiving HIV care. A number of factors are likely to contribute to the high number of persons who remain undiagnosed, including: the long asymptomatic phase of the infection, the stigma surrounding the infection, the fear that it is a deadly infection despite effective therapies, and low risk perception. A recent study shows no evidence of a decline in the prevalence of undiagnosed infection between 2001 and 2008 across England and Wales [1].

The overall crude prevalence rate of 1.4 persons living with HIV infection per 1000 population (1.9/1000 men and 0.91/1000 women) is low compared with rates seen in low- and middle-income countries and similar to other countries in Europe [2]. However, crude rates mask high prevalence rates of HIV infection among

specific populations, namely men who have sex with men (MSM), African and Caribbean communities and persons with a history of injecting drug use [3].

The introduction of antiretroviral therapies in the mid 1990s resulted in a rapid decline in AIDS and death reports and a steady rise in persons living with diagnosed HIV. By 2009, over 65,000 persons (43,000 men and 22,000 women) were attending HIV services for their care, nearly a three-fold increase since 2000 (22,500 in total). The rise in prevalent cases has been particularly striking among adults aged 50 years and over, with a tripling in cases between 2000 and 2009 (from 2432 to 12,063). Older adults now represent one in five of all adults seen for HIV care.

Between 2000 and 2007, approximately 70% of HIV diagnosed persons were receiving antiretroviral therapy; this increased to 78% in 2009. This rise reflects the 2008 British HIV Association (BHIVA) guidelines [4] that recommend the initiation of treatment when an individual's CD4 cell count reaches 350 cells/mm<sup>3</sup> or below. The proportion of individuals with a CD4 cell count less than 350 cells/mm<sup>3</sup> who did not receive treatment in 2009 was 17% compared to 25% in 2007.

The continued increase in the number of persons living with HIV over the past decade is due to an ageing cohort on effective therapies as well as an increase in new diagnoses. The annual number of new diagnoses rose substantially in the late 1990s and reached a peak of almost 8000 in 2005 before reducing to around 6500 cases over the past few years. (An estimated 6750 persons were newly diagnosed with HIV infection in 2010.) The relatively small decline in new diagnoses in recent years is largely due to fewer reports among persons infected heterosexually abroad (mainly in sub-Saharan Africa) whilst cases in MSM remain unacceptably high.

The geographical distribution of the HIV epidemic has also changed over the past decade. Whereas new and prevalent cases were focused in London in the early part of the epidemic, a greater proportional increase in cases diagnosed in regions outside London was observed during the first decade of the millennium especially in Yorkshire and the Humber (250% increase), the North East (240%) and the East Midlands (230%) compared to London (20% increase). Despite these trends, London remains the region with the highest absolute number of cases diagnosed annually and with more than 40% of cases diagnosed in London. Similarly, SOPHID data indicate a shift towards higher numbers of persons accessing HIV care outside the capital, although 44% (28,000) of all diagnosed persons access their care in London.

## Late presentations

Morbidity and mortality associated with HIV infection is greatly reduced in the UK in the era of antiretroviral therapy; nevertheless, over 500 AIDS diagnoses and 500 deaths are reported in those infected each year. Most of the AIDS presentations and three-quarters of deaths were among late presenters.

About half of all adults diagnosed in 2009 presented at a late stage of their HIV infection and had a CD4 cell count less than 350 cells/mm<sup>3</sup>. Late presentation was more common among heterosexual men (66%) followed by heterosexual women (59%) and MSM (39%). Persons diagnosed late are more than 10 times more likely to die within the year of their diagnosis [5,6]. The risk increases to 14 times among older adults [7].

## Exposure category

### *Men who have sex with men*

MSM remains the group at greatest risk of HIV infection and accounted for 42% of all newly diagnosed cases in 2010. The prevalence of HIV among this group is very high (5% overall and over 10% in London) and similar to other high-income countries in Europe, Northern America and Australia. The annual number of new diagnoses among MSM has remained at record high levels for the past 6 years and will exceed 3000 in 2010. Most (>85%) will have acquired their infection in the UK and one in four within 4–5 months of their diagnosis.

Although studies on sexual risk behaviours indicate higher rates of condom use among MSM compared to the general heterosexual population, MSM report, on average, a much higher number of casual sexual partners and are more likely to engage in higher-risk sexual behaviours (in particular unprotected, anal sex). These factors, coupled with the fact that HIV prevalence is around 100 times higher among MSM than the general population, result in higher rates of HIV transmission in this group of men. Co-infection with other STIs (in particular, gonorrhoea and syphilis) is common among MSM living with HIV, and this group is more likely to present with repeat STI infections than other MSM. Hepatitis A, B and C infections are also common among both HIV-negative and -positive MSM.

### *Heterosexual transmission*

Heterosexually transmitted infections began to rise in the late 1990s and these represent around half of HIV infections diagnosed in recent years. Persons of black African and to a lesser extent those of Caribbean ethnicity account for the large majority of heterosexual transmissions reported in the UK. Prevalence rates of HIV infection in these communities are in the order of 5% and 1%, respectively.

While the majority of MSM probably acquire their infection in the UK, follow-up of cases for epidemiological information indicates that most heterosexual infections (68% in 2009) are acquired outside the UK in the country of origin of migrants. Recent data, however, also show that infections acquired through heterosexual contact within the UK have been slowly on the rise since 2005 (although this has remained relatively stable at approximately 1100 cases annually over the past 3 years). Given a decline in the absolute number of infections probably acquired abroad, the proportion of people infected heterosexually within the UK has increased: from 15% in 2005 to 32% in 2009.

### *Injecting drug users*

Harm-reduction programmes among IDU, such as providing clean needles and substitution therapies, have been important in curbing the spread of HIV among this group. As a result, the prevalence of HIV among persons with a history of injecting drug use remains relatively low in the UK overall (1.5% among current users) compared to other developed countries. Nevertheless, there is some variation across the country with a higher rate in London (4.1%) and it has increased from the low level found in the early 1990s (0.7%). The uptake of HIV testing is improving in this group, with three-quarters now reporting that they have ever tested; however, almost a third of IDU with HIV remain unaware of their infection [8].

IDU are also at high risk of other infectious agents. Around a half are infected with hepatitis C, a sixth with hepatitis B and about a third of injecting drug users report a symptom of a bacterial infection (such as a sore or abscess) at an injecting site in the past year. Recent increases in HIV and high rates of other blood-borne viruses underscore the need for sustaining, and expanding in some areas, harm-reduction programmes.

### *Mother-to-child transmission*

The unlinked anonymous serosurveillance testing of residual bloodspots taken for routine neonatal screening indicates that the prevalence of HIV among pregnant women in the UK is low at around 2.2/1000 pregnant women. HIV prevalence among women giving birth is higher in London (3.9/1000) and has remained stable since 2004. Rates outside London are much lower (0.5/1000) but have shown a gradual rise since 2000 when the prevalence was 0.2/1000. Moreover, the provision of universal HIV testing and antiretroviral therapy for women found to be HIV positive during their pregnancy has dramatically reduced mother-to-child transmission rates from almost 30% to less than 2% in the most recent years. Overall, since the beginning of the epidemic, approximately 11,500 children have been born to HIV-infected mothers, and of these, 8% also became infected.

## Current priorities

### *HIV testing*

The high number of persons who remain undiagnosed and are diagnosed late has prompted a call for expanded and earlier testing. In the UK, HIV testing has been largely confined to antenatal and STI clinic settings. Antenatal screening for HIV, introduced in 1999, has been very successful ensuring high uptake rates for HIV testing among pregnant women. In 2009, over 95% of the 600,000 pregnant women were tested for HIV as part of routine care. Uptake of an HIV test among STI clinic attendees reached 77% in 2009 and almost one million tests were performed in this setting.

In addition to these traditional settings, national guidelines were published in 2008 [9,10] advocating the offer and recommendation of an HIV test to all adults registering in general practice and to general medical admission patients in areas where diagnosed HIV prevalence is greater than 2/1000 among 15–59 year olds. SOPHID data show primary care trusts (PCTs) in England where the prevalence of diagnosed HIV infection exceeds this. In 2009, over a quarter of PCTs had a diagnosed prevalence above this threshold; the majority of these are located in London [11].

In response to the 2008 guidelines, eight pilot studies investigating the expansion of testing beyond antenatal and STI clinics were recently funded by the Department of Health (England). A recent initial evaluation of these pilots shows that routine HIV testing in the hospital and primary care settings is feasible and acceptable to both staff and patients and successful in diagnosing individuals with previously undiagnosed HIV infection [12]. Given that routine bloods are collected on admission, the routine offer of a HIV test to all patients admitted to a general medical ward provides a real opportunity for diagnosing new HIV infections. This should be prioritised and widely implemented in high-prevalence areas. Similarly, testing new registrants in primary care in high-prevalence areas should also be implemented. However, there is likely to be a cost implication in this setting where there may be a greater reliance on point-of-care tests.

Alongside the routine offer of a test in clinical settings, the most at-risk populations should continue to be targeted for HIV testing. The release of new guidelines by the National Institute of Clinical Excellence (NICE) aimed at improving testing uptakes in MSM and black African communities [13,14] is particularly welcome and these should be widely disseminated to local commissioners. Finally, as HIV testing is expanded, it will be critical to closely monitor the success of these interventions, including their cost-effectiveness at the local and national level.

## Ensuring access to high quality of care

HIV has become a treatable chronic condition when diagnosed promptly. There is now a challenge in ensuring that the growing and ageing cohort of persons living with HIV can access and receive high-quality care. Since the mid 1990s, SOPHID data, have been used by commissioners to fund local HIV services. Supplemented by other surveillance data the London survey has enabled the development of clinical outcomes agreed by key stakeholders. The findings indicate that the level of care received by HIV patients is high. In 2009, 80% of London patients had a CD4 cell count within 1 month of HIV diagnosis (used as a proxy for entry into care) and almost 95% within 3 months; 90% of patients had an undetectable viral load (<50 copies) within a year of starting antiretroviral therapy; and 93% of patients had a CD4 cell count above 200 cells/mm<sup>3</sup> after 1 year in HIV care. Between 2005 and 2008, 1.5% of patients died within a year of diagnosis, with almost all deaths occurring among those diagnosed with a CD4 cell count that was less than 200 cells/mm<sup>3</sup>. These indicators, to be extended to the rest of the country, will be especially important with the expansion of testing outside traditional settings.

## Conclusions

Over the past decade, the number of persons living with HIV in the UK has steadily increased. This has been the result of the increased life expectancy of persons on highly effective therapies as well as ongoing HIV transmissions. The epidemic has been largely concentrated in MSM and heterosexuals who acquired their infection abroad, however, the latter are on the decline while heterosexually acquired infections in the UK show signs of rising, albeit slowly.

Earlier diagnosis of HIV infection has led to reduced morbidity and fewer deaths. Furthermore, prompt treatment has a knock-on effect on public health in reducing onward transmission. Expanding HIV testing to non-traditional settings is a public health priority to reduce late diagnosis and the number of persons unaware of their infection. Once diagnosed, the care received in the UK is generally prompt and of a high standard.

Prevention efforts are required to curb HIV transmission among injecting drug users and African and Caribbean communities living in the UK. Finally, the unacceptably high rate of HIV infections among MSM underscores the need for a review of prevention efforts in this group in particular. Behaviour change alone is unlikely to curb the epidemic, and effective prevention will require a combination of medical (including treatment), behavioural, social and structural interventions. A coordinated response with better markers to track these efforts is required.

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# Twenty years' working in HIV nursing: a personal journey

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## Introduction

This is a personal account of my journey working with HIV patients in the last two decades. I hesitated when I was asked to write this article – my usual response would have been to say 'no' – however, I have enjoyed reflecting back over so many memories, both happy and sad.

My HIV nursing experience started in 1991 in one of the largest specialist HIV treatment centres in Europe, a purpose-built 20-bed inpatient and day unit for people with HIV in London that was opened in the late 1980s by the Princess of Wales.

At that time, it was not yet known that nebulised pentamidine was both a cytotoxic drug and one that often induced coughing and therefore should be administered in a negative-pressure environment, but it was prescribed to the majority of our patients, and we administered it in groups of three to six patients. Another abiding memory from that time is of the ice machines, where patients and visitors could help themselves to ice cubes, but which were later found to be breeding grounds for cryptosporidia and condemned [1].

More entrenched are my memories of groups of relatives and friends supporting each other as they were preparing to say 'goodbye' to a loved one. A father just finding out that his son is gay, meeting his son's partner, and then his son dying of AIDS. Or of people like Elizabeth Taylor and Joan Collins appearing unheralded, to visit friends who were inpatients on the ward.

## Previous experience

I trained in Glasgow in the mid-1980s, and moved to a large London teaching hospital in 1988. I remember discussing with my nursing colleagues my success in landing a job in London, thinking I was going up in the world. However, when I arrived, I was disappointed by the standards of care, particularly those of cleanliness, and by the nursing uniforms. During my training, our ward domestics (the cleaners) were formidable people, very much part of the ward team, and practically in charge. They kept their ward areas extremely clean and tidy, without clutter.

In Glasgow, I had been used to strict uniforms, with white nursing shoes and white nursing hats with either a green stripe for enrolled nurse or a blue stripe for staff nurse. In London, the uniforms were in

various colours and it was confusing for me to know who was who, never mind for the patients. Nursing staff also travelled home in their uniform, whereas in Scotland, this was not allowed, and if you were caught wearing your uniform outside or wearing it unironed, you had to report to the No. 7 (now the senior nurse).

All my previous nursing experience had been on 'nightingale wards', but on the HIV ward, we nursed patients in their own rooms where we could have private conversations. Patients could use a commode without worrying about the patient in the next bed. Most importantly, we were able to care for a dying person without moving him to the end of the ward, screened off and with all the other patients 'knowing' what was happening. At the time I thought: 'This is how patients should be cared for'. There were some disadvantages. Not all patients enjoyed being in a single room, as they felt isolated and lonely. I also remember my first time being left 'in charge of a shift' and finding that patients and staff were not always visible, hence the higher nurse-patient ratio. However, I feel the benefits outweighed the negatives.

It was my first experience of a multidisciplinary team conducting a ward round, putting the patient first and at the centre of the care, and where no medical or nursing decision was made without the agreement of the patient and their carers/loved ones. Although this was taught during my training, I had not seen it in action before. Additionally, within the team, we were all on first-name terms, an unusual situation even now.

## A privileged position

These first 5 years were invaluable, and allowed me to develop my core values of having respect, integrity, preserving dignity and privacy, confidentiality and valuing the diversity of all patients. I do feel very privileged to have cared for patients at a time when there was no treatment, and to have witnessed how aggressive and powerful HIV can be without treatment.

## Reality check

Later, I found myself nursing and managing an HIV/sexual health outpatient and day ward centre, linked to a large research department, in the same teaching hospital. At this point, I felt very experienced within my field. After all, I had cared

for people from all walks of life, including celebrities. I had the experience and skill to be able to talk openly and confidently about death, I could help my patients make informed choices about their future and disclosure, and I could act as their advocate. However, I was about to find myself on yet another steep learning curve when I entered one of Europe's busiest GUM centres.

During my first few weeks' orientation, I shadowed a very experienced GU nurse, and was taught how to perform male and female sexual screening. I remember how awkward I felt initially, seeing patients who were fully clothed and not lying on a hospital bed in their pyjamas. I felt very embarrassed, not really knowing where to look, while my new colleague had such ease and confidence when asking the most intimate questions and discussing such sensitive matters as when the patient last had sex.

### Sense of loss through change

In 2000, the London Lighthouse merged with the Terrence Higgins Trust. It was the end of an era. Yet, in the same year, the largest ever annual total of new HIV diagnoses in the UK was reported.

When the statistics about the rise of STIs (including hepatitis C co-infection) within the HIV population appeared, there was a flurry of activity [2]. Our patients had often expressed their discomfort about seeing their own HIV physician for both STI screening and treatment, and were visiting other hospital GUM services. We had to change our way of working. We began using motivational interviewing to facilitate discussion around condom use and negotiating safer sex, and also began training HIV nurses within GUM. The aims of the National Health Strategy 2001 [3] included reducing the rates of STIs, HIV and unintended pregnancies and provided the impetus for us to introduce a specialised nurse-led women's health clinic and develop more robust links with maternity services.

### Treatment changes

Treatment regimens changed radically after the late 1990s. From the two-drug regimens of zidovudine and didanosine to, for example, a combination of didanosine every 6 hours (dissolved rather laboriously in purified water, and taken 2 hours away from any other drug) with indinavir taken three times daily (requiring an empty stomach so that patients had to set their alarm to ring during the night), plus stavudine. Many patients felt their whole lives revolved around taking tablets. Other drugs caused profuse diarrhoea and/or significant taste disturbance.

In early 2000, we began to see an increasing level of HIV drug resistance with one in four new patients being infected with virus resistant to some treatments. We evaluated and developed our work

around adherence, always remembering that encouraging adherence was the responsibility of the whole team.

Around 2002, our treatment choices changed to combinations with a lower pill burden. Typical examples of first-line treatments at the time are Combivir (zidovudine and lamivudine) and efavirenz or tenofovir, lamivudine and efavirenz. Adherence remained a challenge even with the improved pill burden, as it still does today.

Although there were local and BHIVA national prescribing guidelines at this time, physicians often prescribed what they felt was best for the patient based on their own experience. This regularly sparked heated debates between physicians and other practitioners, which, though sometimes uncomfortable, were also beneficial in the absence of robust scientific evidence.

### Extending nursing roles

Further nursing-led initiatives were introduced at this time to help patients manage the side-effects of therapy, including a metabolic clinic. The team was multidisciplinary and included a senior consultant, dietitian, physiotherapist, senior nurse and a psychologist. It introduced an exercise programme in collaboration with the local YMCA gym, and a weight-management programme and lipid review, amongst other things. The clinic also worked with nurse-led New-Fill clinics for patients with lipodystrophy.

For many of my patients in the early 2000s, lipodystrophy was a devastating side effect of ART, with disfigurement by swollen abdomens and fatty buffalo humps across the shoulder blades [4]. I remember feeling sad, thinking, 'what have we done to these patients? They are living longer, but is this a quality way of life?'

Mental health difficulties were also significant for many patients with HIV, and ranged from depression, anxiety, adjustment disorders, body image, self esteem to relationship problems. The double jeopardy of having both HIV and mental illness threatened to exacerbate stigma, prejudice and discrimination. To assist and support patients, we introduced a nurse-led psychiatric liaison clinic, run by a mental health nurse, who worked alongside our psychiatrist.

During all this time, continuous evaluation and audit of our services took place. What was working? What wasn't? We always involved our patients, receiving feedback from them formally or informally, and the process was very much driven by their needs. Of course, cost, space and time limitations were always constraints but we made many improvements to our outpatients clinic, such as introducing day-care facilities and having a resource area, where patients could update themselves on the latest research and advice,

where to go for more support and how to access the voluntary sector organisations.

## Personal goals

In 2003, I was appointed as HIV Clinical Nurse Specialist, a role I had always aspired to. I could now manage my own caseload of patients autonomously. I hoped to provide seamless holistic care with outpatients and inpatients via nurse-led clinics, advising patients on starting or switching therapy and promoting adherence, offering in-depth education on side-effects and possible long-term toxicity, and supporting and integrating patients to the clinic and referring them on to other healthcare providers or agencies, as appropriate. As a team, we held excellent, dynamic multidisciplinary meetings, where every member of staff was allowed a voice and the patient's view was always considered.

The CNS was also involved in giving patients their HIV-positive result. This had the advantage of continuity of care. Rather than having another healthcare provider give the result, the CNS could support newly diagnosed patients from this point onwards, introducing them to the clinic and staff on the day-care unit, and arranging their follow-up appointments. Our assessment of patients' acceptance of their diagnosis and personal circumstances helped us to plan care that was specific and sensitive to their individual needs.

## Steep learning curves

Another steep learning curve for me has been dealing with the ever-changing and diverse patient population. Finding out about the culture, different sexual practices and the need for different approaches to communication (especially given my own Glasgow accent), for example, of patients from sub-Saharan Africa has been fascinating. Some patients recounted traumatic stories of torture, imprisonment and male/female rape, while at the same time struggling with Home Office bureaucracy only to be given the status of 'No Recourse to Public Funds'.

## Moving to the coast

In late 2004, after being in London for 17 years, I took on a senior nursing role in Brighton. Although exciting to leave the Big Smoke, all my HIV nursing experience had been based at one hospital and it felt like I was leaving more than just a job. Some of the patients there I had known for over 15 years. I had nursed their partners and loved ones at the end of their lives, and had also often known their wider circle of friends and families. I felt I had been part of their journey, and had witnessed them start to live their lives again and plan their futures with the advent of the new ART drug regimens.

However, in 2005, owing to a massive local service re-organisation, I was redeployed and I joined another department. Nothing could have prepared

me for returning to the nightingale wards, with consultants who could only be addressed by surname and title, and where patients appeared to have little choice in the care that was being offered to them. I felt like I was in another world. I saw many examples of poor attitudes, amongst nurses and doctors, that demonstrated stigmatisation and discrimination. I did not last there very long.

Since 2007 I have worked in the Community HIV Specialist Team in Brighton and Hove. Our integrated team consists of an HIV clinical nurse specialist, HIV CPN, psychiatrist, and social worker and we offer full and holistic assessments and care-planning support.

Successful partnership working has evolved here. However, the ongoing reduction of funding and the changing NHS agendas force us to be more transparent and efficient about our patient-focused outcomes, and require continual re-evaluation of the care we provide.

Many of the patients in my current caseload are the most complex cases in Brighton – 30% of our HIV population is over 50 years old [5]. At times I have to take a moment to absorb the astonishing fact that the majority of my patients are living full and relatively healthy lives.

## Conclusion

After many years of working in a hospital or clinic setting, it is a privilege to be allowed into a patient's home to carry out nursing assessments – to be able to assess the patient from the moment of being invited in. This way of working requires different boundaries and presents different challenges. With no uniform, no name badge to hide behind, the altered power balance and the resulting impact on the patient–nurse relationship has taken me outside my comfort zone of the traditional clinical environment.

My learning still continues. We now work with a chronic disease model and are gaining more experience with our patients' co-morbidities, while empowering and encouraging them to make informed decisions about their future. We have come a long way since the turn of this century. However, I challenge the recent idea that HIV can be seen like any other chronic disease. No other chronic condition carries the same stigma and the risk of onward transmission. It is a myth that HIV stigma is no longer there. I come across it daily. Much of my time with patients is spent discussing the potential benefits of disclosure to family members and the damage caused by keeping such a secret.

The system is about to change again, and with the new NHS reform in England, the effects of cost savings are likely to cause closure of some voluntary organisations and the restructuring of HIV teams. However, the fundamentals of our nursing care, from communication with agreed care plans and accurate documentation, to treating patients

with dignity and respect, stay as important today as they were when I entered HIV care in 1991.

As HIV nurses, we have always been creative, flexible and open to change; continually increasing our knowledge, experience and skills; maintaining our core values of respect to patients and colleagues, with integrity; continuing to learn from mistakes, sharing best practice and supporting each other. More than ever, I find myself in the role of an advocate for patients, being able to listen and understand their complex and changing needs and enabling them to be heard.

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# HIV and pregnancy: past, present and future

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## The past

I remember the UK's early prevention measures after the first cases of AIDS were diagnosed in 1983 [1]. These were followed by an unforgettable, hard-hitting, public information campaign depicting tombstones and AIDS-related death. Designed to shock, this style of public health information played on inciting fear of a terrible threat aimed at the mainstream family unit. I believe that this campaign, combined with early epidemiological evidence indicating that HIV was transmitted through behaviours that were generally condemned as illegal, or socially unacceptable [2], created the platform for the fear and stigma around HIV testing that exists today.

In my early midwifery career, between the mid-1980s and 1990s, midwives had little input into HIV testing. Testing remained within the remit of specialisms such as genitourinary medicine (GUM), and where great emphasis was placed on pre- and post-test counselling. It was important that the same nurse or doctor saw the patient before, and afterwards for the result, and only those with specific training could offer the test. I recall that the maternity hospital where I worked in 1990 managed pregnant woman who used intravenous drugs on the psychiatric unit where they were placed on detoxification programmes and often targeted for HIV testing by the medical staff.

In 1999, antenatal HIV testing was introduced nationally as a result of a Department of Health

publication [3]. The directive recommended that all pregnant women should be offered and advised to take up HIV screening. The basic premise for the implementation of antenatal screening was that if drug treatment were to be given to HIV-positive pregnant women and their babies, and if breastfeeding were avoided, the risk of mother-to-child transmission of HIV could be reduced from 25–30% to less than 1% [4].

Manchester Primary Care Trust responded by setting up a strategy group that had the task of organising internal hospital procedure, care pathways, data collection and audit. A comprehensive resource pack, and HIV information leaflets, for women were developed and all policies and guidelines were standardised across the three Manchester maternity hospitals to ensure a streamlined service and equity of care across the city.

Initially, the HIV test was to be offered by midwives on an 'opt-out' basis. However, the strategy group felt uncomfortable with the language of the DH directive [3] ('recommending' the HIV test) and felt that the emphasis should be on choice, with avoidance of coercion. The midwives' pre-test discussion was to be documented in the maternal notes and, if a woman declined the test, it was not to be re-visited later. This is in contrast to current practice where thinking has evolved to agree with an opt-out strategy, for midwives to recommend and advise HIV testing especially in high-risk groups (such as women from sub-Saharan Africa), and also to re-offer the test at the next visit if not initially accepted.

The HIV strategy group created the role of the HIV liaison midwife in September 2001. It had become evident that although midwives were now expected to play a major part in illness prevention and were seen as being well placed to positively influence health outcomes for women and their families [5,6], in reality practitioners were voicing anxieties about offering the HIV test. I had conversations with midwives at the time who freely admitted that they told women whom they thought to be 'nice ladies' that they would not need the HIV test as it was really only for 'drug users and homeless people'.

The role was initially for one day a week and was situated within the Black Health Agency, a voluntary HIV organisation in Manchester. The aim was to support the midwives in practice who felt uncomfortable talking about sex and were worried about discussing HIV in case it offended the woman and her partner. Midwives also felt they lacked knowledge about HIV, which was a concern as this factor was known to have a detrimental effect on uptake of the HIV test [7]. Annual mandatory training was therefore made a priority, and midwives were offered regular update sessions using case scenarios to encourage discussion.

### The present

The role is now full time, city wide and integrated into the hospital trust. It continues to act as the focal point for practitioners in the North West in terms of antenatal HIV referral, training, strategic planning and development, and has an impact both in national and international HIV policy.

The number of HIV-positive women managed in the three Manchester maternity hospitals continues to rise every year, with 66 women in 2010 showing a massive increase from only eight or nine women in 2000–2001. All HIV-positive pregnant women diagnosed via antenatal screening within Manchester are referred directly to me from the Regional virology laboratory. I also receive referrals from GUM/ID consultants for known HIV-positive women and women who have been exposed to HIV during pregnancy, for example via an HIV-positive partner.

The first consultation with a woman is pivotal not only in assessing social circumstances, immigration issues, domestic abuse and safeguarding risk, but also in providing the essential information the woman needs to protect her unborn baby from HIV transmission. I discuss what HIV means to health, the benefits of medication for herself and the neonate, infant feeding advice and safer sex messages to reduce the risk to her partner. After this, I facilitate a fast-track appointment for review by the HIV consultant, and continuing care is managed by a multidisciplinary team including a named obstetrician and a paediatrician. The role of HIV voluntary organisations such the George House

Trust is important in providing support for immigration, welfare and emotional issues and women have said that this input has 'saved their lives' and made them realise that they are not alone living with HIV.

Women often fear that their diagnosis will be made known to families and friends, leading them to transfer from their booking hospitals and travel miles to maintain confidentiality. My role often involves tracking women across the city, facilitating antenatal and HIV care to ensure that the risk to the unborn baby is minimised. I also spend time following up women who do not access services (bearing in mind that this is a recommendation from CEMACH [8]) and keep in touch with women who are moved to different districts at short notice by the Border Agency.

### The future: family health and HIV

In recent practice I have seen an increase in referrals for HIV-negative pregnant women who have HIV-positive male partners. I have also cared for four women who tested HIV negative at their booking visit in a previous pregnancy and who had since seroconverted because their partners' HIV-positive status had not been known.

I am occasionally contacted by paediatricians looking after newly diagnosed HIV-positive infants who seek information about the HIV screen offered to the mother during pregnancy. It is commonplace for the mother of the baby to state that the midwives did not offer her an HIV test. After review of the notes however, it has been evident in every case that the woman was offered testing but declined. At midwifery training, I highlight the importance of documentation and also of ensuring that the test is re-offered at a later appointment. If it is declined then, the reasons for declining should also be outlined in the maternity notes.

My vision for the future is to recommend that male partners of all pregnant women should be included in antenatal HIV counselling and screening. The rationale is that the men are a captive audience (as they attend the antenatal clinic or scans with their partners) and the health benefits for the unborn baby would be phenomenal. It would also give the HIV team an opportunity to intervene for men who do receive an HIV-positive result in order to prevent onward infection for the pregnant woman.

In April 2011, I will be conducting a feasibility study in which 300 questionnaires will be offered to men attending antenatal clinics for the 20-week scan appointment. They will be asked whether they would like to be included in antenatal HIV testing. Depending on the results of this research, I hope to follow up with a pilot study with the ultimate aim of providing HIV testing for male partners.

## Conclusion

The last 10 years have seen many challenges for midwives in practice in relation to their public health responsibilities. The implementation of antenatal HIV screening with a supportive HIV specialist role has allowed staff to explore their own attitudes, knowledge and beliefs about some of the most vulnerable and hard-to-reach women within our society.

Midwives and obstetricians now see HIV testing as integral to maternity care. At a recent training session, all staff present said that they felt happy to discuss the matter further if a woman had reservations about the HIV test, although most could not remember the last time a pregnant woman had declined HIV testing.

My vision for the future is to reduce the numbers of untested and undiagnosed HIV-positive people in Manchester and to make a difference for the small, but significant number of HIV-positive children infected with HIV after their mother seroconverted during pregnancy. I would hope that couples counselling and testing for HIV will become the norm as midwives embrace the family model.

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# Living with HIV for three decades

Tom Matthews

On Sunday 29th January 1986, while preparing a meal for guests, I received a telephone call from Jon, a friend in London, I hadn't seen for 6 months. I was busy trying to prevent a sauce from separating, while he brought me up to date with what had been happening in his life. He finished by saying that he had received a diagnosis of Kaposi sarcoma the previous Friday. I put that information to the back of my mind. It wasn't until the guests had left, the table was cleared, the dishwasher had been filled, the dogs had had their night time walk and I had finally settled in bed, that the consequences of what he had shared really made their impact on me. I realised that tomorrow I would have to get a test.

Work was really hectic; I was opening a new residential unit for multiply and profoundly handicapped young people. As I really didn't believe the test result would be positive, and I had so many other appointments, I decided to take the option of telephoning for the result. It was 2 o'clock in the afternoon when I made the call. I was

booked in for a sleep-in that night but at least I had one of my dogs for company. I was able to share the results with my deputy, who was also a personal friend, but I had to call my partner and tell him over the telephone. I didn't get to hug him for almost 24 hours.

The first time I went back to the clinic after getting the results, they had no medication to offer me and no written information either. They gave me a prognosis of 2 years. All they could say was that if I started to feel unwell, then I should come back to see them straight away. Another consultant, however, recruited me on to the management committee of a newly formed HIV agency in Leeds. In order to meet other positive people I had to travel to either London or Brighton.

We live in a world that promises that tomorrow will bring us something 'bigger and better' than what we have. Realising and accepting that I didn't have too many tomorrows, I started to give attention to each day, a path that eventually led me to

Buddhism. I was 39 years old and felt that if I did have only 2 years, I was grateful for the life I had had. I didn't feel angry; on one level I accepted the prognosis my consultant had given me.

In March, the group moved into a huge portacabin, next to Leeds General Infirmary (LGI), right in the centre of the city, and 5 minutes' walk from the GUM clinic. In June 1986, I was the founder member of Body Positive, Leeds. I had started to visit guys who had been hospitalised in the four single-bed units in the Brotherton wing, at LGI, that had been provided for inpatient HIV care. The beds were on a 'Skin' ward and the wing had originally been built for private clinical care. I heard that the motivation for this provision for HIV patients had actually originated with nurses.

In those days nothing could leave the rooms without being in red, black or yellow plastic sacks and visitors were encouraged to wear gowns and masks. One of the frequent complaints from the guys I visited was that the tea lady wouldn't come in to their rooms, and a Styrofoam cup would be left outside their doors.

As much as I loved my work, I was finding that the long commute (90 miles a day) and the irregular shift patterns were not helping my general health. I therefore applied for the post of AIDS Liaison Officer for Leeds City Council and was surprised when I was offered the post. It was such a relief to be working 'regular' hours again.

Late one evening, 12 months later, I too was admitted, on to this ward, with what was eventually diagnosed to be a 'bleeding colon'. It produced a tremendous amount of pain in my bowels. At that time, if someone rang the ward asking for you, it was accepted practice for a nurse to come to check with you before they admitted you were actually an inpatient. When they came to tell me my parents had called, I explained I had yet to disclose my HIV status to them. They were the only people I hadn't told, but I knew that I had to tell them soon, because I had been doing interviews on Radio Leeds and I didn't want them to find out that way. More nurses came to see me in my room and when the situation was explained to them, they encouraged me not to tell them when they came to see me the following day. 'You look like death' was their opinion, so they visited the blanket cupboard and brought samples back to my room, to see which colour would do the most for my complexion.

In February 1989, I moved to Birmingham to take up the post of Programme Manager for HIV for the West Midlands Regional Health Authority. My responsibility, over a 4-year period, was to ensure that every one of the region's 25 District Health Authorities was able to provide an appropriate response to the needs of their populations. At my first World AIDS Conference in Montreal in 1989, I

realised how fortunate I was to live in the UK and have the services of the NHS available to me.

In 1991, my T cell count halved and I was told I needed to start treatment with zidovudine. In the first 5 years that I had lived with HIV, 99% of my friends had died from HIV-related conditions and I had strong feelings that this drug had somehow played a significant part in their deaths. I stalled for several months until I was visiting a friend in San Francisco. While there, I discovered a protocol that had followed 500 patients over a period of 2 years. The major difference between this protocol and what was being followed in the UK was the dose of zidovudine prescribed. In San Francisco, patients were given 100 mg, five times daily whereas in the UK, the dose being prescribed was then 1500 mg; three times the amount given in the protocol. I had managed to survive my original prognosis by 3 years and felt that, as it was the only drug available, I should take it. Back in the UK though, clinicians used every tactic they could think of to try and persuade me to start on the higher dose but, eventually, they reluctantly agreed to the lower dose. For 3 years I tolerated this treatment very well, with no side effects, but then my T cell count began to fall again and I was prescribed didanosine. Two months later, I had two cerebral strokes and I remembered nothing for 2 months. I had no speech and was occasionally incontinent. To me, my recovery felt natural, but apparently others were surprised. I took a comprehensive cognitive function test, the results were great, and I took up a post as a Commissioner.

Ten months later my consultant told me that my HIV infection was taking me towards dementia. Having survived my initial 2-year prognosis, and having lived the last 5 years one day at a time, I was determined that I should have at least a year of retirement before I died. This was something none of my friends had had. I therefore decided to take the same cognitive tests as previously. This time the results were horrific, and I immediately applied for early retirement on medical grounds. Three weeks into a planned 8-week holiday, I had a seizure in San Francisco and actually stopped breathing for a period of time. Although this was considered to be the best city in the world for inpatient HIV care, travel insurance was still not available for people living with HIV. So, 24 hours after treatment in the outpatient department at Davies Medical Centre, I flew back to Birmingham for those tests I couldn't afford in California. The tests were inconclusive, but I found I could no longer tolerate either zidovudine or didanosine, the only drugs that were known to pass through the blood-brain barrier.

Five months later, in 1996, I went to a 1-day conference at the Maudesley Hospital on 'HIV-related dementia' and discovered a trial of a drug called '1592' (now known as abacavir). Through my consultant, I discovered I would have

to apply for one of 60 places, spread across four continents. I filled in the application and sent it, complete with the results of a third cognitive test, to the Chelsea and Westminster Hospital in London.

The bills for the services of the paramedics and the Davies Medical Centre arrived: £2,175.00. After the shock, I realised that without their interventions I wouldn't still be alive and sent off the appropriate money order. It reminded me what a wonderful thing the NHS is.

By December 1996, I was spending 18 hours a day in bed and needed a stick to visit the bathroom. This no longer felt like a life worth living and I would have been happy to die.

However, in January 1997, I started triple antiretroviral therapy and experienced an immediate increase in my quality of life (accompanied by the appropriate CD4 cell count and viral load test results). In June 1997, I was offered a place on the trial in London and transferred my total healthcare to the Chelsea and Westminster Hospital for the next 2 years. In September 1999, my healthcare was transferred back to Heartlands Hospital in Birmingham.

After an extensive discussion with my HIV consultant in 2005, I came to realise the wonderful truth that I had a future!

I now had the opportunity for a third career. What would I choose? After some consideration, counselling seemed to be the perfect choice. It would provide further opportunity to be with people, whom I consider to be the most interesting part of life, with the flexibility of working hours.

I have come to realise that living with HIV has provided me with so many opportunities I wouldn't have had without that diagnosis. Obviously, it isn't something I would recommend to others, but it has taken me to places and brought me to meet people that I believe have made my life so much richer. I have less concern for the material and gain more pleasure from experiences and people.

I have learned to live with my friends 'in the now' because I know that there is no guarantee of a tomorrow for any of us.

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## Living with HIV

Robert Fieldhouse

Editor, BASELINE Magazine

**I**t's almost 7 years since my HIV diagnosis. I think I had picked it up 2 years previously, in either the September or October. By the November of 2002 I felt very unwell. The whole thing felt a little ridiculous, really. Preventable clearly, and compounded by the fact that I had been working helping people make choices around HIV treatments for many years and had seen first hand how the diagnosis can make you vulnerable and take your life off track, momentarily at least.

On the one hand, I was simply yet another gay man with too much time, money and opportunity. It's too awful to acknowledge an inevitability to my diagnosis, but on the other hand, I was in my early thirties with a series of negative HIV tests behind me, and had just gone through the break up of a 7-year relationship. Excuses they are not, but research at the time was showing that it was men just like this who were most likely to be getting diagnosed with HIV and knowing this did help me begin to deal with my diagnosis.

I thought I had food poisoning. Even went as far as complaining at my local Japanese restaurant on Kant Strasse in Berlin where I had been living at the time, thinking the sickness and rigours were down to a dodgy miso soup. Sure enough, the disabling

assault on my body, which had left me bed-ridden for three weeks, was a fairly decisive seroconversion illness. By the time I came back to England at Christmas, I looked and felt somehow 'different'.

Eighteen months of oddness ensued. Breathing difficulties, extreme tiredness, skin changes, blinding headaches, weight loss and generally feeling 'out of sorts.'

I finally tested on 1st September. In a way, I was forced to do it as I was due to present at the National Conference for People living with HIV about being recently diagnosed and I was struggling with an opener for my talk. I felt a little out of place, as I was, at that time by all accounts, HIV negative. So I thought: 'Take the test and if it comes back positive, by the time the conference begins you will have been diagnosed 3 days and if you can hold it together, it will send out a powerful message to the 40 people who may have been struggling with their own diagnosis for weeks, months or years'. People responded to my honesty about the new situation and, I hope, took a further step towards accepting their own diagnoses.

I'd had the good fortune of working at Body Positive in London just as the new therapies were becoming more widely available in 1997. I used to advocate

for people to get a viral load test or try to convince them to switch away from dual therapy. Back then treatment was pretty much just saquinavir or indinavir with AZT or d4T (and perhaps some ddI and ritonavir thrown, just to calm your stomach) and not much else. By the time I came to use treatments myself, regimens were far improved and fixed to a certain degree. Treatments have never really given me many problems; at least not in comparison to the gains in health they promised and delivered.

I started treatment at a CD4 cell count of 200 cells/mm<sup>3</sup> or 14%. The week before, I'd suffered with headaches to the point that I'd had to step off the Cardiff to London train at Reading and take a taxi to a local hotel to go to bed as I simply could not make it back to my flat in the East End due to the pain. I remembered the conversation I'd had with the nurse about a big juggernaut being right around the corner. I felt like I had got away with it up until now, but feared that with a viral load of 1,000,000 I could easily come down with a lymphoma or some such complicating condition that would stuff things right up. With the first dose, I felt the fight back had begun, but in all honesty, it was 6 months until I felt like my old self again.

I've had a CD4 cell count of more than 500 T cells/mm<sup>3</sup> on treatment for 6 years now, and with three grandparents who lived well into their eighties, I have never wasted much time worrying about how my diagnosis will affect my lifespan. I am utterly convinced that I will see a cure in my lifetime and that I will have lived through a remarkable period in medicine.

I don't really live in the real world. I have never had to face the dilemma of disclosing my status to my employer. Most of my friends are HIV positive. HIV has always given more than it took away. I am less certain of the life I would otherwise have led than I am of how much I enjoy the one I lead today.

I've watched HIV's complexion and gender change. I have seen it tenaciously keep people trapped in poverty, feeling bad about themselves, cut off from the lives they should really have led. I've seen women just get on with it; pick up their kids and the tatters of their lives and start again. I've seen people mess around with their meds and get cancer or have a heart attack. But I feel fortunate to have seen all of this, as I have learned as much from others as I have taught, I hope.

I've also seen HIV drop further down the agenda. I'm watching now as the NHS is being mauled. Speculation abounds that hospitals will close; that services will be dismantled and people with chronic conditions and an uncertain future face an even more precarious one. I worry that HIV care will suffer as those nurses who nursed through the early years of AIDS retire; that HIV care will become faceless and take on an increasingly conveyor

belt-like nature where we'll all be pricking ourselves at home and sending in a blood spot for viral load testing. We might only get to see a nurse once a year for an MOT, but my nurse is more than a mechanic, and I hope valuable contributors are not lost if the job is to become only rudimentary. Alternatively, maybe the imminent changes bode well for nurses who may assume more responsibility in the changing NHS. This is something I am sure would be universally welcomed by people living with HIV.

I do take my pills regularly. I get 900 T cells back as the reward. I'm really happy with my meds – all taken once daily. I sometimes look yellow, often dependent upon how much I have been drinking, and my vitamin D was low in the last year but daily supplementation has remedied that. I recently fractured a couple of ribs, but it took just 3 or 4 weeks to recover. I did not have the time for it to take longer. The more time that passes post diagnosis, the less impact HIV is having on my life. I am nearly 40; the tiredness I sometimes feel is more due to overwork than HIV. I don't remember where I have put my keys or my money, but I have never been any different. I don't exercise so my current physique is down to pies and pinot more than my HIV meds.

I am surrounded by wonderful friends here in Birmingham and have a very stable home life. I don't have to worry about my immigration status, or where money is coming from for the next meal, or how my kids are going to hide their status at school. I know I am lucky to have had access to treatments and to have lived through a time in which treatment programmes have proliferated around the world.

There's nothing remarkable about my story, but it is perhaps exactly that which other people living with HIV respond to. I've dealt with my diagnosis; have faced the same dilemmas about starting therapy, switching it around, getting my cholesterol down, gaining or losing weight, about how to tell people, and how to deal with their reaction.

I'd like to think I will age disgracefully, become the Keith Richards of HIV and that I will be fortunate to be able to continue working with people with HIV far into my old age, to give them the confidence to take treatment and get on with their lives.

Some lovely nurses in Stirling told me yesterday that if my liver packs up, they would happily take care of me. I thought that was a superb gesture. Thank you.

Thanks also to Tom, Martin, Phil, Susan, Stephen, Jane and David for the love and support they have shown me over the years.

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# A decade of HIV Nursing: what was happening in the real world?

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The last 10 years have seen enormous changes in the landscape of HIV. The epidemic has evolved into a number of discrete and separate entities. There have also been major shifts in policy, programming, funding and the experience of living with HIV for many people. This article examines and reflects on some of these changes, from an international perspective, focusing mainly on the African continent. What has changed? What is the same?

## Things can only get better

Quickly reviewing this writer's articles for *HIV Nursing* on international issues over the last 10 years, there is a clear shift in the discourse. Early in the 2000s, there was focus on the benefits of antiretroviral treatment (ART) in developing countries, the prevalence of HIV stigma, and the need for an inclusive approach towards countries most affected. Towards the end of the decade, topics included palliative care for people living with HIV (PLHIV), the need for a rights-based approach, the growing prevalence of HIV in Eastern Europe, and the drive for 'universal access' to treatment and care – a theme very dominant in current discourses, defined in 2010 by the Secretary General of the United Nations, Ban Ki Moon, as:

'... more than ensuring that those who need treatment or prevention services receive them. It implies an extra effort to reach those who are marginalized, criminalized or disenfranchised.' [1]

Those of us working in the HIV sector are often too ready to paint a picture of gloom. Why do reports from Africa, for example, always paint such an irredeemably grim picture? Linda Polman, author of an excellent text on the problems of international aid propping up aggressive governments [2], famously calls this 'poverty porn'.

In reality, an objective look at the last 10 years suggests that, in many ways, things are improving in the HIV sector. The number of people receiving ART is now 4.5m more than in 2001 [3], and although the World Health Organization's '3x5' campaign (3m people on ART by 2005) failed to reach its target, the acceleration of access to treatment is continuing to benefit the morbidity and mortality of PLHIV – and reduce infectivity. A recent announcement that microbicides have finally reached the status of proof of concept [4] is a significant step in the empowerment of women to

protect themselves against HIV. Notions that the link between HIV and AIDS is unproven – a not uncommon belief in 2001, helped by highly anomalous statements (and policies) from South Africa – are now largely consigned to the dustbin.

And there is evidence that in Africa, where HIV continues to have the most severe impact, the number of new HIV infections had begun to level off by 2006 [5]. There is also a much more prevalent rights-based approach to HIV programming than in 2001; evidenced by the significant contribution of civil society at the international level. For example, the UN agency coordinating the fight against HIV (UNAIDS) is adopting a much more consultative approach, and the voice of international and regional HIV organisations is now always heard in Geneva – a phenomenon that in 2001 was patchy and intermittent at best, and at worst ignored.

There is also more funding. Since 2001, sources of funding allocated for HIV prevention and treatment have diversified and include: the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM); the Clinton Foundation; the Bill and Melinda Gates Foundation; and PEPFAR (the US President's Emergency Plan For AIDS Relief). Billions of dollars are being pumped into HIV, and whilst there are issues around the equity and effectiveness of all international development funding [6], there is little doubt that as a result of this substantial monetary contribution, more people receive ART, more programmes are in place to address HIV prevention, and funding is available for further research into future prevention strategies, such as microbicides.

This increase in funding is accompanied by a much more robust approach to transparency, for both multilateral (where money is given directly to organisations) and bilateral funding (where money is given to governments). During the last decade, the tracking of corruption and financial mismanagement became much more efficient. In 2005 for example, the GFATM withdrew funding for a time from Uganda, after it discovered someone in the country's Ministry of Health took nearly \$300,000 of Global Fund money [7].

## Reasons to be fearful ...

As in all narratives, there is a dark side. Truth is rarely pure, and never simple. Yes, there are significant improvements, but there are also complexities, and some disappointments. The search for a vaccine against HIV continues but it is

still eluding researchers. Although some progress is being made in demonstrating a benefit from ART as prevention [8], it requires very careful management to prevent drug resistance in people with undiagnosed HIV receiving suboptimal doses of ART designed for prevention, rather than treatment.

The HIV epidemic in Eastern Europe continues to escalate, fuelled by the sharing of needles and syringes amongst injecting drug users (IDU) in countries with appalling harm reduction policies. Access to services is, in some regions, as low as 7% [9], and punitive action against drug users obscures public health advances, especially in the Russian Federation [10]. Not all is bad though, and lessons from the African context are being applied, evidenced by a much more robust civil society than 10 years ago (especially in Ukraine), and a better understanding of the contextual factors driving people to put themselves at risk of HIV. Programmes are in place and are having a positive impact on HIV prevention, support and care, often in spite of intransigent national policy.

Another consequence of improvements in ART access is that PLHIV are living much longer. This is posing a range of challenges, for example in countries with a high number of children living with HIV who are now surviving into adolescence. Zambia, with 120,000 children and young people living with HIV, is having to address seriously policies and programmes to ensure that HIV services are able to meet the sexual health and reproductive needs of this group. It is important to ensure that, as the young people explore their sexuality, they do not unintentionally spread the virus to others, or put themselves at risk of re-infection, and that they also have sufficient awareness of how to plan their transition into adulthood [11].

### Ongoing problems: what hasn't changed?

This discussion began with areas that have improved in 10 years. Sadly, there are also elements that were present in 2001 that still pose a threat to the effective fight against HIV.

Stigma, of HIV and men who have sex with men (MSM), is a well-reported phenomenon, including in this journal [12]. This article won't spend time discussing these generalised and resistant attitudes. Sadly though, stigma seems as strong now as in 2001. Indeed, there is evidence of regression in some areas, with news in 2009 that Uganda was considering legislation introducing capital punishment for some activities relating to HIV and homosexuality [13]. Together with the death of Ugandan gay activist David Kato earlier in 2011 [14] – suspected by many to be related to his pro-gay activities – there is concern that attitudes in some African countries fail to reflect the rights-based

approaches that underpin HIV programming in other regions.

Another stubborn feature of HIV is limited access to ART. Treatment reach is indeed improving, but it is ironic that some areas remain ineffectual, and perhaps the most shocking is the Russian Federation. Here, there are constant stock-outs where people already on treatment are denied medication because of shortfalls at local clinics [15].

Finally, health systems in many affected countries remain under severe strain, because of the continued 'brain drain' (mass emigration of qualified medical and nursing staff away from poorer countries). This issue remains crucial, but has not been addressed sufficiently in the past decade. Sub-Saharan Africa is the worst affected: it has 11% of the world's population and 24% of the global burden of disease, but only 3% of the world's health workers. In this region, there are around 750,000 health workers for 682 million people. For OECD countries, this figure is 10–15 times higher. Although there may be a global average of 9.3 health workers per 1000 people, there is a huge difference between the North American rate of 41.7 and the African rate of 2.2 per 1000 [16]. Another study found that in countries where HIV prevalence exceeds 3%, a doubling of the medical brain drain rate is associated with a 20% increase in adult deaths from AIDS [17].

### The future?

This very selective review highlights several of the key topics from the last decade, and readers will, no doubt, have their own suggestions for further discussion. As for the next 10 years, no writer should ever be tempted to predict the future. However, it is intriguing to wonder what a look back over 2011–2021 will show.

More people will certainly be on ART – indeed, Millennium Development Goal 6 aims to achieve universal access to 'treatment for all', by 2015 [18]. It will be interesting to see whether health systems and NGOs in affected countries will actually be able to deliver this, even if drugs are available. Health and social systems will be challenged in supporting the increasing number of people surviving through access to ART (in the same way that Western welfare services are now stretched in caring for an ageing population). While an otherwise healthy person living with HIV requires little intervention (their capacity to live and work is no different from a non-infected person), many years of needing to monitor CD4 cell counts and provide ART may start to threaten systems in poorer countries after the initial euphoria of universal (or at least expanded) access. In 2021, we may see that the blessing of maximum coverage proves an expensive and draining demand.

Rates of new infections on the African continent will fall, aided by prevention strategies such as

microbicides, male circumcision and condom availability, but the stigmatisation of many of the groups at most risk (e.g. sex workers, MSM, IDU) will always pose a threat to effective public health programming. One hopes that by 2021, post-Soviet Eastern Europe will have gained some ground in addressing its haphazard approach to harm reduction, thus addressing the needs of IDU – although this may depend on international agencies negotiating with local governments on what resources are required, and what they are allowed to deliver.

Perhaps in 2021, there will be less need for many of us to work in the HIV sector, due to falling demand. That's our aim, surely? Where would we work then?

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# The future of HIV and its impact on nursing.

## I: Prevention and diagnosis of HIV

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### Introduction

**I**t is now 30 years since the first report of five homosexual men who were diagnosed with Pneumocystis pneumonia (PCP) [1] presaged the start of the HIV epidemic. Much has changed since then, although unfortunately much has remained the same. HIV, as it came to be known a few years later, has changed from a terminal to a long-term chronic illness with people living longer following the advent of antiretroviral treatment.

HIV care is, of course, set within a much wider NHS. In 2010, the Government published a White Paper on the future of the NHS [2]. In it were outlined radical changes, described as the biggest shake-up of the NHS since its inception in 1948, to the commissioning, provision and payment for care throughout the NHS. The NHS is changing. In addition, the provision of testing and subsequent management of HIV have also been changing with guidelines on HIV testing [3], improving uptake of HIV testing within men who have sex with men (MSM) and black African communities [4,5] and reducing late diagnosis of HIV [6] all recently published.

Nurses have always been at the forefront of care for those living with HIV. Initially, we provided acceptance and support to those dying; then, as medications developed, we supported those starting and taking treatment for HIV. Now, we manage specific cohorts of patients with the development of Advanced Practice within HIV nursing. This care has never been in isolation, but set within the wider profession that has evolved and which has been moulded by the wider NHS reforms; of which there have been many. So, as the new Government makes its mark on the NHS, as new medications and tests make their mark on HIV, and as new reports make their mark on the wider nursing profession, HIV nursing will continue to evolve and adapt.

Over the next 10 years there are a number of areas where we will see change, and these include: HIV prevention, expanding access to HIV testing, care of stable patients (long-term conditions) and management of those presenting late with HIV (acute care). Nursing will either take on a pivotal role or be challenged by these potential changes.

This article explores the potential impact and challenges of the changes on the NHS and HIV nursing with respect to HIV prevention and diagnosis of HIV infection. In a further article, to be published later this year, we will go on to explore HIV care and Advanced Practice in HIV nursing.

### HIV prevention: what commissioning changes could mean

The White Paper [2] suggests that commissioning for HIV prevention services will be placed within the local government arena. Local public health doctors will be put in charge and will have responsibility for reporting back to the local population on local public health targets. The funding of HIV prevention and HIV care provision will be split. While the benefit of this could be that prevention would be locally commissioned to meet local HIV priorities, a shortcoming might be that some commissioning consortia will not see prevention as a local priority at all.

In addition, it could prove very hard to remove HIV prevention activity from HIV care activity and make the funding of services very difficult and complex. Consider for a moment your own work and whether you can separate your HIV prevention activity from the HIV care that you provide to your patients.

Another example of a potential difficulty is the funding of post-exposure prophylaxis for HIV after sexual exposure (PEPSE). In London, starter packs are funded by the HIV London Consortium, with continuation of PEPSE being funded from primary care trust (PCT) budgets. If local commissioning consortia do not identify PEPSE as a local public health priority, then how will it continue to be funded? Furthermore, how can PEPSE be continued for one person and not another, if one consortium commissions while another does not? HIV is presently an open-access service and one of the challenges with localised commissioning will be to continue that accessibility. Many readers will be aware of inequalities that have previously existed with the funding of voluntary sector services and the difficulties and frustration this led to in terms of provision of support for patients living in the 'wrong' postcode.

The White Paper also suggests that the health provider market should be opened up. While it sounds like a big leap, and feels totally against the ethics of the current NHS in which many of us work, a consequence of localised funding might be that nurses themselves could set up and develop companies that bid, for example, to provide prevention or PEPSE services within local areas.

## HIV prevention: future service developments and their implications

Over the next 5–10 years, it is likely that the UK will see the development and implementation of guidelines for the provision of pre-exposure prophylaxis (PrEP) to those people who are at significant risk of acquiring HIV infection.

### *Pre-exposure prophylaxis*

Recent information regarding the benefits of PrEP for HIV [7] suggests that this could be an effective way of reducing the risk of HIV transmission. Certainly the Centers for Disease Control (CDC) in the US have now issued initial preliminary guidance on its use [8], which is aimed at MSM who are at high risk of exposure to the virus. It is therefore likely that guidance in the UK for similar situations will follow. The US guidance requires that the PrEP recipient:

- Is at substantial, ongoing, high risk for acquiring HIV infection.
- Is screened and treated for sexually transmitted infections and treated as necessary, with ongoing screening as necessary.
- Is provided with risk-reduction and PrEP medication adherence counselling and condoms.
- Has a routine HIV test every 2–3 months.
- Has adherence assessed regularly and interventions offered as necessary where adherence is reduced.

It is very likely that when PrEP does become available in the UK, we will follow a similar line and PrEP would be available only to people who are at serious risk of being infected with HIV. The exact definition of this would require a wider discussion and consultation, but is likely to include people who have accessed PEPSE a certain number of times and where other interventions have been tried but continue to be unsuccessful. Given that in some clinics nurses lead on the management of PEPSE, it is possible to surmise that nurses will have some responsibility in leading on the identification of those at risk and the implementation of PrEP.

Once commenced, possibly with an agreed contract between the provider of PrEP and the recipient for agreed follow-up and an intervention plan, the recipient will have regular follow-up to assess ongoing need, recent risk, HIV status, STI screening and treatment, toxicity effects of PrEP medication and risk-reduction counselling and interventions. Nurses have many of the skills required to carry out this type of service (adherence, ongoing patient review, prescribing, asymptomatic and symptomatic sexual health screening and treatment provision) and many nurses are now training in motivational interviewing techniques (currently used for adherence support) but which can also be transferred for use in sexual risk-reduction interventions. It could therefore be

reasonable to assume PrEP services could be led or coordinated by an Advanced Nurse Practitioner in nurse-led clinics.

## Improving diagnosis of HIV infection

### *Expanding access to HIV testing*

The proportion of people remaining undiagnosed has remained fairly constant. Epidemiological statistics, through unlinked anonymous testing continue to show that approximately 27% of people living with HIV are undiagnosed [9]. This has led to calls for increased testing and earlier diagnosis of HIV infection. Indeed, the Chief Medical Officer has called for primary care to be more involved in the testing of HIV patients [10] and in 2010, a coalition of organisations working in HIV came together to launch the Halve It campaign [11]. Halve It aims to halve the proportion of people diagnosed late with HIV (CD4 cell count <350) and to also halve the proportion of people living with HIV within 5 years. At present, most HIV tests are carried out in either GUM or antenatal settings. The BHIVA [3] and NICE [4] guidelines, as well as the Halve It campaign, all conclude that we must improve and increase accessibility and acceptability of HIV testing within primary care and other settings.

The impact of these strategy and service-delivery documents should be to increase the number of HIV tests being carried out in primary care and non-traditional settings. There have already been a number of pilot projects set within primary care that suggest this is possible [6,11–13]. In particular, two studies [11,12] outline work carried out where point-of-care (rapid) HIV testing was offered routinely by practice nurses and healthcare assistants. This highlights how, in the future, nursing will remain central to, and play a critical role in, the challenge to expand HIV testing in order to reduce the number of those remaining undiagnosed. It requires that 'HIV nursing' be expanded to include practice nurses and will challenge our colleagues to develop the skills and competencies required to provide testing. Much of the support to carry this out is already in place. NHVNA has developed both e-learning modules and the Competencies that could guide other colleagues ([www.nhivna.org](http://www.nhivna.org)). In addition, community-based nurses in HIV (clinical nurse specialist or community matrons) who already have close links with primary care can also support other colleagues in developing these skills.

A further challenge will be to ensure that those patients being diagnosed within primary care or non-traditional settings can quickly and easily access secondary care. Clear referral pathways will need to be developed. Traditionally this has always been from clinician to clinician; however, if nurses (either NHS or other provider-based) provide HIV testing in various settings and initial assessments within HIV clinics, then nurse-based referral

pathways could easily be developed. The *Standards for HIV Clinical Care* [14] recommend that all patients should be assessed by a doctor who provides HIV care within 2 weeks of a positive HIV test result. In the future, nurse-based referral pathways could fit this standard.

### Home-testing kits

Currently, home-testing kits for HIV are not available in the UK. However, this situation is being reviewed and it is likely, given the wide availability of home testing in other countries, that kits will also be approved for use in the UK. The emotional effects of an HIV diagnosis can be devastating when carried out in the traditional GUM setting, and there is a concern about the effect that such a diagnosis could have at home, with little or perhaps no support. If we consider for a moment how home testing might work, then we need to address this concern and it is therefore likely that the kits will have limited availability.

It might be possible to provide home-testing kits via a controlled service (such as controlled internet provision) whereby the person purchasing would complete an assessment prior to payment. This process would take the patient through the issues and suggest other ways to access testing where appropriate, and also ensure that the purchaser considers other testing choices (thus maintaining choice and informed consent) and what to do and how to access services should the test react and suggest HIV infection. It would mean that the burden of responsibility would be on the purchaser to make the choice to access follow-up services. Generally, this is already the case, and many readers will be aware of newly diagnosed patients who are lost to follow-up, despite much support and many attempts to engage or re-engage them.

## Conclusions

The NHS is changing, and HIV provision along with it. This article has explored and offered some predictions about how this may affect HIV prevention. What is certain is that change will occur and that it will affect nursing. We may find ourselves outside the traditional GUM or HIV clinic providing support for testing and prevention services; we may find ourselves based in the community, in primary care or in third-sector organisations (which are already successfully providing some level of service). What is important is that nurses provide an active voice and participate in the continuing debate.

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