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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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Managing co-infection: a nurse's reflection of HIV/TB

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I guess I have always been fascinated with infectious diseases. For me, thinking back now, it was perhaps my parents' influence, through their work in the field of TB and public health, that first aroused my interest. The human species has often provided the vehicle for microbes and viruses, many of which coming from other animals – AIDS from African monkeys, TB from cattle and birds. Most of these happened naturally, although we 'humans' have been responsible for others. How is this possible? Changing our lifestyles – that is, our homes, diets, sexual behaviour and, these days, even our levels of stress – can and will alter the progression of a disease or illness [1]. These factors have enabled diseases to thrive and place an increased burden on our immune systems, as in the case of HIV/TB co-infection.

TB is increasing, and the worst affected areas are those with the highest levels of poverty and HIV infection. TB is the most important infectious cause of global mortality, with 8 million new cases and 2 million dying each year [2].

TB is the biggest killer of people with AIDS. An estimated one-third of the 42 million people living with HIV/AIDS worldwide are co-infected with TB. About 90% of people living with HIV die within a few months of becoming sick with TB if they are not treated [3]. Globally, approximately 9% of all new TB cases in adults (aged 15–49 years) are attributable to HIV infection. The leading cause of HIV-related morbidity is attributed to TB. It is also the second most common opportunistic infection in the UK. In 2003, TB contributed to 27% of all AIDS diagnoses [4].

The impact of HIV on TB incidence in the UK is not well defined. In order to rectify this, the respiratory and HIV departments of The Communicable Disease Surveillance Centre are examining available data to increase our understanding of the HIV/TB epidemic. Work is under way to improve estimates of HIV/TB co-infection rates and also to examine the risk factors for co-infection [5]. The London TB Nurses Network has been a strong force in the commitment to driving nurse-led TB services in London. In conjunction with the Health Protection Agency and University College London, they have undertaken a pan-London needs assessment of clinical, social and environmental factors known to complicate the management of TB patients and affect outcomes to treatment. Preliminary analysis has generated important insights into the TB service and patient management, including fragmented services. The project also highlighted the rate of co-infection, which was much higher in this study than estimated by other methods [5].

As a nurse who has worked in the field of TB for several years, I have found that the most complicated patient group comprises those that are co-infected with HIV/TB. Clinical and nursing management of these patients is far from straightforward. HIV-infected individuals have a much higher risk of becoming ill during or after therapy. Other infections and severe complications are commonplace when HIV/TB infection suppresses immune responses. For these reasons, and for other complex issues that arise, it is recommended that a multidisciplinary approach to the management of these patients is undertaken.

The treatment of TB in HIV-infected adults is usually the same as in those that are not infected with HIV, but there are some important exceptions:

- Some intermittent treatment regimens are contraindicated in HIV-infected patients because of unacceptably high rates of relapse, frequently with organisms that have acquired rifampicin resistance. Consequently, patients with CD4 counts <100 cells/μL should receive daily, or a minimum of three times weekly, anti-tuberculosis treatment.
- Adherence should be monitored and recorded. HIV-infected patients are less likely to complete their course of treatment than those that are not infected with HIV.
- HIV-infected patients are often taking medication, some of which may interact with anti-tuberculosis medications. Rifampicin interacts with antiretroviral medication.
- There are overlapping toxicity profiles and drug interactions with some anti-tuberculosis and antiretroviral drugs, further complicating the concurrent use of highly active antiretroviral therapy (HAART) and anti-tuberculosis treatment. HIV-infected patients with TB are more likely to develop adverse drug reactions and interactions than those who are not infected with HIV.
- The timing and commencement of HAART in relation to the start of TB treatment in the context of preventing the risk of further HIV progression is a concern and should be discussed among the physicians caring for the patient [4].

In my experience, there are many problems that

nurses and other healthcare professionals involved in treating patients should be aware of. My earliest memory of managing a case load of patients in this group was the importance of picking up early signs of any problems that affect treatment completion and the general decline in health. Some patients that are co-infected may fail to absorb TB drugs properly; this can increase the risk of treatment failure, which in turn increases the risk of relapse. Drugs and drug interactions can have an undesired effect on HAART and anti-tuberculosis treatment. As a nurse in the front line managing these patients, it is partly my responsibility to monitor a patient's progress in order to be able to report back to the patient's physician as early as possible, and thereby aid in reducing resistance and drug toxicity.

TB remains the most important HIV-related disease; it appears early in the course of HIV disease and causes a swift decline in the immune system and in general health. Infection by HIV has created an additional burden and impact on the global prevalence of TB. The problems of HIV/TB co-infection are complex and cannot be achieved by fragmented services and quick solutions. In order to reduce the incidence of TB and HIV/TB co-infection, it is vital that patients have access to treatment and are supported through it, with a commitment of resources, expert clinical skills, intelligent management and leadership.

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Hepatitis C and HIV co-infection

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This feature article covers the treatment and management of clients who are co-infected with both HIV and Hepatitis C virus (HCV). The differences between treatment and disease progression for those who are co-infected and those who are mono-infected are also discussed.

What is hepatitis C?

Hepatitis A and B were identified in the 1970s. It soon became apparent that around 10% of people developed hepatitis following blood transfusion [1]. The hepatitis genome was cloned in 1989 and was found to be the cause of 90% of the non-A and non-B hepatitis among recipients of blood transfusions.

HCV is a blood-borne virus that causes inflammation to the liver. Hepatic fibrosis occurs as a result of the host immune reaction to the virus. However, this progresses over decades rather than years. The virus also causes cirrhosis and can be the cause of primary liver cancer.

When looking at HIV patients co-infected with HCV, HCV has a deleterious effect on HIV progression and is associated with a quicker progression to AIDS or death. In addition, whereas 20–30% of HCV-mono-infected individuals will progress to cirrhosis over 15–30 years, HIV/HCV-co-infected individuals develop cirrhosis and cancer on average 10 years sooner. This has manifested itself in a proportional increase in the number of deaths from end-stage liver disease, and HCV has become one of the major causes of death among people with HIV [2].

HIV/HCV-co-infected individuals have a higher HCV viraemia than those mono-infected with HCV. This correlates both with CD4 count and amount of immunosuppressant. Co-infection is not helped by alcohol use, increased age at acquisition of HCV, or hepatitis B infection. For example, if the patient is over 40 years old at the time of acquiring HCV, the disease progression can be quicker [3].

Hepatocellular carcinoma (HCC) is thought to occur in 1–4% of individuals with HCV with related cirrhosis each year. This occurs within a shorter space of time and at an earlier age in individuals also infected with HIV [4].

Investigations

The normal clinical work for any HIV patient remains the same. Additional details required from co-infected patients include: any intravenous drug use past or current; any history of snorting drugs; any current and past alcohol use; any past or previous psychiatric illness, including any self harm or intentional suicide attempts irrespective of length of time since the event; any sexual intercourse with an individual infected either with HIV or HCV; the possible length of time the individual has been infected with either or both viruses; and their home circumstances and support network. Further tests include blood tests for HCV genotype and HCV viral load, and liver biopsy (depending on the centre protocol).

Hepatoxicity

Antiretroviral therapy has always had the potential to cause hepatoxicity. HCV causes a two- to three-fold increase in potential toxicity. However, closely monitored patients can manage HCV infection and HAART effectively. By contrast, all patients on any regimens with either didanosine, stavudine or zalcitabine will need a regimen change owing to the possibility of developing hypersensitivity, lactic acidosis and toxicity prior to commencing interferon therapy. Zidovudine can cause anaemia, and close monitoring of the patient's blood, especially full blood count, is essential. Nevirapine is associated with increased fibrosis; until further research has been carried out, nevirapine should only be used when absolutely necessary in co-infected patients [5].

Eligibility criteria

The patient must have a CD4 count above 200 cells/ml before initiating drug treatment. Below that level, the viral response is poor. The higher the CD4 count the better. However, the APRICOT (AIDS PEGASYS Ribavirin International co-infection Trial) study suggests that CD4 counts may not be a predictor of treatment success [6]. Patients should abstain from alcohol and keep their drug habit under control. Some centres treat current injecting drug users who are stable and others do not. Each treatment centre has its own protocol.

All vaccinations for hepatitis A and B need to be up to date. If the patient is on HAART, their regimen needs to be modified as above. The aim of the treatment is to have a 2-log drop unit in the HCV viral load at 12 weeks, with a sustained viral response after 6, 9 and 11 months of treatment. There should then be a sustained viral response at 6 months post-treatment and a sustained viral response at yearly intervals.

When considering treatment, if the HIV is stable then HCV treatment can commence. If the HIV is

unstable, the HIV is addressed first. It is important that patients are treated in a centre with expertise in both HIV and HCV. For those patients with advanced liver cirrhosis, close liaison with a hepatologist is vital.

Liver biopsy

Some centres no longer undertake a liver biopsy for genotype 2 and 3 patients. However, this is also decided on unit preference. Our criterion here in Manchester is to provide a liver biopsy for all HIV-positive patients, regardless of their genotype.

Treatment

Most centres dealing with co-infected patients treat them with pegylated interferon alpha 2a (pegasay) and ribavarin for 48 weeks: a subcutaneous (sc) injection once a week of 180 µg pegasay and 400 mg ribavarin twice-daily (bd) tablets morning and night.

Side effects

All patients will have some side effects. These include: weight loss of anything up to 2 st. over the treatment period; hair loss; nausea; and diarrhoea. Patients can become snappy and irritable with family and friends. They become tired and lethargic, and their sleeping pattern can become erratic. The loss of appetite is hard to manage as the ribavarin has to be taken with food; on an empty stomach, it causes gastric irritation. Any pre-existing skin problem can flare up, as can any previous herpes infection, both genital and facial. This treatment can increase mood swings and lead to depression, and patients can often become very weepy and emotional. They can also become neutropenic and develop thrombocytopenia.

Patients who are already on HAART need careful help and support to cope with the extra pill burden and the side effects. It must be stressed that HCV treatment is time limited. Initially, patients will require regular hospital visits to monitor their blood and to test for any toxicity, and patients will need to watch for any hypersensitivity.

Support for this group is very important and having knowledge of both HCV and HIV is vital. Patients should be able to contact the nurse during the day, with easily available and flexible clinic appointments, in order to discuss any issues they may have with both their HCV and HIV. Space and time are needed to talk through the issues so that the patient and nurse/doctor can make choices about when to start treatment.

When starting patients on treatment, they need to be informed that there can be a drop in their CD4 count. This is purely to do with the treatment and the effect it has on the immune system. Some patients hold great store by their CD4 counts and careful explanation of the effects of treatment on the CD4 count needs to be given. If the patient was stable prior to treatment, CD4 counts do not need to be measured more regularly than previously. In some cases, the CD4 count can drop up to 100 points.

Clearance rates

For co-infected patients with genotype 1, the clearance rate is about 29% on pegasay 180 µg sc weekly and ribavarin 400 mg bd. For genotype 2 and 3 patients, the clearance rate is around 62% with this same treatment.

Non-responders and relapsers

Treatment is limited for non-responders and relapsers. If they have been treated with normal interferon and not the new pegylated variety, it is worth giving them treatment with the new formulation. There are very limited data to show that a non-responder might benefit from maintenance therapy to slow the progression to cirrhosis and carcinoma. This is for mono-infected patients and is part of the HALT-C (Hepatitis C Antiviral Long-Term Treatment Against Cirrhosis) clinical trial. There are no data on co-infected patients who have failed therapy.

Concluding comments

Clinics and treatment centres around the country are seeing an increase in sexually acquired transmission of HCV. When initially screening clients, screening for HCV should be considered and, for those who are sexually active, screening should be undertaken once or twice a year. All consultations should include advice on transmission of HCV and the need to avoid this virus when infected with HIV.

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Living with HIV: why do so many die of preventable diseases?

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As diseases go, TB is ancient. It has been identified in Egyptian mummies from over 4000 years ago, although to actually see the bacterium responsible, *Mycobacterium tuberculosis*, medical science had to wait for the invention and development of the microscope in the 19th century. A TB vaccine was produced as early as the 1920s, and an effective antibiotic – in the form of streptomycin – by 1944.

Since then, TB chemotherapy has progressed, and despite current concerns about drug resistance, one would expect such a treatable and preventable infectious disease to be at least on the wane. However, current statistics suggest otherwise. Instead of being contained, TB continues to stalk the developing world in apparent contradiction of scientific advances. Each year, there are an estimated 8 million new cases of TB and nearly 2 million deaths [1].

This is due, at least in part, to HIV infection; there are thought to be around 10 million people co-infected with HIV and TB, 90% of these in developing countries. In most parts of the HIV-affected world, TB is the most common cause of death in people living with HIV/AIDS (PLWHA), accounting for 13% of all deaths – indeed, it is the most common disease associated with HIV infection. HIV diminishes the effectiveness of cell-mediated immunity, and the pathogenesis of TB is altered, leading to a rapid increase in progression; a co-infected person is 30–50 times more likely to become sick with TB than a person who is HIV negative. In regions where antiretroviral (ARV) therapy is available, it is thought to be associated with reduced rates of co-infection and reduced mortality, but elsewhere the picture is much less positive – especially with delays in ARV provision.

This article is not about TB *per se*, but the above is intended as a reminder of what is a shocking paradox of the HIV pandemic. While HIV remains incurable and we are many years from developing a successful vaccine, this disease is still partly treatable; however, many PLWHA are still dying of one of the oldest diseases in medical history – TB. The following discussion will describe a global campaign that aims to address this, and related features of the HIV paradox, by raising the profile on current and available interventions that if applied appropriately, could extend the lives of PLWHA – especially in areas where ARVs will not be available for some time.

Treatment

Year on year, new HIV infections continue to increase; recent figures confirm that the virus is not being contained in some regions [2], and it is the developing and middle-income regions that are – as always – hardest hit. In some regions, progress is being made, but the overall picture remains gloomy, an assessment brought into sharp relief by 'new' countries entering the HIV arena, such as China, and the apparent shift in Uganda away from encouraging condom use to promoting abstinence. There is one certainty – HIV is likely to be a major threat to world health for many more years to come.

Since the 1996 International AIDS Conference (IAC) in Vancouver, at which data demonstrating the benefits of ARVs, especially in combination, were presented, the provision of ARVs for PLWHA has become an increasingly dominant factor in the global HIV/AIDS strategy, as well as a potent area for advocacy. Geographical inequity, and the apparent intransigence of large pharmaceutical companies in providing adequate amounts of ARVs at a reasonable price – or hesitation in releasing the patents so that cheaper versions of medications can be produced within countries with a high burden of HIV/AIDS – has resulted in the huge disparities between the developed and developing world.

The need for further access to ARVs is undeniable – in 2005 alone, over 3 million people will die of HIV-related conditions, many of whom could have lived for much longer if access to treatments had been available. However, universal access is still many years away. Recently released figures noting the progress of the World Health Organization's '3 by 5' campaign to provide access for 3 million people by the end of 2005 [3] confirm there has been some improvement in the number of people receiving ARVs – currently standing at around 1 million. But this is short of the 3 million people who were the target of the campaign, and far short of the 6 million people estimated to require ARVs.

Providing universal access to ARVs is clearly a worthy cause, but is accompanied by many complexities. These are, in part, logistical, but are also related to the levels of testing and monitoring required for finding those people who would benefit

from ARVs. For some regions, these factors coalesce into a substantial delay in access to ARVs for PLWHA who would benefit from such medication. In this article, I do not intend to delve further into this still very much heated debate, which is discussed elsewhere (e.g. [4]). However, it is the delay in ARV provision which exposes PLWHA to opportunistic infections for a much longer period, and it is this 'window' – between diagnosis and the need for ARVs in response to low CD4 counts – that the global campaign, 'AIDS-Care-Watch' (ACW), hopes to address, and is discussed below.

ACW

ACW is a global civil society campaign that aims to highlight the need for a comprehensive package of care for PLWHA, and has been conceived to provide an avenue for treatment advocates worldwide to unite and advocate soundly for this need. The key principle underpinning the campaign is simply this: why must so many people die as they wait for ARVs? How can provision be made to keep people alive in what has been called, for some, the long walk to treatment? The campaign considers that in the continuing emphasis on ARVs, there is a 'hidden crisis' emerging, whereby PLWHA without access to ARVs are also not being given sufficient protection and treatment against opportunistic infections – most of which are preventable.

In developing countries in particular, PLWHA are exposed to many more potential opportunistic infections than elsewhere, and many of these can be treated. ACW identifies a number of factors which could, if targeted and facilitated as required, reduce the number of people dying of AIDS-related conditions in the absence of ARVs. These are listed in Panel 1.

None of the interventions listed in Panel 1 is novel, and all are likely to be part of current programmes. However, the campaign hopes that by raising awareness and tracking progress, together they can maximise the possibilities of survival for PLWHA in the absence of ARVs.

How is the campaign to do this? How can a full continuum of care be maintained for PLWHA? Over the duration of the campaign, there will be a concerted effort to collate evidence on the availability and quality of healthcare services available to PLWHA. In addition, the campaign will:

- Recognise and support the efforts of frontline workers;
- Identify critical opportunities and needs for improvements in health systems; and
- Hold relevant institutions and organisations to account against their explicit commitments on the provision of HIV/AIDS care.

It is the latter point that makes 2005 such an important year for global HIV strategies. There are two main reasons: the increasing dominance of the Millennium Development Goals (MDGs) in the discourse of international development, and the proximity of a major review in 2006 of the implementation of a declaration made in 2001 following the United Nations General Assembly Special Session on HIV/AIDS to achieve specific targets on HIV and AIDS within a certain timescale. The review is likely to provide positive as well as negative results if the problems in achieving the MDGs are an indication. The recent report of the United Nations Development Programme [5] and the MDG Report [6] confirmed that many of the MDGs, especially in Africa, are far from being met. Why is this so? Were the goals set with the full cognisance of affected nations? During the period 2005–2006, many governments and agencies will be called to account.

ACW and its partners aim to ensure widespread access to a comprehensive package of care, improving health literacy among PLWHA, and identifying and minimising the factors that accelerate the development of AIDS-related conditions. Healthcare workers – especially in developing countries – have a vital role to play, for in the delivery of care 'packages', a holistic perspective will help to protect the health of PLWHA, even in the absence of ARVs. Nursing and medical organisations are also ideally placed to lobby governments, so that health ministries consider research and funding into non-ARV care strategies until ARVs are widely available. All measures will

Panel 1: **Factors for reducing the number of people dying of AIDS-related conditions in the absence of ARVs**

- Treatment for TB and other opportunistic infections.
- Improving treatment literacy: ensuring that PLWHA are aware of treatments, alternatives and disease progression.
- Highlighting the need for quality home-based care.
- Increasing the reach and effectiveness of voluntary counselling and testing.
- The provision of clean water and adequate nutrition.
- Maximising harm reduction.
- Ensuring traditional healing and treatment approaches are available.
- Reduce HIV stigma.

contribute towards the health of PLWHA in what in some regions is becoming a much longer walk to ARV treatment than was expected.

In 2004, at the International AIDS Conference in Bangkok, Nelson Mandela said that 'TB is often a death sentence for people with AIDS. It does not have to be this way.' ACW intends to ensure that the 'crisis' that includes the many PLWHA dying of TB, and the millions more exposed to an environment in which their health as a PLWHA is under threat, is hidden no more. The question: 'how can these millions of people stay alive while they are waiting for ARVs?' must be asked at all levels of civil society.

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More information about ACW can be found at www.aidscarewatch.org

For more information about becoming a partner to the campaign, contact Abigail Erikson on: abigail@aidscarewatch.org

TB and HIV co-infection

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TB has been recognised since the dawn of recorded history. The earliest evidence of TB in humans is from a Neolithic grave in Germany, dating as far back as 5000 BC. By the mid-17th century, TB ('consumption') was responsible for one in five deaths, becoming known as the 'white plague'. However, with the introduction of anti-TB chemotherapy in the 1960s and the discovery of the BCG vaccination, there was a rapid decline in TB disease and deaths, and this continued for 40 years in the UK. HIV, by contrast, is a 'new kid on the block'. First reported in California in 1981, when five young men were admitted to various hospitals suffering from an atypical pneumonia caused by the commonly occurring microorganism *Pneumocystis carinii*, HIV has gone on to infect more than 42 million individuals worldwide and kill more than 20 million [1]. Over the past 20 years, HIV infection has emerged as the most important predisposing factor for developing overt TB in people co-infected with *Mycobacterium tuberculosis* (MTB) [2]. Without a doubt, HIV has had a profound impact on the epidemiology, natural history and clinical presentation of TB.

Epidemiology

The World Health Organization estimates that there are 2 billion people, a third of the world's population, infected with MTB, resulting in approximately 8 million new cases of TB disease and nearly 2 million deaths annually. It has been estimated that approximately 10 million people are co-infected with MTB and HIV, and more than 90% of those with co-infection reside in developing countries. From another perspective, approximately a third of the 40 million people who are infected with HIV are co-infected with MTB. In some areas of sub-Saharan Africa, more than 60% of patients with TB are infected with HIV [3]. However, in the UK, even though the national rate is much lower in comparison to the rest of the world, we face our own mini-pandemic, particularly in the capital. There are, on average, 7000 new cases of TB nationally every year. Since 1997, there has been a slow but steady increase in the number of TB cases reported annually. London is now considered a global hotspot for TB, with nearly half of all UK cases residing there. In some parts of London, TB rates are 10 times the national rate – higher than in some countries of the former Soviet Union. It is estimated that approximately 10% of London TB patients are co-infected with HIV [4].

In the general population, if an individual has latent TB infection, their natural defences prevent the TB from causing active disease. However, if their defences have been damaged by HIV infection, it is unlikely that the TB will be kept under control. HIV-positive individuals with latent TB infection have a 5–10% annual risk of developing active disease, a risk that approximates the lifetime risk in HIV-negative individuals with latent TB infection. The risk of primary progressive TB in HIV-positive individuals is as high as 40%, compared with approximately 5% in the HIV-negative population. In fact, there are countless complications associated with co-infection with TB/HIV, despite adequate TB therapy. First, TB is more difficult to diagnose in HIV-positive individuals – for reasons which will be explained in the next section. Second, TB progresses faster in those infected with HIV and can occur earlier in HIV infection than other opportunistic infections, regardless of CD4 count [5]. In an HIV-positive individual, TB is more likely to be fatal if undiagnosed or left untreated. Finally, TB is the only AIDS-related opportunistic infection which poses a risk to the general population. It has also been recently shown that the risk of developing TB is already significantly increased in the first year following HIV infection [6].

Clinical presentation

As previously mentioned, infection with HIV can make TB difficult to diagnose, depending on the stage of immunodeficiency. In the early stages of HIV infection, the clinical manifestation resembles that of TB disease in HIV-seronegative individuals, with fever, night sweats, weight loss and malaise commonly occurring. The chest radiograph frequently reveals typical apical infiltrates and cavitary disease, and sputum smears generally demonstrate the presence of acid-fast bacilli, indicating infectious pulmonary TB. TB is often the initial manifestation of HIV disease, causing significant distress for the patient dealing with a dual diagnosis of two stigmatising diseases.

However, in the setting of advanced HIV infection, TB often presents atypically, with extrapulmonary disease being a prominent feature. Bronchopulmonary symptoms such as cough and haemoptysis are often absent in patients with progressive immunodeficiency. The chest radiograph may reveal atypical infiltrates, pleural effusion or, indeed, may reveal no abnormality at all. This is because their inflammatory reaction is reduced and subsequently there is less cavitation of pulmonary lesions. As there is less cavitation, fewer tubercle bacilli gain access to the sputum,

and, consequently, patients generally have a lower acid-fast bacilli burden in the sputum, and therefore are generally less infectious than non-HIV-infected individuals with active pulmonary TB [7]. If the patient is immunocompromised, it is important that clinical specimens other than sputum are submitted for culture when non-pulmonary TB is suspected – for example, urine, blood, cerebrospinal fluid, pleural and pericardial fluid or biopsy specimens. The use of tuberculin skin testing in the presence of HIV infection is debatable, owing to its lack of sensitivity and poor specificity, particularly in the presence of moderate to severe immunodeficiency. More recent diagnostic developments include the ELISPOT and QUANTIFERON blood tests. These detect the secretion of γ-interferon by cells that are specific for MTB antigens. It seems that these tests are more sensitive and specific than skin testing; however, it remains to be seen how useful they are in patients with severe immunodeficiency.

Case study: DS

This case involved a 36-year-old man from Rwanda who was admitted to hospital via the accident and emergency department complaining of a 4-month history of weight loss, fevers, diarrhoea and general malaise. He had an intermittent cough but was not unduly concerned about this. He denied TB contact and he also denied any history of high-risk sexual behaviour.

He was unable to produce a sputum sample for 2 days, so an induced sample was obtained, which 1 day later showed acid-fast bacilli on smear microscopy. The patient was commenced on standard quadruple therapy comprising rifampicin, isoniazid, pyrazinamide and ethambutol. The patient was already in respiratory isolation as a result of his symptoms, and this strategy was continued.

The patient was approached the following day about HIV testing, in accordance with the hospital TB policy, but he refused, stating that he did not partake in high-risk activity. He remained in hospital for a further 2 weeks and was discharged home, where he would take his TB medication unsupervised.

His sputum sample culture after 5 weeks confirmed fully drug-sensitive MTB. When he next attended an outpatient appointment, HIV testing was again broached, and again the patient remained very defensive. It was on his next visit that the patient himself requested an HIV antibody test. This was done and was found to be positive. Further blood tests showed a CD4 count of 16 cells/ml and an HIV viral load of >500,000 copies/ml.

While all of this was taking place, the patient had also been refused asylum status in the country and was in the process of appealing. He was commenced on first-line antiretroviral therapy comprising tenofovir, lamivudine and an increased dose of efavirenz to compensate for the reduction in plasma levels of this agent when co-administered with rifampicin.

He received monthly follow-up for the duration of his TB treatment, and during this time his CD4 count rose to 120 cells/ml and his viral load dropped to below the level of detection.

Approximately 3 months after completing treatment, the patient presented to the HIV service having lost 5 kg in the previous month and was feeling very unwell. His surrogate markers showed that his CD4 count had dropped to 45 cells/ml and his viral load had risen to 280,000 copies/ml. The patient eventually admitted to poor adherence to his antiretroviral therapy and ongoing significant alcohol intake. He was investigated thoroughly for his rapid weight loss while an in-patient, and nothing abnormal was detected. He then had a bronchoscopy from which bronchial washings were taken, and these showed acid-fast bacilli on smear microscopy.

It was debated whether the patient had immune reconstitution inflammatory syndrome; however, he was commenced on treatment for presumptive drug-resistant TB. The patient initially denied any barriers to adherence to his first TB regimen, although he later disclosed that he missed a significant number of doses due to his excessive alcohol intake. He was advised that directly observed therapy would be provided at the hospital for this second regimen; he was referred to a specialist HIV community nurse for ongoing adherence support with his antiretroviral therapy and was referred to the community alcohol support services. He subsequently attended three times per week for directly observed therapy. His sputum culture confirmed multi-drug resistant TB and he has now completed 18 months of treatment. His CD4 count has risen to 110 cells/ml and his HIV viral load has been undetectable throughout treatment.

His asylum status has not yet been decided and he is currently being counselled regarding informing his wife and children at home about his HIV status, as they are as yet unaware and have not been tested.

Conclusion

There are many other aspects of TB and HIV co-infection which could be discussed at length, including the treatment of both and the problems this brings with it; the phenomenon of immune reconstitution inflammatory syndrome; the benefit of directly observed therapy; and, of course, the worsening problem of multi-drug resistance. However, these are all articles in their own right, and time and word constraints do not allow me to discuss them here. Suffice to say that TB remains a significant ongoing threat and, when co-existing with HIV infection, as so eloquently expressed by Robert Pratt [8], we are faced with 'truly the terrible synergistic twins of the AIDS pandemic'.

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Living stories: the haemophilia and HIV life history project

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Introduction: the haemophilia and HIV life history project

Thirty people with haemophilia and HIV volunteered to tell their story for a life history project. The project was financed by Heritage Lottery Fund, and based at Brighton University; the recordings are stored at The British Library Sound Archive. The aim of the haemophilia and HIV life history project was to enable and encourage people to record their views and memories of the events and experiences that surrounded this dramatic moment in National Health Service (NHS) history and to set up a rich resource which could be preserved for the future. Over the years, doctors, social scientists and journalists in the UK and elsewhere have written extensively about the social, medical, legal, political and psychological issues surrounding the infection of people with haemophilia [1–12], but the voices of people with haemophilia and HIV (those most intimately involved) have rarely been heard. This project will ensure that the views and feelings of people with haemophilia and HIV will now form a lasting contribution towards the documented history of HIV in the UK.

Over an 18-month period from September 2003, 30 in-depth life history interviews were recorded and transcribed. Interviews lasted from 3 to 10 hours, often over a number of days, and allowed people to recollect in their own way the experiences and emotions of their past. The 30 people involved in the project represent the experiences of people who were diagnosed with HIV at different stages in their lives, live in different parts of the country and attend different healthcare establishments, and they include people who have been particularly vocal about their experiences and others who have remained silent. Joseph was one of the 30 volunteers to tell his story:

> 'Haemophilia, for all its severity, was never a challenge that I imagined I would lose to. I always believed that I could fight back from any bleed, and I could always make life work in my favour; there was always a real self-belief, a determination and a positiveness. But HIV and hepatitis … they had such a profound change on the way I could deal with my haemophilia and, more importantly, was the psychological blow' [13].

Joseph was infected with HIV through factor VIII, the medical treatment he received from the NHS to control the muscle and joint bleeds he suffered because of his haemophilia. Joseph was diagnosed with HIV in 1985, along with 1246 other people in the UK, at 18 years old. The ages of those with haemophilia who were infected with HIV ranged from 9 months to 60 years [14]. Remembering the time of his HIV diagnosis Joseph continues:

> 'When we first found out, and we understood that it was linked with AIDS, there was a great deal of depression, real depression. The purpose out of life had kind of almost gone out of the window, and all the fighting up to that point to overcome the haemophilia side had seemed sort of pretty pointless. And all these ideas where I'd been planning a future, that had suddenly seemed so bright, because I'd got treatment for my haemophilia … they all kind of evaporated really' [13].

Oral history and health

Oral history has been defined as 'the interviewing of eye witness participants in the events of the past for the purposes of historical reconstruction' [15]. Oral history provides a meaningful narrative of past events by asking those involved, often those whose voices are rarely heard, to share their experiences and emotions, and it ensures that those voices sit beside the more traditional resources more commonly used in the documentation of history.

Over the last 20 years, there has been an increase in the use of oral history by many disciplines to improve understanding of health and illness. For an excellent overview of life history or 'biographical' methods in health studies see article by Rickard [16]. Despite this increasing use of oral testimony in the study of health and illness, it is the voices of health professionals that still tend to be heard and used far more than the voices of the service users. For example, Thompson celebrates the emergence and acknowledgement of oral history in relation to healthcare [17], but the references he presents are dominated by physicians and providers of care, and accounts from the users of healthcare services are notably absent. Patient accounts that are used tend to be presented as isolated, individual voices, rather than as part of a rigorous life history study of a collective experience. Thompson emphasises how important it is to collect oral histories from service

users as well as professionals: 'to include a users perspective of health and welfare in today's practice of oral history is not simply a question of adding a complementary source to match documented evidence, it is more likely to challenge and subvert understanding of care and control, the boundaries between health and welfare, the location of centres and margins and notions of status and eligibility in all sectors of society and conditions of life' [17].

Oral history and HIV/AIDS

For the HIV/AIDS epidemic, the voices of patients have probably been more readily utilised than in any other health condition. A number of histories [18–21] use personal narratives to better explain and understand the history of the epidemic. However, the construction of this history is still dominated by the views and the experiences of medical practitioners and scientists. Rickard's work in the late 1990s sought to address this imbalance in the UK [22]. The HIV/AIDS Testimonies Project, a series of 40 interviews with people infected with HIV and unwell with AIDS, was not concerned with the views of healthcare professionals or the history of the medical advances, but was entirely focussed on the experiences of people with HIV/AIDS and on how those experiences shaped their lives.

Rickard's HIV life history work has been highly influential in the planning of the haemophilia and HIV project. A separate heamophilia and HIV collection was considered appropriate because of the many different and specific medical, social and political issues that emerged.

Thematic analysis of the life history data

The haemophilia and HIV life history project provides social and healthcare workers with a resource to understand the multitude of issues that arise for patients living with HIV for over 20 years. Life history research allows the interviewee to construct their own in-depth narrative from which themes may emerge which can enlighten and inform us about the individual and the collective experience. There is no hypothesis to prove or disprove but instead a dense resource of life experiences and the meanings and emotions that people attach to those experiences. Thematic and narrative analysis of the interviews generates a wealth of information and insight. The narratives are from people with haemophilia and HIV, but the stories and the meanings attached to them can offer healthcare workers in a variety of specialities an enhanced understanding of how adults and children face imminent death and chronic illness.

The haemophilia and HIV life history collection illuminates the events surrounding HIV diagnosis: how people with haemophilia or their parents were informed and how that process and subsequent events were influenced by the media portrayal of the epidemic. The accounts explain and illustrate the impact of HIV on friendships, family dynamics, current and new relationships, school, work, sex and parenting. Common to the life histories in the haemophilia and HIV collection, but distinct from many other HIV life histories, are the reflections from patients on their sometimes challenging relationship with a healthcare service that prescribed the medical treatment that infected them. Other distinctive issues for this group of people include the government recompense payout to those with haemophilia; issues of co-infection with hepatitis B, hepatitis C and, potentially, Creutzfeldt-Jakob disease (CJD); and specific HIV drug interactions and side effects associated with other underlying conditions. Many of the narrators were children when infected with HIV and are able to recount their experiences from the perspective of an adolescent. Additionally, many interviewees tell of their brothers and other male family members who were also infected (haemophilia is an X-linked, recessive disorder, therefore generally only males suffer the symptoms) – some alive and some who have died. These life histories, from people infected for over 20 years, offer clear insight into the constant re-adjustment required for living with HIV for that length of time. These people explain how, after being given just a few years to live in 1985, in the latter part of the 1990s they had to reconsider a future that they did not expect to have.

A changing sense of mortality

Focussing briefly on one prevelant theme from the life history interviews – the changing sense of mortality – we will illustrate the richness and value of life history data. All the interviewees discuss the difficult process of re-adjusting to their changing life expectancy. For older patients, this changing life expectancy was repeated throughout their lives. Supporting people through such re-adjustment is a strange and unfamiliar territory for healthcare workers and this role, in relation to people with HIV or with other chronic illness, can be enhanced by the understanding provided by patient life history accounts [23].

> 'And it's been good now that the last couple [of haemophilia and HIV events] we went to … no one's died. All the same faces are still there. And that's quite nice, to think that we've come through that period of time, and, I think there's only been one death, or two deaths this year, which is nice, and, it's good to see that people are now having to make different choices. From the early days, do I go to Australia, and do I go white-water rafting down the Grand Canyon? to now, oh shit! I need to think about going back to work if I'm going to be well' [24].

The reference by Gareth to only one or two deaths among his peers in the last few years as 'nice' is not intended to be ironic; coming from a man still in his forties this extract shows not only the massive impact of HIV treatment on the altered life expectancy of people with HIV [11], but also the normalisation of death and bereavement among this group of people. Gareth light-heartedly encapsulates the difference in thinking over 20 years, from trying to fit in important experiences before death, to coping with an unexpected future. Many people interviewed reflected on this change of attitude from the past; waiting to die, to their present; planning a future. The birth of children is a particular landmark.

> '… when Jessica was born, I thought, you're not going to see her live. You're not going to see her 5th birthday and then you're not going to see her 10th birthday. And she was 18 last week and I'm still here' [25].

For many people with haemophilia, HIV was not the first potentially life-threatening condition that they had to contend with. Prior to the availability of effective blood clotting products, people with severe haemophilia were considered very fortunate to live into adulthood. Even now, when effective clotting treatment is available, haemophilia can still be fatal, particularly due to cerebral haemorrhage. David, the eldest participant in the project born in 1935, recalls his childhood:

> 'I would spend an average of 6 to 7 months in hospital … in a year … for the first 10, 12 years of my life or more…. in many ways, it has been a journey from darkness into light, because my childhood was full of darkness of pain and illness and that sort of thing. So haemophilia was very severe in those days. It was life-threatening. On several occasions I almost died, and my parents were called in, thinking I was going to die' [26].

Later in the interview David says:

> 'Well, I'm 70 now. When I was born, the average age of a haemophiliac was 18 years. My parents would be astounded to see me still alive' [26].

With the widespread introduction of clotting concentrates in the 1970s [12], people with haemophilia experienced a dramatic change in their lifestyle and their life expectancy. Factor concentrates, available as a self-administered home treatment, offered a new sense of independence and relief from hospital admissions. With the advent of prophylaxis management, people with haemophilia could lead a relatively normal life.

By the early 1980s, it became clear that the revolutionary treatment that had made such a positive impact on the lives of those with haemophilia was to have devastating consequences, although initially the extent of the damage was underestimated.

> 'The information was that the risks of catching the virus that causes AIDS was so minimal and the damage that could be done to joints could be avoided by using factor VIII. Doctors were saying, "Carry on using the treatment", I've got booklets … that say all these things, "Do not stop using Factor, it is only a minimal risk, it is only likely to be less than one in a thousand people with haemophilia will be infected with HIV". And the reality was, it was one in three' [27].

Every single interviewee refers to the likely prospect of death at the point of HIV diagnosis. During 1985, when almost all of the participants were diagnosed, HIV was perceived and portrayed as fatal with no prospect of recovery. The impact of an impending death that AIDS signified at the time is difficult to overstate, and the change in world view is elegantly explained by Mark:

> '… the early years in London, my horizons were expanding in all respects. Had a good future to look forward to and that comes crashing in on you with an HIV diagnosis and you know that at some point you're gonna become very ill and die very quickly and very nastily' [28].

For most people interviewed it was the 'knowledge' of an imminent death that had a direct and immediate impact rather than ill health caused by HIV. How do people live their lives when they believe they have only a few years to live?

> 'But, for a few years there was nothing to talk about. We were just going to die. We'd been given this virus that was going to kill us, so, you had to make choices pretty quick on how you were going to deal with it' [24].

> 'You're in school talking about career options and stuff like that. What can I do? I nearly died a couple of months beforehand and now the people were talking to me about career options' [29].

For many people with haemophilia and HIV the prediction was correct, and by 1990 nearly a quarter of those diagnosed in 1985 had died [14]. The accounts of people interviewed include memories about their friends, brothers and uncles who died in the early years. Witnessing the deaths of friends and close family members made waiting for death even more difficult, distressing and confusing. The life histories illustrate how the experience of waiting to die could change over time. Haydn and his brother were infected as young adults. Haydn was married with two young children; his wife also became infected.

> 'As the years progressed you would think that you'd become more at ease with it because you seemed okay but it didn't seem to work that way, it worked in completely the opposite way, you became more anxious. Because you

> thought, right that's 5 years I'm counting … it's got to be next year then, and then that year would pass and then you'd think, well that's another year. It took it seemed like eternity before I did start to think that maybe I could plan next year ahead of us' [30].

Then, with the advent of combination therapy in 1997, 12 years after their HIV diagnosis, another re-adjustment, this time to a possible though never certain future. That latter adjustment was easier for some than others. Suresh and his elder brother were both infected with HIV late in their teens. The eldest brother died just before they were to start on HIV therapy. Suresh explains the difficulties of re-adjusting to the prospect of a future:

> 'Then I went on triple therapy and I actually improved. And that gives you faith that yeah, there will be a tomorrow … The sad fact is that my friends and I haven't prepared for tomorrow. Because we weren't given tomorrow, we were just given today and that was it …' [31].

Similarly, Ian realises that this new 'future' presented some very real complexities:

> 'So, as I say, physically I was getting better, mentally I was in a real funny place. Because I was thinking, what do you do with this time?... At the end of the day Dianne had been used to idea that I wasn't going to be there and we struggled with something that should have been really happy, which was that there was a future. We had a future but we didn't know what to do with it …' [32].

Ben was diagnosed with HIV at aged 6, informed at 12 and spent most of his teenage life seriously unwell with AIDS-related illnesses. Since he started on antiretroviral therapy Ben has remained well, but ill health and assumptions about an imminent death have had a profound impact on how he now constructs a future for himself.

> 'When I was young, like I said, any achievement I seem to have made just got dashed on the rocks by some sort of illness. So when I was a kid I sort of gave up. I haven't given up on life it's like I've given up on a future' [33].

Conclusion

This project represents 400 people who have lived through a dramatic history and who are still faced with the challenge of managing their haemophilia, a number of chronic infections – HIV, hepatitis B, hepatitis C and possibly CJD – and the complexities of multiple treatment regimens. HIV infection is now manageable and people with haemophilia, like so many others with HIV, are now furthering their education, returning to work and re-considering long-term relationships and children. These stories should remind us that patients present to the health service with a complex past. Many people are still experiencing great sadness and loss, anger and blame while they re-adjust and re-assess their future.

Despite the trauma in remembering past events and the painful awareness that those past events are still shaping their current lives, those interviewed express immense gratitude and pride that their stories will become part of the recorded history of HIV in the UK.

> 'I think for me it's just the fact that there's gonna be a lasting memory of a good portion of haemophiliacs who have gone through the same as me. Yeah, we've had little media stories here and there, but nobody really knows the whole truth of what's happened, nobody really knows the whole story and nobody really knows how we all have gone through it and what's happened to us. Whereas this is a sort of an everlasting audio documentary … and I think this is probably the only thing that will still be there when we've all gone' [34].

It has been impossible in this article to present the depth and the breath of experiences and emotions that people recounted throughout their interviews. It is likely that future written publications will focus on individual themes. For readers who would like more information about the content of the interviews, a summary of each interview can be accessed from the British Library on-line catalogue [35] and entire interviews can be heard, in accordance with the expressed wishes of participants, at the British Library Sound Archive at Kings Cross in London. On World AIDS Day, 1st December 2005, the Living Stories website will be launched (www.livingstories.org.uk). The website will present a selection of profiles of people with haemophilia and HIV involved in the project and will illustrate key themes using audio extracts from the interviews.

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Third International AIDS Society Conference on HIV Pathogenesis and Treatment

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The third International AIDS Society (IAS) Conference, held in Rio de Janeiro, Brazil, on 24–27 July 2005, was the first international conference I have attended and I thoroughly enjoyed the experience. I admit I wasn't so thrilled by the two attempted robberies in my first hour in Rio but I got off lightly compared with some delegates who were mugged at knife-point!

Before delving into the specifics, a brief word on two overriding impressions of the conference. First, where were all the nurses? I met one nurse from the USA and she herself had not met any others. This was a scientific conference and perhaps nurses are not asked to attend or do not request to go, either through lack of funding or time. However, with our unique place in the multi-disciplinary team, together with our ever-extending role in nurse-led clinics and prescribing, we should be there to hear first hand the latest information in the field. My second general impression was of the dichotomy in delegates attending the sessions on prevention compared with those attending the sessions on treatment. It appeared to me that those attending the prevention sessions were mainly delegates from the developing world, whereas those attending the treatment sessions were mainly from the developed world. This made me consider what the focus of our management of the epidemic is in the developing world. Could it be that we think that while we have treatment we don't need to look at prevention developments?

The major highlight in prevention was the impact of male circumcision on the female-to-male transmission of HIV [1]. This study, carried out in South Africa, constitutes the first randomised controlled trial of circumcision as an HIV prevention measure. Circumcision was performed by a doctor on over 3000 men aged 16–24; the men were tested for HIV and their sexual histories were taken every 3 months for 21 months. The control arm had the same screening without circumcision. At the end of the study, 18 HIV seroconversions had occurred in the circumcision arm and 51 in the control arm, showing that circumcision provides 65% protection against HIV in female-to-male transmission.

The major area discussed with regards to treatment was an update on trials using chemokine receptor CCR5 antagonists, with presentations and posters from three pharmaceutical companies. These seem hopeful, with phase I and IIa trials nearing completion. These drugs will prevent the attachment of HIV onto CD4 cells. The drugs were presented as synergistic with antiretroviral therapies currently in use, and can potentially be boosted with ritonavir and possible once-daily dosings. There are concerns regarding side effects, with one company reporting seizures in animal trials and another reporting flatulence and postural hypotension. There had been concern that CCR5 antagonists could cause an emergence of CXCR4-tropic virus, but this does not appear to be happening.

A satellite symposium was held to discuss women and gender-based violence. Research was presented showing gender-based violence as a cause of HIV infection [2], whereby women are at greater risk through forced or coercive sex because their ability to negotiate prevention behaviours is limited [3] and whereby childhood sexual abuse can lead to an increase in HIV risk-taking behaviour [4]. A rape victim explained that the rape was not the cause of her HIV but that the consequential self-hatred resulted in risky sexual behaviour and HIV infection. Much data were also presented showing that women experience violence as a consequence of disclosure of HIV; this included a study in the USA where 18% of HIV-positive women reported disclosure-related violence [5].

Non-occupational post-exposure prophylaxis is a regimen of drugs given for 4–6 weeks to people who have been exposed to HIV, usually sexually but potentially via needles too. There is no research to show its benefits (for obvious ethical reasons) but it is available in most treatment centres when requested.

A poster from St Thomas' Hospital, London, looked at non-occupational post-exposure prophylaxis (PEP) in a retrospective review of clients attending clinic from January 2000 until November 2004. They reported no seroconversions and increasing numbers of PEP prescriptions, and expressed concern that there is a reliance on PEP as HIV prevention in some clients. They recommended that PEP be managed by adherence nurses on the genitourinary (GU) clinic to overcome problems of follow-up and documentation. A poster presented by University College London Hospital Mortimer Market Centre described a survey on awareness of PEP in HIV-positive and HIV-negative gay men attending their GU clinic. They showed people were relatively unaware of PEP,

with only 19% reporting having discussed it with their doctors. They also found that HIV-positive men were not discussing PEP with their partners and 12% said they would not take PEP even if offered.

Chelsea and Westminster Healthcare NHS Trust, London, presented a poster reporting significant thyroid disease in HIV-infected individuals receiving highly active antiretroviral therapy (HAART). Hyperthyroid disease was associated with protease inhibitors and hypothyroid disease was associated with non-nucleoside reverse transcriptase inhibitors (NNRTIs). This was not related to CD4 count.

I attended a session titled 'HIV/TB co-infection: new visions, new directions'. Sadly, this involved an hour of very concerning statistics about the levels of TB in the world and how this is being driven by infection with HIV. There seemed to be no new visions or directions, just a cry for us to work together more.

IAS was an amazing experience, both of mind-blowing science and of soul-searching about my practice. Nurses: do make every effort to get to any similar events.

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NHIVNA update

Well the summer is over but as we enter a new season the Executive Committee is looking forward to progressing to a new stage in NHIVNA's growth and development.

In November we will be planning the programme for next year's conference. The date is set for 29–30 June 2006, the venue is almost confirmed for Leeds and we are currently exploring some different options. We hope to keep the registration fees at 2005 prices and also we want to offer a variety of accommodation options depending on your budgets and level of funding – that way we hope to encourage more delegates to attend. Do put the date in your diaries and also start planning early when looking for funding – most pharmaceutical companies are planning their expenditure now, so make sure you get your requests in early!

If you require any further information on the conference contact Andy Rogers at Mediscript Ltd at andy@mediscript.ltd.uk, but you will receive the first announcement in November.

We are also changing how NHIVNA is funded and supported by our pharmaceutical sponsors; it is anticipated that this new level of funding will support NHIVNA to undertake more activities in line with our aims of providing education, research and support for nurses.

It is the time of year when you will be receiving your membership renewal forms – I hope that you find membership of NHIVNA to be of value. Please do not forget you get free subscription to *AIDS Treatment Update*, *HIV Nursing*, *NHIVNA Newsletter*, access to free study days across the country and grants and scholarships – well worth the £35.00. Do encourage colleagues to become members. The greater our membership, the greater our voice on a national and international level.

We are still looking for volunteers to work on the *HIV Nursing* competencies subgroups, we are looking for nurses across the country and from all areas of HIV nursing, for example: in- and out-patient care, community, research, women and children. If you are interested then please contact Jacqueline English at Mediscript Ltd at jacqueline@mediscript.ltd.uk. Jacqueline will forward your details to the steering group.

Many thanks to those who applied to be a member on the Executive Committee – I found it heartening that there were so many of you out there who want to be a part of the Association. We were particularly looking for a member who had an educational component to their role. I have pleasure in welcoming Siân Edwards to the committee. Siân is a Lecturer Practitioner in HIV/Sexual Health at Brighton University and has many years experience as a nurse in HIV, working overseas in Africa and also with patients with haemophilia in the UK. We are hoping that the other applicants will work with NHIVNA on the *HIV Nursing* Competencies.

Nicky Perry, Chair, NHIVNA, Brighton

HIV NURSING

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