

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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Health promotion

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Reflecting on the year and our daily practice, we are continually reminded that HIV is now a treatable medical condition, with the majority of those living with the virus remaining fit and well on treatment. This has also been a year where increasing importance and attention have been placed on improving the general health of our patients: from facilitating increased HIV testing in all healthcare settings [1,2]; to earlier treatment of HIV once the CD4 cell count has fallen below 350 cells/mm³, thus reducing morbidity and mortality [3,4]; and further published data that reminds us that not all antiretroviral treatments are the same [3,5,6]. The promotion and prevention of adverse effects on health and well-being is both a NHIVNA generic HIV Nursing competency and core KSF (Knowledge and Skills Frameworks) competency. This issue of *HIV Nursing* seeks to demonstrate how HIV nurses are incorporating this into their daily practice to improve the long-term health of their patients.

The first article by Simon Farnworth looks at smoking amongst people living within HIV. He discusses the links between smoking addiction, HIV, cardiovascular health and lifestyle and describes how an innovative smoking cessation clinic was established within his service. Through collaboration with the NHS smoking cessation team and developing competence in the required skills and knowledge, Simon illustrates how the relationships established through HIV care can be used to assist patients in their quest to stop smoking.

The theme of maintenance and improvement in the cardiovascular health of people living longer with HIV is continued in our second article by Clare Stradling. Clare looks at why people with HIV infection are more likely to have heart disease and provides practical knowledge on lifestyle changes that nurses can impart to patients to assist in reducing their risk of cardiovascular disease.

Matthew Grundy-Bowers focuses on sexual health and highlights that that poor sexual health disproportionately affects men who have sex with men (MSM) and women. In his article, Matthew reflects upon national guidelines, both governmental and professional, to improve the sexual health of people with HIV and provides us with a comprehensive practical overview of the key issues that nurses should be aware of and raise with patients.

The very recent publication of the UK's HIV testing guidelines [1] has reminded us that, in spite of over quarter of a century of HIV, we have still made little impact in diagnosing the undiagnosed. In our fourth article, Catrin Evans provides a stark reminder of the continuing difference between continents in HIV diagnosis and treatment. Only 10-12% of people living with HIV in sub-Saharan Africa know their status [7] and there is also the disturbing similarity that many opportunities to diagnose HIV continue to be missed during routine medical encounters [7]. Catrin describes the rationale, evidence for, and concerns about provider-initiated HIV testing and counselling (PITC) in sub-Saharan Africa, giving us an understanding of the opportunities and challenges PITC presents for nurses.

In the last article, Ian Hodgson picks up on *HIV Nursing* 8.1, which considered different aspects of nursing research. In his article, Ian reflects on his NHIVNA grant sponsored trip to Swaziland to collect qualitative research data.

Happy reading!

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HIV and smoking cessation

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It has been said many times, and in many ways, but there is no escaping the fact that the dynamics and nature of caring for our patient population has changed immeasurably since the advent of antiretroviral therapy. We are seeing an ageing patient population as increasingly effective treatments prolong life expectancy. In the UK alone, 10% of patients are over the age of 50 [1]. The phenomenon of diagnosis being made at a much older age is now emerging, and three-quarters of those patients over 50 will have been diagnosed within the last 10 years. A further 40% are over the age of 40. Cardiovascular disease, as well as a range of age-related diseases, has emerged as a major risk to the health of our cohort of patients and has fast become a marker by which we judge the quality of life and future longevity of those infected with HIV.

Further complicating the cardiovascular risk is the high number of smokers amongst the HIV patient population. Analysis of DAD cohort study data [2] showed that 52% of the patients in the study population were smokers. This is in comparison to 25% of the general population in the UK who are smokers [3]. Information from other studies in the USA and Europe puts the figure as high as 72% of those with HIV being current or ex-smokers. It has been further demonstrated that more than half of those over 50 years of age were smokers [4]. I do not have the exact figures for the smoking rate amongst my own patient cohort but judging by the number of times I have gone to call a patient from the waiting room only to find that they have 'popped out for a ciggie', I would assume it is equally as large! I'm sure this is something echoed in other HIV clinics around the country.

Studies of HIV-positive smokers in the post-HAART era have also demonstrated increased respiratory illness, decreased quality of life and significantly increased mortality [5]. Emerging evidence also demonstrates a link to increased risk of HIV acquisition and seroconversion, probably due to lowered antibody response [6]. Faster HIV progression has been suggested but has yet to be effectively demonstrated. Smokers in the general population have a 1.5-fold increased risk of cardiac disease while those in the HIV-positive population have a twofold increased risk [2]. In addition, 42% of patients with reported myocardial infarction amongst the DAD cohort were smokers [2]. Smoking represented the largest risk factor. Add to this the increased risk of a range of cancers and lung disease and we can see what we are potentially facing. Smoking remains the single, most

preventable cause of death. A review of metabolic and cardiovascular risks affecting patients with HIV published in the *New England Journal of Medicine* [7] concluded that stopping smoking was more likely to reduce cardiovascular risk in patients with HIV than either switching treatment or commencing of lipid-lowering agents.

Smoking is, however, a highly complex and powerful addiction. Studies have shown that 70% of smokers report wishing to stop, while 30% attempt to quit smoking each year. However, only 2–3% will succeed when attempting to quit through will-power alone. When a smoker quits as part of a smoking-cessation programme with nicotine replacement therapy and multiple one-to-one interventions, it has been demonstrated that smokers are 10 times more likely to succeed. It is on this evidence that smoking-cessation services are based, and they form the cornerstone of local and governmental public health targets to help smokers quit.

As we can see, there is a very real need for smoking-cessation services aimed at the HIV patient cohort, yet from current evidence, there seems to be a lack of such services or at least an understanding of how to access them. The clinical audit report published by BHIVA in 2006 [8] showed that only 37% of clinicians questioned in 137 HIV centres nationally felt that they had sufficient access to smoking-cessation services. It is also stated in the audit that access to smoking-cessation services was essential in light of the cardiovascular and respiratory risk of those with HIV.

As a nurse specialising in HIV over many years and as a manager of an HIV outpatient centre, I have been keen to offer health promotion services in the clinic and, in 2007, asked patients using a questionnaire what services they would be keen to access. Of those who responded, 24% stated that they would be keen to attend a stop-smoking service held at the clinic. If we can assume that our rate of smokers is around 50% then this accounts for almost half of them. This led to us to approach the local primary care trust (PCT), Kensington and Chelsea, to introduce a smoking-cessation service for service users attending all the HIV outpatients across the directorate but based at the Kobler Clinic. Nurses underwent training in order to become level 2 stop-smoking advisors. As a result of this we now have three nurses who are able to offer a course of six one-to-one sessions with patients. This begins with an initial 'pre quit' session in order to assess the patient's level of addiction and readiness to quit.

This is followed by a further five visits where nicotine replacement therapy is requested by the advisor and dispensed by a local pharmacy. The patient pays a one-off prescription charge for the full 5-week course (unless they are exempt from charges). Carbon monoxide breath levels are taken at each visit, both as a motivator and as a measure of adherence to quitting.

The stop-smoking service has initiated much conversation between clinicians and patients about smoking. Even where patients feel they are unable to attend at our centre, publicity about the service has led to referrals and advice for patients on how to access other, more local services via the NHS Go Smoke Free network or through non-governmental organisation services such as GMFA – the gay men's health charity. Those patients who have attended our service have reported that by being able to access smoking-cessation support within their HIV centre, they feel more able to discuss issues openly where they feel their HIV status will be understood and accepted.

As smoking addiction, HIV and lifestyle are often inexplicably linked and intertwined, the sessions can become very intense with patients opening up and talking about all aspects of their lives. These have ranged from issues related to their diagnosis, stigma, relationships, and psychological and general health concerns. Often these are issues that patients have never discussed in the clinic previously and seem to stem from the 'taking stock' that a decision to stop smoking often initiates. This has, in turn, led to referrals to other members of the multidisciplinary team, mental health services, the Living Well programme, and the YMCA gym membership scheme, to name but a few.

Since launching the service in late 2007, we have seen close to 50 patients through the clinic and, when last calculated, our success rate was 38%. This compares favourably with NICE guidelines, which recommend a success rate of 34% for such a service and with the success rate of smokers attempting to quit alone, which has been shown to be between 2 and 3%. Long-term success will be studied as the PCT will contact all quitters a year after completing the course. As we have been running the service for less than a year, we do not yet have this data. However, owing to the nature of the HIV service, there can be ongoing assessment of successful

quitting and support for patients as they attend for their routine follow-up care.

I feel that nurses in an HIV setting are ideally suited to undertake such a service. After all, as we support patients in their adherence to antiretroviral drugs, why not also support them equally with the non-adherence to another type of drug! The service has also given more junior members of the team the chance to work more independently and spend time with patients in a consultation setting. As it is not necessary to have a nursing qualification to be a stop-smoking advisor, the role is open to non-qualified members of the team such as healthcare assistants. On the whole, undertaking the service has given us another skill and aspect to our role, and one that is completely independent. More than this I feel passionately that we owe it to our patients, who we work so hard to keep well and stable, to not let them succumb to preventable illness and disease brought on by a continuing addiction to smoking.

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Preventing heart disease

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This article will look at why people with HIV infection are more likely to have heart disease and what lifestyle changes can be made to reduce this risk.

Background

Cardiovascular disease (CVD) covers a wide array of disorders affecting the heart and blood vessels, including heart attacks or myocardial infarction (MI), strokes or cerebrovascular accidents (CVA), and peripheral vascular disease (PVD), which all result from a progression of atherosclerosis (hardening of the arteries). CVD remains the main cause of premature death in the UK [1]. With successful antiretroviral treatment, people with HIV infection are living longer and are starting to suffer from diseases associated with older age. CVD currently ranks fourth as the cause of death in the UK HIV population [2].

Why is there an increased risk of CVD in HIV?

The epidemiological evidence from several large HIV cohorts suggests that relative rates of CVD are higher in the HIV-infected population than in the general population [3–5]. There is evidence to suggest that there are three main factors contributing to this increased risk: infection; antiretroviral treatment; and traditional CVD risk factors that are also associated with the non-HIV population.

Infection

Excess inflammation is known to cause endothelial dysfunction and this has been found to be greater in patients with HIV than in uninfected controls,

when measured with surrogate markers [6]. This theory of uncontrolled viraemia inducing an inflammatory state and accelerating atherosclerosis was recently highlighted in the SMART study where the group on intermittent antiretroviral therapy experienced a greater rate of MI than the group on continuous antiretroviral therapy [7].

Antiretroviral treatment

Many studies have suggested that there is an association between exposure to antiretroviral drugs (in particular protease inhibitors) and the risk of MI. This can only partly be explained by their effect on lipids [5]. The emerging picture, illustrated by the DAD cohort data, is that of the role of specific agents. Initial analysis attributed increased risk primarily to cumulative use of protease inhibitors, with a relative risk (RR) of 1.16 [3]; whereas further analysis has implicated recent use of didanosine (RR=1.4) and abacavir (RR=1.9) [8].

Traditional risk factors

Analysis of data from several large cohorts indicates that traditional risk factors may have a greater influence than risks attributed to antiretroviral therapy [9]. The relative risks of MI associated with smoking (2.83), obesity (1.7) and cholesterol (1.26) were found to be greater than the relative risk associated with protease inhibitor use (1.16) [3]. Some of these traditional risk factors may also have a significant effect on the increased risk of CVD in the HIV population due to their higher prevalence than in the general population. For example, smoking rates are higher in HIV cohorts, ranging from 35% to 72%, than in age-matched, uninfected controls [10],

Table 1. Commonly used CVD risk assessment tools.

Version of cardiovascular risk assessment tool	Equation based on data from:	Web link
JBS/BNF*†	Modified Framingham	http://cvrisk.mvm.ed.ac.uk/calculator/bnf.htm * http://www.patient.co.uk/showdoc/40000133/†
ETHRISK*	Modified Framingham	http://www.epi.bris.ac.uk/CVDethrisk/CHD_CVD_form.html
QRISK2	England and Wales (n=2.3million)	http://qr2.dyndns.org/index.php
ASSIGN‡	Scotland (n=13,297)	http://assign-score.com/site/form

* Recommended by BHIVA guidelines [14]
† recommended by NICE guidelines [15]
‡ recommended by SIGN guidelines [18]

with average rates of 24% in the UK population [11]. Similarly, cross-sectional studies have shown that HIV patients consume more saturated fat compared to uninfected control groups [12] suggesting that quality of diet may be a contributing factor to dyslipidaemia.

Whilst the relative rates of MI are higher in the HIV population, the absolute rates are lower, due to the overall younger age of the HIV population. However, there is no room for complacency with the gradual worsening of the cardiovascular risk profile observed in the DAD cohort as patients are ageing [13]. Therefore, it is essential that prevention of CVD be incorporated into routine HIV clinical management.

Identifying patients at high cardiovascular risk

An individual's risk of developing CVD can be estimated using an equation (such as Framingham, QRISK, or ASSIGN) that has been derived from longitudinal data on incidence of CVD and association with multiple risk factors (see Table 1). Simply enter the individual's data on age, gender, blood pressure, HDL, etc into one of the online calculators.

Screening for cardiovascular risk is required to identify patients at high risk or with existing CVD, as they will benefit most from interventions to reduce risk. High risk is defined as a score of >20% for the

Table 2. Key components for CVD prevention.

Guideline objective [15]	Can be achieved by reducing intake of these foods	Alternative food choices	Affect on plasma lipids [17]
Reduce total fat intake to <30% of the total energy intake	Snacks – crisps, biscuits, cakes, ice cream, pastries Fats (most animal fats, butter, lard and vegetable fats such as palm oil and coconut oil)	Wholegrain breakfast cereals, unsalted nuts and dried fruit. Less meat and processed foods Fish, beans, pulses, eggs Vegetable oils (e.g. canola/rapeseed, olive, walnut, soya)	↓ LDL
Reduce saturated fat intake to <10% of total energy intake	Fatty meats (e.g. beef, lamb) Processed meats (e.g. sausages, salami, corned beef, pies) Pizza, chips	Chicken without skin Low-fat dairy products (e.g. milk, cheese, yogurt) Vegetable kebab	↓ LDL
Eat at least five portions a day of fruit and vegetables	Doesn't include potatoes! One portion = a handful	Eat a 'rainbow' of colours to obtain the full selection of vitamins and minerals	↓ Blood pressure
Eat at least two servings of omega 3 fatty acid-containing fish per week	White fish and canned tuna are low in omega 3 fats	Mackerel, kippers, pilchards, trout, salmon, sprats, sardines, herring	(Higher doses from supplements are required to ↓ TG)
Moderate alcohol intake of <3 units/day	No binge drinking!	Red wine is preferable	↑ HDL
At least half an hour of moderate-intensity activity per day Choose to move rather than be moved'	Can accumulate 10-minute bouts of activity that will increase the heart rate, breathing rate and make you feel slightly sweaty	Walking, cycling, tennis, golf, badminton, vacuuming, cleaning windows or floors, skipping, walking up stairs	↑ HDL ↓ LDL ↓ TG
Smoking cessation	Ask, Advise, Assist & Arrange (see article p. 4)	NHS helpline 0800 1690169	↑ HDL

LDL, low-density lipoprotein; HDL, high-density lipoprotein; TG, triglycerides

10-year risk of developing CVD using the Framingham equation.

Lifestyle intervention

A strong case exists for the efficacy and safety of primary prevention through lifestyle changes, and these options should be offered to patients first. The following advice is appropriate for all patients at whatever risk score, as the recommendations are common to guidelines for the general population [16], primary and secondary prevention of CVD [15] and HIV treatment guidelines [14].

The key components of CVD prevention evidenced in the NICE guidelines are presented in Table 2.

In addition to this, epidemiological evidence points towards consumption of a Mediterranean diet that includes a greater proportion of fats taken in the form of mono-unsaturated fats (MUFA); higher intakes of soluble fibre from oats, beans, pulses, legumes, vegetables and wholegrains; less salt; and maintenance of desirable weight.

Broadly speaking these recommendations can be achieved simply by changing from ready-made meals and processed foods to home cooking from raw ingredients. Consequently, cooking methods become important with emphasis on baking, grilling or steaming in preference to frying or boiling. This obviously has time and convenience implications and many patients, therefore, find it beneficial to discuss the different ways to accommodate these changes within their own personal circumstances with a dietician. Some primary care trusts offer opportunities for practical learning with supermarket tours and cooking sessions. Like any behaviour change, it is difficult and involves breaking old habits and creating new ones. Patients may require further assistance in reaching the decision that change is beneficial and worthwhile. Dieticians are experienced at motivational interviewing and negotiating change with small manageable steps.

Some patients do not wish to be referred to a dietician and may feel more comfortable attending group sessions on heart disease and lifestyle. Nurses are well placed to re-enforce public health messages, as they are usually the first point of contact as patients enter the HIV service, and have established good rapport with existing patients.

Referral to specialist services

Patients at high risk of CVD (with scores above 20%) or dyslipidaemia (raised low-density lipoprotein and/or triglycerides) require referral to a dietician for more specialised advice, such as the Portfolio diet, which includes additional functional foods like soya, plant stanols, nuts and soluble fibre. Similarly, patients with hypertension would benefit from referral to the dietician for advice on the DASH (Dietary approaches to stop hypertension) diet. If a

specialist HIV dietician is not available in your unit, referrals can be made via the GP or directly to the dietetic department within your hospital. Patients who do not achieve targets (reduction in cardiovascular risk or lipid levels) will require appropriate second-line management from a specialist metabolic physician in collaboration with the HIV team, with lipid lowering agents and/or switching antiretroviral therapy.

Conclusion

People with HIV infection are at increased risk of CVD and numbers are likely to rise with the ageing population and longer exposure to antiretroviral drugs. As healthcare professionals, we need to be creative and innovative with ideas to promote and encourage positive behaviour change in the clients we come into contact with.

Useful websites for further resources

Resources on all aspects of CVD	bhf.org.uk
Food Fact sheets	bda.uk.com
Recipes and tips	5aday.nhs.uk
Organised walks	www.whi.org.uk
Volunteer dog walking	www.cinnamon.org.uk

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Sexual health and HIV

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Introduction

Maintaining and promoting good sexual health is not only important for preventing sexually acquired infections and unintended pregnancies, but also for the prevention of transmission and acquisition of resistant strains of HIV, hepatitis C, preventable infertility and anogenital cancers [1]. Sexual health, although having been in the spotlight for a long time [2], has primarily focused on sexual infection and disease prevention [3]; however, this focus is now shifting to become more inclusive of other aspects of human sexuality. It now encompasses the broad spectrum from sex education in schools [4] to sexual function, in part because of the HIV epidemic and its associated research. Poor sexual health disproportionately affects men who have sex with men (MSM) and women [1], and in the UK the focus is now on developing a sexually healthy society, with a large number of government initiatives and standards set by health organisations [5–8].

What is sexual health?

Sexual health is not a timeless concept [9] and the definition is broad; however, there are a number of definitions and three overarching themes [10]:

- The capacity to enjoy and control sexual and reproductive behaviour in accordance with a social and personal ethic;
- Freedom from fear, shame, guilt, false beliefs and other psychological factors inhibiting sexual response and impairing sexual relationship;

- Freedom from organic disorders, disease and deficiencies that interfere with sexual and reproductive functions.

Assessing sexual health

A sexual history should be taken on a 6-monthly basis and patients should be offered annual sexual health screens [11]. Patients engaging in high-risk behaviours and those with symptoms should be offered a check-up more regularly. Risk-taking behaviours and barebacking are common: one in three MSM engage in unprotected anal sex [12]. While being essential to identify and discuss, it is important to approach sexual risk-taking and drug use with sensitivity, as a judgemental approach will alienate and become a barrier for people attending services for diagnosis and treatment [9,12,13]. Routine sexual histories should identify potential sites of infection and include questions about sexual practices that may increase the likelihood of transmission of infections: multiple sexual partners, drug use for sex, unprotected intercourse, the use of sex toys that are shared and shared lubricant when sex involves multiple partners. A travel history is also useful.

Screening

Asymptomatic patients should have routine checks for gonorrhoea, chlamydia, syphilis, and hepatitis B and C. Always ensure that patients are up to date with their hepatitis A and B vaccinations and, if vaccinated, annual checks of their anti-HBs to ensure adequate protection. Routine examination should include the skin, oral cavity, anus, vagina or penis and testicles. Patients with symptoms should

be screened dependent on symptoms as per national guidelines [14]. However, in routine presentations a high index of suspicion for the unusual should always be exercised in patients engaging in high-risk behaviours given the increases in previously uncommon conditions such as LGV and irregular presentations of conditions such as syphilis. Atypical anogenital lesions should be referred for assessment to exclude pre-cancerous changes (intraepithelial neoplasia) or other chronic dermatological complaints.

Women and HIV

It is recommended that women with HIV should have an initial colposcopy at diagnosis followed up with annual cervical cytology [11]. Contraception is as important as it is for negative women; however, consideration is required for interactions with antiretroviral therapy. For example, as liver enzyme-inducing medication such as atazanavir increases the metabolism of progesterone-only emergency contraception, a woman would require double the dose of the contraception [15]. Pre-conceptual care and pregnancy services are also necessary as specialist advice or support may be required for interventions such as sperm washing, changes in treatment and support post delivery.

Sexual function

Sexual function issues are common in patients with HIV [16]. This is hardly surprising given the psychological and physical impact that HIV can have – the diagnosis itself, the fear of transmission, altered body image, stigma, fear of rejection, discordant relationships, loss of a partner, the impact of the disease on the body, the various medications and co-infections, to name but a few. Untreated sexual dysfunction may cause other issues, including unprotected anal sex because of erectile dysfunction as it is difficult to use condoms, or complete avoidance of sex and forming attachments, so impacting on quality of life. Assessments of patients should include questions about sexual function, with referral to specialist services as appropriate. Do make sure, however, you understand what is available before assessing sexual function as it is a little unfair to raise a patient's expectations and not be able to follow through with appropriate interventions.

Raising status issues

Discussing HIV status with prospective partners is fraught with potential problems and issues of rejection, stigma and potentially violence [9]. As well as 'killing the mood', stigma may lead to low self-esteem, which in itself can lead to increased sexual risk-taking [9]. However, talking about HIV status in a discordant relationship can lead to both partners working hard to maintain the negative partner's negativity [17]. Where both partners are HIV-positive, it is also important for sexual partners to

broach status issues of resistant HIV and hepatitis C, especially if they are planning to engage in unprotected sex.

Legal issues

Since the successful prosecution of a man in Scotland in 2001 [18], there have been relatively few prosecutions for reckless transmission of HIV. However, it is important to discuss with patients the potential legal issues if they are engaging in risky sexual behaviours. There is a wide assumption of safety from prosecution if you inform your negative or untested partner of your HIV status prior to unprotected sex [19]. The law can also apply to other infections [20], although there have been no successful prosecutions as yet [19]. This has potential implications for HIV-positive patients who are co-infected with hepatitis C or infections like herpes, or have resistant strains of HIV.

Health promotion and protection

When working with patients it is important to discuss post-exposure prophylaxis for sexual exposure (PEPSE), ensuring that they are aware of when it should be used and how it can be accessed especially out of hours. Also (where indicated) discussions should occur relating to risk-taking behaviours, drug use (including alcohol and smoking), resistant HIV and hepatitis C.

Implementing sexual health initiatives

When implementing initiatives it is important to make them as seamless as possible for the patient and, where possible, involve patients in the planning stages. It is also best to avoid, where possible, extra clinic visits, referrals to various other professionals/services and multiple long waits. It may be easier and more convenient for the patient to have any further tests incorporated into their routine blood screens/appointments. Using proformas can standardise care and make auditing easier for clinicians. The use of questionnaires that patients fill in can also speed up the process (especially for asymptomatic patients). This can be supported with prompts on computer systems or in the patients' notes. If local sexual health contraceptive services are not co-located/integrated, developing links is very helpful.

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Provider-initiated HIV testing and counselling in sub-Saharan Africa: opportunities and challenges for nurses

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Introduction

Since 2007, WHO/UNAIDS has recommended that countries with generalised HIV epidemics should adopt a policy of provider-initiated HIV testing (PITC) in clinical settings. Specifically, the guidelines suggest that:

HIV testing and counselling should be recommended by the health care provider as part of the normal standard of care provided to

the patient, regardless of whether the patient shows signs and symptoms of underlying HIV infection or the patient's reason for presenting to the health facility [1].

This policy complements existing 'voluntary counselling and testing' (VCT) programmes that rely on individuals to self-refer for testing [2].

In sub-Saharan Africa, nurses are at the forefront of HIV care [3]. The expansion of PITC has a

potentially massive impact on nursing roles and workloads, yet there has been surprisingly little nursing involvement in HIV policy development and surprisingly little research on nurses' experiences of conducting HIV testing [4–6]. This literature review considers some of the concerns that PITC has generated and assesses the limited available evidence to identify the challenges and opportunities that PITC raises for nurses in this region.

Rationale for PITC

PITC is a response to the fact that only 10–12% of people living with HIV in sub-Saharan Africa know their status, and that many opportunities to diagnose HIV are missed during routine medical encounters [1]. For example, in a large Kenyan hospital, a PITC pilot found that 11% of women coming for cervical cancer treatment were HIV-positive (84% of these were identified for the first time) [7]. A study in a Ugandan hospital found that only 20% of patients discharged from a medical ward had received an HIV test [8]. The subsequent implementation of PITC in this hospital found that HIV prevalence was 25% (81% of patients were tested for the first time) [9]. Another study in the Emergency departments of two hospitals in Uganda found that 50% of those tested were HIV-positive, and that 88% of the sample had consulted a doctor in the previous 6 months but had not been referred for testing [10]. Similar findings have been reported in a number of other healthcare settings [11–15].

Concerns about PITC

PITC has a strong public health rationale but its introduction has been accompanied by vigorous debates about whether this is the right approach given the context of HIV-related stigma and lack of human and physical resources in the sub-Saharan African context. There is also concern that the PITC policy could be misused by some governments as a way to support mandatory testing [16–22]. Three main concerns have been expressed, specifically: (1) how to safeguard human rights (particularly voluntary informed consent, privacy and confidentiality) within a routine approach; (2) how to ensure that testing is accompanied by protection from stigma and discrimination; and (3) how to ensure that testing is linked to high-quality follow-up treatment and care services.

WHO/UNAIDS have responded to these concerns by stating that the implementation of PITC must be accompanied by efforts to create an 'enabling environment', specified as a health service structure where:

HIV testing and counselling is confidential and is accompanied by counselling and informed consent, staff are adequately trained, the person undergoing the test is offered or referred to appropriate follow up services and an adequate social policy and legal framework is in place to prevent discrimination [1].

Evidence on the PITC process in sub-Saharan Africa

A small number of studies on the PITC process suggest that the boundaries between voluntary informed consent and coercion can become rather blurred. For example, in a study of HIV testing practices in a public hospital in Uganda, of the 20% of patients who received an HIV test during admission, only 29% of these had received any pre-test counselling at all [8]. In another study of routine antenatal HIV testing in a South African hospital, out of a sample of 56 women, 88% said they had felt compelled to agree to the test, and 28% admitted fearing that refusal would have compromised their care [23]. In another Ugandan study of 10 antenatal clinics, qualitative research showed that many pregnant women objected to what they perceived as 'forced' HIV testing and observations showed that some women were tested in spite of their objections [24]. Other studies in antenatal and community-based settings, however, indicate that individuals did not feel coerced into giving their consent [25–29].

Many studies have shown that uptake of testing does not always translate into collecting results or registering for follow-up treatment [30]. This would seem to indicate that some people are being tested before they are ready to face the implications of their diagnosis. For example, in a large antenatal programme in Cote d'Ivoire ($n=6,982$), 72% of women accepted the test but of those who were HIV-positive only 45% returned to collect their results and only 35% enrolled in a follow-up programme. In a study of these 'non-returners', women indicated that staff behaviour and stigma had been the main factors affecting their decision [31]. With respect to the former, women noted that they would not have taken the test if it had been properly explained, they were unhappy with post-test counselling and they were afraid of the staff (worried about being shouted at). Similar views on staff behaviour and a general distrust of nurses and of their ability to maintain confidentiality have been cited in other studies [32–36].

A number of studies indicate that in some cases, nurses who are used to working within a rather hierarchical, didactic and paternalistic professional culture, find there is a conflict between the facilitative/empowering ethos of counselling and more traditional professional roles in which nurses 'know best' and should tell patients what to do [37]. Nurses in a Tanzanian study for example, found it very difficult to adopt a non-directive approach, complaining that it was too vague. They commented that patients also found it confusing as they were used to receiving authoritative advice [37]. Another Tanzanian study found that nurses had difficulties allowing patients to make their own informed choices. There was a strong perception that a 'good counsellor' was one who could persuade a patient to get tested. Non-consent was

considered 'counsellor failure' so nurses tended to persist in recommending a test until the patient finally gave in [38].

Other studies in South Africa have found that nurses were extremely positive about their work despite the fact that increased HIV testing and treatment had created greater workloads. The authors suggested that after years of watching helplessly as people died of AIDS, nurses are enthused by the ability to do something positive and to see results [39]. Similar findings have been reported in other South African research in which the introduction of HIV testing and treatment has been accompanied by an upsurge of staff motivation [40, 41]. These studies conclude that some nurses are viewing HIV as an opportunity to embrace new patient-centred and empowering philosophies of care [3]. Interestingly, when asked about the challenges in their work, nurses downplay the technical, diagnostic or clinical complexities of HIV, but rather stress that counselling, patient support and empowerment is by far the most difficult part of their job – made worse by the context of poverty, which characterises many patients' lives [39].

The question of how to maintain confidentiality and privacy is another concern within the PITC process. In many sub-Saharan African countries patients are accompanied to healthcare settings by family members, and ward environments and clinics are characterised by over-crowding and lack of space for private discussions [19]. Nurses in many studies have noted lack of private space as a major constraint to pre-/post-HIV test discussions [30]. There are frequent articles in the media reporting breaches in confidentiality in medical settings [17, 32, 42] but research on this topic is very limited. Some studies point out that nurse-counsellors sometimes struggle with their obligation to maintain confidentiality in situations where third parties are clearly at risk but further information on how nurses handle such ethical dilemmas is lacking [43–45].

Evidence on the PITC health-system context

In a context of staff shortages and heavy workloads, most studies have unsurprisingly found that lack of time and lack of staff are cited by nurses as key factors compromising their ability to provide good-quality testing services [40, 45–48]. Inadequate health facilities are also cited as major constraints (e.g. lack of a proper testing room, running out of testing supplies, lack of information-giving tools, overcrowded waiting areas). In the long term, this situation creates considerable emotional stress and burnout [49]. In one study, for example, HIV counsellors describe the pressure of trying to deal with complex client issues in situations where there are long queues outside the testing room and colleagues are banging on the door to hurry them up [50]. Additionally, many nurses note that they

need more (and on-going) training, access to up-to-date counselling tools/aids and more mentoring and support from peers and managers [38, 40, 41, 51]. For example, nurses in two studies complained that senior staff were primarily interested in gathering statistics, rather than driving forward service improvements [43, 50]. This is again unsurprising in a context where health services are highly centralised, hierarchical and bureaucratic and where senior nurses' scope of practice is oriented to management/administration rather than to clinical leadership [52].

Research has also found that in spite of nurses taking on greatly expanded roles and responsibilities associated with HIV, these have rarely been accompanied by promotions, greater remuneration or other workplace incentives. This situation saps nurses' motivation. Some studies indicate that high levels of stress and frustration, combined with a sense of powerlessness within the working environment, is directly linked to poor-quality care, including rudeness to patients [37, 53, 54].

Conclusion and recommendations

The above evidence stems primarily from outpatient and antenatal settings. It paints a rather contradictory picture and raises serious concerns about the extent to which the 'enabling environment' set out in the WHO/UNAIDS (2007) PITC guidelines is actually being implemented. In particular, the meaning of voluntary informed consent is questionable if counselling is occurring in such pressurised conditions. There is no evidence to date on the experiences of nurses or patients of PITC within hospital settings (which suffer from similar health system constraints). This is a knowledge gap that needs to be filled.

With respect to nurses, existing evidence (though small-scale and certainly not representative of the range of nursing practice in different sub-Saharan African settings), gives cause for great optimism on the one hand and concern on the other. It appears to show that, in spite of the constraints, nurses are willing to embrace the patient-centred philosophy of care that underpins HIV/AIDS policy. On the other hand, it indicates that the emotional labour of caring for HIV-positive patients is high and that ways must be found to give nurses appropriate support.

This review suggests three areas in which the PITC implementation process can be strengthened:

- Research/audit to explore nurse and patient experiences, and to identify best practice and key obstacles. In particular, there is a pressing need for observational research to investigate 'real-time' counselling and communication practices. There is also a need for longitudinal follow-up studies that compare long-term patient outcomes following PITC with VCT.

■ Greater nurse participation in policy development.

■ Reinforcement of nurse training and mentoring.

In conclusion, it is clear that the scale-up of HIV testing and treatment through PITC brings with it many challenges but also tremendous opportunities to improve patient care and to develop nursing practice. It is incumbent upon policy makers and nurse leaders to provide the infrastructure and resources to create a climate in which individuals will want to be tested and can trust their nurses to provide quality care.

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Dust, sugar-cane and hip-hop: real world research in Africa

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The last edition of *HIV Nursing* includes a range of papers considering aspects of nursing research. This article continues the topic, reflecting on a recent trip to Swaziland, in Southern Africa, to collect qualitative research data.

Research is boring?

Talking about research is inherently boring. Students sitting through dull university sessions about design, data analysis, epistemology and the intricacies of NU*DIST frequently wish they were anywhere else, and quite often – mentally at least – move to another place well before the lecture ends.

Actually doing research is the opposite: it is exciting, invigorating, frightening and fascinating. The researcher reveals new truths, discovers that the world they thought was straightforward and rational is a chaotic and unnerving place. And, what they expect quite often turns into something completely different. For Robert Pirsig [1], the 'real purpose of the scientific method is to make sure Nature hasn't misled you into thinking you know something you don't actually know'. And whilst this statement refers more specifically to empirical science (for example, randomised controlled trials), there's no

doubt the purpose of any research is to go 'out there' and see what's going on.

The following reflection is about the exciting part of research – doing it, and describes some of the experiences of this writer collecting interview data in southern Africa as part of a larger study exploring the use of antiretroviral therapy in a resource-poor context. In the trajectory from pharmacy to patient, what factors may lead to the increased likelihood of non-adherence, and are these the same as in the developed world?

Antiretroviral therapy in developing countries

Adherence to antiretroviral therapy in countries like the UK, with virtually universal coverage, is discussed regularly. Factors that lead to non-adherence include depression, a wish to avoid side-effects, complex social and psychological factors or simply forgetting a dose. In a robust health system such as in the UK, problems are often detected early, CD4 cell counts monitored, viral loads tracked, and the patient is steered back towards a recommended regimen, hopefully within a short time.

What about in resource-poor regions, however? Do the same problems with adherence occur? Do additional factors make use of antiretroviral therapy regimens even more complex?

Using antiretroviral therapy in regions of high HIV prevalence has had a huge impact in improving the mortality and morbidity of people living with HIV [2]. The massive roll-out over the past years is not without controversy though – antiretroviral therapy is a complex drug regime, with a narrow range of effectiveness; risks of resistance or drug toxicity are ever-present consequences of poorly managed treatment programmes. Problems such as HIV stigma, and logistics in dissemination [3] and competing health beliefs, especially in regions where the local traditional healer – rather than a western healthcare practitioner – is the first point of contact for 80% of the population, all threaten safe and efficacious administration of antiretroviral therapy. None the less, treatment advocates are unequivocal in their support for rapid treatment roll-out – proposing, for example, that success with directly observed treatment (DOT) in the care of tuberculosis can translate to the antiretroviral therapy context, with the health benefits outweighing inherent difficulties [4].

The WHO encourages a public health approach, focusing not on highly technical strategies more usual in developed countries – such as regular CD4 cell count monitoring – but instead on community participation, simplification and standardisation of treatment regimes [5]. Prosaic measures such as blister packs and fixed-dose combinations can reduce the likelihood of administration error and increase patient adherence [6]. Home-based care

programmes can also have a positive impact [7] – by delivering antiretroviral therapy to the home, ensuring a 'medicine companion' and implementing personal adherence plans, a relatively high level of adherence can be achieved.

Study location

The aim of this study was to explore the use of antiretroviral therapy in one context, and reveal factors impacting on the effectiveness and efficacy of treatment as a managed medication in a resource-poor setting: Swaziland.

Swaziland is a high, cool, verdant area of Africa looking not unlike parts of Devon. As an autonomous, and to all intents and purposes independent country, it has a government, and a King, whose 13 wives enjoy all the regal splendour and (relative) wealth expected of their status. According to the human development index (HDI), published by the UNDP in 2007 [8], Swaziland is at 141, and has one of the highest rates of adult HIV prevalence in the world, at around 34% of the adult population. Access to HIV treatment in Swaziland is around 42% – not ideal, but higher than the much wealthier South Africa (28%) and the Russian Federation (16%) [2].

St Marie's Hospital (name has been changed) is a medium-sized general hospital, serving a large part of eastern Swaziland. Situated near a main route to the Mozambique border only 30 miles away, the roads are busy with lorries full of sugar-cane, Swaziland's major export. The hospital has two large outpatient clinics – one for patients with TB, and the other providing treatment and support for people living with HIV. This is where most of the interviews took place.

Conducting interviews

Research design is the overarching framework for all components of a given study – the general approach (or methodology), method for collecting data, and strategy for data analysis. The design of *this* study includes interviews with around 20 patients – and it was the role of this writer to manage the overall research project and undertake the interviews.

Interviews are a popular method for collecting social data; however, they do have disadvantages. The skills of the questioner largely determine the quality of the data; and respondents don't always *really* know the world about which they're being asked. Truth is relative, and often context-dependent. Interviewers forgetting this often unwisely claim an unrealistic, literal truth from data. That said, interviews are a flexible and refreshingly interactive approach (compared to, say, questionnaires), which potentially reveal the deep and rich qualities of a respondent's world, and perspective.

Setting up interviews, especially in a new location, is challenging. The local maven, or 'information

specialist' [9] can be a great help. Their advice and connections can save hours trying to learn local systems and processes. In St Marie's, I soon found Sarah, a youngish, keen and (best of all) well-connected clinic secretary, happy to steer appropriate respondents my way. Gatekeepers and key informants such as this are like gold dust, and the other key support was the study translator, Tulani, a young Swazi with perfect English. His Nike hoody, and keen interest in mobile phones, confirmed something of the global soul in our world, and for the whole 2 weeks, his patience and grace made the busyness of conducting (in total) 25 interviews a much less traumatic time than it could have been.

The antiretroviral therapy clinic at St Marie's is a small, crowded and bustling room – I clearly needed a more peaceful setting for the interviews. Sarah discovered a small concrete office just outside, close to the adjacent TB unit. We soon got accustomed to the background music from the large radio outside, tuned to the local hip-hop station, and which, I thought, would relax the respondents. When we actually started the interviews, our interviewees were accommodating and more than willing to share their thoughts. The interview schedule covered issues such as taking therapy, travelling to the clinic (some came 20 miles), problems with adherence, and whether or not they sought help and advice from people other than clinic staff (most denied this – though some admitted they asked their mothers).

In difficult areas for research, sensitivity is vital [10]. Personal material should always be treated with respect in any context, for research must always be 'carried out in ways that are sensitive to the nature of human and cultural social contexts'[11, p. 290]. For HIV, extra care is required, for even in areas where HIV has a high prevalence, many people have yet to come fully to terms with their diagnosis. HIV stigma is a real danger, and so throughout the interviews, we assured the respondents that their thoughts and comments would be treated sensitively. All respondents in this study were prepared, and signed a consent form, prior to the interview.

Not all our interviews were hospital-based. Remote 'outreach' clinics more than 2-hours' drive from the main hospital provide community-based services. One, in the middle of a huge sugar-cane plantation, had no room available for interviewing, so Tulani and I parked ourselves in the open air, around the corner from the entrance. Although only about 50 miles from the main town, the difference here was startling. Respondents were more guarded – friendly, but less confident. When a 14-year-old girl wandered across from the clinic to be interviewed, without a guardian, we could only make small talk. A research interview here would have been unethical, and even while chatting about her trip

from a nearby village, it soon became evident her understanding of HIV and therapy was limited. We talked a little more, and then she headed home along the dirt road carrying a large sack of rice from the World Food Programme. Seeing this, and hearing the brushing of a hot breeze pushing through the nearby sugar-cane fields, the cool clinical setting of a western clinic seemed a million miles away.

First findings

We completed the interviews with days to spare, and before heading back to the UK, I sat in my room and started reviewing the data. For some respondents, therapy boosts the 'soldiers' in the body, so the person feels stronger. Contrary to comments from medical and nursing staff, respondents deny seeking the advice of traditional healers, and instead claim to discuss treatment problems with the local treatment supporters (expert patients). All claim they never miss a dose, apart from very rare occasions – like losing the medicine bag, or being stuck in a shopping queue.

Saving the interviews in .mp3 format (and backing up – always important!), I reflected on my glimpses into this other world – where food is short, every family is affected by HIV, and much of the health system depends on external support from other continents. People living with HIV here have many of the same hopes and dreams as elsewhere. They seek treatment; hope their children are safe and receive an education; their understanding of HIV and antiretroviral therapy is, on the whole, sophisticated and informed, and their desire is to maximise the benefits afforded by the hospitals and clinics.

Like all research projects, the findings are intriguing, but reveal much more that can be explored. Were the respondents telling the 'truth' about always adhering to their treatment? Why were the opinions of the medical and nursing staff – that patients regularly default on recommended regimes – so different to the comments from the patients themselves? In theory, at least, people on treatment can survive for many years, enjoying a 'normal' lifespan. How can countries like Swaziland cope with so many people with a chronic disease such as HIV?

This study is still in its early stages, and further analysis is due, supplemented by observational data, and more interviews later in 2008. A more sophisticated picture will emerge and in the end, the findings will hopefully, contribute towards improving patient safety.

Conclusions

For this researcher, planning research in Africa, travelling and collecting data was an unparalleled experience. It brought alive the dry, academic language of research theory. Meeting and talking

with 'real' people makes the preparation worthwhile, and often – as with all cultural interchange – leads to the researcher learning as much about him or herself as about the respondent. The privilege of engaging with another person's world can never be underestimated.

Is research boring?

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NHIVNA update

The NHIVNA Committee has just held its annual away-day and has again begun planning in earnest for next year's conference and all our other activities. The feedback from the 10th Annual Conference in Glasgow was very positive and there were plenty of suggestions to take forward into the programme for next year. Thanks to all who completed the conference evaluation form.

Next year will see us visiting Birmingham for the conference, and dates for your diaries are 25 and 26 June 2009. We will be sending out the first announcement later this year. Now is the time to start thinking about preparing abstracts for the conference.

Membership renewal time is coming soon, and the renewal forms and information will be sent out shortly. When you consider that you get *HIV Nursing*, *NHIVNA Newsletter*, *AIDS Treatment Update*, free registration for study days and access to grants and scholarships, we hope that you will agree the membership is very good value for money. If existing members sign up during November to pay by direct debit, they will receive a £5 discount – so consider renewing your 2009 membership early enough to benefit from this offer.

At the conference we announced the appointment of two new committee members: Juliet Bennett and Catherine Donoghue.

They have just attended their first committee meeting and planning session. We have also appointed a new Honorary Secretary: Zoë Sheppard of St Mary's Hospital

The final Competencies study day to be held this year is in Birmingham on 20 November. The topic is 'An insight into HIV inpatient care' and places are still available. We have already run well-received study days in London and Liverpool. Remember study days are free to members. Full details for registration for this and all NHIVNA events are via the events link on the website (www.nhivna.org)

The members-only section of the website is growing nicely. We are keen to receive documents for inclusion in this section. If you have nurse-led clinic protocols, guidelines or any documents concerning your practice that you are happy to share with other NHIVNA members please send them to Jacqueline@mediscript.ltd.uk. We are also happy to receive any feedback from you on how the website could be improved; we have some new ideas that you will hopefully see the benefit of, however, we are also very keen to hear your opinions too.

Sheila Morris
Chair

