Volume 9 Number 3 Autumn 2009

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

International issues

Editorial

Features

Research round-up

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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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Responding to international policy developments: challenges and opportunities for HIV nursing

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For all the tragedy associated with HIV, the global response has been responsible for pioneering radical social and cultural change in many countries. Amongst those cultures that have been challenged to change has been the culture of healthcare provision and nursing in particular. The large scale roll-out of routine HIV testing and antiretroviral therapy is again creating a massive challenge to established healthcare systems, roles and practices. This edition of *HIV Nursing* is taking an international perspective and includes articles from a range of countries and continents. What they have in common is an emphasis on support for nurses at the forefront of best practice in HIV care, adapting with confidence to the changes taking place in the health systems around them.

One such major change associated with the expansion of HIV care is 'task shifting' – the identification of specific tasks associated with specific aspects of HIV and the reallocation of these tasks to different cadres of healthcare worker. Task shifting can move in both directions. In the case of nursing, it can mean nurses taking on advanced roles (e.g. establishing nurse-led antiretroviral therapy (ART) programmes) or delegating what were previously considered nursing roles to less qualified cadres (e.g. HIV testing or adherence support being done by lay counsellors). The discourse and practices associated with task shifting vary tremendously from context to context and have generated much controversy [1–3]. The WHO, UNAIDS and all other major global health agencies that set the agenda for HIV have embraced task shifting [4,5]. It is seen as one solution to the massive health worker shortage that constitutes one of the key barriers to scaling up crucial HIV interventions. In spite of the task-shifting enthusiasm of global health agencies, however, nurses are ambivalent. As an example, at the recent International Council of Nurses Congress in Durban, a debate on task shifting led to extremely heated exchanges and the motion (which was in favour) was defeated.

The majority of those in the audience of 5,000 were nurses from sub-Saharan Africa.

So what are nurses' key concerns? In Durban, the key concern was that task shifting in reality will become a guise for 'task dumping', cost cutting and the loss of a holistic approach to care [6]. A particular concern was how adequate clinical supervision and quality assurance can be maintained in contexts where there are already extreme staff shortages. It was recognised that examples of successful task shifting existed, but these were considered to be well funded and unrepresentative 'islands of excellence' (services receiving additional donor funding and human resources) that are very different from the ordinary government health services found in most parts of a country. Lack of adequate recognition and remuneration for expanded roles were also key concerns. Many countries in sub-Saharan Africa lack competency-based career or educational pathways. Transplanting task shifting into systems where roles, scope of practice and competencies are not clearly defined through national career progression and salary scales is creating understandable anxiety and professional resistance [7]. HIV nursing leaders have argued that, as with other aspects of HIV, task shifting represents a potential threat to the integrity and identity of the nursing profession but, handled right, it also represents an enormous opportunity for nurses to demonstrate their ability to take on advanced and expanded roles [8]. In many countries, nurses' roles are limited and the task-shifting agenda could be a tremendous driver for the positive development of the nursing profession [9].

Due to the task-shifting and HIV agenda, nursing across the world is receiving unprecedented attention from global health bodies and unprecedented resources are flowing into nursing education and training. The critical challenge for nurses worldwide therefore is to respond proactively to these policy developments and to ensure that nursing issues are recognised. In order for nurses to influence policy, however, they must be able to present convincing evidence to support their demands. There is an urgent need to provide sound evidence of the outcomes and efficacy of nurse-led HIV care. Studies need to evaluate not only whether nurses can provide equivalent care to doctors, but should also assess whether there are quality-of-care differences between interventions delivered by trained nurses vis-à-vis less-qualified healthcare workers. Such evidence needs to include a cost–benefit analysis and a process evaluation to ensure that important contextual factors that affect service delivery are understood (e.g., exploring staff satisfaction, the patient experience or organisational systems and resources). Good-quality evidence on task shifting in relation to nursing is currently very sparse (see Research

round-up, page 22). Generating such evidence internationally represents one of the greatest challenges for HIV nursing in the coming years.

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The ARCAN cascading model: enhancing nursing capacity in East Africa

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Project summary: The African Regional Capacity Building Network for HIV/AIDS Prevention, Treatment, and Care (ARCAN) initiative is a World Bank project. It aims to complement the efforts of the Kenyan, Tanzanian and Ethiopian governments by training nurses and other professions to manage the adverse effects of the AIDS epidemic. Aga Khan University Advanced Nursing Programme is among six institutions given the responsibility of conducting training of trainers (TOT) courses for nurses in the three countries. The training is on HIV/AIDS prevention, management and care, TOT skills development and HIV/AIDS project development and management.

Aims and method: To increase the number of trained healthcare providers and impart the training skills as broadly as possible, ARCAN and the various HIV and AIDS Control Councils are implementing a cascading TOT project for nurses to provide quality care for patients suffering from HIV and AIDS in order improve quality of life, achieve leadership competence, and sustain nursing knowledge and skills through continuing education. Trainers develop skills in implementing, monitoring, and managing pre-identified projects that are developed whilst they are attending the course.

Results: A total of 403 TOT nurses were trained between 2006 and 2008, with 64% coming from the public sector – in line with the fact that the public sector provides 60% of healthcare services in this region. Despite a lack of disbursement of funds for cascading trainings, some TOT nurses have already implemented the planned training in the workplace.

Conclusion: Nurses are capable of developing projects that address the HIV/AIDS pandemic. The TOT nurses have networked to enable cascading of the training. This approach can be used to rationalise the involvement of nurses in HIV/AIDS training activities in developing countries with high prevalence of HIV/AIDS.

Introduction

In June 2006, at the United Nations Special Session on HIV and AIDS, UN member states agreed to work towards a broad goal of 'universal access to comprehensive prevention, treatment, care and support programmes' by 2010 [1]. This ambition has brought governments and international organisations into action and countries have developed national strategies that clearly indicate priorities in the prevention and control of the infection. However, these plans have paid little attention to developing human resource capacity. Universal access to HIV services cannot be possible without strengthened health services, including equipping healthcare workforces with current knowledge and skills in the management of those infected with and affected by the pandemic [2].

The results of a training-needs assessment conducted in 12 African countries by USAID [3], which included Ethiopia, Kenya and Tanzania, illustrated the disparity between the aims of national-level training programmes and the training gaps reported by key informants. The most critical training gaps identified in the country-specific reports included: clinical management of HIV and AIDS for healthcare practitioners at all levels; management skills for programme administrators; counselling and communication for healthcare providers; and community-based delivery.

The assessment findings emphasised the enormity of the existing HIV/AIDS-related training gaps and the critical need to enhance capacities of regional training institutions so that they are more effectively able to respond to the long-term needs. It is against this background that the World Bank-funded project – the African Regional Capacity Building Network for HIV and AIDS Prevention, Care, and Treatment (ARCAN) intervention in the sub-region was established. It aims to complement ongoing Kenyan, Ethiopian and Tanzanian government efforts in this area by supporting HIV and AIDS TOT (training of trainers) courses in the following six thematic areas: nurse, counsellor supervisor, physician, laboratory technologist, programme managers and TB and HIV care providers. Aga

Khan University – Advanced Nursing Studies Programme in East Africa (AKU–ANS EA) is among the six institutions that are given the responsibility of conducting TOT courses for nurses from the three countries. In the context of the global HIV epidemic, nurses are involved in prevention efforts as well as in caring for patients living with HIV or sick with AIDS. Thus, there is need for nurses to be involved as trainers in the fight against HIV and AIDS.

AKU–ANS EA commitment to this initiative is reflected in the mission of Aga Khan University (AKU) in East Africa, to become the premier centre of learning and to provide quality programmes for continuing education that increase competence and lead to the acquisition of higher-level academic awards and degrees. The mission is being achieved by using innovative curricula and adult teaching and learning strategies; and also by developing the capacity to conduct and utilise relevant research, thus enhancing quality of life for those infected with HIV and TB.

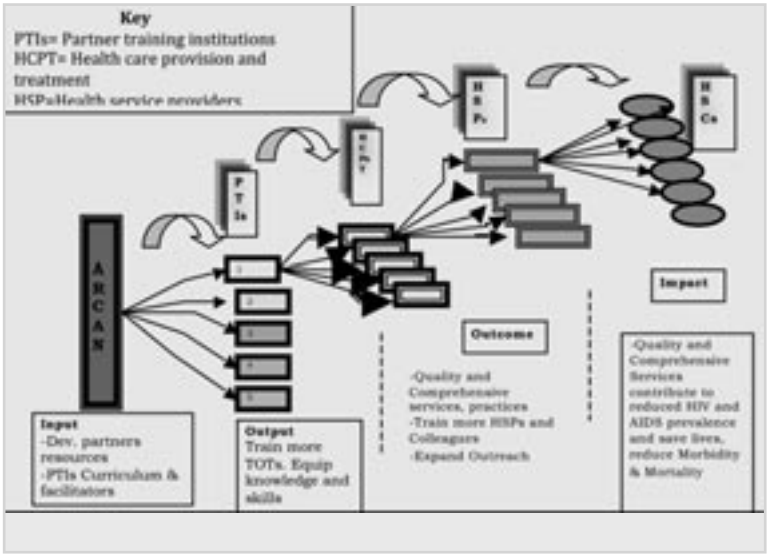

Figure 1: *The cascading model and its multiplier effect*

The ARCAN cascading model

To increase the number of trained healthcare providers and impart training skills as broadly as possible, ARCAN and the various HIV/AIDS Control Councils are implementing a cascading TOT project. Trainers develop skills in implementing, monitoring, and managing pre-identified projects that are developed whilst they are attending the AKU–ANS course. The countries are expected to provide financial support for four trainings of 40 participants per TOT, per year. Thus for a class of 30 TOTs attending the AKU–ANS course, a total of 1,200 healthcare providers will have been trained at a much lower cost than by using traditional training methods. The project, through a series of six courses each year, trains a core of 180 nurse TOTs who, in turn, cascade training that is expected to reach 7,200 health service providers in the three countries experiencing one of the highest prevalence rates in Sub-Saharan Africa. The participants select HIV/AIDS projects that are most urgently needed in their institutions or communities.

AKU–ANS EA adopted the ARCAN cascading model for the TOT programme and is using a multisectoral approach in bringing together facilitators from diverse professional backgrounds.

Project successes

By mid-2009, AKU had conducted 15 trainings and participated in follow-up experience-sharing forums conducted in conjunction with the country's National AIDS Control Councils (NACC), where project work plans developed by nurses were reviewed for compliance with the respective national HIV/AIDS Strategic Plans. In order to meet gaps identified during the experience-sharing forums, AKU has also conducted six refresher training courses addressing the identified gaps in the previous TOT courses.

A total of 403 nurses have graduated as Nurse TOTs in HIV and AIDS, and the group is now officially recognised by the National AIDS Control Councils as national resource trainers in HIV and AIDS. Sixty-four percent of the TOTs were from the public sector, 19.8% from the faith-based health institutions, and 16% from the private sector. Country representation included 37% from Ethiopia, 36% from Kenya and 27% from United Republic of Tanzania. Although not all three governments have disbursed funds to TOTs for cascading activities, several TOTs have cascaded using resources from other funders. The groups have also formed national forums in their individual countries to help mobilise funds for training activities. Continued communication between TOTs and facilitators is enabled through group emailing systems managed by one of the alumni.

Cascading the training

TOTs who were able to get funding support cascaded training in the area of prevention of new infections, improvement of quality of life, and mitigation of economic impact in HIV and AIDS. Those from educational institutions used the course materials to initiate change in the existing curriculum, as indicated by the following comment: 'I did not implement my work plan due to unavailability of the fund. Instead I had integrated the HIV and AIDS knowledge I got from the training in the normal Community Health Nursing and Community Medicine class sessions.' (graduate from Hubert Kairuki Memorial University, Dar es Salaam). Training was the most common activity undertaken by the TOTs in the workplace: community-level, youths, PLWHAs and caregivers, and training of discordant couples.

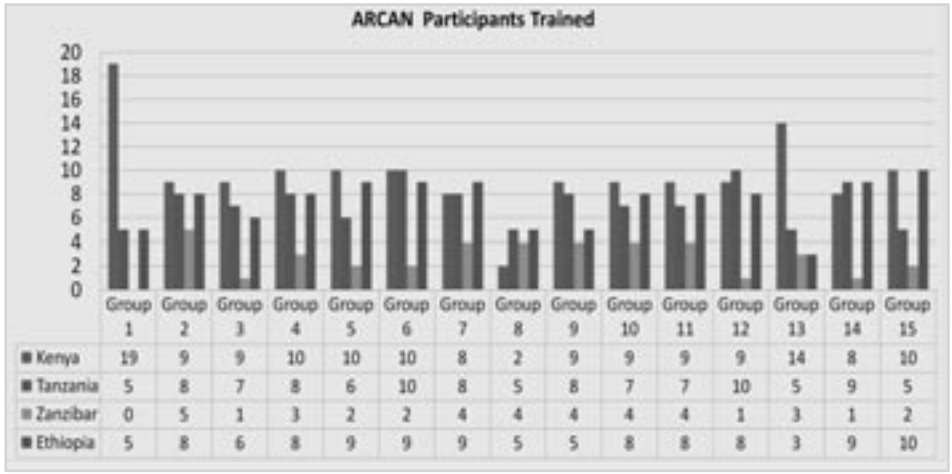

Figure 2: *Country-by-country breakdown of ARCAN training achieved.*

Project challenges

Since the project began in 2006, experience has afforded many lessons regarding the implementation of nurse TOT programmes. Training participants and facilitators have identified lessons learned through innovations and challenges encountered over time.

Cascading funds

Each graduate was expected to cascade their training with a set target for the number of trainees to be reached each year. However, this was not possible as originally planned due to lack of reliable sources of funding at the national level. Only a limited number of TOTs managed to mobilise funds to cascade their training in their workplaces. Because of the inability to meet their targets, several TOTs interviewed during experience-sharing national meetings and refresher courses felt that they could have trained more healthcare providers or community groups had funds been available.

Unmet capacity-building needs

Based on ARCAN's innovative approach in training course participants, the demand for the courses outstripped the available funds, suggesting a greater need for capacity-building in prevention, treatment, care and support among nurses in the three countries.

Realising the TOT course goals

Although having a skill to train others is important to enable TOTs to perform their role as trainers, facilitators realised that in addition, project planning and management, and entrepreneurship courses were required to ensure TOTs' success in cascading the planned trainings.

Harmonisation of the national curriculum

The difficulty in the adoption of the ARCAN curriculum and the inclusion of ARCAN TOTs by National AIDS Councils in country-specific HIV and AIDS trainings were noted. The national stakeholders in HIV and AIDS prevention, treatment, care and support fully participated in the review of the curriculum, selection of the participants and organisation of national network meetings with TOTs; however, recognition of the need to harmonise training curricula was a more difficult area in which to establish dialogue and feedback. Thus the use of TOTs in national training is still being discussed.

Vertical integration

The project lost one year, as a new structure to support the co-ordination of the training by the six institutions was being set up in Tanzania – and when implementation started, the national integration of the project was difficult as the situation on the ground had changed for cascading, especially the funding availability. Hence, though a lot has been done to try and integrate the project nationally, little has been achieved in terms of the disbursement of funds for cascading training by TOTs.

Project innovations

1. *Encouraging TOTs to be innovative:* To realise their goals, TOTs require additional support to implement their work plans and subsequently capitalise on the acquired skills. Follow-ups, experience-sharing meetings at national level, refresher trainings, and inclusion of entrepreneurship and personal development as additional topics, were required to motivate the otherwise disillusioned TOTs who were willing to implement activities proposed in their work plan but could not access national funds. To promote involvement of TOTs in cascading training where funds are lacking, the course participants were trained in entrepreneurship and writing proposals for HIV and AIDS prevention funding.

2. *Networking with ARCAN TOTs from the six thematic areas:* With increasing numbers of TOTs from other thematic areas, ARCAN organised Experience Sharing Workshops in each country that brought together TOTs from all six thematic areas to exchange information, and form networks, to help forge a joint proposal for funding purposes. The success in mobilising the TOTs has helped in the formation of National ARCAN Networks that are working closely with the stakeholders. Trained nurse TOTs also established their own communication network using a group emailing system.

The way forward

Although the ARCAN Project is ending in December 2009, partnerships with the implementing training institutions in Kenya, Ethiopia and Tanzania remain. The lessons learned in the project's lifetime have created a stronger bond between these institutions, leading to the writing of a joint concept paper to seek funds to continue the trainings. This group of institutions has also worked closely together and each has produced guides for both trainers and participants, to facilitate future trainings.

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US perspective: the role of the advanced practice nurse

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Introduction

Currently, President Barack Obama of the United States is proposing major healthcare reform in which the millions of Americans who are uninsured or underinsured would be guaranteed healthcare. At the same time, it is projected this healthcare option could exacerbate the shortage of primary care physicians by as much as 300,000 within the next ten years. According to the American Academy of HIV Medicine (AAHIVM) and the HIV Medicine Association (HIVMA), fewer physicians are choosing HIV care as a career and as many as one third of all physicians currently providing HIV care plan to retire within the next ten years [1]. Advanced practice nurses (APNs) or nurse practitioners (NPs) are uniquely prepared to fill this expected gap. Research has shown that HIV care provided by NPs, as well as physician assistants (PAs), is equal in quality and outcomes to that of HIV physician specialists [2]. This article will outline the role of the APN in the HIV epidemic, as well as discuss the possible impact current APN education programme changes may have in the care of HIV-infected persons in the US.

Historical impact

Advanced practice nurses, whether in the role of academicians, clinical specialists or NPs, have been at the forefront of HIV care and practice in the United States since the advent of the epidemic in the early 1980s. While the HIV epidemic and its resultant devastation – progression to AIDS and influx of severely ill patients into hospitals – often led to surprise, fear and sometimes irrational responses in the inadequately prepared healthcare systems of the United States, nurses in general met the evolving needs of this growing patient population. It is an advanced practice clinician, Cliff Morrison, who is credited with the design and establishment of the first specialty care unit for HIV and AIDS within a hospital, at San Francisco General Hospital in 1983 [3]. In this unit, registered nurses and advanced practice clinicians provided specialty care for this diverse and challenging patient population with a condition that typically led to death. One might suspect that, like the backgrounds from which these nurses came – oncology and infectious diseases, as well as medical-surgical experience – the differentiation between registered nurse and advanced practice nurse often became irrelevant and blurred. The goal was to meet the needs of the patients and their families.

As the HIV epidemic progressed, effective therapies became available and those infected began to live with their infection, facing further challenges of surviving; HIV nursing practice likewise evolved over time. As treatment of chronic infection and control of opportunistic infections changed to outpatient ambulatory management, the complexity of this management increased. Primary care NPs – family nurse practitioners (FNPs), adult nurse practitioners (ANPs) and paediatric nurse practitioners (PNPs) – became skilled in the management of complex therapies, viral dynamics and resistance, comorbidities and multiple psychosocial issues. Physician HIV specialists generally embraced and worked collaboratively with NPs in caring for their growing HIV-infected populations.

Certification and HIV specialty

Certification as an AIDS Certified Registered Nurse is available through the HIV/AIDS Nursing Certification Board. However, a specific advanced practice exam was not available until November, 2003. Since that time, APNs with the educational preparation of a master's degree or higher, who function as NPs or clinical specialists, have been able to take this exam, demonstrating advanced knowledge, skill and expertise in HIV nursing practice and earning the credential AACRN – Advanced AIDS Certified Registered Nurse [4]. While HIV nursing is recognised as a specialty by the American Nurses Association, role delineation studies are currently under way in order to obtain accreditation of certification as a specialty by the American Board of Nursing Specialties (ABNS), a further step seen as necessary to assure excellence in HIV nursing, especially for advanced practice nurses [5]. Some of this may change as educational and specialty requirements for advanced practice change over the next few years (see, The future of AP education …, below).

Nurse practitioners are able to demonstrate expertise by gaining accreditation as an HIV Specialist with the AAHIVM, as this mainly-physician organisation does allow NPs to become members and to gain accreditation. NPs are reported to be approximately 10% of the membership of AAHIVM [6]. The designation of HIV

specialist is required by certain institutions and reimbursement organisations. While AAHIVM accreditation leads to designation as an HIV specialist, this designation is sometimes defined by hours of care given or number of patients in the providers' caseloads. Expectations of the HIV specialist range from the basic – an understanding of and familiarity with the latest information about HIV – to the specifics of diagnostic techniques, immunological monitoring, management of HIV disease and opportunistic infections and areas such as preconception counselling. Expectations of the HIV specialist are listed in Panel 1; for paediatrics, see Panel 2.

NP practice in the US

The first NPs were educated in the US at the University of Colorado in 1965 in an effort to meet a shortage of primary care needs in areas of physician shortage. The 325 NP programmes in the US produce about 6000 new NPs each year. Over 125,000 NPs are practising currently in the US, providing 600 million patient visits per year. With over 40 years of outcome research, the holistic care approach of NPs has been shown to consistently provide personalised high-quality and cost-effective care. Studies and systematic reviews most recently reporting these quality outcomes are found in both routine primary care, as well as HIV care [2,7–9]. It is not known how many NPs actually provide HIV care in the US; certainly recognising HIV practice by NPs as an accredited specialty and required certification to practice would provide a better accounting of this number.

The future of AP education: what implications for HIV practice?

Few nursing graduates in the US receive any concentrated or dedicated HIV curriculum content in their basic or advanced nursing courses. Within the Master of Science programme at University of California San Francisco, a minor in HIV/AIDS Nursing is available. The Massachusetts General Institute of Health Professionals School of Nursing offers a nine-hour certificate curriculum. Some universities have global capacity-building programmes in resource-poor settings that provide students with opportunities within their curriculum, but in general HIV content is lacking

In 2004 the members of the American Association of Colleges in Nursing (AACN), the primary accrediting body for nursing education programmes in the US, endorsed the position statement on the Practice Doctorate in Nursing and voted to move the level of educational preparation for advanced practice nurses from the master's degree level to the doctorate level by the year 2015. What does this mean for current NP programmes? They will need to transition to Doctorate of Nursing Practice (DNP) programmes in order to be AACN-accredited. A roadmap for this has been developed and published, along with 'The Essentials of the Doctoral Education for Advanced Practice Nursing' [10]. Rationales for this change in educational requirement include the increasing complexity of healthcare in the US, concern for quality of care, the need for non-research clinical doctorate preparation to help fulfil clinical faculty needs, and the need to be prepared at the same level as other healthcare professionals that already require or have transitioned to doctorate-level education, such as pharmacists, physical therapists and clinical psychologists.

There are currently 200 or more DNP programmes approved or in formation in 34 states. Some have questioned whether this education change might lead to further healthcare provider shortages; yet enrolment in DNP programmes went from 1,874 in 2007 to 3,415 in 2008, and graduates increased from 122 to 361 in the same period. It is important to note that currently practising NPs will be 'grandfathered' and able to continue to practise if they are already licensed and accredited for advanced practice. Those NPs will not be forced to return to school for doctorate-level education although they may voluntarily do so.

The AACN's Consensus Model for Advanced Practice Registered Nurses (APRNs) designates the following four roles for advanced practice: Certified Registered Nurse Anesthetist (CRNA); Certified Nurse Midwife (CNM); Clinical Nurse Specialist (CNS); and the Certified Nurse Practitioner (CNP) [11]. How does one become an APRN? The routes to achieving this are as follows:

- completion of an accredited graduate-level education programme in one of the four recognised roles;
- national certification that measures role and population foci competencies;
- acquisition of advanced clinical knowledge and skills for direct care;
- practice builds on that of the registered nurse, with greater knowledge, skills and autonomy;
- educational preparedness to assume responsibility and accountability of health promotion and maintenance, as well as diagnosis and management of problems;
- sufficient experience for licensure.

Why is this important to advanced HIV nursing practice? The model provides for regulation through licensure, accreditation, certification and educational requirements that are consistent state to state, reducing barriers to practice following relocation. One way this will occur is that licensure will occur at the level of role and population foci – and this is important in relation to HIV practice. The specialty areas or population foci will be family/individual across the lifespan; adult/gerontology; neonatal; paediatrics; women's

Panel 1: **Expectations of an HIV specialist** [12]

An HIV specialist should have an understanding of and familiarity with the following areas:

- Latest information about HIV disease and treatments. Advances in antiretroviral therapy continue to make HIV a dynamic field. Data regarding new drugs and their combinations continue to emerge, changing standards of practice. Familiarity with these new drugs, their side effects, including treatment-related lipid disorders, and interactions with other drugs is a feature of basic HIV care.
- State-of-the-art diagnostic techniques, including quantitative viral measures and resistance testing.
- Immune system monitoring.
- Strategies to promote treatment adherence, including methods to elicit information about adherence from patients, techniques to measure adherence in clinical practice, and referral sources for adherence support services.
- Management of opportunistic infections and diseases. Basic familiarity with the clinical presentation and proper diagnostic approach to opportunistic diseases and a strong grasp of the therapeutic strategies to manage them are an essential part of basic HIV care.
- Management of HIV-infected patients suffering from commonly associated comorbid conditions, including tuberculosis, hepatitis B and C, and syphilis.
- Access and referral to clinical trials.
- Post-exposure prophylaxis protocols and infection control issues.
- Guidelines for prophylaxis to prevent vertical transmission and systems for referral to obstetrics providers with experience in management of HIV-infected pregnant women.
- Care coordination. Proper referral to other providers for specialty care (e.g., oral, ophthalmological, obstetrics, gynaecology, dermatology, nutrition, drug treatment).
- Patient education, including risk reduction/harm reduction counselling.
- Preconception counselling for women of childbearing age, including knowledge of contraceptive methods and ways to prepare for a healthy pregnancy.

Panel 2: **Expectations of an HIV specialist in paediatrics** [12]

The HIV specialist in paediatrics should collaborate with the mother's HIV specialist and obstetrics care provider to obtain maternal history prior to and during delivery.

In addition to the expectations of the medical specialist, an HIV specialist in paediatrics should have an understanding of:

- Factors associated with perinatal HIV transmission, including the impact of maternal viral load, antiretroviral therapy, mode of delivery, mode of feeding (breastfeeding vs. bottle feeding), and interventions to reduce transmission.
- Diagnostic testing schedule for the HIV-exposed infant, including interpretation of HIV tests in the newborn, appropriate diagnostic tests, and recommended testing schedules.
- The diagnosis, treatment, and prophylaxis of infections in HIV-infected and HIV-exposed infants, children, and adolescents.
- Immune system monitoring, including an understanding of the normal range of CD4 counts in children at different ages.
- Antiretroviral treatment of HIV-infected infants, children, and adolescents, including timing of initiation, the pharmacokinetics of particular antiretroviral agents, appropriate antiretroviral combinations, adverse effects of medications, and adverse interactions of medications.
- Regulatory requirements, including those regarding expedited and newborn testing for newborns, and reporting and partner notification for adolescents.
- Immunisation schedules for HIV-infected infants and children, as well as for non-infected infants and children living in homes with HIV-infected person(s).
- Mental health, psychosocial and educational needs of HIV-infected children and their families, including those related to disclosure of the infection, loss of family members, sexual responsibility, and educational difficulties.
- Adherence monitoring and support, including barriers to adherence specific to children and adolescents of different ages and developmental levels, and approaches to overcome such barriers.

health/gender-related; and psychiatry/mental health. Focus of practice beyond role and population foci will be linked to specific healthcare needs. Primary care of HIV-infected persons is one of those specific healthcare needs that definitely links to population foci and practice role as an NP or DNP. Several of the DNP Essentials are focused at preparing the DNP to provide leadership of teams as well as direct population-based care, thus positioning the DNP to care for the special populations like the HIV-infected and fill the possible gaps and shortages of physician-providers that may occur [11].

Summary

It is well known that the US healthcare system needs reform, and this impending reform could impact on HIV care as well as NP practice, either positively or negatively. US nurse practitioners also face educational and regulatory changes in advanced practice nursing that should lead to even more practice opportunities and improved outcomes for populations of HIV-infected persons. APNs who are HIV specialists currently provide high-quality care with cost-effective and positive outcomes; they are prepared and willing to provide population-based care for the HIV-infected population of the US.

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European perspective: a focus on Ukraine

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According to a report published earlier this year by UNAIDS, 'Hidden HIV epidemic amongst MSM in Eastern Europe and Central Asia', [1], there is a serious, yet invisible, incidence of HIV infection amongst men who have sex with men (MSM). Ukraine is cited as a country of particular concern, and the report calls for renewed government commitment to support programmes to amplify service access for this group, and ratify as quickly as possible new legislation that will set targets for HIV prevention and treatment.

Ukraine is an intriguing country. Once part of the Soviet Union, it has large areas of flat, prairie-like farmland. Remnants of the Cold War are still clearly in evidence, and all villages, and many houses – especially in the more rural areas – still have nuclear bomb shelters, now used as storage for gardening tools. In the mid-80s, however, there was real fear across much of Europe that nuclear war was imminent, and Ukraine, as the Soviet region where many nuclear missiles were stored, would have been one of the first to be targeted by Western nuclear weaponry.

Now, Ukraine's legacy from that period is similar to others in the region, a health system under severe strain, and inflexibility in addressing the complex needs of most-at-risk populations (MARPs) vulnerable to HIV. Currently, Ukraine has the highest prevalence of HIV in the European region, with 1.6% of the adult population between the ages of 15 and 49 infected [2]. This is around 440,000 people, and figures state that in 2007, 40% of new infections were attributable to injecting drug use (IDU). As a result, this group dominates the landscape of HIV. Harm reduction for IDU in Ukraine is gaining some ground, though largely due to the support of external agencies. Reluctance of the state health service for example, to provide substitution therapy for IDU, has certainly slowed progress.

In the context of MSM, a statistic that does give cause for concern is that in 2007, only 0.2% of new infections were reported in MSM [3]. This figure is just too low, according to UNAIDS – and is likely to be due to high levels of stigma against this group, resulting in a reluctance to attend voluntary counselling and testing services, the main source of

HIV prevalence data. This produces a poor picture of the actual number of infections in MSM, and in the last 20 years, only 158 MSM have been officially registered as living with HIV [1], which in a country having a population of over 46 million, is for UNAIDS simply unrealistic. An additional reason to suspect this figure an underestimation is suggested by reports saying that between 177,000 and 430,000 MSM live in Ukraine, and HIV prevalence ranges from 4.4% to 23.2%, according to region – the majority living in Odessa [4].

Partly as a result of skewed statistics, but also because of the high risk of HIV in IDU, funding has been steered largely towards the latter group. Much funding for harm reduction in Ukraine is from international donors such as the Global Fund, which is disbursing up to US$230 million, the bulk of which will be focused on IDU [5]. For people working in the field of HIV, the largely unaddressed vulnerability of MSM is a matter for great concern, especially as recent statistics suggest that knowledge about, and use of, condoms for anal sex declined from 2003–2007, with the percentage of MSM reporting the use of a condom the last time they had anal sex with a male partner falling from 70% to 38% [6].

What of the future in this at-risk group in Ukraine? In the context of IDU the International HIV/AIDS Alliance Ukraine argues that strong community involvement in contributing towards a national response to HIV is especially valuable [7]. For MSM, international NGOs are becoming more involved in addressing their vulnerabilities, and if government targets for increasing access to preventative services are put in place, then this could indicate progress. However, until attitudes towards MSM become more positive, and significant funding and resources are provided on a similar scale as that for IDU, then general progress will be slow, and fears of a hidden HIV epidemic will not be groundless.

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HIV in Australia

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Summary

This account presents two distinctive features of the HIV epidemic in Australia: firstly, the profile of HIV infection among the indigenous Aboriginal and Torres Strait Islanders; and secondly the impressive primary care-focused model for HIV management that Australia has adopted.

Background

Australia has one of the lowest rates of HIV/AIDS among developed countries (4.4 per 100,000). The rate of infection per population is very close to that of the UK though the absolute numbers are lower in Australia, where the population is approximately 20 million, compared with a population of 60 million in the UK. Between 1981 and 2008 in Australia, 28,099 people have been diagnosed with HIV infection, 6,762 have died, and the current number of people living with HIV is 16,692 [1]. Although prevalence rates are similar, the shape of the epidemic in Australia is very different from other Western countries, and varies considerably across the continent. Annual surveillance data show that HIV transmission in Australia continues to be primarily among Men who have Sex with Men (MSM). Of newly diagnosed infection 2003–2007, which increased by 21% on previous years, homosexual contact was the reported risk for 68% of cases, heterosexual contact 21% (39% of heterosexual cases were among people who came from countries of high HIV prevalence or whose partners were from such countries), only 3% was attributed to intravenous drug use and in 8% of cases the risk remains indeterminate. Among those newly diagnosed with HIV there exists a subcategory where HIV infection has been acquired in the last year, and of those cases, 86% were MSM [2]. These figures are raising serious questions in Australia as to the appropriateness and effectiveness of current health promotion among MSM [3].

HIV infection in the indigenous population

Within the overall national statistics, there is a contrasting picture among the indigenous population, the Aboriginal and Torres Strait Islanders, amongst whom homosexual contact for HIV diagnosed infection is comparatively low (with 50% of cases of HIV infection, compared to 80% in the non-indigenous Australian-born population). Heterosexual contact is far more significant for transmission of HIV (28% compared to 12% in the non-indigenous Australian population) with 30% of cases being women compared to 6% being women in the non-indigenous Australian-born population. HIV infection attributable to IV drug use is also much higher in the indigenous population (18% compared to 3% in the non-indigenous Australian-born population) [4].

Australia's indigenous population is subject to excess levels of morbidity and mortality related to chronic heart disease, diabetes, hypertension, respiratory conditions, and substance abuse. Indigenous communities are often remote, isolated and socio-economically disadvantaged, with low educational attainment, low literacy levels, inadequate nutrition, unemployment, poor housing, poor child health and high levels of domestic violence. Life expectancy among the indigenous population is 19 years lower than that of non-indigenous Australians [5]. The indigenous population has significantly less access to culturally and linguistically appropriate primary care services for testing, treatment and follow-up of sexually transmitted infections and HIV, a situation further exacerbated by the limited number of clinicians – particularly same-gender physicians – who are able to deal with sexual health issues competently and sensitively. Health-seeking behaviour based on presentation of genital symptoms or awareness of sexual risk is limited, and 'sexual health' is a concept restricted to the well-resourced metropolitan areas.

The rate of sexually transmitted infections among indigenous people is extremely high: the rate of infectious syphilis in 2007 was 40 per 100,000 (and transmitted through heterosexual contact), compared to 6 per 100,000 in the non-indigenous population (transmitted predominantly through homosexual contact) [4]. The extent of such treatable infections indicates a poor engagement with healthcare services. In indigenous communities, the amount of 'shame' associated with acquiring STIs, and especially HIV, makes confidentiality absolutely paramount, and fear of disclosure is a strong contributing factor which results in poor access to, and provision of care and treatment for those in need.

Given all these crucial factors, high levels of HIV infection and rapid transmission of the virus could be expected in the indigenous communities. National surveillance studies remain incomplete, but it does seem that in reality the rates of HIV are significantly lower than expected. HIV infection rates among indigenous people are similar to those within the non-indigenous population, the rates having remained stable and tending to be

restricted to 'outbreaks' in specific communities. There has always been fear and concern that 'when' HIV became established among the Aboriginal and Torres Strait Island people, the infection was likely to be catastrophic. Those predictions have not been realised.

In so many ways, indigenous Australia presents like a developing country – but within in a first-world context – and yet indigenous HIV infection rates do not match the expectations in developing countries. The reasons why HIV has not been transmitted as predicted are not entirely clear, but are best explained by the discrete nature of local sexual networks: who is having sex with whom, and how often and where. There is no conclusive research evidence, because of the sensitivity of this issue, but Professor Frank Bowden from the Australian National University Medical School explains it using the term 'assortative partnering': people living in small, remote areas may travel extensively across the country but they appear to maintain sexual partners that they already know, who are from the same background and the same culture. The 'bridges' for infection to be introduced from a sexual network with high prevalence – for example, a homosexual sexual network in a capital city – to the sexual group of low prevalence – a small, remote aboriginal community – have been few [6].

Where HIV infection has occurred among indigenous people, it has occurred within isolated communities in small numbers, and intensive public health measures have been rapidly mobilised to prevent onward transmission. In individual cases when good healthcare provision and support is lacking – and HIV treatment is a low priority in the face of so many other pressing needs (particularly the great fear of disclosure) – onward transmission of the virus will also be reduced because of ill-health and death [7].

HIV infection in the indigenous population has not become the catastrophic situation that was feared and has not demanded large-scale public healthcare measures. In human terms, however, for an indigenous Australian, HIV infection is likely to add another unmanageable dimension to an overwhelming list of health and social problems [8].

The history and geography of HIV in indigenous Australia – where the population is spread across a vast country, often in remote communities – is very different to the history of HIV in non-indigenous Australia where the majority of infections affect gay men in the major capital cities (Sydney, Melbourne and Brisbane). Australia is heralded as having had one of the most effective responses to the HIV crisis in the early 1980s, due to a combination of rapid and co-ordinated mobilisation of the affected groups (sex workers, IV drug-users and gay men) and unprecedented bilateral political support resulting in the implementation of extensive public health campaigns focused on harm reduction. Australia was the first country in the world to establish needle-exchange programmes.

The primary care-based model

The care and treatment of patients with HIV infection in Australia today is impressively managed most commonly by primary care physicians. Community-based sexual health clinics and gay men's health clinics were established long before the advent of AIDS and HIV infection, and so GPs with a 'special interest' became central to the care and management of HIV patients from the beginning. Since 1998 a more formalised system has been introduced which enables GPs to become registered on the s100 Prescribers Programme which is designed, delivered and monitored by the Australasian Society for HIV Medicine (ASHM). Being a registered s100 prescriber involves initial training, ongoing mentoring and a variety of means to obtain the required clinical medical education points (CME) to gain, and maintain, the 'Certification of Community HIV s100 Prescribers' [9]. Currently in Australia there are 173 GPs with the s100 certificate enabling them to prescribe antiretroviral treatments, and around 40 who would be considered specialist HIV GPs with high HIV-positive patient caseloads.

In a study conducted at La Trobe University in 2006 [10], a majority of patients identified their HIV s100 GP as the key physician for their HIV-specific care and treatment. In the report 'Life as we know it', 0.4% of respondents identified a hospital HIV specialist as their main HIV physician, 32% identified an outpatient HIV specialist but 43.2% identified, as their main HIV physician, their HIV s100 GP. Over 60% of respondents said their HIV s100 GP was their most important source of information on HIV treatment and management.

For contemporary HIV infection, the primary care physician is perfectly placed to deal with issues of healthy ageing, chronic illness, health promotion and early screening. Addressing the complex comorbidities that chronic HIV disease now presents – cardiovascular disease, diabetes, and hepatic, renal, vascular and cognitive disorders – is what GPs do best. It may well be because of this predominance of community care and treatment for those with HIV infection, that Australia is leading the world in early commencement of antiretroviral treatment. In 2007, Egger demonstrated that in Australia antiretroviral therapy is initiated at a CD4 count of 239 – higher than anywhere else in the world [11].

The main criticism of the primary care-based model is that patients are often 'over- serviced', presenting at hospital outpatient clinics as well as to their specialist GPs, and there is often repetitive care management rather than effective shared care. The complexities of current-day HIV management still demand good tertiary inpatient care, and the challenge today is to perfect the primary care focus model by improving co-ordination, simplifying

communication and ensuring smooth-flowing referral systems between primary care and the tertiary service.

The role of nursing in HIV

In Australia, HIV specialist nursing is not as formalised and not as well paid as in the UK. HIV specialist nurses and HIV nurse-led clinics are certainly present in Australia, particularly in areas where there are high HIV patient caseloads and in remote isolated communities. But in a country where nurses require separate registration in each of the seven states and territories, and with the relatively low numbers of people with HIV infection being spread across a huge geographical distance, the incentives and motivation required to build national cohesion between HIV nurse specialists are no longer evident and the structure of the healthcare service undermines any such cohesion.

Conclusion

Australia presents a good example of how HIV care and management can be undertaken predominantly by primary care physicians. This model works well because the majority of people with HIV live in the inner suburbs of Australia's main cities, where access to a HIV specialist GP is relatively easy. In other more remote areas and isolated communities, however, access to good HIV care and treatment is far more challenging. Fortunately, the feared, and predicted, rapid HIV transmission among Australia's indigenous people, often based in the more remote areas of Australia, has not occurred – but if the situation changes, and HIV becomes established in the indigenous population, there will be enormous issues to address. It is important to mention before concluding that in Papua New Guinea (PNG), Australia's nearest neighbour, there is a rapidly expanding, predominantly heterosexual, HIV epidemic (currently 2% of the population infected and increasing to a predicted 5% by 2012) [12]. The very close proximity of Australia to PNG and the close family and cultural connections between the people of PNG with some Torres Strait Islanders raises anxiety and concern about the potential impact the neighbouring epidemic could have on the indigenous and non-indigenous people of Australia. HIV in Australia, as presented in this account, could still change.

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Subsequent to this issue going to press, the National Centre in HIV Epidemiology and Clinical Research has published HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia: 2009 Annual Surveillance Report *(see [2] for link).*

Adherence to HIV treatment in the developing world: what can we learn?

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This paper is companion to an article published previously in this journal, reflecting on experiences collecting qualitative data as part of a study investigating issues around adherence to antiretroviral treatment (ART) in Swaziland [1]. The following is an account of findings from that study, focusing on the qualitative components and describing the barriers to adherence.

Access to antiretroviral treatment

Currently, there are 9.7 million people living with HIV (PLHIV) requiring treatment. Only 3 million (31%) are receiving drugs [2]. Lack of access to treatment is not limited to the southern hemisphere – only 16% of people in Russia with advanced HIV disease have access [2]. Over recent years there has been a rapid increase in treatment access, partly as the result of initiatives such as the WHO's '3×5' campaign (to get 3 million people on ART by 2005). The current drive by international agencies, for 'universal access' to HIV prevention, treatment and care by 2010, seeks to increase this momentum [3], and speaking this year, UNAIDS Executive Director Michel Sidibé said, 'Universal access means saving lives and restoring dignity to people. It encompasses stopping mothers from dying and babies from being infected with the virus; stopping people living with HIV from dying of tuberculosis; and stopping drug users from becoming infected with HIV.' [4].

Adherence

Adherence – taking drugs exactly as prescribed – to antiretroviral treatment remains an ongoing challenge in HIV care, in all regions. Since the availability of tablets containing a mixture of drugs, regimens have been less complex, making adherence easier to achieve. Adherence is vital to maintain, to avoid drug resistance, and compromised clinical outcome [5]. There are numerous barriers to adherence, and the focus of this study was to investigate issues facing patients in a poor-resource setting with high HIV prevalence.

Study location

The study was based in Swaziland, a small, landlocked and semi-autonomous region in the eastern part of South Africa. With a population of around 1 million, Swaziland is ranked 97 (out of 177) on the human development index [5], and has one of the world's highest HIV prevalence rates in adults aged 15–49, at around 26.1% [1]. Figures released in February 2009 suggest that last year, 42% of pregnant mothers were HIV positive [6]. Access to treatment in Swaziland is currently at around 42% [7].

The study location was a hospital in eastern Swaziland, serving a large, mainly rural population. Data were collected from the ART clinic in the hospital itself, and from rural satellite clinics in a 30-mile radius of the hospital.

Study design

The study design was in two parts. The first was based on a failure-modes-and-effects analysis (FMEA), an approach recommended for investigating drug delivery processes [8]. Here a checklist is used during a period of observation to identify possible reasons why a person prescribed ART may not receive the required medication.

The second stage entailed a series of semi-structured interviews, with an interview schedule derived from the initial FMEA, thus tracking in more depth some of the key issues that impact on effective ART use in this context. Eight clinicians (including two doctors, three nurses, and three pharmacy workers) agreed to participate. In addition, 14 patients were recruited for the study. The sampling frame was constructed in order to reflect gender, age and location (urban or rural). All participants received detailed information about the study, and signed consent forms. For respondents whose first language was not English, a Swazi bilingual translator was available for all interviews. The University of Bradford School of Health Research Ethics Committee approved the study. This article focuses on the second stage of the study.

Findings

Following the preliminary findings from the FMEA, interview questions were tailored for particular respondent groups. For the healthcare workers, questions explored their working environment, and what they perceived as challenges in doing their work effectively. For PLHIV, the approach was more towards the lived experience of being HIV infected, and issues around taking medication. In particular, the study aimed to reveal factors around health beliefs, and whether individual constructs of HIV would have any impact on patients taking medication.

The three themes to be considered here are: perceptions of HIV and treatment; factors that could

lead to non-adherence to ART regimens; and the interface between healthcare professionals and patients in this context.

Theme 1: Perceptions of HIV and treatment

Speaking to the patients, there was universal acknowledgement of the value of taking antiretroviral drugs: they were life saving, and to jeopardise the benefits is something patients would never consider. The following quote from a patient encapsulates the belief in how antiretroviral treatment has improved quality of life:

> *I know that there are some people that don't take their medication seriously, but I was told at the clinic that I have only one life, so I must take the medication seriously.*

Knowledge of HIV was relatively sophisticated. Patients were fully aware of the mortal nature of the virus, and that health, without treatment, would be seriously compromised:

> *[HIV] is a deadly killing disease and when you are taking the tablets you can live a healthy life.*

Metaphors used to describe the effects of HIV were mostly battle-related. Many respondents constructed the impact of HIV, and the benefits of ART, to be a battle, with their body's soldiers weakened by HIV:

> *HIV kills the soldiers in the body so that you become weak.*

ART treatment is a reinforcing army:

> *The tablets stop the virus from increasing, and give the soldiers a power to fight the virus.*

A common perception of people living in many regions of Africa is the impact of traditional beliefs on taking treatments. Here, the respondents were adamant that mixing ART with traditional medicines would weaken its effect:

> *The treatment is not to be mixed with the traditional healer medicine. I don't believe in the traditional healer.*

Sources of information about HIV are varied: in each locality, there are community treatment supporters providing a local contact point, though patients do not always access them in the first instance:

> *IH: Has she ever talked to a treatment supporter?*
>
> *Respondent: No. She was advised by her sister.*

For the healthcare staff, however, local treatment supporters provide a useful service:

> *They're our expert clients. They work in conjunction with the community clinics, they can also pick out individual patients in the community who have problems with adherence. They just spend time with them and explain to them how to take medication and advise them not to stop.*

According to one nurse respondent, patients get potentially conflicting information about HIV from the radio, newspapers and various NGOs (non-governmental organisations). At interview, patients in most instances cited their family members as useful advisers:

> *IH: If she feels unwell at home who does she talk to? Who is her first point of contact?*
>
> *Patient: I speak to my mother.*
>
> *IH: Anyone else?*
>
> *Patient: Always my mother.*

Theme 2: Factors that could lead to non-adherence

Findings here suggest that there are specific factors in this context that can jeopardise a patient's ability to take ART according to the prescribed regimen. Some involve the patients themselves, and some are located externally.

Talking with the patients, they shared the following as reasons for non-adherence:

- Tablets getting lost
- Having a bag containing the tablets stolen
- Stuck in a shopping queue, unable to get home
- Feeling ill due to HIV symptoms
- Not having any food, and therefore abiding by medical advice to take tablets only with food

Attending the hospital was also problematic for some. Satellite clinics exist, but patients often prefer the relative anonymity of a busy clinic, rather than a quiet rural setting near their home. Reasons for not getting to the hospital were usually lack of money for transport, or being unable to leave work in time. Nursing staff also cited confusion about instructions for taking ART – for example, confusing three pills twice a day with two pills three times a day. The potential for this form of non-adherence was amplified during the period of this study, when the hospital ran short of combination therapy (Trimune), and began distributing the treatment in its original three-tablet form. This creates tension for the staff, as one nurse explained:

> *When we're having a shortage of drugs, we have to explain to the patient we are sorry, we are not going to give you a two-month supply we are going to give you one month.*

In interviews, healthcare workers were clearly concerned that this increase in complexity may impact on adherence.

Theme 3: Interface between healthcare worker and patient

Healthcare workers at the hospital include medical staff, qualified nurses, counsellors and unqualified

support staff. Interviews confirmed that the work is extremely stressful. Sometimes, according to one nurse, this is due to lack of knowledge and limited in-service training. Another cited the pressure dealing with particular client groups:

> *Mostly, we don't have a private consultation office, so right now I'm using this office. What distracts me the most are the children. It depresses me seeing the impact of HIV on children.*

Perceptions of the patients and their willingness – or not – to adhere to prescribed regimens were varied. From the patient's perspective, ART is a vital and necessary treatment that must not be missed:

> *I never forget to take the tablets, but sometimes when I am going to church, I will take the tablets at 6.30 [instead of 7.00 pm].*

Healthcare staff had a range of opinions about why patients fail to take their medication. Some were empathetic. For an experienced nurse, with many years' experience in counselling and supporting PLHIV:

> *There could be several factors – one is the disclosure problem. He hasn't disclosed so he cannot take the drugs openly. He waits until everybody has gone before he can take in his pills. Or maybe he gets too sick to take the pills on his own, so who can help him take the pills if the family members do not know? Another [reason, is] at times, I don't know if they are misinformed or don't get the instructions.*

Some consider the patients are less motivated:

> *Some just don't care what's happening around them, and because they are not sick they just don't get it. They will only care when they are sick. They just lack the full understanding, so if you can counsel them a million times, if they don't want to take what you are saying they won't, until they are sick. That is when you gain their cooperation.*

Yet others blame patients' predilection to drinking as a common precursor to not taking ART when they should. This inconsistency – patients claiming to do their utmost to adhere, and healthcare staff holding a range of opinions about why they may not – was evident throughout the data.

Regarding traditional healers, here a nurse describes when a patient first appears in the clinic:

> *Most patients, when they come in have already been through a traditional healer. A lot of them have fresh marks, and come to us in desperation. They've been to the church, the traditional healers, and there is nothing. That's why we tend to get a lot of patients coming very late.*

This statement is revealing – patients interviewed during this study suggest that their traditional healers have little to offer, once treatment is started. Certainly healthcare staff agree that traditional healers are a central part of patients' lives:

> *They see them for everything – social problems, everything and including the HIV, of course.*

Discussion and recommendations

Some factors impacting on adherence in this context can be seen to be a mix, of some elements that are not unusual in ART clinics anywhere in the world, and others that are more specific to the developing-world context. Feeling ill, losing tablets, forgetting, are all common precursors for non-adherence. The challenges in distributing ART in developing countries entail particular difficulties, which can never be underestimated [9]. Certainly, providing free and community-based medication is an effective strategy [10], which explains the success of programmes such as those in Uganda, where adherence is relatively high, assisted no doubt by a 'medicine companion' to help overcome some of the barriers [11].

In the Swazi context, the use of treatment supporters, satellite clinics and free access to medication certainly increases attendance, and improves adherence. However, given that adherence in its broadest sense includes all the stages prior to a patient receiving treatment, pressures on healthcare workers leading – potentially – to prescription and dispensing errors, is a key factor to consider in this stressful environment. Strengthening motivation must be a policy priority, as well as an approach shifting the paradigm of HIV to chronic rather than acute, broadening the perspective beyond the clinical context and centering more on the patient [12].

There are perhaps three lessons that can be learnt from these findings.

First, issues around adherence are obviously complex. This is not unusual, of course, but in this context there are clearly additional factors contributing towards the risk of non-adherence – many which are overtly extrinsic (so outside patients' control), for example, a lack of food and shortage of drug supply. For healthcare staff everywhere, it is vital not to focus simply on intrinsic elements when a patient fails to follow a regimen correctly. Inconsistency between the assumptions of staff about reasons for non-adherence, and the patient's own perceptions, is a barrier to effective interactions. Given that, according to social psychological theory, it is part of the human condition to overestimate intrinsic motives for behaviour, this is always likely to be a quality that healthcare workers need to be aware of, in themselves and others.

Second, sources of information on treatment and illness are varied. As medication weaves its course

through prescribing, dispensing and administration, social constructions are attached and conflated with the illness experience itself, and there is a potential for many interpretations [13]. While the hospital provides detailed information (and on the evidence of the interviews here, patients seem cognisant of issues around HIV damage, and the need for treatment), there are also many alternative sources of information, complicated by the sheer number of people living with HIV. Many families in the same community will be affected, and collective knowledge – including of local traditional healers – potentially obfuscates the precise messaging required for ART use. However, there should be no assumptions – in this study, once treatment is initiated, patients seem less willing to accept blindly the local interventions, perhaps suggesting a more sophisticated view of treatment management than healthcare workers assume.

Third, HIV stigma in this context remains strong – and though the prevalence in Swaziland is one of the word's highest, negative perceptions of people living with HIV continue to impair the day-to-day lives of affected people. Recently, a Swazi politician was obliged to apologise after publicly calling for people living with HIV to be 'branded' on the buttocks [14]. Healthcare workers here, and in any health system, must always assume that the PLHIV is under pressure not to disclose, hence adding an additional layer of anxiety to a disease already generating mortal fears. Resulting pressures can lead to problems with adherence.

Limitations

This study has limitations, such as a single location, small sample, and subjective interpretation of the qualitative data. However, as a mixed-design FMEA together with semi-structured interviews and observation, it certainly offers a range of potential factors for further research, especially around the impact of a resource-poor setting, and on the ability of a patient to adhere to treatment regimens – including lack of medication due to supply problems.

Conclusion

Swaziland is a country under siege, not from a human army, but one that is viral. This study reveals a range of factors impinging on the safe and sustainable use of ART for a disease affecting large parts of the community. HIV poses a significant threat to the social, political and economic infrastructure in Swaziland, and until the goals of universal access to ART and HIV prevention and care are met, the country will continue to suffer severe deprivation.

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The HIV Nurse Education Project, Lusaka: initial evaluation and progress report

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Introduction

The HIV Nurse Education Project was established in February 2006 as part of a new link between University Teaching Hospital (UTH), Lusaka, Zambia and Brighton and Sussex University Hospitals (BSUH), Brighton, England. This is an outline of the progress of the HIV Nurse Education Project to date, with an initial evaluation, and explains the changes to nursing practice and service delivery that have been achieved.

Needs assessment for HIV nurse education at UTH

An initial assessment was undertaken in February 2006 to consider the potential link between UTH and BSUH. During the assessment visit, one of the key areas identified by the Director of Nursing at UTH was the need for focused nurse education related to HIV patient care and particularly to the nurse's role in the administration, monitoring and support of patients on antiretroviral therapy. Communication was established between the Director of Nursing at UTH, the HIV Nurse Consultant at BSUH and the Senior Lecturer for HIV and Sexual Health at the School of Nursing, University of Brighton. A questionnaire was devised to assess the educational needs of nurses at UTH, and it was randomly distributed to 30 nurses across the hospital. The key HIV nurse education areas identified were stigma, the role of the nurse, care of opportunistic infections, pregnancy and all aspects of antiretroviral therapy (*see* Panel 1).

In addition there were focus groups held in Brighton with nurses who had either an interest in working overseas, or previous experience of teaching or nursing in Africa. These meetings assisted in devising culturally relevant teaching styles and in planning for course certificates and opening and closing ceremonies.

Methods of teaching

A variety of teaching methods were used in the first and subsequent courses that aimed to promote inclusive learning and maximum participation in the learning process. The range of teaching styles was intended to facilitate skills development and the application of theory to practice and included lecturing, games, demonstrations, discussion, brainstorming, case scenarios, role play and group work (*see* Figures 1 and 2).

Panel 1: Aims of the project

- Deliver a sustainable HIV course to meet the educational needs of nurses at University Teaching Hospital, Lusaka and build on the knowledge and skills required in the care and treatment of patients with HIV infection;
- Increase the nurses' motivation and their self-belief that as nurses they were a vital component in meeting these needs, and would be able to make a difference;
- Deliver a 'train the trainers' programme to enable roll-out of skills development across the hospital and to include district site courses facilitated by the Zambian team.

To date, there have been 206 nurses trained at UTH including matrons, ward sisters and enrolled nurses. The Brighton and Zambian team continue to work together on the project with regular exchange visits to develop the project further or to support new courses such as district hospital training. Following the first course, the project was awarded £60,000 from DelPHE funding (Development Project in Higher Education, administered by the British Council and the Department for International Development) to ensure that the collaborative work between the HIV nurses in Brighton and Lusaka could be continued for at least 3 years.

Methods of evaluation

Detailed written evaluations were requested from each individual using a reflective diary, with feedback relating to each of the teaching sessions presented and how the session might impact on nursing practice. In addition, verbal evaluations of

Figure 1: *Example of group work.*

the whole course were recorded on the last day. Each course included 'time for action' planning to enable participants to identify issues and challenges in their clinical areas and to formulate plans to address these issues. These action plans are reviewed at regular management meetings and most groups have been successful (with management support) in implementing the majority of actions identified, although understaffing has had an adverse effect on some implementation. The progress with action plans is evaluated by the HIV Nurse Education team when the teams from Zambia and Brighton come together.

The Project's achievements

The nursing link between Brighton/Sussex Hospitals and Lusaka University Teaching Hospital has been active for 3 years and there have been a number of achievements to date:

- The initial workshop was delivered by the Brighton team – Eileen Nixon and Sian Edwards. Now the local facilitators are able to facilitate the workshop on their own, with a lot of support from the management team at UTH and the British Council. As well as training nurses within UTH there have been attendees from three private hospitals in Lusaka. More recently, the programme was rolled out to one of the district hospitals based in Kafue, where the same model was used to deliver HIV nursing skills training. Course participants included staff from urban clinics and, for the first time, some non-nursing students such as a physiotherapist, radiographer, pharmacy technician, clinical officer and laboratory technician. Senior staff from Kafue hospital have now joined the HIV Nurse Education team at UTH to continue to develop training in their area.
- Following the first course, two clinical nurses and two tutors were trained in delivering the HIV Nurse Educating course. More recently other senior clinical nurses have been supported to teach on the course as a way of succession planning and developing a robust team of nurse educators.
- Nursing Grand Rounds have been established and are available for all nurses throughout the hospital once a month. Each department takes a turn at presenting each month, and a noticeable change in reflective nursing practice has resulted.
- In addition, five stigma workshops have been delivered by the International Aids Alliance in which 53 senior nurses and 50 enrolled nurses have been trained, and two of the Zambian team presented the project at the NHIVNA Conference in 2007. In June 2009, Evelyn Mwamba and Lasidah Mwaba were invited to speak at the conference again on their experiences of adherence issues from their practice.

Figure 2: *Example of an ARV game (adapted from* Aids Alliance Community Engagement For Antiretroviral Therapy Trainers Manual, 2006)

- There has been considerable managerial support from the Managing Director and Director of Nursing at UTH in sustaining the delivery of the HIV Nurse Education programme and, as a result of the programme's impact, the management team has subsequently developed a training programme for non-medical hospital staff.

Outcomes and impact on practice

It is worth noting the exceptional success of this relationship, and the outcomes that have clearly had a major impact on practice:

- Student nurses are now placed in the HIV clinic for one week of their training.
- In pregnancy, syphilis tests are conducted at 36 and 40 weeks, and repeat CD4 cell counts at 26 weeks, to ensure all antenatal women have access to the correct antiretroviral treatment.
- Male partners' involvement in antenatal care has improved: in September 2006, there were no male partners whereas in July 2009, 250 male partners attended.
- The HIV counselling and testing of fathers when their children are ill has greatly increased: in September 2006, 60 men tested, rising to 500 men in July 2009.
- Post-exposure prophylaxis (PEP) availability has been improved, with new policies and pathways being put in place.
- HIV rapid testing kits are available in each department, and so far 20 nurses have been trained in HIV testing and are delivering cascade training.
- A new workplace policy for HIV-positive healthcare workers, taken forward through one of the HIV Nurse Education courses, is now national policy and has been agreed by the Ministry of Health.
- The staff clinic for HIV-positive healthcare workers at UTH has been re-established.
- Stigma among the workers has reduced, especially among the nurses, after the Stigma

and Discrimination Workshop sessions. HIV/AIDS-positive nurses have now started attending the ART clinic at UTH. Prior to the stigma workshops, staff would go to another clinic, even hiding their identity for fear of being recognised by colleagues. Some staff are now willing to attend the ART clinic in full nurses' uniform and with identity cards on.

Further training of Zambian partners

In December, 2008, the Zambian team – Lasidah Shawa Mwaba, Mary Jaramba, Universe Mulenga and Evelyn Mwamba – visited BSUH on an exchange programme for 2 weeks. The HIV Nurse Educators attended a mentorship course specifically designed by the School of Nursing at the University of Brighton to enable the Zambian team to set up a mentorship programme at UTH for the HIV Nurse Education Project. Further development of mentorship for nurses working with HIV patients is being undertaken in conjunction with the Centre for Infectious Diseases Research Zambia (CIDRZ).

On the same visit, the Zambian team had another very important opportunity, visiting the House of Lords to attend the Tropical Health and Education Trust (THET) Anniversary event and meeting His Excellency the Zambian High Commissioner to the UK. This was an excellent setting for the project and an occasion to be remembered by all.

Since then, further private funding has been secured for another year to extend the HIV Nurse Education project to another district, based on the same 'train the trainers' skills development model. Further links have also been established with the School of Nursing at the University of Brighton, which is developing a critical care curriculum with tutors from UTH.

Conclusion

The strength of the relationship that has been established between the Brighton and Zambian HIV Nurse Education teams and the friendship that exists among the women in this link has been a powerful enabler of the achievements outlined above. The level of individual involvement and strong sense of belonging is sustained by the commitment that they all clearly feel to their work, and to each other.

Although a formal outcome evaluation of the project is still to be finalised, there have been many tangible achievements to date in both professional and clinical terms and in direct and indirect benefits to patients with HIV at University Teaching Hospital in Zambia.

Acknowledgements

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Research round-up:
Stigma, telecounselling, and nurse management

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Scaling up stigma

Roura M, Urassa M, Busza J *et al*. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania. *Sex Transm Infect*, 2009, **85**, 308–312.

This is a fascinating and potentially worrying short research report. It presents findings from a qualitative study conducted in a rural district in Northern Tanzania where voluntary counselling and testing (VCT) and antiretroviral therapy (ART) facilities have been widely rolled out since 2005. The researchers sought to explore what impact the availability of ART was having on social perceptions of HIV, including HIV-related stigma. They also explored people's attitudes to HIV testing in the light of treatment availability. Interviews and focus groups were conducted with 91 community leaders, 77 ART clients and 16 health providers. The team found a complex and contradictory interplay between ART, stigma and HIV testing. There was considerable evidence to suggest that ART is reducing 'self-stigma' and 'burden stigma' – i.e. people with HIV were feeling more able to integrate into their social networks because, on treatment, they perceived themselves as less of a social and financial burden. There was a sense that HIV was becoming more normalised as it was increasingly described as having become one of many difficult but manageable health problems faced by the population in that area.

However, the researchers found that a pervasive HIV-associated 'blame stigma' remained very prominent in the community. People with HIV were characterised as morally corrupt and irresponsible and were blamed for having caught the infection. In fact, some community leaders felt that ART was encouraging people to continue 'morally deviant' behaviours with no sanction. Some suggested that ART formulations should include drugs to induce impotence to ensure prevention of onward sexual transmission. ART was seen as making it more difficult to identify people living with HIV and was thus felt to encourage risky behaviours and increase the potential for HIV transmission. The researchers also found widespread belief in alternative disease aetiologies (such as witchcraft) in the community. Thus, in a context of blame and stigma associated with HIV, the researchers found that in spite of ART availability, community members were still reluctant to seek testing or treatment, and receive a definitive medical diagnosis, when attribution of symptoms to an alternative cause (such as witchcraft) received no social sanction and in fact could trigger social support.

This research casts some doubt on the assumption that ART availability will lead to a reduction in HIV-related stigma and an increase in uptake of testing. The researchers suggest that the counterbalancing trends of normalisation of HIV and deeply persistent blame stigma mean that significant and sustained community mobilisation efforts need to accompany all ART and VCT programmes.

Telephone counselling promotes adherence

Cook P, McCabe M, Emiliozzi S, Pointer L. Telephone nurse counselling improves HIV medication adherence: an effectiveness study, *J Assoc Nurses AIDS Care*, 2009, **20**, 316–325.

This paper reports on an effectiveness study in the USA that evaluated the impact of a nurse-led telecounselling intervention on adherence to ART. The intervention utilised Prochaska's transtheoretical model as a guiding framework and delivered counselling and motivational interviewing inputs based on the participants' perceived readiness for change in the context of potential barriers that they had previously identified. The sample consisted of 98 participants who were starting ART using the same fixed-dose combination medication (lopinavir/ritonavir). The participants were recruited from sites across the USA using a brochure distributed to HIV care settings by pharmaceutical representatives. The intervention was delivered by specially trained call centre nurses. The main outcome measures were medication adherence (assessed through self-report), a self-efficacy score and investigation of reasons for non-adherence. The sample was said to be similar to the national HIV epidemic in terms of sex, race/ethnicity and age. The sample was followed up over a 6-month period with participants receiving four phone calls with an average call length of 7.5 minutes. The results were compared with adherence levels that would be expected amongst a similar population, derived from findings synthesised from many previous adherence studies. Over half the sample (58%) was lost to follow-up during the course of the study. This is a high rate but the sub-sample lost to attrition did not have any significantly different characteristics to those who did not attrite, and the researchers felt that the attrition was unrelated to patients' ART experiences.

Of the remaining sample, the percentage of participants still receiving ART was 76% at 6 months and was significantly higher than the expected rate of 50%. Similarly, the percentage of participants reporting a minimum of 95% adherence at 6 months was significantly higher than expected (76% of the sample reported 95% adherence at 6 months, compared with an expected 50%). Adherence was significantly associated with psychological predictors (e.g. self-efficacy and participant concerns) and was not statistically associated with medication regimen characteristics or sociodemographic factors. The researchers conclude that psychologically oriented telecounselling shows promise in promoting adherence and can do so in a cost-effective manner. However, they recognise the limitations of the study, which included a high attrition rate and lack of a control group. The results therefore add to a number of other studies on telephone interventions that are suggestive of beneficial effect rather than conclusive. A large-scale randomised controlled trial (RCT) is needed to provide further evidence on the efficacy of adherence-related telecounselling.

Nurse management of ART matches doctor care in South African trial

Wood R, Fox M, Conradie F *et al*. Nurse management is not inferior to doctor management of ARV patients: the CIPRA South Africa randomized trial. 5th International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, Cape Town, 2009, Abstr. LBPED03, available at: www.ias2009.org/pag/Abstracts.aspx?AID=3822 (last accessed 2 September 2009).

Exciting results of a large RCT based in South Africa were reported by Woods *et al*. at the recent IAS conference in South Africa. Based on a large sample of patients (n=816) followed up over almost 2 years, there were no statistically significant differences in any of the clinical outcome measures between nurse- and doctor-managed ART care. This study provides much-needed 'hard' evidence that will potentially support the task-shifting agenda and the roll-out of nurse-led ART programmes across sub-Saharan Africa. It will be important however to consider more information on the context and process of this intervention (including training inputs, available resources, cost–benefit analysis, clinical supervision inputs, quality assurance procedures, health provider views and the patient experience) in order to fully assess its potential for replication.

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NHIVNA update

Having just recovered from a successful annual conference in Birmingham – the feedback has been overwhelmingly positive – we will take all your comments, both positive and negative, on board as we begin the business of putting together the programme for next year's conference. A huge thank-you to all who organised, presented, chaired, contributed, supported, sponsored and attended the conference in Birmingham. Most of the presentations are now available on the NHIVNA website, along with notices of award winners and details of those who were awarded scholarships.

Plans are under way for the **12th Annual Conference** in Brighton on 29 and 30 June, 2010 – please note that it is earlier in the week than previous conferences. There will be plenty of time both to register and let colleagues know of the exciting and packed programme as it develops; however, the important task is to begin your abstracts and posters for the Brighton Conference – you could start the groundwork now. Keep your eye on the website for information on deadlines as they are publicised. This year we had our greatest-ever number of abstracts submitted, at 52! I hope we can be even more successful next year.

We have just launched the 'list-serve' email service for members: apologies to those whose inboxes ground to a halt with some first-day glitches. As the service beds in, we hope you will find it a useful asset. We will be keeping a close eye on how it develops. Thanks for your patience with this.

We have announced details of the three remaining competency study days for 2009 – attendance at the study days is of course free to members.

Full information on all NHIVNA events is available on the website: www.nhivna.org

Sheila Morris, Chair, NHIVNA

HIV NURSING

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