

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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HIV nursing: past, present and future

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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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Twenty five years on: where are we going?

Jane Bruton

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Twenty-five years on from when the first AIDS case was identified, what are we facing as HIV nurses? In the UK, in 2005, there were an estimated 63,500 people living with HIV and of these, 32%, more than 20,000 people, remained unaware of their condition. We saw the highest number of new infections diagnosed amongst men who have sex with men (MSM) since 1990. One in every 450 women giving birth was HIV-positive [1]. At least one-quarter of HIV deaths in 2004–2005 was due to late diagnosis. In the light of this the British HIV Association (BHIVA) has recommended that both the Expert Advisory Group on AIDS (EAGA) and the Department of Health consider how to promote more routine HIV testing in specialist HIV/GU/sexual health settings, as well as generic healthcare services [2]. The British Association for Sexual Health and HIV (BASHH) guidelines recommend an opt-out approach to HIV testing in GUM clinics regardless of risk [3].

There are now 47,000 people accessing HIV care. Almost half of those are from the Black and Minority Ethnic (BME) community. The geographical distribution of those living with HIV is changing. A projection by the Health Protection Agency (HPA) suggests that by 2007 over half of the HIV-positive population will be resident outside London. Sexually transmitted infections (STIs) continue to rise particularly among young people (16–24 year olds) and in HIV-positive MSM there was a 10% rise in gonorrhoea and a 23% rise in syphilis in 2005. In specialist drug centres in London the prevalence of HIV amongst intravenous drug users (IVDU) remains high at 3.2% compared with the rest of the UK. Sharing of injecting equipment amongst IVDUs is reported as being higher than in the mid-1990s.

With increasing numbers and complexity of HIV, BHIVA is currently consulting on a co-ordinated multi-sectoral approach that will ensure standardisation for care delivery. Recommendations will be based on providing HIV services through a tiered system that will enable service provision for patients with requirements for treatment at different levels of complexity.

There are currently nine HIV-positive people in jail who have been convicted of recklessly causing serious bodily harm by allegedly transmitting the virus to sexual partners. The UK government continues to deny the rights of failed asylum seekers to healthcare; some have been deported [4]. Stigma and prejudice remains a problem.

In the NHS we are in the middle of a financial crisis, the roll-out of payment-by-results and yet another

reorganisation. Hospital beds are being closed, nurses and other health workers are being made redundant and newly qualified doctors and nurses cannot find work. There is a drive towards primary care and a mixed economy for the provision of health care [5]; HIV funding is currently being reviewed by the HIV Commissioners; HIV patients are obliged to give their real post code; and, as Paul Clift points out in this journal, there is a drive towards GPs managing non-HIV-related problems.

The good news is HIV treatments are getting easier to take, with fewer side effects and a smaller pill burden. Our diagnostic methods and care management are becoming more sophisticated. People living with HIV can have longer and better-quality lives.

HIV nurse-led care is on the map. Patient involvement is growing. HIV care remains open access which means that patients can still self-refer.

Amid all this change, both to the disease and to the economics of healthcare, it is important to reflect on our experiences particularly over the last 10 years to pick out the key ways in which HIV, the NHS and nursing have developed. This will better equip us for facing the challenges of the future.

From 1995 to 2005

The biggest change over the last 10 years, since the introduction of highly active antiretroviral therapy (HAART), is that HIV has ceased to be a terminal disease. Care before 1996 was largely delivered in inpatient and community settings with a network of statutory and voluntary organisations co-ordinated to support young (mainly gay) men and their carers living and dying with HIV. Now HIV is described as a chronic condition, like diabetes, which can be managed in outpatient clinics with greater opportunity for patient self-management. However, HIV care is no less complex, particularly with increasing co-infection. The number of deaths has levelled off to about 400 per year – a quarter of the 1995 figures. With 7,450 new infections last year it is believed that the annual number of new infections may be stabilising, because each year previously since the beginning of the epidemic saw a steady increase. Over the last 10 years there has been a three-fold increase in people accessing HIV care.

The number of new diagnoses and the prevalence rate remains highest in London. However in 1996 only 14% of people with HIV were living outside London; this had increased to 47% by 2005. The highest proportional increase in HIV cases over the last 10 years has been in the East of England with a

seven-fold increase in the last year, the East Midlands with a six-fold increase and the West Midlands with a five-fold increase. Clearly these changes since 1996 underpin the analysis and thinking of the Commissioners as they set about reviewing how, where and by whom care is being delivered.

That, then, is the trajectory of the disease. The trajectory of the NHS is less easy to predict. The two-and-half decades of HIV have coincided with two-and-half decades of radical change in care delivery and the structures of the NHS, and in nursing, overseen by both Conservative and Labour governments. These have impacted on the development of nursing in general and HIV nursing in particular.

In the early 1990s, the NHS underwent major changes culminating in the introduction of the market and the concept of the patient as consumer. Patient rights were promoted by the Government but this was a concept that had been understood for some time in HIV. It was also a period of bed and hospital closures but, against the general grain, in HIV new facilities were being opened and our funding was ring-fenced. Senior medical staff had managed to capture the listening ear of the Health Minister, Norman Fowler, about the seriousness of the epidemic. Sadly we were often criticised by other nurses for having too much money and too many resources, a myth that is perpetuated today.

In nursing, theory and practice were evolving in a direction that was to put HIV nursing at the forefront of innovation. The introduction of the Nursing Process and holism was designed to challenge the practice of task allocation and the medical model. Central to the new approach was the distinction between 'care' and 'cure'. As Pashley and Henry [6] point out:

This distinction will enable nurses to become *professionals of care* rather than *handmaidens of cure*.

HIV provided us with the opportunity to make this theory a reality: on virgin territory and fully resourced we could implement real, patient-centered, holistic nursing care.

At the same time as these developments in nursing theory, nursing roles in practice were expanding – from administering IV antibiotics through to the development of new specialist roles. By 1992 the UKCC [7] had provided a framework, 'The Scope of Professional Practice', for developing nursing roles. What was crucial in the statement was the principle that all developments in nurses' roles must be in the patients' interest and not compromise the provision of nursing care. The NMC have gone on to incorporate the framework within the code of conduct

The NHS has undergone further dramatic changes under Labour; central to these is 'The NHS Plan: A

10-year vision for the future NHS', which has been followed by a raft of further legislation reintroducing the market, Foundation Trusts and the concept of a mixed economy for health. There is one key issue from the NHS Plan to consider in relation to HIV nursing and that is the endorsement of the expanding role of the clinical nurse. The NHS plan states:

Advanced nursing roles have emerged in the belief that nurses and midwives can make a valuable contribution.

The challenge for nurses has been to protect the core of the nursing role from being eroded and

UK milestones	
USA reports first AIDS cases in immunocompromised gay men	▶ 1981
HIV virus identified	▶ 1983
Diagnostic antibody test developed	▶ 1984
	▶ 1985
	▶ 1986
FDA approves first antiretroviral	▶ 1987
	▶ 1988
	▶ 1989
	▶ 1990
Freddie Mercury dies of AIDS-related illness	▶ 1991
	▶ 1992
~15 million people living with HIV world-wide	▶ 1993
	▶ 1994
	▶ 1995
Protease inhibitors approved and combination therapy shown to better suppress HIV in clinical trials	▶ 1996
	▶ 1997
	▶ 1998
	▶ 1999
~30 million people living with HIV world-wide	▶ 2000
	▶ 2001
	▶ 2002
WHO/UNAIDS 3 by 5 initiative	▶ 2003
	▶ 2004
~38 million people living with HIV world-wide	▶ 2005

HIV/AIDS: 25 years of the epidemic. From the Health Protection Agency 'A complex picture: HIV and other sexually transmitted infections in the UK: 2006'.

devalued, in the context of the explosion of new roles over the past few years and with the development of the Nurse Consultant. We have needed to ensure that nurses are 'maxi nurses' not 'mini doctors'. Certainly, the concept of the Nurse Consultant did not come from within nursing but it nevertheless addresses the need to keep expert nurses in clinical practice by creating a clinical career structure. Hicks and Hennessy [8] warn that:

Specialist roles continue to develop out of the need to reduce economies of scale and the demands of reducing doctors' hours rather than as a response to the challenges in health care and expert nursing practice.

This underlines the contradiction in which we exist today: nurses are valued and yet the concept of care that is at the heart of nursing is being undervalued.

This could not be better illustrated by developments in the last 12 months; while there is still validation of the expanding role of nursing, nurses at every level are being squeezed from all directions: reduction in both general and some of the specialist posts; the reduction in, or banning of the use of, temporary staff; plus skill-mix reviews to reduce the ratio of qualified to unqualified nurses. The irony is that 3 years ago we were discussing the impending nursing shortage. Now qualified nurses can't find jobs.

The impact of this for nursing in general is significant but it may be greater for HIV nursing where we have been operating with trained teams of nurses with specialist nurses as part of those teams. Nurses in HIV have to clearly define what nurse-led care is and what role untrained staff have within care delivery that complements rather than undermines holism.

There is one further concern, amongst many, for HIV nurses in today's climate that needs careful consideration: the potential fragmentation of HIV care and its effect on the concept of holism. HIV Nurses, through the development of nurse-led care, could turn this concern into opportunities for innovative care.

HIV has become a chronic disease but that does not imply that it is simple to manage. To liken HIV to diabetes becomes tempting but this runs the danger of ignoring the impact of stigma and discrimination. With ever-increasing numbers, changing epidemiology, an aging cohort, complex treatments and the complexities of co-infection, HIV is a medical condition that requires careful monitoring and the provision of specialist care, not least because of the continuing psycho-social issues. The proposal from BHIVA to create a tiered multi-agency approach to care recognises the need for different levels of specialist care and for standardisation of practice. However there is a danger of fragmenting the care for patients.

Patients will be expected to move between services at different stages in their condition. This change of care centre and practitioners would be at the times when a patient may feel most vulnerable. It potentially underestimates the importance of the doctor-patient and nurse-patient relationship. We have to think very carefully how this model can be implemented without rocking the main tenets of holism.

The drive for patients to return to primary care for their non-HIV needs could lead to further fragmentation. Patients have been used to receiving all their care from their HIV physician. We have been used to providing or co-ordinating their whole care in the spirit of a holistic approach. Who will become the key practitioner co-ordinating the care in the future: the GP or the HIV physician? How will a patient decide what is a non-HIV-related problem? How will patients be assured confidentiality? These questions have to be addressed very quickly before the move to primary care is simply forced through by restrictions on the provision of non-HIV medications. Nurses have a key role to play in considering innovations that will maintain the principles of holistic care that has been fundamental to the development of HIV care.

Finally, for inpatient care, the financial imperative from acute Trusts to continually reduce the skill mix and nursing numbers threatens the holistic approach that we have built over that last 20 years and forces us more towards task allocation and away from primary nursing. We must begin to develop a benchmark for inpatient HIV care.

There are challenging times ahead but as nurse-led care becomes embedded within HIV there are great opportunities for nurses to make a difference.

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Let's go to the circus? A personal look at the International AIDS Conferences

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Introduction

This year saw the 16th International AIDS Conference (IAC) in Toronto. Only 16? Covering almost the lifetime of the epidemic, this simply seems too few a number and too short a time. Of the 16, two in particular stand out because of the paradigm shifts they generated in HIV policy and treatment: 1996 (Vancouver), where evidence for the efficacy of highly active antiretroviral therapy (HAART) was confirmed; and 2000 when, for the first time, the IAC was held in a developing country. For better or worse, the IAC has become a premier event in the HIV calendar, but as we look back 10 years to Vancouver, we do need to ask: how effective is the IAC in reaching affected people? What does it really do?

This admittedly subjective review concludes with a key question: is it time to provide local events that attract similar levels of funding as the IACs, that may be more able to connect with affected people?

Antecedents

Many delegates emerged after the very first IAC in Atlanta, Georgia in 1985 reeling at the impact of AIDS on the developed and developing world. It was the first incurable and uncontrollable infectious disease in the West for a generation and by 1985 the truly destructive nature of the human immunodeficiency virus (HIV) was apparent – especially its devastating prevalence in developing countries, in regions already facing significant health, social and economic problems. Since then, HIV has also confirmed the toxic nature of stigma, based on a natural tendency for societies to construct hierarchies of disease, ranking the more acceptable and palatable above the blameworthy or distasteful. This ranking is always highly arbitrary, and usually based on fear: blaming an individual is a useful way of sublimating personal anxieties of possible exposure to frightening disease.

The IAC, which has as its custodian the International AIDS Society (IAS), has always been something of an anomaly. The first conference was held only 4 years after the first cases of AIDS in California and it was aimed largely at the North American context. Its focus, according to Peter Piot speaking earlier this year 'was really on gay men in North America and there was total resistance to imagining that there could be an unfolding heterosexual epidemic in Africa' [1].

The controversy and activism that are now part of the IAC's fabric (spontaneously planned protests have become something of a tradition) was a feature even in 1985, when Act-Up, a Paris-based activist group, stormed the opening ceremony, carrying 'silence is death' posters. In the years following, the annual event (it became bi-annual from 1994 onwards) was mainly scientific, and shuttled around the wealthiest cities in the world. It was not until the fifth in 1989 in Montreal that a specifically social component was added to the conference, and from this came one of the most robust features of the event: skills-building sessions, aimed at empowering people at the local level to tackle the effects of the epidemic.

This conflation of science and society has not been without tension: science and people have never been comfortable bedfellows. Science is generally cautious, but carries the aura of omnipotence that can be irritating; society on the other hand demands results and solutions immediately, but is quick to criticise poorly developed scientific and technical strategies. This is a response that, for the scientist at least, confirms the need for caution, but generates much chagrin for non-scientists, especially around access to treatment and the apparent 'power' of drug companies.

Vancouver in 1996: the 'antiretroviral IAC'

This tension was kicked up a notch at the 1996 IAC in Vancouver. A number of abstracts presented here confirmed that properly managed antiretrovirals, especially in combinations, have a significant impact on the morbidity of people with symptomatic HIV disease, and the mantra of the conference became 'treat and treat hard'. The rest is history: at a stroke, AIDS was wiped out in the (wealthy) countries able to afford – and deliver safely – antiretrovirals.

This development, even now, 10 years later, promises much but remains problematic. Advances in treatment patently do not benefit the majority of affected people. A protest during the Vancouver IAC by Act-Up and their poster 'Merck; Roche; Abbott? Greed=Death' epitomised the narrative that began in 1985 and continues to this day, fuelled now by the proven benefits of antiretrovirals. Perhaps the anger has good cause, for even in 2006 only 25% people requiring

treatment have access [2]. This appalling circumstance is not confined to the developing countries of the South, the figure is 13% in the Russian Federation. In the years following 1996, it has always been the most developed countries and the least affected who could afford treatment.

Further evidence that the broader international AIDS community was ignoring the majority was perceived by many to be the IAC location: it was always in regions largely unaffected by the virus. Even in the very early days of the epidemic, African regions have always been disproportionately affected. In 1998 there were around 28 million people living with HIV, 19 million were in Africa, but the IACs until 1996 had been held in some of the wealthiest developed countries: five times in North America, five times in Europe, and once in Japan.

Holding the 1998 IAC in Geneva (its sixth time in Europe) stoked this controversy, not helped by the contribution to conference events in Geneva being small from developing regions. Also the conference theme of 'Bridging the Gap' was perhaps the last straw, and from this point on IACs would never quite be the same.

Durban in 2000: the developing world does exist

So, the 2000 event went to Durban in South Africa (the theme, 'Breaking the silence', has since been branded, and proves one of the most enduring). It was seen as a watershed – the first time in the southern hemisphere, in a developing country and one facing devastating levels of HIV prevalence (in 2000 prevalence was 24% of the adult population).

It was therefore ironic that the event was marred by becoming something of a showcase for AIDS denialists, bolstered by comments made during the opening ceremony by President Thabo Mbeki – he questioned the link between HIV and AIDS – which sadly overshadowed what could and should have been a landmark event. At least from this point on it was confirmed the IAC would alternate between developed and developing regions. That said, Nelson Mandela's rousing and empowering speech in the closing ceremony for many formalised the reality of HIV: a disease wreaking havoc on the continent, and requiring African resolve to fight it.

In spite of the many thousands of worthy presentations in the three IACs since 2000, often the most memorable events are those impacting emotionally or dramatically. Barcelona in 2002 ('Knowledge and Commitment for Action') was seen as over-emphasising treatment and not prevention, and is remembered for the closing ceremony mayhem when US Secretary of Health Tommy Thompson tried (and failed) to speak above the chanting of activists; Bangkok in 2004 ('Access for All') with its particularly idiosyncratic (and

largely non-Thai) opening and closing ceremonies, together with the snubbing of a prominent affected person, Paisaon Suwannawong of the Thai Drug Users' Network, who had a clear view of VIPs leaving the arena prior to his presentation

And Toronto in 2006? Its theme – 'Time to deliver', flags increasing frustration that the demands posed on the world by HIV still seem to outstrip our capacity to respond. The social impact of the disease was even more evident, especially the predominance of HIV stigma, which according to Mary Robinson, until recently UN High Commissioner for Human Rights, is 'exceptional in its scale, its context, and its causes' [3]. A final memory for many is the impassioned closing speech by Stephen Lewis, outgoing UN Special Envoy for HIV/Aids to Africa. To the delight of delegates, he accused the South African government of acting in a way that was 'wrong, immoral and indefensible' [4] in its approach to HIV policy and ambiguous messages about links between HIV and AIDS – a perception held by the majority of delegates. Lewis also re-emphasised the need to continue antiretroviral roll-out: 'treatment is keeping people alive...we cannot let the treatment slow' [4].

And now?

In the 21 years since Atlanta, we have learnt that the HIV epidemic is not only multi-faceted, but also Janus-faced. On the one hand it is a truly modern disease with a discourse shaped by global communication, and attracting a huge range of interventions from advocates, agencies, governments and industry. It seems also pre-renaissance – frightening, confusing and incurable.'

The IAC will always be something of a compromise. At best it gives an opportunity for networking, for (some) affected people to have their say, for those of us in civil society a place to share and discuss our work in a welcoming and non-judgemental context. The skills-building events give more practical approaches to community-based initiatives. There are also problems: for many it is just a shop window for drug companies, or an event exposing the rift between the scientific and social communities. An event that is exclusive because of cost and location, marginalising the majority of affected people. It also seems to lack consideration of some significant issues: for example in Toronto in 2006 UNICEF was quiet (in spite of increasing concerns about the impact of HIV on children).

Some of the tension between science and the community has been relieved with the launch in 2001 of the bi-annual IAS Conference on HIV pathogenesis and treatment. This siphons off some of the more 'hardcore' science from the IAC, allowing greater emphasis on community and development, and one can only hope that the event rises to the challenge of exploring ways to

connect with affected people more effectively, and at the same time to perhaps examine alternatives to what has become a massive and expensive event. In Toronto 9,000 presentations (including posters) were given, and 25,000 people attended – a city-sized circus without the clowns.

IAC themes have always indicated key issues in HIV and AIDS. Let's hope the event in Mexico City in 2008 has one that reflects positive developments, rather than another call to account.

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Antiretroviral Resistance in Clinical Practice

Edited by Anna Maria Geretti

Antiretroviral Resistance in Clinical Practice is a novel publication that has been developed to serve as a handbook for physicians dealing with the problems of antiretroviral resistance in their practice.

Antiretroviral Resistance in Clinical Practice covers an extensive range of topics (see below) written by eminent and internationally renowned authors led by the Editor Dr Anna Maria Geretti. Dr Geretti is a Consultant Medical Virologist and Honorary Senior Lecturer based at the Royal Free Hospital in London, and has a special interest in antiretroviral therapy and resistance.

The book examines the mechanisms of resistance to reverse transcriptase, protease and entry inhibitors with contributions from Charles Boucher, Noortje van Maarseveen, Nicola Mackie, Anne-Geneviève Marcellin, Eva Poveda and Vincent Soriano. With chapters by Martin Däumer and Tobias Sing, Alessandro Cozzi-Lepri, Karin Metzner, Carlo-Federico Perno and Ada Bertoli, Caroline Sabin and Martin Schutten, readers will be able to gain a valuable insight into the complex topic of resistance and obtain an update on the various methods used to measure, predict and interpret resistance.

Françoise Brun-Vézinet and Diane Descamps review the overall benefits of resistance testing, while Andrea De Luca examines the impact of resistance on viral fitness.

Marta Boffito investigates the pharmacokinetic implications of resistance, and Ricardo Camacho discusses the implications of HIV-1 subtypes on resistance testing, while Clare Booth gives an overview of transmitted resistance.

Finally, there is a chapter dedicated to a series of case studies, compiled by experienced clinicians, which are accompanied by an expert commentary.

Antiretroviral Resistance in Clinical Practice will prove to be a valuable handbook to all those who want to understand the increasingly complex problem of antiretroviral drug resistance in HIV medicine.



Topics covered in *Antiretroviral Resistance in Clinical Practice*:

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Criminal law and the transmission of HIV

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The question of whether – and if so, in what circumstances – a person should be held criminally liable for transmitting HIV to a sexual partner is one that has become increasingly important in the light of the ever-growing number of convictions for this offence. Nurses and healthcare professionals, as much as those living with HIV and AIDS, need to be aware of the way in which the law operates: not only because those they care for may find themselves facing criminal charges and ending up in prison, but because they may be implicated in the prosecutions themselves [1]. In this brief article I set out the current law (which applies as much to liability for the transmission of other serious STIs), and raise some issues about which the nursing and healthcare professions need to be aware.

There have, to date, been 10 court cases involving people alleged to have transmitted HIV to sexual partners [2]. All but two of the prosecutions have been cases involving heterosexual sex, eight have been of men, and three have been against men of African origin. In nine cases there have been convictions, and in each of these the defendant has been convicted under section 20 of the Offences Against the Person Act 1861 for recklessly causing serious bodily harm. In all of the successful prosecutions the defendant has been sentenced to immediate custody for periods of between 2 and 4.5 years in respect of the offences with which they were charged.

It is very clear that the courts are treating the reckless transmission of HIV as a very serious offence. In 2003 only 55% of adults convicted under section 20 were sentenced to immediate imprisonment, and of that 55%, only 4% received sentences longer than 3 years. In the HIV transmission cases 100% of those convicted have received immediate imprisonment, and the majority received sentences of 3 years or more [3].

Until the decision of the Court of Appeal in the case of *Feston Konzani* [4], the law was as follows. A person could be convicted for reckless transmission of HIV during sex if (a) she or he was diagnosed HIV positive and knew this; (b) was aware of the risk of transmitting HIV at the time she or he had sex with a partner; and (c) in fact transmitted HIV to that partner. She or he would not be guilty of the offence if (despite knowing her or his HIV-positive status and in fact transmitting HIV) the partner to whom HIV was transmitted consented to the risk of becoming infected, or if the person charged honestly believed that there was such consent.

One of the key questions that the law had not answered was the meaning of consent in this context. Since *Konzani* this has been clarified. The only kind of consent that will work as a defence is *informed* consent. In other words, a person who wants to raise the defence of consent will only be successful if the person to whom HIV was transmitted willingly or consciously consented to the risk. It is not enough for a defendant to say, 'my partner agreed to have unprotected sex, therefore she (or he) consented to the risk of transmission'. Instead, the Court of Appeal seems to be implying that consent will only operate as a defence where there has been prior disclosure of known HIV-positive status to the partner. The Court did recognise that there might be exceptional circumstances where consent could exist despite a lack of disclosure (e.g. where the person making the complaint met the defendant in a hospital where she or he was undergoing treatment for their HIV infection or for an AIDS-related illness); but in general it seems safe to say that informed consent can only exist where disclosure has occurred.

One of the most important recent developments was in one of the two cases involving sex between gay men. For the first time the virological evidence (which was produced by the prosecution in order to demonstrate the source and route of transmission) was challenged. The expert in this case (Dr Anna-Maria Geretti of the Royal Free Hospital) explained that such evidence was not, in itself, sufficiently conclusive to establish that the defendant had passed the virus to the complainant. As a result of her testimony the judge directed the jury to reach a not guilty verdict.

People will, of course, hold a variety of views about the moral status of those who, knowing their HIV-positive status, fail to disclose this fact to partners, or who lie about this when asked. But the morality of a person's conduct is never a sufficient condition to justify criminalisation (otherwise lying, adultery and whole host of other immoral conduct would attract criminal liability). In the context of HIV transmission it is vital, when thinking about the appropriate response, to remember that HIV and AIDS must first and foremost be understood as a public health issue; and any legal response should acknowledge the adverse impact that criminalisation of transmission may have. Consider, for example, the following:

- Because only those who know their HIV-positive status can be criminally liable this may operate (even if only for a very few) as a disincentive to testing.

- It is unclear in English law whether appropriate condom use will preclude a finding of recklessness. If we want to encourage the use of condoms (which is a far better prevention technique than disclosure) it is critical that those who do use them should not feel that they risk being criminalised in the event that transmission nevertheless occurs.
- Because there is a *de facto* requirement for an HIV-positive person to disclose prior to sex (in case transmission occurs, a case is brought against them, and they want to argue that there was consent to the risk of transmission) this may provide a disincentive for a person who has not disclosed to disclose in the event of condom failure. (They may be, in effect, confessing to the commission of a criminal offence.) This could have negative implications as far as enabling the partner to access post-exposure prophylaxis is concerned.
- If the criminal law is indicating that disclosure by HIV-positive people is necessary to avoid liability, people may (wrongly) assume that non-disclosers are HIV negative. If this were the effect, this would be catastrophic as far as prevention efforts are concerned.
- Effective sexual health management and advice (and qualitative research into sexual behaviour) depends on full and frank disclosure, within a trusting relationship based on confidentiality. As the law stands, the notes and records of health professionals may be used by the prosecution as evidence that a defendant was aware of his or her HIV-positive status and of the risks associated with sex. If people fear that information they provide may be used against them they may choose not to access health services, and if they do access them, not tell the truth.
- There may be an adverse impact on the framing of sexual health advice (should nurses and

health professionals warn their patients and clients about the legal implications of disclosure to them about unsafe sex? And if so, how might this damage the carer/patient relationship?)

- Prison may result in adverse health outcomes, both for the convicted person and those with whom she or he may be in sexual contact there.
- Most significantly perhaps, the criminalisation of reckless transmission undermines the message of shared responsibility for sexual health.

Healthcare professionals need to think carefully about the implications of criminalisation for their work, and, irrespective of their own moral position, address the effects that the law may have both on their day-to-day relationships with patients and clients, and on the management of the epidemic.

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1. For further discussion see the draft BHIVA briefing paper *HIV Transmission, the Law and the Work of the Clinical Team* (available at <http://www.bhiva.org/>).
2. For an account of the cases up to October 2005, see the Sigma Research Report *Grievous Harm* (available at <http://www.sigmaresearch.org.uk/downloads/report05b.pdf>).
3. Sentencing Guidelines Council Consultation on *Assaults and other Offences Against the Person* (September 2005) (available at <http://www.sentencing-guidelines.gov.uk/consultations/closed/index.html>).
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A personal account of HIV nursing past and present

Jane Bruton

HIV Nurse Manager, Chelsea and Westminster Hospital, London

So there we were in the early 1980s, confronted by a new disease with no cure, high mortality, affecting socially excluded and stigmatised groups, images of plague in the press and outrageous suggestions about what to do with those infected.

The belief was, as Richard Wells said:

If we get it right for AIDS we get it right for the whole of nursing.

I, like many other nurses attracted to HIV nursing, wanted to do something about this injustice. It is hard to summarise those early years of nursing patients with HIV and AIDS for fear of leaving out crucial points. This is probably best illustrated by my experiences as sister in 1987 on the infectious diseases ward in an old isolation hospital in Leicester, which had been designated the city's HIV/AIDS ward. I knew from the local gay community that most patients with HIV dreaded the day they would be admitted. What did I find? A group of nurses unprepared for, and in some cases unwilling to, nurse patients with HIV. Some were homophobic; they nursed HIV patients in isolation, they restricted the visiting and there was little expertise in acute HIV or palliative care. There was no community support or task allocation and ambulance men arrived in space suits but only with the HIV admissions even though they had been carrying patients with meningococcal meningitis for years with barely a mask on!

I think, on reflection, the nurses must have felt very isolated. Their family and friends were worried about them working there. For the patients the environment was bare and soulless with no day room. Some had lost their jobs because of their HIV. Most had not discussed their diagnosis with anyone. I soon realised that this was the start of a series of battles in a war.

By 1989 I had moved to the HIV specialist ward at the Middlesex Hospital, Central London. It was one of the first specialist units to be opened, in a blaze of publicity, in London in 1987. Their experience had been much the same as mine only magnified ten-fold. There were almost siege conditions with regular hate-mail and letters of support, the press and religious evangelists were trying to get in and the hospital support staff were trying to get out (if they hadn't refused to come on the ward in the first place). The walls of the ward protected the nurses and patients against the hostile and hysterical

outside world. Nurses became the gatekeepers of the patients' dignity and privacy. So naturally the patient and their world had become the centre of the care and partnerships established. In the absence of a cure everything rested on care.

There was little hierarchy of knowledge, patients often knew as much as doctors and nurses. The relationships between doctor, nurse and patient were equalising. The medical model was disarmed and vulnerable and many of the traditional structures and roles were dismantled: for example out went restricted visiting, the Consultant ward round and nurses' uniforms, and in came multi-disciplinary working, involvement of partners and patients' freedom to go out for a coffee or to the theatre whilst an inpatient.

In its place we built an environment that was like home – safe and comfortable, where patients and partners were welcomed literally with open arms. One of our patients Oscar Moore [1] described it like this:

And then (I) painfully inched my way to the hospital and fell back waiting for the healing hands. Suddenly I was in paradise. This was like a four-star hotel, where they are pleased to see you and serve you. For a start it was an HIV ward, so there was no unpleasant undertone ... The whole atmosphere after the stiff starched white uniforms and Aryan politics of Glasgow was like sinking into the deep sofa of a hotel lobby and being plied with cakes. The nurses were in jeans and T-shirts and were intelligent and funny.

We were becoming multi-skilled experts with the constant exposure to the new manifestations of the disease. Patients had control over their life decisions, should they choose to, which at that time was as much about the right to life-saving treatment as it was to ensure open discussions about stopping active treatment. Funerals were planned. Everything was celebrated. Everything was centred on normalising what was a very abnormal world where patients' social and personal lives were collapsing.

By 1995, when HAART began, what had we achieved? Well, good and bad really. It must be said there were a lot of casualties from burnout on the way. Boundaries were not initially considered important or understood. Primary/key nursing was embedded in the inpatient setting and caseload

management in the outpatient setting. Specialist Nurses grew up in primary care to advise on and deliver palliative care and active treatment.

HAART has transformed HIV and the lives of those affected by HIV – patients, friends, carers and healthcare workers. With HAART came the ideal conditions for the raising of cure over care and the right conditions for the revival of the medical model.

The early impact in the inpatient setting created tensions mainly around the end-of-life decisions. We had been clear about when to discuss stopping active treatment and to move to palliation; now of course there was uncertainty in the light of the well-observed phenomenon of the Lazarus effect. It was unnerving for all. This shifted the balance within the partnership of doctor, nurse and patient, towards a more medical-led approach. These uncertainties meant patients were treated actively until the end. Death rates were decreasing dramatically but we did begin to see patients dying on the ward before we could have got them home. This remains a challenging issue today.

The success of HAART was marked, ironically, by a decrease in clinical nurse specialist posts, a cutting back on the voluntary and statutory services and ward closures. All the major units had their beds at least halved and the London Lighthouse closed. Whilst this was good news, at the time it was a huge loss for staff and patients. The future of HIV nursing felt very insecure. However, despite these changes, what is life-affirming is that the continuity of philosophy and structures of care were not lost in most units.

When I moved to the Chelsea and Westminster in 1999 I realised that despite little contact between the nurses on the units, we were doing virtually the same thing. It was like moving back into a familiar

old house. Everything was where I expected it to be. However, the job of challenging the re-emerging medical model was urgent.

The impact of HAART in the Kobler clinic (at the Chelsea and Westminster), as with other HIV outpatient settings, has seen a growing disjuncture between service and patient needs. The nurses recognised that the patients' needs, although no longer palliative were equally, if not more, complex but lay largely hidden. The nurses' roles previously so well defined were being squeezed by a set of urgent clinical tasks managing the doctors' growing clinics. It was acknowledged that consultant-led consultations were no longer viable, numbers of patients increased and there were longer waits for appointments.

The turning point came when we established clinical teams with nurse-led care at the heart of this concept. Each consultant and a primary nurse led one of three teams of experts from the multi-disciplinary team. Within the team, relationships are beginning to equalise and this can enhance the partnership with the patients. The next step has been to establish an active patient forum that aims to ensure patient involvement at every level. Last week we completed our first joint patient-staff audit of the phlebotomy service. For me, we have gone full circle back to those times when patients were right there determining the services they wanted. There is a way to go but this is a start.

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Then and now: a patient's personal view of a changing world

Paul Cliff

Board of Directors
UK Coalition of People Living with HIV and AIDS (writing in my personal capacity)

We're now 25 years into the HIV pandemic and it has changed out of all recognition. Twenty-five years ago pretty much all that we knew was that there existed a range of serious and often fatal symptoms, which might have a common underlying cause. The medical profession knew as little then as did people living – or dying – with it. That lack of knowledge, perfectly legitimate at the time, was too often compounded by woeful ignorance and prejudice, not only in the

media but also in the medical profession itself; usually this manifested in prurient homophobia.

In the face of medical lack of knowledge, increasing numbers of people with HIV felt compelled to find out all they could, becoming lay experts in their own right. 'It's frightening sometimes how much they know,' commented Dr Robert Gallo, a co-discoverer of HIV-1. (Why should a doctor be frightened about how much a patient knows?) This phenomenon continues, and has been a shaping

force in the response to HIV in the UK and globally; indeed some of the finest treatment experts in the UK are non-medical people with HIV working with the *National AIDS Manual* and with *Positive Nation* magazine. What has made this response by patients particularly effective is the consideration given to it by HIV doctors and nurses.

I was diagnosed with HIV infection in 1988, back in the pre-HAART era. The clinic I attended was outside London. As with clinics and health care workers elsewhere, it was a GUM clinic with GUM staff having to deal with something new and far more serious than routine STIs. Initially it did not cope well. Some younger specialist registrars rose to the challenge (and are probably now consultants) but the old guard seemed – to us, the patients – out of their depth, distant and unresponsive; it was not helpful that a senior clinician at that clinic had been quoted in the local paper as saying ‘there will be no epidemic here’ (only a few years later there most certainly was an epidemic) or later, in a meeting with myself, that ‘there is no need for a specialist HIV consultant’. They also seemed to have difficulty engaging with patients as anything other than passive recipients of care. As for inpatients, they were hidden away in a garret under the eaves of the old local hospital (now sold off to private owners) in a remote isolation ward.

That situation was already changing elsewhere; at my own clinic it changed with the appointment of a new, younger, HIV consultant. This was somebody who was not only fully up to speed with HIV pathogenesis and the rapidly developing treatments, but was – and is – fully at ease with this new breed of knowledgeable patient. Sadly it took quite some time for us patients to realise that the regime had changed; our cynicism had deep roots from long experience of not being listened to and of having to put up with second best or go to London. But with time it became clear that the local clinic service was getting better, that we were beginning to be heard and our views were actually being sought. And this has paid dividends. Thanks to a suggestion from this new lead consultant, patients organised and came up with a model for bringing their voice right into the heart of decision-making. This in turn led to patients and clinic staff forming an alliance on big issues, negotiating with the hospital to improve services or to keep cuts to a minimum. Thanks to the efforts of this consultant, and with generous support from the Elton John AIDS Foundation, we gained a specialist ward for dedicated HIV care and treatment of patients with advanced disease progression in a considerate, sensitive environment.

In the larger centres of London, Brighton and elsewhere we have seen great strides in terms of service provision from clinics that felt as if they were barely coping evolving into modern centres of excellence. These have often been achieved by patients and clinicians working together, or at least

with patients being consulted, if not always listened to. In the process, we patients came to establish a relationship with our doctors more like that of the old family doctor. It is impossible to overstate the importance of this to gay male patients, who may – and sometimes did – find that they were being regarded and treated as human beings by figures in authority for the first time. In addition, the HIV clinic became a preferred point of first call, preferred to GPs who were not clued up about HIV or about symptoms associated with HIV.

Now there are new challenges, some of them profound. GUM and HIV clinics are under financial constraint as never before, and there is increasing pressure on patients to use primary care for non-HIV-related matters. This may be fine in theory, but what illness is non-HIV-related? How is the patient supposed to know? And assuming that the patient is not expected to know, then how effective is triage? How HIV-aware are the GPs to whom HIV patients are referred? Indeed it is this issue of making optimum (and cost-effective) use of primary and secondary care services that seems to be causing the most concern to patients, particularly those who have been living long-term with HIV. The sad fact is that GPs are not universally trusted, particularly by gay men with long memories of homophobia and more recent experience of breaches of confidence in GP surgeries. We know from experience in Brighton that this problem can be overcome, but the increasing pressure on patients to make more use of primary care does so regardless of whether primary care is ready. And this leads on to another area of change. In order that services are used to best advantage, and in order for patients to feel safe accessing GPs, patients and specialists need to be involved with each other in constructive activism. But new activists are not coming on-stream in sufficient numbers to take over from the former generation of activists, and persuading consultants to become activists is at times an uphill struggle.

There is a tension currently between a hope that the service, which long-term patients like myself have become used to, will continue, and the certainty that it won't. There are demands from some patients to see their HIV doctor less often, and demands to ‘normalise’ HIV in order to see it as any other manageable chronic illness. We have to accept, I think, that some people are simply resistant to change. For myself, I see adapting to changing circumstances as one of the strategies that has kept me going this long. Some years ago I was in conversation with an American AIDS activist who commented that ‘the virus mutates and so must we’ by which I understood him to mean that we have to adapt our strategies to changing circumstances.

There are further real challenges in the short-to-medium term around access to HIV care and treatment, in particular by migrant people in the face of the current disgusting xenophobia

intertwined with racism peddled by the conservative press and a complicit government. I care passionately about the well-being of my African sisters and brothers with HIV and have no desire to see a service that treats me while excluding them.

Although we have seen big changes in the way services look, and some of us have seen big changes in the way that we are involved in the services provided in our clinics, there remains a feeling that the real changes are yet to come. The fear is that these changes, for example the greater use of primary care, are not thought through but are being driven through anyway in an attempt at saving money whatever the cost to the real value of the service. BHIVA Standards for Care recommendations for tier 1 and tier 2 clinical services may be fine in large urban areas where a patient can reasonably pass back and forth between the two as their care and treatment needs fluctuate. It seems – to me – less reasonable for most

of the country where patients may already have a lengthy journey to their existing clinic; are they now to be expected to trek across country between the two? Or is BHIVA going to accept explicitly that this is not an option for people in rural areas including most of Scotland and Wales? And in the light of increasing for-profit involvement in healthcare, for how long will the NHS provide healthcare free at the point of delivery? How long will it be until GUM outpatient services are outsourced? Are health care workers, including consultants, ready to take up the challenge, alongside patient-activists, of ensuring the continued future of a health service free at the point of delivery for all who need it?

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A volunteer's personal experience

Around 1982 or 1983 I first learned that my son was gay. I took the news very badly; we did not fall out, but I felt that his life would be very sad and lonely. Around the same time I started to read about a new illness that was appearing in San Francisco. It was affecting mostly young men and causing much suffering and bad health. Over the next couple of years more and more people were becoming ill, and many were dying. They were mostly young gay men. I worried about it constantly, and feared the worst. There appeared to be several cases in London by now, and lots of horrendous advertisements were appearing in the Press.

About this time I read an advertisement asking for volunteers to work in the old St. Stephen's Hospital with people with HIV. I did not think I would be accepted as I felt I was too old, and did not have much skill; it was mostly for drivers to bring patients to and from the hospital, and I did not even drive. Anyway, I was invited to attend a training weekend. There were about 20 of us; one of the speakers was a Sister from T.Mac and she asked if there was anyone who could cook, and would start a special Tea Party day, on the ward. It would bring patients out of their rooms and be a very social occasion.

I volunteered for this, and started the very next week. It proved to be a great success and is still going on to this day. We now also try to be on the ward every day for tea, and also every evening for a tea and biscuit round. We also work in Day Care and the Outpatient clinic.

After a few years the Hospital was demolished and all the patients went to the Westminster Hospital while a new hospital was being built. The volunteers went with them. It took about 10 years to build and then we all returned to the new Chelsea and Westminster Hospital. We kept the name St. Stephen's Volunteers as by now we had formed a good group.

That brings me up to today, I am the only one left of the original Volunteers, but over the years we have recruited many more and now have about 30 very dedicated volunteers doing much work. We have the support and trust of the staff who really treat us as part of the team.

For myself, it changed my life; I have met many wonderful people, have made lots of deep friendships, have travelled to many countries to meet up with them and have had patients and their families stay at my home. There has also been a lot of sadness and loss. I did eventually lose my son, which has been my hardest battle, but I received so much support from everyone, and although it is never far from my mind, I managed to get through it with their help. One other thing I have learned is to be able to listen to patients and often their families.

I love Tuesday afternoons, I love being on the ward and try to give pleasure to all, staff and patients alike, but they give me so much more. I must also mention my family, who have supported and encouraged me at all times.

Jean Hunt, *St Stephen's Volunteers*
First published on the St Stephen's Volunteers website
(www.ststephensvolunteers.org) and reprinted with kind permission of the author.

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**13th Annual Conference
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25–28 April 2007

Edinburgh International Conference Centre

**1st Annual Conference
of the Children's HIV Association (CHIVA)**

25 May or 8 June 2007

Birmingham (to be confirmed)

**9th Annual Conference
of the National HIV Nurses
Association (NHIVNA)**

28–29 June 2007

One Great George Street, London

11th Annual Resistance Meeting

26 September 2007

London

**British HIV Association (BHIVA)
Autumn Conference**

11–12 October 2007

Queen Elizabeth II Conference Centre,
London

**14th Annual Conference
of the British HIV Association (BHIVA)**

23–25 April 2008

Waterfront Hall, Belfast

**10th Annual Conference
of the National HIV Nurses
Association (NHIVNA)**

26–27 June 2008

Glasgow

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NHIVNA update

NHIVNA are pleased to be able to provide you with the journal as part of your membership to the association and I hope you agree that it does provide value for money. Zoe Sheppard, from the executive committee, is taking over from Eileen Nixon on the editorial board and will be working with Jane and Ian to bring you articles of interest and relevance to practice. Thanks to Eileen for all her hard work over the past couple of years on the journal.

The executive committee have been busy planning activities for next year and these include next year's conference to be held in London. A copy of the provisional programme will be on the website soon. The website www.nhivna.org has been revamped and will be a valuable resource to keep members up to date with all of our activities.

All NHIVNA members will also receive a questionnaire about NHIVNA. We really want to hear your views on the association. This will be the first time we have conducted a survey so I hope that you will spend a few minutes completing it and you might win free membership of NHIVNA for a year.

The HIV Nursing generic competencies are on the website and the specialist competencies will be there shortly. Please do provide us with your feedback – good or bad! They will be officially launched at the conference in June. In line with the competencies, next year we will be running four study days

NHIVNA study days

London	7	February 2007
Scotland	28	February 2007
Manchester	12	September 2007
Birmingham	21	November 2007

around the country. The aim of the day is to assist nurses with the theory around the competencies. Attendance at the day will help you with meeting the competencies and can be used in your annual appraisals. The days will be free for members. Again watch the website and your post box as information is on its way!

Nicky Perry, Chair, NHIVNA, Brighton



National HIV Nurses Association

9th Annual Conference of the National HIV Nurses Association

28–29 June 2007, One Great George Street, London

Dear Colleague

Sessions to include:

Launch of the NHIVNA competencies

Working within nursing networks and standards

Criminalisation, reckless transmission and sexual health

Managing adolescents and transitional care

Nursing projects in resource-poor countries

HIV and social exclusion

It gives me great pleasure to announce our 9th Annual Conference, which will be held in London 22–29 June 2007. London is one of the world's most remarkable and exciting cities and the perfect place to hold our NHIVNA conference in 2007. There really is something to appeal to everyone and whatever your interests may be, the city has it covered.

The programme is currently in the development stages, speakers are now being invited to participate and I feel sure that there will be many exciting additions over the next few weeks.

We will be organising a Gala Dinner on Thursday 28 June and we anticipate an evening of good food, wine and after-dinner entertainment, including dancing.

More detailed information regarding registration, abstract submission, accommodation and scholarships and awards will be released in January 2007.

Nicky Perry, Chair

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