

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

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

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

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Editorial Office

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Late presentation

Ian Hodgson

Independent Consultant, HIV Education and Research

Welcome to this edition of *HIV Nursing*. As we reach the end of another year, the battle against HIV continues unabated. Perhaps the highlight of this year's calendar was the *18th International AIDS Conference*, held in Vienna during July. For this writer, it was the sixth such event, and there are striking similarities between them. For example, at each, there are a couple of important announcements (in Vienna, they were around a possible cure for HIV, and research suggesting microbicides do work after all). There were also numerous demonstrations by lobby groups, seeking attention for neglected causes – in Vienna these included human rights, the homeless, and injection drug users. There are also complaints about what is missing – so, some African delegates were unhappy with the focus on Europe, and other delegates were concerned about gender issues receiving limited attention. This year, the Global Village (where NGOs showcase their wares) was, according to some, the best one so far, with allocated 'zones' for various interest groups, such as disability, sex workers and MSM. The stands distributing free drink and cakes were especially welcome.

December also means the release of UNAIDS' annual update on the HIV epidemic, and this year [1] the news, whilst not ecstatic, was guardedly positive. It is important in our field to acknowledge improvements; we are so often too ready to paint an irredeemably gloomy picture. So, the report suggests that 5 million people – a 13-fold increase since 2004 – are now receiving HIV treatment; in some countries it is now thought that mother-to-child transmission of HIV can be eradicated by 2015; and in parts of the world, the numbers of people newly infected with HIV are declining, including in many African countries.

This is excellent news, though progress is by no means universal. Central and Eastern Europe continues to see rapid increases in the number of people infected with HIV, through widespread injection drug use and poor harm reduction services, and antiquated post-Soviet health systems simply unable to cope with such a complex, occult illness.

So, if the battle is not over, there is improvement, and if this is to continue there are predicates, including the need to get people *tested*, and then if required, to get people treated before their health is severely jeopardised by HIV. Sadly, many still enter health systems at an advanced stage of HIV infection, symptomatic and gravely ill. As argued by Moreno *et al.* [2], these *late presenters* require a

much more aggressive form of treatment, which is often not able to reverse physical decline, and (from a public health perspective) also means there is increased risk of HIV transmission within the community from people not accessing ART clinics.

This edition of *HIV Nursing* considers some of the broader issues around late presentation, and the articles all consider some aspect of HIV treatment and care for patients unaware of (or in denial about) their HIV status. Christina Casley and Lesley Sinclair provide two very personal case studies describing the plight of 'David' and 'Anna' – late-presenting patients, reacting in very different ways to their diagnosis and treatment. The need for all members of the multidisciplinary team to engage meaningfully with traumatised patients is highlighted as significant by the writers: 'it is vital to understand the impact of diagnosis ... and ensure that trust is maintained.'

Getting people tested in the first place is vital, and in an article describing a London-based pilot project designed to increase the number of HIV tests taken, Emma Passera and Irene Browne discuss the ways in which reducing the stigma associated with an HIV test can have a huge impact in motivating people to come forward. The following article on the HINTS study describes a series of pilot schemes in London, funded by the Department of Health, set up to explore the best ways for rolling out HIV testing in areas of relatively high prevalence.

Charlotte Hamilton, addressing a similar theme, discusses how lessons learned in scaling up chlamydia testing could be applied to HIV. If we can 'normalise' the HIV test – remove both its mystique and nurses' tendency to require a detailed sexual history prior to testing – then many more people may be willing to be tested.

These articles suggest that, if more people are tested, then the number of people presenting late would lessen; however, in regions where HIV stigma remains prevalent (leading not only to discrimination, but also self-stigma of a person affected by HIV), rolling out treatment and care is difficult. Ruth Burtholt, in an intriguing review, discusses issues around HIV stigma in Central and Eastern Europe. Here, new HIV infections continue to escalate rapidly amongst the most at-risk populations, and HIV stigma from general society and also from healthcare workers is bound to have a significant, negative impact on access to treatment, and willingness to be tested.

Our final piece relates not specifically to late presentation, but to the challenge in ensuring that

children living with HIV are able to take their treatments successfully and with minimum difficulty. Dean Krechevsky and colleagues describe a novel approach where children are 'taught' how to swallow the larger tablets not available in paediatric formulations, using a method that recognises the context of the child, his/her individual coping strategies, and the role of parents. The writers suggest this could 'shift the responsibility of a new task away from the child in isolation, so that it is shared with significant others'.

As always, we invite feedback, and if you would like to comment on any of the articles in this edition, send a message to: hivnursing@mediscript.ltd.uk.

References

1. Report on the Global AIDS Epidemic, 2010. UNAIDS, Geneva, 2010. Available at: www.unaids.org/globalreport/Global_report.htm (last accessed January 2011).
2. Moreno S, Mocroft A, Monforte A. Medical and societal consequences of late presentation. *Antiviral Therapy*, 2010, **15** (Suppl 1), 9-15.

Correspondence to: Ian Hodgson, Independent Consultant, HIV Education and Research (email: hodgsonian@gmail.com)

CALL FOR PAPERS 2011

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

HIV Nursing welcomes all articles, editorial letters, case reports and other contributions which would be of interest to healthcare professionals working in the field of HIV.

If you have recently completed a dissertation for a degree, set up a project that has improved the service of care for your patients, or conducted some interesting research, please let us know.

As professional nurses, one of the best ways to raise our profile is by demonstrating innovative work that improves the lives of patients, family, and staff within the domain of HIV care.

HIV Nursing aims to provide a forum for those at the forefront of caring for people affected by HIV and is intended to provide a medium of communication on issues relating to HIV care.

Readers' contributions are highly valued.

If you wish to contact **HIV Nursing** please email: hivnursing@mediscript.ltd.uk or send items by post to: The Editors, HIV Nursing, Mediscript Ltd, 1 Mountview Court, 310 Friern Barnet Lane, London N20 0LD, UK

The themes for 2011's issues will include:

- Issue **11.1**: HIV: Past, Present and Future
- Issue **11.2**: Management in the community
- Issue **11.3**: Sexual health
- Issue **11.4**: Youth issues

Late presentations: challenges when an individual is diagnosed HIV-positive at an advanced stage

Christina Casley¹ and Lesley Sinclair²

¹Ward Sister and ²Matron, Chelsea and Westminster Hospital, London, UK

Introduction

Having worked in an HIV inpatient unit since 1995 (so, the pre-HAART era), it is striking that there are still acutely ill patients being diagnosed with HIV at an advanced stage, often with CD4 cell counts in single figures. This article reflects on why this is still the case, who these patients tend to be, and the issues and challenges that they – and the nursing team – face.

Reviewing the literature confirms that the definition of 'late presenter' is far from universally agreed. Adler *et al.* [1] identify nine different definitions, including time from HIV diagnosis to AIDS diagnosis. The most frequently used are based on CD4 cell count, and earlier studies often base 'late presentation' on a CD4 cell count of less than 200 cells/mm³, or in some studies even less than 50. Now that the 2008 BHIVA guidelines [2] recommend starting HAART at a CD4 count of around 350 cells/mm³, patients presenting at this level of immune depletion (and lower) may be considered 'late presenters'. Clearly, not all such patients have symptomatic disease, but in the cases discussed here, late-presenting patients are those with advanced symptomatic disease. As Adler *et al.* [1] point out, the lack of consensus around a universally accepted definition of late diagnosis does hinder determining rates and trends, even across Europe.

Our understanding of why patients still present so late is enhanced by looking at who these patients are. Studies suggest that late-presenting patients tend to be male, older, heterosexual and often in a long-standing relationship [3] – perhaps confirming the beneficial effect that antenatal screening has in detecting undiagnosed women. It also suggests some 'low-risk' groups miss out on early testing opportunities in primary care. Migrants are also at a greater risk of presenting late than people born in the country of study [1] possibly because of cultural, socioeconomic and linguistic barriers. Fear of disclosure and the accompanying stigma play a significant part, particularly in African and Asian communities but also in smaller out-of-London towns, where a close-knit community, however generally supportive, can create anxiety for patients concerned about disclosure, especially when they use local healthcare resources.

To illustrate some of the issues late-presenting patients encounter, and the challenges raised for staff, we discuss two patient-based case studies below (names have been changed to protect confidentiality).

David

David, a 31-year-old IT engineer, presented to A&E with a 2-week history of increasing shortness of breath. Amoxycillin had been started by his GP for a chest infection but had been ineffective. On assessment in A&E he was found to be tachypnoeic (respiratory rate 40, shallow breaths, using accessory muscles) and tachycardic, with a heart rate of 140/min. An arterial blood gas confirmed he was hypoxic and a level 1 bed was made ready on the acute admissions ward. A chest radiograph showed a 'ground glass' appearance and a diagnosis of severe pneumonia was made. An HIV test was performed and the result was positive. Within the first 6 hours he was reviewed by the ITU team owing to type 1 respiratory failure, and Vapotherm (a high-flow warmed oxygen system) was commenced with support from the critical outreach team.

Following his positive result, David was referred to the HIV team, informed of his diagnosis and transferred to the HIV specialist ward. Treatment for PCP (*Pneumocystis carinii* pneumonia) was commenced presumptively as he was too unwell to undergo an induced sputum or bronchoscopy. His condition stabilised but he continued to need very high levels of oxygen and would desaturate rapidly if it was removed, even for a few seconds.

We gradually got to know David over the subsequent days and weeks, and found him to be a gentle, courteous man. Of Pakistani origin, he had lived in the UK for several years, and appeared very dedicated to his work in IT, living alone and with relatively few friends. His parents lived in Saudi Arabia, and he would usually see them twice a year.

As soon as he was hospitalised they flew over to be with him. They were clearly a caring family but David was adamant they should not know about his HIV status, and did not think they were aware that he had had relationships with men. In discussions with a health advisor and other staff,

support around disclosure was raised but he maintained he felt that they would respond better when he was discharged from hospital. His mother had offered to care for him at home and he was glad of this and how supportive they had been.

The day following David's admission to the inpatient unit, his parents asked a nurse how they could protect themselves from contracting HIV in the light of his mother staying with her son on discharge. The nurse was taken aback and asked them why they had asked the question and whether they had been given any information suggesting their son had the virus. His father suggested they were just using HIV as an example. They were told we were treating him for pneumonia and if they had further concerns we would try to help. However his parents were not keen to speak in detail further. This conversation was not shared with David as he remained extremely unwell and insistent we told the parents nothing of his status.

David was commenced on antiretroviral treatment (ART) soon after his admission and was supported by nursing staff in his adherence. Medications became another point of anxiety for staff as his mother now visited every day for long periods and would sometimes enter the room as medications were being discussed. David would quickly change the subject and when later gently challenged, state that he did not want her to get distressed. This desire to protect his parents from his diagnosis raised real challenges for the team, particularly as they were aware that his parents may well have correctly guessed his status. In one incident, David's nursing folder disappeared and when his mother was asked if she had seen it, she retrieved it from his wardrobe. The nurse anxiously checked it for mention of HIV but it appeared to have none.

As David's condition slowly deteriorated, other family members contacted the ward. On a couple of occasions a relative from North America who claimed to be a doctor phoned the nurses asking what medications he was on and who his consultant was. This request was politely declined but again put nursing staff in a difficult position and demonstrated how fragile confidentiality is, particularly in a hospital context.

After over 6 weeks of treatment, David began deteriorating rapidly. A decision was taken not to send him to intensive care or start non-invasive ventilation on the ward as the scarring and damage to his lungs – the result of prolonged severe pneumonia – rendered such intervention futile.

After discussions with the HIV consultant and team, David decided not to have further active treatment and was started on the Liverpool Care Pathway [4] His parents were also informed of the prognosis and that his care was now palliative. A further conversation occurred between his father and the

consultant during which his positive status was discussed. To our knowledge neither David nor his mother were aware of this. Even at this point, David tried to protect his mother from her concerns for him and maintained his stoical and uncomplaining manner until he died. Other family members arrived in time for David's last hours, which resulted in continued pressure on the nursing staff and further probing questions.

David's family were extremely grateful for the care he had received. The ward team had done their utmost to protect David's wishes with respect to maintaining confidentiality but it was a significant strain on staff and must have been for him too. I do wonder whether an opportunity was missed early in his admission to reconcile his parents' suspicions with the reality of his condition and whether some acceptance of the situation for all could have been achieved. To quote one nurse, 'it remains very difficult to balance David's wishes with the reality of what his relatives can see happening'. It is a sad reflection that fear and stigma continue around HIV over 20 years since the first 'late presenters' were diagnosed. Perhaps the most important thing we do as nurses in this context is allow our patients a place of acceptance and respect on the ward that the outside world sometimes finds hard to countenance.

The next case highlights the complex needs of a patient when adjusting to an HIV-positive diagnosis and late presentation, when there are simultaneous social and cognitive needs.

Anna

Anna was a 30-year-old lady from Central Asia, with limited English and socially isolated. She was admitted to a hospital after she was found wandering alone in the streets, seemingly psychotic and confused. Initially, her symptoms were presumed to be a result of mental illness; however, a scan soon revealed cerebral changes. Her family lived overseas and there was only limited contact with a boyfriend, therefore collecting an accurate picture for Anna was difficult. Following investigations, Anna tested HIV-positive, with a presumptive diagnosis of progressive multifocal leukoencephalopathy (PML). Her CD4 cell count was less than 50 cells/mm³ and she had a high viral load. Assessing her memory and cognition was difficult due to language barriers. Regular inclusion of interpreters was critical to review her needs and work to establish a care plan. Although Anna had been informed of her HIV diagnosis, she frequently seemed to have difficulty recalling this information. She appeared not always to comprehend her HIV diagnosis and she pleaded that she only wished to return to work. Helping Anna understand her diagnosis was a significant component of care among the nursing team and health advisors. The struggle she had with her diagnosis impacted upon her willingness and

ability to take medication, exacerbated further by persistent anticipatory nausea when medications were dispensed to her. Her cognition often meant that she could present as naïve or child-like, and constantly sought support from team members, as we struggled through the language barriers.

Anna's admission was complicated further by her limited social support, and her increased vulnerability in the community as a young woman who appeared to have intermittent confusion. Her care required small steps, from testing different approaches to taking antiretroviral therapy without nausea or vomiting, to understanding adherence and the importance of medications, to building life skills and developing a comprehensive package of care to support Anna in the community

In many ways, Anna was traumatised by her diagnosis and the seemingly sudden changes in her health. Griffen [5] suggests that there is evidence of a link between post-traumatic stress disorder and HIV diagnosis, which can be exacerbated by abuse. On reflection, we recognised Anna's trauma and pain; however, did we fully recognise the traumatic nature and stress of her experience?

By working with Anna and recognising her anguish, the nurses established a therapeutic relationship, which outside the mental health setting, may perhaps be unrecognised or undervalued in acute or general healthcare settings. Dziopa and Ahern [6] describe a therapeutic relationship as one that is based on elements such as trust, equality and being genuine. Is this an innate ability of a nurse or a well-established skill built on emotional intelligence, recognition of the individual and respect? For Anna, the conversations and interactions with the nurses that promoted her individuality and worked to return her sense of control and ownership around her medications, were perhaps key in avoiding further feelings of trauma. By also supporting Anna in a non-judgemental way and promoting a sense of normality for her as an equal partner in her own care, we were able to demonstrate that being HIV-positive did not mean social isolation and exclusion.

Anna eventually moved back into the community. On discharge, she was cooking for herself, able to manage her own medications without nausea and

vomiting and had begun to understand her HIV diagnosis. Working and caring for Anna called for an understanding of the significance and turmoil a positive diagnosis can present for individuals faced with changes and challenges to their physical, mental and social well-being.

The challenges for nurses and multidisciplinary team members supporting individuals who are diagnosed HIV-positive, and are regarded as late presentations, are many. As these case studies suggest, there is a need to work within what can be a chaotic picture and to establish a therapeutic relationship, demonstrating without doubt a safe space without stigma or judgement. It is vital to understand the impact of diagnosis in terms of fear and stigma for the individual and to ensure that trust is maintained by working within the boundaries of confidentiality. Balancing this complex approach to care in today's healthcare environment may not be easy; however, it is only by empathy, skilled care and a holistic approach, that we can meet an individual's needs. HIV again presents a challenge to healthcare teams to be the best they can be.

References

1. Adler A, Mounier-Jack S, Croker RJ. Late diagnosis of HIV in Europe: definitional and public health challenges. *AIDS Care*, 2009, **21**, 284-293.
2. British HIV Association. British HIV Association guidelines for the treatment of HIV-1-infected adults with antiretroviral therapy 2008. *HIV Medicine*, 2008, **9**, 563-608.
3. Gilbert VL, Dougan S, Sinka K, Evans G. Late diagnosis of HIV infection among individuals with low, unrecognised or unacknowledged risks in England, Wales and Northern Ireland. *AIDS Care*, 2006, **18**, 133-139.
4. Marie Curie Palliative Care Institute. Liverpool Care Pathway for the Dying Patient. Available at: www.liv.ac.uk/mcpcil/liverpool-care-pathway/ (last accessed December 2010).
5. Griffen PT. Posttraumatic stress response to HIV diagnosis can impact medication adherence. *HIV Clinician*, 2010, **22**(2), 1-3.
6. Dziopa F, Ahern K. What makes a quality therapeutic relationship in psychiatric/mental health nursing: a review of the research literature. *Internet Journal of Advanced Nursing Practice*, 2009, **10**, 1.

Correspondence to: Christina Casley, Ward Sister, Chelsea and Westminster Hospital, NHS Foundation Trust, 396 Fulham Road, London SW10 9NH, UK (email: christina.casley@chelwest.nhs.uk)

The Harrow HIV Testing in Primary Care Pilot study

Emma Passera and Irene Browne

Community HIV Clinical Nurse Specialist Service, Caryl Thomas Clinic, Harrow, London

This article details the process, implementation and outcomes of the Harrow PCT HIV Testing in Primary Care Pilot study, which ran between October 2008 and March 2009. The pilot study was developed to increase the number of HIV tests being performed within Harrow among both symptomatic and asymptomatic individuals, in order to reduce the incidence of late diagnosis, and also the stigma and prejudice associated with HIV testing among professionals and the general population.

The article also provides recommendations for the further delivery of HIV testing within primary care and the development of the role of the Community HIV Clinical Nurse Specialist in relation to both HIV testing and enhanced services for individuals living with HIV within primary care.

Background

In July 2001, the Department of Health published the first National Strategy for Sexual Health and HIV [1]. The strategy addressed the rising prevalence of sexually transmitted infections (STIs) and HIV, and set out to raise standards of services across the UK in line with the NHS plan [2]. The aims of the strategy associated with STIs have been implemented with some success, for example the chlamydia screening programme, whereas improvements within the field of HIV have generally been slower. Difficulties in beginning to meet the aims of the strategy within HIV may be because of historical attitudes towards HIV and the associated stigma within the general population and amongst professionals. The aims of the strategy with respect to HIV were to reduce transmission and the prevalence of undiagnosed HIV, improve health and social care for HIV-positive individuals and reduce the stigma associated with HIV. The strategy proposed that the offer of HIV testing should be increased, and set a target and outlined a programme to reduce the number of undiagnosed infections. The strategy called for a multicentre approach within all aspects of primary and secondary healthcare.

It is estimated that there are currently 86,500 people living with HIV in the UK, a quarter of whom are unaware of their status [3]. However, many of these people may have had multiple contacts with healthcare workers for the treatment of problems that could be associated with their HIV-positive status, such as opportunistic infections or illnesses

that are considered AIDS-defining. In 2009, an estimated 52% (3450/6630) and 30% of adults (aged over 15 years) were diagnosed late or very late with a CD4 cell count less than 350 or 200 cells/mm³ within 3 months of diagnosis, respectively. This has a significant impact on the patient and can result in worse prognosis, significantly increased risk of permanent disability, more related health problems, higher drug therapy burden, onward transmission to sexual partners, and ultimately, higher morbidity and mortality [3]. Of the 516 people infected with HIV who were reported to have died in 2009, 73% had been diagnosed late [3].

The National Strategy for Sexual Health and HIV [1] suggested that GPs can make a significant contribution, particularly for those people who are reluctant to attend GUM services. It mentions that HIV testing in primary care has always been 'possible', but that it requires more training and education to support GPs in the role.

There are two general situations that provide valuable opportunities to diagnose HIV infection in primary care. The first is when a patient presents with symptoms or medical conditions suggestive of HIV. The main clinical opportunities for diagnosing symptomatic HIV infection are either in primary HIV infection (HIV seroconversion) where patients may present with flu-like symptoms, pyrexia or rash; or conditions associated with longer-standing HIV infection such as general lymphadenopathy, pneumonia, herpes infections and oral candidiasis. In the second situation, an asymptomatic patient may be offered an HIV test because the patient is, or may have been, at risk of HIV infection. GPs and practice nurses have ideal opportunities to discuss and assess the risk of having or acquiring HIV with individual patients during routine consultations such as travel advice, new-patient registrations, contraceptive care and cervical screening.

Harrow PCT currently serves a population of 214,800 and is the fifth most diverse population in the country, having a large East African/Asian community. At the time of the study 256, HIV-positive adults were accessing care in Harrow. This number does not include those choosing not to pursue the care offered (either locally or outside Harrow) or the undiagnosed population. Between 2004 and 2007 [4,5], the number of HIV-positive individuals in Harrow rose by approximately a quarter and continues to increase. This is thought to be due to an increase both in new diagnoses and survival.

HIV testing in the pilot study

Methods

■ Initial audit

In the initial phase of the pilot, a questionnaire was sent to GPs and practice nurses within Harrow. They were asked if they currently undertook HIV testing routinely within their practice and, if not, where they thought HIV testing ought to take place and what they perceived were the barriers to HIV testing in general practice. Questions were also asked about their knowledge and confidence in dealing with HIV.

The respondents were mostly GPs with an interest in sexual health and HIV who had performed HIV tests to some extent. The GPs felt that HIV testing should take place in primary care. They were already testing some patients but needed more training to be testing to an optimum level, and to be in line with current guidance. GPs highlighted funding as the main barrier that prevented them from practising in line with current testing guidance. Another barrier to testing was the lack of in-house phlebotomy services.

Results were manually collated and a full audit report was presented to Harrow PCT. Funding for the pilot was subsequently granted which allowed for 500 tests to be undertaken within the pilot study,

but in order to complete the pilot in a timely manner, a 6-month time limit was set.

■ Training and pilot phase

The audit report was then sent to GPs with an outline of the proposed pilot and an invitation to GPs and practice nurses to take part. Initial replies from GPs were mostly queries about the pilot, cost implications and funding.

Alongside this groundwork, alternative types of test were researched and discussed with the local NHS trust microbiologist in order to overcome the difficulties that GPs faced with their limited phlebotomy services. Point-of-care testing was not initially advised owing to the potential for false-positive results. Dried blood spot-type tests were suggested but there was a need for a specialist laboratory to carry out this type of test. Dried blood spot tests also have a risk of false-positive results. A condition of the pilot protocol was that a venepuncture test be performed following a positive result. GPs could also use regular venepuncture antibody testing through the local NHS trust laboratory by simply attaching one of the red 'pilot' stickers provided to their regular microbiology forms so that the forms could be identified as being part of the pilot by the laboratory staff.

A small core of interested surgeries had been identified through the original GP questionnaire audit and constructive liaison with these practices and the other interested GPs began in order to start the pilot. Eventually, seven of the 39 Harrow general practices signed up.

Formal training sessions took place in the GUM clinic and provided the opportunity for primary care practitioners to meet the working group. The session content included an overview of HIV, the modern HIV paradigm, the testing process and the HIV pilot outline. Alternative sessions were arranged when requested by GPs and practice nurses. A further education session was provided by the lead HIV consultant and the community HIV CNS via the local postgraduate GP tutors.

GPs and practice nurses were trained to test all Harrow residents who fell within the criteria recommended in the UK National Guidelines for HIV Testing 2008 [6]. Panel 2 shows the criteria for inclusion.

GP resource packs were compiled and distributed to participating surgeries with guidance on their use. Contents included hard copies of documentation such as audit forms and pre-test discussion prompt card, test kits and instructions, patient information leaflets and current guidance from BHIVA, MeDFASH and the Department of Health. Memory sticks were also provided that contained all documentation and guidance in electronic form in order for documentation to be downloaded onto local GP database management systems.

Panel 1: The aims and objectives of the Harrow HIV Testing in Primary Care Pilot

Aims:

- Increase the number of HIV tests being performed within Harrow, among both symptomatic and asymptomatic individuals
- Reduce rate of late diagnosis
- Facilitate competence in the HIV testing process for GPs and practice nurses
- Educate GPs and practice nurses on the current understanding of the HIV disease process and patients' healthcare needs
- Reduce stigma and prejudice among the general population and among professionals

Objectives:

- By increasing volumes of HIV tests being performed within Harrow PCT, the disparity between the known and estimated population of HIV-infected individuals may be reduced
- Early diagnosis will enable timely treatment with less complex and better tolerated antiretroviral therapy, a better prognosis and higher quality of life
- To reduce costs through early diagnosis avoiding lengthy periods of alternative diagnostic testing, possible treatment and/or hospitalisation for overwhelming opportunistic infection, less costly antiretroviral therapy, fewer demands on social care, and better preventative stance on all kinds of transmission

Panel 2: Criteria for inclusion on the Harrow HIV Testing Pilot and in normal practice

Routine testing for all people who belong to a group at higher risk of HIV infection:

- All individuals diagnosed with a sexually transmitted infection
- All individuals with a current or former partner with HIV
- All men who have sex with men
- All female sexual contacts of men who have sex with men
- All individuals who report a history of injecting drug use
- All individuals from a country of high HIV prevalence (Table provided to GPs)
- All sexual contacts of individuals from countries of high HIV prevalence

Posters were issued to be displayed in all surgery waiting areas to inform patients that the surgery was taking part in the Harrow HIV Testing Pilot and that, if they met one of the criteria, or would simply like a test, they should ask their GP or practice nurse. Testing commenced in October 2008.

Communication with participating surgeries occurred throughout the pilot although the busy nature of general practice did not allow for many face-to-face meetings beyond the initial training sessions. Updates and new publications were distributed to facilitate the pilot.

Results

Despite only seven centres participating in the pilot, even fewer HIV tests than expected were undertaken. Very few tests were performed by participating GPs and practice nurses or, if tests had been done, they were not included in the audit. Over the 6-month period between 1 October 2008 and 31 March 2009, only 19 audit forms were returned. We understand that some forms may have been misdirected but these have not yet been recovered.

There are many reasons for the low level of testing; the foremost is probably evident from the initial questionnaire sent to GPs. GPs simply do not have adequate resources, budgeting or training to be able to take on this role. A major contributing factor also seems to be that GPs and practice nurses lack confidence to become involved in what is historically seen as a distinct area of expertise. Not enough is yet understood by primary care workers to identify their own role within the modern HIV paradigm.

Documentation was kept as simple as possible, with step-by-step guides provided, including a flow chart and a basic tick-box audit form. Supporting information was available within the resource pack or on a memory clip if required and a contact number was given. However, none of the audit forms returned had been fully completed despite

the simple design. The audit form was re-issued shortly after the outset of the audit to include minor changes to the criteria for testing. No updated audit forms were returned although we did continue to receive audit forms up to the end of the pilot. This could have been a result of the updated forms being sent to participating surgeries electronically rather than as hard copies.

Despite the availability of the dried blood spot test kits, all but one of the tests done was by venepuncture antibody testing. There may have been some reluctance to perform the dried blood spot test; however, most tests requested were for investigation of illness so other bloods were also being done.

Other possible reasons for low returns include the following:

- Criteria for testing were not followed, resulting in fewer patients being tested
- Practice nurses had either received a poor response from patients or had not offered HIV testing or screening to patients that they were seeing in usual consultations
- Patients were tested but pilot stickers were not used on microbiology forms and therefore tests were not included as part of the pilot
- Audit forms were not completed and/or returned to the correct place
- Full dedication to the pilot across each practice was not achieved
- Continued contribution to the pilot from each individual practitioner was not achieved

Despite the low numbers of audit forms returned, useful information was obtained. Of the patients tested, 58% were considered to have symptoms that may be associated with HIV infection. This confirms that potentially undiagnosed patients do present in primary care. Also, 26% of the tests were carried out at the patient's request, confirming the need for providing HIV tests within primary care.

Summary

The pilot was successful in many of its original aims. It provided training for Harrow's interested GPs and practice nurses on the current understanding of the HIV disease process and the patient's healthcare needs. It raised awareness of the need for HIV testing in primary care, and highlighted the barriers to rolling out HIV testing throughout the PCT. While raising the profile of the community HIV CNS service and opening communication channels with primary care practitioners, it also identified service development needs within the HIV CNS service, to provide a more cost-effective single clinical assessment process for people living with HIV in Harrow. The improved understanding of symptoms of HIV infection and the testing process, along with increased public awareness, will help to reduce

stigma and prejudice among the general population and professionals.

Recommendations

The following recommendations are provided for consideration in the development of models of HIV testing and the role of the community HIV CNS, in relation to both HIV testing and enhanced services for individuals living with HIV within primary care that will meet the current UK national guidelines [6].

- Local GP with interest in sexual health and HIV to be member of Harrow Sexual Health and HIV Strategy Group
- GP representative to lead further HIV testing pilot with support from Community HIV CNS service
- Development of walk-in weekly HIV testing sessions within the existing community HIV CNS service
- Development of community-based HIV services, including HIV testing and management of stable patients living with HIV jointly led by GP with interest in sexual health and HIV and the Community HIV CNS service
- Provision of HIV awareness and testing training to a range of statutory and voluntary providers with a view to development of voluntary/outreach HIV screening
- An HIV educational training programme to be developed and implemented for healthcare providers across Harrow including GPs and

practice nurses as well as community nurses such as district nursing health visitors and other specialist nursing teams

References

1. Department of Health. Better prevention. Better services. Better sexual health. The National Strategy for Sexual Health and HIV. 2001. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133 (last accessed December 2010).
2. Department of Health. The NHS Plan: a plan for investment, a plan for reform. Cm 4818-I. 2000. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002960 (last accessed December 2010).
3. Health Protection Agency. HIV in the United Kingdom: 2010 Report. Health Protection Report 2010 4(47). Available at: www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1011HIVUK2010Report/ (last accessed December 2010).
4. Harrow Sexual Health and HIV Strategy 2006–2010. Available at: www2.harrow.gov.uk/mgConvert2PDF.aspx?ID=18255&J=1 (last accessed December 2010).
5. Health Protection Agency. SOPHID: Survey of prevalent HIV infections diagnosed 2009. Available at: www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1228207185359 (last accessed December 2010).
6. BHIVA, BASHH, BIS. UK National Guidelines for HIV Testing 2008. Available at: www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf (last accessed December 2010).

Correspondence to: Emma Passera,
Community HIV Clinical Nurse Specialist Service,
Caryl Thomas Clinic, Harrow,
London HA1 4UQ, UK
(email: emma.passera@harrowpct.nhs.uk)

Fear, loathing and HIV testing: why the UK reluctance to test?

Introduction

HIV is now a treatable medical condition and the majority of those who live with the virus remain fit and well on treatment. Early diagnosis is one of the most important steps that can be taken to secure good outcomes for patients with HIV. However, undiagnosed and late diagnosis of HIV remains a concern in the UK. A national audit by the British HIV Association (BHIVA) showed that late diagnosis was the most important factor associated with HIV-related morbidity and mortality in the UK. In 2006, 24% of deaths occurring amongst HIV-positive adults were directly attributable to the diagnosis of HIV being made too late for effective treatment [1]. Late diagnosis has also been associated with an impaired response to antiretroviral therapy and increased cost to healthcare services [2,3]. Patients also remain at risk of unwittingly passing the infection on to others. Health Protection Agency data [4] state that in 2009 there were an estimated 86,500 people living with HIV in the UK, of whom approximately a quarter (26%, 22,500) were unaware of their diagnosis.

In order to address the problem of late diagnosis, the BHIVA UK National Guidelines for HIV Testing [5] recommend that all patients, where the local diagnosed HIV prevalence is greater than two per thousand among 15–59-year-olds, should be offered and encouraged to accept HIV testing in a wider range of settings than is currently the case. Patients with specific indicator conditions should be routinely recommended to have an HIV test and all doctors, nurses and midwives should be able to obtain informed consent for an HIV test in the same way that they currently do for any other medical investigation. The extent to which the guidelines have been implemented is not known.

HIV testing has been routinely offered, with a recommendation to accept, to all patients attending antenatal clinics and sexually transmitted infection (STI) clinics since 1999 and 2001, respectively [6,7]. Consequently, in the UK the majority of diagnostic HIV testing occurs within these settings [8]. Since its introduction in 1999, uptake of HIV testing among women in antenatal care has reached 95% nationally and the proportion of women who remain undiagnosed after delivery has fallen from 27% in 2000 to 12% in 2009 [9].

The HINTS study

To explore ways in which the testing guidelines [5] might best be implemented, the Department of Health (DH) funded eight demonstration projects to

pilot the expansion of HIV testing outside traditional settings. Three types of settings were assessed: hospitals, primary care and community outreach. The results of pilots have been published in an interim report [9].

The goals of one of the pilots, the HIV Testing in Non-traditional Settings (HINTS) study, were to determine the acceptability and feasibility, to patients and staff, of the routine offer of an HIV test in four different healthcare settings: an emergency department, an acute care unit, an outpatient dermatology service and a primary care setting. Other intentions for the study were to find out what the perceptions of, and barriers to, HIV testing might be and also how feasible it is to offer testing in departments where there are other priorities and different services offered. The experiences of people who were diagnosed through this route were considered and also whether they were effectively transferred to care.

The settings chosen were all in areas of relatively high HIV prevalence (Table 1). Lambeth has the highest diagnosed rate in the UK and all the other sites have a prevalence of around 7/1000, which is well in excess of the recommended prevalence cut-off of 2/1000 [5].

A mixed-methods, multi-site study was designed to collect quantitative data, including HIV-testing behaviour, patient demographics and responses from patient and staff questionnaires. Qualitative data were gathered from semi-structured interviews and focus groups.

All 16–65-year-olds were given a routine offer of an HIV test: oral fluid in the emergency department, dermatology outpatients and primary care; and serology in the acute care unit where the test was added to the routine investigations. Exclusion criteria were known HIV-positivity, or if the person

Table 1: Settings chosen for the HINTS study

Settings	Primary care trust	HIV prevalence
Homerton Acute Care Unit	City and Hackney	7.70/1000
King's College Dermatology Outpatients	Lambeth	11.92/1000
Chelsea and Westminster Emergency Dept	Kensington and Chelsea	7.77/1000
North End Medical Centre	Hammersmith and Fulham	7.76/1000

offering the test judged that the patient was not capable of properly consenting to have the test.

Of the 6349 patients offered a test in all settings, 4111 (65%) accepted and eight individuals were newly diagnosed with HIV. All were transferred to care, and two sexual partners later tested HIV positive. There were seven false reactive results.

Emergency department patients were more likely to test if they were younger, or offered the test by clinical rather than non-clinical staff. An association was observed between test uptake and ethnicity in acute care unit patients.

Responses from 635 (528 emergency department, 107 acute care unit) patient questionnaires suggest the offer of an HIV test in this setting was acceptable to 95%. There was no significant difference in reported acceptability by gender, ethnicity, age or HIV testing history. Half of the patients had never tested before. The most commonly cited reasons for declining a test were having recently tested (43%) and self-perception of low risk of HIV infection (40%).

Before the study, staff had anxieties about the feasibility of carrying out the testing and its impact on service delivery. After the study, staff focus groups demonstrated a high level of satisfaction that the delivery of testing was feasible with no negative impact on the department. To date, 42% of the emergency department and 57% of the acute care unit staff agreed that they would feel comfortable offering HIV tests. However, the majority believed they would require further training to do so.

The key messages from the HINTS study are that routinely offering HIV testing in non-traditional settings is a highly acceptable strategy to both patients and staff. It is an effective strategy, identifying previously undiagnosed individuals and transferring them to care. It is feasible to deliver HIV testing in all these settings but further staff training and resources would be required.

The interim report [9] concludes that the results of the pilots provide evidence that the 2008 national guidelines' [5] recommendations of a routine offer of

an HIV test to new registrants in primary care and general medical admissions in high-prevalence areas are feasible, acceptable and effective in identifying previously undiagnosed persons. Therefore, HIV testing in these settings should be made a priority. Community-based pilots that targeted the most at-risk populations were also shown to be highly acceptable and effective and resulted in many individuals being newly diagnosed with HIV infection and transferred into care.

However, establishing HIV testing in healthcare and community settings also requires robust protocols to ensure the timely transfer of patients with reactive or positive test results into care and support services.

References

1. British HIV Association (BHIVA). 2005–6 Full results of the mortality audit. Available at: www.bhiva.org/NationalAuditReports.aspx (last accessed December 2010).
2. Stöhr W, Dunn DT, Porter K *et al.* on behalf of the UK CHIC Study. CD4 cell count and initiation of antiretroviral therapy: trends in seven UK centres, 1997–2003. *HIV Medicine*, 2007, **8**, 135–141.
3. Krentz HB, Auld MC, Gill MJ. The high cost of medical care for patients who present late (CD4<200 cells/ μ L) with HIV infection. *HIV Medicine*, 2004, **5**, 93–98.
4. Health Protection Agency. HIV in the United Kingdom: 2010 Report. Health Protection Report 2010 4(47). Available at: www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1011HIVUK2010Report/ (last accessed December 2010).
5. BHIVA, BASHH, BIS. UK National Guidelines for HIV Testing 2008. Available at: www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf (last accessed December 2010).
6. Department of Health. The national strategy for sexual health and HIV. Better prevention, better services, better sexual health. Department of Health, London, 2001. Available at www.medfash.org.uk/publications/documents/nat_shs-2001.pdf (last accessed January 2011).
7. Health Service Circular. Reducing mother to baby transmission of HIV. HSC 1999/183. Department of Health, London, 1999.
8. Tweed E, Hale A, Hurrelle M *et al.* Monitoring HIV testing in diverse healthcare settings: results from a sentinel surveillance pilot study. *Sexually Transmitted Infections*, 2010, **86**, 360–364.
9. Health Protection Agency. Time to test for HIV: Expanded healthcare and community HIV testing in England. Interim report. November 2010. Available at: www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1011TimetoTestHIVTesting (last accessed January 2011).

Sex, bugs and nursing assessment: chlamydia screening in the UK and the role of the nurse

Charlotte Hamilton

Contraception and Sexual Health (CASH) Nurse, Bradford and Airedale Community Health Services

Background

It is now 8 years since the introduction of a screening programme for chlamydia in the UK. The programme has been successful in increasing the number of young people screened, and a high disease burden (one in 10) has been observed as the programme has expanded [1].

Perhaps the lessons learned from it can be applied to screening for other sexual infections, including HIV in the wider community, by encouraging opportunistic screening and de-stigmatising the process.

Chlamydia in the UK

Chlamydia, from the Greek *chlamys*, meaning cloak, is a sexually acquired micro-organism. It has been identified as the most prevalent sexually transmitted infection (STI) in the UK; currently one in 14 sexually active people under 25 has the infection [2]. This figure is higher in some regions. It is often asymptomatic if left untreated, and complications can include pelvic inflammatory disease (PID), long-term pain and infertility [3]. The annual cost of chlamydia and its consequences in the UK is estimated to be more than £100 million [4]. The government White Paper 'Choosing Health' [5] identified it as a key public health issue, and this led to the first phase of the National Chlamydia Screening Programme (NCSP) in 2002. The screening programme offers opportunistic screening to asymptomatic men and women under the age of 25 in a variety of settings.

Screening initiatives

The National Chlamydia Screening Programme (NCSP) was launched to reduce the onward transmission and complications of undiagnosed chlamydia. Findings in the first 5 years of data show that screening volumes increased from just over 17,000 to over 343,100 in 5 years. Between 1st January 2010 and 31st March 2010, 560,175 tests were reported outside genitourinary medicine (GUM) clinics. This equates to 8.1% of the target population. There has since been an increase of 91% in the number of tests compared to the year before. Also, the proportion of men accepting screening between 2008/2009 and 2009/2010 went up by 78% [2].

The results show an overall positivity rate of 9.7% in women, and 8.7% in men, in the first 5 years. The figure now stands at 6% [2]. A decline in positivity is to be expected as the numbers tested increase. However, a focus of the screening programme is now to ensure that the most at-risk groups for STIs are being targeted [2]. With such high chlamydia infection rates, identifying a client as having one STI is a valuable opportunity to carry out a full sexual health screen including HIV testing [6]. Those diagnosed so far (and their partners) are people who would have been missed in the absence of a screening programme, and this reinforces the feasibility and acumen of screening outside GUM settings [2].

The screening programme has not yet met its targets [7]. The Vital Signs Indicator (VSI) had an expectation that 17% of the target population should be screened in 2008/9. For this period, national coverage was at 15.9%. In 2009/10 the target rose to 25% and rose again in 2010/11 to 35% [7]. However, the screening volumes are enormous, and this presents a valuable opportunity to raise the issue of sexual health and a rare chance to access men to offer screening of all STIs.

Specific issues

Results from the programme confirm that a robust screening programme can have a significant impact in acquiring vital details of the incidence and prevalence of a disease that, although it has no early signs and symptoms, can have catastrophic consequences for those who are infected – in many ways not unlike the characteristics of HIV infection.

The literature confirms that in the context of chlamydia screening, there are a number of key points:

- Healthcare workers offering screening need clear guidance and appropriate resources to encourage testing, and to ensure informed consent
- Insisting on taking a full sexual history can act as a barrier to both offering, and accepting, screening – a sexual history is not necessary unless the test is positive, which is when the opportunity should be taken for performing a full sexual health screen (including an HIV test)
- Testing can be normalised and de-stigmatised

by offering screening to everyone who is eligible.

- Finally, screening should be offered in a variety of locations especially to target men, as they infrequently access healthcare settings

The role of the nurse

Nurses are the front line of healthcare, but can find it difficult to raise the issue of sexual health screening. The nature of a screening programme offers nurses a chance to introduce the subject of sexual health and offer screening on an opportunistic basis. Routinely offering the test outside GUM settings de-stigmatises it [8], and this 'licence' to bring up the subject can be used, for example, as part of the HPV vaccination programme, during contraceptive consultations or follow-ups, at new patient medical checks, or during routine consultations for any health issue in settings such as general practices, CASH clinics, termination of pregnancy services or in education settings. General practices are becoming more willing to provide sexual health services, now that the activity attracts financial payments through the QOF (Quality and Outcomes Framework) system. The initiatives that gain QOF points do change according to local priorities, although how these will be affected by the impending funding reviews (following the 2010 General Election) is yet to be seen.

However, given the impetus on nurses to deliver this service, it is imperative they are given appropriate time, training and support to carry out an effective screening programme. They require education and guidance to carry out a sensitive sexual history (where appropriate), and the skills to discuss the benefits of testing, whilst assessing a person's risk. Many nurses find it hard to address sexuality and homosexuality, and although attitudes to same-sex relationships have improved in the UK in recent times, there is still the potential for prejudice. Education can help ensure these attitudes are not a barrier to obtaining an accurate history, and do not cause embarrassment to either patient or nurse. The most effective training combines formal education with a period of observed and supervised practice. If nurses are properly equipped with these skills, embarrassment for nurses and patients is minimised, and barriers to effective screening are reduced.

Recommendations and reflections

The chlamydia screening programme presents both challenges and opportunities. It does give nurses the chance to address the issue of sexual health and promote STI screening in a variety of contexts – and it can normalise the testing process, providing opportunities to offer an HIV test. Minimising the need for a full sexual history (unless a test is positive) potentially makes the programme more acceptable.

Working in CASH services in a semi-rural setting in Yorkshire, I rarely see clients asking specifically for an HIV test, but as the campaign for chlamydia screening is receiving increasing publicity, young people in particular are keener for further tests. There is no doubt that when sexual health is raised, particularly where a positive result is received, the nurse is presented with an excellent opportunity to offer HIV testing as part of a full sexual health check, and to discuss safer sex and minimising risk behaviours. The stigma of the HIV test is reduced when introduced as part of the chlamydia screening programme. Unfortunately, many clinicians still believe that lengthy pre-test counselling is required prior to testing. This is not always the case unless the patient requests or needs it. The essential elements that the pre-test discussion should cover are:

- The benefits of testing to the individual
- Details of how the result will be given

This approach has been successful in GUM and antenatal clinics and is generally acceptable in other settings [9] although, for this approach to be sufficient, it is essential that a newly diagnosed individual is immediately referred for HIV treatment and care; therefore staff should be fully equipped to deal with a positive result.

Further research is required into the attitudes of young men towards testing: they are more difficult to target opportunistically than women [9]. It is often women who attend GP or CASH services (for contraception, pregnancy testing and cervical screening). However, thanks to the NCSP, large numbers of men (and women) are being screened who would not otherwise have considered their own sexual health. Discussing chlamydia and other STIs is becoming more acceptable and accessible, and for the first time there are national television campaigns advertising STI screening, for example the 'Worth talking about' initiative [2]. This is surely a positive development in the field of sexual health.

Future studies may be useful in examining the attitudes of staff members other than clinicians, as reception and front-line staff can act as a barrier or an opportunity to access sexual health screening. If testing for HIV and other STIs is sufficiently scaled-up, providing treatment and care for those who are affected will have a significant impact on public health in the UK.

References

1. Department of Health. NCSP: Five years. The fifth annual report of the National Chlamydia Screening Programme 2007/08. Available at www.chlamydia-screening.nhs.uk/ps/assets/pdfs/publications/reports/NCSPA-rprt-07_08.pdf (last accessed January 2011).
2. The bigger picture: the National Chlamydia Screening Programme 2008/09 Annual Report. NCSP, London, Available at: www.chlamydia-screening.nhs.uk/ps/assets/pdfs/publications/reports/NCSPA-rprt-08_09.pdf (last accessed January 2011).

3. Garnett GP. How much infertility does chlamydia cause? *Sexually Transmitted Infections*, 2008, 84, 157–158.
4. Department of Health. The National Chlamydia Screening Programme: Phase 3 Guide (August 2005). Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4118418 (last accessed December 2010).
5. Department of Health. Choosing Health: Making healthy choices easier. Cm 6374. Stationery Office, London, 2004.
6. BHIVA, BASHH, BIS. UK National Guidelines for HIV Testing 2008. Available at: www.bhiva.org/documents/Guidelines/Testing/GiinesHIVTest08.pdf (last accessed December 2010).
7. National Chlamydia Screening Programme. Maintaining Momentum: Annual Report of the National Chlamydia Screening Programme in England 2006/7. Health Protection Agency, London, 2007. Available at: www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1204013012687 (last accessed December 2010).
8. Foley E, Patel R. Destigmatising STIs: remaining challenges, new opportunities. *Sexually Transmitted Infections*, 2001, 77, 306–307
9. Sanders L, Nsuami M, Cropley L, Taylor S. Reasons given by high school students for refusing sexually transmitted disease screening. *Health Education Journal*, 2007, 66, 44–57.

Correspondence to: Charlotte Hamilton, Contraception and Sexual Health Nurse, CASH Clinic, Keighley Health Centre, Oakworth Road, Keighley BD21 1SA, UK (email: charlotte@bluewedge.co.uk)

The impact of HIV stigma in Central and Eastern Europe: a review of the literature

Ruth Burholt

Staff Nurse, Royal Sussex County Hospital, Brighton, UK

Introduction and background

The upward trend of HIV infections across the countries of Central and Eastern Europe (CEE) calls for an effective health response, including the uniqueness of holistic nursing care. Many issues impact on the care of people living with HIV (PLHIV), and a thematic analysis of current literature reveals key issues to be: the concept of stigma surrounding HIV; social representation of the HIV epidemic and the appropriate health messages; and finally, the nurse–client relationship.

This article focuses on stigma and its potential impact on the nursing care of PLHIV in CEE. This includes a consideration of how stigma affects prevention and testing, confidentiality issues and the support of minority groups.

Evidence suggests that further culturally specific research is required to examine the possible impact of stigma in driving the epidemic, which accordingly will define what tailored public health initiatives are needed in CEE. Alongside this, holistic HIV nurse education is shown to be lacking in many European regions, including the UK and CEE. Ethical values need to be strengthened, promoting respect of the individual and a focus on client-centred care. The involvement of nursing and the multidisciplinary team in research, and the use of evidence-based initiatives are significantly absent.

This review is timely, not only because of multifaceted aspects of HIV nursing in Europe, but also to generate new knowledge surrounding

transitional health risk environments globally and the effects of stigmatising attitudes.

'Derek lost his entire family to AIDS. One year [after diagnosis] they are still not talking to him' [1]

Introduction

HIV epidemics in CEE are not arbitrary developments, but intrinsically linked with the actions of society, rooted in cultural, political and socioeconomic structures [2]. The annual rate of new infections in some countries of CEE is reported to be the fastest growing in the world – 40% higher than sub-Saharan Africa [3]. A desired public health response has been well documented [4–6], but there is scant evidence that the daily practice of nurses caring for PLHIV is being enriched.

The 2008 World Health Organization (WHO) statement on nursing and midwifery for HIV/AIDS in Europe responds to this ongoing challenge, confirming that nurses are pivotal in making a positive impact in prevention, support, treatment and care [7].

Nurses, in the role of health educator for example, can be integral to inform and initiate behaviour change among individuals at risk of contracting HIV [8].

The HIV epidemic in the countries of CEE is markedly different in comparison to Western Europe [9,10] and some experts suggest this is due to the creation of an HIV risk environment arising from the

inequalities of socio-political transition [2,4,11,12]. The political-economic shift from communism to a liberal market economy has been oxygen to the fires of HIV [4,5,13].

One factor that does impact on HIV care and prevention is an apparent failure during the formative years of economic liberalisation to understand and reform the Soviet healthcare system. This resulted in the survival of vertical health systems (anomalous in the West) where medical staff are at the epicentre of all control and treatment. These centralised healthcare systems were exposed to the new realities of medical practice, evidence-based medicine and previously unknown infections and epidemics [4,11].

The division of service delivery and surveillance according to pathologies stunted the health response, for example the rapid increase of numbers of PLHIV with tuberculosis in CEE [11]. To act appropriately involves recognising the methods of contagion [14], which for some people are considered immoral and socially uncomfortable, generating the fear that is inherent within discriminating and stigmatising behaviours towards PLHIV. For people to accept HIV and AIDS means an acceptance of the behaviours leading to the infection. It has been untraditional, alien and politically unsound to do so, leading sometimes to the refusal of respect and services in CEE [1,11,15].

HIV in CEE is a concentrated epidemic, affecting already marginalised groups, such as injecting drug users (IDU), prisoners, homosexuals, sex workers and minority ethnic groups, and contracting HIV can make that person all the more undesirably 'different' [16]. The issue of stigma is crucial in this context. Health-related stigma is defined by the condition or illness upon which people make a value judgement. This can result in rejection, labelling, loss of respect and status, shame and blame. These practices can be actual and overt, or for some PLHIV, perceived or internalised. Each variation of stigmatising behaviour can lead to social inequality by unfair treatment on the basis of HIV or presumed seropositive status.

For numerous PLHIV in countries of CEE, shame and fear of discrimination is reported to be of highest concern [17–19] and potentially an obstacle to accessing healthcare. Nurses are well placed to provide expert knowledge and non-judgemental advice and information to facilitate care delivery. In contrast to the UK, nurses involved in the area of HIV in the CEE do not normally have specialist post-registration training. As PLHIV can present in any part of the healthcare system, nurses are sometimes ill equipped in terms of clinical and ethical knowledge. Preliminary findings suggest this could be a result of the lack of HIV educational policy in the nursing curriculum within Europe [20–22].

HIV nursing has changed significantly since the advent of antiretroviral treatment (ART) in the 1990s. There has been a shift from fatal disease to a chronic manageable condition, and although universal access to treatment is integral to the 2010 WHO goal [3], this has not been fully realised globally – especially in the CEE. Many PLHIV either cannot or do not access healthcare facilities for ART [10,17,23].

Testing

Perceived stigmatising behaviours are demonstrated in a Balkan sexual health survey [18] exploring the uptake of HIV testing amongst high-school students believing themselves to be at risk. Internalised stigma is apparent amongst the sample, even though the experience of those having had an HIV test was generally positive.

From a healthcare provider's viewpoint, a European-wide questionnaire echoes this sentiment [10] and both studies confirm that obstacles to testing arise from society's perceptions of the diagnostic outcome, and not from prejudiced healthcare professionals themselves.

Equally, in a UK qualitative study designed to define the trend of HIV testing amongst African migrants [24], findings suggest that stigma and fear restrict people from being tested, due to perceived stigmatising reactions from healthcare professionals, and awe of impending death.

Confidentiality

Lack of patient confidentiality is reported to be an issue in some CEE healthcare systems [10,18,25,26]. It is a barrier to treatment if confidentiality is threatened, and registered nurses must be responsible for valuing each client as an individual [1,27]. In-depth interviews with 42 PLHIV in Serbia and Montenegro demonstrate challenges posed by their health status, services and by society generally [26]. With regards to the healthcare professional, themes arising from the conversations underpin a lack of HIV-related knowledge and a lack of impartiality and confidentiality.

This is particularly found in the opinions of clinicians, who are in turn ostracised by some peers for caring for PLHIV. An analysis of this study illustrates how, if the educated and respected healthcare professional displays judgmental and discriminatory attitudes towards disadvantaged people, then this can be construed as justifiable for society to perpetuate.

This insight is further demonstrated by the International HIV/AIDS Alliance in Ukraine survey of 492 people living with HIV and AIDS [17]. The study concludes that, although healthcare professionals are the most aware of the respondents' HIV status, paradoxically, they are described as being the most intolerant in Ukrainian society.

Treatment by nurses

A Baltic study [20] that used scenarios with fictional patients found that, although all were mainly compliant, Estonian nurses were least prepared to undertake certain nursing activities. In the light of a growing epidemic in this area – the highest estimated adult HIV prevalence in Europe [28] – it seems that negative responses are not necessarily reduced by familiarity [16].

Another study [22], comparing Eastern European nurses' assessment of infection risk, concluded that while nursing education urgently needs to include HIV-related practical training, the unspecified nature of the fear of contagion is often not discussed.

Some responses are positive however, and the characteristics of some specialist healthcare professionals do display non-judgmental and egalitarian attitudes to PLHIV, for example in the UK and Romania [29,30]. This shared sense of association is echoed in a paper focusing on the subject of staff burnout related to AIDS care [31]. It demonstrates that the stigmatising nature of others surrounding the condition causes the emotional exhaustion. However, a feature of all these studies is that specialist HIV nurses can develop a commonality with PLHIV, an autonomous and exclusive therapeutic relationship.

Minority groups

Some groups of already stigmatised people in society face a double jeopardy. For example, a 2004 qualitative study on the vulnerability and HIV risk environment of 42 Roma in Hungary and Bulgaria alerts us to the lack of research and health surveillance in these groups in CEE [32]. The principal theme arising is that a cultural- and gender-sensitive prevention programme needs to be introduced, but with the endorsement and involvement of the Roma community. Frustratingly sexual health figures for Roma are unknown but it is a ripe risk environment according to supporting evidence on marginalised groups [2,12,32,33].

Several papers point to this in the UK, also [10,12,24]. In minority groups, uncertain citizenship status and lack of knowledge of the legal position on being diagnosed with HIV prevents access to health services.

Conclusion and recommendations

The original aim of this paper was to consider the aspects of stigma and the nurse's role in caring for PLHIV and those at risk. This has been explored by looking at literature within a European context. While there are negative aspects such as barriers to treatment, the themes have also displayed positive developments.

Aiming to reduce stigma in itself is too ambiguous and immeasurable. However, the practical aspects

of raising awareness through public health initiatives and integrated nursing training are of note. From the evidence reviewed, a holistic approach to HIV education in nursing training is lacking in both the UK and CEE. This includes practical and ethical training, which would reduce fear of contagion and raise awareness of HIV signs and symptoms in general care settings.

It is apparent from several papers that nurses could engage more in the active treatment of PLHIV in CEE. This would create a more multidisciplinary environment that could help the medics' case management and also advance nursing roles. It is vital to share lessons learned and experiences, in order to support nursing globally. A number of recommendations are pertinent here:

- Specialist courses for HIV nurses to develop evidence-based knowledge and skills
- Implementation of multidisciplinary team working to enhance client-centred care and outcomes.
- Sharing of HIV expertise and new knowledge learned to support the global community of nursing.
- Dissemination of information to help guide non-specialist healthcare systems.

Linked in with these notions is the public health approach. It is an overarching theme from the literature that culturally specific HIV campaigns in CEE are needed. Therefore, meaningful and tailored projects are called for, and this ought not to be the healthcare establishment or NGO simply relaying or importing information, but should include input from minority service users and peer groups.

In addition, there is the need for culturally tailored public health initiatives in CEE: the promotion of locally nurse-led research would involve this group of healthcare professionals in an area that often lacks them. Nurses can be pivotal in expressing and reflecting the needs of society – and by this token may shape the public health content to make it relevant, effective and timely.

This literature review has demonstrated that nurses, as members of any society, are involved in inhibiting or furthering the stigma of HIV. Studies prove so far that measures can be taken to improve the situation in CEE, but also that the reality for PLHIV is far from ideal. There is scant evidence that the relationship between PLHIV and healthcare professionals exists, but in this instance, new developments and techniques from the UK can be shared if relevant.

If prevailing regional expertise and institutional determination are applied, the 6th Millennium Development Goal of curbing and reversing HIV by 2015 may be attainable. The global profession of nursing has a responsibility to be involved in realising this goal.

References

- International Council of Nurses. Nurses: fighting AIDS stigma, caring for all. Information and action tool kit. Geneva, ICN, 2003; p34. Available at: www.icn.ch/publications/2003-nurses-fighting-aids-stigma-caring-for-all/2003-nurses-fighting-aids-stigma-caring-for-all.html (last accessed December 2010).
- Barnett T, Whiteside A. *AIDS in the Twenty-first Century. Disease and Globalisation*. 2nd edn. Palgrave Macmillan, Basingstoke, 2006.
- World Health Organization. Towards universal access. Scaling up priority HIV/AIDS interventions in the health sector. WHO, Geneva, 2007.
- Coker RJ, Atun RA, McKee M. Healthcare system frailties and public health control of communicable disease on the European Union's new eastern border. *Lancet*, 2004, **363**, 1389–1392.
- Hamers FF, Downs AM. HIV in central and eastern Europe. *Lancet*, 2004, **361**, 1035–1044.
- MacLehose L, McKee M, Weinberg J. Responding to the challenge of communicable disease in Europe. *Science*, 2002, **295**, 2047–2050.
- European Forum of National Nursing and Midwifery Associations. *10th Annual Meeting of the European Forum of National Nursing and Midwifery Associations and WHO 2006*. Available at: www.euro.who.int/__data/assets/pdf_file/0008/102221/E89511.pdf (last accessed December 2010).
- Pratt R. *HIV & AIDS. A Foundation for Nursing and Healthcare Practice*. 5th edn. Arnold, London, 2003.
- Smith, P.W. An application of a multiregion systems model to the HIV/AIDS epidemic in Europe. PhD thesis, University of Manchester, 2003.
- Mounier-Jack S, Adler A, de Sa J, Coker R. Testing times: unmet need in testing, treatment and care for HIV/AIDS in EUROPE. London School of Hygiene and Tropical Medicine, London, 2008. Available at: www.cdprg.org/Docs/EuropeHIV.pdf (last accessed December 2010).
- Schwalbe N, Lazarus J, Adeyi O. *HIV/AIDS and tuberculosis control in post-Soviet Union countries*. In: *Health Systems and the Challenge of Communicable Diseases: Experiences from Europe and Latin America* (Coker R, Atun R, McKee eds). Open University Press, Milton Keynes, 2008.
- Atun R, McKee M, Coker R, Gurol-Urganci I. Health systems responses to 25 years of HIV in Europe: inequities persist and challenges remain. *Health Policy*, 2007, **86**, 181–194.
- Kelly JA, Amirkhanian YA. The newest epidemic: a review of HIV/AIDS in Central and Eastern Europe. *Int J STD AIDS*, 2003, **14**, 361–371.
- Goodwin R, Reado A, Kwiatkowska A *et al*. Values and sexual behaviour in Central and Eastern Europe. *Journal of Health Psychology*, 2002, **7**, 45–56.
- Whiteside A. *HIV/AIDS. A Very Short Introduction*. Oxford University Press, Oxford, 2008.
- Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Penguin, London, 1963.
- International HIV/AIDS Alliance in Ukraine. Access to rights and services of people living with HIV in Ukraine. International HIV/AIDS Alliance in Ukraine, Kiev, 2005. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=60 (last accessed December 2010).
- Delva W, Wuillaume F, Vansteelandt S *et al*. HIV testing and sexually transmitted infection care among sexually active youth in the Balkans. *AIDS Patient Care and STDs*, 2008, **22**, 817–821.
- Adler A, Mounier-Jack S, Coker RJ. Late diagnosis of HIV in Europe: definitional and public health challenges. *AIDS Care*, 2009, **21**, 284–293.
- Vaiimaki M, Makkonen P, Blek-Vehkaluoto M *et al*. Willingness to care for patients with HIV/AIDS. *Nursing Ethics*, 2008, **15**, 586–600.
- Tierney, A. HIV/AIDS: knowledge, attitudes and education of nurses: a review of the research. *Journal of Clinical Nursing*, 1995, **4**, 13–21.
- Klewer J. Assessments of HIV transmission risks in clinical situations by nursing staff from Poland and Germany. *HIV & AIDS Review*, 2004, **3**, 20–22.
- LoBiondo-Wood G, Haber J. *Nursing Research: Methods, Critical Appraisal and Utilization*. Mosby, St Louis, 2002.
- Burns F, Imrie JY, Nazroo J *et al*. Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilisation of HIV health and social care services by African migrants in Britain. *AIDS Care*, 2007, **19**, 102–108.
- Hodgson I. *HIV and AIDS in Europe*. University of Bradford, Bradford, 2007.
- Bernays S, Rhodes T, Prodanovic A. *HIV treatment access, delivery and uncertainty: a qualitative study in Serbia and Montenegro*. Belgrade: United Nations Development Program, 2007.
- Nursing and Midwifery Council. *Code of Professional Conduct: Standards for Conduct, Performance and Ethics*. NMC, London, 2004.
- UNAIDS. North America, Western and Central Europe. *AIDS epidemic update. Regional Summary*. Joint United Nations Programme on HIV/AIDS/WHO, Geneva, 2008. Available at: www.data.unaids.org/pub/Report/2008/jc1532_epibriefs_na_merica_europe_en.pdf (last accessed December 2010).
- Nitu C. HIV nursing in Romania: more than vampires. *HIV Nursing*, 2009, **9**(1), 18–19.
- Hodgson I. Empathy, inclusion and enclaves: the culture of care of people with HIV/AIDS and nursing implications. *Journal of Advanced Nursing*, 2006, **55**, 283–290.
- Hayter M. Burnout and AIDS care-related factors in HIV clinical nurse specialist in the North of England. *Journal of Advanced Nursing*, 1999, **29**, 984–993.
- Kelly J, Amirkhanian YA, Kabakchieva E *et al*. Gender roles and HIV risk sexual risk vulnerability of Roma (gypsies) men and women in Bulgaria and Hungary: an ethnographic study. *AIDS Care*, 2004, **16**, 231–245.
- Rhodes T, Simic M. Transition and the HIV risk environment. *British Medical Journal*. 2005, **331**, 220–223.

Correspondence to: Ruth Burholt, Staff Nurse,
Royal Sussex County Hospital, Eastern Road,
Brighton BN2 5BE, UK
(email: ruth.burholt@bsuh.nhs.uk)

Teaching pill swallowing to HIV-infected children

Dean Krechevsky^{1,3}, Diane Melvin^{1,3} and Stephen Head^{2,3}

¹Clinical Psychologist, CNWL Foundation Trust; ²Clinical Nurse Specialist, Imperial College NHS Trust; ³Family HIV Clinic, St Mary's Hospital, London, UK

Introduction

HIV therapies, in particular antiretroviral therapy (ART) combinations that include a protease inhibitor (PI), can significantly prolong and improve children's lives [1]. Many of these drugs are not available in paediatric formulations, which mean that treatment regimens often consist of multiple large capsules to be swallowed daily. PI capsules are too big to be hidden in foods, and even where this is possible, such administration is not recommended as it can lead to food aversion and lack of trust in the caregiver [2]. Thus, it is imperative that children learn to swallow the capsules with as little fuss and anxiety as possible.

Any physical difficulty in pill swallowing can be compounded by the experience of coercion, discomfort or anxiety. Knowledge and understanding of HIV varies widely among infected children and younger children are unlikely to appreciate the vital significance of consistent and long-term medicine taking. Parents and family members may therefore focus on achieving compliance by any means, sometimes resorting to bribery or punishment. However, families who achieve good adherence to pill swallowing do so because they have made it a normal routine in life [2]. A study of the developmental factors in adherence behaviour found it to be a complex process with knowledge and responsibility for management positively associated with child age while medication adherence decreased with age [3].

Various techniques have been used to enhance adherence in children including reinforcement [4], relaxation strategies and reward programmes [5]. Although rewards have been successfully used, ideally only praise should be given as a reward because the long-term aim is to establish sustainable pill-swallowing behaviour in the absence of positive or negative reinforcement. The primary behavioural techniques used to teach pill swallowing are shaping procedures [6,7] and behavioural modelling [8]. Shaping consists of presenting placebo pills of progressively larger size, ending when the target size is reached. Modelling, performed by a facilitator, demonstrates the steps involved in pill swallowing.

This article describes our experience at a large teaching hospital in central London of teaching pill

swallowing to 40 HIV-positive children and young adolescents (5–13 years). There are aspects of HIV infection that set it apart from other chronic conditions, such as leukaemia, on which other pill-swallowing studies have been based. Paediatric HIV cases are almost always accompanied by parental infection. As well as the additional stress of coping with both parental and child infection [9] parents may also be taking the same or similar medication as the child. It is not known whether this latter situation could be beneficial for pill-swallowing training. Studies have varied as to whether parents are included during pill-swallowing training [8,10].

Unlike previous pill-swallowing studies, the participants in the current study were mainly from sub-Saharan Africa. The impact of secrecy and stigma associated with HIV may be particularly relevant for families of African origin for whom talking openly about HIV or illness in general may be taboo [11]. Furthermore, some of the families in the study were not living in their own accommodation, which meant that the taking of medication by both parents and children had to remain secretive within the household. Low household income and minority status have both been linked to poor adherence in pill swallowing [12,13].

Method

The purpose of this audit was to gather information about the pill-swallowing procedure used by psychologists within this service and its relationship to the following outcomes: (a) immediate success of procedure (defined as swallowing all placebos); (b) relationship to future success in taking ART medication measured by adherence rating of medical staff and health parameters i.e. CD4 cell count and viral load measures.

Setting

All training procedures took place in the London specialist paediatric outpatient service.

Participants/population studied

Consecutive referrals ($n=40$) to the psychologist from the paediatric HIV consultant were included in 'pill school' during the years 2006–2008. All children had vertically acquired HIV and were either starting ART medicines for the first time ($n=9$) or

were being considered for switching from liquid formulations to tablets ($n=30$). One other child had been on medicines for less than a year but had been struggling to cope.

Shaping/modelling

Shaping is a special form of conditioning and involves the reinforcement of a succession of behaviours. Placebo pills are presented in increasingly larger sizes until the target pill is reached; however, the child only ever sees one size of pill at a time. The specific steps involved in teaching the skill are demonstrated by the psychologist, and this procedure is called modelling.

Procedure ('Pill school')

In line with the procedure put forward by Czyzewski *et al.* [2], most of the modelling process proceeded as suggested. However, clinical experience had indicated that when working with this multicultural/multilingual population, it was not always possible for the training to take place without the parent/others in the room; therefore, the procedure deviated from the recommended format for some of the families. All training procedures were conducted during sessions lasting about 15–30 minutes. One clinical psychologist served as the 'modeller'.

Pill swallowing was seen as a developmental task that children would master when ready as opposed to strict behavioural tasks. Semantics such as 'failure' were not used and instead the child was 'unable to achieve the task at this time'.

Materials

The training stimuli were five graduated sizes of placebo capsule.

Results

Population characteristics

Of the 40 children referred for pill school during this time there were 23 boys and 17 girls. There was a wide age range of 5–13 years (mean: 7.9 years) with nearly two-thirds (62%) in the 5–8-year age group. All but two children were living with at least one biological parent (95%). These two were in the long-term care of wider family members. Thirty-three children (82.5%) had at least one parent taking ART medicines themselves, although it was not always recorded whether this was the parent accompanying the child to the session for pill swallowing. For seven (17.5%) children, it was recorded that the parent was not on medication.

In terms of ethnicity, 28 (70%) children were born to black African parents, four had Caucasian parents, three were from mixed black/Caucasian parents and five were from other ethnic groups. While 21 children (53%) were born in the UK, another 19

(47%) were born abroad, although most of this latter group had lived in the UK for a number of years.

These demographics are generally in keeping with the clinic population although the mean age of this sample is younger and there are more boys than in the clinic population as a whole.

Outcomes from pill school

Pill school, as defined in [2], was followed as recommended for 32 (80%) of the children; the procedure deviated from the recommended format for the remaining eight (20%) children. For these eight children, the parent was present in the room during the procedure for five; for two children, both siblings undertaking the technique were in the room; and for the last child, both an interpreter and a parent were in the room.

Most children undertook one session in pill school and achieved success at swallowing all placebos. There were eight children who needed more than one session. There was no difference between boys and girls in ability to swallow the placebos. Likewise, there were no differences between success at pill swallowing and ethnicity, whether the child was born in the UK, family constellation or birth order. The presence of a carer or other in the session did not significantly influence success at pill swallowing; however, the number of children who took part in the study was quite small.

Later measures of adherence

At 4–6 months following the procedure, the medical notes were reviewed; comments from the medical consultant about the child's medicine-taking were obtained as well as the current viral load. The child's medicine-taking was defined as 'good' (taking medication >95% of the time; i.e. not missing any doses), 'variable' (taking medication <95% of the time; i.e. missing occasional doses) and 'poor' (taking little or none). Of the 40 children who underwent pill school, the medical consultant reported 'good' adherence in 22 (55%) of the children. This report was corroborated by blood results reflecting undetectable HIV-1 viral load of <50 copies/ml. Thirteen children (33.5%) who had undertaken the procedure had variable adherence and this was reflected in some viral load suppression of >50 and <10,000 copies/ml. The remaining five children were reported as having poor adherence and this was reflected in little viral suppression.

There were some other interesting associations that merit further exploration. For example, later-born children were more likely to have a report of 'good' adherence and were more likely to be successful at swallowing the placebos. Also, 'only' children were more likely to have 'variable' adherence. Slightly more of the children born outside the UK (12/19) were rated by the doctor as having good adherence compared with those born in the UK

(10/21). Moreover, the eight children who needed more than one pill school session or who did not complete the pill-swallowing task had a subsequent 'poor' rating of adherence and increased viral load. No differences in later medicine-taking were found for children whether or not they had been on medicines prior to attending pill school.

Discussion

Many of the psychological interventions suggested by our service strive to enhance the coping behaviour of children and their families living with a chronic health condition rather than react to maladjustment if/when it occurs. This involves identifying effective coping strategies in children and their parents and deciding how to build on these. A systemic approach, which attempts to deal with the interactional life of the family group, shifts the responsibility of a new task away from the child in isolation so that it is shared with significant others, for example, enhancing the competencies of children and families in mastering anxiety associated with physical procedures and treatments.

The procedure of shaping and modelling is one part of an approach that helps children and families to master a difficult treatment regimen. It was a technique developed in the United States and was adapted for use with one UK clinic population of families of predominantly sub-Saharan origin. This review suggests that pill school helps children get started on tablets but the relationship with longer-term adherence is more complex.

Some of the adaptations that proved useful with this population included having parent/s present from the outset during the procedure. Having the parent in the room may help reduce anxiety and better fit cultural expectations. On the occasions that a parent was present in the room, it meant that shared responsibility for pill taking within the family could be enhanced. Parents often observed the procedure and commented that they might implement a similar procedure in the home setting. The parent's presence encouraged ideas about sharing the responsibility of medicine taking with their child and enhanced the possibility of parents being good models for the child.

The various adaptations proved helpful in implementing the procedure and enhanced modelling may increase shared responsibility and ownership of 'the task' within the family. More research is needed to see if further flexibility in the procedure, perhaps through enhanced modelling or parents taking a more active role than proposed in previous literature, may influence longer-term adherence and enhance family coping with the child's medicine-taking.

Additional resources

A videotape demonstrating the pill-swallowing training described in this article was produced by Baylor College of Medicine through an unrestricted educational grant from Hoffman-La Roche Ltd. A copy of the videotape is available from Nancy R Calles, RN, BSN, Texas Children's Hospital, MC1-4000, 6621 Fannin Street, Houston, TX 77030, USA (email: nrcalles@texaschildrenshospital.org or www.baylorids.org).

References

1. PENTA Steering Committee, Welch S, Shatland M, Lyall EG *et al.* PENTA 2009 guidelines for the use of antiretroviral therapy in paediatric HIV-1 infection. *HIV Medicine*, 2009, **10**, 591-613.
2. Czyzewski DI, Runyan RD, Lopez MA, Calles NR. Teaching and maintaining pill swallowing in HIV-infected children. *AIDS Reader*, 2000, **10**(2).
3. McQuaid EL, Kopel SJ, Klein RB, Fritz GK. Medication adherence in pediatric asthma: reasoning, responsibility, and behavior. *Journal of Pediatric Psychology*, 2003, **28**, 323-333.
4. Wright L, Woodcock JM, Scott R. Conditioning children when refusal of oral medication is life threatening. *Pediatrics*, 1969, **44**, 969-972.
5. Funk MJ, Mullins LL, Olson RA. Teaching children to swallow pills: a case study. *Child Health Care*, 1984, **13**, 20-23.
6. Walco GA. A behavioural treatment for difficulty in swallowing pills. *Journal of Behavior Therapy and Experimental Psychiatry*, 1987, **8**, 90-96.
7. Sallows GO. Behavioural treatment of swallowing difficulty. *Journal of Behavior Therapy and Experimental Psychiatry*, 1980, **11**, 45-47.
8. Dahlquist LM, Blount RL. Teaching a six year old girl to swallow pills. *Journal of Behavior Therapy and Experimental Psychiatry*, 1984, **15**, 171-173.
9. Lwin R, Melvin D. Paediatric HIV infection. *Journal of Child Psychology and Psychiatry*, 2001, **42**, 427-438.
10. Pelco LE, Kissel RC, Parrish JM, Miltenberger RG. Behavioral management of oral medication administration difficulties among children: a review of literature with case illustrations. *Journal of Developmental and Behavioral Pediatrics*, 1987, **8**, 90-96.
11. de Baets AJ, Scofovo S, Parsons R, Pazvakauamuwa IE. HIV disclosure and discussions about grief with Shona children; a comparison between healthcare workers and community members in Eastern Zimbabwe. *Social Sciences Medicine*, 2008, **66**, 479-491.
12. Simoni JM, Montgomery A, Martin E, New M, Demas PA, Rana S. Adherence to antiretroviral therapy for paediatric HIV infection: a qualitative systemic review with recommendations for research and clinical management. *Pediatrics*, 2007, **119**, 1371-1383.
13. Mellins CA, Brackis-Cott E, Dolezal C, Abrams EJ. The role of psychosocial and family factors in adherence to antiretroviral treatments in human immunodeficiency virus-infected children. *Pediatric Infectious Disease Journal*, 2004, **23**, 1035-1041.

Correspondence to: Dean Krechevsky,
Clinical Health Psychology Department,
Clarence Wing, St Mary's Hospital, Praed Street,
London W2 1NY, UK
(email: dean.krechevsky@imperial.nhs.uk)