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HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day to day matters affecting the lives of patients.

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Editorial

Eileen Nixon

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We are now well into the beginning of 2004 and I hope that we all experience good fortune both personally and professionally for the coming year. But, how do we give fortune a helping hand in our professional lives? How do we use current political and policy proposals to improve our working lives and, more importantly, to enhance the patient experience for people with HIV disease?

Over the last few years, the numbers of people newly diagnosed with HIV continue to increase and many HIV services are finding logistical difficulties in providing treatment and care within existing resources [1]. Although we are all mindful of the momentous struggle in tackling the HIV/AIDS pandemic in sub-Saharan Africa and other developing countries, the approach to this is inevitably a global one and only we as individuals can decide on the personal contribution we want to make.

Within the UK context of health policy, national standards and patient expectations, there is now real opportunity for healthcare professionals to capitalise on current Department of Health recommendations to relieve the escalating demand on services. There are many aspects of these recommendations that relate to nursing and the development of nursing roles. The National Strategy for Sexual Health and HIV [2] advises both long-term workforce planning and an increase in enhanced nursing practice to improve access and efficiency for treatment and care in line with the modernisation agenda identified in The NHS Plan [3]. In addition the Recommended Standards for NHS HIV Services [4] highlight a range of challenges for all healthcare workers in HIV from initial patient diagnosis until palliative or terminal stages of disease.

Certainly, there is a wide number and variety of HIV nurse-led initiatives happening across the UK, from nurse-led clinics for new patients and patients stable on or off therapy, adherence posts, HIV triage

and nurse-led sexually transmitted infection (STI) screening clinics. So, how do we continue to develop nursing roles at a time when resources are becoming tighter? I think we need to evaluate existing nursing roles and skill mix in our local areas in relation to technical and economic efficiency. Exploring different ways of working may release some capacity for nursing workloads without compromising the quality of services. This will enable us to work closely with our commissioners to identify what nursing resources are required to deliver these policy aims and to undertake realistic and evidence-based workforce planning to address increasing patient caseloads. Time invested in this now may well be rewarded in the future.

Of course, there is a fine balancing act between managing day-to-day workloads and taking a more strategic approach to developing nursing roles. We also need to be wary of compromising the basic care needs of patients by expanding nursing roles without appropriate resources. In addition, it is imperative that we highlight the Code of Professional Conduct [5] to support any training and competencies required to undertake new and innovative roles.

Although there are many different challenges for HIV nurses in the UK today, let's not miss this opportunity to build and expand nursing roles and ensure we allow current directives to work for nurses and patients.

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Three by Five: a real hope for developing countries?

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'We must meet the challenge of expanding access to HIV treatment. This requires overcoming the formidable barrier of creating sufficient operational capacity ... we have adopted a target of 3 million people on antiretroviral treatment by 2005: a massive challenge, but one we cannot afford to miss.' [1]

Three by Five

Brave words that encapsulate the immense public health challenge that the World Health Organization (WHO) set itself a couple of months ago. In just under 2 years, the number of people receiving antiretroviral treatment will be scaled up from the few hundred thousand who currently have access to three million by the end of 2005 (hence Three by Five).

Clearly, there is a need for a globalised strategy to distribute antiretrovirals, given the benefits of treatment that have become increasingly obvious

since 1996. The provision of antiretroviral therapy significantly improves the health of an individual, and by extension, has huge social and economic implications as well. Family and friends do not lose a loved one, and economic collapse in some countries could be prevented. Also, by maintaining a relatively low viral load, the general infectivity of a population is reduced.

So the case is made for antiretroviral therapy, but access in resource-poor countries has been a key issue for years: the Treatment Action Campaign (TAC) has fought long and hard for a more fair distribution of antiretrovirals in countries where HIV has infected large numbers of people. According to WHO [1], 400,000 HIV-positive people currently receive antiretrovirals across the world, but nearly 6 million could benefit (Figure 1). It is this massive disparity, which is increasingly called an issue of human rights rather than just public health, that led to the WHO initiative. Figures in the WHO document

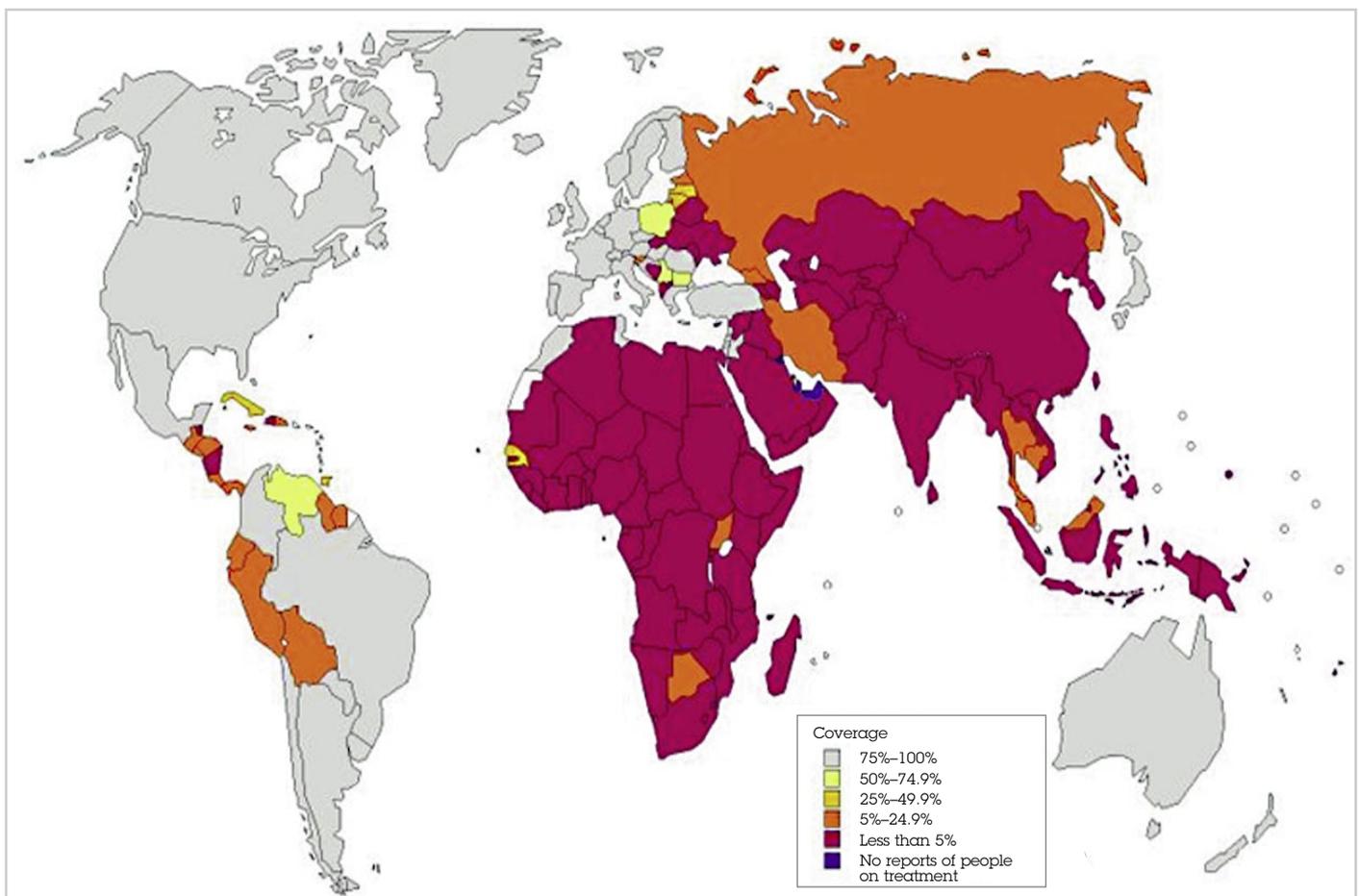


Figure 1: Availability of antiretroviral drugs worldwide.

attest to the severity of the current crisis. In Africa, for example, of the 4.4 million people who require antiretroviral therapy, only 100,000 have access. Compare this with the Americas, where of 250,000 people thought to require therapy, 210,000 are on treatment [1].

Three by Five began in September 2003, when representatives of WHO, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund to Fight AIDS, Tuberculosis and Malaria agreed that a lack of access to antiretrovirals must be re-classified as a global emergency (not before time, perhaps). From this, on World AIDS Day 2003, the WHO Director-General, Dr Lee Jong-Wook, officially announced Three by Five. The cost of Three by Five is estimated to be around \$5.5 billion, and though the WHO remains upbeat, there can be little doubt that funding will be an issue.

The Global Fund set up by Kofi Annan to combat HIV, and tuberculosis is struggling to get donor countries to open their wallets [2], while US government intransigence in preferring to donate only to specific projects (rather than generic initiatives such as the Global Fund) continues to cause problems. Nevertheless, funding issues aside, Three by Five promises, if successful, to be a remarkable achievement. So, how will it work?

Delivering antiretrovirals

Pragmatics first. The actual medications involved in the roll-out are three generic fixed-dose combinations, consisting of stavudine (d4T), lamivudine (3TC) and nevirapine [3]. Community volunteers and healthcare workers, as well as medical staff in the field, will distribute these.

Broader issues around delivering antiretrovirals are essentially economic, social, political and logistical, and the WHO report [1] proposes the following five action points to shape the emergency scaling-up of antiretroviral distribution:

- Develop global leadership, alliance and advocacy: this will include the deployment of hundreds of WHO personnel to drive Three by Five. Ethical guidelines will also be produced to ensure equitable distribution (not as easy as it sounds).
- Provide urgent, sustained country support: WHO intends to assist countries in developing systems to drive Three by Five, including the recruitment of care staff, involvement of trade unions and intensive in-service training focusing on antiretroviral therapy.
- Simplified, standardised tools for delivering antiretrovirals: here, the strategy will help health workers identify and enrol people living with HIV, deliver therapy and track the results.
- Create an effective, reliable supply of medicines and diagnostics: essentially, Three by Five is underpinned by a constant supply of medica-

tion, and an AIDS Medicines and Diagnostics Service will be established to co-ordinate the procurement of treatment and testing equipment.

- Rapidly identify and re-apply new knowledge and successes.

As with all documents of this kind, actual details are eschewed in favour of broad statements of intent. The practicalities involved are immense and are dependent upon a co-ordinated effort across much of the southern hemisphere. The obstacles that must be overcome in order to achieve Three by Five include [4]: the need for political commitment; the effective recruitment and training of healthcare workers; and the need to use all contacts with the public health system. Three particular issues are raised below, although of course there are others.

Stigma

The first issue to be addressed is stigma, which remains as potent a problem as when HIV first appeared 20 or more years ago. The WHO report suggests that stigma will be reduced as a result of Three by Five and, to some extent, this is true. Once HIV is perceived as a chronic, treatable condition, much of the mystique around it may be removed.

However, stigma is a complex phenomenon, and a tool used by cultures to exclude those felt to have broken rules, so that the dominant stereotype of people living with HIV is a stigmatising one that casts them as immoral [5]. The downgrading of HIV to a manageable disease is unlikely to change this perception of HIV as effectively as WHO suggests [1], and it is vital that WHO appreciates the social mechanisms underpinning stigma. Will WHO, in the final analysis, find enough people willing to come forward for testing and treatment? Recent research suggests that the use of testing services and disclosure of status is constrained because of 'anticipated and actual stigma experienced by people living with HIV' [6], and this is also a problem relating to treatment [7]. In the light of this and of additional fears around the lack of confidentiality, WHO should, in tandem with the roll-out of antiretrovirals, support initiatives that galvanise community action and promote human rights-based legislative programmes.

The Three by Five proposal seems to indicate this will take place but, given that antiretroviral treatment, if available, is always predicated on having a person to treat, the issue above is crucial.

Equitability

Another factor referred to in the WHO report [1] concerns equity in the distribution of antiretrovirals, an issue demanding immediate consideration. Studies suggest that the criteria for exclusion from subsidised antiretroviral treatment (when available) differ markedly between countries. These decisions were often based on social merit, level of

income and number of dependents [7]. Providing treatment on a first-come, first-served basis tends to favour richer, urban and more educated people [8]. Placing treatment centres within large referral hospitals, which lack community-based programmes, will reduce opportunities to link treatment with prevention and, in parallel, reduce any fall in stigma. Antiretroviral distribution is not blind, and it is to be hoped that the reports' proposed ethical guidelines adequately address this crucial factor and avoid placing further pressure on front-line staff, which might lead to inconsistencies and corruption.

Ensuring adherence

The third challenge is to encourage adherence. Farmer [9] and others have written extensively of the ways in which antiretrovirals and other treatments requiring continuous monitoring can be given in resource-poor areas. There has been some success in Haiti with directly observed highly active antiretroviral therapy, where community health-care workers visit people being treated with antiretrovirals at home. But this is not replicated in Trinidad and Tobago, where people with HIV did not want home visits [4]. Experience with directly observed therapy for tuberculosis in Africa has been highly variable [10]: treatment completion rates vary from 37% (low) in the Central African Republic to 78% (moderate) in Kenya and Tanzania. Ensuring people regularly take a complex and toxic regimen is a challenge even in countries with highly developed healthcare systems. The Three by Five initiative will need to draw on all available resources and insights into national and local mores if treatments are to be maintained in highly disparate cultural and social contexts.

Concluding comments

'If the number of people able to access life-saving antiretroviral treatment exceed 3 million by 2005, we face a humanitarian catastrophe ... as many as

6 million people need antiretroviral medication NOW. We are still running the danger of doing too much too late' [11].

The Three by Five initiative represents a bold and vital step in the fight against HIV, and lessons learned here will pave the way for the roll-out of HIV vaccines in 10 years or so. People living with HIV across the globe, especially in resource-poor countries, are being offered a glimmer of hope, and with 8000 people dying each day of HIV, any gain is of benefit.

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HIV nursing: self-medication

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Introduction

This article will describe the rationale for an initiative introducing 'self-medication' onto an inpatient HIV ward. Self-medication is a process whereby selected inpatients in a designated ward/clinical area are responsible for the storage and administration of their own medicines [1]. A 2-month long audit was undertaken when the scheme was first introduced. The findings and recommendations of this audit will be presented in this article. The scheme has been a success and could be of value on similar units with certain provisos based on the results of the pilot and the auditors' observations.

Background

Patients rarely take their drugs as prescribed [2]. Yet 95–100% adherence/compliance with highly active antiretroviral therapy (HAART) is a crucial prerequisite for people with HIV disease currently on or contemplating starting a regimen, and the health-care workers involved in this process [3,4].

As an inpatient nurse this issue is especially problematic. Here patients may be long-term non-progressors with much drug 'experience', which restricts their treatment options. Consequently, they may be taking a harrowingly complex regimen. Patients may have issues with drug and alcohol addiction that inhibit their routine and motivation. If a patient is admitted to the ward newly diagnosed HIV-positive with an opportunistic infection, commencing even a simple HAART regimen may be difficult alongside all of the other adjustment issues they face.

Patients on the ward have access to a specialist HIV nurse with expertise in 'adherence issues' [5] as well as specialist pharmacist support and a wealth of written information. However, assistance and support from the nursing staff who actually give the HAART regimens is often *ad hoc* and inhibited by the conventional methods of drug administration employed on a hospital ward, either dispensing drugs from a drug trolley or a drug cupboard in the 'treatment room'. Often the patients' 'understanding' of their regimens is only checked as they are given a large bag of medications on discharge. It was in this context that a self-medication scheme, already successfully implemented on another HIV inpatient ward in another hospital, was embarked upon (Royal Free Hospital, London).

The self-medication scheme

Aims

The aims of the scheme were:

- to encourage patients to be more actively involved and responsible for their health through self-medication;
- to improve patients' and nurses' knowledge of the drugs taken; and
- to support patients starting on new drug regimens.

Near patient medication

As stated, self-medication is a process whereby selected inpatients in a designated ward area are responsible for the storage and administration of their own drugs. This necessarily involves 'near patient medication', which can be described as a new model for pharmacy delivery that centralises the supply and administration of medicines at the patient's bedside and facilitates discharge. The patients have individual lockers by their beds with a master and individual key for access, with the patient's own labelled drugs in that locker.

Audit of the scheme

During the 2-month audit of the self-medication scheme:

- each member of the team participated in a 30-minute teaching session;
- medication was dispensed by the pharmacy, labelled with the patient's name and stored in a locked cupboard attached to their patient locker. The patient's own drugs (PODs) were assessed by the pharmacist;
- the scheme excluded *prn* (as required) and controlled drugs;
- the patient was assessed by the nurse using an eight-question assessment tool (Table 1) and assigned to one of three levels:

(1) Red: all medication was dispensed by the nurse and the patient had no access to the locker key. Drugs were signed for by the nurse on the drug chart.

(2) Amber: the patient observed the nurse dispensing his/her drugs, or the nurse observed/assessed the patient dispensing his/her own drugs. The patient had no access to the key. The nurse signed for the drugs on the drug chart.

(3) Green: the patient dispensed his/her own drugs. He/she signed a consent form accepting responsibility for this role and the safe-keeping of

the key. A blue patient sheet was completed for the patient listing his/her drug regimen;

- The patient's level was confirmed or re-assessed daily and recorded.

Evaluation of the 2-month audit

The following procedures were carried out as part of the evaluation:

- an anonymous patient questionnaire was circulated weekly; there were 12 responses;
- a documentation audit, which was repeated weekly;
- staff questionnaires: there were 15 responses from a possible 25;
- continuous feedback/comment sheets were available on the ward throughout the audit.

Results of the evaluation

The documentation audit showed that:

- the nurses failed to reassess Red patients daily;
- the blue patient sheet was not always completed or updated when new drugs were added;
- the audit failed to capture the frequency/pattern of patients' movement between levels;
- the drugs in lockers did not always correspond to the drugs prescribed; some were missing or no longer prescribed;
- the patients' consents to re-use their own drugs (PODs) were not always signed; and
- the check list was rarely used.

Though there was no specific question in the audit, the auditor noted by week 2 that the patients' movement between levels was slow, if it occurred at all, and that the majority of patients remained 'Red' for their hospital stay.

The patient questionnaires showed that:

- most respondents were 'Green' patients;
- all respondents either liked or preferred the scheme depending on whether they had previous experience of hospital drug administration;
- the patients commented that drugs were on time; the system was less paternalistic and left the nurses time to do other things.

The staff questionnaires showed that there were advantages and disadvantages for both patients and nurses.

Advantages for the patient

- patient empowerment through education and reduced paternalism;
- increased convenience;
- improved nurse-patient relationship; and
- improved patient adherence with their drug regimen.

Advantages for the nurse

- increased convenience;
- increased role in promoting adherence to drug regimens;

- a safer method of drug administration as patients understood the drugs they took;
- improved nurses' knowledge of drug regimens.

Disadvantages for the patient

- the system was slow to respond to assessment changes (i.e. availability of patient-labelled drugs);
- the environment was poorly adapted for the scheme: poor light at night, low-level lockers necessitating bending; and
- safety: not rechecking the patient's level daily.

Disadvantages for the nurse

- the lack of pharmacy support;
- safety: not removing drugs when prescriptions changed;
- environment (see above); and
- time-consuming if not all drugs were present in the locker.

Recommendations following the evaluation

Following the evaluation, a number of recommendations were made:

- environment: larger lockers, better light at night and small stools to use by beds were needed;
- pharmacy support: greater technical support was required to get drugs to the bedside quickly, to organise stock, to complete the blue patient sheets, to organise To Take Away (TTAs) drugs, to check patients' own drugs (PODs) and to review ward stock levels;
- education and training: to explore reasons for the nurses' failure to move patients between levels, considering lack of confidence and/or training;
- other issues, including patients found to be at risk of self-harm if assessed by a psychiatrist, and controlled drugs and *prn* drugs in the scheme.

Discussion and conclusions

Two years after the audit, the scheme continues on the ward and remains popular. The recommendations, though some were simple, have proved time-consuming to resolve. The environment has been adapted, there are larger lockers, brighter torches and kick stools available in the bay. The keys have never been lost despite the ominous early predictions of the nurses.

The assessment tool used (Table 1) has proved safe and inclusive. Discussions with the psychiatric team prevent the unnecessary exclusion of patients with a history of self harm but not currently at risk. *Prn* and controlled drugs still remain outside the scheme. This is partly due to the burdensome bureaucracy of processing this change through the Trust's drug committee. However, on the ward, controlled drugs and *prn* drugs are used mainly for

Table 1: Questionnaire summary.

	Yes	No	Comments
Initial questions			
1. Does the patient wish to be excluded from the self-medication scheme?	<input type="checkbox"/>	<input type="checkbox"/>	
2. Is the patient too ill to take part/physically unable to administer his/her own drugs?	<input type="checkbox"/>	<input type="checkbox"/>	
3. Is the patient confused?	<input type="checkbox"/>	<input type="checkbox"/>	
4. Does the patient have any history of self-harm?	<input type="checkbox"/>	<input type="checkbox"/>	
5. Does someone other than the patient administer medications in the community (i.e. district nurse)?	<input type="checkbox"/>	<input type="checkbox"/>	
Following questions			
6. Are there any gaps in the patient's understanding of: the medication, purpose, dosage, special instructions, possible side effects?	<input type="checkbox"/>	<input type="checkbox"/>	
7. The patient cannot cope with: click locks/screw tops/blister packs/cabinet?	<input type="checkbox"/>	<input type="checkbox"/>	
8. The patient cannot read the table: impaired vision, written understanding of English?	<input type="checkbox"/>	<input type="checkbox"/>	

If the answer to any of the initial questions (1–5) is **Yes**, the patient is not suitable for the self-medication programme. Enter this patient at Level 1. If the answer to any of the following questions (6–8) is **Yes**, the patient should be entered at Level 2.

Level 1 Red Patient is not able to self-medicate at present. Key to be locked in bedside cabinet. Nursing staff to administer medications as prescribed.

Level 2 Amber Patient needs supervision and education when administering medication. Further education and counselling to be given about medication. Patient will have no access to medication in the cabinet.

Level 3 Green Patient is capable and, if consent obtained, responsible for self-medication. Patient responsible for key. Review prescription chart with the patient at least once a day and record if drugs omitted.

Assessing nurse signature

Print name and designation

Date:

symptom control, and 'experimentally' in the sense that there are frequent changes in order to seek the 'right' drug for that patient and that symptom. These frequent changes would prove to be burdensome for the pharmacists and delay the process of effective symptom control.

The issues with pharmacy support have proved difficult to resolve as they are not due to ill will from that team but other work pressures. Patients' drugs are rarely ready quickly or in the locker. Providing labelled drugs for all levels of patient proved to be so prohibitively time-consuming for the pharmacist that we were forced to use stock drugs for all of the Red level patients. The nurses undertook this task and, unfortunately, it is a low priority, and so some

drugs are in the stock cupboard and some are in the patients' lockers, and the simplicity of this method of drug administration is often lost. The nurses spend so much time looking or waiting for drugs that it is a disincentive to their role in patient education and supervision. This accounts for the failure to consistently progress each patient through the three levels of the scheme so that all are Green when they leave the ward.

This issue has proved to be a crucial barrier to the fulfilment of the original aims of the scheme, namely, improved patient and nurse drug knowledge, support for patients on new regimens and a more active role for patients in hospital drug administration.

Others contemplating the use of this scheme should first ensure that pharmacists can provide both resources and enthusiasm. If a similar unit wonders whether the use of the scheme can improve adherence, there is little conclusive evidence from the literature or the audit described. However, the audit, and also use of the scheme over time, have revealed other benefits not anticipated at the outset, namely, spending more time with the patient in a one-to-one situation by the bedside, the greater ability of the nurse to identify those patients unable to contemplate a new drug regimen or, indeed, their current drug regimens before the day they leave hospital. We conclude that self-medication is a safer and more patient-centred method of drug administration on a hospital ward.

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NHIVNA update

All NHIVNA members will have received a flier notifying them of the closing dates for the NHIVNA/Boehringer Ingelheim scholarships and grants for 2004. Money is available if you would like support to undertake a research project, apply for a travel scholarship or attend a conference at which you are presenting. The closing dates are 30 April and 31 October 2004. Email me at: nicky.perry@bsuh.nhs.uk or ring 01273 665147 if you would like an application pack.

Plans for our annual conference are well under way. 'Diversity in HIV Nursing' will be held in Manchester on 24 and 25 June. Plenary topics will cover HIV nursing in women, children, adolescents and co-infection in adults. Workshops will be held on sexual health and HIV and the nursing issues and ethics of caring for asylum-seekers, and there will be a discussion forum on the latest developments around once-daily therapy and adherence, in which a doctor, nurse and pharmacist will all share their views with you. Concurrent sessions will be held to give you the opportunity to present your research or examples of good practice. We have listened to the feedback from last year and have tried to make this year's conference more interactive, with discussion panels, debates, workshops and more time in the programme to ask questions and share experience. As always we encourage you to submit an abstract for the conference. Abstracts do not have to be research-based: they can be examples of good

practice or nurse-led initiatives that are happening in your centres; remember there are prizes to give away! The deadline for submission is Friday 30 April. If you have not received information regarding this year's conference yet, contact our conference organiser on nhivna@conass.co.uk or ring 0797 331 5915.

NHIVNA wants to play an active part in helping to develop nurses' knowledge and skills. One of the ways we are doing this is by running a series of workshops around the country aimed at D-, E- and F-grade nurses. The first is being piloted in London. The topics to be included are managing newly diagnosed patients and treatment support, with emphasis on the nurses' role and how nurses can develop skills to run nurse-led clinics, and write nurse-led policies and guidelines. We will keep you informed of future days to be held. We are running these days with the support of an unrestricted educational grant from GlaxoSmithKline.

The NHIVNA website is getting a new look for 2004, so if you want further information on the grants, conference or links to other useful sites, then log on to www.nhivna.org.uk

Nicky Perry, Chair, NHIVNA, Brighton

Book review

HIV and AIDS: a foundation for nursing and healthcare practice

Robert J Pratt

Edward Arnold Limited, London, 2003,
ISBN 0340706392, £18.99

After a wait of nearly 9 years, the latest (5th) edition of this ground-breaking text has just hit the bookshelves with a resounding thump (literally, it seems to weigh at least a third more than the 4th edition). There are more chapters (an increase from 19 to 23), though no appendices, a wise choice given the fact those in the 4th edition dated very quickly.

Comparing the two editions, what impacts upon the reader immediately is that each is very much locked into its own *zeitgeist*. Each represents the current state of knowledge within the rapidly changing context of HIV and AIDS, as well as broader global advances in the fields of politics, culture, science, technology and medicine.

Perhaps the most obvious feature of the new edition is the plethora of websites in the reference lists, reflecting perhaps the shift from paper to byte that has overtaken the world since 1995. Another new feature, and remember, the last edition appeared just before the 1996 Vancouver conference at which antiretrovirals really took off, is the in-depth consideration of antiretroviral treatment. There is also a section on problems of adherence, a notion that was not such an issue in 1995, given the limited treatment options available. Complementary therapies also get a look-in, again a result of major changes in the nature of care interventions in all specialities, not just HIV.

Sections on children and women with HIV remain, albeit updated. The detailed consideration of the science of HIV, immunology and modes of transmission are current and informative. The cover suggests the book is intended for 'healthcare practice' as well as nursing, though throughout the emphasis is very much on the latter. It's good to see Carol Pellowe's contribution on HIV in the industrially developing world; as with all 'fault line seeking' diseases (such as HIV and tuberculosis), countries in the southern hemisphere are always affected the most. Sexual inequalities in these regions are especially crucial in the spread of HIV for, as Carol says, 'the oppression of women by men has a major impact on a woman's ability to protect herself against infection or access to treatment'.

What is also interesting from an educational perspective is the addition of learning outcomes at the opening of each chapter, and summaries at the close. Certainly this is the standard for clinical texts published in the new millennium, but it was by no means standard in the mid-1990s. These additions

to the text add rigour and direction to the new edition, allowing a more systematic consideration of the material.

So, overall, this is a significant book, though I do have some gripes (which reviewers don't?). There is a marked emphasis on the mechanics or pragmatics of HIV. Thus, prominent themes in the book are science, treatment, infection control, transmission, symptomatology and co-infections. Of course, we need to know about all these, and this book covers them well. But what of the problems around HIV stigma? Many major non-governmental organisations (World Health Organization, United Nations Joint Programme on HIV/AIDS, Terrence Higgins Trust, National AIDS Trust, International Council of Nurses, International Red Cross/Crescent Society) currently have extensive programmes aimed at reducing what many see as a construct as harmful as the virus itself, and one that impacts directly on nursing care [1]. Also, HIV vaccines get only a passing mention: a shame, as many consider these to be the only long-term solution to controlling HIV in the developing world, even with limited efficacy [2]. A chapter explaining the science of vaccines and the serious challenges in the field would have perhaps been useful. Another feature I would have liked to see is some reference to fiction published in recent years. For example, Adele Minchin's *The Beat Goes On* [3] and Meja Mwangi's *The Last Plague* [4] both consider the personal impact of HIV upon UK teenagers and Kenyan villagers respectively. Fiction can provide valuable insights into how the virus interacts with people living in their communities, away from the hustle and bustle of clinical practice and far from the reach of sophisticated healthcare systems.

But these are personal views. As Prof Pratt says in the introduction, 'almost 20 years on, the goals are the same, the dangers are still real, the challenges are still there', and this book continues to constitute an important nexus between medicine, immunology/virology, epidemiology and the delivery of care. As such it remains at the forefront of UK-based texts and a valuable resource for specialists and non-specialists. I'll continue to recommend it to all students and qualified nurses who wish to understand HIV.

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A pilot study of the lived experience of HIV-positive patients with lipodystrophy

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This research was undertaken from October 2001 until June 2002. It is surprising that at that time there was little literature on the psychosocial aspects of this condition. Although, it was acknowledged that lipodystrophy could have an adverse effect on a person's general well-being [1,2].

Lipodystrophy was first noticed during 1997 among people who had been taking protease inhibitors for several months [3]. Originally named 'Crix belly', the syndrome was reported as abnormal weight gain among people taking the protease inhibitor indinavir (Crixivan, Merck Sharp & Dohme, Rahway, NJ, USA).

Body fat changes include both fat loss (lipoatrophy) and fat accumulation (lipodystrophy). Fulutz and Turcot [4], at the San Diego Lipodystrophy Workshop in 1999, produced a working definition of these fat redistribution and related metabolic disorders, which included the following bodily features:

- sunken cheeks;
- increase of fat in the face;
- prominent veins in the legs (not associated with heavy exercise or muscle-building routines);
- loss of fat in the arms and legs;
- loss of shape in the buttocks;
- increase in fat around the gut, called truncal or central obesity (this is not the soft fat deposit under the skin that is associated with ageing, but a rapid increase in girth caused by the accumulation of hard fat deposits behind the abdominal muscles);
- breast enlargement;
- fat pad on back of neck (sometimes called buffalo hump); and
- lipomas (fatty growths in different parts of the body).

Methodology

Experiences throughout a person's life as well as their social and physical environment influence the individual's identity and perspective of the world [5]. In the context of healthcare, people will have experiences that have moulded their ideas, perceptions and assumptions about health and illness. It is therefore necessary to employ research methods that enable these perspectives to be recognised, and to assign value to personal experience and knowledge.

Phenomenology was chosen as the research approach, because the researcher wanted to explore people's lived experiences [6]. The qualitative method chosen was phenomenology after Van Manen [7].

Sample

A purposeful sample group was used for this study, as this method of sampling selects individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge.

The inclusion criteria were:

1. Patients would be HIV positive.
2. Patients would have been on antiretroviral therapy for more than 6 months.
3. Patients' viral load was below the level of detection (less than 50 copies, and their CD4 count would be above 100 copies per ml).
4. The patient would have been defined as having lipodystrophy by their HIV consultant and themselves.

All patients were accessing their HIV care at the HIV outpatients department at the Royal Sussex County Hospital, Brighton and were already under the care of the Community HIV Nursing Team.

Of the five participants who took part in the study there were two women and three men. Three participants were of white British and two of Hispanic origin. Ages of the participants ranged from 34–62 years. All participants had been HIV positive for more than 5 years, and had been on antiretroviral medication for at least 5 years. All the CD4 counts were about 200 copies/ml and all the viral loads were undetectable.

Ethics and analysis

To address the ethical implications of this study, the research proposal was submitted to and passed by the Local Ethics Committee. Patients were given information sheets explaining the study and were asked to sign a consent form. All patients were interviewed in their own homes to enable them to feel more comfortable with their surroundings and feel more in control over the interview process.

All interviews were taped and typed up verbatim. The researcher read and re-read the transcripts multiple times, putting phrases and categories in the side margins. These were then clustered into

related aspects and, with continuous immersion and reflection, themes began to develop. Five essential themes were derived, which will be explored under separate headings below.

Having no control

All of the participants who were interviewed talked about experiencing changes, which gave them a sense of having 'lost control' over their body shape.

'It's like waking up in the morning in a different body. You're still the same person, but in a different body, and there is nothing you can do about it, and you can do everything you can do by the book. You're just trapped in another body, you can't choose, you haven't done anything wrong. You can't get rid of it because it takes you everywhere. The real you is not there, this is the new you, (laughs) and when it's self-inflicted it's okay, but when it's something else, I did not ask for this you know, why do I get this?'

Another participant felt that although they were doing everything right, their body was still changing so the control was with the 'powerful' others.

'... then it started to be an issue ... and all these veins and all this muscle, I started to hate them. It was not me, I'm doing everything right and this is happening. I don't like it. I don't want it!'

Life constantly changing and adapting

Another aspect, which was a constant theme, was the participants' constantly changing lives and the need for yet again more adapting.

'... How does your mind adjust to this? You are adjusting 24 hours to medication, side effects, this and that, new life, now you live, now you die, it's as basic as doing things when and how you want, normal people take this for granted.'

Most patients with serious progressive illness confront a range of psychological challenges including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline and death, and coping with uncertainty.

The researcher found that participants claimed that they had previously been able to cope with HIV and still feel good about themselves but that now, with the body changes, coping had become increasingly more difficult. One participant found himself filling his cheeks full of air so that his face did not look so thin.

'I was in the bus, and I looked at myself in the reflection and thought "Oh! What am I doing?" I realised I had been doing it unconsciously and now I'm doing it consciously.'

Adapting to and coping with lipodystrophy appears to be an endless aspect that patients are

dealing with in their own way. They long for the feeling of being normal and accepted, and this is part of continually trying to cope and adapt.

'... I want some normality, so I try to look a bit normal more than anything else, but yes, still, sometimes it takes a bit of courage to face the music and dance really.'

Having low self-esteem

The data revealed that all five participants had a negative internal perception that could be attributed to the physical and psychological limitations that lipodystrophy had caused.

'... when I look awful like a witch, this affects my self-esteem, with all the hard work I've done in the counselling sessions and inner child workshops, this has been bashed by my physical appearance, how I look, how people portray me ...'

It is not surprising that body changes can have such a negative impact on self-esteem. Our culture attaches great significance to physical appearance and makes it a critical component of self-worth. For women and for gay men this is especially emphasised, which may have accentuated the psychological distress evident in this sample of respondents.

'It's quite extraordinary how it does affect you. But I don't tend to look at myself anymore anyway (pulls a face in disgust).'

Feeling isolated

All of the participants had various issues around isolation, usually from the impact of body image and potential forced disclosure. Disfigured people often experience extreme discomfort in social situations and consequently avoid them [8].

'I separated myself from my friends; what I did, I locked myself away for so long without seeing anybody and then I was scared to see them again, because during that period of time I lost much more weight, so I was even more worried ... (laughs).'

Effects on social relations related mainly to social withdrawal; this was due to people staring. One participant talked of how when doing his shopping he would not look at anybody, as he knew people would stop and look.

'... I walk with my face down; I don't walk looking at anybody. What you can't see, can't hurt you ... I always put a book to hide myself ... I hide myself all the time under my collar. My hood on my top ...'

Needing information

All of the participants expressed concerns about information, mainly being informed of up to date changes about lipodystrophy and its treatment.

Doctor-patient relations and attitudes of health care providers were a common issue for participants, with patients experiencing doctor's minimisation, or frank disregard, of the impact of lipodystrophy.

'... but you know, the doctor, he actually said to me, "It just happens," sort of thing. You know, he actually thought: "Well it happens. What do you want me to do about it!" ...'

Results

The availability of highly active antiretroviral therapy (HAART) has changed the horizon of daily life for patients infected with HIV. Along with the improved prognosis of survival, many successfully treated patients infected with HIV have been able to normalise their lives. In this context lipodystrophy unexpectedly appeared. The pathogenesis of lipodystrophy is not known, although this problem is considered to be an untoward effect of long-term antiretroviral therapy.

For several reasons, body changes affect the quality of life of patients. Body changes are usually noticed suddenly and they produce an unhealthy or undernourished aspect that resembles wasting, which leads to disfigurement of the body.

The five main themes, which have been discussed, all intertwine with each other. They appear to have a knock-on effect, within the life of each participant. The main aspects of the negative impact of lipodystrophy are attributable to stigmatisation. Body changes caused by lipodystrophy can be readily seen by others, particularly facial atrophy, which may identify AIDS in a way that is similar to that of wasting in the past. Some patients with facial atrophy feel they have 'the word AIDS permanently written on their face'. This situation can become very unpleasant for patients, having an impact on their relations with others, including their partners and friends.

It can determine the quality of their lives by limiting physical activity, lowering self-esteem, and bringing fear, dependency, loneliness and isolation. In a culture that prizes appearance, body shape distortions have driven some patients to retreat from social activities.

Patients felt less attractive and were unlikely to go out and meet people. They were permanently self-conscious about their bodies and, for some, the benefit of survival outweighed these limitations. For most, there was an overwhelming feeling of a lack of control of their HIV infection and life, which introduced the possibility of their mood becoming low and losing interest in complying with their complex antiretroviral regimens.

Discussion and conclusions

This pilot study of the lived experiences of patients with lipodystrophy has recognised that

lipodystrophy may have important psychological repercussions. The best psychological approach for this problem is not known at present, although for nurses working with patients with lipodystrophy there are a number of areas that can benefit patient care. I have related these areas to the five themes:

1. Having no control: nurses can support their patients by exploring why they feel they have no control. Understanding and empathising will enable the nurse to assist patients to modify and manage their living conditions, so making major emotional adjustments.
2. Life constantly changing and adapting: nurses are in a prime position to empower patients to change their lifestyles. It is important to consider the role of lifestyle modification in the long-term management of the signs and symptoms of lipodystrophy. Dietary changes, increased exercise and discontinuation of smoking may have positive effects on HIV-related lipodystrophy without the potential side effects of adding additional medication to antiretroviral regimens.
3. Having a low self-esteem: patients' level of mood is affected by low self-esteem. Nurses must be made aware that denial has been shown to correlate with low self-esteem and depression in HIV patients [9]. The unpredictability of the course of the syndrome and the sudden and often reversible disruptions in psychological and physical states require nurses to continuously assess their patients before interventions can be made.
4. Feeling isolated: inherent in this aspect is the feeling that isolation requires involvement. Patients often recognise that their Clinical Nurse Specialist may be the only professional involved in caring routinely for them, so they can be a key player in exploring and sharing ways of dealing with this issue. Setting up an informal support group may also be beneficial. This could enable patients to share their feelings, thoughts and individual coping mechanisms.
5. Needing information: healthcare professionals should continue to inform patients about the limited information and knowledge on the pathogenesis and epidemiology of lipodystrophy. Treatments, for example New-fill, should be talked through with the patient to address the issues around access, side effects and support.

Lipodystrophy is a major cause of concern for a growing proportion of patients infected with HIV, who are compelled to receive long-term antiretroviral therapy. This problem may dramatically diminish the effectiveness of current antiretroviral regimens. While awaiting to discover its pathogenesis and to design effective preventive and therapeutic approaches, as healthcare professionals we need to assess the impact that lipodystrophy may have on the everyday life of patients infected with HIV.

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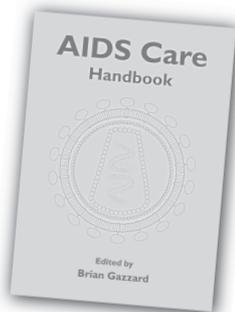
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