

# HIV NURSING

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# 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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# Editorial

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## Introduction

Children living with HIV in the UK today are facing complicated issues and uncertain futures.

The Family Clinic at St Mary's Hospital, Paddington cares for one hundred and eighty infected children with a growing number of new patients at a rate of one a week.

## Undiagnosed and infected babies

Babies who are undiagnosed, but infected with the virus, are at risk of becoming very sick within the first few months of life (the infant immune responses are immature and much less efficient in controlling viral replication) [1]. These babies are sometimes left with long-term physical and neurological disabilities. (HIV-infected children presenting with early severe disease were most likely to have neurological and developmental abnormalities) [2]. Depending on the severity of the disabilities these children need regular outpatient appointments with various specialists. In the long term they need assistance at school in different areas depending on their needs. This raises issues for the child who may already feel quite isolated at school.

## Issues for children and adolescents

Some of the vertically infected children have been through mono- and dual therapy; they are drug experienced and coping with high pill burdens and unforgiving regimes. Drug-resistant virus is an issue and sadly these children have limited treatment options. Children approaching adolescence have historically been overprotected by their parents and health carers alike, who believed they would not live past ten years of age. The transition for families and their carers has been a gradual one and together we are focusing on helping children to live with a chronic illness rather than a terminal one.

Young people seen in the clinic are small for their age and late starting puberty, which can cause low self-esteem. At a time when adolescents are developing and experimenting sexually, patients in the family clinic often feel isolated and find it more difficult than others to develop relationships. Adolescents in the same way as adults are exposed to the prejudices of others and continue to feel the stigma surrounding HIV.

## Diagnosis

When children reach a certain level of maturity, we work towards disclosing their full diagnosis to

them. The team works closely with parents and children, as this is a very sensitive time for the whole family. (Most teenagers were given their HIV diagnosis in the presence of a healthcare professional. There was wide variation on their views at which age this was best done [3]). Children often have many questions around how their parents were infected, why they have not been told their full diagnosis earlier and what they can expect in the future. Teenagers concerns varied widely from relationship issues, HIV transmission becoming a parent, managing work and HIV, secrecy at school and arguments with parents [3]. Many have experienced the loss of a parent or sibling and are frightened about what the diagnosis will mean for them. Patients who have recently arrived in the UK may have a very different perception of what being HIV positive means. The team works with these families to reassure and build confidence in the systems in place here in the UK.

## Recent immigrants in the UK

Families who have recently come to the UK from overseas are dealing with a state system and healthcare system that are unfamiliar to them. For some families English may not be used as the first language and children may have a better understanding of English than their parents, and used as interpreters in conversations that may be inappropriate for their age and level of understanding. These children are exposed to an unfamiliar culture, sometimes language, religion and schooling system. This transition alone is a massive one, without having a disease that differentiates them from their peers.

There are families who are living in the UK with uncertain immigration status. They have to wait whilst the Home Office makes decisions about their future. The children in these families are living in conditions that are far from ideal. They may be afraid of immigration officers and others in authority and live in constant fear of being deported back to a country where in some cases they will have little or no access to antiretroviral treatment. When caring for these children, it is important to remember what they may have already been through in their short lives before arriving in the UK.

## Conclusions

St Mary's Family Clinic cares for the whole family: the multidisciplinary family approach has been an

effective way of delivering medical, social and psychological care [4]. Parents and children are seen in the same department. There is a multi-disciplinary team who has a specialist interest in caring for families infected with HIV. Many of the above issues are raised in clinic and the team works closely towards supporting children and parents through every stage of their disease progression. The Family Clinic has a separate Adolescent Clinic, focusing specifically on the needs of adolescents and the importance of a smooth transition into adult services when the individual feels ready. This clinic works well and has become a positive experience for all involved, as the emphasis is very much on the developing into adulthood through the service. (Whilst healthcare concerns and service needs varied between younger and older teenagers, the common theme was around opportunities which increase independence and choice [3].

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# Oceans apart? Comparing HIV services for children and adolescents in the UK and USA

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## Introduction

In the UK, highly active antiretroviral therapy (HAART) has had a dramatic impact on the life expectancy and natural disease history of HIV-infected children [1]. Since the inception of HAART, healthcare providers have been challenged with issues around supporting adherence to therapies [2–4] and providing services for adolescents infected with HIV [5].

In April 2000, limited research in the UK around supporting adherence in children/families with HIV and minimal service provision for adolescents infected with HIV prompted me to undertake a travel scholarship [6] to compare service provision in the USA for HIV infected children and adolescents.

I chose to visit the USA for a number of reasons:

- The treatment of children with HIV infection was comparatively more developed in the USA than in the UK.
- There was a greater number of US centres supporting and treating children and families with HIV than here in Europe. This was reflected in the funds allocated for research in the two regions. The Paediatric AIDS Clinical Trials Group (PACTG), in the USA, had a budget of US\$40 million per annum, compared with the European budget of around US\$200,000 [7].

- The reported number of children outside of Africa infected with HIV and receiving treatments was highest in the USA. [8]
- USA was treating more adolescents with HIV than any other country.
- USA had a greater population of children with diverse cultural and ethnic backgrounds to explore.
- Nurse-led support clinics were well established in the USA.

## Experiences and findings

Comparing experiences and practice with others can be beneficial and challenging. Regardless of the results, benchmarking one's own practice against those provided by others can have positive outcomes for patients and practitioners alike.

Despite differences in the populations observed in the UK/USA and some variance in nursing roles, the main conclusion drawn from the visit was that we shared a lot of common ground in our approach to supporting children and families infected and affected with HIV. Whether by adherence to combination therapies or support around sharing diagnosis with children, the similarities and outcomes were apparent. As for service provision for adolescents, not only were we geographically distant, I believed we were miles apart in service

provision. The centres in the USA had established systems for treating and screening adolescents in general. For those infected with HIV, health services and voluntary organisations provided very extensive medical and social services and focused greatly on the sexual health and psychosocial needs of this vulnerable group.

In relation to treatment access compared with the UK clinics, the main difference observed was that many more children were enrolled in clinical trials. The reasons for this were numerous, lack of finance, poverty and inferior health insurance schemes to name but a few. While some health insurance schemes supported funding of certain symptomatic treatments, there were some which did not. However, enrolment within a protocol or trial meant greater access to such supportive symptomatic treatments and investigations. While the whole insurance system seemed very confusing to me, it was reassuring to note that throughout each state, no matter what the health insurance scheme each child was under, they always had access to antiretroviral treatments, either through initiatives such as the state health scheme (for those families in receipt of benefits) or via clinical trials. All children have access to antiretroviral treatments and no child would be denied treatment.

### Supporting adherence to combination therapies

In each of the centres, the problems encountered by children and families, which directly and indirectly impacted on their ability to adhere to therapies, were observed. The general structures required for adherence to succeed [2,3], such as adequate housing and finance, were similarly lacking and comparable to the socio-economic constraints faced by some of the families in the UK. Families were often from the lower end of the social structure, in substandard housing and in receipt of benefits.

Reassuringly, similar strategies to support children with adherence to combination therapies were seen in all US clinics and these were comparable to our practice at St Mary's. Quality of life for children taking medications, child protection issues and the use of gastrostomy tubes to promote adherence were again comparable to our experiences, as were the adherence aids employed. Aids such as drug information leaflets, colour-coded charts, diaries, pill crushers/cutters, timers and watches were all promoted by the nurse practitioners. Timing for starting treatments and multidisciplinary treatment approaches were similar and as established in paediatric HIV settings in the UK were deemed the most appropriate for caring for HIV-infected children [9].

As is well recognised with paediatric antiretrovirals, palatability and formulation of medications are crucial elements to achieving optimal adherence [2-4]. Many of the children seen in US clinics were

very treatment-experienced and faced the unenviable task of having to take protease inhibitors. Encouragingly, two centres had considered this issue for children in their care. The centres in Boston and Houston [10,11] had set up Pill Schools to teach children the art of swallowing large medications. While the concept was impressive and novel to our practice in the UK, it was limited in the range of children for whom it might succeed. Nevertheless, it was an interesting and challenging approach. The schools were run via psychology department staff, with referrals mainly for children aged 3-5 years old in whom 4 main difficulties had been identified: general behavioural issues; pill swallowing difficulties; anticipatory anxiety; and learned aversion.

Of interest, an adaptation of the Pill School was subsequently incorporated into the service provision at St Mary's on my return with good rates of success. [12].

### Adolescents with HIV

General provision of medical care for adolescents in the USA differs greatly from that in the UK. Throughout each city and state, adolescent needs are considered as specific, unique and different from children and adults alike. Although this was recognised in the health and social care settings in UK, we were still reasonably lacking in the provision of services for this group. In the USA, it was apparent they are more advanced in their approach to care provision for adolescents. In all the centres visited adolescents had departments and services catering for their specific needs. With regard to HIV, two centres in particular stood out. Each offered a very comprehensive and detailed adolescent programme. These were The HAPPENS Program [13] in Boston and the Montefiore Program in the Bronx, New York [14]. Both centres offered a similar service and both were widely accessed by adolescents for sexual health and HIV care.

Since this visit, it is reassuring to note that service provision and transitional clinics in the UK are now becoming more established and recognised [5].

### Differing roles?

The nurse practitioner role in the USA is well established. The role differed greatly from its UK counterpart. The Clinical Nurse Specialist, allowing the nurse to perform many roles within his/her practice. Generally nurse practitioners within the clinic teams managed children's care and followed them through their treatment protocols, taking on many of the physician's roles. The physicians themselves were generally involved in setting up protocols, conducting research and acting as a resource on a consultative basis for the nurse practitioners. However, the medics assumed overall responsibility for the children attending the clinic. The nurse practitioners performed all examinations.

ordered blood tests and investigations, prescribed medications and referred to other services on an *ad hoc* basis.

Whilst we had endeavoured to set up nurse-led clinics within the team at St Mary's, nursing practice and the scope to expand our role invariably limited the extent to which we could carry out some of these duties. Obvious differences in the expanded role of the nurse practitioner left me feeling very restricted within my role and encouraged an overwhelming desire to expand the scope of my practice.

## Conclusion and recommendations

When I initially applied for the travel scholarship, I did not truly appreciate how difficult and tiring it would be. The scholarship was viewed (by some) as the chance to have an exciting holiday. However, nothing could have been further from the truth, as I soon found out. While planning the trip, I remember my colleagues saying that I should build some extra time into the itinerary to relax and take in the sights. How I wish I had listened to them. The itinerary was intense. Meeting new people each day, visiting different centres, absorbing and processing information in the designated time proved to be a mighty task and allowed little time for sightseeing. Yet, on the other hand it was challenging, thought-provoking and very enjoyable. More importantly, it has given me the chance to incorporate some new ideas into our practices at St Mary's.

So for anyone thinking of applying for a scholarship and who sees it as a means to have a free holiday, think again. It's hard work!

Despite these apparent drawbacks, I thoroughly enjoyed this experience. It is not every day you get awarded a travel scholarship. It is probably a once in a lifetime opportunity. So, to those of you who are lucky enough to be given this chance, I say good luck, enjoy it, but most of all, be realistic about what you can do in the time you have.

With NHVNA [15] and Boehringer Ingelheim now offering nurses the opportunity to access funds for

travel scholarships I would whole-heartedly encourage you to apply.

## Acknowledgement

This article is dedicated to the memory of Rebecca Handel. I would like to thank Jo Dodge and Children with AIDS Charity for supporting this travel scholarship.

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# Sexual health in Ireland

Carol Pellowe

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**A**t last year's NHIVNA conference [1] in Brighton, I presented my research on screening pregnant asylum seekers in London, which is part of my doctoral thesis [2], due to be completed this autumn. My main interest is whether the preparation of midwives to undertake antenatal HIV testing meets the needs of the women identified HIV positive as a result. The process has highlighted some interesting aspects, the most shocking of which is the plight of newly arrived pregnant asylum seekers, for whom an HIV diagnosis is an additional burden to what has all too often been a traumatic experience. Since last summer I have interviewed women of African origin with residency, specialist HIV and generalist midwives.

The policy of offering and recommending the test to all pregnant women is clearly identifying those who would have missed otherwise, but the shock of diagnosis needs careful handling, as disclosure remains a key issue. The role of the specialist midwife is paramount to ensuring the woman's care is co-ordinated and that she is supported throughout. The care that these women receive appears to be based on one-to-one care, the most coveted form of midwifery, available to only a few women. Whilst the period between diagnosis and delivery is well managed, one wonders who picks up this caring role post-discharge.

The bonus of being a winner of the Bristol Myers Squibb Travel Scholarship Award is the opportunity to attend conferences one would otherwise have missed. Due to contacts in Dublin, I attended the Second Annual Sexual Health Conference in September 2003 [3] and can thoroughly recommend it. Sandra Delamere, an advanced nurse practitioner in sexual health at St James's Hospital, Dublin was the organiser along with her colleagues, Joan Flynn and Phyllis O'Grady. Sandra was active in the European Nurses' AIDS Association (ENAA) and has a wealth of experience in conference organisation.

The venue was the Guinness Storehouse, which has superb conference facilities as well as excellent refreshments, and the conference attracted attendees from all over Ireland. The focus of the day was celebrating achievements in sexual health and Ireland has much to be proud of. Dr Fiona Mulcahy, consultant in genito-urinary medicine, described a scheme in Dublin whereby sexually transmitted diseases were increasingly being diagnosed and treated in the community. Protocols had been devised for general practitioners and others to

manage uncomplicated cases with assistance from health advisers and refer others efficiently to the clinic. Training had been provided on taking a sexual history and the requirements for a sexually transmitted infection screen for both men and women. Within the programme is a plan to vaccinate all adolescents against hepatitis B and increase detection of asymptomatic chlamydia. Despite the initial difficulties, this project is clearly paying dividends not only in identifying and treating sexually transmitted infections but reducing lengthy waiting times in the genito-urinary medicine clinic.

Agnes Higgins, Assistant Director of the School of Nursing and Midwifery at Trinity College, gave a fascinating and amusing presentation on the history of sexuality and mental health. This included the period when women were treated for having a 'wandering uterus' and male masturbation was a sign of mental demoralisation, more debilitating for the upper classes than for servants! Policing sexuality included such draconian methods as segregation, institutionisation, sterilisation and suppression with drugs. Thankfully, such times are past but Agnes reminded us of the need to include sexuality in mental health assessments, as failure to enquire about sexual partners, contraception, sexual dysfunction and sexual abuse can miss a key element in diagnosis.

Sandra Delamere described her role as one of the first advanced nurse practitioners in sexual health in Ireland. She has been instrumental in the development of sexual health nursing in Ireland and, in particular, in nurse prescribing, which is currently being piloted in ten sites. It is hoped that this will be a stepping-stone towards independent nurse prescribing. In addition, Sandra is participating in the development of a master's level course in sexual health for advanced nurse practitioners.

Pauline Sheils, a clinical nurse specialist in sexual health and illness/disability since 2002, described her role at the National Rehabilitation Unit, which covers patient services, education and research. She has a client caseload that includes individual and couple counselling, education on the impact of illness/disability and advice on aids and appliances. A considerable amount of her time is spent on staff education around the impact of illness/disability on sexual function and disability and she is currently undertaking a research project on establishing the sexual needs of patients following a cerebrovascular accident.

Kate Newitt and Miriam Karp, sexual health coordinators of the Belfast Sexual Health Team have been working together for 14 years and covered two of their current projects. The first concerned using peer educators to promote sexual health. This is part of a European study, Prevention of HIV/AIDS and sexually transmitted infection in Europe (PHASE), which is concerned with the development of best practice. Their project aims to develop and evaluate practice that targets women in local communities and their chosen areas are the Shanklin Road, the Falls and East Belfast. The women were aged between 25 and 60 years old and to date over 150 women have attended the peer education course. In her summary, Kate reminded us that such projects are not just about getting the messages right, but about creating opportunities for people to get it right for themselves.

Their second presentation was the Cascade training project, which provides a range of AIDS education courses for 32,000 healthcare staff. This was established by the Eastern Health Board AIDS Steering Group and comprises trainers working in nine AIDS awareness teams. Their remit was extensive, ranging from induction courses to sharps injury awareness.

The afternoon sessions were a series of round table discussions on topics of special interest. Dr Anne King presented the successes and problems of running a young persons' clinic at St James's Hospital. Sinead McDonagh described her role as the HIV liaison nurse for HIV-positive pregnant women. As this is a particular interest of mine, it was interesting to note the similarities to London,

especially as regards asylum seekers. Brian O'Donnell, a staff nurse at the genito-urinary medicine clinic, Royal Victoria Hospital, Belfast spoke of his role in treating erectile dysfunction, using several case histories. Finally, Dr Grainne Courtney, an associate specialist in genito-urinary medicine at St James's Hospital, addressed the issues involved in providing sexual healthcare within the prison service. Despite the enormous barriers to providing a comprehensive service, they have not only undertaken a major study to highlight the prevalence of hepatitis B and C and HIV, they have begun to establish a successful and highly appropriate service.

As we retired to the Gravity Bar with its magnificent views of Dublin for a very welcome glass of Guinness, I was struck by how much had been achieved in a very short space of time by very dedicated and motivated people, and how wonderful that both the North and the South could celebrate these developments together. I strongly recommend anyone interested in sexual health to attend the next annual conference.

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# A long and winding road? The lead-up to Bangkok, 2004

Ian Hodgson

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As the 15th International AIDS Conference (IAC) in Bangkok looms, it is perhaps appropriate to reflect: what is the current 'shape' of HIV? What are the developments since the last IAC in Barcelona, 2002? This paper will provide an individual, but hopefully informative, overview of the current state of HIV.

## The current state

At the end of 2003, the number of people living with HIV was estimated to be around 40 million. Fourteen thousand people are infected each day, 95% in low to middle income countries. Two thousand of these are children under 15 [1]. Since the last IAC to date, over 6 million people have died.

These numbers are still difficult to visualise, even after 20 years of the epidemic. Indeed, the novelty has gone, and even with their inexorable rise, statistics like this soon lose their potency: as have the many strategies that have come and gone to tackle the spread and impact of HIV. One report suggests that 'beyond a few notable successes, the record of tacking this pandemic has been poor' [2].

There have been some successes: Thailand is one example. Here political leadership has had a huge impact on cutting the numbers of new HIV infections and developing national anti-discrimination policies (for more details on the Thai situation, see Ainsworth *et al.* [3]). Elsewhere, however, it is the quickly changing landscape of the pandemic that is perhaps of most concern. Since the IAC in 2002, China has 'admitted' formally to having around 1 million HIV-positive people [4], and by 2010 it is expected that up to 10 million people could be HIV-positive in that country alone. The major route of transmission has up until now been the sharing of contaminated needles among the injecting drug users (IDUs); inevitably the virus will disseminate into the general population. Given that methadone is a key factor in the support of IDU, it is perhaps surprising that this medication is not listed in the recently updated version of the World Health Organization (WHO) Essential Medicine List [5]. But that is for another discussion.

Also since 2002, political shifts in Europe suggest inevitable changes to future health policy across the European Union (EU). According to a WHO press release, 'AIDS is rapidly spreading in Eastern Europe, and is on the rise again in Western Europe'

[6]. Over 1.5 million people now live with HIV in Eastern Europe and Central Asia – compared to only 30,000 in 1995. In the same press release, Peter Piot, the Executive Director, the Joint United Nations Programme on HIV/AIDS (UNAIDS), stated that 'Europe and Central Asia are at the centre of the fastest-growing HIV epidemic in the world'.

The recent expansion of the EU eastwards now means the Western European region – with its relatively stable HIV epidemic – will be faced with significantly different health contexts from countries such as two that have just joined the EU club: Latvia and Estonia. These Baltic States are members of a larger group that are the worst affected by HIV in the region [4]. Not helped by its proximity to the drug-trafficking route into the Russian Federation, it is thought that in Estonia alone 1% of the population are IDU, the chief mode of HIV transmission in that country.

One feature of the 2002 IAC was the plethora of discussions around the production of an effective HIV vaccine [7]. Sadly, the poor results from a large phase III trial in Thailand, published in 2003, confirmed the silent fears of many: that it could be years before any dent is made in the immunological armour of HIV [8]. Other trials are in progress, but as usual time will be a factor. If, as hoped, a vaccine against HIV is successfully produced in around 2010, around 30 million more people will have been infected with the virus.

## Progress?

So what, if any, progress has been made since the 2002 IAC?

A key development since 2002 is the reduction in the price of antiretroviral drugs (ARVs), largely because of major ARV producers releasing their patents to 'pirate' companies. This, together with the '3x5' programme led by the WHO [9,10], suggests that equal and fair access to ARVs in developing countries is becoming more likely. Other national policy shifts are also likely to speed this up. For example, recent changes in the stance of the US government will now allow the purchase of 'pirated' (and hence much cheaper) versions of ARVs with some of the \$15bn promised by the Bush administration to fight HIV. Blocked until recently by the ex-Eli Lilly CEO who heads the Bush programme, the move was hailed by many as a positive shift [11].

In Mozambique, ARVs are to be provided free to 8,000 adults, a programme jointly funded by the Bill Clinton Foundation and the World Bank. In a country with an infection rate of 13.6% (one of the highest in the world; to compare, the UK has a rate of 0.001%), access to sufficient numbers of ARVs could make a huge impact on the social and economic infrastructure of the country, as well as improving the quality of life for many. However, (and this shows the real problem with any ARV distribution programme), only about 40% of people in Mozambique have access to any kind of healthcare [12].

A second feature of the epidemic that continues to pose a serious challenge is HIV stigma. Still as strong as 20 years ago, HIV stigma remains a truly intransigent phenomenon, refusing to substantially shift in its ability to be a barrier to the effective support of HIV-positive people [13]. What should be of real concern to nurses are the findings from a report published in 2003, suggesting that in the Asia-Pacific region at least, the 'major area of discrimination in each country is in the health sector' [14].

Since 2002, large numbers of non-governmental organisations (NGOs), such as in the UK the Terence Higgins Trust (THT), and internationally the International Red Cross/Crescent (IFRC) and UNAIDS, have scaled up their anti-stigma activities, and recent isolated actions provide glimmers of hope in the fight against HIV stigma. In South Africa at the beginning of May, a leading opposition politician Mangosuthu Buthelezi announced in public in an unprecedented show of transparency that his son had died of AIDS [15]. This new trend for openness is mirrored elsewhere. In Malawi, which has more than 10% of its 11 million population infected with HIV, many politicians in the lead up to a general election have been making public what has so often in the past been hidden: admitting they have lost family members to AIDS [16].

In a related move, 12 MPs in Zimbabwe have recently announced publicly that they would be tested for HIV in order that they 'may desire to break the stigma associated with HIV' [17].

## Conclusions

This paper, in examining the period since the last IAC in 2002, has briefly considered some features of HIV that remain problematic: the inexorable rise in the number of new infections, the shifting landscape of HIV, an apparent stall in the development of an HIV vaccine. It has also addressed some glimmers of hope: a reduction in the cost of ARVs, and apparent moves to face up to HIV stigma.

In the IAC at Bangkok in July, these and other issues will no doubt dominate, but it is the opinion of this writer that a number of elements must be

prominent at the IAC if any semblance of progress in the fight against HIV is to continue:

- Consideration of the need to keep HIV-positive people healthy before they can gain access to ARVs;
- The need for more people to 'come out' about the affect HIV has had on their lives, in order to begin the dismantling of HIV-stigma;
- A special focus must be made on the needs of HIV-positive IDU: a doubly marginalized group

Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, said earlier this year:

*'... let the world rally to the prospect of bringing this cataclysm to an end sooner than later. And that means working on every front, on emergency footing simultaneously: care, prevention, treatment, microbicides, and vaccines.'* [18]

The IAC in Bangkok will allow some progress to be made on these fronts. It is to be hoped that in the lead up to the IAC in Toronto in 2006, the evidence of this will be plain for all to see.

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## NHIVNA update

It looks as though we will have a record number of delegates at this year's conference on the 24 and 25 June in Manchester. *Diversity in HIV Nursing* aims to cover topics such as women and HIV, children and adolescents, a treatment update and a discussion on the adherence guidelines. We are also covering tuberculosis, hepatitis C and how one centre has set up a nurse-led co-infection service. This year we also wanted to give delegates the opportunity to be able to ask questions and share experiences, so plenty of time has been built into the programme. Also, for the first time we are running workshops. The workshops, which will cover sexual health and HIV, and asylum seekers and access to treatment.

A record number of abstracts have been submitted, and we have some very diverse and interesting topics to share in the concurrent sessions. There will be a wide variety of poster presentations. We are also pleased to still be able to offer awards for the best research presentations with support from the Krattinger Rennison Awards. Bristol-Myers Squibb are offering a travel scholarship and the NHIVNA/Boehringer Ingelheim Scholarships have a grant to give away for the best presentation demonstrating a nurse-led clinical practice initiative that has made an impact on patient care. The awards will be given out at the gala dinner on 24 June, at Barnes Wallace Restaurant, which promises to be as much fun as last year!

If you have not received information regarding this year's conference yet, contact our conference organiser on [nhivna@conass.co.uk](mailto:nhivna@conass.co.uk) or ring 0797 331 5915.

Thank you to those members who submitted applications for the NHIVNA/Boehringer Ingelheim scholarships for research, travel and science. We had five applications and all were successful. We are especially pleased to be able to help support two nurses who are presenting at the International AIDS Conference in Bangkok. The closing date for the next round of grants is the 30 October 2004. If you would like further information, contact me at [nicky.perry@bsuh.nhs.uk](mailto:nicky.perry@bsuh.nhs.uk) or 01273 665147.

NHIVNA's aim to provide education opportunities for nurses' continues with further workshops in collaboration with GlaxoSmithKline. The aim of the workshops is to develop nurse's knowledge and skills and are aimed at D, E and F grade nurses. The day follows a patient journey from diagnosis to treatment, with the emphasis on the nurse's role and how nurses can develop skills to run nurse-led clinics and write nurse-led policies and guidelines. We have dates for 15 September in Nottingham, 13 October in Cambridge and 24 November in Edinburgh. We hope to continue them in 2005, so if we are not near you yet, watch this space. If you would like further information, contact [nhivna@conass.co.uk](mailto:nhivna@conass.co.uk). We will also be holding a workshop on co-infection supported by Gilead. A date for this year has yet to be set but you will be notified. Mediscript will also be running *HIV Resistance and Clinical Pharmacology Workshop 2004* (see page 14) for nurses and pharmacists in November.

I hope to see as many of you as possible at the conference in June.

**Nicky Perry, Chair, NHIVNA, Brighton**

# Non-Hodgkin's lymphoma in patients with HIV

Tom Fernandez<sup>1</sup>, Filippo Ferro<sup>2</sup> and Robert Hammond<sup>3</sup>

Charge Nurse<sup>1</sup>, Staff Nurse<sup>2</sup> and Clinical Nurse Specialist, HIV<sup>3</sup>  
The Royal Free Hampstead NHS Trust, London

## Introduction

**N**on-Hodgkin's lymphoma (NHL) is a type of cancer involving uncontrolled multiplication of the white blood cells called lymphocytes. It most commonly occurs in the lymph nodes, gastrointestinal tract, liver or kidneys, but can be present in less usual sites such as the rectum, mouth or muscles. NHL that first occurs in the central nervous system (CNS) is known as primary CNS lymphoma. However, the focus of this article will be on the risk factors, diagnosis and optimum treatment options for NHL (as opposed to primary CNS lymphoma) and the psychological and emotional impact of diagnosis.

## Background

NHL is the most common lymphoma seen in people with HIV, and as such is diagnostic of AIDS. Whilst the advent of highly active antiretroviral therapy (HAART) has brought about a decrease in most AIDS-related opportunist infections, it is as yet unclear whether there has been a true decrease in the prevalence of NHL. Historically, the majority of cases of primary CNS lymphoma had been diagnosed in individuals with CD4 count <200, or with a history of multiple opportunist infections. This has diminished with the advent of HAART, to be replaced more recently with a relative increase in NHL associated with duration of HIV infection, which in some instances relates to people living longer on successful antiviral regimes. In fact, NHL has made up a higher proportion of AIDS diagnoses since the decline of other opportunist infections [1].

NHL in people with HIV is more aggressive and responds less well to treatment than in HIV-negative counterparts. However, the advent of HAART has improved the general outlook, as survival times in the pre-HAART era were as low as 4–11 months for NHL and only 2–4 months for Primary CNS Lymphoma [2].

## Causes and risk factors

AIDS-related NHL is overwhelmingly of B-cell origin, but the causes of NHL are probably multivariate and associated with over-active B-lymphocytes and prolonged immune deficiency [3]. This is probably related to HIV disrupting normal levels of cytokines, which may be compounded by other viruses such as Epstein-Barr virus [4]. The most common risk factors identified from large cohorts for developing

NHL appear to be the patient's age, their nadir (lowest ever) CD4 count and no prior history of having taken HAART [5]. However, it is worth remembering that NHL can present in the absence of these factors, and we have recently seen a spate of patients improving and stable on HAART, present with unexpected NHL.

## Presentation and diagnosis

Whilst the profile of individuals developing NHL has broadened to include those with no previous AIDS diagnosis, and generally higher CD4 counts [6], presentation would appear to remain the same.

Common symptoms are night sweats, fevers, unexpected weight loss, lethargy and anorexia, with signs such as enlarged lymph nodes and hepatosplenomegaly. Depending on an individual's health status and onset of symptoms, differential diagnosis may include mycobacterial infection or other less common viral or fungal conditions. Sometimes symptoms can be difficult to differentiate from constitutional symptoms of advanced disease.

Diagnosis can be aided by a patient's history, symptom pattern and blood tests such as lymphoma markers or lactate dehydrogenase (LDH). Non-invasive radiological imaging of suspicious areas and potential areas for malignant infiltration (such as the chest, abdomen, head and pelvis) should be undertaken. But definitive diagnosis is usually made by histological analysis of material from aspirate or tissue biopsy. Since early treatment is associated with fewer complications and better outcomes in terms of remission, but is rarely commenced without a confirmed histological diagnosis, the need for informed consent for rapid diagnostic screening is crucial [7].

## Treatment and care

The most widely used NHL chemotherapy combination in both the general and HIV-positive population is CHOP, made up of four different drugs that attack the cancer cells in different ways. These drugs are cyclophosphamide, doxorubicin, vincristine and prednisolone. This chemotherapy regimen is usually administered intravenously once every three weeks.

Each treatment is known as a cycle and a patient would generally expect to receive six cycles of chemotherapy. This will obviously depend on their

response to treatment but some patients may require additional cycles after the standard course of six. Clinicians can monitor the effectiveness of the chemotherapy through blood tests, clinical examination, re-assessment of symptoms and in interpretation of computed tomography (CT) scans, which are undertaken before chemotherapy is initiated, half way through and at the end of the treatment.

## Case study

Ben was a 37-year old gay man first diagnosed with HIV in 1990 with a CD4 count of 400 and a viral load, as first measured in 1997, around 10,000. These values remained relatively stable for the next few years during which he was largely asymptomatic. However, by the end of 2001 he had experienced a gradual decline in his CD4 count associated with an increase in his viral load but not sufficient to start antiviral therapy.

Although he had presented with swollen lymph nodes on a few occasions, fine needle aspirate (FNA) had proven negative for both neoplasia and tuberculosis and he was otherwise well. However, in late 2002 he presented with an enlarged cervical lymph node associated with some loss of weight, cough and a degree of lethargy. Further investigations were undertaken to screen for the possibility of mycobacterial infection, toxoplasmosis and lymphoma, which included serological screening, chest X-ray, computed tomography (CT) scans of the chest, abdomen and pelvis and FNA of the enlarged node. His viral load was 478,000 and CD4 count 294.

The FNA result was inconclusive so Ben was referred for urgent excision and biopsy in January 2003, which histologically confirmed a diagnosis of high-grade non-Hodgkin's lymphoma. He was advised to start HAART immediately as part of his treatment protocol and commenced on tenofovir 300 mg, lamivudine 300 mg and efavirenz 600 mg all once a day in addition to Septrin for *Pneumocystis carinii* pneumonia (PCP) prophylaxis.

Fortunately, the CT scans showed no other adenopathy and further staging including bone marrow aspirate and lumbar puncture showed no evidence of malignant infiltration. Ben was able to start his chemotherapy that week and began cyclophosphamide/doxorubicin/vincristine/prednisolone (CHOP) treatment with the addition of intrathecal methotrexate (as per protocol) due to his 'head and neck involvement'. This was reasonably well tolerated although he was troubled by nausea and some discomfort and headache from the

lumbar puncture. However, after just one cycle of treatment the upper cervical node in question was no longer palpable.

Recent studies have suggested that rituximab, a monoclonal antibody used in conjunction with chemotherapy, is more effective in treating NHL than treatment with chemotherapy alone. This antibody works against the CD20 antigen, which is found in most high-grade NHL. Coiffier *et al.* [8] presented impressive data showing good response rates in non-HIV-infected NHL patients who received CHOP and rituximab, whilst Spina *et al.* [9]

The second cycle of CHOP was delayed due to neutropenia, which was rectified by the addition of granulocyte colony-stimulating factor (G-CSF) to which he had a good response, and resumed his treatment schedule. By now he was also responding well to his HAART, from which he suffered only the minor problems of insomnia and vivid dreams – usually relieved by benzodiazepines. Consequently, his viral load had dropped to <400.

By his fourth cycle a decision was made to add in rituximab as response to treatment at this stage was not sufficient. However, his response to HAART continued to improve and his viral load became undetectable for the first time. He remained on Septrin for the duration of his chemotherapy as it can cause further decreases in CD4 counts.

After the sixth cycle, Ben was offered radiotherapy to irradiate any local activity but declined and completed two more cycles of chemotherapy plus rituximab instead.

Treatment was completed by September 2003, at which time Ben had resumed work. His end-of-treatment CT scans and PET (positron emission tomography) confirm he is in complete remission and he was advised to stop taking Septrin. He will, however, need to continue his anti-HIV therapy and will be under follow-up from our lymphoma team for at least the next 5 years.

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demonstrated improved response rates in HIV patients who received cyclophosphamide, doxorubicin and etoposide (CDE) chemotherapy and rituximab. For those patients with CD-20 positive NHL, CHOP plus rituximab is now the standard treatment at the Royal Free Hospital HIV Unit.

In addition, patients will be advised to start antiretroviral therapy (if they are not already on it), as the chemotherapy is likely to affect their immune system. Evidence suggests that patients responding to HAART are those most likely to experience treatment success and prolonged survival in lymphoma [10]. They will also be prescribed Septrin or an alternative prophylaxis to counter any drop in CD4 count and increased risk of PCP.

Most importantly there are safety aspects to consider when caring for patients receiving chemotherapy, which include ensuring the patient has consented for the specified treatment and has an understanding of the full effects of chemotherapy.

There is a myriad of potential side-effects caused by CHOP. The most common are nausea and vomiting, myelosuppression (depletion of bone marrow affecting the white cell, platelet, haemoglobin and absolute CD4 counts), alopecia and mucositis. Other side-effects include nail pigmentation, discoloured urine, disruption of menstrual cycle, sterility in men, constipation, peripheral neuropathy, haemorrhagic cystitis and elevated bilirubin levels. Antiretroviral drugs and drug interactions can exacerbate some of these side-effects, therefore careful consideration and monitoring is required when planning each treatment.

Patients will also require certain drugs before and after each cycle of chemotherapy, such as steroids and anti-sickness drugs to counteract some of the nastier side-effects of treatment. Experienced nurses play a vital role in symptom control and patient management by negotiating the use of other agents such as antibacterial mouthwashes, anti-diarrhoea medication, analgesia and allopurinol to prevent gout-like symptoms as the tumour breaks down. Subcutaneous injections of granulocyte colony stimulating factor (G-CSF) can help prevent neutropenia-related problems and keep the patient on track for scheduled cycles of treatment. In addition, patients should be educated about preventing infections and recognising signs of infection early in order to know what action to take.

When illness is complex and needs broaden, patients can benefit from the collaboration of the multidisciplinary team in both the acute and community settings, involving for example the palliative care team, HIV community nurses, district nurses, dieticians, psychologists and social workers.

At the Royal Free Hospital, HIV patients with NHL are fortunate to be able to receive their

chemotherapy within the HIV day centre which contributes greatly towards continuity of care. Here, careful and continual collaboration between the patient and both HIV and oncology teams is essential to ensure treatment success and avoid the pitfalls of therapy [11]. Furthermore, the open access walk-in service can easily be consulted when patients experience problems secondary to their chemotherapy.

## Prognosis and outcomes

Patients diagnosed with NHL have a much better prognosis in the post-HAART era than ever before. However, certain factors seem to affect survival; these include the clinical stage of the lymphoma, a concurrent AIDS diagnosis or active opportunist infection at the time of diagnosis, and prolonged delays in cycles of chemotherapy due to other clinical problems. There seems little question, however, that effective antiretroviral therapy looks likely to play the largest part in survival rates and prognosis. Whilst some data suggests that 2-year survival can be as high as 62%, in reality we do not have sufficient long-term data on this group of patients [12]. However, in our experience, if the patient is lymphoma-free after 1 year, prognosis appears to be greatly improved.

## Conclusion

A diagnosis of NHL can have a profound impact on the health of individuals with HIV, as dissemination can cause dysfunction in vital body systems and also disrupt normally 'stable' HIV infection. The sense of urgency in controlling and eradicating the lymphoma can leave little time for delay, and impinge on an individual's feelings of choice and control. In addition, the weight of a cancer diagnosis can introduce strong feelings of disillusionment, uncertainty and mortality [13]. During chemotherapy individuals may need to suspend their 'normal' lives and focus their positive energies on enduring chemotherapy, adhering to their HAART regime and fighting the cancer itself. However, even when chemotherapy is successful and lymphoma no longer present, initial talk is of a 'remission' rather than a 'cure'. In an age where AIDS can be viewed as a chronic illness with increased life expectancy [14], living with the additional uncertainty of relapse can pose a major psychological burden for many years to come.

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## Diary

### 24-25 June 2004

6TH NATIONAL CONFERENCE OF THE NATIONAL HIV NURSES ASSOCIATION (NHIVNA), MANCHESTER, UK  
 Contact: NHIVNA Secretariat,  
 1 Mountview Court, 310 Friern Barnet Lane,  
 London N20 0LD, UK  
 Tel: 020 8446 8898; Fax: 020 8446 9194  
 Email: bhiva@bhiva.org  
 Website: <http://www.bhiva.org>

### 11-16 July 2004

XV INTERNATIONAL AIDS CONFERENCE, BANGKOK, THAILAND  
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 The Netherlands  
 Tel: +31 20 521 0036  
 Fax: +31 20 521 0039  
 Email: [program@aids2004.org](mailto:program@aids2004.org)

### 8-9 October 2004

10TH ANNUAL CONFERENCE OF THE BRITISH HIV ASSOCIATION (BHIVA), LONDON, UK  
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 310 Friern Barnet Lane, London N20 0LD, UK  
 Tel: 020 8369 5380; Fax: 020 8446 9194  
 Email: [bhiva@bhiva.org](mailto:bhiva@bhiva.org)  
 Website: <http://www.bhiva.org>

### 23-24 October 2004

11TH ANNUAL HIV/AIDS UPDATE CONFERENCE, SOUTH PADRE ISLAND, TEXAS, USA  
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 Email: [crsmith.vac@thcac.org](mailto:crsmith.vac@thcac.org)  
 Website: <http://www.valleyaids.org>

### 14-18 November 2004

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### 20 November 2004

16TH ANNUAL CONFERENCE OF ASSOCIATION OF NURSES IN AIDS CARE, NEW YORK, USA  
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Professor Jonathan Weber;  
Dr Jack Whitescarver; Professor Alan Whiteside;  
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**...and not a single case of primary PI resistance in the ARV-naive.**

