

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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Assessment

Jane Bruton

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The main theme of this edition of *HIV Nursing* is the assessment process. Assessment is one of the four core competences developed by NHIVNA for nurses working with HIV-positive patients in any clinical setting [1], and is perhaps the most crucial part of the nursing process [2].

As part of the process, nurse assessment should be patient-centred, interpersonal, collaborative and systematic. It is not a 'once-only' event but a continuous process [3]. The assessment consultation, whether it is on the first admission to an inpatient ward or the first visit to an HIV outpatient clinic, is the opportunity to establish the beginnings of the nurse-patient relationship by building trust and a rapport with the patient. Unfortunately, it is often the part of the process that nurses don't always have enough time for in the context of a busy ward, clinic or in the community. Assessments very often are a once-only event, and the key challenge is to ensure that assessment is integrated into the heart of our practice and that the most effective tools to do this are developed.

In the study of nursing, many methods and frameworks for assessment and delivery of care have been explored, and there have been a number of developments in the last 20 years. Most significant is the move away from a universal biomedical model towards a more holistic approach to care, appreciating that patient perspective and context should be part of care planning. Nursing models have become popular, promising a holistic framework and more individualised care. In reality however, they were often interpreted in practice as simply a framework or structure for assessment, based on concepts such as self-care deficits or activities of daily living. Models were intended to be more than this, and their emphasis on the need to understand the process of health and illness for the individual in the context of society remains one of their greatest strengths. In HIV units during the 1990s, nursing models considered most relevant to HIV nursing were needs-based models, such as Roper Logan Tierney [4] and Orem [5].

The need to continue to develop holistic frameworks for comprehensive assessment remains a vital issue in HIV care as increasing numbers of nurses move into advanced practice roles. Pratt [6] argues for a combined approach to nursing assessment, using both a needs-based assessment of the activities of daily living, and the Burford Nursing Development Unit model [7], suggesting there is a potential with the needs-based assessment to dehumanise the patient. Nursing assessment must understand the illness and how it is affecting the person in their normal context of

family, friends, work and how it is making them feel, and as Pratt says, the Burford approach "In essence aims to help the nurse to see the person in relation to their illness as opposed a 'patient with an illness.'"

The assessment competencies in the NHIVNA document try to address the impact of the development of roles in HIV nursing, and the need for nurses to advance their assessment skills both in physical assessment and in history taking and the link to clinical decision-making. All the articles in this edition of *HIV Nursing* consider some aspect of assessment in planning and delivering care to people affected by HIV. Kim Gardiner's article opens the journal, with an in-depth discussion of perhaps the most challenging aspect of adherence to antiretroviral therapy – the support of children. It is vital, she argues, to ensure that the assessment of risk of non-adherence is carried out as early as possible.

Two other potentially vulnerable groups, asylum seekers and refugees, are the subjects of Shaun Watson's article, in which he discusses their care management, suggesting that assessment here is the 'cornerstone of effective nursing'. The NHIVNA assessment competency underlines the breadth of knowledge and skills required to understand the clinical, psychological, social and spiritual needs of the patients; set in their context at home, at work, in health and illness, with their family and friends. In this paper, we see these articulated in an especially difficult setting.

Camilla Hawkins, an occupational therapist, reflects on how helping a patient prepare a meal can be a significant and life-changing event, impacting as it does on their self-worth, and ability to engage socially. Assessment, she suggests, is key to this process, and it is vital for the practitioner to assess and plan around the patient's own context and lifestyle in order to help them reach their goals – and for the practitioner to also broaden their insights.

Juliet Bennett and Martin Jones, in considering nurse prescribing, recognise that nurses' being able to prescribe within the consultation, without having to find a doctor to write the script, saves time that can be spent on a more comprehensive assessment of the patient's needs. After undertaking a study investigating aspects of nurse prescribing, they suggest that nurses are becoming more aware of the importance of an accurate and comprehensive assessment as they take independent clinical decisions, and prescribe on the basis of those decisions.

This journal also includes a paper describing the results of a study suggesting that, with the changing policies

HIV in the UK: the HPA figures

Jane Bruton

Another year, and the Health Protection Agency (HPA) figures make depressing reading. At the end of 2007, new HIV diagnoses were 7,734 – as high as for the past 4 years. Fifty-five percent were heterosexual infections and the total number of newly diagnosed men who have sex with men (MSM) continues to increase. Significantly, last year, four-fifths of all new HIV infections were acquired in the UK; heterosexual transmission within the UK has nearly doubled in 4 years.

It is estimated that there were 77,400 people living with HIV, of whom 28% remain unaware.

The number of late diagnoses has remained unacceptably high, about the same as last year, at 31%, which stresses the imperative to support and encourage the implementation of the new BHIVA HIV testing guidelines. The uptake of testing was recorded as 75% of all attendees in GUM clinics and 95% of women in antenatal clinics. Heterosexual men remain the greatest proportion of late presenters, which suggests poor uptake of testing compared with MSM, who make up 19% of the late presenters. The HPA recommend testing for all patients between 15 and 59 attending GP surgeries and for all general medical admissions in high prevalence areas, that is areas with a prevalence greater than two in 1000.

There are record numbers of patients accessing HIV care in the UK – 56,556 – which is a threefold increase since 1998 and an 8.6% increase from 2006. Seventy percent of patients receive antiretroviral therapy; one in five with severe immunosuppression is not on treatment.

The proportion of cases in London continues to decline and is now less than half, at 48%. East of

England has seen a sevenfold increase in their patient cohort in 10 years from 549 to 3693. The need for investment in resources and services has been highlighted by the HPA. No doubt most services will be feeling the strain; nurses need to take an active part in business planning and mapping out the future services.

Finally, by the end of June 2008, 8,831 children had been born in the UK to HIV-infected mothers and, of these children, 816 (9%) were found to be positive. If the estimated number of undiagnosed mothers is added to these figures, the percentage of infected infants drops to less than 5%.

The HPA concluded that there must be improvements in HIV testing uptake in GUM and antenatal care, and an expansion of testing, particularly in high-prevalence areas. Sexual health promotion must have a higher profile, particularly amongst those groups at greater risk of acquiring HIV. Finally, new care pathways that encourage earlier commencement of antiretroviral therapy should be implemented.

All this means that we need to look at where we need increased resources, new services, innovative ways of working and planning future HIV services to meet the ever-increasing demand and needs of our patients.

References

HIV in the UK: 2008 Report. Health Protection Agency. December 2008. Available at www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1227515299695

BHIVA, BASHH, BIS. *UK National Guidelines for HIV Testing*. BHIVA, London, 2008. Available at www.bhiva.org/cms1222621.asp

Assessing risk of non-compliance to HAART: some practical considerations

Kim Gardiner

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Introduction

Advances in the care of HIV, namely the development of highly active antiretroviral therapy (HAART) are such that HIV is now considered a long-term health condition alongside conditions such as diabetes or haemophilia rather than a rapidly fatal disease [1]. It is well documented that, like adults who live with HIV infection, children living with the virus can often live for many years before needing to commence complex treatment for viral suppression. Therefore, in many cases the problems associated with adherence or compliance are not experienced until a pre-pubertal age [2, 3]. Children and young people requiring HAART often struggle with adherence or compliance, as does any child requiring medication to control symptoms of a long-term condition [1]. The reasons for these difficulties are primarily the same regardless of condition; however, the implications of non-adherence for young people living with HIV are more severe. The evidence is such that, for anyone taking HAART today, an adherence level greater than 95% is required to ensure that the viral load remains undetectable. The consequences of not suppressing the virus include an increase in illness through opportunistic infections and the development of resistance to current and possibly future treatment options [2]. This article considers key ways in which the assessment of non-compliance risk in young people, in hospital and community, can maximise the benefits of this vital treatment.

Background

The prevalence of HIV in children continues to increase in the UK despite interventions to prevent mother-to-child transmission [4]. This increase results from diagnoses following immigration and the continuing diagnosis of children born prior to routine antenatal HIV testing [5,6]. There are currently approximately 1,050 infected children and young people under the age of 16 years living in the UK and Northern Ireland with around half being under 11 years of age [6]. Many of these children are being diagnosed during their later primary school years and this raises issues related to compliance and disclosure, the solutions to which are ultimately dependent on each individual child's level of knowledge and understanding, together with support from within their family [3].

What is compliance?

For many years, as health professionals we have considered adherence to be one of the most important

factors when contemplating medication for our patients. It has been defined as taking medication 'at the right time, in the right doses and in the right way' [7, p.1). More recently the term 'compliance' has been favoured as it encompasses all that we know as adherence, together with those other equally important aspects such as attendance at routine follow-up appointments or sessions specific to need [8].

Assessing compliance to HAART in children and young people

Given the definition above, it's hardly surprising that HAART for children and young people is not without its difficulties. The majority of those children who require HAART for viral suppression rely on a parent/guardian being 'compliant' in all aspects of their healthcare on their behalf. They cannot take themselves to appointments at a young age or be wholly responsible for ensuring they take the correct doses at the correct times. Starting a child on HAART for the first time without some form of initial, and then ongoing, assessment is potentially setting them up to fail, with the implications of an unsuppressed viral load and inevitable development of resistance. Therefore, an assessment of the child's readiness to start antiretroviral therapy must be completed and consideration given to all aspects of that child's life, including home and school.

Pre-HAART considerations

Parents/guardians are ultimately responsible for administering HAART to their children. Thus, some important considerations when striving to achieve and maintain 100% compliance/concordance with medication is to ensure that a proposed regimen is as simple as possible and, if appropriate, to involve a parent in the decision-making process.

There are some basic questions when assessing a potential risk of non-compliance to HAART:

- Does the child attend all appointments or is there a history of repeated non-attendance?
- Does the parent attend all of their own appointments or is there a history of repeated non-attendance?
- How compliant is the parent with their own medication?
- Have there been any issues or (child protection) concerns in relation to other children in the family and medication?

- Have there been any concerns in respect of prevention of mother-to-child transmission?
- How much does the child know about their HIV?

This list is not exhaustive, but serves to highlight how a few very simple questions are good early indicators of potential non/poor compliance. Other more specific considerations are listed in Table 1.

Table 1. Other considerations when assessing potential non-compliance to HAART in children

- Family's readiness and motivation for managing combination therapy
- Understanding of reasons for treatment and commitment required of each child and parent
- Who will take responsibility for giving medication
- Family's health beliefs and cultural issues
- Timing for commencement of treatment
- Housing and immigration status
- Child's and parent's previous and current experiences of antiretroviral treatments
- Practicalities of storing and collecting medications
- Child's and family's daily routines and the impact treatments may have on this
- Other family members on treatments
- Parent's health needs
- Type of regimen
- Detailed plan for follow-up: who, how and when? How will this impact on family life?
- Anticipation of potential problems
- Current health needs of the child
- Child's understanding of their diagnosis and how long they have known
- Parental preference of treatments, if possible
- Pre-treatment requirements, e.g. developmental review
- A detailed plan for follow-up
- Should plan include use of placebos

From Head S. Protocol to enhance adherence (2003, reviewed 2007) accessed from www.chiva.org.uk on 29th November 2008.

Factors that impede compliance

There have been many studies in recent years that question various factors affecting compliance with antiretroviral therapy in children and young people. Wrubel uses grounded theory to look at paediatric adherence from the viewpoint of the children's mothers with an overall aim to ascertain which, if any, daily activities impede or facilitate adherence. Four common themes were identified from the narratives. These were: mothers' attitudes and feelings related to adherence practices; impact of medication on adherence practices; interactions of mothers and

children related to adherence practices; and developmental issues and responsibility for medication adherence. Taken together these illustrate the complexities of maintaining a level of medication adherence to maintain viral suppression. Attitudes, feelings and beliefs about medication efficacy, the impact of HAART on daily routine and relationship with the child, and feelings concerning stigma and guilt were also voiced. This study also shows that non-adherence was possibly used by those who had immense guilt feelings as a way of removing that daily reminder of viral transmission. Mothers also reported problems giving medication in public and also where a truthful disclosure had not taken place [9].

The study, although relatively small-scale, demonstrates many of the barriers faced on a regular basis when considering HAART for children and young people. There are many more which all must be given due consideration at frequent intervals along the child/young person's journey through paediatric HIV services, transition and eventually into adult services (Table 2).

Table 2. Factors affecting a child's or young person's compliance with HAART

- Familial
 - Parental denial
 - Lack of understanding
 - Frequent non-attendance at own and/child's health appointments
 - Recent bereavement/change in primary caregiver
 - Fear of disclosure/discrimination/stigma
 - Other children/young people at home
- Individual
 - Taste and volume of liquid formulations
 - Size and number of tablets/capsules (pill burden)
 - Recent part or full disclosure
 - Adolescence
- Environmental
 - Poor housing
 - Shared accommodation (storage issues for some medication)
 - Lack of affordable transport for appointments/to collect medication
- Social
 - Poverty
 - Fear of exclusion from peer groups
 - 'Medication doesn't fit in with my lifestyle'
 - Regular time off school for appointments

Many other studies show similar results regarding the complexities of children's adherence to HAART. Taste and volume of liquid formulations/pill burden were also cited as reasons for poor adherence [10–13]

As nurses we must not undervalue the role research plays in informing practice and should note and remember that the culture of nursing has changed. We have been given, and have been expected to take responsibility for delivering care supported by best practice, a sound evidence base and validated research [14].

Community support: a valuable part of pre-HAART assessment

A community-based practitioner, whether a clinical nurse specialist or other involved professional, complements the hospital-based team and adds to the whole picture. S/he can play an important part in ongoing adherence support but also be invaluable during that pre-HAART assessment period.

Historically, it is widely acknowledged that people dress smartly, often 'in their Sunday best' to visit the doctor. For many families, though this may be a desire in reality, embarrassment about the poor state of housing can inhibit initiating a conversation or answering truthfully about poor living conditions, which in turn may impede compliance.

By visiting at home over time it is often easier to see how each individual family functions on a daily basis: who has responsibility for what; how much the child or young person in question is relied upon; who is likely to be responsible for supervising medication, etc.

Housing does play a role in adherence to medication. Living in shared accommodation not only impacts on a family's daily life but can impede a HAART regimen, for example, access to a refrigerator for storage of certain medications. This could be solved simply with the provision of a small fridge kept in a bedroom; not ideal, but it can promote compliance and help prevent inadvertent disclosure.

Which preparations? Which regimen?

When thinking about a regimen along with nationally agreed guidelines [2], it is important to consider this against the age of the child; which formulation they can take without too much difficulty, i.e. liquids/tablets/capsules; and resistance mutations. In addition, the child's and family's lifestyle should be acknowledged in relation to the possibility of a once-daily as opposed to a twice-daily regimen.

The majority of the tablet/capsule preparations are large and can be a cause of anxiety for parent and child. One way of assessing a child's ability to take these is to practice 'pill swallowing'. This can be performed at home or in the clinic and can be done as simply as using a variety of different-sized sweets. Tic-tacs and jelly beans are a good choice to include as they tend to represent most medications size-wise. It also adds a bit of fun whilst demystifying any difficulties in taking tablets.

Conclusion

Children's adherence to HAART is influenced by family lifestyle and acceptance of HIV status within

the family; those who have not reached that understanding have the most problems related to adherence, and require further family assessment in relation to HAART. A major difference between HIV and most long-term conditions is that it is a family disease in which there are usually at least one or more others living with HIV in the same family. A community-based clinical nurse specialist has the privilege of working with children and families in their own home, where many of the complex issues associated with adherence are more easily identified and plans for maintenance can be fully supported. Many of the families do design adherence tools, such as sticker charts and have an openly supportive approach to HIV within the home. Those of concern remain the families who are unable to support each other in a way that is conducive to good adherence and mutual support to manage their lifestyles in a positive way.

References

1. Byrne M, Honig J, Jurgrau A *et al.* Achieving adherence with antiretroviral medication for pediatric HIV disease. *AIDS Read*, 2002, **12**, 151-164.
2. Sharland M, di Zub GC, Ramos JT *et al.* PENTA guidelines for the use of antiretroviral therapy in paediatric HIV infection. *Pediatric European Network for Treatment of AIDS. HIV Med*, 2002, **3**, 215-226.
3. Miah J, Waugh S, Divac A *et al.* Talking with Children, Young People and Families about Chronic Illness and Living with HIV. National Children's Bureau, London, 2004.
4. Tookey P. Obstetric and paediatric HIV surveillance data from the UK and Ireland. Updated data slides available at: www.nshpc.ucl.ac.uk (last accessed on 19th November 2008).
5. Department of Health (1999) Antenatal Screening Strategy. DH London.
6. www.chipscohort.ac.uk. Summary data to end of March 2008 (last accessed 12th November 2008).
7. NAM. *Adherence: Patient Information Booklet*. 4th edn. 2007, p1. Available at: www.aidsmap.com/files/file1000882.pdf (last accessed 6th December 2008).
8. Available at: web.mac.com/walkermd/iWeb/psychiatry_for_patients_and_families/glossary (last accessed 28th November 2008).
9. Wrubel J. Pediatric adherence: perspectives of mothers of children with HIV. *Soc Sci Med*, 2005, **61**, 2423-2433.
10. Gibb D, Goodall RL, Giacomet V *et al.* Adherence to prescribed antiretroviral therapy in human immunodeficiency virus-infected children in the PENTA 5 trial. *Pediatr Infect Dis J*, 2003, **22**, 56-62.
11. Hammami N, Nöstlinger C, Hoérée T *et al.* Integrating adherence to highly active antiretroviral therapy into children's daily lives: a qualitative study. *Pediatrics*, 2004, **114**, e591-e597.
12. Dolezal C, Mellins C, Brackis-Cott E, Abrams EJ. The reliability of reports of medical adherence from children with HIV and their adult caregivers. *J Pediatr Psychol*, 2005, **28**, 355-361.
13. Williams P, Storm D, Montepiedra G *et al.* Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*, 2006, **118**, e1745-e1757.
14. Nursing and Midwifery Council. *The NMC code of professional conduct: standards for conduct, performance and ethics*. NMC, London, 2004.

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Asylum seekers and refugees: issues regarding assessment

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Introduction

A comprehensive patient assessment is the cornerstone of effective nursing care; without a thorough, holistic assessment we may be unable to meet patients' needs. The initial assessments should inform and shape the care we provide. For those living with HIV, the initial assessment can be a scary encounter; discussing extremely sensitive and private areas of a person's life and looking at the many complex physical, emotional and psychosocial issues facing an individual can be very difficult.

'Why do you need to know that?'

'Why are you asking me that question?'

'What has that got to do with why I am here?'

Familiar questions? For those who are seeking asylum these initial nursing assessments may be made more problematic due to language, culture, trauma and gender barriers. This article aims to examine some of the issues regarding assessment of asylum seekers.

Who are asylum seekers and refugees?

Worldwide, there are approximately 22 million asylum seekers or refugees. In 2007, the UK Borders Agency had 28,300 claims for asylum (individuals and their dependents) of which 28% were granted refugee status, 8% were granted humanitarian protection/discretionary leave and 5% were granted asylum on appeal after an initial failed claim. Most asylum seekers were Afghan, Iranian, Chinese, Iraqi or Eritrean. Most of those seeking asylum were single men under 40 years of age. Many of the families seeking asylum in the UK had only one parent; the other may have been missing or dead.

The right to claim asylum is protected by international law. Under the 1951 Geneva Convention Relating to the Status of Refugees, individuals can seek asylum if they can prove that they are at risk of being persecuted in their own country, because of their race, religion, nationality, political opinion or membership of a particular social group, and are unable or unwilling to seek protection from the authorities in their own country. Granting asylum means giving someone permission to remain in another country because of that risk of persecution. Legally, a person who has

asked for asylum in the UK and is waiting for a decision is called an asylum seeker. Someone who has received a positive decision on an asylum claim is called a refugee. Asylum seekers are also able to claim under the 1950 European Convention of Human Rights. Claims can be based on Article 3 – prohibition on torture and inhuman or degrading treatment; or Article 8 – right to respect for family and private life. The European Union Asylum Qualitative Directive ensures that common criteria for identifying people in need of international protection are applied and that a minimum level of benefits is available for those granted asylum status in European Union member states.

The many UK laws surrounding asylum change with every new government and the issue is a constant political 'hot potato'. This makes claiming for asylum a lengthy, frustrating and repetitive process.

The assessment process

Patients may seek asylum, perhaps due to persecution because of race, nationality, sexuality, faith or political opinion, or perhaps to escape war, rape/sexual assault, torture or other degrading treatment. They may also have HIV along with tuberculosis, hepatitis and any number of physical, emotional and psychological health issues, pregnancy or childcare issues and loss, not only of family and friends, but also of culture, identity, social status and material wealth. Their circumstances may involve sensitive issues and their needs can be highly complex. As healthcare professionals we need to understand all of these issues to assist patients to live a healthy and productive life in a new but alien country, in which they may be isolated from family, unable to read, write or speak the language, or unaware of the law, health system and social services. Where do you begin?

Before any assessment can take place, the required level and type of help with communication must be established. In some cases the use of interpreters, advocates and translation will play a vital role in the assessment process. When working with interpreters, it is important to check what support is available for the interpreters afterwards, especially as you may have been discussing highly sensitive and distressing issues. Stigma surrounds HIV and stigma surrounds those seeking asylum. It may be that asylum seekers are wary about seeking healthcare and talking openly to strangers about issues in their life or aspects of their history. Working

as part of a multidisciplinary team may mean that as nurses we may not be best placed to gather all the information we need on our own and asking question after question may not be a helpful approach. Referrals to the psychologist, counsellor, social worker, dietitian or worker from a specialist voluntary agency may be beneficial and it helps to find out who the patient is most comfortable talking to. Whether in outpatients, on the ward or in the community, the environment that is appropriate for each patient should be considered; a small enclosed room, though good for some, may induce terror in others. Meeting patients in a park or coffee house could be a possibility.

It is worth pointing out that some people do not tell the truth. As nurses we work in a non-judgemental, holistic and professional way but it is important to get as much physical, verbal and documentary evidence as possible to build up a realistic story when making an assessment. This may be more important in the case of supporting an asylum claim. People may claim to have escaped war when in fact they have come from a peaceful homeland; they may have self-inflicted injuries (including gunshot and knife wounds), false identities, fictitious children and be untruthful about their sexuality. However, this is a very small minority of cases and the UK Borders Agency does not look favourably on fraudulent claims. If fraud is committed, it may be important to work with other members of the multidisciplinary team to investigate the reasons for this; some asylum seekers are desperate to stay in the UK under any circumstances and may take desperate measures to ensure this happens.

The NHVNA Competencies concerning assessment are very comprehensive and the first few patient assessments should be equally so. It should never be assumed that HIV is the biggest issue in a patient's life. For someone living with HIV and seeking asylum, there may be many more pressing issues to deal with first. It may be advisable to compare assessments with colleagues (especially psychologist/counsellor or social worker) to look for commonalities or possible conflicts in stories. The four main areas of the NHVNA Competencies of assessment, and care planning to meet health and well-being needs, include social, physical, spiritual and emotional assessment.

Depending upon where, when and why someone decides (or is asked) to test for HIV may determine their reaction to a positive result. Many people are testing late for HIV so present with more physical symptoms; however, for asylum seekers, the psychological, emotional and social impact of their situation is often most important.

Psychosocial/emotional assessment

The way that individuals express distress differs between and within cultures, which makes

assessment and treatment of psychological health problems extremely complex. Assessment of these areas may need time and require a more open mind. It is important to understand any cultural taboos such as who patients can talk to, what they can talk about and the level of communication they can have with strangers. An awareness of cultural coping mechanisms may be needed, for example, to prevent a cultural norm being classified as schizophrenia or psychosis. The role that self-harm and suicide play within certain cultures may need exploration and a sensitive touch. Noting significant trigger factors (especially for those who may have come from a traumatic background) is useful. Patients may have specific fears such as a wariness of men, uniforms, small rooms or loud noises.

Psychological distress is common. People may experience:

- Extreme sadness – caused by the loss of family and friends, especially to war or famine, and the loss of identity, body image, role and status. If possible, a picture of the life at home (when all was well) and what work/study a patient did, who was around and feelings around this, should be obtained.
- Anxiety, stress, depression and panic attacks – due to any of the issues mentioned above. These may also manifest as weakness, headaches, abdominal, neck or back pain with no apparent physical basis.
- Problems with memory, concentration and disorientation.
- Poor sleep patterns – 20% of the overall adult refugee population (and 35% of over those 65 years of age) admits to a serious sleep problem.

Social assessment

Money and housing can be two of the most important issues that asylum seekers have to deal with. Keeping well fed, sheltered and safe in a new country will impact on all other areas of psychological/emotional and physical health, yet it is the area where there is most controversy and heartbreak.

Once an asylum seeker has entered into the legal process, he/she is entitled to housing and some financial help; however, the situation is less clear when people have not accessed legal help to remain or have been refused asylum. The amount of benefit is fairly low and in times of rising food costs and heating bills, many asylum seekers are living in poverty. An awareness of local HIV and asylum seeker/refugee volunteer agencies is needed to support patients, especially those agencies that may offer subsidised food or could provide individuals with charitable, financial or specialised support.

Housing offered may not always be suitable especially for those who may be vulnerable or who

have children. There may be a feeling of 'better this than nothing' but if the hostel or bed and breakfast accommodation is not suitable for the individual, help may be needed, for example, in writing letters of support and medical summaries. This may be especially true in cases where there may be damp or squalid conditions that may affect health, or threats of violence, racism or sexism.

Physical assessment

A significant number of asylum seekers are prone to particular health problems especially communicable disease such as hepatitis A, B and C, tuberculosis, measles, malaria and meningitis. There may be disfiguring physical effects of war and torture (gun and knife wounds), landmine injuries (loss of limbs and sight), beatings and malnutrition (extreme wasting, wounds and sores).

The main physical health issues encountered by asylum seekers include the following.

- Gastrointestinal symptoms such as gastritis and peptic ulceration are common. En route, people may have consumed contaminated water and food so it is important to consider parasitic diseases, dysentery, cholera and typhoid (although rare). A new diet of unfamiliar processed, rich foods may have devastating gastrointestinal effects and, with a lack of funds, these foods may be the most accessible or tempting.
- Chronic illness such as heart disease, diabetes, hypertension and stroke can be more common in other countries such those in Eastern Europe and South Asia.
- Sickle cell anaemia and thalassaemia are more common in black African, Indian and Pakistani people or those from Middle Eastern or Mediterranean countries. Screening may be needed, particularly for pregnant women. This may be something that has not been diagnosed or discussed at home.
- Fungal infections and scabies are common dermatological problems as a result of poor hygiene and living conditions.
- An increase in upper and lower respiratory tract infections may be associated with poor living conditions, poor nutrition and smoking. Patients should be monitored for pneumocystis pneumonia, cytomegalovirus and other HIV-related infections.
- Ophthalmic problems with higher incidences of glaucoma occur in areas where diabetes is more common or where nerve gas has been used in war.

Spiritual assessment

Faith plays an important role for some, providing strength, sustenance, identity and self-esteem. Working with faith communities may be beneficial during the assessment period, and beyond, especially when working around areas of psychological distress. An awareness of who to talk to, especially those sympathetic to HIV, is useful; help can be obtained from local sources, the hospital chaplaincy team and volunteer agencies such as THT Direct.

Summary

In conclusion, there are as many issues as there are countries of the world, and everyone has a unique culture and way of living. To assist asylum seekers to live a healthy, productive life in their new country is a challenging yet fulfilling role, but one that will involve a multidisciplinary approach to care in order to ensure that patients feel safe and secure with the choices they have made.

Further reading

Asylum Statistics United Kingdom 2007 (2008). ISBN 1358-150X.

NHIVNA. *National HIV Nursing Competencies*. NHIVA, London, 2007. Available at www.nhivna.org/competencies/index.php (last accessed 8th December 2008).

Burnett A, Fassil F. *Meeting the health needs of refugee and asylum seekers in the UK: an information resource pack for health workers*. Department of Health, London, 2002.

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Culture, HIV and food: 'what's in a meal?' Reflections on the role of occupational therapy in HIV care

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"Assessment of meal preparation involves more than task analysis"

Occupational therapists (OTs) commonly assess, evaluate and treat people by analysing their daily activities. As an OT working in the HIV field for the past 12 years, I have observed many changes. For example, there has been an increasing diversity of the client demographic, a widening age range, greater life expectancy reflecting the benefits of antiretroviral therapy, and an increasing long-term need for social and health resources. All these have implications on OT practice.

Over time, this changing client need has altered the focus of an OT's role. In the early stages of my HIV 'career', I frequently carried out home assessments, enabling people to return home better able to manage deteriorating function, or even to die. I often taught stress management strategies, including relaxation techniques. These elements are no longer a significant part of my role, and currently a high proportion of my time involves assessing physical and cognitive function, working alongside clients and other professionals – especially community colleagues – to manage the increasingly 'episodic' nature of HIV-related illness.

Task performance, participation and productivity are important indicators of function and wellbeing in physical, psychological and cognitive domains. The ability to prepare food in some form is part of a range of personal care and domestic tasks that together may be taken as an indicator of preparedness for discharge.

Meaning and purpose

Though healthcare professionals aspire to holism, the preparation and eating of food can be viewed as not much more than 'a means to an end': a nutritional necessity. However, many elements are involved in the meal-preparation process, including dynamic and static balance, hand function, hand-eye coordination, object recognition, cognitive skills of sequencing, structuring, memory, attention, psychological elements of motivation and purpose, to name but a few. The therapist considers these

aspects and their interplay as part of the process of activity analysis, assessment and treatment.

Preparing food for self and others can be a vital element of a person's life, involving productivity, role performance, self-perception and self-worth, cultural and social meaning and validation, and it is apparent that the seemingly simple task of preparing food takes on great significance for a person living with HIV, as they work towards regaining function.

For clients who have been in the hospital or rehabilitation environment for weeks or months, the opportunity to purchase and select ingredients to create a meal can have immense personal value. They may also (if they have the opportunity) share food with others, and this acts as a tangible demonstration of their 'recovery' and progress, as well as creating an important social event. Appetite can be stimulated by the process of food preparation and by the tastes of traditional and familiar foods.

Personal learning and reflection

Despite attempts in many services to address varying dietary needs, it can be extremely challenging to meet all individual preferences. Through many years' experience of meal-preparation assessment, I quickly observed that the generic concept of the 'African' menu choice has little meaning to those from this vast continent. Even when using similar ingredients, great diversity exists in preparation method and ingredient combination. It is also necessary to work within the practical constraints that exist within a rehabilitation or hospital environment – ingredient availability, suitability of utensils, cost, time constraints preventing the preparation of certain ingredients, or simply therapist unfamiliarity with the preferred ingredients and their preparation. Clients often request 'gari', maize meal, potato leaves, tilapia or 'fufu', and I find myself often needing to adjust what I consider 'safe' techniques, for example when cutting ingredients, or heating oil. From a white British perspective it may be usual to use a chopping board, but many clients from various African regions prefer to hold items in one palm, cutting with the other hand. Similarly, ingredient quantities and cooking method or sequence used vary – the intensity of heat

preferred, and amount of oil used was novel to me during my early experience assessing clients from the African continent.

Conclusion: we are what we eat

Meal preparation offers a non-threatening opportunity for assessment, and provides a very tangible 'reward' at its conclusion, potentially increasing a person's desire to participate. Depending on the person's function, preparation for the activity can also offer a wealth of assessment opportunities – money management, budgeting, transport and mobility assessment, timing, planning and memory skills. When successful (and the therapist should be sufficiently skilled to grade the task appropriately), it can act as a substantial confidence boost, creating an opportunity for the client to demonstrate skill performance and mastery. Importantly within the client-therapist relationship it also offers scope for the client to be the

'expert' and, depending on circumstances, enabling the therapist to 'take a back seat' and allow the client to lead.

Familiar food can connect us with our culture, our family and past events and can therefore be very meaningful. Perhaps it should be unsurprising that at the conclusion of one particular meal preparation assessment, a client said, 'I came home today'. Not an indication of disorientation or confusion, but a simple statement that summed up the meaning and value the activity held for her.

Further reading

O'Brien K, Bayoumi A, Davis A *et al.* Exploring 'disability' from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Can J Infect Dis Med Microbiol*, 2006, **17**, Suppl A, Abstr 422.

Nurse prescribing in HIV: opportunities and threats

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Nurse prescribing: an overview to date

Non-medical prescribing was finally initiated in the UK in autumn 1994, over 15 years after the Royal College of Nursing (RCN) first published evidence of the case for nurse prescribing. There are some who see this, perhaps with justification, as 'one of, if not the hardest fought battle in nursing history' [1], and as part of the seemingly constant struggle of Nursing to be recognised as an autonomous profession.

The Cumberledge Report [2] recommended that nurses' roles should expand to include prescribing as one means of meeting government directives for reducing pressures on already stretched resources and of meeting the increasingly high expectations of service users. The optimistic Crown Report that followed [3] described several other potential benefits that might arise from this extended role. These included improvements in patient care, better use of nurses' and patients' time and improved multidisciplinary communication. It also suggested that greater professional autonomy would improve job satisfaction keeping experienced nurses within clinical practice as a result. A second Crown Report [4] supported a more extensive and flexible approach to non-medical prescribing with the introduction of supplementary prescribers. To date there are approximately 10,000 qualified Independent Nurse Prescribers (INPs) in the UK.

The impact of nurse prescribing

The majority of evidence to date, albeit relatively limited, suggests that nurses are, in general, positive about their prescribing role [5], with benefits including time-savings and convenience, increased job satisfaction and better-informed patients. However, there have also been some concerns identified. Luker *et al.* [6] highlighted nurses' fear of making errors in diagnosis. Study participants acknowledged some considerable anxiety about writing prescriptions in terms of assuming responsibility for diagnosing conditions; however, their anxiety reduced as their experience in the role grew.

The 'battle' for autonomy continued until very recently when finally nurse prescribers were granted access to the entire *British National Formulary* (BNF), very obviously determined by individual practitioners' levels of competency. The frustration revealed by Brooks *et al.* [7] and others with the limitations of the initial non-medical prescribers' formulary should now be a thing of the past.

Several pieces of research look at the prerequisites for good prescribing practice, including educational preparation and clinical support. Brooks *et al.* [7] found that informal team support, largely from other nurse prescribers, was perceived to be the most valuable. In addition the study found a problematic lack of formal mentorship and clinical supervision for the study participants when they first

began to prescribe. This implies that practitioners working in isolation, as is the case for many HIV Specialist Nurses, may find this to be a negative influence on their prescribing practice. In addition several studies have identified a lack of support from medical colleagues [7,8].

Luker *et al.* [6] also evaluated the initial pilot sites for nurse prescribing from the patient perspective. The researchers found the vast majority of patients were in favour of nurses being able to prescribe and a significant number of positive responses focused on the nurse-patient relationship, including nurse accessibility and approachability, expertise and consultation style. Brooks *et al.* [7] also focused on the patient viewpoint and found similar benefits. This study noted that the reassurance, health promotion and continuity of care offered by prescribing nurses were also welcomed and valued by patients. It is interesting to note that Latter *et al.* [9] suggested that patients believed that nurse prescribers would only provide limited help. However, this view was reported prior to the extension of the available formulary and needs to be reassessed in light of recent legislative changes.

Stevenson *et al.* [10] and Rycroft-Malone [11] both identified a lack of a 'concordance approach' in medication-related nursing interactions. Both studies found that communication between nurses and patients, in consultations where prescribing took place, were largely 'asymmetrical and paternalistic' with one-way information-giving predominating and participation by patients being actively limited. This finding would appear to be especially relevant to the field of HIV, where considerable emphasis is placed on treatment adherence, and where nurses are involved in, and often leading on, the provision of care relating to it.

Study purpose

There remains a paucity of literature that explores the reality of nurses' experiences as prescribers. The aim of this study was therefore to explore the experience of HIV Specialist Nurses who were operating as independent prescribers. This article summarises some of the benefits and potential problems arising from this extended role, as perceived by study participants, and considers the impact of this on working relationships.

Methods

By advertising on the NHIVNA website and by word of mouth a total of 12 INPs (including the two study authors) working within the speciality of HIV were identified. It is believed that this was the vast majority of, if not all, such qualified practitioners practising at the time of the study, spring 2007.

The research was conducted in two phases. All identified nurses were contacted to ascertain their

willingness and/or availability to participate in the study. First, a 14-item postal questionnaire was sent to those who had agreed to participate ($n=10$, as the authors did not participate). The questions had the aim of obtaining data on the practical aspects of the nurses' prescribing and were anonymous and confidential. Eight of the 10 questionnaires were returned.

The eight respondents were then invited to attend a focus group to explore some of the key findings in more depth. Marshall and Rossman [12], describe focus groups as 'socially orientated; studying participants in a natural, real-life atmosphere'. These fora allow the facilitator flexibility and yield quick, valid results at low cost. A focus group was appropriate for our purpose as this qualitative approach seeks to understand the perceptions, emotions and individuality of participants' experience and to share experience. Group discussion is particularly appropriate in this case, where the researchers had a series of open-ended questions and wanted to reveal dimensions of understanding and attitudes through communication. Patton [13] draws attention to some other advantages of focus groups, in that they allow contact with a number of participants at one time, provide some internal verification of the data and can be enjoyable for the participants.

Seven INPs attended the focus group discussion. The participants were experienced HIV nurses on Bands 7 and 8, a mix of clinical nurse specialists, nurse consultants and similar job-holders employed in HIV clinics and in community settings. The group was moderated by the authors and tape-recorded with participants' consent. An independent secretary transcribed the content. The qualitative data was then analysed using content theme analysis, ensuring both typical and atypical data were considered and direct quotes used as examples of themes, to maintain rigour and validity.

Findings

The impact of independent prescribing on HIV nurses themselves

The questionnaire responses included a number of positive comments about job satisfaction. Nurses reported spending less time looking for doctors to sign prescriptions and patients received a more efficient service with reduced waiting times. With increasing numbers of patients who are stable on antiretroviral therapy, doctors' time was used more effectively, focusing on patients with more complex medical needs. INPs felt that their new role improved access to medicines, benefiting in particular those patients from marginalised groups who found regular or frequent clinic attendance more difficult.

In the focus group discussion, nurses described confidence about when they would and would not

prescribe, demonstrating the ability to resist pressure from patients whether it was for antiretroviral drugs:

'Yesterday [] I refused to prescribe [for] a very, very difficult patient who is on T20 (enfuvirtide) who doesn't keep his appointments, has got multiple resistance... and you know, he'll promise to come and he doesn't come and I think, 'I'm not paid to take all that responsibility, no thank you'. [] I feel quite happy about that and I know the doctors are quite happy about that as well.'

Or for other drugs:

'In terms of temazepam, knowing how easy it is for someone to just continue that prescription, I don't think I'd want to do it to be honest with you, but if I did it would be for a few days on the proviso that they went to their GP to discuss the problem.'

And:

'I'm under increasing pressure from one of my clients just over something very stupid which is Senokot, which he eats and he drinks []. But he knows I'm not going to prescribe it for him and it hasn't made him - it's just an acceptance. I don't think that he thinks any less of me. I'd happily prescribe his fluconazole when he needs it, or aciclovir.'

The impact of independent prescribing on nurse-patient relationships

The quality of pre-existing nurse-patient relationships was seen by the group as an aid to independent prescribing, although one participant added a note of caution:

'I think our semi-close relationship with our patients gives us that perfect position to prescribe.'

'The relationship we've got with our patients is close enough to agree, disagree, have an argument. I don't think we'd lose patients because we're not going to prescribe.'

'Well we might. They'll move on to another centre.'

The HIV INPs expressed feelings of anxiety about making diagnoses in order to prescribe:

'It sort of puts us under that pressure. I've got some symptoms before me.'

'Because prescribing in some circumstances like that is totally dependent on you making an accurate assessment of what the problem is and I mean if you were assessing somebody's rash and you say 'it's shingles' and it turns out to be a nevirapine-related reaction ...'

Another participant had contemplated undertaking the clinical module on patient examination but decided not to pursue this. Others felt that the difference between nurses'

and doctors' roles in clinical diagnoses remained clear:

'There is a distinction between nurses at their best doing what nurses do and being rewarded for that, and doctors.'

The impact of independent prescribing on nurse-doctor relationships

While the discussion revealed mostly positive and supportive nurse-doctor relationships, some nurses expressed concern about inheriting prescribing practice with which they disagreed:

'It's about making it clear to patients, I'm not not prescribing this for you because I'm a nurse and that person's a doctor, I'm not prescribing this for you because it's my professional judgement that [the medication]'s not required. Now if another [] clinician feels differently then that's their ultimate decision, this is mine.'

'It's uncomfortable for us sometimes because we know that we've actually undermined what the doctor's been saying, which isn't comfortable, but that's what we believe is correct.'

The impact of independent prescribing on relationships with the pharmaceutical industry

The pharmaceutical industry has started to 'invest' in specialist nurses who they realise are in a position to influence prescribing practice, and as nurses take on more active roles in prescribing they will be increasingly exposed to such influences.

Study participants acknowledged this, but felt that HIV nurses are used to dealing with representatives of pharmaceutical companies. They believed that independent prescribing was unlikely to give rise to any new problems with this relationship.

'Nurses in HIV have got quite used to that rub-up against the pharmaceutical industry and know the potential dangers out there, you know, coercion, ethics and stuff.'

Nurses' perceptions of patient satisfaction

In the focus group, HIV INPs widely perceived patient satisfaction with nurse prescribing, which stems from the benefits of trust in long-term nurse-patient relationships, for example, they felt:

'I've been working in the same place for a long time. I think I would be surprised if people were suddenly unhappy because, you know, they're happy with everything else.'

'... we see them at least two or three times a year and we are going to see these people for many, many years, so I think that the relationship that we have with our patients tends to be quite fluid and quite amicable and I think that probably they just don't really mind who's going to give them the medication...'

'Oh, now you can prescribe, that's brilliant. Now I don't need to hang around 30 minutes... while you phone someone.'

However several people agreed that there is another common viewpoint:

'People are interested in what you can do for them, actually...with your nurse prescribing qualification, and so it's either the 'glad factor' of what I can possibly do for you, or the 'fear factor' of what I might be costing you or putting you at risk your service, so there are both of those elements out there.'

Barriers to independent nurse prescribing in HIV

Some HIV INPs had experienced problems using their qualification in practice. One acute centre caused delay by requesting a formulary and another sought to limit the range of drugs prescribed, to the frustration of the HIV INPs:

'The clinic is actually limiting the range of non-HIV medications that I can prescribe, even if many of these agents prove very useful in treatment support aims.'

Other reasons for delay in practising as an INP included the need to rewrite job descriptions and review pay bands, arranging contracts for nurses who were employed outside the clinic and identifying a budget. One person felt that writing the prescription himself saved time, but a community nurse was concerned about the potential for increased pressure on this already stretched resource:

'When I do sessions in the clinic I do feel terribly constrained [by time] and very much. I honestly don't know how I would feel if I was seeing patients, starting them on treatment and reviewing them routinely all the time, because I would feel very constrained. You've got half-an-hour. For me to feel completely like I have really given, not all but some patients, the kind of time that they need, I'm talking an hour usually and then a home visit can often be more like two, for a complex patient.'

Discussion

With HIV care moving to a chronic disease management model [14] and the majority of patients stable on highly active antiretroviral therapy, there is considerable potential for Specialist Nurses to manage this cohort clinically. With many clinics already moving towards clinical nurse-led services, the numbers of nurses taking on extended roles will inevitably increase. Our employers, our medical colleagues, and indeed HIV nurses themselves need to explore and clarify attitudes to roles that extend beyond traditional boundaries.

The participants in this study felt that the nurse becoming the prescriber had not affected nurse-

patient relationships negatively. HIV INPs reported the benefits of being in long-term relationships with their patients, who they believed would continue to disclose concerns that they might not trouble to report to a doctor. This was felt to be true, even when nurses challenged doctors' prescribing 'habits' or refused patients' requests, for example, for sleeping pills, indicating the confidence and autonomy of the INPs in the study.

Contrary to the findings of Stevenson and Rycroft-Malone [10,11], treatment adherence through a holistic and partnership approach has been a priority for most nurses working in HIV over recent years. In many HIV treatment centres the in-depth, resource-intensive area of adherence support has largely been taken on by non-medical practitioners, in particular nurses and pharmacists, whose skills in assessing and supporting adherence are developing apace.

Participants saw prescribing medicines as a further opportunity for nurses to work in partnership with patients and to influence patients' medicine-taking behaviour. The study authors questioned whether or not the 'power' of the prescriber, as 'gatekeeper' to medicines, could have an impact on the ability of INPs to maintain a truly holistic approach and a non-judgemental, supportive role. However, in their experience to date, the participants only perceived that there would be benefits to patient care in this respect, and did not share the researchers' concerns that nurse-patient relationships might be negatively affected.

In reality there will often be an element of uncertainty about clinical diagnoses, and literature suggests that nurses in particular can find tolerating this uncertainty difficult [15]. Traditionally this risk has been taken by doctors whose medical training prepares them for this responsibility. However, nurse involvement in reaching clinical diagnoses, while often informal, is frequently significant yet historically has not been acknowledged [16]. Now, however, the opportunity for nurses to take on this new role suggests an acceptance of nurse involvement in diagnosis. INPs will have to learn to manage this level of accountability, as they accept responsibility for autonomy in clinical decision-making.

This study found that professional boundaries between doctors and INPs were clearly defined. Participants agreed that making clinical diagnoses in HIV clinical practice is often complicated and that INPs must be sure to work within their level of competence; and also consider undertaking further education in this area. An additional response, to an open-ended item in the questionnaire, was that regarding independent prescribing: 'junior nurses see it as aspirational'. This could be seen as support for one of the aims given in the Crown Report [3] that independent prescribing could support the retention of experienced nurses in clinical roles.

Those questioned also felt confident in their relationships with the pharmaceutical industry. They felt that they were already well aware of the potential for influence and conflict of interest. However it could be argued that this is rather a naive view as there is considerable evidence to the contrary [17]. Studies have revealed the power of advertising and marketing, amongst many other potential external influences on prescribing practice.

Conclusion

The Department of Health reports a desire to make better use of existing skilled professionals and ensure more flexible multidisciplinary working. Non-medical prescribing is seen as one way to improve the quality of services to patients, while maintaining patient safety, increasing patient choice and improving access to healthcare. Its success will rely on nurses being able and willing to take on this responsibility, on team work and multiprofessional co-operation, on adequate funding and structured effective support mechanisms.

In the field of HIV, independent prescribing by nurses is in its infancy. Although the authors believe that most UK-based HIV Specialist Nurses who are qualified to prescribe participated in this research, the numbers were few and the full potential for, and impact of, independent prescribing in HIV nursing is yet to be realised.

Historically, in the UK, HIV-positive patients have driven service development with vocal and well-informed campaigns demanding that their needs be met. Future research into independent prescribing in HIV care should explore patients' perceptions and experiences of the care provided by nurses who prescribe their treatments and whether the nurse-patient relationship and/or the standard of care has changed as a result of this expanded role of nurses.

References

1. Jones M (ed.) *Nurse Prescribing, Politics to Practice*. Baillière Tindall, London, 2004.
2. Department of Health and Social Security. *Neighbourhood Nursing – A Focus for Care. Report of the community nursing review* (Cumberledge Report). HMSO, London, 1986.
3. Department of Health. *Report of the Advisory Group on Nurse Prescribing*. (Crown Report). HMSO, London, 1989.
4. *The Crown Report. Final Report of the Review of Prescribing, Supply and Administration of Medicines*. Department of Health, London, 1998
5. Lewis-Evans A, Jester R. Nurse prescribers' experiences of prescribing. *J Clin Nurs*, 2004, **13**, 796–805.
6. Luker K, Hogg C, Austin L *et al*. Decision making: the context of nurse prescribing. *J Adv Nurs*, **27**, 657–665.
7. Brooks N, Otway C, Rashid C *et al*. The patient's view: the benefits and limitations of nurse prescribing. *Br J Commun Nurs* 2001, **6**, 342–348.
8. Nolan P, Hague MS, Badger F *et al*. Mental health nurses' perceptions of nurse prescribing. *J Adv Nurs*, 2001, **36**, 527–534.
9. Latter S, Maben J, Myall M, Young A. Perceptions and practice of concordance in nurses prescribing consultations: findings from a national questionnaire survey and case studies. *Int J Nurs Stud*, 2007, **44**, 9–18.
10. Stevenson FA, Cox K, Britten N, Dundar Y. A systematic review of the research: communication between patients and health care professionals about medicines. *Health Expect*, 2004, **7**, 235–245.
11. Rycroft-Malone J. Patient participation in nurse-patient interactions about medication. Unpublished PhD thesis, University of Southampton, 2002
12. Marshall C, Rossman GB. *Designing Qualitative Research* (2nd edn), Sage, London, 1995.
13. Patton MQ. *Qualitative Evaluation and Research Methods* (2nd edn). Sage, London, 1990.
14. BHIVA, RCP, BASHH, BIS. *Standards for HIV Clinical Care*. BHIVA, London, 2007.
15. Luker K, Austin L, Hogg C *et al*. *Evaluation of Nurse Prescribing. Final Report*. Liverpool. University of Liverpool and University of York, 1998.
16. Baird A. Crown II: the implications of nurse prescribing for practice nursing. *Br J Commun Nurs*, 2000, **5**, 454–461.
17. Chapman S. Nurse Prescribing; Can nurses manage it? *In: Nurse Prescribing, Politics to Practice* (Jones M, ed.). Baillière Tindall, London, 2004, pp 279–281.

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Difficulties in co-working between primary and secondary care for people with HIV: an experience from East London

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Introduction

The HIV Clinical Nurse Specialist (CNS) team of Newham Primary Care Trust (PCT) conducted a small project to establish links with local GPs and to share information, with the aim of improving services for HIV patients within the borough.

Background

The nature of HIV disease has changed dramatically since the epidemic began over 20 years ago and HIV is now seen as a chronic rather than a terminal illness [1]. However, it remains a life-threatening, incurable condition, which presents complex challenges for health professionals and services. In response to this the *National Strategy for Sexual Health and HIV* [2] set out a plan to improve the way services are delivered. The aims of the Strategy include reducing HIV transmission and prevalence of undiagnosed infection, improving health and social care for people living with HIV and reducing stigma associated with HIV.

There is emphasis within the *Strategy* on the importance of integrating specialist HIV care and primary care and on developing new models of working with the aim of increasing uptake of HIV testing, by providing patients with a choice of easily available services. This is echoed in the more recent Department of Health White Paper *Our Health, Our Care, Our Say* [3], which states that sexual health services need to be more easily accessible to improve prevention of infection and access to treatment. As demand for services has increased over recent years it is no longer sensible or economically viable to deliver sexual healthcare only in hospital-based specialist centres and many sexual health services, including HIV testing, can now be effectively delivered in more diverse care settings.

In addition to this, the government has pledged to improve care for people with long-term conditions by moving away from reactive care based in acute services towards a systematic, patient-centred approach and it has proposed a model that aims to improve care for patients with chronic illnesses [4]. This includes improving care provided in primary and community settings and working in new ways to involve primary and secondary care, including

GPs, nurses, hospital consultants and social services [5]. These proposed changes have the potential to affect service delivery for HIV-positive patients and emphasise the point that the government's key strategy for improving services is the integration of care delivery.

Another imminent change to the structure of service provision in the NHS is practice-based commissioning whereby GPs will commission more services than PCTs [6]. Competition to provide cost-effective services that also meet client needs may lead to the redesign of many services, and specialist services such as HIV care providers need to think about how they can work in partnership with primary care more effectively to meet the demands of the changing healthcare climate.

Demographics of Newham

The London Borough of Newham has a population of 243,891 people, of whom approximately 150,000 were born in the UK and around 40% are white [7]. Nearly half the population is unemployed and around 24,000 people have a long-term health condition that limits their daily life [8]. Newham also has a young population with historically high rates of teenage pregnancy, although these are now beginning to fall [9].

In 2004 there were 83 new HIV diagnoses in Newham and 1081 Newham residents attended a clinic for treatment [9]. The number of HIV cases in the borough has been rising over recent years and in 2001 the rate of infection was higher than in the rest of east London, London and England [8]. Most of the infections are heterosexually acquired, reflecting the high number of infections acquired overseas [9].

Aims of the project

As a result of the proposed changes to service delivery and the changing demographics of HIV disease, the CNS team in Newham decided to conduct a small project to find out what was happening locally within primary care and to see how they could improve the services they offered to GPs. Newham PCT employs five CNS to work with HIV patients in the community. The team consists of two CNS working with adults, two working with children and families, and one working with

children covering two neighbouring boroughs. The adult and children and family nurses provide care to HIV-positive patients residing within Newham, regardless of where they receive their HIV care. The team provides a range of support, advice and education services to patients, carers and health professionals.

The CNS team offered to visit all 66 GP practices in Newham by calling the practices and offering to visit them either at their practice meeting or another convenient time. The primary aim was to inform the GPs of the CNS service, including how to refer into the service and to find out what kind of support the GPs would require from the CNS. The secondary aims were to find out if GP practices were offering HIV testing to their patients and what the barriers were to offering/providing testing, to find out what issues GPs had with caring for HIV patients and what they felt they needed to improve their services. This was not done as a formal research project but rather as an information-sharing exercise. All GP practices were offered one opportunity to accept a visit. The project was carried out by two members of the nursing team over a 2-year period and during this time there was one change of personnel. During the course of the project GP practice staff expressed many opinions about HIV patients and HIV care and some common themes emerged.

Results

The CNS team gained access to meetings at only 21 of the 66 GP practices in Newham. During the discussions with practice staff common themes developed that fell into two categories: issues raised about managing HIV-positive patients within the practice and issues about HIV testing within primary care.

Managing HIV positive patients within the GP practice

A number of practices stated that they did not have good communication with treatment centres of clients they knew were HIV positive. Some expressed particular concerns about drug interactions. If the practice does not receive communication from a treatment centre regarding a client, they are unaware of medication prescribed by that centre. Therefore GPs felt they were prescribing 'blindly' when these patients visited them and were concerned that the patient could experience difficulties as a result of drug interactions. This was expressed particularly strongly at one practice in relation to HIV-positive children, about whom they did not receive any communication from the paediatrician managing the HIV. It was suggested at one practice that the GP consider contacting the treatment centre and requesting information but this was felt to be too time-consuming.

There appeared to be a general frustration among the GPs about the lack of communication with GU clinics about patients that they have referred there for either sexual healthcare or HIV testing. Even when the patient had given permission for communication with their GPs, GPs reported that this did not seem to happen.

HIV testing within primary care

A significant proportion of GP practices stated that they refer patients to GU clinics for HIV testing. Some said they thought HIV testing during appointments was too time-consuming and some GPs preferred the patients to request testing rather than for them to have to broach the subject. In the present climate, where emphasis is increasingly shifting from secondary to primary care, it is interesting that GPs do not appear to see HIV testing within this framework. Indeed one practice said that they did not believe HIV testing was the responsibility of GPs.

Some practices expressed a lack of confidence and specialist knowledge to undertake pre- and post-test counselling as well as HIV testing. However, from conversation with the GPs visited, it was evident that there is a lack of knowledge as well as some outdated views regarding HIV care. One GP asked if all equipment used on HIV-positive patients (e.g. speculums) still needs to be thrown out. Another stated that all patients should inform the GP of their HIV status so they knew when to wear two pairs of gloves for procedures.

However, two practices wanted pre- and post-test counselling to take place within their practices and a number requested posters and leaflets about testing to be available in their waiting areas.

While some practices stated that they encouraged patients to disclose their HIV status to them, it was not explained how they did this. Others expressed concerns about patients disclosing their status to them because of their responsibility to inform of this diagnosis in medico-legal situations.

Discussion

Gaining access to GP practices proved very difficult for the CNS team. Practice managers did not respond to messages left or return telephone calls, and it was particularly interesting to note how many practices did not have any forum for someone external to address the whole clinical team. While acknowledging the increasing time pressures under which GPs are working, a large number are missing the opportunity of being kept updated and receiving specialist training as well as gaining support from a wider team.

The lack of liaison and communication about known HIV-positive patients is of concern. While, historically, GU clinics have intentionally not communicated with primary care for confidentiality reasons, when permission has been given and all

are aware of diagnoses, there seems no good explanation for why GPs are not receiving updates on their patients. However, GPs could also be more proactive in seeking information, especially when they are concerned about prescribing other medication. Closer working relationships between GU clinics and GPs may mean that outdated views regarding HIV can be addressed and enable GPs to remain updated on changes in practice and treatment.

Historically, HIV clinicians have taken on the treatment and management of all health needs of their patients. However, recent changes in funding by the London Consortium for HIV [10] means that non-HIV medication can no longer be prescribed by HIV physicians. This means primary care and HIV clinics need to develop a way of communicating that works practically to ensure safety for patients around medication.

Conclusion

The CNS experience from attempting to visit all GP practices in the London Borough of Newham has highlighted a number of issues. GPs desperately need up-to-date information and education about HIV but the difficulty in accessing GP practices shows that delivering this will not be easy. GPs need to be aware of the need to update their knowledge and to engage with educational opportunities. Meanwhile clinics need to work at creating

communication channels that include primary care. Unless this happens, there will be an impact on specialist HIV services as well as patient care.

References

1. Barker, PM, McCannon J, Venter WDF, Mmbara NW. Managing HIV as a chronic disease: using interactive data to improve clinical care. *S Afr J HIV Med*, 2004, **17**, 7–11.
2. Department of Health. *The National Strategy for Sexual Health and HIV*. Department of Health, London, 2001.
3. Department of Health. *Our health, our care, our say: a new direction for community services*. Department of Health, London, 2006.
4. Department of Health. *NHS Improvement Plan*. Department of Health, London, 2004.
5. Department of Health. *Supporting people with long-term conditions: an NHS and social care model to support innovation and integration*. Department of Health, London, 2005.
6. Department of Health. *Practice based commissioning: promoting clinical engagement*. Department of Health, London, 2004.
7. HMSO (2001).
8. Newham Primary Care Trust. *Newham Public Health Report*. (2006).
9. SOPHID (2004).
10. HIV Strategic Planning and Modernisation Subgroup of HIV Consortium, London HIV Strategy (2005).

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Conference report: Children's HIV Association (CHIVA) Autumn Conference 2008

Sheila Donaghy

The CHIVA parallel sessions held alongside the BHIVA Autumn Conference in October had a packed and varied programme as usual. CHIVA was set up in 2000 and is an Association of professionals involved in the care of children and families, infected or affected by HIV. Membership includes doctors, nurses, psychologists, social workers, dietitians, pharmacists and support service workers.

The contents of the CHIVA sessions try to meet the needs and interests of the mixed audience. In general, the more scientific talks happen in the morning, progressing to areas of psychosocial support later in the day. Time is allocated to allow for discussions and questions. There is time to socialise and network in the breaks and the day ends with a nice meal.

In the morning Claire Townsend and Pat Tookey (Institute of Child Health) gave feedback on their audit of perinatal transmission of HIV in England since 2000. The transmission of HIV from mothers to

infants has been reduced to around 1% and has been a huge success. Claire and Pat looked at the cases where babies had still become infected and separated out cases where the mother had been diagnosed prior to delivery from undiagnosed women. The risk of mother-to-child transmission was very low where mothers were diagnosed and managed appropriately. In undiagnosed women there was difficulty getting the full information about the antenatal and intrapartum care of the women. There was further discussion that a baby now being born with HIV should be seen as a Serious Untoward Incident and investigated as such so that any lessons could be learnt and care changed appropriately.

After coffee, 'HIV and the Developing Brain' was the topic with four speakers covering different aspects of this important area and the session ended with an expert discussion forum. After lunch the issues of testing children were discussed. Michael Eisenhut

(Luton and Dunstable Hospital NHS Trust) presented an audit of the mothers with HIV at their clinic to establish whether the children had been tested. An initial audit found high levels of untested children. They then undertook a further audit to follow up whether any more of the untested children had now been tested. Their results showed there were still many untested children despite a focus on the importance of testing and offers of further counselling. Some of the reasons for not testing their children were anxiety, guilt if the child was found to have HIV, and fear of disclosure of maternal diagnosis.

Katia Prime (St George's Hospital, London) gave an excellent talk on late presentation of adolescents in the United Kingdom and Ireland who were infected by vertical transmission. This showed that there were often delays between adolescents presenting and being tested for HIV. There were further discussions around the difficulties of getting children tested. New guidelines have been published recently on normalising HIV testing for adults and there is a plan to update the guidance around testing children for HIV. A day-long conference was held in December 2008 entitled 'Don't Forget the Children', which focused on what should be done about testing the children of HIV-positive parents attending adult HIV services.

Steve Welch (Birmingham Heartlands Hospital) gave an overview of the updated PENTA (Paediatric European Network for the Treatment of AIDS) treatment guidelines for children with HIV. The main changes are the recommendation that all infants infected with HIV start antiretroviral therapy urgently and the raising of thresholds for starting therapy in the other age groups. Other

presentations during the day also supported starting antiretroviral therapy early in infected infants. Both the European Infant Cohort Collaboration and the CHER trial showed improved outcomes for infants starting therapy early. The CHER trial demonstrated that early therapy reduced mortality by 76% and HIV progression by 75% in South African infants. The US and WHO guidelines all now recommend early treatment of infected infants. The difficulties of achieving this in developing countries was highlighted by showing that there are 250,000 pregnancies annually to women with HIV in South Africa compared with 15,000 in the whole of Europe.

The day ended with a lively presentation of a fun, educational interactive DVD to help children learn more about their health and HIV. Finally there was a discussion about the benefits of residential weekends for young people with HIV and the proposal of the idea of summer camps for this group of young people.

These conferences are valuable opportunities for nurses and other colleagues working in family HIV throughout the UK and Ireland to get together for excellent updates and discussions around medical and psychosocial care. The spring CHIVA conferences are held outside London; this year's was in Liverpool and in May 2009, it will be in Manchester.

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NHIVNA update

■ The first announcement is now available for the 11th Annual Conference. The conference will be held in Birmingham, 25–26 June 2008. This year we have the support of a local host, Maxine Owen from Birmingham Heartlands Hospital. The conference subcommittee has already begun to put together an exciting programme with excellent speakers and topics.

■ There are scholarships available to help student nurses and junior nurses attend the annual conference. Further information on the conference, abstracts and the scholarship applications is available from the website (www.nhivna.org)

■ As you will have seen, the members-only section of the website is now up and running. To ensure the new site is active and very much

alive, we need contributions from members for this section. Ideally, we are looking for HIV nursing-related guidelines and protocols. Any documentation that you would be willing to share with colleagues would be much appreciated. If you would like to submit please contact jacqueline@mediscript.ltd.uk.

■ Plans have begun in earnest for the study days programme for 2009. Please check the website for the latest information as it becomes available.

■ I want to thank the NHIVNA Executive Committee and the Secretariat for all their hard work and commitment in 2008, and wish you all a joyous and peaceful festive season.

Sheila Morris
Chair

2009

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