

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Editorial Board

Juliet Bennett

Independent Nurse Advisor

Catrin Evans

International Coordinator and Deputy Director Postgraduate Studies (Research Education), School of Nursing, Midwifery and Physiotherapy, University of Nottingham, Nottingham

Ian Hodgson

Policy and Advocacy Manager, Health and Development Networks

Advisory Panel

Jane Bruton

HIV Nurse Manager
Chelsea and Westminster Hospital, London

Margaret Clapson

Paediatric Clinical Nurse Specialist
Great Ormond Street Hospital, London

Zoë Sheppard

Ward Manager
St Mary's Hospital NHS Trust, London

Judith Sunderland

Lecturer
City University, London

HIV testing

Editorial

Normalisation for whom?

Carol Pellowe **1**

Features

Testing for HIV in primary care

A GP's perspective on the *UK National Guidelines on HIV Testing 2008*

Juliet Bennett..... **2**

'Well, it's not on our radar at all right now'

Views on HIV testing and the *UK National Guidelines on HIV Testing 2008* from an A&E consultant

Catrin Evans..... **6**

Antenatal HIV screening: a midwife's perspective

Lynne Sivyour **8**

Point of care rapid HIV testing: considerations for service provision

Juliet Bennett **12**

Children with undiagnosed HIV in the UK and Ireland: are we doing the right thing?

Djamel Hamadache **17**

'People are creating policy up there, they are not coming down'

Nurses' views on the expansion of routine provider-initiated HIV testing and counselling in Nairobi, Kenya

Catrin Evans and Eunice Ndirangu **20**

HIV nursing in Poland

Barbara Daniluk-Kula **25**

Research round-up

Focus on testing

Catrin Evans..... **27**

NHIVNA update

Sheila Morris **28**

Now listed in EMBASE, CINAHL, EMNursing, Compendex, GEOBASE, Mosby Yearbooks, Scopus, Thomson Gale and Elsevier Bibliographic databases

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Volume 9 Number 2 Summer 2009

ISSN 1474-7359

Endorsed by



National HIV Nurses Association

Although great care has been taken in compiling and checking the information given in this publication to ensure that it is accurate, the authors, publisher, sponsor and its servants or agents shall not be responsible or in any way liable for the continued currency of the information or for any errors, omissions or inaccuracies in this publication whether arising from negligence or otherwise howsoever or for any consequences arising therefrom.

The opinions expressed in this publication are, where named, those of the individual authors, and do not necessarily represent those of the publisher or sponsor.

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.

Now listed in

EMBASE, EMNursing, Compendex, GEOBASE, Mosby Yearbooks, Scopus and CINAHL databases

HIV Nursing is also indexed and licensed for inclusion in the Thomson Gale and Elsevier Bibliographic databases

Editorial Office

Editorial Director: Fatima Patel

Mediscript Limited
1 Mountview Court, 310 Friem Barnet Lane,
London N20 0LD, UK

Printed in England

Summer 2009

© Mediscript, 2009

All rights reserved. No part of this publication may be translated, reproduced, stored in a retrieval system, or transmitted in any form, by any means, electrical, mechanical, photocopying, recording or broadcasting or otherwise, without prior permission from the publisher.

Normalisation for whom?

Carol Pellowe

Deputy Director, Faculty of Health and Human Sciences, School of Community Health and Social Care, Thames Valley University, London

Testing for HIV infection remains the critical turning point for accessing appropriate and effective treatment. It has been undertaken for more than 20 years yet we still identify people too late for them to maximise the benefits of antiretroviral therapy. The *UK National Guidelines for HIV Testing 2008* [1] propose the normalisation of the test and extending the range of services which currently offer the test. Testing is this issue's main theme and is addressed by several contributors who consider the success and implications of such a change in policy.

In the UK maternity services, the move to a policy of a 'universal offer' in the late 1990s has been hugely successful as demonstrated by the increased numbers of women diagnosed antenatally and the significant reduction in mother-to-child transmission. Despite the shock of diagnosis, these women feel supported by the relationship they develop with their specialist midwife and doctor, which often continues long after delivery. This is an excellent example of how a service can provide both an effective and a supportive service. However, if the women could have been tested before getting pregnant, they might have been able to consider the situation for themselves without the added implications for their unborn children. However, the question is, would they have taken advantage of such an offer or was the pregnancy the stimulus?

The *UK National Guidelines for HIV Testing 2008* [1] propose extending the availability of testing to sexual health and point of care services (for example General Practice). For this to be successful, those involved need to be skilled communicators. There must also be a rapid and reliable referral system in place. Raising the issue of HIV testing during a consultation for a contraceptive seems appropriate; however, would that be so for other consultations? Too often guidance directed at primary care practitioners is focused on a single subject, which does not take account of 'real life'. For example, rarely does a GP see someone with high blood pressure without other health issues, yet some guidance on managing hypertension does not take into account other co-morbidities/health factors. What is the trigger (or incentive) to this offer and how are general practitioners and other healthcare workers prompted to make the offer?

Increasing the provision of testing is one part of the solution but a more difficult one is acceptability.

From the patient/client's perspective, HIV has not become normalised but largely forgotten by the public and, when it is raised, frightening.

In a recent BBC news item [2] marking 25 years since US Health and Human Services Secretary, Margaret Heckler, made the historic announcement of the discovery of a virus thought to cause AIDS, one person who has lived with HIV since the early 1980s described living with it as 'a nightmare', due to its consequences and unpredictability, like living with a house guest who has outstayed their welcome. The stigma of HIV remains, and whereas in so many other conditions we test in order to treat and cure, in this instance we treat to contain. Testing is important in terms of accessing treatment and being able to live a near normal life, but for the individual it brings a possible lifelong burden of living with something that cannot easily be discussed openly.

Despite nearly 30 years of health promotion the legitimacy of safer sex messages is still questioned. While influential figures such as Pope Benedict XVI and many other religious leaders condemn condom distribution on the grounds of increasing promiscuity and worsening the HIV situation [3], people will be vulnerable to infection although reticent to talk openly about their sexual behaviour for fear of offending others. In welcoming these new developments in service provision, we must recognise that because normalisation may not currently be possible for every individual, the approach to testing in all services must be both informative and supportive.

References

1. BHIVA, BASHH, BIS. *UK National Guidelines for HIV Testing 2008*. BHIVA, London. Available at www.bhiva.org/cms1222621.asp (last accessed 15th May 2009).
2. BBC News. I can buy life. That's not fair. 23 April 2009. Available at <http://news.bbc.co.uk/1/hi/health/8013896.stm> (last accessed 11th May 2009).
3. BBC News. Pope rejects condom distribution. 18 March 2009. Available at http://news.bbc.co.uk/today/hi/today/newsid_7950000/7950045.stm (last accessed 11th May 2009).

Correspondence to: Carol Pellowe,
Faculty of Health and Human Sciences, School of
Community Health and Social Care, Thames
Valley University, Boston Manor Road, Brentford,
Middlesex TW8 9GA.
(email: carol.pellowe@tvu.ac.uk)

Testing for HIV in primary care

a general practitioner's perspective on the UK National Guidelines for HIV Testing 2008

Juliet Bennett

Independent Nurse Advisor

The case for early diagnosis of HIV is compelling. As nurses in the field, we are all aware of the benefits of early treatment, both for the individual and for public health, in reducing associated morbidity and mortality (through timely access to antiretroviral therapy), and reducing the potential for onward HIV transmission. Self-awareness of HIV seropositivity can be a powerful tool for transmission prevention as evidence suggests that some people with HIV reduce higher-risk sexual practice shortly after they learn of their status [1].

We also know that early diagnosis and treatment is cost-effective, with one study estimating costs for direct care of late presenters to be two-and-a-half times more, for every month of care, than those who present earlier in the disease process [2]. However, despite medical advances and these other significant advantages in early diagnosis, many people still present late with HIV infection [3]. In May 2005, Sullivan *et al.* [4] reported a significant number of missed opportunities for earlier diagnosis in people who had sought medical care in the 12 months prior to being tested.

These findings were consistent with an HPA report in the same year [5] that found that GPs were not testing for HIV in individuals who considered themselves to be at low risk of HIV infection, even when they presented with symptoms indicative of immune suppression. Clearly there were, and still remain, missed opportunities for diagnosis. Consequently the HPA recommended that HIV testing should be further expanded through 'targeted promotion and opportunistic HIV testing in healthcare settings.' It stressed the need for 'primary care practitioners to be supported in particular, to assess the health needs of migrants and gay men including discussing the need for HIV testing to ensure these groups are diagnosed as early as possible'.

HIV testing has traditionally been carried out in specialist settings for reasons of stigma, fear of discrimination and the need for exceptional levels of patient confidentiality. However the knock-on effect has been that many non-HIV specialists and primary care healthcare professionals feel deskilled in recognising and diagnosing HIV infection, through lack of experience. This is now seen as an impediment to efforts to reduce transmission.

Dr Martin Fisher (Royal Sussex County Hospital, Brighton) kindly supplied Figure 1, which demonstrates the potential opportunities for

intervention by healthcare professionals during HIV disease progression and the requirement for training and campaigns to raise awareness.

The relatively recent *UK National Guidelines for HIV Testing 2008* [6] offer concrete advice and guidance with a view to 'normalising' HIV testing in this country. *HIV Nursing* interviewed two clinicians in order to find out more about the perceptions of medical staff in the light of these guidelines. In this article, a GP gives his perspective, while in the following article, an A&E consultant describes his views.

Dr A works in primary healthcare in a group practice in 'leafy Buckinghamshire', an area of relative affluence with low levels of deprivation. Its population is largely White of UK origin, with approximately 15% who are Asian or European. Very few Black African or Afro-Caribbeans attend this practice.

What were your first impressions of the new HIV Testing Guidelines when they were launched last year?

To be honest I wasn't aware of the guidelines until now. If they have been sent to me, then I'm afraid that they fell under my radar. We receive so much advisory material, especially by email, that I never have the time to read. Generally, I prioritise information coming from NICE or the Royal Colleges.

Now that you have seen them do you feel that they will be useful?

It is only on reading on the back of the document, the list of who contributed to the writing committee that the credibility of these guidelines is made clear. I'm afraid that they didn't grab my attention before, but now that I've read them they appear comprehensive and relevant to my practice.

Are you aware of the HIV prevalence rate in your area and does this influence your practice?

I believe that it is roughly 2:1000. This is one reason that HIV infection can 'fall off our radar', compared with the common diseases that we see all the time, such as asthma and diabetes, which I feel competent and confident to deal with because I have the experience and am relatively up to date.

What do you perceive to be the barriers to increasing HIV testing in primary care?

Historically our microbiology labs have been reluctant to encourage testing in our medical centre

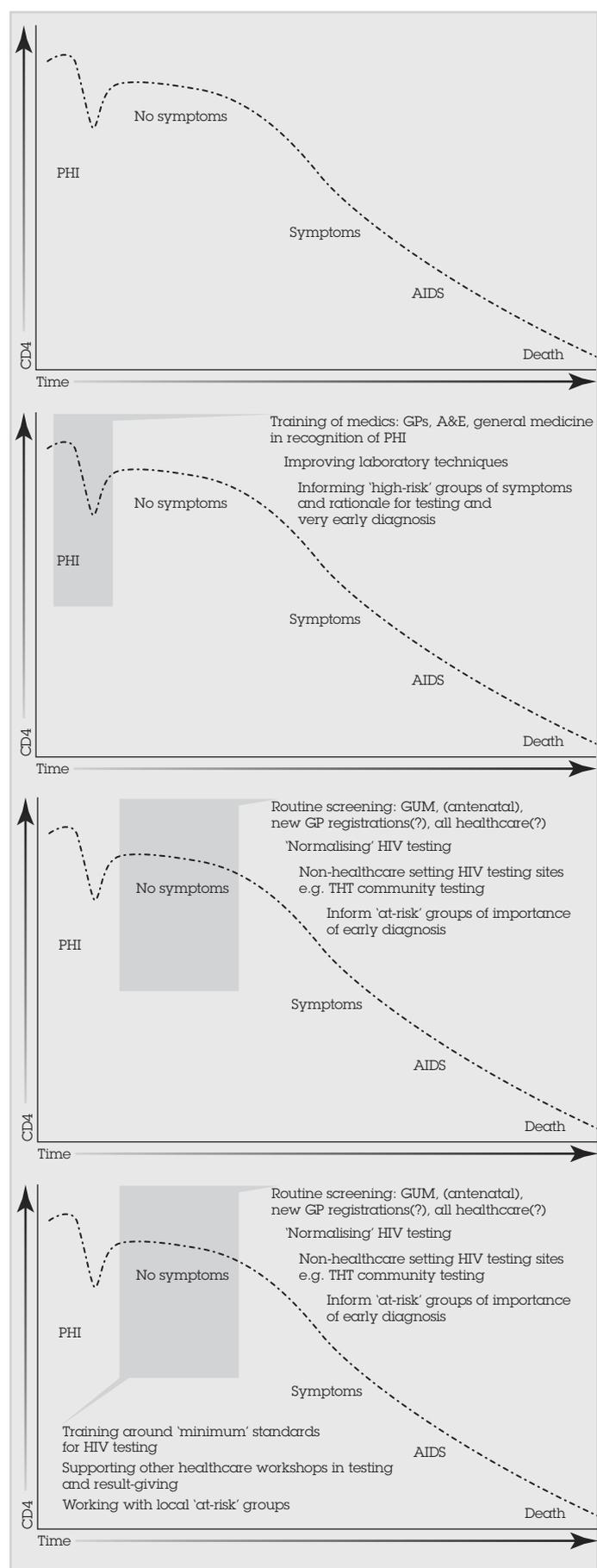


Figure 1: Diagnosing the undiagnosed.

and advise us to refer patients to GUM services. I also admit that I haven't felt very comfortable raising the subject of HIV risk, especially with

patients from certain countries of origin, for fear of being perceived as racist. In these cases there are also often language barriers so it's even harder to broach such sensitive issues.

A commonly held belief is that patients require in-depth and lengthy pre-test counselling and special skills for delivering HIV-positive results.

Yes, this has also been a factor. Previously my perception was that as GPs we were not equipped to do the counselling and therefore could not directly offer the test.

How might these guidelines help you?

The guidelines have reassured me that pre-test discussion doesn't have to be done by a specialist working in the HIV field, and that it can be done adequately in primary care. HIV test-related counselling has been demystified. I am also now aware of the possibility of using rapid test kits for point of care testing in our practice.

How useful is the list of clinical indicators? Which would you have previously considered as potentially HIV-related?

I found this list rather surprising. Several of these symptoms are ones which I may have overlooked in the past, for example, recurrent ear infections and gingivitis. I do see quite a lot of oral *Candida*, although usually in those taking medication for asthma and bronchiectitis. It is a useful list but seroconversion illness symptoms will often be vague. It is hard to identify 'the unusual' from the numbers of more common viral illnesses that we see every day.

Is there anything that you might do differently now, having read the guidelines?

Well, as I said, I do feel reassured that primary healthcare can, and should be offering HIV testing much more widely. Obviously I have to be more aware of possible related symptoms and I still have concerns about the logistics of offering this service in everyday practice.

So what do you feel you need, in terms of skills and resources, in order to normalise testing in your practice?

To date we haven't had the infrastructure. Within our practice blood test results are supplied to patients by the reception staff. This would have to be explored as I'm aware it may deter people from testing. Also, the labs will need to be supportive of this and contracts/service level agreements redrafted.

I also think there needs to be a national awareness campaign, probably targeting all healthcare professionals and offering training to improve confidence in obtaining consent and giving HIV-

positive results. I would also need to see the evidence regarding the specificity and sensitivity of the rapid tests, and there would be much consideration about the process of running a POCT within the existing system for patient consultations offered by most practices. Obtaining informed consent takes time, and that is always a stretched resource.

References

1. Steward WT, Remien RH, Truong HM *et al.* A move toward serosorting following acute HIV diagnosis: part 1 of 4 on findings from the NIMH Multi-site Acute HIV Infection Study. *National HIV Prevention Conference*, Atlanta, Georgia, December 2007. Presentation C20-1. Available at www.2007nhpc.org (last accessed 14th May 2009).
2. Gill MJ, Krentz HB, Auld CM. The high cost of providing medical care to patients who present late (<100/mm³) with HIV infection. *10th Conference on Retroviruses and Opportunistic Infections*, Boston, February 2003. Abstr. 915.
3. Health Protection Agency. *HIV in the United Kingdom: 2008 Report*. Available at www.hpa.org.uk (last accessed 11th May 2009).
4. Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. *Lancet*, 2005, **330**, 1301–1302.
5. The UK Collaborative Group for HIV and STI Surveillance. *A Complex Picture. HIV and other Sexually Transmitted Infections in the United Kingdom: 2006*. London: Health Protection Agency, Centre for Infections. November 2006. Available at www.hpa.org.uk (last accessed 14th May 2009)
6. BHIVA, BIS, BASHH. *UK National Guidelines for HIV Testing 2008*. BHIVA, London, 2008. Available at www.bhiva.org/cms1222621.asp (last accessed 14th May 2009).

Correspondence to: Juliet Bennett.
(email: jv_bennett@yahoo.co.uk)

KALETRA PI

KALETRA ADVERT

'Well, it's not on our radar at all right now'

Views on HIV testing and the *UK National Guidelines for HIV Testing 2008* from an A&E consultant

Catrin Evans

Lecturer, School of Nursing, Midwifery and Physiotherapy, Nottingham University

In this interview, a consultant working in the A&E department of a large teaching hospital in the East Midlands talks about HIV testing. His comments raise substantive questions about how to increase and make HIV testing more routine within A&E and acute admissions units in the context of a relatively low HIV population prevalence (in this region it was only just over 0.2%, the level identified in the *UK National Guidelines for HIV Testing 2008* [1] as warranting a greater emphasis on testing¹).

Had you heard of these guidelines before this meeting, had they been sent to you or anything like that?

No, not at all, they may have been sent in the midst of a mass of emails but certainly, as I said, it's not on the radar and not on the radar of any of my colleagues.

Have there been any meetings in your department to discuss HIV testing?

No, nothing.

What do you do at the moment regarding HIV testing?

We don't do any HIV testing as such within the department. The only time where it's raised as an issue is when people present with needlestick injuries etc. Any HIV testing would be done elsewhere or on the wards once someone has been admitted if they are very sick, so we might identify someone where there's a suspicion of HIV. But again, it's pretty rare that we see anyone with AIDS-related illnesses, and anyway that's slightly different to testing someone for HIV. It's really only in the context of people presenting with specific needlestick injuries. And here, we don't do the testing but we may take blood that's then put in storage and then we refer them onto occupational health or the GUM clinic. I'm not sure if that blood is utilised, but we don't specifically do the testing – that's done elsewhere. We just initiate the treatment, but we don't do any of the counselling or anything like that.

¹ A number of key issues were identified, including the pressure to meet other potentially conflicting targets such as the 4-hour waiting times, the logistical/resource implications for how testing could be implemented, the need to develop follow-up care pathways, and whether public health is part of an emergency department's remit at all.

That's interesting because BHIVA is concerned that many of those diagnosed late have often presented within the preceding months at their GP practice or in A&E and their symptoms haven't been recognised and that is why there is a real push to sensitise medical staff and increase testing. What do you think would be the best way of doing this? Do you think it is appropriate at all in A&E to be doing more HIV testing?

I know that in the States, there's a lot more testing in A&E, there's a lot of screening but it's connected to the seroprevalence in the area. To date, here in this large city, we don't see so much – I came from another large city where we used to see a lot of HIV in injecting drug users so it seemed to be much more on the agenda there than here. Here, to date, it's never been such a big issue, but I know the figures have gone up.

Yes, the prevalence is just over 0.2% now.

I think it's just such a massive thing – I mean where they've tried to implement it in the States there's such a huge push – you've got to have a national drive for it from national bodies, and then there have to be champions for it locally and within the department. For that you need to have a pretty high seroprevalence rate to make it viable. I don't think there's enough evidence out there yet to tell us whether it would be cost-effective. With all the other drives, like the 4-hour target and all that, screening is way down the agenda. I think a couple of years ago, we did a very brief thing on Chlamydia screening and that kind of fell apart basically, again, because of the difficulties of maintaining it. And then there's the issue of when you find people, getting them linked to the services afterwards.

One of the issues is around using the opportunities of contact with healthcare to suggest HIV testing to groups who might be vulnerable and who might not be accessing other services like GPs, for example, recent immigrants from sub-Saharan Africa.

Yes, maybe this isn't such a big issue in the UK as it is in the US because here you have universal access to healthcare whereas in the States there are many people who won't access healthcare at all. But yes, I suppose there are still groups of people who will attend emergency departments who won't go to a GP, but then these are equally the group of people

who even if they test positive, might not go for follow-up – they test positive but don't do anything about it. I think they've found in places where they've done this that the number of people getting tested is one thing but the number getting linked into care and follow-up is another...I think it was quite low. There are a lot of resources that you would need to put into this to make it work. I can't see it happening here for a while. You would definitely need extra resources and then there's the question of who would be the people doing this? I don't think it would be A&E staff. I guess we have a parallel thing with alcohol screening going on at the moment, where we screen people for alcohol problems. This has only just started and there is now a next-day clinic run by dedicated people, where patients can drop in the next day – and patients opt to come to these clinics.

They have to come back ...

Yes, they have to come back, but access is easier than before. I think it's pointless doing any kind of screening unless you at least have that next bit.

Do the A&E staff do the alcohol screening?

Yes, but it's only one question – something about their alcohol intake and then, depending on the answer, staff ask whether patients think that their injury is related to alcohol. If patients agree, then they're invited to come back the following day.

Do you think that a similar kind of question could work with HIV?

I don't know. I guess the first question is whether you're going to do universal screening, and, if not, how you're going to identify people at risk. There would be issues of training staff to recognise this. And who's going to do it? Asking the question? Doing the counselling, following-up the result and then linking them into follow-up. It's a massive undertaking.

I suppose I was thinking whether you could raise it as an issue and then let people know where they could go to get a test.

Again, I suppose most people have their own GPs and that's where they go for screening. That's where the screening should be done. I suppose it's against the ethos of the department really. It's a bit like doing things like injury prevention, health promotion in general. Are they part of the remit of the emergency department? And is screening what we should be doing? Although I guess we've been doing opportunistic tetanus immunisations for

years, so there are examples of where we do things that are beyond the remit of just reactive treatment.

Do you know of any departments in the country that are offering HIV testing?

Not that I'm aware of.

When you look at this list of clinical indicator diseases [1], in these cases would you normally suspect HIV or suggest that testing should be done?

Yes, this is what we would expect to see in high-risk groups or among people who are immunocompromised.

Would you suggest a test? Would you write in the notes that a test should be done?

Well, no because we tend to treat only the symptoms that they're presenting with, and we know that testing, that kind of thing would go on elsewhere if they got admitted. I think it's really quite rare that people would actually think about HIV because it's so low on the radar to be honest. We'd only really think about it if it was a typical presentation – say an atypical pneumonia in a young man – then we'd think about risk groups, but not otherwise.

Have you found these guidelines helpful?

Well, this is stuff that people should know. Maybe they would be useful if you were seeing the prevalence in the community rising, then there probably needs to be a bit more education. It's been quite interesting actually because I wasn't aware of this. I think if these guidelines are going to be implemented then it needs to be evaluated as part of a research project.

I guess it's a case of 'watch this space' right now?

Yes, I get the feeling from the States and elsewhere that the verdict is still out on the efficacy of this approach.

References

1. BHIVA, BASHH, BIS. *UK National Guidelines for HIV Testing 2008*. BHIVA, London. Available at www.bhiva.org/cms1222621.asp (last accessed 15th May 2009).

Correspondence to: Catrin Evans,
Lecturer, School of Nursing, Midwifery and
Physiotherapy, Nottingham University, B Floor,
Queens Medical Centre,
Nottingham, NG7 2UH, UK.
(email: catrin.evans@nottingham.ac.uk)

Antenatal HIV screening: a midwife's perspective

Lynne Sivyour

HIV Specialist Midwife, Homerton Hospital, London

Since the routine offer and recommendation of the HIV test in pregnancy, a policy that was implemented in almost all English maternity units by the end of 2001 and throughout the UK by 2003, more than 95% of HIV-infected women are now diagnosed by the time of delivery. This has been a huge success story resulting in a decrease in mother-to-child transmission (MTCT) rates from approximately 20% in 1997 to 3% in 2005 [1].

As the HIV Specialist Midwife at Homerton Hospital, Hackney where we care for approximately 40–50 culturally diverse, HIV-positive pregnant women per annum, I wanted to take a look back and see how far we have come with antenatal HIV screening in the UK. I also ask what lessons can be learned, what can be improved, and suggest some implications for the future of HIV screening more generally.

Looking back: the history of antenatal HIV screening

In 1998, it became evident that approaches to HIV testing in the UK were failing to identify a substantial number of HIV-positive pregnant women. Data from the unlinked anonymous survey that tested dried infant blood spots for maternal HIV antibody revealed that more than 70% of HIV-positive women remained unaware of their diagnosis at the time of delivery [1]. This resulted in high MTCT rates – an estimated 12–26.5% in 1997 [2], with many women only becoming aware of their status through having a sick child diagnosed with an HIV infection or AIDS.

In 1994, the American–French Paediatric Clinical Trial Group (PACTG 076) discovered that zidovudine (AZT) given to the mother in pregnancy, intravenously during labour and to the baby for 6 weeks after birth could reduce MTCT rates by two-thirds, to 6–8% [3]. This risk could be further reduced by 12–15% if breastfeeding was avoided [4].

Although the Department of Health [5] recommended in 1994 that the HIV test be available in all antenatal clinics and routinely recommended in high prevalence areas (e.g. London), in practice few units were offering universal testing. The test was often only selectively offered to 'high risk' women, or to those requesting it [6]. Some units offered a separate pre-test counselling appointment prior to the test taking place. This largely resulted in low uptake rates of 10–30% in the mid-1990s [7].

However, in 1998, new data indicated that elective Caesarean section combined with AZT and the avoidance of breastfeeding could further reduce the transmission rate to 1–2% [8].

Government recommendations

The government responded by setting up a working party in 1998 [4] to look into ways of reducing MTCT. Their recommendations resulted in the Department of Health issuing a directive in 1999 [1] stating that all pregnant women should be offered and recommended an HIV test as an integral and routine part of antenatal screening. National targets included a 50% uptake of the test by the end of 2000, and a 90% uptake by the end of 2002. The aim was to identify 80% of HIV-infected pregnant women in order to offer them advice and treatment during antenatal care. It was anticipated that by 2002 this would result in an 80% reduction in the number of children acquiring HIV from their infected mothers during pregnancy, birth or through breastfeeding.

Data collected by the National Study of HIV in Pregnancy and Childhood (NSHPC) showed that a third of English Units had reached the 90% uptake rate target by 2002 with over a half achieving 80% [7]. In 2003, by which time the antenatal HIV testing policy had been implemented throughout the UK, virtually all units were reaching uptake rates of 80–90%.

In 2006, the NSHPC was able to demonstrate through collating its records with unlinked anonymous seroprevalence surveys that the Department of Health's target of at least 80% of HIV-infected pregnant women being diagnosed before delivery had been exceeded [9].

Training midwives

In order for the antenatal screening policy to be successful, midwives had to be trained to enable them to successfully and confidently offer the HIV test, understand its importance and implications, and answer women's questions. Educational programmes varied as there were no set guidelines on how to go about this.

Many hospitals, including the Homerton, introduced a series of mandatory training days that all midwives had to attend. This eventually evolved into a quarterly 1-day training event run between three hospitals for all new midwives. The aim of the training was to increase HIV knowledge, explore

attitudes, and alleviate fears using a range of training methods including interactive games that explored knowledge gaps and attitudes, role-play, and talks from HIV physicians, specialist midwives and HIV-positive speakers. The groups were kept deliberately small, with no more than 18 participants, to encourage more open and livelier interactions. The topics covered included the following.

- Informed consent
- How to offer and recommend an HIV test
- Documentation
- The importance of re-offering the test if declined
- How to give a negative result
- The window period
- Safer sex
- Confidentiality
- What happens when the test is positive
- The management of positive women in pregnancy, labour etc.

Many of our midwives were particularly enthused and challenged after hearing an HIV-positive woman speak of her experience of living with HIV. In verbal and written feedback through evaluation forms, many stated this to be the highlight.

Other midwives with little prior knowledge of HIV became strong advocates for the test once they understood just how successful the preventative measures and treatments can be for pregnant women, their partners and children. Studies have shown that a positive attitude from a midwife has a greater effect on uptake than even knowledge itself [10]. It has been my experience that if a midwife believes in the test, she will promote it.

With uptake rates currently well over 90% in most UK hospitals, midwives appear to be successfully offering the test. However, more research is needed to measure just how successful training programmes have been in improving midwives' levels of knowledge, understanding, attitudes and confidence.

Normalising the test

Normalisation of the HIV test as a routine opt-out test has also played a significant part in increasing uptake rates. Midwives offer the HIV test at the same time as other antenatal blood tests, prompted by a tick box on a computer screen or in the handheld notes. They have a designated responsibility to document whether the test was agreed or declined, to check results, give negative results, and ensure informed consent.

If the test is declined at Homerton, it should be re-offered at 20 weeks or at any point. If the test is declined, midwives should explore the reasons for this. For example, many Orthodox Jewish women decline. However, if the health promotion messages are stressed, such as prevention for the baby and healthcare for the mother, or it is suggested that it can be transmitted from non-sterile needles abroad,

they may accept. Anyone with anxieties can be referred to the specialist midwife for counselling. It is known that those who refuse the test are more likely to be positive [10].

The only randomised trial published to date on testing methods [10] demonstrated that a universal opt-out approach did not cause anxiety and had higher uptake than other methods. It was found that assessing the risk merely reduced the numbers of patients tested. Simplifying the test procedure to the universal opt-out approach, and reducing the need for lengthy (or two-stage) pre-test counselling has clearly increased uptake, and therefore indicates that it is acceptable to most women. More research on women's experiences is required, however.

The specialist midwife's role

The role of the HIV specialist midwife as a key member of the multidisciplinary team was first developed and recognised in many hospitals as a result of BHIVA recommendations [11]. This ensured that a lead person was identified to provide peer-support and training, to ensure protocols and care pathways were followed, to highlight problems, promote communication between departments, and work closely within the multidisciplinary team. In some hospitals where, for example, HIV prevalence is low, health advisers can take on a similar role and give positive results, counsel women and families, teach and provide specialist support to midwives and hospital staff.

The multidisciplinary team

Pregnant women living with HIV often present with varied and very complex needs. For many, receiving an HIV-positive result is like having a 'stick of dynamite' thrown into their family situation and the question is, will their family survive? There are often deep fears about notifying a partner that include possible rejection, blame and domestic violence, as well as adjustment reactions such as grief, denial and depression. Others have more pressing problems such as uncertainties about immigration status and fear of dispersal and/or deportation. Poverty, poor housing and lack of access to public funds also cause severe difficulties for some.

Some women have strong cultural and spiritual belief systems that make it difficult for them to engage in western HIV healthcare. They believe that they will be healed through prayer or traditional remedies, or that HIV is a curse.

Approximately 60% of the women we see are aware of their HIV status prior to pregnancy and may present with more complex medical management issues, for example, they may have resistant virus, co-morbidities or co-infections.

A multidisciplinary approach is, therefore, vital to promote communication, develop strategies for more complex cases and ensure specialist input [11].

Antenatal screening: where are we now?

According to the NSHPC and the unlinked anonymous survey figures, approximately 1340 HIV-positive women gave birth in the UK in 2007 [12]. Of these, 1240 women were diagnosed before delivery and most accepted and received antiretroviral therapy; eight infants were found to be HIV-positive. Therefore, 100 women remained undiagnosed at delivery and there were an estimated 25 infants who may have been infected with HIV; however, only eight so far have been diagnosed).

Currently about 10 HIV-positive infants are born every year to diagnosed women – a 1% transmission rate. Since 2001, reportedly over 200 HIV-infected infants have been born to undiagnosed women (about 20–30 a year). About half of these infants are diagnosed in their first year of life and the remainder at older ages, either when they present with symptoms, or when their mothers were diagnosed in a subsequent pregnancy. The question is, are these transmissions avoidable?

How can we improve?

In the *Perinatal Transmission of HIV in England* audit [12], it was discovered that of 33 infants born to women diagnosed with HIV before delivery, two children died, and 20% of the survivors had AIDS-defining illnesses. However, of the 54 infants born to women undiagnosed at delivery, nine have died and 60% of the survivors had AIDS-defining illnesses. Thus, prognosis and morbidity is demonstrably poorer where the mother has remained undiagnosed at delivery.

Contributory factors to perinatal infection have included the following [12].

- The antenatal test not being offered or being declined.
- A delay in antenatal testing or reporting of the results.
- Seroconversion in pregnancy.
- Concurrent infections or conditions.
- Delay in initiating or changing antiretroviral therapy.
- Late diagnosis.
- Premature delivery.
- Failure in communication within or between Trusts.
- Adverse social circumstances in many families.

There is currently a national review of antenatal infectious screening underway, which the results of the perinatal audit will feed into. In order to improve, it is clear that maternity units need to maximise protocols to achieve even higher uptake rates and ensure timely testing and result giving.

All women should have access to a test and interventions. Where there this has not happened, the circumstances should be reviewed to improve systems. Cases of MTCT, where an infant has been infected, should be treated as a serious untoward incident and investigated to see what lessons can be learned [12].

For women who decline the test, a clear policy should be in place. The audit [12] recommends a re-offer for testing at least once and preferably in the second trimester.

Women with risk factors for seroconversion in pregnancy, for example women who have a newly diagnosed HIV-positive partner, need to be identified and closely monitored in order to offer them prompt treatment. There is still much debate in the HIV sector about the re-offer of a routine third trimester test at 32–36 weeks, its cost-effectiveness and likely efficacy [P. Tookey, personal communication].

On the labour wards, all HIV-positive women should have individualised birth plans available, and should be actively managed if they are having normal deliveries. Where there are queries about the management of a case there should be prompt liaison between the Obstetric, HIV and Paediatric teams to ensure all measures to prevent transmission are implemented. Untested women arriving in late pregnancy or in labour, or prior to invasive procedures should be offered a rapid HIV test [12].

As the HIV test has become normalised in the antenatal setting there is a danger that the initial energy put into training may have waned. Certainly some hospitals in London have had difficulty with funding and releasing midwives for specific HIV training, which is often no longer mandatory, as they also need training in many other areas. It is clearly important to keep up the impetus and profile if we are to continue to improve.

Implications for the future

The antenatal screening model can be heralded as an example of how routine opt-out testing dramatically improves uptake rates, and also significantly increases the number of women diagnosed by delivery. It has resulted in the earlier diagnosis of asymptomatic women with higher median CD4 cell counts compared with other women and heterosexual men at diagnosis, a circumstance which also reduces morbidity, mortality and onward transmission [13].

The *UK National Guidelines for HIV Testing 2008* has recognised this success, and in a bid to bring down the rates of late diagnosis, is recommending that opt-out testing be offered more widely and routinely in certain settings, for example in GUM clinics, termination of pregnancy services, drug

dependency programmes, services for those diagnosed with TB, hepatitis B/C, and lymphoma and in primary care where prevalence of HIV infection exceeds 2 in 1000 [13].

Similarly the 'Don't forget the children' conference, highlighted that all children with significant risk of HIV should be tested as a routine [14]. Evidence suggests that vertically infected children can survive to their teenage years without being diagnosed [15]. It is, therefore, important that health professionals remember to ask about, and test, children in high-risk groups. For a more comprehensive list of high-risk groups and recommendations for testing, please see [13].

Some of the lessons that can be learned from the antenatal screening model include: the need for specific, targeted training and funding; the importance of normalising and simplifying the HIV test; designated responsibility; and reducing the need for lengthy pre-test discussions. Appointing a professional lead could be a good way to monitor, and audit services, support staff and promote communication with the HIV team. The MDT also has a vital role to play in providing clear care pathways, giving advice on complex issues, supporting staff, and offering training.

Whilst the antenatal screening policy has been hugely successful in the UK, as a model and an example, there is no room for complacency. If we want to continue to increase uptake rates, the impetus on training must be maintained, our testing processes need to be constantly refined, and high standards of care provided on the labour wards. Our goal should be to reduce the number of infected women still undiagnosed at delivery and to improve the management of diagnosed women.

Whilst caring for HIV-positive women in pregnancy can be very challenging, it is also very rewarding as the majority are delighted when their babies are finally pronounced negative, and they discover, with support, that they can live with HIV and also have a future.

References

1. Department of Health. Reducing Mother to Baby Transmission of HIV. Health Services Circular 1999/183. Department of Health, London, 1999.
2. Duong T, Ades AE, Gibb DM *et al*. Vertical transmission rates for HIV in the British Isles: estimates based on surveillance data. *BMJ*, 1999, **319**, 1227-1229.
3. Centres for Disease Control and Prevention. Public Health Service Task Force recommendations for the use of antiretroviral drugs in pregnant women infected with HIV-1 for maternal health and reducing perinatal HIV-1 transmission in the United States. *MMWR CDC Morbid Mortal Wkly Rep*, 1998, **47**, 1.
4. Intercollegiate Working Party for Enhancing Voluntary Confidential HIV Testing in Pregnancy. *Reducing mother to child transmission of HIV infection in the United Kingdom. Recommendations of an Intercollegiate Working Party for Enhancing Voluntary Confidential HIV Testing in Pregnancy*. Royal College of Paediatrics and Child Health, London, 1998.
5. Deputy Chief Medical Officer, Chief Nursing Officer. *Antenatal testing for HIV*. Department of Health, London, 1994. PL/CO (94)3.
6. Tookey PA, Gibb DM, Ades AE *et al*. Performance of antenatal HIV screening strategies in the United Kingdom. *J Med Screen*, 1998, **5**, 133-136.
7. Townsend CL, Cliffe S, Tookey PA. Uptake of antenatal HIV testing in the UK: 2000-2003. *J Publ Health*, 2006, **28**, 248-252.
8. European Collaborative Study 1998. Therapeutic and other interventions to reduce the risk of mother to child transmission of HIV 1 in Europe. *Br J Obstetr Gynaecol*, 1998, **10**, 704-709.
9. The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues. HIV and Other Sexually Transmitted Infections in the United Kingdom: 2005. London: Health Protection Agency Centre for Infections, November 2005.
10. Simpson WM, Johnstone FD, Boyd FM *et al*. Uptake and acceptability of antenatal HIV testing: randomised controlled trial of different methods of offering the test. *BMJ*, 1998, **316**, 262-267.
11. de Ruiter A, Mercey D, J Anderson *et al*. British HIV Association and Children's HIV Association guidelines for the management of HIV infection in pregnant women 2008. *HIV Med*, 2008, **9**, 452-502. Available at www.bhiva.org/cms1221368.asp (last accessed 15th May 2009).
12. NSHPC, AIAU, CHIVA. Audit of Perinatal Transmission of HIV in England 2002-2005 (slide show summary). Available at www.nshpc.ucl.ac.uk (last accessed 15th May 2009).
13. BHIVA, BASHH, BIS. *UK National Guidelines for HIV Testing 2008*. BHIVA, London. Available at www.bhiva.org/cms1222621.asp (last accessed 15th May 2009).
14. BHIVA/CHIVA Consensus Conference 'Don't Forget the Children'. 10th December 2008, London. Presentations available at www.bhiva.org/cms1223342.asp (last accessed 13th May 2009).
15. Judd A, Ferrand RA, Jungmann E *et al*. Vertically acquired HIV infection diagnosed in adolescence and early adulthood in the United Kingdom and Ireland: finds from national surveillance. *HIV Med*, 2009, **10**, 2009, 253-245.

Correspondence to: Lynne Sivyour,
HIV Specialist Midwife, Antenatal Clinic,
Homerton Hospital, Homerton Row, London E9 6RS.
(email: lynne.sivyour@homerton.nhs.uk)

Point of care rapid HIV testing: considerations for service provision

Juliet Bennett

Independent Nurse Advisor

This article aims to provide an outline of the benefits and potential difficulties of setting up a point of care testing (POCT) service for diagnosing HIV infection and suggests the important considerations for policy and practice, including clinical governance issues. In addition to a review of the relevant literature, several existing POCT HIV service providers were interviewed about their experience of setting up a similar service, and they offered substantial advice. The contribution of the following organisations is acknowledged with thanks: Terrence Higgins Trust, London; Body Positive North West, Manchester; Chelsea and Westminster NHS Trust, London; and Tower Hamlets PCT, London.

Point of care testing for HIV refers to the practice, undertaken by healthcare professionals, of providing comprehensive HIV counselling and screening for HIV infection, at the point at which an individual accesses healthcare, in conjunction with a confirmatory test where appropriate. Several test kits are available that give a rapid result using blood from a finger prick or venepuncture, or a salivary sample (a specifically designed test kit only) without recourse to a designated laboratory. Results are visible within 1–60 minutes depending on test kit used, and the service user is informed during the same patient episode/appointment. Confirmatory testing is required at an approved laboratory for all patients with a preliminary reactive or equivocal result. POCT requires that pre- and post-test counselling be modified.

The BHIVA Mortality Audit [1] revealed that about a quarter of HIV diagnoses are made late (i.e. where CD4 cell counts at diagnosis are <200 cells/mm³), and that late diagnoses accounted for approximately one-third of HIV-related deaths. In order to try and tackle this problem, the *National Guidelines for HIV Testing 2008* [2] recommend

'normalising' HIV testing by applying opt-out approaches, and also suggest some other innovative strategies in order to make the test more accessible, particularly for those in higher-risk groups who may not normally access GUM services.

Acceptability of POCT for HIV

Weatherburn et al.'s [3] review of a rapid HIV POCT pilot scheme found that one-third of all clients presenting for a test had never previously tested for HIV, of whom 22% said they had never tested before because they had not known where to get tested. In addition, more than half of all service users reported that their main reason for choosing POCT over other options for HIV testing was because the test result is available at the same visit. This response was significantly more common among those who had tested before than those who had not.

It has been argued that with traditional methods of HIV testing where clients return several days later for their results, this period allows an opportunity for reflection and the possibility to involve family/partners etc, in decision-making. Equally, for many, this waiting period is one of considerable anxiety, and a significant proportion of tested individuals do not return for their results.

A further 32% of all respondents stated that it is more convenient to come 'here'. This answer was assumed to refer both to the 'after hours' nature of the service and to the absence of any need for an appointment. It could also include the physical setting of the intervention (i.e. not in a hospital or in primary care), although this was rarely mentioned specifically. Where a variety of testing sites can be provided, this may increase uptake as other venues are perceived as less stigmatising than attending a GUM clinic. The recent BASHH Guidelines [4] reflect this, advising that rapid tests are indeed appropriate for use in outreach community-based settings where specific services can be established for at-risk populations, removing the potential barrier of contacting the patient at a later time with results.

In the analysis of interviews with people who had tested HIV positive with POCT, Weatherburn et al. [3] found that overall satisfaction with the service was very high, as was satisfaction with onward referral pathways for service users for standard HIV care.

Panel 1: Service objectives

- To increase accessibility of screening for HIV infection in groups known to be at higher risk and/or those groups thought to be reluctant to present for testing to existing services.
- To reduce prevalence of undiagnosed infection.
- To identify and support people with unrecognised HIV infection and link them to clinical services.
- To further reduce onward transmission of HIV infection.

Ethical implications of POCT

Inevitably, a risk associated with increased ease of testing for disease, in all areas of medicine, is that people may be subject to testing without giving their specific and voluntary consent. However, to date, HIV POCT has been, and is advisably, provided by members of staff experienced in working within the field of sexual health and who are aware of the need for adequate pre-test discussion in order to obtain informed consent from service users.

Rapid testing reduces the time between information-giving and receipt of results, and there is therefore less opportunity to abandon the test once initiated. People who may have chosen not to return for their result in other circumstances may have been choosing to exercise their right not to know. GMC guidelines on obtaining consent [5] advise 'that patients are allowed sufficient time to reflect, before and after making any treatment/care related decisions, especially where the information is complex'.

Rapid testing may also reduce the possibility of maintaining patient confidentiality where results are given in an outreach setting. When setting up clinics and selecting venues, consideration must be given, to who has access to the testing area and to provision of privacy for distressed individuals; and also to who will have access to results.

Also relevant to note is the potential for a higher rate of false-positive results with point of care rapid tests, especially in those whose risk of infection is low. The National HIV Testing Guidelines [2] recommend that POCT programmes are targeted towards communities where undiagnosed HIV prevalence is high.

However, targeted testing (i.e. actively promoting testing on subgroups of the population who have been found to have higher risk of infection, whether based on behaviour, clinical or demographic characteristics) may have an associated risk of fuelling stigma in groups that are often already marginalised, isolated and/or experiencing prejudice. Those who are leading such service development should consider this possibility in the choice of venues for POCT and in advertising the service, and seek further professional advice, for example from the HPA, if necessary.

Four providers of POCT for HIV were interviewed in relation to their current eligibility criteria for clients accessing the service.

Anticipated prevalence rates

Overall HIV prevalence in the sites, reported by Sigma [2] was 2–3%. This was also the rate reported by the four services interviewed. However, on average, 2% of the reactive POCT results were not confirmed on the confirmatory serology test. That is, they were false-positive results (or misinterpreted results).

Panel 2: Eligibility criteria for POCT service use

- Three out of four service providers accepted people over 16 years of age. One provider had an age limit of at least 18 years. (Note that under current English law young people aged 16 years and over are assumed to have the capacity to consent to medical treatment and can be treated in the same way as adults.)
- Pregnant women: three out of four service providers interviewed accept pregnant women for POCT.
- All providers agreed that clients are not eligible if assessed to be under the influence of drugs or alcohol. These potential service users should have an appointment made to return when they have recovered capacity to give consent (see [5,6]).
- If individuals present after possible exposure to HIV during sex or intravenous drug use within the previous 72 hours, they should be referred urgently to A&E for PEP/PEPSE assessment [7].
- If primary HIV infection/seroconversion is suspected, it is appropriate for the individual to be tested at the point of care; however, regardless of the test result, patients should be referred to a specialist centre for retesting (in 7 days' time, if their first/POC test was non-reactive/negative).
- It is considered acceptable for individuals to use a pseudonym but they should make a note of the name they use and preferably use a genuine date of birth. Ensure they are aware that they will not be able to obtain confirmation of the result in writing.

Note that prevalence rates may be significantly higher in specific target groups. For example, results from Newham PCT yielded a 10% prevalence and from Cardiff THT, the prevalence was 12.9%. In all cases the data include clients who, after receiving a POCT, reported having had a previous reactive test result. This issue was reported as relatively common at all sites.

Staffing

An appropriate senior professional should be identified to act as POCT service coordinator with clear lines of accountability and responsibility for all aspects of the service. The MHRA recommends formation of a multidisciplinary POCT Service Committee, which includes representatives from the nursing and administration team and other clinicians, health advisors and the pathology services, to establish robust systems for quality control and audit.

The service providers who were questioned suggested the following in relation to staffing:

- Remote clinics require a minimum of two staff on site. In other clinical settings, one nurse per session was deemed adequate.
- All providers used qualified RGNs only, to administer tests and give the results. In general these were Band 6 nurses. One provider used both Band 5 and 6 nurses.

- No clinics used other healthcare workers to 'counsel' and/or test.
- All providers employed one or two administrative staff and several used these staff to verify test results with the nurse (if trained and competent in reading the specific test).
- The role of the administrator generally included: meeting and greeting the client; registering the client; informing of waiting times; managing the booking system where used; faxing referrals and data as per local procedure guidelines and policy; facilitating completion and return of service evaluation questionnaires; and participating in service evaluation and audit.

Venues

The reasons reported for not having previously had an HIV test [2] highlight the need for effective and innovative advertising and marketing of such new services. In this review, one-third of service users also reported attending because of flexible opening hours, namely the availability of evening clinics and the option to walk in without making an appointment in advance. The non-clinical environment was also assumed to promote attendance and these factors must obviously be taken into account when selecting possible venues for POCT.

Obtaining consent for POCT

Pre-test discussion

One of the main aims of the pre-test discussion is to ensure informed consent. There is no requirement for consent to be given in writing. Indeed several service providers who were interviewed perceived that this would be a potential obstacle to testing as clients may find it intimidating to sign their name. By its very nature POCT requires that pre-test discussion be modified from the usual counselling that accompanies standard HIV testing. Interestingly there is little evidence showing a preference or better psychological adjustment to reactive results where pre-test counselling has been lengthy or in-depth.

All discussion must be carried out by trained professionals and the content and skill with which this aspect of the service is delivered remains a critical component to a safe, efficient and high-quality service. It may be helpful to provide written information about consenting to the test – in a range of languages appropriate to the diversity of the service-using population, and which service users can read whilst waiting to be tested. This may facilitate prompt and relevant discussion.

Pre-test discussion in POCT must recognise specific features of rapid testing kits such as the quick time frame, the possibility of false-positive results and the need for a confirmatory test. However, there remain several critical components regardless of the context in which testing is taking place. Discussion should be documented and should cover the points detailed in Panel 4.

Giving results and the post-test discussion

On occasion the patient will request written confirmation of a test result. At POCT it is unlikely that the patient will be known to the service. It may be possible, and acceptable to the patient, to inform the patient's GP of the result and refer them back to their GP to provide written confirmation. If this is declined then a patient accessing POCT must be correctly identified, both prior to blood testing, and when the result is given, by referring to photographic ID and documenting the method of identification and a reference number, both in

Panel 3: A variety of venues was used by the four service providers interviewed and included the following.

- Roving clinics that go to churches, for example, where the congregation includes many people who have originated from areas of high HIV prevalence
- Leisure centres
- Voluntary sector venues (particularly those who exist to support immigrants from areas of high prevalence)
- NHS and private sexual health services such as the Marie Stopes and Brook Advisory Centres
- Drug and alcohol services
- Gay men's groups
- Medical services treating TB and hepatitis B/C infection

Panel 4: Points to cover during the pre-test discussion.

- Respect the individual's right to decline testing or not to know the result (although the patient's reasons for this decision should be explored). Ensure that service users do not feel pressured or coerced into testing. Record details of such consultations in the patient's notes, including where informed consent has been obtained.
- Take into account any difficulties in communication such as with language or due to mental health problems, and provide appropriate additional support.
- Ensure understanding of what the test involves.
- Include discussion regarding the benefits of testing for the individual.
- Offer reassurance regarding confidentiality. Service users should be told that it is standard practice to inform GPs of a reactive result on confirmation of that result. Note that service users have the option to decline, however, the advantage of informing GPs will be stressed.
- Listen to and address the balance of potential disadvantages and the significant advantages of knowing one's status if HIV positive.
- Explain how the results will be given and what reactive and non-reactive results mean, including the possibility of false positives and the significance of the window period.
- Stress the importance of a confirmatory laboratory blood test in all reactive or equivocal results.

Panel 5: Points to note when giving results during the post-test discussion.

- Clear procedures should be established as to how the patient will be given the result.
- Results must be verified by a second person who has been trained in the interpretation of the specific test kit used.
- Wherever possible, the person who performed the test should also give the result.
- Results should be conveyed face to face, in a confidential environment and in a clear and direct manner.
- The need for a retest must be explained if patients may still be within the 12-week window period after a specific exposure risk.
- Robust referral pathways to GUM/specialist centres are essential for those with reactive and equivocal results who will need to attend for a repeat/confirmatory test.
- Make referral appointments with the client present, if at all possible. The *National Guidelines for HIV Testing 2008* [2] recommend that any person testing positive should be seen by an HIV specialist within 48 hours wherever possible, and certainly within 2 weeks of receiving the result. The appointment should be made with a named healthcare professional and at a time convenient for the service user.
- Note that reactive results were reported by two service providers to be 'incredibly faint' on occasions, in particular during seroconversion.
- Provide contact details for specialist support services as appropriate.

medical records held by the service and in any written correspondence. The confirmatory letter must be addressed to named individuals only and not 'to whom it may concern'.

Giving a non-reactive/negative test result provides a good opportunity for discussion about minimising future risk and/or behavioural change, as well as referral onto other HIV prevention services such as drug treatment, harm reduction, GUM or voluntary sector agencies. Additional referral pathways are also necessary for those with negative results for further health promotion advice and other screening.

Quality assurance

POCT services must establish and implement a rigorous quality assurance programme to monitor and evaluate all functions and services throughout the testing process from entry of the client into the service, through to giving results and onward referral systems. There must also be clearly defined lines of accountability for this. In addition, managers of POCT services must be aware of their responsibilities for clinical governance and of medico-legal implications, for example of erroneous results.

There should be regular on-site audits to include, for example, staff proficiency records/certificates, clinical supervision and observation of practice and

performance, new batch validation, patient satisfaction evaluation and performance reporting.

Advertising/marketing the service

In the Sigma review [3] the means of first hearing about the service varied across sites. A clinic targeting men who have sex with men used the internet site 'gaydar' and other sites to advertise, and this was a successful method for that target group.

Other methods used by the service providers interviewed included posters, leaflets, word of mouth, information from healthcare or social care worker, and advertisements in the local press. Advertising at a range of local venues frequented by the target populations, such as family planning clinics, leisure centres, colleges, libraries and local chemist shops, is suggested. THT used 'outreach' workers to visit venues such as markets and churches that were popular places of congregation with certain targeted communities and gave out leaflets promoting the POCT service. Leafleting GP practices, drug dependency units and homeless person services and advertising in local newspapers and community magazines may also yield results.

It may be beneficial to identify first languages used by the targeted communities in specific areas, for translation of these materials; however, interestingly, other research [8] has indicated that approximately 80% of these communities with higher HIV prevalence, in particular the under-55 age group, do speak sufficient English for translation to be unnecessary.

As could be expected, Weatherburn *et al.* [3] found that promotion of POCT services improved uptake, but that more expensive methods of promotion, for example press and online advertising and dedicated outreach, do not appear to have an impact on uptake of such a service in keeping with their higher costs.

Among both genders and irrespective of sexual identity or practice, the most common answer for first hearing about the service was via the internet. Of all those attending for testing, 37% specified the internet as the source of first hearing about the service. A considerable proportion of service users found out about the service via the THT website. Another website specifically promoting HIV testing and targeting gay men (www.youchoose.org.uk) was also successfully used to advertise the POCT service in Brighton and in the proximity of Lighthouse West.

Heterosexuals of all ethnicities were substantially more likely to cite the promotional leaflet and recommendations from friends as a means of learning about the service [3]. Approximately 15% learnt about the service from a poster.

Communication and partnership working

Patient involvement is particularly and notoriously challenging for services providing GU-related interventions due to the stigma attached to these, the desire of many service users to remain anonymous and, in many cases, the one-off or brief nature of healthcare professional interventions. However, every appropriate opportunity should be taken to informally and formally assess levels of satisfaction with the service and to seek opinions on how the service could be improved.

It is also essential to identify key stakeholders, for example Lead Clinicians in GUM local clinics and the local NHS Trust laboratory, and ask for their support, while emphasising that the POCT service is not in direct competition, especially as reactive results will subsequently be referred to their service. These can be challenging partnerships to establish and maintain, especially where the service requires one collaboration to provide rapid testing and another to receive positive referrals. All sites require clear leadership from POCT service staff, GUM partners and other organisations that may be involved in the referral process.

The local hospital pathology laboratory can play a supportive role in providing advice on a range of issues including the purchase of testing kits, interpretation of results, troubleshooting, quality assurance, and health and safety issues. It is essential that the relationship with this laboratory is fostered, and effective channels of communication are prioritised.

POCT for HIV is, as yet, not widely available nationally. However, many PCTs are now allocating funds and negotiating contracts for service provision. Clearly, setting up these services requires considerable work and negotiation in terms of building relationships, logistical planning and designing robust referral pathways and evaluation

processes. Sharing our knowledge and experience in this area and working effectively across organisations will do much to facilitate a smooth and rapid roll-out process and high standards of care provision.

References

1. BHIVA Audit and Standards Sub-Committee. 2005–2006 Full results of the BHIVA Mortality Audit. Presented at the BHIVA Autumn Conference, London, 2006. Available at: www.bhiva.org/cms1192339.asp (last accessed 11th May 2009).
2. BHIVA, BASHH, BIS. *National Guidelines for HIV Testing 2008*. BHIVA, London, 2008. Available at www.bhiva.org/files/file1031097.pdf (last accessed 11th May 2009).
3. Weatherburn P, Hickson F, Reid D *et al*. Evaluation of the Department of Health-funded fasTest HIV testing in the community pilot. Sigma Research, London, 2006. Available at www.sigmaresearch.org.uk/files/report2006f.pdf (last accessed 11th May 2009).
4. BASHH Clinical Governance Committee. *Guidance on the Appropriate Use of HIV Point of Care Tests*. BASHH, London. Available at www.bashh.org/documents/1176/1176.pdf (last accessed 11th May 2009).
5. General Medical Council. *Guidance for Doctors. Patients and Doctors Making Decisions Together*. GMC, London, 2008. Available at www.gmc-uk.org/news/articles/Consent_guidance.pdf (last accessed 11th May 2009).
6. Department of Health. *Good Practice in Consent Implementation Guide*. DoH, London, 2001. Available at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005762 (last accessed 11th May 2009).
7. Fisher M, Benn P, Evans B *et al*. UK Guideline for the use of post-exposure prophylaxis for HIV following sexual exposure. *Int J STD AIDS*, 2006, **17**, 81–92.
8. Weatherburn P, Ssanyu-Sseruma W, Hickson F. *Project Nasah: an investigation into the HIV treatment information and other needs of African people with HIV resident in England*. Sigma Research, London, 2003. Available at www.sigmaresearch.org.uk/files/report2003a.pdf (last accessed 11th May 2009).

Correspondence to: Juliet Bennett.
(email: jv_bennett@yahoo.co.uk)

Children with undiagnosed HIV in the UK and Ireland: are we doing the right thing?

Djamel Hamadache

Paediatric HIV Nurse Specialist, Chelsea and Westminster Hospital, London

Introduction

Since the introduction of highly active antiretroviral therapy (HAART) to the management of HIV infection, HIV-infected individuals are living longer and their quality of life has improved considerably [1]. Early HIV diagnosis, important for better monitoring of the infection and reduced disease progression has contributed to this increase in life expectancy [1].

The advances in medical research, treatments and management of HIV infection have also benefited the paediatric population. We have witnessed an important shift in the median age of infected children from 7 years old in 1997 to 13 years old in 2005, and the children generally stay in good health. By the end of March 2008, 1460 HIV-infected children living in the UK and Ireland were reported to the Collaborative HIV Paediatric Study (CHIPS) [2]. At the time of writing, 1142 children are alive and currently in follow-up; and 150 adolescents have transferred their HIV care to adult services.

Nevertheless, many children of high-risk population groups living in the UK and Ireland have not yet been tested [3]. The proportion of undiagnosed HIV-infected children is unknown. These children, who can remain asymptomatic for many years, are at significant risk of growth delay, impaired neurocognitive development, advanced disease and death [4]. HIV infection in children can be managed more easily if diagnosed early, ideally within the first years of life. The detection of early clinical signs of disease progression could therefore have a truly positive impact on a child's future.

While most parents with HIV want their children to maintain good health and lead a successful life, a significant number of individuals within high-risk population groups are still reluctant to test their children for HIV.

In 2008, a 10-year-old child died in hospital as a result of HIV-related complications that could have been prevented. Both parents were known to be infected with HIV and were accessing care at the same hospital the child was admitted to after becoming acutely unwell. Unfortunately, the parents omitted to disclose their HIV status to the paediatric team, which delayed the medical diagnosis and led to the child's tragic death.

In an attempt to raise awareness amongst healthcare professionals directly and indirectly involved in the care of HIV-positive patients, this

article analyses the issues related to testing children for HIV in the UK and Ireland. It reflects on current practices and identifies ways of managing challenging situations when dealing with testing the children of parents with unknown or HIV-positive status.

Following the success of the introduction of antenatal 'opt-out' HIV testing and the implementation of national preventative measures of mother-to-child transmission (MTCT), the incidence of newly infected babies has significantly decreased in a number of European countries. The risk of MTCT is now less than 1% [5]. An audit conducted by Pat Tookey between 2002 and 2005 in the UK and Ireland identified 87 HIV-positive newborn babies. Of these infected children, 54 were born to undiagnosed mothers who had either declined antenatal testing or seroconverted during pregnancy [6]. Prolonged breastfeeding was also an important risk factor for MTCT when maternal HIV status was unknown [5,6]. Last year, the British HIV Association published new recommendations to tackle the issue of women's refusal for antenatal HIV testing [5]. Testing the partner of pregnant women for HIV was also strongly suggested.

According to the Health Protection Agency's latest report (2008), an estimated 77,400 adults were living with HIV in the UK at the end of 2007, with a steady increase of HIV transmission amongst heterosexuals, especially within the black ethnic community [7,8]. Over a quarter (28%) were unaware of their infection, consequently putting their potential offspring at risk of contracting HIV or becoming unwell [7].

Increasing the uptake of adult HIV testing in high clinical risk populations is paramount in order to identify children at potential risk of perinatal infection. Since the publication of the *UK National Guidelines for HIV Testing 2008* [9], several audits focusing on HIV testing in the adult population, were conducted in the UK and presented at the 15th Annual British HIV Association Conference in 2009. Access to HIV testing and care, delay in test results, and psychosocial circumstances are important issues preventing individuals from undertaking an HIV test [10-12].

UNAIDS has expressed increasing concern about the impact that new legislation on criminalisation and HIV transmission could have on public health [13]. It is generally believed that the criminalisation of HIV transmission could lead to the decline of HIV

testing uptake amongst high-risk population groups. This increases stigma against people living with HIV who, in turn, feel less inclined to discuss their HIV status with sexual partners [13]. The consequences of this recent legislation could particularly affect adolescents with known HIV-positive status, who are more likely to practise high-risk behaviours during sexual intercourse with casual partners and fail to discuss their HIV status [14].

HIV-infected children are surviving from childhood to adulthood with or without HAART. Recent findings from Prime *et al.* identified 38 adolescents diagnosed with HIV to the end of 2005. They were all 13 years of age and above with a median CD4 cell count below 250 cells/mm³ [15]. These children contracted HIV perinatally and survived through childhood to adolescence with no symptoms: 11 of 38 infected adolescents developed an AIDS-defining illness before, or within 2 years, of diagnosis; and 32 of 38 started antiretroviral therapy (HAART) within 1 year of their HIV diagnosis. HIV-infected adolescents are facing new challenges including evolving medical, social and psychological needs [16].

The *UK Guidelines on HIV Testing 2008* [9] have reiterated the importance of testing children of HIV-infected parents regardless of parental gender, age, sexual orientation, and child's age. Asghar *et al.* recently presented interesting data [17]. They audited 542 case notes at an adult HIV specialist centre in London. The study demonstrated that healthcare professionals failed to record any discussion or inquiry about existing children of infected individuals attending the unit in almost half of the cases reviewed [17–19]. In total, 125 children were identified who had not been tested. The conclusion from this is clearly alarming and could be one of the reasons why children in the UK remain undiagnosed. A national survey would be necessary in order to provide evidence on the extent of the problem in the UK and Ireland.

Healthcare professionals involved in the care of current and newly diagnosed HIV-positive adults should really consider asking questions about existing children living within or outside the UK. This crucial information can be recorded and discussion about the need for testing the child initiated. Where specialist services are available, referrals should be considered when dealing with more complex situations. The main objective is to keep the family engaged with specialist services in order to reach a final agreement on testing the child for HIV.

A local audit targeted 324 medical practitioners in a wide range of medical settings in a UK teaching hospital [10]. Mitchell and co-workers highlighted the poor knowledge of existing HIV testing guidelines in 67% of respondents and only 36% of the practitioners felt confident with the HIV testing process. The majority of doctors (57.5%) underestimated the extent of undiagnosed HIV in

the UK and Ireland and 60% had concerns around pre-test discussions. This emphasises the importance of education and regular training updates on HIV for healthcare practitioners.

In general, testing children for HIV is relatively straightforward. This is a good opportunity to encourage open discussions about the presence of HIV-positive members within the family and share any concerns within a controlled environment. However, a number of HIV-infected parents do not want to think, or have never thought, about testing their children for HIV. These families usually believe that not testing their children is the best way to protect them or prevent them from getting upset.

Eisenhut [20] presented results from an audit highlighting difficult issues and misconceptions that families encounter when considering testing their child for HIV. From the asymptomatic child to the fear of parental disclosure to the child, many parents underestimated the potential risk for the child to be infected or to become acutely unwell. Most HIV-infected women who took part in the audit believed that their children were unlikely to be infected as they never experienced any health issues. Stigma, guilt and fear of isolation were also reasons amongst parents' responses.

The father of an HIV-positive teenager who was diagnosed many years ago once told me:

I know I should really consider testing my two younger daughters but I do not feel strong enough to face the same stress and fears of having to cope with another HIV-positive child.

This father has not yet tested for HIV and his positive partner does not access any HIV care.

In practice, the fear of having to deal with a new diagnosis and the concerns that emerge from the disclosure of parental infection, as the child gets older, are well established reasons for not testing. Regardless of the medical setting, healthcare professionals need to be confident to approach and reassure families. In situations of parental refusal, negotiation between the two parties should lead to the child being tested, taking into consideration individual medical and psychosocial circumstances.

I am reluctant to test my child as I am worried my wife will take my child and leave me if the test comes back positive.

Healthcare professionals need to be sensitive to the impact a child's positive result could have on family dynamics, particularly if parents are unaware of their own HIV status. Indeed, parents may question the integrity of their relationship and the mother could also be at risk of being rejected by her extended family. A mother with two children seen in clinic once admitted:

I cannot disclose my HIV diagnosis as my family will think I am a prostitute because I have HIV.

Another mother of two older children recently tested positive for HIV following her husband's new diagnosis. As well as dealing with, and accepting, her positive result, the family is facing stress and anxiety whilst the children are in the process of being tested. During one of the multiple sessions with the psychologist, the mother said to her husband:

*I trust myself but I don't trust you any more.
From now on, I know that I am only living for
my daughters.*

These situations remain an exception and give us an idea of how complex testing children for HIV can sometimes be. Appropriate referral to specialised paediatric HIV services, where available, is recommended in these unusual situations.

HIV in children is a preventable disease and HIV-related complications can be avoided as long as families in high-risk population groups are identified and diagnosed early. Therefore, healthcare professionals working with adults in HIV and non-HIV care settings across the UK and Ireland should strongly consider discussing and performing HIV testing. Discussions about the HIV status of existing children are crucial and will enable identification of those who remain undiagnosed. Appropriate referral to paediatric services is recommended.

The Children's HIV Association (CHIVA) is currently updating national guidelines to support any healthcare professionals working with adults or children in primary, secondary and tertiary care settings with the process of testing children for HIV [21].

The UK National Guidelines for HIV Testing 2008 [9] reinforce the fact that:

It is within the competence of all clinicians and appropriately trained healthcare workers to obtain consent and perform an HIV test. There is no need for special counselling skills beyond those required for routine clinical practice.

References

1. Chief Medical Officer. *No time to wait: the importance of early diagnosis of HIV. On the state of the public health: Annual report of the Chief Medical Officer 2003*. Department of Health, London, 2003. Available at www.dh.gov.uk/en/Publicationsandstatistics/Publications/AnnualReports/DH_4086602 (last accessed 14th May 2009).
2. Collaborative HIV Paediatric Study (CHIPS). *Annual Report 2007/8*. May 2008. Available at www.chipscohort.ac.uk/documents/CHIPS_Annual_Report_2007-8.pdf (last accessed 14th May 2009).
3. Wood C, Daniels J, Lyall H *et al*. Don't forget the children: the dangers of undiagnosed HIV infection in children with HIV-positive parents attending adult HIV services. *HIV Med*, 2009, **10** (suppl. 1), Abstract P50.
4. Aldrovandi GM. The natural history of pediatric HIV disease. In: *Pediatric HIV Care*. Cambridge University Press, Cambridge, 2005; pp 111-133.
5. de Ruiter A, Mercey D, Anderson J *et al*. British HIV Association and Children's HIV Association guidelines for the management of HIV infection in pregnant women 2008. *HIV Med*, 2008, **9**, 452-502.
6. Tookey P. The UK epidemiology of undiagnosed HIV infection in children. BHIVA/CHIVA Consensus Conference 'Don't Forget the Children'. London, 2008.
7. Health Protection Agency. *HIV in the United Kingdom. 2008*. Available at www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1227515299695?p=1158945066450 (last accessed 14th May 2009).
8. Apea V, Khan P, A De Masi *et al*. Newly diagnosed HIV infection in an inner London genito-urinary medicine (GUM) clinic. *HIV Med*, 2009, **10** (suppl. 1), Abstr. P13.
9. BHIVA, BASHH, BIS. *UK National Guidelines for HIV Testing 2008*. BHIVA, London, 2008. Available at www.bhiva.org/cms1222621.asp (last accessed 14th May 2009).
10. Mitchell L, Bushby S, Chauhan M. An audit of current HIV testing practices and awareness of the UK National Guidelines for HIV Testing 2008 among doctors working in a UK teaching hospital. *HIV Med*, 2009, **10** (suppl. 1), Abstr. P91.
11. Premchand N, Golds K, Ong ELC. Diagnosing the undiagnosed: the real world experience from a northeast England regional infectious diseases Unit. *HIV Med*, 2009, **10** (suppl. 1), Abstr. P93.
12. Welz T, Hamzah L, Moses S *et al*. Positive HIV tests in a South London hospital: who did the test and what happened next? *HIV Med*, 2009, **10** (suppl. 1), Abstr. P101.
13. Elliot R. Criminal Law, Public Health and HIV Transmission: A Policy Options Paper, UNAIDS, Geneva, 2002. Available at http://data.unaids.org/publications/IRC-pub02/JC733-CriminalLaw_en.pdf (last accessed 14th May 2009).
14. Ferrand R, Kirkpatrick E, de Esteban N *et al*. Sexual behaviour of HIV-infected adolescents in the UK. *Eighth International Congress on Drug Therapy in HIV Infection (HIV8)*. Glasgow, 2006. Abstr. 262.
15. Judd A, Ferrand R, Jungmann E *et al*. Late presentation of vertically transmitted HIV infection in adolescence. Presentation at the BHIVA Autumn Conference, CHIVA Parallel Sessions. London, 2008. Available at www.chiva.org.uk/news/chivaoct08/presentations/pdf/k-primeoctoct08.ppt.pdf (last accessed 14th May 2009).
16. Gibb DM, Duong T, Tookey PA *et al*. Decline in mortality, AIDS, and hospital admissions in perinatally HIV-1 infected children in the United Kingdom and Ireland. *BMJ*, 2003, **327**, 1019-1024.
17. Asghar US, Young F, Croucher A, Wood C. Do we know the HIV status of our patients' children at our adult HIV unit? *HIV Med*, 2009, **10** (suppl. 1), Abstr. O12.
18. McDonald NM, Anderson P, Winter A *et al*. Documentation and testing of existing children of HIV-positive women. *HIV Med*, 2009, **10** (suppl. 1), Abstr. P94.
19. Schoeman S, Hettarachchai N, Street E. Testing the children: are we diagnosing the undiagnosed? *HIV Med*, 2009, **10** (suppl. 1), Abstr. P60.
20. Eisenhut M, Sharma V, Connan M *et al*. Are children of HIV-infected adults in the UK being tested? Luton Adult HIV Clinic Audit. BHIVA Autumn Conference, CHIVA Parallel Sessions, London, 2008. Available at www.chiva.org.uk/news/chivaoct08/presentations/pdf/m-eisenhutoct08.pdf (last accessed 14th May 2009).
21. Donaghy S. *Testing children for HIV*. Children's HIV Association, London, 2008. Available at www.chiva.org.uk/protocols/index.html (last accessed 14th May).

Correspondence to: Djamel Hamadache, Paediatric Outpatients Department, Chelsea and Westminster Hospital, 369 Fulham Road, London SW10 9NH.
(email: djamel.hamadache@chelwest.nhs.uk)

'People are creating policy up there, they are not coming down'

Nurses' views on the expansion of routine provider-initiated HIV testing and counselling in Nairobi, Kenya

Catrin Evans¹ and Eunice Ndirangu²

¹Lecturer, School of Nursing, Midwifery and Physiotherapy, Nottingham University, UK and

²Lecturer, Advanced Nursing Studies Programme, Aga Khan University, Nairobi, Kenya

Introduction

In this report, we present selected findings from an exploratory piece of qualitative research on HIV testing that was undertaken in 2007–2008 with nurses in Nairobi, Kenya. At the same time, we share our own story of how this research came about and how NHIVNA research funding was able to lay the foundations for a larger study that will hopefully give voice to patients and HIV nurses in Nairobi and will develop HIV nursing research capacity in the country.

Developing a research collaboration

In 2006, Eunice Ndirangu, a BSc-qualified nurse from Kenya won a prestigious scholarship to fund an MSc in the UK. Eunice came to the University of Nottingham and completed her MSc in Advanced Nursing Practice – a programme that Catrin Evans is involved in. When Eunice returned to Kenya, she was quickly offered a job as a lecturer with the Aga Khan University in Nairobi, working on their Advanced Nursing Studies programme. A common problem for nurse-lecturers in Kenya (as in the UK) is that they are heavily drawn into teaching responsibilities and find little time or support for research. In a context of severe human resource shortages, teaching is clearly vital, but there is also a critical need to develop an evidence base for nursing that is context-specific and that addresses questions of relevance to local nursing practice. Catrin and Eunice decided to undertake some research together (funded by a NHIVNA/Boehringer Ingelheim Research Grant), exploring the implications for nurses of the recently announced World Health Organization (WHO) (and national) guidelines promoting the widespread expansion of routine provider-initiated opt-out HIV testing in Kenya [1–3].

Background to routine provider-initiated HIV testing and counselling

In a previous paper, we have described the rationale for, and potential challenges of, routine provider-initiated HIV testing and counselling (PITC) in sub-Saharan Africa [4]. In this region, 89% of the

population has not been tested for HIV. Routine testing aims to increase the numbers of people diagnosed early, minimise morbidity and mortality from AIDS by enabling timely treatment and care, and prevent onward transmission through intensive post-test counselling. The public health rationale for expanded HIV testing seems clear. However, a number of concerns have been raised, focusing primarily on challenges foreseen in the implementation process set within the contexts of human and health service resource shortages and severe social stigma [5]. Key concerns focus on whether/how informed consent, privacy and confidentiality will be upheld in overstretched healthcare settings, and whether appropriate post-test counselling, treatment and support will be provided to all those who need it. Quantitative research demonstrates that routine testing is effective in increasing testing uptake, however qualitative evidence on the implementation process is lacking [6].

In Kenya, nurses are the main providers of HIV-related services and much of the burden of changed HIV testing practice has fallen upon their shoulders. Two studies from Southern Africa indicate that nurses find HIV testing a stressful and difficult job owing to the challenge of supporting patients through an emotionally charged time and feeling unsupported in their work environments [7,8]. Similar research has not yet been carried out in Kenya. Support for nurses is critical in ensuring that expanded HIV testing is carried out in a patient-centred manner.

Research aims and methods

This research set out to explore two questions:

- What are nurses' views on routine provider-initiated HIV testing and counselling (PITC)?
- From a nursing perspective, what are the challenges and facilitators of good practice in implementing routine HIV testing and counselling?

The research aimed to explore nurses' views and experiences of HIV testing from their own perspectives. For this reason, it adopted a qualitative approach [9]. Ethical permission was obtained from the Aga Khan University Research Ethics Committee, the Kenyan Ministry of

Education, Science and Technology and individual hospital ethics committees. The research comprised two focus group discussions and 15 semi-structured interviews with nurses working in government health facilities in and around Nairobi (where routine testing has been in use since 2005). Written, informed consent was obtained from all research participants. The focus group discussions explored general views and attitudes to routine HIV testing whereas the interviews explored nurses' own personal experiences [10]. Of the interviewees, 10 worked on in-patient wards (medical or TB wards), four worked in health centres (of which one was an HIV comprehensive care centre) and one worked as a research nurse on an HIV treatment project. Amongst the focus group participants (n=12), 10 worked on in-patient wards (mainly medical wards) and two worked in health centres (of which one was an HIV comprehensive care centre). The sample was specifically selected in order to reflect a range of different hospitals and health centres. Nurses from nine different hospitals, three health centres and one non-governmental organisation were represented. The sampling strategy means that the findings give a general (and hopefully fairly representative) view from a range of workplaces. The disadvantage of this is that it becomes more difficult to link the findings (and subsequent recommendations) to specific workplace situations or policies. The data were analysed thematically and the key themes were agreed by Catrin and Eunice [11].

In this article, we focus on just one initial theme from the findings: 'nurses' views and attitudes towards routine HIV testing'. Other themes focus on the implementation of routine testing, specifically; 'pre-test process and informed consent', 'post-test support and confidentiality', 'counselling challenges', and 'organisational support' and will be presented in subsequent papers.

Nurses' views and attitudes to routine provider-initiated HIV testing and counselling

Current obstacles to testing

Nurses felt that current low rates of HIV testing were strongly associated with denial (or lack of personalised risk perception), a lack of knowledge or understanding about the availability and accessibility of HIV treatment, and with social stigma. In spite of the fact that treatment and care has become more widely available throughout Nairobi, past experience means that many people still view HIV as a death sentence. In addition, although treatment is theoretically free, it incurs many other costs such as those associated with transport to attend clinic appointments, getting an adequate diet or obtaining associated medical tests. Together, these factors create significant psychological and material barriers to HIV testing:

It's not very easy you see. People fear the outcome, because maybe stigma, and still, why should I know about this disease when there is no treatment? Let me stay with it. I die like everybody else who is suffering from any other disease (P5:16).

An unwillingness or inability to contemplate the potential impact of an HIV diagnosis on a long-standing relationship was cited as another potential barrier to HIV testing. This was particularly the case for women:

So the uncertainties is contributing a lot to people fearing to be tested, especially the married people because they are not sure ... as the day goes by you don't know where your partner is, so you just live by the grace of God that by the end of the day that HIV doesn't come into the house ... we keep on living with that fear (FGD2:3).

Nurses also noted that men in particular were more reluctant to come for testing (and to seek healthcare in general), and felt that a lack of male counsellors may also be a barrier:

It is to do with health seeking behaviour. You won't see a man going to hospital because he has a cold ... so they are not feeling sick and you are telling them to be tested. Also the issue of gender, you find that the hospitals are women dominated – rarely will I go to find a man counsellor (FGD2:7).

The social stigma surrounding HIV was cited as the most significant obstacle to HIV testing. Nurses noted that people are very reluctant to have a test in a clinic in their own locality due to fears over confidentiality. The perceived negative reaction of relatives or partners is another obstacle. The focus group discussions generated a great deal of debate about how nurses themselves contributed to stigma and fear. They noted their own reluctance to get tested and to discuss HIV openly within their communities:

As staff, we need to change our own attitudes towards the testing. I remember there was a time we were just in a session for PITC and I was asking how many of us can go to the VCT we have in the hospital to be tested, and nobody raised their hand. So the question is, if I cannot access the VCT, how do I expect somebody who is a stranger to access it? It shows I have no confidence in the system ... if I cannot believe in it, how can I sell the same policy to somebody else? If I have never been tested, I don't know how it feels to wait anxiously for a result to come through? For us to move, we have to open up. Let us talk not from a point of ignorance but of knowledge. I know my status and this is why I'm attending to you and I can declare it if called upon' (FGD2:2).

In addition, there was an open recognition amongst nurses that, at times, an organisational/professional culture of gossip and judgementalism (directed towards other nurses as well as patients) was contributing to HIV-related stigma and fear of testing:

I also think that the attitude of the health worker ... we have not really improved so much, I think we are also discussing these patients despite saying that we are going to keep the confidentiality. I think it has killed the morale of the community (FGD2:1).

As noted in the quotes above, nurses felt that a first step in addressing these obstacles was for nurses themselves to be supported to face their own HIV risk and to create a professional culture that would support HIV-positive nurses, and uphold confidentiality:

Let it start with us, first we have to kill the stigma within ourselves and within our colleagues...we should just kill that so that we can implement PITC (P15:15).

Potential benefits for routine testing

On the whole, the study participants supported PITC and identified many potential advantages to routine HIV testing. These included the following.

■ Reducing stigma:

I think stigma is reduced, because most patients you see, they get diagnosed and they go back into the community and have seen the importance of testing and treatment. So you find one patient will bring another – and says – ‘if it was not because of this hospital set up and the testing I would have been dead by now’ (P4:17).

■ Normalising HIV and reducing the amount of pre-test counselling that is required:

I think pre-test counselling is a way of stigmatising HIV/AIDS. It is stigmatising the disease because we are treating it as a special case. It is a special disease, you must be protected, you have to do this and this counselling for you to give consent. Consent for what? You would have cancer, it would also kill you and hypertension its going to kill you. If we make it one among many that stigma will come down (FGD2:2).

■ Taking the pressure off the patient. The provider-initiated approach could encourage some patients to discuss their HIV concerns when they may previously have hesitated to speak out:

I think it is a good idea. Before that, a patient would come inside his heart wanting to do the test but just asking would be a problem, so when you come forward and tell them, most of them accept (FGD1:1).

■ Prevention of unnecessary illness and death

■ Enhancing prevention efforts

■ Reducing waiting times due to use of rapid tests

However, in many interviews, nurses stressed that PITC implementation and acceptance required concurrent community awareness-raising events to tackle stigma and a reliable supply of testing kits and antiretroviral treatment to avoid disappointment and disillusionment amongst patients:

Sometimes you do the test, you may not have the drugs...you don't have the nevirapine, you don't have the AZT, you may not even have the septrin to start the babies on – so you find that even now you know their HIV status, so what? It ends there (FGD2:4).

In addition, some nurses reiterated that follow-up care of those with HIV also needed to become more 'normalised' and less segregated, to reduce stigma and to enhance confidentiality:

There are certain cubicles, like if the relatives come and now they know that if you are in that cubicle, you are HIV positive, so even if you tell them all the information, relatives won't want to be tested for HIV because they don't want to be associated with that cubicle...in my place if you are seen going to that pharmacy for HIV drugs then you are scared because of the stigma, so most of them opt not to take the drugs (FGD1:2).

Potential benefits for routine testing

Although there was broad support for PITC, many nurses also expressed reservations and were particularly aware of the potential for PITC to breach human rights. The main concerns were as follows.

■ People may be deterred from seeking care if they know it will involve an HIV test:

Many people would run away from hospitals. They will seek healthcare from other places. Back doors, pharmacies and wrong places (P6:15).

■ Patients may feel pressurised or coerced into having a test:

The patient will look at you like you are the superior and just opt for the test even when they were not really psychologically prepared (FGD1:2).

■ PITC may affect the trust between patient and professional:

Some patients will wonder, why is she telling me to go for an HIV test, what does she think of me? They might think you are judging them when you are not (FGD1:5).

■ Patients need to be able to make an informed decision:

People should be given health education so that you can know the advantages and disadvantages of being tested so they can make an informed decision. You are not forced (P5:17).

- Fears that confidentiality is easily breached, especially in overcrowded ward environments:

Sometimes in our set ups we have patients who have to share beds and the next patient sees the result so I feel at that point we've lost it (FGD1:2).

... In a maternity setting, it is the office that you receive reports, that doubles as a counselling room, that doubles as a discharge room. You know it is everything so it becomes very difficult to say that you can assure privacy and confidentiality (FGD2:3).

- Concern that condensing pre-test counselling fails to adequately prepare patients for a positive result:

In 10 minutes the thing is done...and when they end up positive, you find most of them are not able to cope (FGD1:3).

Nurses noted some resistance amongst staff and also community members when PITC was first introduced in their clinical settings, but most felt that the fears about driving people away from treatment had ultimately been unfounded. None the less, one anecdote reveals that PITC implementation needs careful management:

Yah, when we started the PITC programme, word went around the community that when you go there you are forced to be tested. Though you are not really forced but if it is suggested at every entry point, the people look at it as coercion...so we experienced a decline in the numbers of clients that we were receiving, especially the children (FGD2:4).

In sum, nurses gave PITC a cautious welcome, but their own experiences gave rise to considerable caution about the nature of its implementation.

Nursing roles and HIV policy implementation

A very strong theme that emerged from the findings (particularly from the focus group discussions) was the way in which nurses felt disempowered, characterising themselves as the objects rather than the agents of HIV policy-making:

If you look at all the programme implementation, anything on HIV, it ends up with the nurse. If the nurse does not implement, then the whole programme falls back. But if you look at who is being rewarded for that particular programme, the nurse is at the back, so you see there is a lot of de-motivation and if a new programme comes it is received with a lot of negativity because it is an increase in their work load. Somebody is going to be funded for that programme, they are going to have their papers well done because of that programme, yet it is the effort and the sweat of a certain nurse who did the hard work, yet they are not recognised (FGD2: 6).

Thus, on one hand, PITC was welcomed for its potential to tackle HIV transmission and care, but on the other, it was seen as yet another example where nurses felt that their own role in policy/service development and implementation was being overlooked:

I would say that so long as our state policy shall continue to be formulated in ivory towers, and the nurses and the patients, the consumers, are never involved – we shall continue to suffer. So long as people come there and they sit in Grand Regency, sit in Intercontinental and they say, now, let us introduce a new program ... but we are not going to be down there to see this nurse who has seventy patients. People are creating policy up there, they are not coming down (FG1:4).

Nurses complained strongly about a lack of recognition of their expertise and of their hard work, and complained that sponsored programmes were creating a target-driven culture:

Like when you have the donors who maybe funded the training, they also want their numbers to justify the money for the training. So you find that they are pressurizing the staff such that you are no longer interested in the patient welfare and this has been really a complaint from many health workers. Such that you are given numbers – if you do not test this many numbers then you are a failure...and the providers are wondering where this 50 will come from, if we coerce these patients to be tested then we are going to sound a scaring alarm to most of them who are coming around and they won't even come. And then it won't be provider-initiated, it will be provider-coercion (FGD2:5).

A target-driven approach to PITC seemed to be operating in a number of different health facilities. The strict monitoring of testing targets within a hierarchical organisational structure led to nurses feeling pressured to emphasise quantity over quality and to spend precious time on administration:

Okay one of the challenges we as nurses we also face in terms of HIV is that we are judged by the number of clients we see but not with the quality of work ... because if you see all those mothers at the PMTCT they will be very happy when they come for the supervisory visit but they will not bother to find out the quality of work you did with each client ... And then – reporting – you come at the end of the month and you find that the whole table is full of papers, books – if you miss to fill one copy like this, somebody comes on your neck the next day and says that you are late for this or that report – what – so you find the nurse is overwhelmed and the nurse is doing

the work of the clinician, the doctor, the clerk, and even a counsellor ... You have been saying that the nurse is the backbone but it is coming to a time when the backbone is breaking so someone needs to recognise that (FGD2:3).

As the above quote illustrates, some nurses expressed a sense of burnout, overwhelmed with the quantity and complexity of the work they were being expected to do. This attitude was in marked contrast to that of the few interviewees who were lucky enough to work in supportive environments where they had been encouraged to develop autonomous roles:

It was a new role for nursing, which when I look at critically had also been the missing link in assisting our patients to understand HIV/AIDS at an early stage. Other nurses felt it was an added burden to them and were afraid of giving the wrong results. But I felt that at least as a nurse, I had ownership of HIV patients because my opinions on management and treatment were highly regarded (P1:1).

The above example was unusual, however. Nurses commented that there was little incentive to take on additional roles when these were not recognised, and noted that they also faced resistance from doctors or clinical officers in taking on additional diagnostic responsibilities:

Even when it comes to doing PITC, if you are trained and the other nurse counsellor is not there, you are not much willing to do it – there is no recognition for it, there are no funds, so you just wait until she comes back (P2:5) ... The doctors feel you are undermining them – there is so much you know, but you are not allowed to practise (P5:9).

In sum, nurses' attitudes to PITC were strongly coloured by the nature of their working environments and those in which they felt they had little control, or where they received little recognition had a negative impact on staff motivation and quality of care.

Conclusion and reflections

These findings support the call for caution in rolling out PITC [12,13]. The Nairobi nurses have identified a similar range of potential advantages and disadvantages as other commentators [5,14]. Their views concur with the 2007 WHO guidelines [3], which stress that PITC should only be implemented alongside efforts to create an 'enabling environment' including community awareness-raising and provision of adequate treatment and follow-up services. The 2007 WHO guidelines [3] also stress the need for staff training. Interestingly, these guidelines refer to staff as 'health workers' (recognising that different cadres and even lay

people perform HIV testing in different contexts). Use of the generic term 'health workers', however, fails to make explicit the reality that in many countries (as in Kenya) it is primarily nurses who conduct HIV testing, and that the introduction of new testing policies needs to be considered alongside wider professional debates on the development, expansion and recognition of nurses' roles within the wider workforce structure. This study clearly demonstrates that the addition of more and more 'tasks' to nurses' job descriptions without a concurrent attempt to develop professional recognition and autonomy (as well as mechanisms for nurses to participate in policy-making) inevitably leads to dissatisfaction, de-motivation and a task- and target-oriented approach to patient care [16–18].

The findings of this study have been disseminated to selected study participants, nursing leaders, educators and practitioners at two international conferences in East Africa. A further paper (in progress) will outline the complexities of HIV testing from a nursing perspective. However, we have both felt that interviewing nurses about their practice provides only a partial picture of the complexities of delivering HIV care. Moreover, in all of the debates on PITC in sub-Saharan Africa, the patient voice has been singularly absent. For this reason, we are continuing our research collaboration and Eunice has now embarked on a PhD in Nursing at Nottingham University where she will work closely with an established HIV service provider in Kenya to observe everyday practice in PITC and to interview patients about their experiences of the testing process and subsequent follow-up care. The findings from the in-depth follow-up study will hopefully produce recommendations for practice development and material that can be used in PITC training.

Acknowledgements

We are grateful for the support of a NHIVNA/Boehringer Ingelheim Research Grant. Thanks to all the nurses who participated in the study.

References

1. Ministry of Health. *Kenya National HIV/AIDS Strategic Plan 2005/6–2009/10*. National AIDS Control Council, Ministry of Health, Nairobi, Kenya, 2005.
2. National AIDS and STD Control Programme. *Guidelines for HIV Testing in Clinical Settings*. Ministry of Health, Kenya, 2004.
3. WHO/UNAIDS. *Guidance on provider-initiated HIV testing and counselling in health facilities*. World Health Organization, Geneva, 2007. Available at www.who.int/hiv/pub/vct/pitc2007/en/index.html (last accessed 11th May 2009).
4. Evans C, Ndirangu E. The nursing implications of routine provider-initiated HIV testing and counselling in sub-Saharan Africa: a critical review of new policy guidance from WHO/UNAIDS. *Int J Nursing Studies*, 2009, **46**, 723–731.
5. Csete J, Schleifer R, Cohen J. Opt-out testing for HIV in Africa: a caution. *Lancet*, 2004, **363**, 493–494.

6. UNAIDS Reference Group on HIV and Human Rights. *Statement and recommendations on scaling up HIV testing and counselling*. UNAIDS, Geneva, 2007. Available at http://data.unaids.org/pub/ExternalDocument/2007/20070905_rghr_statement_testing_en.pdf (last accessed 11th May 2009).
7. Mavhandu-Mudzusi A, Netshandama V, Dhavhana-Maselesele M. Nurse's experiences of delivering voluntary counselling and testing services for people living with HIV/AIDS in the Vhembe district, Limpopo province, South Africa. *Nursing Health Sci*, 2007, **9**, 254–262.
8. Mkhabela M, Mavundla T, Sukati N. Experiences of nurses working in voluntary counselling and testing services in Swaziland. *J Assoc Nurse AIDS Care*, 2008, **19**, 470–479.
9. Green J, Thorogood N. *Qualitative Methods for Health Research*. Sage, London, 2004.
10. Barbour R. *Doing Focus Groups*. Sage, London, 2007.
11. Silverman D. *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. Sage, London, 1993.
12. Asante A. Scaling up HIV prevention: why routine or mandatory testing is not feasible for sub-Saharan Africa. *Bull World Health Organ*, 2007, **85**, 644–645.
13. Gruskin S, Ahmed S, Ferguson L. Provider-initiated HIV testing and counselling in health facilities: what does this mean for the health and human rights of pregnant women? *Dev World Bioethics*, 2008, **8**, 23–32.
14. Tarantola D. HIV testing: breaking the deadly cycle. *Health Human Rights*, 2005, **8**, 37–41.
15. Holzemer B. Building a qualified global health workforce. *Int Nursing Rev*, 2008, **55**, 241–242.
16. Rennie S, Behets F. Desperately seeking targets: the ethics of routine HIV testing in low income countries. *Bull World Health Organ*, 2006, **84**, 1–11.
17. Rohleder P, Schwartz L. 'What I've noticed is that they need the stats': Lay HIV counsellor's reports of working in a task-oriented health care system. *AIDS Care*, 2005, **17**, 397–406.

Correspondence to: Catrin Evans,
Lecturer, School of Nursing, Midwifery and
Physiotherapy, Nottingham University, B Floor,
Queens Medical Centre,
Nottingham, NG7 2UH, UK.
(email: catrin.evans@nottingham.ac.uk)

HIV nursing in Poland

Barbara Daniluk-Kula

National AIDS Centre, Warsaw, Poland

Since the beginning of the HIV epidemic, incidence and prevalence in Poland have remained at stable levels and, so far, HIV has been kept under control. The very first case of HIV infection was seen in Poland in 1985, and the first case of AIDS 1 year later. Up to the end of 2008, HIV has been diagnosed in 12,068 Polish citizens, 2189 cases of AIDS have been noted, and 962 people have died. In addition, at the end of 2008, 3822 patients were receiving antiretroviral treatment, which included 117 children. HIV patients are treated in 18 reference units (hospitals) around the country.

People living with HIV (PLHIV), and admitted to the Warsaw Hospital for Infectious Diseases, are currently dispersed to all wards. HIV-positive patients are not isolated in any way and are treated no differently from those who are HIV-negative. In Poland, medical personnel are responsible for their own and their patients' safety and are obliged to treat all patients as potentially infected with HIV. This is a far cry from the early days of the epidemic. In 1985, the hospital was asked to prepare a place for the first Polish HIV-positive patient. The woman had come back from her job abroad and was directed to the hospital straight from the international Okecie airport, accompanied by her luggage. The nurses had been asked to turn a ward into a room exclusively for her use. All furniture and equipment was taken out, the ward was disinfected and only the most necessary items were returned. The patient was given new personal belongings, such as cutlery and towels for

her use only, and all these items were cleaned and disinfected individually. She had a separate WC and a shower, again for her personal use, and she was not allowed to leave her room or be in contact with any other patients. At the time, everyone, including the medical staff, was frightened of HIV transmission.

These days, a relatively large group of HIV patients are regularly treated at the same Warsaw hospital. Over time, patients have made friends with one another and formed a strong social group. This mutual support has had a very beneficial influence on patients' psychological states and also on the outcome of the treatment. It also ensures that nobody living with HIV feels lonely or isolated at this hospital.

Unfortunately, there are still sometimes acts of discrimination, usually by HIV-negative patients, which are a sad result of the low level of common knowledge about HIV in Poland. Generally, however, over the last 10 years, problems from stigma and discrimination have been reducing. For example, in the early 1990s, the priest Arkadiusz Nowak was unable to establish hospices for people with AIDS because there was such strong opposition on the part of local populations. Medical and nursing personnel who took care of HIV-positive patients at this time also had to cope with stigma and often preferred not to state accurately where they worked, or in which ward of the hospital. This situation can be contrasted with the events 10 years later, when, in 2000, a hospice for people with AIDS

was opened in Otwock, near Warsaw, without comment. This positive shift has been brought about by social campaigns launched by, among others, the National AIDS Centre.

The patient profile is also changing. Initially, most patients had acquired HIV through intravenous drug use, but now the majority of patients are men who have sex with men (MSM). More recently, while some patients have also been infected through contaminated blood products, there are now increasing numbers of people being infected via heterosexual sex, confirming that HIV is a problem for all of us.

Treating patients with HIV is not always easy, particularly those who have other serious problems such as drug addiction. Drug use can make a patient's behaviour erratic and nurses can be subjected to abuse. In addition, illegal drug use can lead to serious trouble with the police and judicial system, as well as with criminal associates. Nurses often have to assist patients, especially those in hospices, with these matters, for example, helping patients to answer court summons, and even trying to trace the patient's estranged family and friends.

At the start of the HIV epidemic in the 1980s, Poland was experiencing severe economic and political crises, with martial law, food rationing, very poor supply of goods to shops, and a shortage of even the simplest cleaning items. Surprisingly, during those economically difficult years, as one HIV nurse recalls, medical staff caring for HIV patients always received the best possible equipment, and as much as was needed (much to the envy of colleagues from other specialties). The quality of gloves, bedclothes, and medical utensils designated for HIV patients was always the best. Paradoxically, due to current financial difficulties in the Polish healthcare system, this is no longer the case. Nurses now receive poor-quality equipment in comparison, and do not always feel completely protected while working.

The introduction of antiretroviral therapy (ART) has undoubtedly created a huge change for both patients living with HIV and medical staff. At present, treatment is completely free for any patient who fulfils medical and legal criteria. Post-exposure prophylaxis is also available, considerably reducing anxiety and increasing job security for doctors and

nurses. So far, there has not been a single case of HIV in Poland caused by exposure in a healthcare setting.

Antiretroviral therapy gives patients better quality of life, and greater life expectancy. Patients begin to feel more secure about life, and visit the hospital more often for diagnosis or treatment. Over time, the relationship between nurses and patients develops and flourishes. As nurses observe patients' health improvements, it makes their work easier from the psychological point of view. In the early days of the epidemic, the emotional load for nurses was much heavier when patients were passing away one by one. Nurses note now that their work brings them much more satisfaction.

The success of ART brings with it the need for long-term psychological support for the infected and their families. While the perception of HIV by healthcare professionals has changed greatly over the years – from fear to acceptance, or even viewing HIV as less contagious than, for example, hepatitis C – many myths, false beliefs and prejudices continue to flourish in general society. HIV-positive diagnoses still come as a shock for individuals and their families, and thus, there is a great need for reliable and level-headed HIV and AIDS education that is presented in a friendly environment, and in a caring way. In hospitals, this extra duty usually falls to already overstretched nurses and many do not feel sufficiently prepared to perform this task, as very little training is available. Recently, as part of its activities, the National AIDS Centre conducted 13 elementary-level workshops for 448 medical staff including nurses and midwives. Unfortunately, this was not sufficient to train all those who wished to take part. Updated guidelines for treating patients are also required.

In summary, Polish nurses who take care of HIV patients are very committed to their work and to helping their patients. However, they need more professional support, particularly in those aspects of the epidemic that are uniquely Polish.

Correspondence to: Barbara Daniluk-Kula, _____
National AIDS Centre, Warsaw, Poland.
(email: b.kula@centrum.aids.gov.pl)

Research round-up: focus on testing

Catrin Evans

Lecturer, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

This issue's Research round-up reviews two studies focusing on people's views about routine HIV testing and the experience of being tested. Many of the published studies on this topic (in high-income countries) come from the USA, where routine testing guidelines published by the Centers for Disease Control have been rolled out nationally since 2006 (CDC, 2006). These guidelines recommend routine screening of all patients aged 13–64 years in any healthcare setting. Pre-test counselling and written consent are no longer requirements. A number of studies and clinical audits on HIV testing in the UK were presented at this year's BHIVA conference and have been written up by AIDSMap – published as their *HIV News Update* (April 7th), and available at www.aidsmap.com. For this reason, these very recent UK studies/audits are not presented again here. The final study reviewed looks at our understanding of symptoms in HIV infection.

Hult, J, Maurer S, Moskowitz J. I'm sorry, you're positive: a qualitative study of individual experiences of testing positive for HIV. *AIDS Care*, 2009, 21, 185–188.

This was a longitudinal study that involved multiple interviews over an 18-month period with 50, primarily male, participants. It took place in San Francisco, USA and found that the way in which a positive test result was communicated by health workers left a lasting impact on patients; 14% of the participants commented that obvious judgementalism, distress or anxiety in the health worker had been deeply unsettling and upsetting for them. Conversely, pointing to the possible consequences of a routine testing approach, 6% of the respondents felt that giving a positive test result had become routine for some providers who communicated the result in an impersonal and scripted manner. Other participants, however, described providers who had been empathetic, positive and helpful in giving advice and further guidance. One-third of the sample had felt surprise or disbelief upon receiving the results; 14% had felt severely depressed; 2% felt suicidal and many described typical reactions of extreme shock (dizziness, dry mouth, feeling numb and surreal). Many noted that they could not take in the information that was being given and could not remember what they had been told. A number of respondents (28%) were not surprised, however, as they had been expecting a positive result.

The study demonstrates that providers need to be competent, confident and sensitive to the emotional state of someone receiving a diagnosis such as this. It confirms the importance of training for health workers in

how to break bad news. This training is critical if HIV testing is to be expanded into non-specialist settings. Likewise, the study reinforces the need to rapidly refer people receiving a positive diagnosis to a specialist centre for follow-up care and counselling, as very little of the initial discussion is likely to be remembered in any depth.

Burrage J, Zimet G, Cox D et al. The Centers for Disease Control and Prevention Revised Recommendations for HIV testing: reactions of women attending community health clinics. *J Assoc Nurses AIDS Care*, 2008, 19, 66–74.

This study explored the reactions to routine HIV testing of women attending community health clinics in urban Indianapolis. Thirty women were interviewed. The majority viewed opt-out screening as an acceptable public health strategy but noted that a prerequisite for this was a sense of trust in the provider and the maintenance of confidentiality. The women stressed the continued need for verbal informed consent. Interestingly, they opposed the elimination of the requirement for pre-test counselling, noting that it would be difficult to make informed choices without adequate information and time for reflection. The women spontaneously raised the need for post-test counselling and support. These findings emphasise the importance of developing a good rapport and trusting relationship with the healthcare provider who is offering HIV testing. It also suggests that further research on the patient experience of HIV testing and of the significance of pre-test counselling may be necessary in order to determine the most appropriate HIV-testing protocols in different clinical areas and with different client groups.

Willard S, Holzemer W, Wantland D et al. Does 'asymptomatic' mean without symptoms for those living with HIV infection? *AIDS Care*, 2009, 21, 322–328.

This study reports the results of a large multinational study conducted by nurse researchers in five countries (USA, Norway, Taiwan, South Africa and Kenya). It challenges the notion that the period between initial seroconversion and the development of AIDS should be classified as 'asymptomatic'. The study surveyed 1,992 HIV-positive people with the following profile: 35% female, 65% male; average age of 42 years; 55% had diagnoses of AIDS; 70% were taking antiretroviral drugs; and 60% had serious comorbidities. The study divided the participants into three groups based on their CD4 cell counts (0–200, 201–350, >350 cells/mm³). The survey asked questions about

the participants' health status and physical/psychological symptoms. After assessing the number of symptoms reported, the study found that there were no significant differences among the three groups, suggesting that symptoms were being experienced at even modest or high CD4 cell counts. The most common symptoms were: fatigue, depression, muscle aches, worry, difficulty concentrating and memory loss. The authors noted that some of these symptoms could occur as isolated problems or as part of many other health conditions. None the less, the findings suggest that nurses should always question their patients about health-related symptoms and symptom management, regardless of CD4 cell counts. In doing so, they may uncover underlying conditions that are reducing their patients' quality of life.

NHIVNA update

Plans are well under way for the **11th Annual Conference** and you should have recently received the second announcement. The conference is being held in Birmingham on 25–26 June and there is still time to register and to let colleagues know of the exciting and packed programme.

This year, we have organised a pre-conference study day, supported by Gilead and BMS, on cardiovascular risk assessment. Initial details have been included with the second announcement. I do hope that you will consider attending this day in addition to the conference. Scholarships are available to assist nurses who are able to attend the pre-conference study day as well as the entire Annual Conference. Further details about this will be sent out shortly. Please see the NHIVNA website (www.nhivna.org) for the latest conference information.

Sadly, both Eileen Nixon and Brenda Mann are resigning from the Executive Committee this summer and, after many years of active contribution, step down at the conference in June. Both Eileen and Brenda have been involved with NHIVNA for many years, latterly with Brenda as Treasurer and Eileen as Competency and Projects officer. Eileen was instrumental in the development of the *HIV Nursing Competencies* and, even before

she manages to escape, her last job on this front is planning an audit of their uptake. However, with resignations come recruitments and we are now entering our first election experience for NHIVNA committee members. Nominations have now closed and the ballot papers will be sent out soon. We plan to announce the new members at the AGM at the June conference.

We shall also be unveiling our new weblearning project at the AGM. This is a very exciting online learning tool for nurses working in, or interested in, HIV.

We continue to need your help with contributing to the website. We are keen to receive submissions of protocols/guidelines that you may think could be of use to other colleagues. We would also like to hear of your 'Competencies experience' – how using the competencies has impacted on your practice; changed attitudes of management; or how you have interpreted or met the competencies. All NHIVNA communication should be sent to jacqueline@mediscript.ltd.uk.

Full information on all NHIVNA events is available on the website (www.nhivna.org). We hope to see you in Birmingham for the conference in June.

Sheila Morris, Chair NHIVNA