

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

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

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

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Thirty years of HIV – progress and politics

Ian Hodgson

Independent Consultant HIV Education and Research

Welcome to this edition of *HIV Nursing*. After our long hot UK summer – well, long and damp – the landscape of HIV, and the treatment and care of those who are affected, continues to evolve. Indeed, this year – June 5th, to be precise – marks the 30th anniversary of the first published article describing an increased incidence of *pneumocystis pneumonia* in previously fit young men living in the United States [1]. The rest, as we say, is history – and those of us working in the HIV sector have seen great strides taken in the fight against HIV. We've also witnessed appalling political and social intransigence, in Europe and beyond, contributing to HIV's catastrophic impact on the lives of millions of people.

This was illustrated most recently at the 10th International Conference on AIDS in Asia and the Pacific (ICAAP), held in South Korea during August 2011. Here, there was a violent police crackdown on activists outside the conference venue demonstrating for better access to antiretroviral treatment (ART), and at least one major NGO, the International HIV/AIDS Alliance, suspended its activities at the conference in solidarity with the activists [2].

According to a report released at ICAAP [3], some countries in the region – notably India, Cambodia and Thailand – are significantly reducing their HIV infection rates. However, HIV stigma remains a major barrier to accessing treatment and care for people living with HIV (PLHIV), especially if they are in already stigmatised groups, such as sex workers (SW) or injecting drug users (IDU). Access to ART varies – as the demonstrators at the conference would attest – with Cambodia leading the pack (80% access). Across the Asia-Pacific region, only 60% have access. This is better than some other parts of the world – access in the Russian Federation, for example, is around 20% [4] – but clearly not ideal. For Western Europeans, where ART access is close to universal, it is easy to forget there are large swathes of the world where, for a person with symptomatic HIV, obtaining treatment is by no means certain, and in places highly unlikely.

Another conclusion from ICAAP was that HIV prevention programmes are failing to reach most-at-risk young people, and a significant proportion of new infections in the region are in those under 25. Young people in many regions, especially adolescents, are at particular risk of HIV infection, due to the nature of their developmental stage (experimentation, need for experience, and

disengagement from familial constraints), and poor support from educators and health systems. Young people constitute 41% of all new HIV infections [5].

This edition of *HIV Nursing* includes a focus on issues relating to children and young people. Supporting this group as they become sexually active is a key role for public health services, and CASH Nurse Charlotte Hamilton, using a case study, illustrates some of the approaches and strategies when advising young people about sexuality and sexual health, especially following possible exposure to infection. She emphasises the importance of listening, of avoiding a hectoring approach and of respecting their views rather than enforcing rigidity.

Ensuring appropriate support is available for young people already living with HIV is vital, especially around effective management of disclosure, knowledge about treatment and sexual health. Barnardo's Team Leader Jill Hellings provides details of services available for this group in the north-west of England. Here, emphasis is placed on providing peer networks and information about living with HIV, while offering a safe space for discussing emerging issues such as bullying, and drug and alcohol awareness.

Research is vital to make sure services for children and young people are accurately targeted and age appropriate. Collecting data from this group can be challenging, however, and in an article reflecting on studies from Bangladesh and Myanmar, I look at ethical and logistical issues, especially in such difficult contexts as sex work. Here we are reminded again about the need to appreciate the perspectives of adolescents and young people. What is their world? What are their hopes and fears?

In communities more broadly, information about living with HIV is vital for quality of life, sexual safety and social cohesion. Denise Cummins, a Clinical Nurse Consultant (HIV Disease) based in Australia, describes an intriguing and innovative project where HIV education sessions are provided for PLHIV in rural Nepal. Here, the value of engaging and relevant workshops is clear and, as the paper confirms, positive responses from participants, and the desire for more such events, confirm that relatively small-scale projects like this can have a significant beneficial impact for PLHIV at the community level.

Our final article, staying in the international domain, is a report written by HIV Clinical Nurse Specialist Shena Boyle, who won the NHIVNA and

Gilead HIV Nursing Award 2010. Shena used her award to find out more about South Africa, which included attendance at the 5th South African AIDS Conference, held in Durban earlier this year. Noting the conference theme of 'Leadership, Delivery and Accountability', the report reminds us of the complexity of HIV in the social and treatment contexts – especially in South Africa, still the most severely HIV-affected country on the African continent, and with a history of idiosyncratic (and sometimes downright egregious) policies towards HIV – particularly treatment. This report gives hope that recent political, health system and civil society initiatives may at last provide a more joined-up strategy for tackling HIV.

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

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Reasons to be tearful: what to advise about STI following unprotected sex

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Background

Case study

Sexual health promotion is an important aspect of holistic nursing care. However, nurses find it difficult to discuss sexual health and sexual behaviour with their clients. When dealing with young people, special consideration should be given to sexual health because of their tendency to engage in high-risk behaviour, which increases their vulnerability to sexually transmitted infections and unplanned pregnancy.

Case studies are useful both for their uniqueness and their commonality. I chose this method to learn more about a particular client group whilst retaining the meaningful characteristics of real-life events. [6]. This case study analyses a health promotion opportunity encountered at work recently. I am a contraception and sexual health (CASH) nurse working in a multidisciplinary team, in primary care. The anonymity and confidentiality of this patient will be protected in line with Nursing & Midwifery Council (NMC) guidance [7]. She will be referred to as Ellen, and has allowed me to use her case for this study.

STIs and the young

The highest rates of sexually transmitted infections (STIs) are in those under 25. There are clear inequalities in the sexual health of young people, such as relatively high rates of unintended pregnancies and sexually transmitted infections (excepting HIV). Although people aged 16 to 24 years represent only 12% of the population, they account for nearly half of STIs diagnosed in genito-urinary medicine (GUM) clinics [1]. Young people are more likely to become re-infected with STIs, excepting HIV, than any other group. In 2010 the highest-risk group for HIV new diagnosis was age 30–34, but under-25s accounted for over 1600 new cases [2]. In England, at least 11% of 16- to 19-year-old women and 12% of 16- to 19-year-old men presenting with an acute STI at a GUM clinic will become re-infected with an STI within a year [2]. While targeted policies and services already exist to address these inequalities [such as the National Chlamydia Screening Programme (NCSP) and young persons' drop-in clinics], there is some evidence to suggest that an increased focus on behaviour change could help further reduce inequalities [3]. Adolescents and young people may be particularly vulnerable to confusion about safer sex practices because of interchanging and ambiguous use of terminologies such as 'safe' sex and contraception [4]. It is easy to see that this increased exposure to STIs also results in higher risk of HIV transmission. According to Bekaert [5] the consequences of all STIs are worse for teenagers than the broader population – as they tend to take more risks, attend late for testing and have unrealistic perceptions of their risks. In addition, she says that many young people who are well educated about unprotected sex nevertheless accept the dangers, and that boys are more likely to take risks than girls. [5].

Background

The Department of Health issued guidance setting out the principles of good practice for health professionals when dealing with young sexually active people. These include:

- providing the young person with the time and support to make an informed choice, including exploring whether the relationship is mutually agreed or whether there may be coercion or abuse;
- always encouraging the young person to talk to a parent, carer or another trusted adult;
- identifying any additional counselling or support needs [8].

Under the guidelines laid down by the Law Lord Fraser [8], minors can consent to their own treatment without parental consent where certain conditions are met, such as capacity to understand, encouragement to involve a parent where possible, and treatment being in their best interests [9]. These 'Fraser guidelines' have been incorporated into Department of Health (DH) guidance for health professionals dealing with minors [8].

Sexual health service providers should make it clear to clients that young people under 16 have the same right to confidentiality as adults. However, it should also be explained that confidentiality cannot be absolute if a health professional believes there is a risk to the health, safety or welfare of a young person, or others, that is so serious as to outweigh the young person's right to privacy [8].

The challenges in supporting young people: the story of Ellen

Ellen was a 15-year-old girl who attended a teenagers' drop-in CASH session. She was assessed as competent under the Fraser guidelines. A discussion took place about confidentiality. She was an attractive and articulate girl, but was a little nervous about coming to the clinic. Although petite, she did look her age, and was wearing fashionable clothes and artfully applied make-up.

Having had unprotected sex, Ellen's primary concern was pregnancy. Her sexual history revealed that this was her third-ever sexual partner. She had not consistently used condoms with any of them. She was issued emergency and reliable ongoing contraception. There was a discussion about the many factors surrounding under-age sex. Crucially, Ellen's sexual partners were the same age as her and, although this is still against the law [10], she assured me that she had consented and there had been no pressure or coercion. We discussed delaying further sexual activity but Ellen stated her intention to continue this sexual relationship.

Ellen was asymptomatic for infection. However, in line with our service policy, she was offered opportunistic screening for asymptomatic infections, including chlamydia, gonorrhoea, HIV and syphilis. If symptomatic, she would have been offered extra swab tests (cultures) for *Trichomonas vaginalis*, candida, bacterial vaginosis and for gonorrhoea, so that susceptibility testing could be performed and resistant strains identified [2]. At first Ellen refused outright. She felt she was not personally at risk, and that screening was unnecessary. She did not think her partners were likely to have posed a risk. Many young people distance themselves from the 'type' of person likely to contract a sexually transmitted infection, often citing this as the reason they decline screening, along with anxieties regarding a partner's reaction to diagnosis of an STI [11]. These stereotypical beliefs can adversely affect the uptake of screening, as well as influencing decisions regarding condom use [4].

Approximately 5–10% of sexually active women aged under 24, and of men aged between 20 and 24, may currently be infected with chlamydia. Improved availability of community-based screening for young adults through the NCSP has resulted in more chlamydia diagnoses [2]. Risk factors for this infection include age (under 25 years), more than one sexual partner in the past year (more significantly, a new sexual partner), and lack of consistent use of condoms [12]. Ellen was in all these risk groups, and I explained this to her. Young people also accounted for 50% of all gonorrhoea diagnoses in GUM in 2009 [2].

We had a discussion about different screening methods and their efficacy [12]. Ellen decided to

return for swabs, after the appropriate 'window period' for chlamydia and gonorrhoea, so the tests would be more reliable [12]. She was also offered HIV and syphilis screening in accordance with the UK National Guidelines for HIV Testing [13]. Ellen proved to be negative for gonorrhoea, syphilis and HIV. However she was chlamydia positive.

Although Ellen had tested negative for HIV, it was made clear to her that she must return for repeat HIV screening after 12 weeks, and that a test before then might not be accurate [14]. Although Ellen has not revealed any other high-risk behaviours for HIV, such as contact with a known infected partner, commercial sex work, drug use or risks abroad, she has tested positive for another sexual infection. This is a strong indicator for HIV screening to be encouraged [12].

Ellen was treated with azithromycin 1 gram as a single dose (taken in the clinic). This is the most effective treatment currently for chlamydia, and has few problems with compliance [14]. Young people are often willing to inform their current partners about positive chlamydia diagnoses, but are more ambivalent about informing their previous partners [15]. Ellen had brought her current sexual partner with her (a patient referral), as we had requested. She had not found it easy to disclose to him her diagnosis, but realised it was necessary for both of them to be treated. According to Duncan *et al* [11], support services should be available, because notification of a partner can cause great anxiety. Ellen's partner was treated and screened for STIs. He was treated without awaiting his results in line with BASHH guidelines [14]. They were both advised to avoid sexual intercourse (of any kind) for 7 days following treatment. They were given a detailed explanation of their condition with particular emphasis on the long-term implications, reinforced by clear, accurate written information [14].

At first, Ellen was reluctant to give the details of her previous sexual contacts. She felt they would 'blame' her, and it would affect her reputation amongst her peers. This fear of stigmatisation is an understandable reaction from her, and one I personally see frequently. However, when we offered to contact her partners anonymously, she agreed to let us have their details, and the process of partner notification was started. Tracing and notifying people who may have had contact with a sexually transmitted infection is a complex and skilled activity. It is a vitally important strategy in the control of sexual infection [15].

Sexual health promotion

Factors that impede young people's decisions to use condoms include ignorance of prevalence of HIV and STIs, ambiguity about contraception and sexual health and difficulty, for women in particular, in negotiating safer sex practices.

Women tend to associate romantic love with unprotected sex, and see unprotected sex as a declaration of trust, so this can influence decisions to practise safer sex [4]. It is important to take this into account, and offer information and support appropriately. Our discussion covered the prevalence of chlamydia amongst young people in our region (almost one-in-14 people aged under 25) [17]. We also talked about the consequences of untreated or repeated sexual infections, and the possible emotional and physical sequelae. Chlamydia is a well established cause of pelvic inflammatory disease leading to infertility, ectopic pregnancy and chronic pain, which are expensive to treat and have major lifetime consequences for the individuals concerned. Chlamydia also causes eye and chest infections in babies born to infected women.

Ellen had not realised the possible complications and felt quite distraught that she could have had chlamydia for some time without realising it, and for even longer had we not offered the opportunistic screening. We spent some time talking it through, offering support, and Ellen was eventually relieved to have been diagnosed and treated.

Outcome and reflection

Health promotion and education remain the cornerstones of STI and HIV prevention through improving public awareness and encouraging safer sexual behaviour – such as consistent condom use and reducing both the numbers and concurrency of sexual partnerships [2]. Ellen had actually been aware of the need for condoms in preventing STIs. However, she felt she was not personally at risk. Although young people may be knowledgeable about STIs, this knowledge does not necessarily influence their perception of the risk, nor does it automatically equate with behavioural changes [4]. Ellen had not been motivated to negotiate condom use with her partners, even though she knew the risks. A desire for intimacy, belief in monogamy, and perceived low risk of STI acquisition all diminish women's motivation to discuss condom use. This is often the case with younger women [4], and is a scenario I see often in clinic. Cook and Bellis [18] carried out research into risk-taking behaviour, using an anonymous self-administered questionnaire. Although it was a limited sample group of 474 people, all students aged 18–59, it demonstrated that risk-taking behaviour was highest amongst young people and, overall, knowledge of risk had no impact on risk-taking behaviours. It was also noted that risk behaviours tend to cluster, particularly if one risk increases the probability of taking another (for example, alcohol use and unprotected sex) [19].

It is sometimes difficult for health workers not to be frustrated by this behaviour trait, but I try to remember that risk-taking behaviours are common

even amongst educated health professionals (such as doctors and nurses who smoke or drink) and to realise that knowledge alone is not the means to behaviour change. Simply giving patients advice to change is often unrewarding and ineffective.

Therefore, I used a 'motivational interviewing' (MI) approach to tackle these issues with Ellen, and encourage behaviour change on her own terms [20]. This more gentle approach focuses on helping these people talk about and resolve their ambivalence, using their own motivation, commitment and energy to do it [21]. We talked through the consequences of unsafe sex, and Ellen's feelings about it. Hearing Ellen voice her own reasons for practising safer sex and using effective contraception was heartening, and gave me optimism for her future health.

Conclusions and recommendation

Consideration of sexual health is an essential element of the care of young people attending contraception and sexual health services. Risk-taking behaviour is highest among young people. To ignore sexual wellbeing and sexual behaviour in the young increases the vulnerability of those who may already be at risk of sexual ill-health. We should bear in mind that knowledge alone is often not enough to bring about behaviour change, especially in this age group. The more gentle approach that has come to be known as 'motivational interviewing' can work well in healthcare where outcomes can be greatly influenced by lifestyle behaviour change.

In my own practice I am frequently required to prescribe emergency contraception, or treatments for sexually transmitted infections. Many of the young people I see are aware of the dangers of unprotected sex but the knowledge alone does not prevent them from taking this risk. I try to be sensitive in my approach, as risk-taking in some form is part of human nature [18]. A guiding principle of MI is to have the client, rather than the counsellor, voice the arguments for change [20]. MI has been shown to promote behaviour change in various healthcare settings and can improve the doctor-patient relationship and the effectiveness of the consultation [21]. Lecturing, persuading and warning do not work with ambivalent people. MI is a skilful clinical style for eliciting from patients their own good motivations for making behaviour changes, in the interests of their own health. Rollnick *et al.* state that, 'It involves guiding more than directing, dancing rather than wrestling, listening at least as much as telling' [21].

Perhaps information alone is not enough in public health campaigns, and more research needs to be carried out to examine attitudes to risk and resistance to behaviour change.

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Supporting young people living with HIV in Greater Manchester

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Introduction

According to the latest National AIDS Trust (NAT) statistics [1], an estimated 86,500 people are living with HIV in the UK. The most recent Collaborative HIV Paediatric Study (CHIPS) figures [2] indicate that, of these, 1645 are children and young people with diagnosed HIV. Any child living within Manchester City – or the nine other Greater Manchester local authorities – is entitled to a specialist, comprehensive care and support package from both medical and social support services. This article reviews services on offer, and looks in particular at Barnardo's own contribution in this field, the Gregory's Place project.

Greater Manchester services

North Manchester General Hospital

Paediatric healthcare and treatment is provided by North Manchester General Hospital (NMGH). There is a dedicated paediatric HIV team including a paediatric nurse specialist, two consultants, a paediatric dietician, pharmacist and physiotherapist – with plans to provide a paediatric psychologist in the near future. NMGH currently provides treatment for 93 children and young people. Half of these are younger than 12, and the gender split across the 93 is around 50/50 (Figure 1). All these children and young people acquired HIV

via vertical transmission, so have been living with HIV since birth.

A weekly family clinic, for young people to attend appointments with their parent/carer, also offers an option for teenagers to see the consultant or specialist nurse privately for age-appropriate support. In September 2011, NMGH starts a Transition Clinic, to provide services to the 14–24-year age group every 3 weeks. This teenage/young adult clinic is designed to bridge the gap between paediatric and adult treatment services, and will be staffed by both paediatric and adult specialist nurses and consultants.

Manchester Centre for Sexual Health

Young adults living with HIV can also attend the young persons' service based at Manchester Centre for Sexual Health. The HIV clinic here runs within the general young persons' clinic and provides a service to under-25s. This fortnightly evening clinic has a dedicated team of one consultant and a specialist nurse, to enable continuity. Around 60 young people are currently attending and, in contrast to NMGH, this client group is mainly young people who have acquired HIV in their late teens/early 20s. Any children of these young people who may be tested and diagnosed within this clinic are then referred on to the paediatric service at NMGH.

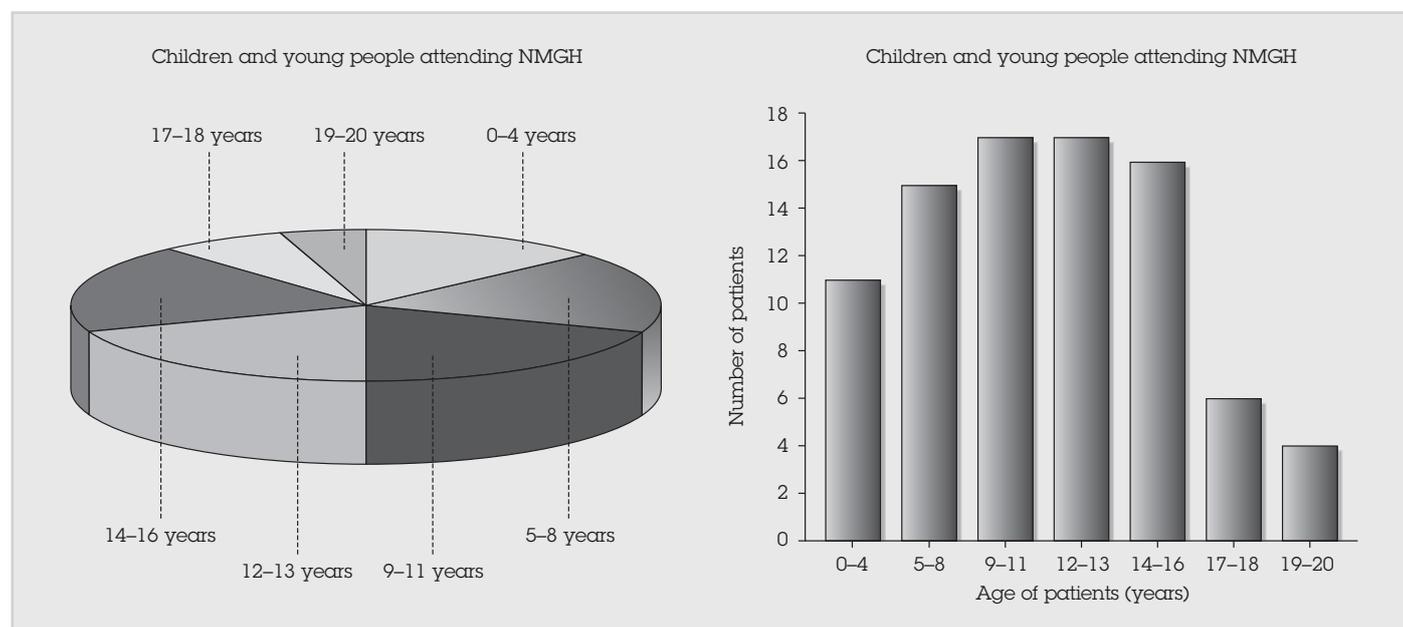


Figure 1: Breakdown in age of children and young people attending for care and support at NMGH (charts and NMGH data kindly provided by Katie Rowson, PSN)

Options for those outside Manchester

There is also a very small number of children and young people within other North West areas (for example, Derbyshire and Lancashire) who are living with HIV, some of whom attend NMGH. Others, however, either access healthcare in adult HIV clinics or in non-HIV-specific paediatric clinics.

Other projects and partnerships

It is clear then that children and young people across Greater Manchester – and some other outlying areas within the North West – have access to a good range of medical, treatment and care services. In addition, these are complemented by a range of holistic, social and emotional support services provided by a specialist Barnardo's project. This project – Gregory's Place – is based close to the city centre and just a couple of doors away from George House Trust (GHT), a large voluntary organisation supporting adults living with HIV. The project delivers services to children, young people and their families, who are living with and affected by HIV. The work is enhanced by the successful partnerships that have been forged with the other Manchester HIV-specific services, and also by the close local links it has with the North West Perinatal and Paediatric HIV Network, and nationally with The Children's HIV Association (CHIVA).

Gregory's Place services

Introduction: The Gregory's Place project social worker attends the NMGH weekly family clinic to offer support, but also available from the project is a range of centre-based and outreach services, including disclosure work, one-to-one sessions and peer support, which are explained below.

Disclosure: The disclosure journey is a daunting prospect for most parents and carers. The Gregory's Place project can assist with preparing the parent/carer for the naming of HIV, and creating a disclosure 'plan'. Parents and carers are given the opportunity to explore worries they may have about their child becoming aware of their HIV status. These worries often arise from guilt about their child being born with HIV, and fears about confidentiality due to children telling people outside the family, or other family members who do not know. However, parental worries are mostly unfounded, as it is unusual for children and young people to lay blame or discuss their HIV status with friends or teachers.

Parents have time to consider the details of the naming of HIV to the child, as follows:

- **Who?** – will this be done by the parent in person, the paediatric specialist nurse (PSN) or the Gregory's Place worker?
- **When?** – will it be at the start of the school holidays? (The timing of school examinations, for example, needs to be kept in mind.)

- **Where?** – will it be at home or at clinic?

There is also the opportunity to consider how the child might respond to the information, and what support they may need after the disclosure has taken place. During the process, all parents/carers are encouraged to keep the dialogue about HIV going and not to simply 'shut down' after HIV has been named – which, unfortunately, is a common experience for children to whom disclosure has been made.

This pre-disclosure work is usually completed over several one-to-one sessions. Sometimes, however, where a number of parents/carers with similar-aged children have been preparing for disclosure, the project has successfully run small group sessions enabling parents/carers to work alongside each other and gain invaluable peer support in the process.

Information: Part of the disclosure plan will be to make sure that the child/young person has access to HIV-specific information very soon after the actual disclosure has taken place. It is very common for children and teenagers to have a wealth of incorrect information about HIV – from the school playground, even from teachers or college tutors. One-to-one sessions are planned to provide information in an accessible, visual and age-appropriate way using a range of interactive materials and tools. Sessions will initially look at the functions and activities of blood, CD4, infections, HIV and medication within the body. They then go on to cover healthy relationships and sex, personal/private information, routes of transmission, rights and responsibilities, and the future. There is also the opportunity to do some 'myth busting' and to challenge stigma and discrimination.

Peer support: Once children and young people are aware of their HIV status and have completed the HIV-specific one-to-one information sessions, they are invited to a peer support group. The project runs three children's/young people's groups. The Children's Peer Support group 'ChiPS' is for younger children aged around 10–13 years – current membership is 11. Then there is the Peer Support Group, 'PSG', which is for teenagers – current membership is 19. There is also the 'A-Team' (A stands, broadly, for 'Affected') for affected teenagers who are aware of HIV within their family – with a current membership of 15. (Affected children and their families can also access a similar range of disclosure support at the Gregory's Place project to that offered to children and young people living with HIV.)

The peer support groups are usually centre-based and provide children and young people with the opportunity to share experiences and spend time in an HIV 'safe space'. Sessions are predominantly HIV focused, with quizzes and games to develop HIV

knowledge, but may also cover general children's and young people's issues – ranging from bullying to drug and alcohol awareness.

Friendship opportunities: In addition to the monthly peer-support groups, young people accessing Gregory's Place services get involved in a variety of other activities. Many of them have been on peer-support group residential events in the Lake District (2005, 2006, 2007 and 2010) for adventure breaks and confidence-building activities. Some have also participated in International HIV projects for young people in Switzerland (2008) and Barcelona (2009), enabling them to learn about their peers' experiences across Europe and make lasting friendships (continued via Facebook). The CHIVA Summer Camps (2010 and 2011) [3] also bring Greater Manchester young people together with around 70 other 13–17-year-olds from across the UK.

Gregory's Place also facilitates an Annual North West Engagement Event, bringing together HIV professionals with young people, to discuss issues away from the clinic setting. Topics explored at past events have included how to improve the way medics communicate with young people and what young people expect and want from transition clinics. A popular constituent of this event is the Expert Panel, comprising adults living with HIV and medics, who answer the many questions that the children and young people have.

Adherence: Recently, the Gregory's Place social worker and NMGH paediatric specialist nurse ran a small adherence group for several young people experiencing problems with adherence. There were weekly sessions (over 5 weeks) where young people explored their own and others' reasons why taking medication is sometimes difficult, with a recap on about how medication works and a self-esteem session. The final session comprised a visit to the NMGH pharmacy and a discussion with the paediatric HIV pharmacist, helping to deconstruct some of the mystery surrounding medication.

Supporting the carers: Vital peer support is on offer via the weekly parent group, for parents and carers living with HIV, and the quarterly PPC (Parents of Positive Children) group for parents and carers of children living with HIV. Throughout the year there are also one-off parenting programmes to enable parents to learn positive parenting strategies and develop confidence in creating effective parenting relationships with their children. A new 5-week course, entitled 'Let's Talk Some More', is due to start in September 2011 and aims to help parents talk more confidently to their children about 'difficult or embarrassing' issues, including puberty and sex.

Conclusion and key points

The value of Gregory's Place can be epitomised in the words of one 17-year old woman living with HIV: 'Since I started seeing my worker [at Barnardo's], my life has changed. Every time we see each other, she helps me build my confidence. She makes me feel great, and safe.'

Over the years, since the launch of Gregory's Place, we have identified key issues to consider when working with children and young people living with, and affected by HIV. Here are just three things to think about next time you are providing a service to a young person living with HIV:

- *Don't leave disclosure too late:* Children should be learning about their health and having their questions answered in an age-appropriate way during primary school. Adolescence – which tends to be a challenging time for all young people – is not the best time to then be told about being HIV positive.
- *Be careful about language and images used to explain HIV:* Children and young people often think far more literally than adults: war imagery – 'goodies and baddies', 'germs' and 'bugs' – can be frightening and uncomfortable for children. In the past, we found some young people thinking of HIV as being purple, because of certain pictures they were shown during their introduction to HIV. Some have thought that they actually have 'bugs' crawling in their blood, and that, because a brand of bleach, 'kills all known germs ... dead', this could be helpful to eradicate the HIV.
- *Remember that peer support is invaluable:* Where possible, give children and young people the opportunity to make contact with others living with HIV – even if it is just once a year at the CHIVA Summer Camp.

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Writing for HIV Nursing

HIV Nursing journal aims to provide a forum for those caring for people infected with and affected by HIV. This year, it has celebrated 10 years of publication by looking at changes in HIV care over the last decade, as well as management in the community, sexual health and youth issues. Readers' contributions are highly valued, and *HIV Nursing* welcomes articles, editorial letters, case reports and other contributions of interest to fellow nurses in HIV care. For information on length and format, please refer to the Author Instructions, available from hivnursing@mediscript.ltd.uk

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What issues are currently affecting your daily life at work? Have any **Newsletter** items caught your eye or raised a comment? You may have something to say about practice innovations, or current HIV issues—or perhaps you could provide a brief review of a recent NHIVNA event?

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6th Annual Conference of the Children's HIV Association (CHIVA)

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Seen and heard: reflecting on two studies exploring the lives of children and young people

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Introduction

November 2009 was the 20th anniversary of the adoption by the United Nations General Assembly of the Convention on the Rights of the Child, an initiative that has transformed the ways in which children are viewed and treated throughout the world [1].

The convention has four principles:

- Non-discrimination, or universality
- Best interests of the child
- Right to life, survival and development
- Respect for the views of the child

Organisations and agencies working to improve the welfare of children face immense challenges promoting health and addressing areas of vulnerability affecting children across the world who continue to experience significant ill-health, malnutrition, abuse and threat [2].

In the context of HIV, there are currently 2.5 million children (under 15) living with HIV, and more than 16 million young people under 18 have lost one or both parents to AIDS [3].

However, it is not only HIV that threatens children today. Other factors – such as poor nutrition, lack of education, child abuse and childhood illnesses where vaccinations are not available – all result in an age group experiencing significant vulnerabilities. According to UNICEF [4], millions of children, particularly in Africa and Asia, lack access to quality healthcare services, micronutrient supplementation, education, improved water sources and sanitation facilities, and adequate shelter.

What are the children's views in all this? This article reflects on two studies undertaken in the last 2 years exploring the experiences of children and young people in specific, vulnerable situations: living with a mother earning income as a sex worker; and being a young person living with HIV. The article provides a selection of findings but also highlights the challenges, and benefits, of hearing the voice of the child or young person: how does the world appear through their eyes? And – for a researcher – what are the ethical imperatives in collecting data from this age group?

Context one: the children of sex workers in Myanmar

Myanmar (Burma) is a country with nearly 50 million people. In Yangon there are an estimated 5000 to 10,000 sex workers [5], with many forced into sex work (SW) for economic reasons – Myanmar is number 138, out of 182, on the human development index [6]. HIV prevalence in Myanmar is around 0.7% (240,000 people) [7], with prevalence in the SW community thought to be dependent on area: the highest prevalence is in Lashio (23.6%), while the rate in Yangon 15.6% [8].

In 2010, a study was undertaken to explore the health and social vulnerabilities facing the children of sex workers in Yangon. A series of interviews and focus groups with children (and their mothers) revealed a number of factors – described by the children – including: loneliness (when their mothers are at work); experiencing stigma because of their mother's occupation; and the importance of school and friendships. Children aged 7–14 were included in the study and, significantly, many were unaware of their mother's work but overheard comments from neighbours and schoolteachers indicating that *something* was distasteful about what their mothers did. Indeed, children had found themselves defending their mothers against negative comments. For one: 'I say to them] my mother is not doing bad things. It is none of your business. When I said that, the neighbour was unhappy.'

The long working hours of sex workers means mothers are often (necessarily) absent, which takes its toll on the children. One comment epitomises their experience: 'I miss my mother when she is out at work.'

Regarding HIV risk, in this context there is no *increased* vulnerability for children, once they are not breastfeeding. However, if a mother is HIV positive, increased likelihood of mortality and morbidity does threaten the lives of her offspring, by proxy.

In addition, this study confirmed that exposure of children to sex work enhanced chances of daughters entering the profession. This risk is confirmed by mothers, both in this study and elsewhere – for example, Ling [9] and Pisani [10]. Under these circumstances, the risk of catching HIV

for daughters and their mothers would increase significantly, given that the higher fee paid by men for unprotected sex is a tempting proposition if economic circumstances are especially dire.

Context two: living with HIV as an adolescent in Zambia

The second study was undertaken during 2010 in Zambia, and explored the experiences, and sexual and reproductive health (SRH) needs of adolescents (aged 10–19) living with HIV. There are approximately 30,000 adolescents living with HIV in Zambia [11], and this qualitative study aimed to explore the psychosocial and SRH needs of this group, by interviewing 116 young people living with HIV in three Zambian regions – Lusaka (urban), Kitwe (urban) and Kalomo (rural).

Similar studies elsewhere have found that this age group are hungry for knowledge (especially around HIV and SRH) [12], require informed and supportive healthcare workers [13] and suffer from poor management of disclosure (of their own status, and their parents' status) [14]. Social networks and family support are both vital [15].

In conducting the Zambia study, the aims were to establish linkage between the needs of adolescents living with HIV, and the capacity of services to meet these needs. Findings were not dissimilar to other studies, and a key quote epitomising many responses is from a 15-year-old boy: 'I think all we need to know is how to live positively as young people growing up with HIV.'

Central to this project was *effective engagement* with, and protection of, participants (who were all aware of their HIV status), and accessing health services where respondents were receiving treatment – in order for the research to establish similarities and contrasts with other studies.

Research with young people: ethics

Ensuring appropriate ethical 'control' over both studies was vital to protect the rights of the respondents. In both studies, activities were in accordance with current guidelines and frameworks for protecting the rights of children, such as guidance endorsed by the International Labour Organization [16] and Save the Children [17]. Given the sensitive nature of this research, the process of data collection was framed around sensitivity, tact, empathy, and ensuring that the respondents' needs were paramount [18]. At times, participants in both studies became distressed, at which point interviews were either terminated and participants returned to their parent or guardian; or continued after a short break if the participants wished.

All potential participants were provided beforehand with an information sheet, written in

their own language and left with them to read or have read out to them by a 'gatekeeper' (a local support worker who confirmed that participants fully understood the nature of the study), or a parent/guardian. Sufficient time was allowed to consider participation, and then an assent form (also in the participant's own language) was given to the parent or guardian for signing. All forms, and related materials identifying participants, were kept securely by the researcher.

Parents/guardians were present during the consenting process with the respondent, and (especially in the cases of younger respondents) usually remained in the building during the interview.

Research with young people: data collection

In both these studies, the views of the child/young person were sought – what was happening in their lives? What did they see and experience? Are there commonalities to apply in other regions and contexts? Both studies confirmed that children and young people are highly sensitive to their environment, solving problems and seeking guidance from social networks, families and experts for dealing with the context and impact of early exposure to situations that many other children never have to face. Children and young people at any age desire support, role models, information for decision-making, and access to education and health services. They also need social protection against potentially threatening situations.

There were lessons learned in both studies about making an environment conducive to collecting data, when working with young people. In Myanmar, we found children were more forthcoming in *groups*, rather than individually – especially the younger participants. We also provided candies and drinks (for children and their mothers) – and these were consumed enthusiastically. We provided drawing materials, asking children to *draw* their schools, homes, friends, as a way of expressing their experiences. This exercise is similar to the 'Body Map Exercise', an effective and well-established tool for participatory group work with children and young people (e.g. [19]) unable to express complex concepts verbally.

In Zambia, where the respondents were generally older, local researchers noted that respondents often misunderstood the questions, or simply had limited knowledge of certain topics – for example, 'contraception'. All children have short attention spans and, in both contexts, respondents are supported and guided to focus on specific topics by utilising different approaches: reshaping questions, drawing, moving to another subject but then returning to the original topic later in the interview.

In addition, in both contexts respondents were at times wary of being overheard, so ensuring privacy was a prime requirement for researchers conducting the interviews, in addition to reinforcing the guarantee of confidentiality and anonymity. Safety and security for all children/young people was paramount in both studies.

Finally, the notion of 'bi-directionality' fits well within this context. A core component of much qualitative research, described eloquently by Aull Davies [20], bi-directionality is where the participant gains benefit from interacting with the researcher. Particularly in the Zambia study, opportunities arose where the respondents asked specific questions for guidance (at the end of the interview), and the researcher was able to direct them to appropriate staff. For the Myanmar study – involving children generally of a younger age group – the experience of being in such a setting was, for some, 'like school' – seen here as a benefit (with crayons, drawing paper, and adults genuinely interested in their wellbeing and 'world').

Conclusion

Both these studies gathered vital data about the world of children and young people. They complied with ethical guidelines for interviewing this age group, and allowed a window onto a landscape where some of their fears, hopes and experiences could be identified and described. The principles here can be applied to similar studies in any context, especially when dealing with such sensitive issues as sexuality, HIV, and potentially threatening domestic circumstances. Children and young people do have views on their lives, and a valid approach is perhaps to consider, when possible, this group as young adults, rather than big children [12]. This is not to deny that there are specific needs unique to this group, but rather to accept that the perspectives of young people and children are a pre-requisite to understanding and appreciating their experiences.

Acknowledgements

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Also, thanks go to the respondents in both studies – without their contribution, the projects would never have been completed.

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HIV education in Nepal: workshops for adults in diverse locations

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Introduction

Nepal is a land-locked country in the Himalayas that experiences civil strife and labour unrest, and is susceptible to natural disaster. It is among the world's poorest and least-developed countries, with almost one-quarter of its population living below the poverty line, and 77% of people living on less than \$2 per day [1].

We have developed and facilitated educational workshops around HIV for various agencies in Nepal over many years. To make logistics easier, we use the internet to organise our volunteer work with local agencies. We provide and exchange knowledge and skills with these agencies, and raise funds to assist participants to attend events, by paying for transport and accommodation.

This article will discuss the outcomes of three 2-day workshops run by Narva Kiran Plus (NKP) for people living with HIV (PLHIV), and peer support workers [2]. NKP was established in 2003 and today is a leading HIV/AIDS service organisation running nine community care centres, providing care and support to over 350 adults and children living with and affected by HIV across the country. In addition, NKP facilitates programmes focusing on children, young people and drug users. We provide ongoing support to this agency, in a voluntary capacity.

HIV and AIDS in Nepal

Since Nepal's first case of AIDS was reported in 1988, the HIV epidemic has evolved from a 'low prevalence' to a 'concentrated epidemic'. The estimated adult HIV prevalence is 0.4%, but among key affected populations this reaches more than 5%. The most at-risk populations are injecting drug users (IDUs), sex workers, men who have sex with men (MSM), migrants and those with sexually transmitted infection (STI) [3].

Most recent estimates of people living with HIV in Nepal suggest that 41% are seasonal labour migrants, 16% are clients of sex workers, and 21% are wives or partners of HIV-positive men. There have been some encouraging trends in HIV prevalence among female sex workers, and this has stabilised at around 2%. HIV has been declining in IDUs, from 51% in 2005 to 34% in 2007. In MSM and returned migrants, prevalence in 2007 was 3.3% and in 2006 1.9% [4].

Women in rural areas are quite vulnerable to HIV infection, contributing factors being low education levels, inferior societal status and difficulties negotiating condom use with spouses returning from overseas work. Large numbers of women are trafficked to work in brothels in India, especially Mumbai. A study indicated that 22–38% of young Nepalese women trafficked to India and returning to Nepal were found to be HIV positive [4].

In the Kathmandu public sector, the national antiretroviral treatment (ART) programme commenced in late in 2004, and currently 13% of PLHIV have access, provided free at 17 different sites spread across the country [4].

Methods

Workshops for NKP were developed and facilitated by two nurses (one HIV specialist, one viral hepatitis specialist) and a social worker, in collaboration with a Nepalese employee of NKP who also worked as the interpreter.

They were held in three locations: Pokhara, Thimura (near Chitwan National Park) and Kathmandu. Two workshops were residential, with participants and facilitators living together.

Evaluation

We had developed written evaluations prior to the workshops, taking into consideration that some participants might be unable to read, or had no experience of the evaluation processes. However, in the field, we found verbal responses more effective, especially when participants were divided into smaller groups, facilitated by the translator. We sought responses on specific issues: what were the key pieces of new information they learnt, and which was the most useful for future use; and which



Figure 1: The workshop locations (Map from *The World Factbook 2009*. Washington, DC: Central Intelligence Agency, 2009. www.cia.gov/library/publications/the-world-factbook/index.html).

sessions were especially beneficial? These, and general comments, were documented – and this approach was incorporated into each workshop.

Workshop outline

The workshops covered many aspects of clinical information and counselling skills related to HIV and hepatitis C (HCV), including:

- HIV issues: challenges in living with HIV and addressing these, advocacy, active listening skills, stages of change, motivational interviewing and visualisation techniques;
- HIV information: viral load, T cells and opportunistic infections, antiretroviral therapy (adherence, resistance and side effects), parent-to-child transmission, serodiscordance, TB and first aid, STIs and 'training the trainer' sessions for condom use;
- Liver information: drug and alcohol use and how to look after your liver.

Results

Most of the 62 participants were HIV positive, with 59 working as peer support workers from HIV agencies or anti-violence NGOs. The workshops are discussed below, by location.

The Pokhara workshop

There were 14 women and 12 men. The women were from an anti-domestic violence group, and the men were either peer support workers or living with HIV. Most had never attended a workshop or training session. None of the women, many of whom were widowed, had ever seen a condom, which supports the UNGASS report stating only 9.7% of migrant men had used condoms with their spouses [4].

The hardest things about living with HIV for attendees arose from the stigma they faced. We learnt that:

- men were unable to apply for jobs overseas due to HIV status, which had led to financial hardship;
- parents were concerned about their children's education, as many HIV-positive children are barred from attending local schools;
- parents were fearful about their children's future: 'that if they became orphans they would be thrown out of their local community.'

They also faced discrimination:

- from treatment allocation policy: single women are given a lower priority for access to antiretroviral treatment, after men and married women;
- and from healthcare workers: one pregnant woman had 'HIV' written on her hand whilst in hospital.

Those attending the workshop appreciated especially the sessions on:

- liver and liver function;
- HCV and alcohol;
- listening skills;
- STIs and condom use;
- T cell counts, viral load and antiretroviral therapy information.

The main challenges of this workshop arose from knowing little about the background of the group prior to contact. The first day of the workshop was a school holiday, and many of the women brought their children, who during the day wandered in and out, distracting the group. As a result, at the end of the first day, we totally revised the next day's outline.

The Thimura workshop

This workshop was held at a rural respite centre, on a river bank opposite the Chitwan National Park. Many local farms and banana plantations surround the site, and there is a small road through the forest and local village, but no public transport access. Participants at the workshop came from local communities, and some were staying longer for respite. As with the first workshop, many had never attended training. Some were peer support workers but most were PLHIV, and there was a local nurse attached to the centre. Many of the participants wanted information about their personal health issues.

When asked about the hardest aspects of living with HIV, responses were varied:

- not being valued in society;
- the stress of living with HIV;
- increased alcohol use associated with stress of being HIV positive;
- poor access to healthcare and health programmes in rural settings;
- disclosure of status;
- transmission of HIV to spouse and children.

Attendees also face significant discrimination:

- from healthcare workers;
- at schools for HIV-positive children;
- from their communities: one woman, when her HIV status became known in her village, was taken to a forest and left alone to live in a cave.

Participants rated specific sessions highly, including:

- parent-to-child transmission;
- viral load information;
- HCV and liver information;
- active listening skills;
- stages of change;
- modes of transmission and STIs.

The participants were keen to apply knowledge gained to their peer support activities, whilst the workshop inspired others to consider taking on a peer support role for the first time.

The challenges of this workshop were the participants' expectations – many thought we were there to do health assessments and provide treatments. Once again, the facilitators' limited knowledge of the group's background was an issue. A few participants were unwell, and we needed to have many breaks during the sessions. The workroom was also our bedroom: sleeping there and then facilitating the workshop, sitting on the hard floor, was physically difficult for some.

The Kathmandu workshop

For this workshop, we co-habited with participants at NKP Hospice on the edge of Kathmandu. Ten women and 12 men attended the event. The women were working as peer support workers and had already attended previous training by the facilitators. Male attendees were younger, and mostly IDU, and for some this was their first workshop. Many confirmed their hope for a healthier life, with improved access to antiretroviral therapy.

For this group, the hardest aspects of living with HIV included:

- sadness due to status;
- poor treatment because of their status and loss of social standing;
- the loss of friendships and loss of contact with relatives;
- the death of husbands;
- discrimination outcomes, including:
 - inequality of treatment – for antiretroviral therapy, men take precedence over women
 - negative experiences of children living with HIV
 - discrimination by healthcare workers.

Participants in Kathmandu especially appreciated a number of sessions, including:

- listening skills;
- antiretroviral therapy updates;
- information on viral load and resistance testing;
- information on HCV and liver care.

Discussion

There were many challenges for this road show. Travelling between workshops over difficult terrain was tiring – it normally takes 8 hours to cover 200 kilometres, due to landslides, breakdowns and waiting in traffic jams on the one-lane highway. The geographical diversity of the three locations, and the impact of local issues, was interesting – especially travelling between an urban environment, a regional lakeside town surrounded

by snow-capped mountains, and a remote rural community living in harmony with wildlife close to the National Park.

In this project, we needed to be highly flexible – for example, children being on site can be distracting, both for their mothers and for the other participants who would become annoyed with constant interruptions. At times, we would ask to send the children out if the information we were covering was sensitive – but then the person accompanying the children would miss the session.

In each case, on the first evening we modified the timetable for the second day of the programme, based on the needs of the group. Each facilitator had varied educational experiences and approaches, and mutual respect for our differences was paramount when agreeing on required changes.

Although we had a western-educated and highly skilled interpreter, there were daily difficulties with translation. Some concepts cannot be translated into Nepali from English – some direct translations of words did not exist. Also, we needed to be mindful of cultural differences and norms. Limited written material was translated into Nepali, and good verbal communication was paramount as many of the participants were illiterate. Our approach to evaluating the workshop was adapted for each context, and eventually we focused on the following: the three most important pieces of information that people would use; what aspects were not useful; and general comments.

Most of the women attendees were illiterate, and none of the women at either of the rural workshops had ever seen a condom. This led to much fun playing with them and doing the 'training the trainer' session. Many were widows, some having been trafficked to brothels in India, and they noted gender discrimination as a key issue.

All the widows had been infected with HIV by their husbands, and one noted: 'My husband had syphilis and then died but it was OK as I have a good life now'. She explained that she was now working in an anti-domestic violence peer support group for women. Another, who was single, stated that she had been unable to access antiretroviral therapy because men, and then married women, have priority. One woman faced discrimination from healthcare workers who wrote 'HIV' on her hand whilst she was in hospital having her baby. Of those who identified as having been trafficked to India for the sex industry – where they became infected with HIV – mental health and adjustment to life back in Nepal with HIV infection were significant issues. Often they do not have access to psychiatric medications, and many women voiced concerns for their children if they became orphans, especially for their daughters.

Another key issue was the use of drugs and alcohol to relieve stresses associated with HIV. Many of



Figure 1: (a) Candles are lit at local shrines, for prayer and reflection. (b) This chef provided food for all the attendees, in very basic conditions.

those infected with HIV from injecting drug use were also hepatitis C positive, and there are currently no treatments for HCV in Nepal. Participants evaluated all sessions relating to HCV and looking after their liver as particularly important and valuable. The use of home-brewed alcohol, 'Roxie', was widespread, and when we facilitated sessions on stages of change and motivational interviewing, much of the small group work related to modifying alcohol intake and behaviour change.

Living with the participants was invaluable. Sharing meals and leisure time gave us opportunities to share many aspects of our lives, and to develop relationships in a short period of time whereby people felt comfortable to disclose issues of importance to them. It allowed us to talk to individuals about personal health issues after the workshop, in privacy. Many of the clinical issues discussed are not seen in our own populations in Australia, so it was an opportunity to revise and increase knowledge on different target populations and clinical issues. Most importantly, it was an opportunity for cultural exchange.

We found that it was essential to have some down time. We had one day off at the end of each workshop to reflect and rest, as it was mentally exhausting running the workshop and dealing with participants' personal issues. Sometimes their stories were shocking and heart-wrenching.

One of our most valuable discoveries was the participants' thirst for knowledge – each workshop was well evaluated, with requests for more training, especially in the rural locations. The sense of community within the peer groups was encouraging. Building relationships and sharing

people's stories was a privilege, noting their personal strength in dealing with the adversities of living with HIV, whilst maintaining hope and a positive outlook.

Conclusion

Providing support and training without being attached to a large HIV/AIDS agency gave us the flexibility to focus on the needs of each group. Although developing the workshops and providing them in Nepal was challenging in many ways, we consider it extremely worthwhile. Positive responses from participants, and the desire for further such events – especially in rural contexts – confirmed that communities also recognise their value.

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NHIVNA and Gilead HIV Nursing Award 2010: a South African experience

Shena Boyle

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Award-winner Shena Boyle shares the insights gained from her attendance at the 5th South African AIDS Conference.

Introduction

In June 2010, at the NHIVNA Annual Conference, I was very privileged to receive the NHIVNA and Gilead HIV Nursing Award 2010 for outstanding contribution to HIV Nursing. I felt extremely honoured to be the recipient of this award and would firstly like to thank NHIVNA and Gilead for making this possible. I would also like to thank my colleagues in Edinburgh for nominating me and for all their help, support and encouragement throughout my 25-plus years working in the field. Last, but certainly not least, I am extremely grateful to all the patients who have so courageously managed their HIV/AIDS and have taught me so much.

The prize enabled me to attend either a national or international conference of my choice and, as I had previously undertaken research entitled 'The Experience of Black Africans attending an Infectious Diseases Unit in Scotland', I decided that the 5th South African AIDS Conference in Durban would provide the opportunity to better understand the effect of the HIV epidemic there. After a 2-week holiday exploring KwaZulu-Natal and trying to gain some knowledge of its history and different cultures, I went to the International Convention Centre in Durban for the conference from 7–10 June 2011.

5th South African AIDS Conference 2011

The theme of this year's conference was Leadership, Delivery and Accountability.

Dr François Venter, Conference Chair and President of the South African HIV Clinicians Society, conducted the first plenary session and official opening ceremony on a very positive note. He addressed approximately 4000 delegates, informing them that, for the first time, the government, researchers and clinicians were working in partnership to fight the HIV/AIDS epidemic. Since April 2010 almost 12 million people had been tested for HIV, the country had more than halved the cost of HIV treatment and 1.4 million

people were on antiretroviral therapy, with the hope that this number would increase to 2.3 million by the end of 2012. Tuberculosis is finally a major focus and TB screening is being carried out in conjunction with HIV testing in some places. The entertainment for the official opening ceremony was provided by the Clermont Community Choir and Jimmy Earl Perry (UNAIDS Goodwill Ambassador for South Africa).

The Nkosi Johnson Memorial Lecture

Mark Heywood, Chair of the UNAIDS Global Reference Group on HIV/AIDS and Human Rights, introduced Mandisa Dlamini, the speaker giving the Nkosi Johnson Memorial Lecture. Back in July 2000, a brave young boy of 11 years, Nkosi Johnson, addressed 10,000 delegates and the media at the Worlds AIDS Conference. He told them that he was HIV positive and pleaded on behalf of all those living with HIV in South Africa for less discrimination, more treatment and better protection and services for infected mothers and babies. Sadly, he died that year, but the fight against HIV continues, and I think he would be very proud to see some of the advances made since that time – but would still be encouraging HIV/AIDS activism.

The 2011 Nkosi Johnson Memorial Lecture was passionately presented by Mandisa Dlamini whose mother was murdered in 1998 when Mandisa was only 13 years old. Gugu Dlamini, a single mother, had been open about her HIV status and had appeared on national television to tell her story – but for this, at a party shortly afterwards, some members of her community dragged her outside, beat her severely and threw her body over a cliff. Mandisa and her mother's boyfriend had to retrieve the body alone because none of the neighbours were willing to help for fear of becoming infected. She recalled feeling that her life had come to an end at this time. At 14 years of age, Mandisa had to work in a tavern to survive and there she was beaten and abused. She was pregnant at 15, gave birth on a Friday and was back in school on the Monday. She told delegates that, in the end, she ran away to Pretoria where she was taken in by a woman who gave her unconditional love, protected her and taught her how to be a strong woman. Unable to fight back the tears, she made a heartfelt plea for the plight of orphans and

vulnerable children to become a priority. Recent statistics show that South Africa has 1.4 million AIDS orphans and 3.25 million orphans in total.

My specific areas of interest at the conference were Prevention of HIV transmission, Treatment, and Social issues, and I focused on attending presentations and viewing posters with these themes. The content of these is outlined below, representing just a few of the topics covered.

Prevention of HIV transmission

Mother-to-child transmission

It was announced at the conference that HIV transmission from mothers to their babies had been slashed to 3.5%, potentially sparing about 67,000 babies from HIV infection [1]. Since April 2010 the South African Health Department has advised that all pregnant women with HIV should be given zidovudine from 14 weeks of pregnancy, plus three antiretroviral drugs during labour (nevirapine, tenofovir and lamivudine). Mothers are started on antiretroviral therapy if their CD4 count is <350 cells/mm³. Newborn babies are given nevirapine syrup for as long as their mothers are breastfeeding them or for 6 weeks if they are not breastfed. It is thought that, by reducing mixed feeding after birth, the transmission rate could be brought down even further.

Medical male circumcision

Medical male circumcision (MMC) has been shown to reduce heterosexually acquired HIV in males by 60%. UNAIDS and the WHO recommend MMC as part of routine HIV prevention in areas with high HIV and low MMC prevalence. A study examining the rapid scale-up of comprehensive, high-quality MMC services found that it can be achieved quickly and safely in urban and rural low-resource, non-medical settings. Efficient use of staff time, facility space and clinical techniques, along with simplified logistics, can treble the number of procedures [2]. It was also suggested that neonatal circumcisions should be increased.

HIV testing and counselling

The South African government has set the ambitious target of testing 15 million persons for HIV infections per year from 2010, as this is seen as a key prevention strategy. These tests are carried out in clinics, workplaces, local communities and hospitals – and a very ambitious project to introduce testing in schools is currently awaiting approval.

Microbicide HIV gel

Recent promising results of a tenofovir-based gel have raised hopes that female-initiated prevention may also soon become viable. This landmark proof-of-concept study by the Centre for the AIDS

Programme of Research in South Africa (CAPRISA) found that the microbicide gel studied reduced HIV infection by 39% and herpes simplex virus-2 infection by 51% and that the gel was both safe and acceptable when used once in 12 hours before sex and once in 12 hours after sex, by women aged 18–40 years [3]. It was recommended that more studies should be carried out to confirm the effectiveness and safety of this gel.

Condoms

The South African government has initiated an extensive free condom distribution programme, providing approximately 2.5 billion male condoms annually from 2010. Female condoms are also distributed, although far fewer due to cost. Schools in South Africa are the only institutions that can reach nearly all youth before they initiate sex: thus HIV education is a mandatory, timetabled and assessed subject for all schools. To this end, the Department of Basic Education has developed its Draft Integrated Strategy on HIV and AIDS 2012–2016.

Treatment

With an HIV prevalence rate of 18%, South Africa has the world's largest antiretroviral therapy programme. The government has put in place large-scale task shifting whereby nurses at primary health clinics are increasingly responsible for initiation and management of antiretroviral therapy. It is hoped to have 2.3 million patients on HIV treatment by the end of 2012. The HPTN052 trial [4], conducted in nine countries including South Africa, proved that people living with HIV and on antiretroviral treatment were much less likely to transmit the virus than those not taking the drugs (triple therapy), thus limiting spread of infection. Eighty per cent of patients in the country taking antiretroviral drugs are still alive 5 years into treatment.

Social issues

'Sangomas' (traditional healers)

These are the traditional healers in the Zulu, Swazi, Xhosa and Ndebele traditions in South Africa. Their holistic and symbolic form of healing is embedded in the beliefs of their culture that ancestors in the afterlife guide and protect the living.

It is estimated that, in some rural communities, around 80% of the population will still seek help from their sangoma before resorting to conventional medicine, with 6.1 traditional healers per 1000 population in contrast to only 0.7 doctors per 1000 population. A poster presentation [5] described a training programme in HIV/AIDS for traditional healers and the development of a referral tool to enable them to refer on to biomedical practitioners. Forty-three traditional healers had already received



Figure 1: Sangomas [image reproduced with kind permission of Andy Rabagliati (www.blog.wizzy.com)].

training and the plan was to extend the project to five more sites in 2011. The presentation concluded that there can be fruitful partnerships between traditional healers and conventional medical practitioners in meeting the challenges posed by HIV/AIDS.

Stigma

A study [6] of 486 clients attending the Foundation for Professional Development clinic described gossip (52.3%), physical assault (16.1%) and physical harassment (15.5%) as the most common experiences of stigma arising out of HIV status. Some clients (10.9%) were also denied sexual and reproductive health rights and a further 6.6% were excluded from family planning services. The researchers concluded that a need exists for wide-reaching programmes to address the stigma experienced within both communities and health services.

Conclusion

The South African government receives financial support from the US government, US charities and the European Union, and it is uncertain whether and for how long these resources can be sustained in the current economic climate. Based on what I heard when working with African patients in Scotland, I believe that South Africa's current government is starting to make significant headway in the fight against HIV/AIDS. There are still many issues to be addressed (multiple concurrent partners, gender inequality, abused orphans and children, poverty, human rights, corruption, same-sex partners and stigma), but South Africa has certainly seen the start of major improvements in the last 5 years.

My thanks again for the award.

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