

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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HIV care: first principles

Ian Hodgson

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Welcome to this edition of *HIV Nursing*. Much has happened around HIV and AIDS in the months since the last edition. World AIDS Day came and went – reminding us of the need to make our leaders more accountable for the promises they made about prevention, treatment and care. World TB Day is also almost upon us at the time of writing and will confirm that the tragedy of TB and HIV co-infection continues to wreak havoc in many countries of high HIV prevalence – accompanied by the spectre of multi-drug-resistant strains. Recent figures suggest that TB kills between 30% and 40% of people living with HIV (PLHIV) in Africa [1], and recent surveys in sub-Saharan Africa also confirm that antiretroviral treatment clinics are increasingly becoming the perfect environment for rapid transmission of TB between PLHIV.

This edition of *HIV Nursing* is special in two ways. First, it is being distributed at the inaugural meeting of the European HIV Nursing Network (EHNN). The meeting, being held in Warsaw, is the first of its kind, and aims to connect the west of Europe, a relatively wealthy region experienced in providing support and care for PLHIV, with countries further east, where following the collapse of the Soviet Union, health systems are under strain, and increasing numbers of new HIV infections place an additional burden on healthcare workers both in the workplace and also with regard to the requirement to keep up to date with best practice.

Secondly, this edition includes articles we hope will be useful in providing information on fundamental aspects of HIV care of value to nurses attending the conference in Warsaw, and forming part of the drive to share best practice between regions. We expect further such information exchange in the future – in both directions. Further details about the network will be reported in future editions of *HIV Nursing*, and further information is available on the website (www.eurohivnursing.net).

The first article provides a snapshot of HIV in the WHO European region. As the article confirms, there are at least three epidemics, and whilst the numbers of people infected with HIV are (relatively) small, it is perhaps shocking that in a region with five of the eight richest countries in the world, a rapid increase in new infections is accompanied in some places by very patchy support mechanisms.

The second article by Breda Ward considers a topic of continuing relevance in countries providing HIV treatments: starting therapy, and issues around adherence. As more areas across Europe scale-up

the provision of antiretroviral therapy, more nurses will inevitably be involved in supporting PLHIV as they embark on complex treatment regimens. This article provides comment on early treatment and adherence to treatment once started.

The dual diagnosis of HIV and cancer is a topic not commonly addressed in the in the context of HIV care, and the third article by Nigel Dodds reports from an ethnographic study, and gives insights into the lived experience of people affected by these conditions. The personal traumas faced by clients in this situation are described, giving an invaluable window into their perceptions and providing a guide for possible interventions.

Continuing the theme of HIV and Europe, Shona Schonning and Raminta Stukyte discuss harm reduction in Eastern Europe. As the region facing the most rapid increase in HIV prevalence, largely through injection drug use (IDU), harm reduction initiatives offer the greatest hope of curbing this public health catastrophe, and this paper provides further details of progress.

Christopher Collister considers issues around HIV testing, a key topic for a number of reasons, not least that HIV remains a highly stigmatised disease, and designing effective strategies to encourage people to attend for testing is a constant challenge. Client confusion about the many types of tests, and knowing what results can (and can't) provide are key elements covered by this article.

The final article, by Sheila Donaghy examines a sensitive topic, but one that many nurses are faced with at some time – talking to HIV-positive children about their diagnosis. The article disusses, with examples from the results of a recent audit, how disclosure of a positive diagnosis to a child can be managed. It concludes with vital insights into how this difficult process can best be facilitated, ensuring the child is well supported.

We hope you find the articles interesting and informative, and as always, if you have comments, queries or require additional information about any of the topics, feel free to email the journal (hivnursing@mediscript.ltd.uk).

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HIV and AIDS in Europe: a snapshot

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For David Haerry of the European AIDS Treatment Group (EATG), the situation around HIV and AIDS in Europe is complex – there is: ‘everything from highest possible standards to developing country disasters – depending on the region/countries you are focusing on’ (personal communication).

The European Parliament in 2004 summarised the situation in this way:

[We recognise] that in our region, persons at the highest risk of and most vulnerable to HIV infection include children and young people, drug injectors and their sexual partners, men who have sex with men, sex workers, trafficked women, prisoners and ethnic minorities and migrant populations which have close links to high prevalence countries. [1]

This snapshot of HIV and AIDS in the European Region of the World Health Organization (WHO) will confirm the rapidly increasing incidence (infections per year) and prevalence (total number of cases), outline some of the challenges facing governments, agencies and civil society, and conclude with a recommendation for better integration between nurses across the region.

The region

The WHO European region comprises 52 countries, and a total population of 882 million. It includes five of the eight G8 (most wealthy) countries, and the nation with the second highest human development index (HDI) ranking in the world – Norway. It also includes the 65th (the Russian Federation), Turkey at 84, and Uzbekistan 113 [2].

Twenty-seven countries of the 52 are members of the European Union (representing around 480 million people). Here, the European Social Model continues to have a positive impact on health policy and human rights, and welfare funding. Many of the remaining countries – mainly in the east – have yet to achieve similar standards, caused by a mix of social, economic and political factors, and excessive structural upheaval over the past 20 years since the collapse of the Soviet Union.

HIV incidence and prevalence

An estimated 2.4 million people live with HIV in Europe, and central Asia [3], although the nature of the epidemic across the region varies. The country with the highest regional incidence of HIV is Estonia, at 504 per million of the population [3]. Outside the EU, 90% of new cases occur in the Russian

Federation, where the primary route of transmission is through injection drug use (IDU).

Specific regional issues

In Western Europe, which includes Scandinavia, UK, France and Germany, the HIV epidemic is classed as mature, and total cumulative cases are around 275,570. New infections in 2006 were 25,241 (82.5 per million of the population [4]). Heterosexual sex is the commonest route of transmission, and has been since 1999, though this is becoming concentrated in populations moving to the region from areas with a high prevalence.

For this part of Europe, key issues include mobile populations, and the need for renewed campaigns around safe sex, especially for men who have sex with men (MSM), where a recent increase in new infections has been detected. These two groups are becoming the focus of public health interventions.

The Central European region includes Turkey, Romania and Poland, and is classed as having a stable HIV epidemic. New infections in 2006 were relatively low at 9.4 per million of the population, although the region is notorious for the highest concentration of paediatric HIV cases. These cases occurred mainly in Romania and were a direct result of government policy in the 1980s to limit access to sex education, contraception and abortions, in order to boost population growth.

Interventions are varied here, with some countries making rapid progress in addressing the epidemic, such as Hungary where a rapid and robust public health response included mass education campaigns, peer education programmes for commercial sex workers and significant HIV testing scale-up [5]. One key element in this region is that as political systems (and funding for health care) becomes more stable, general support required for healthcare workers is increased.

In the east, an area that includes Ukraine, the Russian Federation and Estonia, the epidemic is concentrated and remains focused in specific social groups at special risk of infection. New cases of HIV in 2006 were around 59,866 – 210 per million of the population, and easily the highest in the whole of the European region. The highest percentage of cases was found in the Russian Federation (77%) with 66% of new infections in 2006 occurring in injecting drug users [3].

Key issues include: access to treatment (in the Russian Federation only 11% of people requiring treatment have access [3]); healthcare professionals

working in 'silos', with little communication and lack of nursing autonomy; and poor hospital facilities. The rapid increases in HIV and TB co-infection reported, especially in Estonia, Latvia and Ukraine [4], are also of great concern.

Challenges for the future

Prevention and education

These are clearly important in all three regions, and taboos around sexuality remain a key barrier in implementing prevention strategies. Harm reduction policies – especially in the east – are vital to curb the increasing incidence of new HIV infections in IDU.

Treatment and healthcare

Treatment and healthcare require urgent attention, especially in the east, where facilities in some areas remain poor. Public health policy, especially in the Russian Federation, continues to exercise a 'command and control' approach, reminiscent of the Soviet era. Until proper systems are in place to protect and support affected people, it will fall to the many NGOs in the region to provide the bulk of services. In addition, health systems in many parts of the east are managed 'vertically', with limited interaction between the various sectors, and as there is an increase in HIV/TB co-infection, linking different sectors will be vital in the future for cohesive support and care.

Involving affected people

There is also a call for the further involvement of affected people in the planning and delivery of care:

Informed HIV-positive people know what to expect from the medical care in their community. They can take a more active role in planning their own health care and work in partnership with their health providers'. [6]

Nurses

The Dublin declaration, agreed by European ministers in February 2004, confirmed that countries should:

... strengthen coordination, cooperation and partnership among the countries of Europe and Central Asia ... to scale up local capacity to fight the epidemic and mitigate its consequences in the most affected countries with the greatest needs. [1]

Nurses across the region are in a prime position to have a positive impact on the support and care of PLHIV, but there is clearly a need for the sharing of expertise between countries with established skills and robust infrastructure (mainly in the west) with areas facing rapid increases in HIV infections, and where there are already significant public health problems and weakened health systems.

For the International Council of Nurses:

Nurses must have a clear ... voice in local, national and international HIV/AIDS and sexual health strategies, to implement and share best practice models and initiatives on prevention, treatments and care according to local needs. [7]

Increased integration between countries, and the sharing of best nursing practice is clearly a strategy that will improve the care of PLHIV.

[This article is part of a longer report, prepared for the launch of the European HIV Nursing Network (and available online at: www.eurohivnursing.net).]

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Considerations for starting patients on antiretroviral therapy

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Starting antiretroviral therapy (ART) is without doubt a very big step for people travelling on the path that is HIV. As HIV nurses, we are usually involved in some way in this process and we can use our skills to help prepare the patient as much as possible for what lies ahead and we can assess how ready the patient is to start on lifelong therapy – whether working in an inpatient, outpatient or community setting, or as a specialist nurse. While treatments have become much more conservative in nature due to the fact that newer drugs tend to have fewer side-effects, toxicities and a smaller pill burden, adherence to antiretroviral therapy remains a challenge for many people. The issues considered here include the ongoing debate surrounding when to start antiretroviral therapy and how this may affect patients, particularly in resource-limited countries, and the nurse's role in starting a patient on antiretroviral therapy and some of the challenges faced.

The optimal time to start therapy

The optimal time to start antiretroviral therapy remains one of the major unanswered questions in the current treatment era. This is in no small part due to the lack of randomised control trials in this area. The US treatment guidelines [1] changed in 2007 and now state that antiretroviral therapy should be initiated when the CD4 cell count falls below 350 cells/mm³. The rationale has been cited at length over the past year [1]:

- Simpler, more effective, less toxic and better tolerated drugs are available;
- Data from cohort studies demonstrate benefit from earlier therapy with longer follow-up;
- SMART study showed increased morbidity and mortality (including from non-opportunistic complications) in patients who interrupted therapy compared to continuous therapy, regardless of CD4 count;
- May decrease HIV transmission;
- Theoretical risk of prolonged exposure to high viral load regardless of CD4 count (e.g. lymphoma, Kaposi's sarcoma, neurological complications);
- Early therapy may prevent emergence of X4 or dual/mixed tropic virus, preserving benefit from CCR5 inhibitors;
- Evidence showing greater likelihood of CD4 normalisation, with possible clinical benefits.

The recently published European AIDS Clinical Society guidelines also recommend treatment

initiation at CD4 counts of <350 cells/mm³ [2]. The forthcoming BHIVA treatment guidelines will also recommend that the initiation of therapy should be discussed with all patients with a confirmed CD4 count of <350 cells/mm³, and therapy should be started as soon as the patient is ready (www.bhiva.org). Indeed there are emerging data that endorse the idea of starting antiretroviral therapy at CD4 cell counts considerably higher than 350 cells/mm³. The UK CHIC cohort data demonstrated that patients with a CD4 count between 500 and 649 cells/mm³ were 55% more likely to develop an AIDS-defining illness than patients with a CD4 cell count above 650 cells/mm³ [3].

It is interesting to note that while early initiation of antiretroviral therapy was prominent on the programmes of all the international conferences last year, arguments against early initiation were distinctly lacking. While there is little doubt that efficacy of antiretroviral therapy has improved, and drugs have become more potent, tolerable and easy to take, it is important to emphasise, that once initiated, this is life-long treatment. Patient motivation is a crucial factor when it comes to starting antiretroviral therapy early. With patients currently starting treatment with a CD4 count of between 200 and 250 cells/mm³ generally, it is often the case that many patients are symptomatic and aware that starting therapy will make them feel better. This is obviously great motivation in itself. However, with a higher CD4 cell count, it is very unlikely that patients will be symptomatic or unwell and this motivation is absent. Thus, long-term adherence may be jeopardised in this group. The asymptomatic HIV-positive population contemplating the lifestyle changes necessary to initiate antiretroviral therapy has not been well studied. However, the non-urgent nature of initiating drug therapy in these patients has been described, allowing patient readiness to become a crucial component of the decision to start therapy [4].

As well as the possibility of poor long-term adherence, other themes that must be considered in the context of early treatment initiation are concerns regarding potential long-term side-effects such as the development of resistance, metabolic complications and drug toxicities, and the cost of therapy. In developing countries, there are many concerns about early initiation of antiretroviral therapy. It has been shown that mortality rates in the first year of antiretroviral therapy are higher in developing

countries than in developed ones [5], thus adding to the evidence that antiretroviral therapy should be initiated before serious co-morbidities develop. This may also mean that the WHO guidelines for initiating therapy are set at too-low CD4 cell counts, and that a greater number of people should be on treatment. However, antiretroviral therapy roll-out in the developing world has been rapid: in 2003 only 2% of individuals requiring treatment were receiving it but by December 2006 this figure had increased to 28%. In June 2006, the United Nations General Assembly High-level Meeting on HIV/AIDS agreed to work towards 'universal access to comprehensive prevention programmes, treatment, care and support' by 2010. On the other hand, patients in the developing world do not have access to the same level of monitoring as those in the developed world. Many of those patients who present for testing have already had an opportunistic infection and subsequently a CD4 count of significantly less than 300. Moreover, of those that do require treatment, how many can actually afford it?

When I worked in Lesotho with the Clinton HIV/AIDS Initiative (CHAI), antiretroviral therapy was free at the district hospital. In contrast, all other medications such as anti-hypertensive drugs, diuretics, diabetic medication, etc had to be paid for and as a result many patients were dying from heart disease and other complications. In addition, decentralisation from district hospitals to local health centres was also taking place so that patients would not have to travel so far to receive their antiretroviral medication. However, in some of the local health centres run by mission organisations rather than the government, patients had to pay for their antiretroviral therapy. In addition to the financial implications to patients in developing countries, it is important to consider the impact of starting patients on therapy in the absence of CD4 cell count and viral load monitoring. In recognition of this, WHO guidelines for treatment of patients in resource-limited countries recommend switching treatments only at the time of clinical failure and AIDS events rather than using viral load endpoints. Even in well-monitored patients, resistance develops in patients on suboptimal therapy or with suboptimal adherence. Without monitoring, there are concerns that the limited therapeutic options, later initiation of therapy, interruptions to treatment due to supply problems and transmitted drug resistance will cause significant problems in resource-limited countries.

The role of nurses in starting patients on antiretroviral therapy

Nurses play a central role in starting patients on antiretroviral therapy. This is the case whether the patient is asymptomatic or symptomatic, and being treated as an outpatient or as an inpatient. Our role as nurses cannot be underestimated in assessing patient readiness to start antiretroviral therapy. There is no doubt that HIV has become increasingly

medicalised over the past 10 years and everyday language in the world of HIV is progressively more complicated to our patients. Nurses can bridge the gap between the clinician and the patient in terms of the language used, and the implications of not taking antiretroviral therapy. In addition, they are ideally placed, both geographically and psychologically, to advocate for the patient and while the suggestion to start treatment is invariably made by a clinician, the ultimate outcome should be a shared decision. For example, nurses can advocate for the patient by suggesting that a pill burden may be too great or advise against starting the patient on medication with particular side-effects such as diarrhoea. Unfortunately, providing a choice of drugs is increasingly less of an option as cost becomes an overriding factor. If we are to truly advocate for our patient, then we should empower our patient to negotiate better with their doctor as this is something that has become increasingly difficult to do as the doctor-patient relationship has changed over the years.

Adherence is often treated as the goal of medical intervention when in fact it is the means to an end. For healthcare professionals, 'the end' is viral suppression, prevention of viral replication and subsequent resistance and the maintenance of the health of the patient. These goals may or may not coincide with those of the patient. The issue that must be addressed with patients is why adherence is crucial to them being able to achieve their goals. Unless a patient can see a reason for adherence that is meaningful to him- or herself, the motivation to adhere to the regimen may be missing.

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Two for the price of one: life with a dual diagnosis of HIV and cancer

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Introduction

Cancer continues to be one of the major challenges for healthcare professionals in the 21st century. Overall it is estimated that 2% of the UK's population are alive having received a diagnosis of cancer: that is, around 1.2 million people [1]. The incidence of some cancers including Kaposi's sarcoma, non-Hodgkin's and Hodgkin's lymphoma could be higher for individuals with an HIV-positive diagnosis and recent studies suggest that incidence of non-AIDS-defining cancers are increasing in the HIV-positive population [2].

Like an HIV-positive diagnosis, a cancer diagnosis can affect people in different ways. Whilst HIV/AIDS and cancer are different from a biological standpoint, they also create very different meanings and metaphors for the people affected by them [3,4]. There are many influences and beliefs surrounding these diseases. HIV/AIDS and cancer are not only considered to be diseases, but have also been described as 'folk illnesses' [5], whereby cultural groups provide their own aetiology, diagnosis, prevention strategies and methods of caring and healing.

The stigmatising nature of HIV/AIDS and cancer has been identified [6]. Both diseases represent potential or existing physical limitations. In a cultural context, they also represent 'punishments' for living unhealthy lives, for taking health risks and for excesses of diet and lifestyle. They have also come to symbolise weakness of will, self-indulgence and addiction [7]. However, while cancer is seen to stigmatise individuals because of the widely held fear of the disease itself, HIV/AIDS is associated with people considered by some groups to be morally reprehensible [6]. Those living with cancer become labelled heroically as 'cancer survivors', whilst those with HIV/AIDS continue to be afflicted by discriminatory attitudes and behaviours, and are designated more saliently as 'HIV-positive' or an 'HIV/AIDS patient'. This may be relevant in terms of how one cultural group considers another to be more accountable for their disease [4,6,8].

The consequences of living with a diagnosis of HIV/AIDS and cancer are documented, but there is a dearth of documented evidence on the experiences of living with a dual diagnosis of HIV/AIDS and cancer. However, experience tells us that for this group of individuals, healthcare can be complex and physically demanding. Furthermore, the psychological and social issues facing

individuals can be a great challenge. These phenomena are of interest to the healthcare professional in understanding the meanings and language that this group of patients ascribe to their illness. Such an understanding may improve communication between this patient group and the healthcare professionals involved in their care.

Methods

To gain an understanding of the perceptions of this group an exploratory ethnographic study, using observation and in-depth interviews was carried out in a London NHS HIV oncology clinic. This study attempted to understand the experiences of a small cohort of gay men with a dual diagnosis of HIV and cancer. A number of the emerging themes from this study are discussed here, using quotes from study participants to support them. Every attempt has been made to protect the identity of participants, who have been given pseudonyms.

What a difference a decade makes: becoming HIV-positive

For the men who participated in this study, experiences of both diseases varied greatly depending on when they received their HIV diagnosis. An HIV diagnosis before the advent of successful antiretroviral therapy was accompanied with greater fears and a shorter life expectancy than a more recent diagnosis.

Colin had been diagnosed HIV-positive in 1985 and our interview began with him telling me about his experience of finding out he was HIV-positive:

When they told me it was like total shock because I didn't know anything about HIV. And that time it was scary cos that's when HIV was like 'the thing'. It was a frightening experience, and all I saw was death and I went into a depression for about two years. Yes, two years cos I thought, any minute I'm going to die.

A patient named Mark was diagnosed HIV-positive more recently and he provides a very different perspective to Colin's:

Yeah, it's been alright to be honest with you. From the start it became apparent that I didn't need any medication and that I'm really healthy. The HIV became totally incidental to my life from day one ... Looking at the bigger picture, it's not going to affect my long-term

life, I just see this as a minor obstacle to get over in the meantime, and psychologically it's a bit of a blow, but you know ... worse things happen. And when I got HIV, I just thought, 'Thank God, it could be so much worse', there are so many more worse diseases that you can get other than HIV.

The start of a journey: being diagnosed with cancer

For some then it is apparent that there has been a shift in the way an HIV-positive diagnosis is perceived. Whilst AIDS-defining illnesses and cancers were common in the early years of the HIV epidemic, the success of antiretroviral therapy has changed the epidemiology of this disease. However, the numbers of individuals being diagnosed with an HIV-related cancer or non-HIV related cancer is growing [2]. Such a diagnosis can be particularly shocking.

While the experience of the HIV-positive diagnosis came before the cancer diagnosis for all but one of the men in this study, being diagnosed with cancer was none the less powerful and remained a vivid experience. Perceptions of HIV/AIDS patients to a cancer diagnosis appeared to be at odds with some of the health promotion materials on display in the clinic that advise those living with HIV/AIDS that they can 'Feel Good, Take Control, Stay Healthy' (the title of a leaflet previously available from THT).

Many individuals take their body for granted, the habitual body is familiar to its owner [9]. It was the loss of the familiar body that had signalled a new illness to this group of men. Some described spending a significant period of time suffering from new symptoms, awaiting a diagnosis, in a liminal state [10]. Therefore this group experienced a sense of 'social limbo', where they were not able to explain the changes in their bodies. Derek described the difficulty he experienced leading up to his diagnosis of lymphoma and this sense of uncertainty:

I was in Spain for a couple of months and started feeling ill, which at first I thought was a virus. So when I came back I went to my GP a couple of times and they kept giving me antibiotics. But then I was feeling no better and it got to March and I was concerned so I came up here. And it was from then that they started doing tests, but at first the tests were coming back as all OK. But I knew things weren't right, so after a while I was taken up to the ward and they started finding things in my blood and they didn't know what it was. Anyway it wasn't until about August when they came up with the cancer result.

For the majority of this group, discovering that symptoms were indicative of cancer had resulted in feelings of shock and terror. Stuart, diagnosed HIV-positive 9 years ago, and who had recently

been diagnosed with a rectal lymphoma commented:

Being told that you have cancer is the worst thing, much worse than being told you have HIV.

Luke had been diagnosed HIV-positive 1 year ago, he described feeling that he could cope with his HIV-positive diagnosis but the diagnosis of widespread Kaposi's sarcoma was a far greater burden:

It was horrible because, one of the things I remember thinking and saying when I found out I had HIV was, 'that's fine as long as I never get KS.' It was one thing I didn't want. This has brought me right smack up against my own mortality which HIV didn't do, yeah death feels much closer. This is double jeopardy, or even it's two for the price of one!

Stigma and cancer

The issue of stigma featured highly for this group of men. However, this was experienced differently within the group and appeared to have some relationship to the type of cancer by which they were affected. For example, Andy, a patient with a cerebral lymphoma, said:

I've told work about the cancer but not about the HIV. The same thing with my family, couldn't tell them about the HIV but the cancer is different, don't know why.

One explanation for this is given by another patient:

I've told everyone about my cancer diagnosis because you get sympathy for having cancer don't you ... people just think you deserve to get HIV, like you're a 'guilty' victim, whereas with cancer you're an 'innocent' victim.

For this group of patients with an 'invisible' cancer such as lymphoma or testicular cancer, there was no sense of being stigmatised by their cancer diagnosis. Instead for three of the four patients diagnosed with a lymphoma, the cancer diagnosis appeared to legitimise their illness, enabling them to be open about an illness they had until this point felt they needed to hide. This would appear to be at odds with notions of moral culpability for one's diagnosis of cancer [4]. However, this theory was seen to have some resonance for the men with a more visible form of cancer.

Those with a visible cancer such as Kaposi's sarcoma had not been able to share the positive rewards of being open about their cancer diagnosis, as Colin (a man with Kaposi's sarcoma, undergoing chemotherapy for the second time) discusses:

I didn't go outside because I couldn't let people see me like that because straight away they would know that something was happening and they would be horrified because I looked

like something out of a horror show. It was not me I was looking at, I was looking at something else, so I didn't leave the house for ten months, apart from coming to the hospital. I didn't want to live like this, I just wanted to go to my bed and not wake up because when I felt my face I didn't ever think it would come back.

A further interview with Joe, a man with widespread Kaposi's sarcoma lesions on his chest and in his oral cavity describes a similar sense of stigma:

Some people said that I shouldn't be out in gay clubs, like what right did I have to be out there? What right did I have to be parading my KS? And that was the middle of the road reaction as someone told me that, 'You should go off into a corner and die.' So fairly mild, which was withdrawal to an angry response, about how dare I go out dancing and taking my top off when I've got KS.

Losing control: the differences between being HIV-positive and living with a dual diagnosis of HIV and cancer

A strong theme that emerged in this study was that participants described a sense of 'losing control' now that they had been diagnosed with cancer. For this group, HIV/AIDS had been something in their lives that they had managed to control. This was highlighted by a number of the men who described their HIV disease as being 'like diabetes', and controlled by a medication regime. However, cancer and its associated treatment represented something that they had no control over. Luke describes this:

Before now I dealt with HIV by believing that I can manage it. Now I don't feel like I've got any control. It's like, 'This is what you've got and this is what we're going to do because this is the treatment and that's it.'

Stuart shared these experiences as a transcript from his interview reveals:

I mean my life has changed in a sense that I'm not doing things normally. I mean I'm not going to work now, but with HIV you can lead a normal life. With my HIV I can keep it at bay with the treatment, chop and change treatments around to suit my needs. But with cancer you have to have what they decide to give you. Really there are no choices to be made other than life and death. So I feel like I'm out of control, total lack of control. So if I don't have treatment now I'm finished, that's the long and short of it.

The missing link: explaining cancer

Unsurprisingly, perhaps in part due to the complex nature of this group's dual diagnosis, a wide range

of views and beliefs were held about the causes of cancer. Like many people affected by ill health, this group had developed individual explanations for their illnesses. Explanatory models [5,11,12] are held by both professionals and patients alike, and are not necessarily founded in dominant empirical ways of knowing. This group of men had developed their own understandings, and as such their dual diagnosis can be likened to a folk illness [5], where these beliefs become embedded in the order of how individuals manage and perceive their illness.

Three of the 10 men in this study made some direct link between their two diseases. Andy who had been treated for a lymphoma felt that there must be something that linked his two diseases:

I think it must be connected to the HIV but I don't know how or why. Can't be anything else that's causing it because I eat well, I don't smoke, drink or take drugs either.

A more indirect link was made by two other men in relation to their cancer and their immune systems. First, Luke explains his understanding and this is followed by Derek's:

Luke: I don't think it's a coincidence but I guess it's a lot of different issues coming together. My view is that people are getting different types of cancers and they're becoming more prevalent. Logistically, HIV has had a long time to mutate and we're probably dealing with much more concrete strains of HIV now than maybe we were twenty years ago. So I'm not sure it's got anything to do with lifestyle.

Derek: I think it's just obviously the virus is finding other ways of getting into the system. I don't really know. I don't think anybody ever found out why gay men got Kaposi's, which is what I had first before this lymphoma. There were all sorts of myths about it: I remember the one about amyl nitrate. But I don't know if that was ever established as a cause of it. But now that we know it's caused by a virus, a separate virus to the HIV, I think it's connected to herpes. And you see I had herpes many years ago before I was diagnosed with Kaposi's. But then most of the people who got it back then were doing a lot of sex and drugs, so perhaps it was something to do with that. Oh, I don't really know.

Other men in this group were not able to make any link between their two diseases. For them other explanatory models of their cancer were dominant. Here Steve, Tom and Colin give their explanations.

Steve: Well, I have been concerned how I contacted [sic] it. You know you go back through your family tree and think about whether there was any cancer in my family before but that is not the case in my family. So I'm none the wiser why it's happened to me. I

have thought about smoking but I've never smoked in my life. It's a fallacy to say that smoking causes cancer cos what about people like me who have never smoked. How have we got it?

Tom: Being from the North, cancer seems to be everywhere in the North, so I wonder if that has something to do with it. I don't hear about cancer so much down in London. In the North you hear about the radiation and that causes cancers. Although in London you have more pollution and that must have something to do with these cancers. Me and my partner want to move to the seaside to get away from the pollution.

Colin: Well, it was actually around the time that my brother died, I think it was about 1997, I was under heavy stress, and that's when the KS came up on me. I was watching what was happening to him, watching him deteriorate with his illness and you know I had to help my mum with him, so that put more pressure on me. So I got really stressed-out and that's why the KS appeared.

These three conversations reflect that these men saw no direct connection between their two diseases. Another two similar conversations took place, but instead of seeing smoking, radiation, pollution or stress as causative factors, these two informants believed that their cancer might have been related to food, drugs or sex.

Discussion

HIV and cancer remain complex diseases; many cultural forces and meanings shape their experience. The popular discourse around HIV/AIDS now states that being HIV-positive alone should not impede an individual's ability to experience a healthy lifestyle. However, this small ethnographic exploratory study has highlighted that for these men who already have an HIV-positive diagnosis, a cancer diagnosis has altered their experience of an HIV-positive diagnosis. Their cancer diagnosis has caused them to feel a loss of control, fear, and for some has reinforced old stigmas that are inescapable due to the visible nature of their disease.

This study has focused on the illness experiences of a small cohort of gay men living with a dual diagnosis of HIV/AIDS and cancer and is therefore limited in its applicability. Further studies would be useful to better understand the illness experience of other people who may also be affected by a dual diagnosis of HIV/AIDS and cancer.

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Challenges and accomplishments in reducing drug-related harm in Eastern Europe and Central Asia

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The region of Eastern Europe and Central Asia is home to over 2.8 million injecting drug users (IDU) [1]. Access to harm reduction services such as needle exchange, substitution therapy and other low-threshold services designed to meet the health needs of drug users is improving but remains low, estimated at less than 9% of IDU [2]. This low level of access contributes to the fact that the region has the world's fastest growing HIV epidemic and lowest levels of access to antiretroviral therapy (ART) among those in need. There are many examples of good practice in harm reduction in the region and some countries and donor programmes have made great strides in improving access to the necessary services but, to adequately address the vulnerability faced by drug users in the region, efforts to scale-up harm reduction and reform drug policy must continue.

Growth of drug use and related harms in Eastern Europe and Central Asia

With the fall of the Soviet Union, increased unemployment, eroding social cohesion, the stress of transition and increased supply of injectable drugs (most notably opiates) led the region to experience a rapid increase in the prevalence of injecting drug use. More recently, use (including injection) of amphetamine-type stimulants has been increasing. Most countries in the region responded to the increasing injection drug use with repressive measures that served to aggravate rather than alleviate harm related to drug use. Fear of arrest drove drug users underground and discouraged access to needed health and social services. Pervasive stigma among the general population and even among the medical community fuelled social exclusion, vulnerability to rights violations and a host of health problems such as HIV, hepatitis B and C and overdose. The healthcare system, also suffering from the turmoil of transition, was ill equipped to handle the new phenomena.

In many countries in the region, HIV epidemics are driven by the sharing of injection equipment. UNAIDS estimates that there are around 1.6 million people living with HIV (PLHIV) in the region [3]. It is estimated that as many as 80% of these are current or former drug users [2]. Although reported heterosexual transmission is increasing, 62% of incident cases reported in 2006 were attributed to injecting drug use [3]. Ninety percent of these cases

were located in two countries, Russia and Ukraine. In contrast, Central Europe has low rates of HIV and it is not concentrated among IDU. Eastern Europe and Central Asia have the world's second lowest level of access to ART with only 15% of those in need covered. The countries of Central Europe have reported near universal access while other countries still require scale-up of services [4]. However, countries in this region have established ambitious universal access targets and rates of access are increasing.

Rates of hepatitis C (HCV) infection are very high throughout the region, including the countries of Central Europe – in some cases as high as 60% and with rates approaching 90% among IDU [5]. Rates of HIV/HCV co-infection (which complicates treatment significantly) amongst IDU are also high, often ranging from 20% to 40% and sometimes as high as 80% (Estonia). In many countries drug users are systematically excluded from access to hepatitis treatment and in many, treatment is not available due to the high costs of drugs. Rates of both HIV and HCV are probably underestimated in drug users due to the lack of low-barrier, easily accessible, voluntary testing and counselling (VCT) facilities. In addition to blood borne infections, overdose is also a significant problem. In EU member states there was a steady increase in overdose related deaths throughout the 1990s, making overdose one of the leading causes of death among young people in the EU [6]. There are few data available about the overdose situation in non-EU countries but there is reason to believe that their rates of overdose are high as well. Although more difficult to quantify, in addition to these serious medical and public health issues, discrimination, rights violations and social exclusion are commonly experienced by IDU in Eastern Europe. Harsh drug policies lead to high rates of incarceration of drug users and since risk behaviours (both sex- and drug-related) tend to continue in prison, this contributes to the further spread of infection.

Addiction treatment services are insufficient in most countries in the region, especially in the eastern part of the region. Where substitution therapy (with methadone or buprenorphine) is available, coverage is often low, and in Russia, Tajikistan, Kazakhstan and Armenia these medicines (included on the WHO essential drug list) are still not available at all. In some countries such as Russia, the soviet approach to drug treatment persists. Rehabilitation programmes are rare and underdeveloped. Detox is

offered but service clients are 'registered' and their names included on official lists that are shared with various authorities, a practice that serves to drive clients away from seeking help at these services. Treatment approaches are not evidence-based and quackery is common.

While most governments pursued repressive approaches to the drug issue, civil society organisations took on a public health and human rights-based approach, developing, practising and advocating harm reduction services to address the health and rights needs of drug users. Using innovative, client-centred programming they began to reach into drug-using communities and provide education, skills and equipment necessary to promote health. Needle and syringe exchange programmes have been practised in all countries in the region (except Turkmenistan). Slovenia, Croatia, the Czech Republic, and Kyrgyzstan have shown leadership in harm reduction in the region. In many countries, however, harm reduction services have only been piloted. In Russia, for example, coverage by needle and syringe exchange programmes is estimated at only 2% of those in need. These programmes were (and still are) largely supported by foreign donors although now some governments in the region have begun to finance and institutionalise (through governmental regulations and training programmes) harm reduction services. Kazakhstan and Lithuania have begun to institutionalise harm reduction services.

In some countries, coverage of harm reduction services has been expanded by distributing clean needles through pharmacies, through secondary exchange (when peers distribute needles to their social networks), and peer-driven initiatives (through which peers are rewarded for recruiting new clients to services). Many harm reduction sites have begun to provide broader ranges of services to clients, offering on-site HIV or hepatitis testing, access to naloxone (which can reverse a heroin overdose) or expanded case-management services guiding clients to peripheral medical and social services. Some programmes have been developed to address the needs of special sub-populations of drug users and sex workers such as programmes targeting women and youths for example but these are mostly still only at pilot level. Some harm reduction sites have begun to realise a new role in promoting access to ART for IDU. Peers involved in harm reduction services have proved able to play a vital role in recruiting patients to treatment programmes and in supporting treatment literacy within the drug user community.

The Global Fund, UNODC, international donors and some national governments have undertaken to scale-up access to harm reduction services in the region but there is still a long way to go. In some of the new EU countries of Central Europe the accession process led them to include harm reduction in national drug policy but for some

countries the challenge of securing resources for harm reduction has grown given that EU membership eliminated eligibility for many donor funds. In most other countries in the region, harm reduction programmes and other programmes targeting vulnerable populations are still dependent on international funds. Often, these funds are from HIV programmes, which sometimes limits the scope of harm reduction activities supported. Activities targeting hepatitis, overdose and rights issues are sometimes neglected.

The region's harm reduction network, the Eurasian Harm Reduction Network (EHRN), which unites over 300 activists and organisations in the region, celebrated its 10th anniversary in 2007 and engages in research, advocacy, networking and provides evidence-based technical assistance to programmes through its Harm Reduction Knowledge Hub. Throughout the region national and sub-regional networks have been growing in number and strength as have a number of drug user organisations such as the International Network of People who Use Drugs (INPUD) and organisations of PLHIV and their advocates such as the International Treatment Preparedness Coalition (ITPC/EECA) and the Eastern European Union of PLHIV Organizations (ECUO). These networks continue to push the harm reduction agenda of more humane and effective drug policies and related services. Nurses, of course, have a vital role to play. As the most plentiful of medical professionals, they can contribute to advocacy efforts on the national level as well as within service centres. Within service centres, their tolerance and kindness positively touch the lives of individual drug users in need.

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HIV testing issues for nurses in Europe

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HIV is a rapidly evolving field. Treatments have continued to be developed at a rate seen in few other areas of medicine, both in terms of agents to use against the virus but also in the formulations in which these drugs are made available. Our approach to identifying those with the virus, and thus enabling intervention, has also evolved in recent times. New tests are available to use in new settings and this can only increase our capability for diagnosing the virus. Nurses are a key part of this intervention and this article, whilst in no way an in-depth guide to testing and giving an HIV result, seeks to highlight some issues that nurses can be aware of when being involved in the testing process.

Standard tests for HIV have in the past been laboratory based (antibody tests using ELISA and Western blot) and these have implications on testing availability. New point-of-care tests (POCT) have been created that are portable, user friendly, highly sensitive and specific and can detect antibodies in finger-prick, saliva or urine samples. With the failsafe that those testing reactive with these tests then only need to be confirmed with a standard laboratory test, testing for HIV has become easier, more accessible and less invasive. Nurses are well skilled to perform these tests and support patients around the time of testing.

In 2007, the World Health Organization (WHO) issued guidance on provider-initiated HIV testing and counselling in healthcare settings. Whilst it stresses that these are merely guidelines that need to be put in the context of available resources, they provide an ideal that all healthcare providers can aim towards and adapt to fit their existing cultures and environments.

At the heart of these guidelines is the observation that many testing opportunities for HIV are being missed within healthcare settings and recommends a healthcare provider-initiated 'opt-out' approach to testing including simplified pre-test information. It maintains that all patients maintain the right to understand the test and its benefits but also the right to decline it. It recommends this approach to all patients within a healthcare setting, whose clinical presentation may result from an underlying HIV infection, but also any patient from a 'low level', 'concentrated' or 'generalised epidemic' population.

Low-level populations are defined as those populations where prevalence has not consistently reached over 5% in any sub-population. In a concentrated population, prevalence is consistently

over 5% in any sub-population (but less than 1% in rural pregnant women). A generalised epidemic population is defined as one in which HIV is firmly established within a general population (more than 1% in rural pregnant women).

There are common recommendations for all epidemic types. All patients with signs/symptoms possibly related to HIV should be tested; as should anyone within a high-risk group (men who have sex with men, sex-workers and intravenous drug users), children born to HIV-positive women and any child presenting with failure to thrive. Recommendations for generalised epidemic populations include providing testing for all patients attending in- and outpatient facilities, antenatal/obstetrics, health services for at-risk groups, younger children's/-adolescent services and at sexual health/-reproductive services. Where epidemics are within concentrated sub-groups, the guidelines state that testing should be offered within STI/GU services, services for at-risk groups, antenatal/childbirth services and TB services for that population.

Whilst these guidelines aim towards an ideal situation, they recognise that simply offering testing for HIV is not a solution in encouraging people to test. They talk of the need for an 'enabling environment' in which testing can be effective – by this it is meant that all healthcare provider-initiated testing should be accompanied by a package of supportive prevention, treatment and care services. In summary, where testing is taking place there should be an effort to ensure and provide a supportive social policy to protect and care for those patients who do test – this should ideally include the availability of HAART. Nurses are a key part of ensuring this social policy in supporting patients to consent to informed testing for HIV. Whether nurses are actually performing the test or not, there are principles they can follow to ensure that their patients are supported throughout the testing process.

Pre-test discussion is aimed at enabling the patient to cope with stress and take personal decisions related to HIV. This hugely important stage of the process includes an evaluation of behaviours and risk assessment, this can not only facilitate health promotion at this point but also start to prepare for a possible positive diagnosis. The emphasis at this point is on discussion, but counselling skills may be employed to help the patient reach informed decisions. Why testing is recommended and the benefit it offers can be explored at this stage of the process, as well as confidentiality and disclosure issues.

Panel 1: Risk assessment

- Previous test history
- High-risk group
- Known HIV-infected partner
- Endemic contact
- Blood product recipient/history of surgical interventions
- Patient's expectation of result

Panel 2: Areas to cover during pre-test discussion

- Confidentiality
- Window period
- HIV transmission routes
- Safer sex
- Treatment options
- Insurance issues (if appropriate)
- Support and care available
- Preparation for the result
- Consent to test

Panel 3: Key areas to cover

- Physical and psychological care
- Process of HIV (CD4/VL)
- Monitoring
- Care and support available
- Treatment options and availability
- Partner/child testing
- Sex and onward transmission
- Health promotion and advice

Giving a result

This can be a daunting and emotional process for everyone involved. However, done properly, with confidence and sensitivity, it is a supportive process where not only the result is conveyed, but a point at which feelings and fears can be explored and plans for the future made. It is important to remember that giving a negative diagnosis to a patient who was perhaps expecting a positive result can be not only an emotional time for that patient, but also a key time for health promotion to be offered.

A positive result should be given clearly and concisely with time allowed for the patient to process the information. It is important the patient understands the result not only in terms of having the virus but what care package will now be offered to them. The patient should be given plenty of time to express their emotions. This will be a key point to deal with misconceptions the patient may have about the virus but also to address the patient's immediate concerns, perhaps around disclosure or prognosis. Explanation of CD4 and viral load tests and how these are used to guide care can be given, but most important is an explanation of what support is now available to the patient as a result of knowing their status and how this is to be arranged and accessed. It may be an opportunity to identify whether there are partners or children who also need to be tested and arrangements can be made for these.

This is obviously an emotional time and individual reactions can vary. Common responses though can be suspended belief, expressions of guilt, and fears in regards to the future. Patients are sometimes tearful, but also often silent – what is important is they are allowed time to express their feelings, fears and anxieties and are allowed to ask questions that

will be answered honestly. Much of what is said at this time will not be remembered and it is hugely important to recognise this and allow time for questions to be repeated and information clarified. Most important is that the patient feels there is support for them and that they can access these services.

With good support, distress is usually short lived, severe anxiety is not normal and patients do adjust well to living with HIV. There is no denying that an HIV diagnosis is a life-changing event, but knowing a diagnosis allows a patient to access the care and treatment that is available, and must therefore be approached as a positive and valuable service to offer people. As healthcare providers, we have the skills, experience and confidence in caring for people with HIV. We need to transfer that confidence to patients at the time of diagnosis.

In summary, whilst HIV may be a growing epidemic, nurses are endemic throughout healthcare and are well placed to support and encourage those at risk of infection to seek, access and accept testing, thus enabling access to treatment and support that may be available. Nurses are not only healthcare providers but are also key members of communities, educators and guides, and as such can be a part of enabling societies that encourage those at risk to seek, access and utilise HIV testing, care and treatment. We can ensure that testing opportunities are not lost and encourage informed and supportive testing, ultimately increasing access to HIV care for those who need it before it is too late.

Further reading

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Disclosure of HIV diagnosis: talking to children with HIV about their health

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This article will look at how children with HIV are informed about their illness and outline the findings of an audit on the current management of disclosure of HIV diagnosis to children and young people in the United Kingdom and Ireland.

Background: paediatric HIV

There are more than 1200 children and young people living with HIV in the United Kingdom and the Republic of Ireland [1]. The majority of these children were infected by mother-to-child transmission and are of sub-Saharan African origin. The Collaborative HIV Paediatric Study (CHIPS; www.chipscohort.ac.uk) collects clinical data on these children, their illnesses, medication, blood sample results and growth. Since the arrival of effective antiretroviral therapies the morbidity and mortality of these children has improved dramatically [2]. Life expectancy has greatly improved and HIV is now a chronic illness requiring long-term care and follow-up.

Initially the majority of children with HIV were living in or around London. However, there are now increasing numbers of children and young people being cared for throughout the rest of the United Kingdom and this is coordinated through clinically managed service networks [3].

Talking with children about illness and HIV

In Europe and America, it is generally felt that children have a right to have information about their health shared with them, appropriate to their developmental level, and for them to be involved in their care [4]. Where a child has HIV, parents often feel anxious about talking openly with their child. The median age where children have full naming of their HIV condition is 12 years [5]. Children with other chronic illnesses are likely to know fully about their illness at an earlier age than this. However, disclosure around HIV has to be understood within the context of ongoing fear, stigma and discrimination. Parents worry about the child telling others and risking rejection, and they want to protect their child from this. Many mothers are concerned about telling their child the HIV was passed from them and they fear being blamed or judged. They may worry about the emotional impact or burden on the child or having to face difficult questions from the child. Cultural

differences in approaches to who should talk to children about illness, relationships and sex may influence who actually does talk to the child. Partial disclosure of diagnosis is therefore common for younger children, giving the child information in stages enables the child to make sense of their illness without fully naming it.

Young children may just need information about needing medicines to keep them well or their body strong; about what happens in the clinic and having a check on their health. Children from 6 years upwards would often be given information about white and red blood cells and the role of white blood cells in defending or protecting the body from germs. This can then lead onto explanations about not having enough white blood cells in their blood, making it difficult for them to fight off germs, coughs or colds and this is why they need to take medicines. Over time they can be given more information about bacteria and viruses. Later the child will learn they have a virus in their blood that was damaging their CD4 cells and that they were born with this virus, shortly before they have full naming of the virus being HIV. There are a number of general illustrated children's books on the body, health, blood and fighting germs that can help facilitate these conversations. It is also important to ensure the parents have adequate information so they can feel more confident and comfortable in talking with their child.

The explanations given to the child must be honest and must help them to understand why they come to hospital, have blood tests and take medicines. Partial disclosure helps to break down the information into manageable steps and this information can be built on and expanded over time. It is important to check what the child has understood and to enable them to ask questions or express any worries they have.

Naming of HIV diagnosis

Disclosure of diagnosis should be seen as a process that works towards full naming of the HIV at an appropriate time rather than as a one-off event [6]. Ideally the child or young person would have full naming by 11–12 years of age. Often the aim is to do this before the child moves to secondary school but there may be valid reasons for this being delayed such as cognitive delay in the child or ill health of a parent or child. Disclosing prior to starting secondary school allows the child time to

learn more about living with HIV as a chronic health condition. As the young person matures they will need more information and support about relationships, sexual health issues and learning to live with an illness that is sexually transmissible. At naming the child needs to be told they have a virus called HIV and explain what HIV stands for and what that means. They need to know that the HIV will always be there but that medicines keep it under control. The young people need to be helped to understand that this is private information and to be told who they can talk to. They may find it beneficial to meet or have telephone contact with other young people who know their diagnosis or to go to support groups. As the young person gets older they will make their own choices about who they will tell but they often need help and support in doing this. Most of the children do associate HIV with death and need help to understand that, with treatment, they can expect to live for decades and they should plan for their future around going to college, university or work. Naming of the HIV needs to be followed up by ongoing conversations with the young person and appropriate support and information about HIV and its management. There are many advantages of the child or young person knowing their diagnosis. Open and honest conversations can be held and the young person can participate more fully in decisions about their care. The parents often feel a sense of relief that they are no longer hiding this from the child.

Because of the complex issues around disclosure, families need to have time for discussion of issues such as preparing the child, finding the right words to say and defining and considering how to manage any risks. It is usually best to start working with the parents around the process of disclosure early on. They need to be offered ongoing support and information to help them understand the child's perspective and needs. They may also find it useful to meet parents who have already been through this process or young people who are aware of their diagnosis. Ideally, disclosure takes place in a supportive environment with collaboration and cooperation among parents and providers. Each child and family is assessed and an individualised plan of the process of disclosure is made taking into account the age and maturity of the child, complexity of family situation, and current health issues. In many centres it will be the clinical nurse specialist for paediatric HIV who takes this process forward. In larger centres there is often a team including paediatricians, clinical nurse specialists, clinical psychologists and pharmacists. These team members would usually have meetings where the child's knowledge of their illness is discussed and a plan made of who will lead the disclosure process.

There are documents available on the Children's HIV Association (CHIVA) website (www.chiva.org.uk) that provide guidance around the process of disclosure and how best to support the children and

their families [7,8]. Recording the child's understanding of their illness in the medical notes is important so that everyone caring for the child is aware of what can be discussed with the child.

Transitional care

In the United Kingdom, 50% of the children and young people living with HIV are 10 years and over and although they have many complex needs, the majority are expected to transition into adolescent and adult services. The issues of how to support these young people in learning about their health issues, sexual health, fertility and becoming more involved in their own care is a key part of their treatment. Addressing young people's knowledge about their HIV and sexual health issues is vital for successful transition to adult services [9]. Good joint working with adult colleagues is essential as are clear transition pathways.

CHIVA audit of disclosure practice

The aims of the audit were:

- To obtain an overview of the management of disclosure of diagnosis for children with HIV in the United Kingdom and Ireland.
- To assist in the development of further resources around talking with children about their health and HIV.

CHIVA undertook a semi-structured survey of centres caring for children with HIV and a notes audit in order to provide some baseline data in this area [5]. In total, 33 of 52 centres responded (63%) and 133 sets of notes were reviewed. Of the young people 10 years and over, 91 (68%) had been told that they had HIV. The median age of naming/open discussion of HIV was 12 years and 69 (76%) disclosures were planned while 15 (16%) were unplanned or accidental. Young people usually cope well with learning their diagnosis but need support from their family and the multidisciplinary team during this period. Parental concerns were the most common reason for delays in the disclosure process and especially naming of the diagnosis. The approach to talking with the children and young people and supporting the families was multidisciplinary. Often the clinical nurse specialist or paediatrician spoke with the child or young person about their health, together with the parents.

There was good evidence that clinicians were working in partnership with families in providing support to children and families around the complex issues of the child fully learning of their diagnosis. Whilst only 10 centres were using formal guidelines, 85% of centres were making a plan of preparation and support needed to help the child understand their health condition. There was good documentation of the child's knowledge of their illness in most notes

Most children did have full naming of their HIV by the age of 12 years unless there were reasons such as the young person being developmentally delayed or more work or support being needed for the carers to feel ready for disclosure.

There are various projects under way involving the statutory and voluntary sectors, and young people, which include the development of practice guidelines, leaflets and information for the young people; an interactive DVD-rom, and workbooks. When these are finalised they will be available on the CHIVA website (www.chiva.org.uk).

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NHIVNA update

Thanks to all of you who attended the Inpatients Competencies Study Days held in London on 5th March and Liverpool on 13th March. The feedback we received about the programmes has been very positive and will help to improve the content of the future Competencies Study Days. There are two days still to be held later in the year: one in London on 22nd October (Outpatients and community) and the other in Birmingham on 20th November (Care of inpatients). All NHIVNA members can attend at least one study free of charge. Full details for registration for all NHIVNA events can be found via the events link on the website (www.nhivna.org).

The HIV competencies are now available on the website in a Word format. This will enable you to 'cut and paste' in preparation for developing your annual work plan (www.nhivna.org/competencies).

Plans are well under way for the 10th Annual Conference. By now, you will have received the announcement for the conference in Glasgow on June 26th and 27th. There will also be a pre-conference study day on 25th June. There is still plenty of time to both register and to let colleagues know of the exciting and packed programme.

If you are attending any NHIVNA event please be sure to complete an evaluation form as this helps to identify needs and formulate the programme for future events. Yes, planning has already begun for the 11th Annual Conference that will be held in 2009 and your suggestions and input are essential to ensure the programme is of maximum benefit.

Boehringer Ingelheim offered to sponsor 20 free memberships for new nurses to join NHIVNA – so if you know of a colleague who would gain from membership please let them know of this offer. Anyone applying for free membership should complete a membership form and submit a short supporting statement. Full information is available on the website (www.nhivna.org).

We hope to see you all in Glasgow in June.

Sheila Morris, Chair, NHIVNA

Call for Papers 2008

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

HIV Nursing welcomes all articles, editorial letters, case reports and other contributions which would be of interest to healthcare professionals working in the field of HIV.

If you have recently completed a dissertation for a degree, set up a project that has improved the service of care for your patients, or conducted some interesting research, let us know.

As professional nurses, one of the best ways to raise our profile is by demonstrating innovative work that improves the lives of patients, family, and staff within the domain of HIV care.

HIV Nursing aims to provide a forum for those at the forefront of caring for people affected by HIV and is intended to provide a medium of communication on issues relating to HIV care. Readers' contributions are highly valued.

If you wish to contact **HIV Nursing** please email: hivnursing@mediscript.ltd.uk

or send items by post to:

The Editors, HIV Nursing, Mediscript Ltd, 1 Mountview Court, 310 Friern Barnet Lane, London N20 0LD, UK

The themes for this year's issues include:

Issue 8.2 Research

- How to write an abstract
- Nursing doctorates
- Researching the Expert Patient Programme
- Developing a research proposal
- Research in the community
- The role of audit

Issue 8.3 Focus on the Competencies: Health Promotion

- Diet
- Cardiovascular health
- Smoking cessation
- Sexual health

8.4 Focus on the Competencies: Assessment

- Assessing patients
- Nurse prescribing
- HIV and poverty
- Gender and HIV
- Identity



National HIV Nurses Association

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

26–27 June 2008 ■ Glasgow Marriott Hotel ■ Scotland

Dear Colleague

It gives me great pleasure to announce our **10th Annual Conference**.

The plenary programme is taking shape and we are delighted to confirm that a number of eminent speakers have agreed to participate. One of the many highlights of the conference will be the presentation of the very latest research, education and clinical practice initiatives in HIV nursing during the oral presentation sessions. I would like to encourage as many delegates as possible to submit abstracts for review – especially those nurses who have undertaken their own original nursing research.

Please note that NHVNA is also inviting applications for a number of scholarships and awards. Some are related to the submission of abstracts but there are also awards directed at junior and student nurses, designed to assist them to attend the conference. Full details can be found on the NHVNA website (www.nhvna.org).

As is customary, there will be a Gala Dinner. This year it is to be held at Òran Mór, a converted church, which is now a cultural centre hosting a varying programme of events. We anticipate an evening of good food, fine wine and after-dinner entertainment.

I look forward to welcoming you to Glasgow.

Best wishes

Sheila Morris
Chair, NHVNA

Sessions to include:

Modernising nursing
careers in HIV nursing

Developing roles in HIV
nursing

HIV as a chronic illness:
models of chronic
disease management

Managing adolescents
and transitional care

Current health policy in
relation to HIV

Treatment of HIV
co-infection

