

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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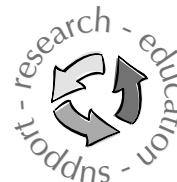
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Aims and Scope

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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Culture, society and HIV: is it a matter of your point of view?

Ian Hodgson

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It should go without saying that an understanding of both culture and context are vital for all meaningful health interventions: 'culture defines much of the world in which people situate themselves and live. If we do not enter and attempt to understand this world, our efforts to convince, change or console others will be ineffective, even harmful' [1]. Medical anthropologists have long separated 'disease' – a pathology identified by 'experts' – from 'illness': an experience defined by the cultural and social contexts in which it emerges. This results in a nexus of beliefs and ideologies about possible sources of the illness, recommended treatments and expected outcomes. In a sense, all illnesses are metaphors, for they absorb and radiate the personalities and social conditions of those who experience symptoms and treatments [2].

In practice, individual experiences of an illness are often lost amid the clamour of disease treatment, mechanics of care delivery or simply a lack of awareness. This issue of *HIV Nursing* focuses on various aspects of the life experience of HIV, and includes a range of articles that represents a holistic perspective, as well as addressing some of the day-to-day, 'real' features of HIV/AIDS.

HIV stigma continues to present people living with HIV/AIDS (PLWHA) with an additional burden. HIV stigma is universal, as potent in areas of low HIV incidence as it is in regions where HIV is endemic – in the latter, there are simply millions more people who are stigmatised. The article '*HIV stigma: where are we now?*' includes a brief review of a recent study investigating HIV stigma as experienced by gay and bisexual men, and members of the African community in the UK. What is evident is the double jeopardy experienced in this context – where groups already at risk of marginalisation face a negative response that is amplified because of their HIV-positive status.

Local and contextual factors in the understanding of HIV, as well as a means to broaden the HIV debate and empower the affected, are discussed in '*HIV and culture: communicating and debating the message*'. Here the author reflects on working for a non-governmental organisation (NGO) based in Thailand, and provides insights into individual and culturally bound perspectives of HIV. The article describes how a Thai/Irish NGO such as Health and Development Networks (HDN) facilitates the dissemination of information and discussion, in

order to maximise awareness and participation in a discourse often dominated by those with the loudest voices – in the case of HIV, often the large inter-government agencies.

In any consideration of culture, it is vital to appreciate the power of belief in shaping perceptions, in particular religious frameworks. As argued by Sara Maitland [3], the re-emergence of religious discourse in public life seems to have caught many of us on the hop. Two articles in this edition of *HIV Nursing* reflect on spirituality and religious viewpoints. Jane Bruton, in the article '*HIV and religion*', suggests that 'religion manages to both help and hinder the fight against HIV/AIDS'. The challenge for health workers is to go beyond our own "position" on religion's role and work with it to promote positive outcomes'. This very succinct statement rightly suggests the positive and negative effects of religion in the context of HIV – the continuing debate around the promotion of the use of condoms and the increasing dominance of the evangelical movement on United States' foreign policy should be of concern to all working in the HIV/AIDS field, and this paper grapples with some of the key features of the debate.

Another, more general, but related discussion is provided in the paper '*How is spirituality constructed and what role does it play in the lives of people living with HIV?*' In the article, Nathaniel Ault teases religion away from spirituality, and suggests that the latter can enable a PLWHA to deal with negative experiences, such as feelings of isolation and rejection, and help the person come to terms with his or her diagnosis. The paper is important for it addresses a topic that, although central to many models of care, is in reality often ignored as insubstantial and irrelevant.

In the more pragmatic article focusing on policy, '*Health tourism and charges for overseas visitors*', Lisa Power debunks the oft-repeated accusation in down-market newspapers that migrants and refugees are travelling to the UK to gain access to antiretrovirals (ARVs). She discusses in some depth the costing of treatments provided for non-UK residents, and concludes that the current system actually discriminates against people travelling to the UK and seeking residence.

This issue of *HIV Nursing* also includes three conference reports. One of these is international: the International Council of Nurses congress, held in

Taiwan on 21–27 May 2005. The report provides an overview of the event, in particular elements relating to HIV/AIDS. Two conferences are national: the 7th National HIV Nurses' Association conference, held on 23–24 June 2005 in Bristol, UK; and the 2nd South African AIDS conference, held on 7–10 June 2005 in Durban. The latter included both controversy and hope, and again raised the influence of context in determining behaviours and beliefs. The apparent ambiguity in comments from the South African Health Minister, Dr Manto Tshabalala-Msimang, regarding appropriate treatments for PLWHA [4] illustrates not only relative perspectives, but also the suggestion of political expediency. The comments also raise a question: in a nation such as the UK where ARVs are freely available, how far should we be critical of countries that may choose less western/rationalist/pharmaceutical approaches to support the millions of PLWHA in their region? Readers will have their views, and while the debate goes on, of course, millions await access to ARVs – a wait that will be

much longer than anticipated in parts of the developing world [5].

'Standing in the shoes' of others is a hackneyed but compelling description of how cultural adeptness in care delivery and health promotion works in practice. Hopefully, this issue will prompt readers who are currently 'shoeless' to at least undo the laces of a new pair.

References

1. Brummelhuis H and Herdt G (eds). *Culture and Sexual Risk: Anthropological Perspectives on AIDS*, Gordon and Breach, Amsterdam, 1995.
2. Farmer, P and Kleinman, A. AIDS as human suffering. *Daedalus*, 1989, **118** (2) 135–140.
3. Maitland, S. Place of enlightenment. *Index on Censorship*, 2004, **4**, 4.
4. Cupido, D. Controversy spreads over 'toxic' AIDS drugs, *The Guardian*, <http://tinyurl.com/7nxdy> (accessed 12 July, 2005).
5. World Health Organization. Progress on global access to antiretroviral therapy: an update on '3x5'. www.who.int/mediacentre/news/releases/2005/pr30/en/index.html (accessed: 12 July, 2005).

HIV and religion

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A woman living with HIV went to church and was told: 'You don't qualify to take holy water'. Another HIV-positive woman wrote: 'This morning I went to church and told to the prayer leader my problem openly and asked him to help me through prayer. They prayed for me. I felt relieved.' These are both quotes from diaries kept by people living with HIV in Ethiopia as part of a research project looking at their experiences of stigma. They show the contradictory impact of religion on HIV, especially in Africa where both religion and the disease are prevalent [1].

The retired Archbishop of Central Africa, the Right Reverend Walter Makhulu, underlines the confusion of these contradictory accounts. He describes the 'strange paradox of religion' he experienced working in Botswana: 'On the one hand you had compassion and a willingness to help those that are living with HIV and AIDS,' – religious communities had set up day care facilities and hospices to feed and care for people with HIV – 'but at the same time there was this very curious censorious attitude, that people get AIDS because they did something evil and they were being punished'. Religion manages both to help and hinder the fight against HIV/AIDS. The challenge for health workers is to go beyond our own 'position' on religion's role and work with it to promote positive outcomes.

A debate has raged in the world of HIV medicine regarding the best approach to HIV prevention. Is it

C (condoms), AB (abstinence and be faithful) or ABC (abstinence, be faithful and use condoms), or the 'radical' strategy of CNN (condoms, needles and negotiation)? We don't have to be reminded of the importance of prevention. In 2004 there were 4.9 million people newly infected with HIV and 3.1 million deaths, bringing the world total of people living with HIV to 39.4 million, the highest number since the beginning of the epidemic [2].

The problem of HIV prevention is multifaceted and cannot be reduced to simply taking the 'right' side in this debate. HIV is a disease of poverty affecting the most vulnerable in society and needs a global response. We know that at a local government level there is not always the political will, or even recognition of the problem, to drive forward prevention campaigns and certainly resources are still lacking. Less than one in five people in the world has access to HIV prevention services [3].

The reality is that this debate is fuelled by religious organisations, particularly the Roman Catholic Church and those in the Bush administration who claim to represent the moral right. They condemn condom use as a mortal sin and warn against the breakdown in sexual morality. The paradox is, this is the same faith that is often the only comfort to an individual living and dying with HIV: 'I went home and prayed to God, the one who never discriminates, and solaced myself,' said one of the Ethiopian women studied [1]; the same faith

organisations tirelessly work helping those with AIDS to survive another day.

But the paradox described by Archbishop Makhulu is costing many lives. The Bush administration's policy has had a material impact on the provision of condoms and prevention advice. First came the reintroduction of the Mexico City policy, or 'global gag rule', in 2001. This barred organisations that receive US international family planning funds from any involvement with abortion. The result: 16 poor countries in Africa, Asia and the Middle East have been cut off from the US Agency for International Development (USAID) condom shipments. In Lesotho alone they had 426,000 condoms donated by USAID between 1998 and 2000, but now they have none [4]. Second, under the US Leadership Against HIV/AIDS, TB and Malaria Act, it was agreed that 33% of HIV prevention funds have to go to 'abstinence until marriage' programmes. Together with the Roman Catholic Church, US politicians have been attempting to undermine confidence in the reliability of condoms suggesting they have microscopic holes through which HIV can pass and other such myths. The debate continued in Bangkok demonstrating more consensus than difference [5].

In November 2004 the *Lancet* entered the fray publishing a consensus statement arguing for HIV prevention to be based on the best available scientific evidence and to put an end to the ideological disputes over HIV prevention programmes. The consensus statement was signed by over 140 HIV/AIDS experts from 36 countries including Archbishop Desmond Tutu, President Museveni of Uganda and representatives of the World Bank and Global Fund. The statement attacked the misinformation from the Catholic Church and US politicians which has undermined condom use and diverted money away from prevention towards abstinence-based approaches. It argues for programmes to contain all three elements (ABC) and to be based on epidemiological evidence, targeting where risk is highest according to the nature of the local epidemic. They acknowledge the importance of accurate information and behaviour change [6]. Despite this statement, a recent report from the Human Rights Watch makes depressing reading. It suggests that the US abstinence-only campaign is being pushed at the highest level in Uganda to the exclusion of the other elements of prevention. Local youth leaders interviewed have said that they do not think this approach is working. However, they know that if abstinence-only is included in a prevention proposal then it will get funded [7].

When addressing the African Bishops at the Vatican in June 2005, although Pope Benedict XVI described the HIV/AIDS epidemic as cruel, he upheld the traditional teachings of the church which he claimed as the only failsafe way to

prevent the spread of HIV/AIDS. He warned that contraception was one of a host of trends contributing to a breakdown in sexual morality. Says Archbishop Makhulu: 'I am sorry if I am harsh with Pope Benedict and his stance but in the end we have to ask ourselves: is moral rectitude the ultimate goal or is human life precious?' He comments that he has met Sisters who were supplying condoms and who were quick to tell him not to tell the Pope. Bishop Makhulu sees this act of defiance as their humanity coming through: 'God isn't going to get worked up - he introduced sex anyway ... this all stems from denial.'

The views of the retired Archbishop are refreshing and based on experience. He believes that denial is the key problem prevalent among governments, those with HIV and their families. He describes the enormous sense of liberation experienced by people when they feel free to talk about HIV and feel a sense of forgiveness. A trip to Uganda highlighted, for him, what it is like when HIV is out in the open: 'They didn't feel the scourge of being seen as evil' he said. The task ahead is to move religion from being censorious to compassionate, from judgemental to caring. The Archbishop described how efforts of religious people have come to the attention of the authorities and in this way may exert some pressure and move governments. He puts the case bluntly: 'If you have a physical condition and you have antibiotics do you deny them? It is as simple as that for me. I feel sorry for people who are burdened with conscience telling people they can't use condoms. The blanket denial of condoms turns millions of people into dishonest people'. For him compassion is the ultimate goal, but he is quick to qualify this as compassion in action. 'It would be a great day when people are liberated and feel free and the sense of shame is removed, so people can live and die in dignity.'

When asked what he would like to see in 5 years time he says: 'Integrity in approach covered by compassion. God wants people to live. I hope and pray that we can be inspired to find a solution to this'. With billions of dollars about to flow into prevention and treatment, it is vital that religion does not get in the way.

References

1. Banteyerga H and Pande R. Experiences of stigma: diaries by people living with HIV and AIDS in Ethiopia. International Center for Research on Women. www.icrw.org (accessed on 18 Jul, 2005).
2. AIDS Epidemic, Dec 2004. *UNAIDS*
3. Report on Global AIDS Epidemic 2004. *UNAIDS*
4. Blummer R. HIV spreads under Bush Africa Policy. *St Petersburg Times*, FL, USA. <http://www.sptimes.com> (accessed on 12 Oct, 2003).
5. Meldrum J. Abstinence debate finds more consensus than difference. Non-aligned Movement (NAM), London, UK. <http://www.aidsmap.com> (accessed on 13 Jul, 2004).
6. Halperin DT, Steiner MJ, Cassell MM *et al*. The time has come for common ground on preventing sexual transmission of HIV. *Lancet*, 2004, **364**, 1913-1914.
7. The less they know the better. Abstinence-only HIV/AIDS programme in Uganda. *Human Rights Watch*, 2005, **17**, 4.

HIV stigma: where are we now?

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Given that this edition of *HIV Nursing* is focusing on cultural and social issues, it seems apposite to revisit HIV stigma. The fact that yet another article is to be written about this apparently intransigent feature of the HIV epidemic confirms that even at this time, over 20 years after HIV became a significant problem facing global health, stigma is as powerful as it ever has been.

HIV stigma has been discussed before in this journal. This article reviews an important study recently carried out by a UK research group, Sigma Research, based in London and the University of Portsmouth, in order to provide additional insights into the complex nature of a phenomenon that simply will not go away. Indeed, postings on an electronic forum (eForum) devoted entirely to discussing HIV stigma, continues to disseminate news reports and member comments that provide evidence for the continuing prevalence of HIV stigma [1].

An inescapable fact is this: HIV stigma is contributing towards the spread of HIV, and the effective monitoring and treatment of the epidemic – for example, it prevents people from being willing to be tested for HIV [2]. In some countries, children are not comfortable with disclosing their HIV status to parents, because ‘their mothers gossip, saying: “I have an evil child in my house who has contracted this disease” [3].

A recent research report published by Sigma Research [4], commissioned by the National AIDS Trust (NAT), London, UK, was released at the beginning of 2005. The report makes shocking reading. According to the lead researchers: ‘HIV-related stigma is deeply embedded in the wider social inequalities such as racism and homophobia that implicate us all. Recognising the way that stigma operates to reinforce power is the first step in addressing and managing it’ [5].

The research comprised 125 people who took part in 20 focus groups. The main inquiry of the research was focused on gay and bisexual men with HIV, African women and African men with HIV because – as the report confirmed – these are the groups that account for the bulk of HIV infection in the UK. The report acknowledges that the selection of this sample, and that undertaking research with this particular tilt, does introduce arbitrary divisions and groupings: perhaps students of research methodology would wish to take this further.

The research findings confirmed that, for these

groups at least, HIV stigma remains a significant part of lived experience, affecting day-to-day living, and the level of integration, if any, with society. In particular:

- HIV stigma – associated with homophobia – in many cases prevents gay men from disclosing their status to their families;
- HIV-positive employees are reluctant to share their status with employers, in case of dismissal;
- Attitudes of the African community, living in the UK, towards African HIV-positive people are very negative, because of an association with immorality;
- Government policy on asylum seekers and immigration can exacerbate stigma and discrimination, by reducing continuous access to local health and social services, especially with regard to dispersal;
- Not disclosing a positive HIV status can have serious, detrimental effects on the individual, and also limit their access to healthcare services.

The experiences described by the respondents emphasised their feelings of being isolated and treated differently. One comment is especially striking: ‘I have a dental problem and I go to this clinic, and I go there two, maybe three times. So eventually I told them about my condition. They explained that I would have to be the last appointment of the day. I have been to that room, and sat on that chair, and the same doctor examined me as before, but after I told them I was HIV positive. So I went for the last appointment of the day last week, they covered the chair, the light, and the doctors were wearing three pairs of gloves.’ (African woman at the African Women’s Group, London, UK) [4].

This report adopts the view that HIV stigma is essentially about power structures, as discussed in other papers [5]. The following statement conveys the perspective of the report and findings succinctly: ‘The experiences of the African respondents show us that HIV-related stigma and discrimination and responses to them depend on the mobilisation of a range of other social and personal factors. HIV infection in itself is not the source of stigma. Rather, stigma works on what a positive diagnosis implies about the person. Stigma operates to maintain power inequalities and to “keep people in their place”. In the case of black African people, HIV stigma depends on underlying racism and xenophobia’ [4].

While the groups participating in this study are

contrasting in many ways, they have both been forced to develop strategies to deal with HIV stigma. For gay and bisexual men, there is a long history of activism and greater personal and/or collective social capital. For African people, with a lower power base and subject – in the case of asylum seekers at least – to government interventions that minimise basic rights, responses have largely come from African people themselves.

The report, while acknowledging the benefits of such a position, also confirms its limitations, and the recommendations from the report are framed around a strategy that calls for the roots of stigma to be addressed primarily, founded on the principle that stigma is essentially a tool for maintaining social inequality. The report includes a number of recommendations for Government and for non-governmental organisations (NGOs) and agencies supporting people living with HIV/AIDS (PLWHA).

For Government, there is a need to review policies for the dispersal of asylum seekers, and a closer collaboration with HIV agencies to ensure those who want to work are able to gain employment. For NGOs and agencies, there must be a careful examination of their practices and policies to ensure there is no residual or institutional racism, homophobia or xenophobia, and there are appropriate mechanisms in place to actually reach the services' users – many respondents in the report commented that being disconnected from HIV agencies increased their feeling of isolation and exacerbated stigma. In addition, the recommendations call for non-HIV organisations – such as the Campaign for Racial Equality (CRE) – to take their part in ensuring that the HIV stigma that arises from inequalities is mitigated by a strong emphasis on individual rights.

To conclude, this study is important in that it adds a vital ingredient to the canon of similar projects. It focuses on the lived experience of social groups that are already at risk of marginalisation, a situation that an HIV-positive diagnosis can only intensify. The alienation and ostracism that arises from HIV stigma and discrimination has been shown to be a universal phenomenon, a fact no country can afford to ignore.

What does this report show us about the current state of HIV stigma? That it remains a method of social control, wielded by societies with rigid rules of inclusion and exclusion, and mores that have narrow definitions of acceptable behaviours. It is, to quote a recent paper, a method of 'social psychological policing' [3], and as such has no place in modern society.

References

1. *Stigma-AIDS*. Managed and moderated by Health and Development Networks (HDN): archives can be viewed at: <http://eforums.healthdev.org/read/?forum=stigma-aids>
2. Nyblade L, Pande R, Mathur S *et al* (ed). *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. International Centre for Research on Women. Washington, DC, USA, 2003.
3. Campbell C, Foulis C-A, Maimane S, and Sibiyi Z. 'I have an evil child in my house': stigma and HIV/AIDS management in a South African community. *Am J Public Health*, 2005, **95**, 808–815.
4. Dodds C, Keogh P, Chime O *et al*. Outsider status: stigma and discrimination experienced by gay men and African people with HIV. *Sigma Research*. www.sigmaresearch.org
5. National AIDS Trust (NAT) Press Release. www.areyouhivprejudiced.co.uk/newsview.aspx?newsid=24 (accessed on 11 Jan, 2005).
6. Parker R and Aggleton P. (2003). HIV and AIDS related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*, 2003, **57**, 13–24.

Health tourism and charges for overseas visitors

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Health tourism has become a hugely controversial issue in the past year, thanks to media coverage and the use of the NHS as a political football in the general election. And HIV, in particular, has been cited repeatedly as a prime area of such abuse of our health system. But what genuine evidence is there for these complaints, and what is the reality of charging for services?

HIV and health tourism were always subjects likely to get entangled because a large part of the recent rises in heterosexual HIV diagnoses are among people infected elsewhere in the world, primarily in sub-Saharan Africa. HIV prejudice and fear have also been frequently misused by anti-immigration

campaigners to attract support. However, just because someone who is diagnosed is from another country originally, does not make them a 'treatment tourist'. The phrase applies to people who have come to the UK solely or primarily in order to access NHS services and what little evidence there is suggests that this is not true for the vast majority of newly diagnosed people with HIV. There is no doubt that some people, usually those who are resourceful and determined to survive, enter the UK after diagnosis because they are aware that if they remain in a country without access to HIV treatments, they will die early. For the majority of migrants with HIV, however, their diagnosis comes late, and as a surprise.

In late 2003, responding to the total lack of evidence for or against HIV treatment of tourists, the Terrence Higgins Trust (THT) and the George House Trust (GHT) undertook a survey of 60 recent migrants who were presented to three of their services (London, Manchester and Birmingham) with HIV-related problems. THT and GHT services were available to these people whatever their immigration status or intent, and so there was no pressure to 'manufacture' an acceptable story.

The survey showed that more than three-quarters of them had waited for nine months or more after entry to the UK before testing; hardly the mark of treatment tourism. In addition, 58% were actively unwell before diagnosis. Only two of the sixty reported knowing their diagnosis before entry and only one person had tested without any external prompting (e.g. antenatal routine, death of a partner, medical intervention). The findings of this survey were from a relatively small sample but, in private discussion, Health Protection Agency staff have confirmed that they correlate well with unpublished data of their own.

Further evidence is provided by national surveillance data, which shows that heterosexuals (of whom around 80% are migrants from sub-Saharan Africa) are diagnosed later than gay men, die more swiftly after diagnosis and have lower CD4 counts on average. Again, these are not the marks of people who are determined to look after their health, even if it means moving to another continent and abandoning their homes and families.

Despite this evidence, in 2004, the Government amended NHS charging regulations for England to remove the right to free treatment of various groups of migrants. Whereas previously there had been a general understanding that anyone who had been in the UK for more than twelve months (and was thus clearly resident, whether or not they were legally recognised) could access free NHS treatment, this was stopped. Additionally, it was clarified that anyone refused asylum or leave to remain was no longer entitled to any new NHS treatment without charge, even when it had been agreed not to remove them from the UK due to prevailing circumstances in their country of origin. Only HIV tests and emergency treatment for life-threatening, opportunistic infections remain free of charge to all.

Ironically, HIV is currently the only sexually transmitted infection (STI) for which such charges can be made. All others are treated free, alongside tuberculosis (TB) and a number of other conditions, on grounds of public health. With many payments' officers newly active within the genitourinary medicine (GUM) setting, and hospital administrations paying renewed attention to charging as a way of managing part of their deficits, clinical staff have found themselves in

some deeply unhelpful situations. THT has seen individuals co-infected with TB and HIV, who need to have both conditions treated simultaneously, absconding from hospital part way through their TB treatment after being handed substantial bills for their HIV treatment. We have also, despite Government assurances to the contrary, witnessed pregnant women being refused antiretrovirals to prevent mother-to-baby transmission of HIV.

This exclusion of HIV from the list of conditions treated free on public-health grounds has been proven, at a hearing of the Parliamentary Select Committee on Health in early 2005, to be neither good for public health nor, in the long run, a cost saving to the public purse. Leaving people untreated means that they are also less likely to be encouraged to maintain safe sex, while having a higher viral load and more likely to be able to pass on the virus. The Committee stated clearly that HIV treatment should be exempted from charges on these grounds, but the minister is yet to respond.

There is now a major national campaign to place HIV alongside other STIs for which treatment is provided free on public-health grounds. The Royal College of Nursing is a signatory, alongside the British Association of Sexual Health and HIV, Citizens Advice and the Medical Foundation for AIDS and Sexual Health (MedFASH). The THT has asked its campaigners to write to their MPs about the problem (<http://www.advocacyonline.net/tht/>) and we are all awaiting the Government's response.

Currently, access to primary care remains free for anyone living in the UK who can actually find a GP with whom they can register. However, this has also been the subject of recent Government attention and a consultation before the General Election had been widely expected to end with recommendations of removal of these rights as well.

In correspondence, Government ministers have defended their position to MPs and voters by saying that it is up to individual clinicians to make decisions about what is, or is not, emergency treatment (such emergency treatment remaining free). However, most hospital administrations are not taking this line and payments' officers are largely enforcing the regulations to the letter. Only the inclusion of HIV in the conditions for which treatment is free can change this. Where is the logic in a system that will treat minor STIs for free on demand, but not the only STI that is still inevitably deadly if untreated? Although HIV is expensive to treat, it is cheaper than ongoing free emergency treatment in intensive care for the opportunistic infections to which the untreated person will undoubtedly succumb, and it is certainly cheaper than ongoing high levels of infectivity helping the virus to spread.

For further information on the campaign to provide free HIV treatment for all, please contact lisa.power@tht.org.uk or yusef.azad@nat.org.uk

Culture and HIV: communicating and debating the message

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The cultural and social aspects of HIV/AIDS are considered here. The author has been working in Chiang Mai, Thailand for much of the last 6 months with a media and advocacy organisation, Health and Development Networks (HDN). The points and comments below are derived from reflections on two factors: working within an international organisation; and the need to ensure a single view of HIV is eschewed in favour of a more eclectic perspective, especially in the context of what is perhaps the most cosmopolitan of infectious diseases.

HDN is a non-governmental organisation (NGO) concerned with advocacy and empowerment, and focuses its work on development-related health issues, primarily HIV/AIDS and tuberculosis (TB) – diseases that tend to track the fault lines of societies [1]. HDN manages and moderates a number of eForums covering a range of subjects, with over 20,000 members, including people living with HIV/AIDS (PLWHA), academics, policy makers, NGOs and advocacy groups. A prime aim of HDN is to mobilise a more effective response to HIV/AIDS and other development-related issues by improving information, communication and the quality of debate.

This sounds grand, of course, but how can one organisation function on behalf of people most affected by HIV, given the multiple interpretations and illness beliefs surrounding the virus? According to Brian Fay [2], when considering culture and perspective, it is important to ask the question: 'Do people in different cultures live in different worlds? Or do they live in the same world differently?' Though this question may feel unduly abstract, it's a vital one when considering the best approaches to take in health promotion and disease prevention. If we adopt the latter approach, although people in different cultures may seem to be in completely different contexts, we actually share a lot more with them than would at first seem.

HIV is clearly an example – one of the few – of a disease that is currently impacting on both the developed and developing worlds in equally devastating ways. There are differences, of course, of scale and social grouping, but essentially there are many similarities. HIV stigma, for example, discussed elsewhere in this edition of *HIV Nursing*, is extremely damaging in whatever context it manifests. Another related feature,

common in many cultural contexts, is personal disempowerment. PLWHA are classified as 'less than' other people, and this negative attitude can manifest anywhere on a behavioural continuum, ranging from avoidance, to physical harm, to murder. In any kind of health intervention, it is vital to understand how the other person understands their (our) world. This enables us to provide focused and sensitive advice that is culturally adept and more likely to lead to a positive outcome than an approach that demands specific responses, more likely to be shaped by our own context and purpose.

In the realm of illness beliefs, it does become more difficult to fully subscribe to Fay's analysis. Cultural perspectives on illness have been a central part of medical anthropology for many years – definitions of the body, the illness 'experience', disease, treatment and who is classed as an 'expert' are often defined by each individual social group, as are the ways bodily disease fits into extant social structures. While the experience of diseases can be similar – symptomatology, for example – there is much more. The human body, according to one writer, 'is the focus of a set of beliefs about its social and psychological significance, its structure and function' [3]. One has only to look at the range of responses to HIV/AIDS across the world to catch a glimpse of this phenomenon, especially with HIV prevention, and the encouragement (or not) of the use of condoms.

In Thailand, HDN engages with local issues by facilitating an eForum, Partners Thailand [4], employing Thai staff to moderate and coordinate the activity. There are challenges. For example, harm reduction for injecting drug users (IDUs) of melding Western and Eastern perspectives of HIV into a meaningful response is a central part of HDN's activity. However, there are challenges; for example, politically, harm reduction for IDUs is much less sophisticated than in the West. Drug use is heavily criminalised in Thailand, and initiatives, such as needle exchanges, are sporadic and have limited government commitment, as confirmed by Paisan Suwannawong of the Thai Drug Users Network in 2004 [5].

Culturally in Thailand, the family is a central locus of societal functioning, and as such, a positive HIV diagnosis for one family member may be assessed in the context of its impact on the family unit; even

if the affected person is a sex worker, where the potential economic effect may supersede moral judgment [6]. NGOs such as HDN must be cognisant of these and other factors that influence the perception and experience of HIV. As illustrations of the need for a flexible perspective, and the role of NGOs such as HDN in widening the debate, two session reports from the 2004 International AIDS Conference in Bangkok are provided here. The reports confirmed that cultural and social responses to HIV are driven more by context than universal beliefs about viruses and pathogens, and illustrate the need for a local response, rather than one driven by an intergovernmental agency in Geneva. The reports were also posted onto the Af-AIDS (a regional e-mail discussion forum on HIV in Africa) HDN eForum [7] soon after the event, allowing access far beyond the confines of the conference.

Report 1

Health promotion and HIV prevention in Africa are always grappling with the imperative of maximum safety balanced with the protection of cultural integrity. In one presentation, a range of traditional sexual practices in Malawi were discussed, that exposed individuals to an increased risk of HIV infection. For example, young girls have to engage in 'removing dust' – their first sexual experience – following a public initiation ceremony. 'Sexual cleansing' is another example, when sex with a 'cleanser' is required following the death of a spouse or child. Clearly both these practices can increase the risk of HIV infection, and local health workers, with the support of traditional healers, developed alternative methods of preserving the sanctity of certain rituals, using traditional medicines. Educational tools were developed based on this new approach, and the result is one in which safety and cultural integrity were protected.

Report 2

Cultural sensitivity must be superseded by essential human rights, especially in the case of vulnerable groups. A presenter from Youth Forum, Zambia presented the most disturbing topic of these sessions, one where cultural relativism – the principle that traditional practices should remain unchanged whenever possible – is indefensible. The speaker alleged there was a 'conspiracy of culture' that contributes towards increased risk of HIV infection in Zambian children. One key example was given: the abuse of a 13-year-old girl by the Paramount Chief, a practice not uncommon in

isolated communities. She developed a sexually transmitted disease, and when the family exposed the cause of her illness, they were stigmatised for being too open. There is also the regular abuse of girls between 3 and 9 years old on the advice of some traditional healers, in order to protect the man from HIV. The session concluded with a deconstruction of the causes of this situation deriving from the lack of legal and policy initiatives. The session emphasised the need to ground the protection of children in Zambia within a strong framework of human rights.

These examples confirm that, to properly understand how people 'see' HIV, it is vital to understand how they make sense of their world: to stand in their shoes. Only then can interventions be properly synchronised with local beliefs. By posting the reports on eForums, a key opportunity is provided for community participation and discussion – a key factor in reducing health inequalities [8]. Differences and similarities of the 'HIV experience' can be addressed, debated and challenged where appropriate.

So, given that a prime aim is empowerment and advocacy, how can HDN claim to 'speak' for the many millions of PLWHA and those affected by the virus, given the multiple interpretations of HIV? It does not try to speak for people – it enables them to speak for themselves. It provides a conduit for discussions and contributions, and empowers individuals to 'speak their world' (the strapline of all HDN eForum postings). The 'world' may seem different to ours, but if Fay is correct, it may be more similar to ours than we think.

References

1. Farmer P. *Infections and Inequalities: the Modern Plagues*. University of California Press, University of California, London, 1999.
2. Fay B. *Contemporary Philosophy of Social Science*. Blackwell Publishing, Oxford, 1996.
3. Helman CG. *Culture, Health and Illness*. Butterworth-Heinemann, Oxford, 1994.
4. HDN eForums. www.hdnet.org (accessed on 18 July 2005).
5. HDN eForum. A turning point for Thai drug users? <http://eforums.healthdev.org/read/messages?id=1585> (accessed on 18 July 2005).
6. Bechtel G and Apakupakul N. AIDS in southern Thailand: stories of krengjai and social conditions. *J Adv Nurs*, 1999, **29**, 471–475.
7. HDN eForum. Standing in their shoes: culture and the context of HIV risk. <http://eforums.healthdev.org/read/messages?id=1804> (accessed on 18 July 2005).
8. Campbell C and Jovchelovitch S. Health, community and development: towards a social psychology of participation. *J Community Appl Soc Psychol*, 2000, **10**, 255–270.

How is spirituality constructed and what role does it play in the lives of people living with HIV?

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Introduction

Working as a nurse within an HIV setting means working with people from varying cultural backgrounds and beliefs. This includes those who differ greatly in their approach to religion and spirituality. Some may seek healing from their deity while others deny any form of overt religious or spiritual belief. This can lead at best to frustration when trying to address spiritual needs within patient care and, at worst, conflict with western approaches to therapeutic interventions within HIV management.

Although research suggests that there is a spiritual aspect to life and everyone has spiritual needs, only some people express these in terms of religion [1]. Indeed, it is argued that we are now faced with a post-modern, 'pick-and-mix' approach to spirituality [2].

A vast amount of research has been carried out in this field, and on its effects on health. Research that relates specifically to HIV suggests that addressing spiritual needs can lead to existential and psychological wellbeing [3–5], relief from symptomology [6] and coping with the medical condition in a better way [7]. These benefits seem to be largely independent of religious denomination [8,9].

However, religious affiliation does not always bring positive effects. Some research suggests that religion can be associated with deleterious effects on health, for example debilitating guilt [10] and refusal of therapy [11], including, in the experience of this author, the use of highly active antiretroviral therapy (HAART).

It has been argued that as nurses we are charged with addressing a patient's spiritual needs since the inception of the National Health Service in 1948 [12]. However, attaining this objective is problematic as an overarching definition that covers all approaches to spirituality is difficult to find [13–15]. Spirituality can be defined from religious, mystic or scientific perspectives, but without apparent definition [11]. Nonetheless, all these definitions have been criticised.

Religious constructs have been criticised for inequality; with deity constructs dominating non-deity [13] constructs, or as constructs about a

dominating male deity [16]. Indeed, religious constructs have also been argued to go as far as blocking spiritual development [17]. In contrast, scientific constructs are criticised for being too mundane and unusable [13].

The aim of this research project, therefore, was to explore how people living with HIV were experiencing and constructing ideas of spirituality and thus identify what role it was playing in their lives. By carrying out this project, it was hoped that a meaning of spirituality within this cohort could be clarified.

Ethical approval was sought and given by both City University and the Harrow Research Ethics Committee.

Methodology

The theoretical framework underpinning this study was constructivist phenomenology. This suggests that multiple constructs of a phenomenon can co-exist within reality [18], which can be seen in the way differing patient cohorts respond to and understand spirituality.

Participant selection

Using primary selection [19], five participants were chosen to reflect a range of spiritual and religious beliefs. The number of participants was also governed by the timescale available for carrying out the research. All participants were HIV positive, diagnosed for at least 1 year, and with no ongoing psychological problems. To aid data interpretation, some demographic details were obtained (see Table 1).

Information sheets were given to each prospective participant and a week was given for them to read the sheets and raise any concerns before giving their consent to take part. A consent form was signed if they chose to participate in the research. The research timetable was then set by the participant, allowing them to choose the time, venue and length of interview. Where participants did not attend on agreed meeting times, it was left to the participant to arrange an appropriate time to prevent a sense of pressure to take part. This was in accordance with guidelines on cultural rigour [20].

Table 1: Demographic details

	Participant A	Participant B	Participant D
Age	31	37	37
Ethnicity	Asian	English	English
Sexuality	Heterosexual	Heterosexual	Gay
Year diagnosed	1999	1988	1998
On HAART?	Yes	No	No
Identified religion	Hindu	None	No
Are you spiritual?	Yes	Yes	Probably

Owing to this procedure, two participants failed to complete the study. An anonymous identifier was allocated to each participant to maintain strict confidentiality throughout the research process.

Ongoing psychological support was available for any participant who felt the interview had raised further issues that required attention.

Interview process

The interview process took the form of an unstructured meeting, exploring the phenomenon of spirituality as experienced by the participant. All interviews were taped with permission, allowing for accurate transcription. Only one predefined question was used within the interview, this being the opening question which was: 'tell me about your experience of spirituality'. At the end of the interview, participants were given the opportunity to say anything they felt they had not had an opportunity to voice during the interview process.

Analysis of data

Data was analysed using Colaizzi's procedural methodology [21] (see Figure 1), with the

1. Reading all the participants' descriptions
2. Extracting significant statements
3. Formulating meanings (hidden and disclosed)
4. Clustering themes for each description
5. Validating the themes for each description
6. Relying on a tolerance for ambiguity
7. Developing an exhaustive description
8. Formulating the exhaustive description into an unequivocal statement of identification of the structure
9. Validating the findings (the structure) with the participants
10. Integrating information from the validation interview into the final description

Figure 1: Colaizzi's procedural methodology.

findings of each step being validated by an independent assessor familiar with phenomenological methodology. This allowed for both qualitative and methodological rigour to be addressed [22].

Findings

There were 104 significant statements identified, which were then grouped under nine theme clusters. These can be seen in Table 2 and illustrated with quotes in Tables 3 and 4.

How spirituality is constructed

The statements supported the idea that people with HIV, like most people in fact, construct spirituality from different viewpoints, which can be both theist and non-theist based [1], suggesting universality and variation (Theme 1). Interestingly, however, both participant B and D used theist and non-theist perspectives at different times.

This suggested that people with HIV can vary their constructs to the point that seemingly incongruous ideas co-exist. This could be argued to illustrate ideas of post-modern 'pick-and-mix' spirituality [2].

A further aspect of the statements showed that for these participants spiritual awareness developed over time (Theme 2). The basics were learnt during childhood and the complexities and nuances understood with the passage of time, with the realisation that it connects all people through rituals or the idea that we can share spirituality with others (Theme 3).

However, interestingly, all participants agreed within their constructs that there was a sense that spiritual connections could be blocked (Theme 4). This was initially seen in those who received their HIV diagnosis, leading to a disconnection

Table 2: Theme clusters

1. Constructs of spirituality are varied
2. Spiritual awareness develops over time
3. Spirituality connects all people
4. Spiritual connections can be blocked
5. Spirituality is an active and dynamic force within peoples lives
6. There is an enhanced sense of spirituality and meaning of life brought on by adversity
7. Spirituality has a sense of journey or mission
8. Spirituality gives various types of support including peace, strength and hope
9. Spirituality guides decision-making and actions which is shown through taking active responsibility in life

Table 3: How is spirituality constructed: themes and illustrative quotes**1. Constructs of spirituality are varied**

'being Hindu or having that religion is a strong sense of doing what you believe is it is right' (A)

'I don't know who God is per se... from what I have read I think it's a presence...' (B)

'my belief is my conscience is my soul' (B)

'it's an ethic.. yeah I was brought up that way... and that sort of goes deep within my psyche. I have a feeling there is some higher power...' (D)

2. Spiritual awareness develops over time

'[my daughter] is very unbelieving and I don't know how to bring that aspect of God and religion and spirituality into her life... she does understand there is a God... but I think she is too young at the moment...' (A)

'but then again I do believe it's something that as you grow older you acquire. You might get the rudiments from your parents' bringing you up through religion... but its something that gets unleashed... sometime...' (B)

3. Spirituality connects all people

'we abide by similar rules like the Catholic Church. A girl has to marry before, and children have to come after, marriage and everything else...' (A)

'I know it's good to be in a room with other spiritual people... 'cos it's like having your batteries recharged... it's a lovely feeling...' (B)

'I get a feeling there's something that binds us all...' (D)

4. Spiritual connections can be blocked

'it [spirituality] was probably not there till later on, 'cos being diagnosed HIV positive was difficult enough as it is...' (A)

'sometimes my guilt is because of the Catholic Church... but there are certain things within my religion which I don't feel are right... genuflecting... praying to Frances of Assisi or even the Virgin Mary... we're made in His likeness... then why shouldn't we be able to contact Him directly..?' (B)

'that's one thing that frustrates me about religion... is this belief that you pray and you actually get cured sort of thing... if there was a loving God he would be curing all and looking after kids in Iraq who had their legs blown off... and certainly He wouldn't be worrying about some little old dear who is praying in some church in Harrow for her husband to get over the flu...' (D)

with their spirituality; but for participants B and D also through religious expressions and their belief that religiosity was seen as hypocritical.

The role of spirituality in people's lives

What was apparent was that for some participants this spirituality was also an active dynamic force which develops over time (Theme 5).

This dynamic relationship helps us to look for answers through conversing or reflecting, provides perceived gifts or blessings, and gives guidance which may or may not be followed, and may therefore lead to existential conflict.

Additionally, this meant that adversity provided these participants with an enhanced sense of spirituality (Theme 6). This was through the challenging of beliefs in existence, in these cases by being diagnosed HIV positive, and facing the prospect of death. However, this process led to a sense of understanding and new beginnings within their lives. This suggests that spirituality within someone's life is not an innate thing that just provides hope, but that it is an active phenomenon

influenced by, and influencing, how a person experiences life.

The statements suggested that the role spirituality played in the lives of these participants was to provide a path or mission in life (Theme 7), which is not predefined, and neither found by chance. This path reflects personal development by challenging both our strengths and weaknesses.

It was also apparent that a sense of spirituality provided support including peace, strength and hope (Theme 8), which helped with dealing with isolation, provided a clearer perspective and validated choices and decisions.

Decision making and actions were also guided by spirituality that could be seen in the sense of honesty and fairness of these actions, and for which participants had a sense of responsibility (Theme 9), showing an ethical dimension.

Discussion

The statements made by the participants suggest that spirituality can be defined as any construct that gave a sense of connection between people and meaning about life; that this develops over time and influences

decisions, actions and choices and, in turn, is influenced by their experiences. It was a dynamic relationship that provided support and validation at times of difficulty and was influenced, moulded and validated by such difficulties. These findings support the work of other researchers, but suggest that such definitions are co-existent rather than mutually exclusive.

What was apparent was that language plays an important part in spirituality. This research raises the argument that current language, used in assessing and discussing spirituality does not encompass all constructs. The 'life ethic' put forward by participant D does not fit theist or non-theist language, thus spiritual language must be inclusive if this ethic were to be elicited in conversation. Further research needs to be carried out in this area.

Additionally, this research did not provide insight into how spirituality affects decisions about beginning and adhering to HAART. For the participants these were not influencing factors; however, anecdotally many nurses working in HIV may argue otherwise. Again, further research exploring this aspect is called for.

Conclusion

Spirituality plays an important role in the lives of people living with HIV. It is both supportive and influential, especially following their HIV diagnosis. It can enable someone to deal and come to terms with their diagnosis. It can assist in combating stress, isolation and rejection that many patients experience and thus help both mental and physical wellbeing.

Table 4: Role spirituality plays: themes and illustrative quotes

5. Spirituality is an active and dynamic force within peoples lives

'it's just a normal thing for me when I am thanking God for letting me go through my day-to-day and this is what I've learnt and this is what I did' (A)

'it's sad 'cos I've turned away from Him... He wants me to go in a particular direction but I haven't got the guts...' (B)

6. There is an enhanced sense of spirituality and meaning of life through adversity

'I think being diagnosed HIV positive has made me appreciate life more as well as understand the whole meaning... and then speaking to God and understanding that I am HIV. You sort of deal with things differently don't you and I want to be reincarnated' (A)

''cos I think HIV is an emotion thing... I know people laugh at me but it wasn't until I was diagnosed and came to terms with it that I became more open and spiritual... I was able to see better for want of a better way of saying it...' (B)

'and then I found myself questioning everything about myself, about the works and the entire ethic came up for review... it was like starting afresh as a baby in a sense...' (D)

7. Spirituality has a sense of journey or mission

'the life that He has given us is for a reason and I am here for a reason and have to understand... find out why I am here... and in return live my life to the full satisfaction and in return He will be satisfied and I will be reincarnated into a better person...' (A)

'I suppose I do feel like the Enterprise... that I am on a mission going places I have never gone before... its like a mission... I am on a mission to gather and send...' (B)

'when I go there may be something left... and I may have contributed to the oneness...' (D)

8. Spirituality gives various types of support including peace, strength and hope

'being HIV positive is a negative point for anyone... but dealing with it and living with and understanding it and putting your negative thoughts into positive beliefs and how you go about it is your spirituality...' (A)

'the both times I fell pregnant I knew... without being blasé or cocky that both my children would be negative... I used my spirituality to bolster that... that positive feeling' (B)

9. Spirituality guides decision-making and actions which is shown through taking active responsibility in life

'there is no good point in telling them [family]... again its plain and simple, black and white... and spirituality does play a role in it...' (A)

'it's [life ethic] about respecting everybody and treating everybody in that way because they are in a sense your brother or sister...' (D)

'you are responsible for your own actions and to a large extent you can decide how to act and need to take responsibility for that...' (D)

References

1. Pattison S. Dumbing down the spirit. *Spirituality in Health Care Contexts*. Orchard H (ed), Jessica Kingsley, London, 2001.
2. Lyall D. Spiritual Institutions?. *Spirituality in Health Care Contexts*. London: Orchard H (ed), Jessica Kingsley, London, 2001.
3. Tuck I, McCain N and Elswick RK. Spirituality and psychosocial factors in persons living with HIV. *J Adv Nurs*, 2001, **33**, 776–783.
4. Coleman CL. Spirituality and sexual orientation: relationship to mental wellbeing and functional health status. *J Adv Nurs*, 2003, **43**, 457–464.
5. Fryback PB and Reinert BR. Spirituality and people with potentially fatal diagnoses. *Nurs Forum*, 1999, **34**, 13–22.
6. Carson VB and Green H. Spiritual well being: a predictor of hardness in-patients with acquired immunodeficiency syndrome. *J Prof Nurs*, 1992, **8**, 209–220.
7. Kendall J. Wellness spirituality in homosexual men with HIV infection. *J Assoc Nurses AIDS Care*, 1994, **5**, 28–34.
8. Oman D and Reed D. Religion and mortality among the community dwelling elderly. *Am J Public Health*, 1998, **88**, 1469–1475.
9. Hummer RA, Rogers RG, Nam CB and Ellison CG. Religious involvement and U.S. adult mortality. *Demography*, 1999, **36**, 273–285.
10. Strawbridge WJ, Cohen RD, Shema SJ and Kaplan GA. Frequent attendance at religious services and mortality over 28 years. *Am J Public Health*, 1997, **87**, 957–961.
11. Spence C and Danielson TS. The faith assembly: a follow-up study of faith healing and mortality. Quoted by Astrow AB, Puchalski MD and Sulmasy DP. Religion, spirituality and health care: social ethical and practical considerations. *Am J Med*, 1987, **110**, 283–287.
12. Orchard H (ed). *Spirituality in Health Care Contexts*. Jessica Kingsley, London, 2001.
13. Henery N. Constructions of spirituality in contemporary nursing theory. *J Adv Nurs*, 2003, **42**, 550–557.
14. Narayanasamy A and Andrews A. The cultural impact of Islam on nursing education. *Nurse Educ Today*, 2000, **7**, 57–64.
15. McSherry W and Draper P. The debates emerging from the literature surrounding the concept of spirituality as applied to nursing. *J Adv Nurs*, 1998, **27**, 683–691.
16. Lauver DR. Commonalities in women's spirituality, and women's health. *Adv Nurs Sci*, 2000, **22**, 76–88.
17. Wright S. Free the spirit. *Nurs Times*, 1997, **93**, 30–32.
18. Annells M. Evaluating phenomenology: usefulness, quality and philosophical foundations. *Nurs Res*, 1999, **6**, 5–19.
19. Morse JM. Designing funded qualitative research. In Denzin NK and Lincoln YS (eds). *Strategies of Qualitative Inquiry*, Sage, London, 1998.
20. Meleis AJ. Culturally competent scholarship: substance and rigour. *Adv Nurs Sci*, 1996, **19**, 1–16.
21. Colaizzi PF. Psychological research as the phenomenologist views it. Cited by Parse RR (2001). *Qualitative Inquiry: The path to scenting*. Jones and Bartlett, London, 1978.
22. Guba EG and Lincoln YS. Fourth Generation Evaluation. Quoted by Maggs-Rapport F. Best research practice: in pursuit of methodological rigour. *J Adv Nurs*, 2001, **35**, 373–383.

The impact of HIV/AIDS on healthcare professions

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Between 21 and 27 May, 2005, more than 3,000 nurses from over 120 countries met in Taipei, Taiwan, attending what is probably the biggest event of its kind in the world: the quadrennial congress of the International Council of Nurses (ICN).

The ICN is a federation of national nursing associations (NNAs) representing nurses in over 120 countries, and was founded in 1899. The ICN headquarters are in Geneva, Switzerland, and the organisation prides itself on the global impact it can have, through the millions of nurses it represents, on global health policy. The ICN is also concerned with providing effective support networks for nurses, and has especially robust links with NNAs in developing countries.

The delegates who attended the congress in May work in a wide range of specialties, and topics discussed during the event were representative of the key health challenges facing nurses across the world, including malaria, tuberculosis (TB), severe acute respiratory syndrome (SARS) and counterfeit medicines. One leitmotif that did dominate the congress was HIV/AIDS, and the remainder of this report will focus on this topic, not only because of

the devastating effect HIV is having on populations, but also because of the immense damage to healthcare systems – not least because of the increasing number of healthcare workers who are infected with the virus, especially in sub-Saharan Africa.

The emphasis on HIV/AIDS was given due prominence by the opening plenary speaker, Stephen Lewis, United Nations Special Envoy for HIV and AIDS in Africa. Having just received the ICN's Health and Human Rights award, Lewis gave an impassioned and emotional speech about the decimation of AIDS in Africa that has 'wrenched the soul' out of society.

Talking about a range of issues, he kept returning to one particular element: the catastrophic affect of AIDS on healthcare workers. He gave examples: in Lusaka, Zambia, 34–44% of nurses are infected with HIV; in Lesotho, in one cohort of nurses trained in 1 year, 18 have died of AIDS. 'We're losing our nurses', Lewis suggested – and stressed the need to ensure that nurses 'are kept alive', through adequate medical and social provision, in order

that healthcare services can be maintained for millions of dependent people.

At another session in the congress, The President of the Zambian Nurses' Association (ZNA), Tom Duati, confirmed that with such a high rate of HIV infection in women in that country (and given the fact that most nurses are female), the healthcare system is at risk of significant fragmentation. For Duati, the biggest concern was the high number of people living with HIV/AIDS (PLWHA) requiring antiretroviral (ARV) medication (200,000) and the actual number of people who received them (25,000) – again, nurses may be affected. A project in partnership with the Norwegian Nurses Association (NSF) to moderate the impact of HIV on the healthcare sector is being developed, and includes education, free access to ARVs if available, and the need to keep the general nursing workforce healthy.

Other sessions during the conference also focused on the impact of HIV/AIDS on the nursing profession; one important event was the launch of the ICN HIV/AIDS Nursing Network. Similar to other ICN nursing networks, such as Emergency Care, and Rural and Remote Nursing, the new network would, according to Tesfa Ghebrehiwet, HIV/AIDS Consultant to the ICN, provide a global forum for nurses involved in the care of PLWHA, and provide opportunities for nurses to lobby and influence health policy. Patrick Robinson, President of the American Association of Nurses in AIDS Care (ANAC) and Brenda Done, of the Canadian Association of Nurses in AIDS Care (CANAC), both shared details of their respective organisations, confirming their support for the network. Dotty Dikwayo, Co-ordinator of the Spartanburg County Alcohol and Drug Commission (SADAC) Network of Nurses and Midwives in AIDS, SC, USA, described how the healthcare system in the region is 'overwhelmed' and confirmed the need for a robust and sustainable support system for carers.

Clearly, the new ICN network can provide this, and another presentation at this launch emphasised a special role for nurses in the HIV/AIDS pandemic: the need to provide care and improve quality of life of PLWHA even in the absence of ARVs. Ian Hodgson, of Health and Development Networks (HDN) gave details of the AIDS-Care-Watch (ACW) campaign, of which HDN are a partner. The campaign aims to highlight the need to keep PLWHA alive until ARVs are available – in some areas for a number of years. Synchronising with other sentiments in the conference, this focus is vital in order that nursing care is maintained in tandem with the roll-out of ARV provision – and highlights the additional benefit that more nurses infected with HIV would remain healthy for longer and be able to maintain the integrity of healthcare systems. A significant – and negative – feature of the experience of PLWHA of the health sector is stigma, and associated discrimination. This is a continuing

and apparently intransigent feature of the HIV/AIDS pandemic, and was the subject of one of the workshops held during the conference. Previous studies have confirmed that the stigmatisation of PLWHA is strong in the healthcare sector generally [1], and in Africa [2], and is also highlighted in a recent HDN eForum structured discussion on stigma in the workplace and institutions [3]. This workshop sought to reveal the engines driving stigma, and ways of mitigating this damaging phenomenon. Focusing on the generic nature of stigma and the self-awareness required to combat it, the session led by David Evans of the Royal College of Nursing in the UK, and Ian Hodgson of HDN, forced participants to confront the potential for stigma in all people – there is no escape in the 'caring' professions.

Other sessions during the congress discussed the 'brain drain' of nurses from developing countries, being poached by western nursing and medical agencies, away from the countries that need them the most. Prof Bill Holzemer of the University of California at San Francisco, USA (UCSF), highlighted the need to maintain resources and – as Lewis pointed out at the beginning of the conference – to keep nurses healthy, and build the capacity of care in the most affected areas.

Discussions and presentations at the ICN congress have confirmed the significant and continuing impact of HIV/AIDS on nursing – not just because of the context of care, but also on nursing itself. The need for support networks, capacity building and an effective reduction in HIV stigma are all vital if in those countries most severely affected by HIV and associated high levels of poverty are to maintain their healthcare systems. This is perhaps most apposite in Africa, as highlighted in other reports, such as that of the Commission for Africa, London, UK (11 March, 2005) [4]. During his presentation, Prof Holzemer cited Gandhi: 'The future depends on what we do in the present' – and it is this thought that must galvanise the international nursing community, through coalitions like the ICN, to act.

Dr Ian Hodgson attended the ICN Congress on behalf of Health and Development Networks (HDN). HDN and the ICN provided funding. This article was originally posted on HDN eForums at: <http://www.hdnet.org>

References

1. Foreman M, Lrya P and Breinbauer C. *Understanding and responding to HIV/AIDS discrimination in the health sector*. Pan American Health Organisation, Washington, DC, USA, 2003.
2. Nyblade L, Pande R, Mathur S *et al*. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. International Center for Research on Women, Washington, DC, USA, 2003.
3. Health and Development Networks HDN – Discussion: *HIV stigma in the workplace and institutions*, 2004. Online summary at: <http://eforums.healthdev.org/read/messages?id=1544> and <http://eforums.healthdev.org/read/messages?id=1545> (accessed on 25 July 2005).
4. Commission for Africa Report, 2005. <http://www.commissionforafrica.org> (Accessed: 26 May, 2005).

7th Annual NHIVNA Conference: Mind, Body and Soul of HIV Nursing

Zoë Cuthbertson

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Congratulations to the NHIVNA Executive Committee on an extremely successful and powerful conference held on 23–24 June, 2005, at the Marriott City Hotel, Bristol. 'Mind, Body and Soul', was the anthem for this meeting, and these areas were covered comprehensively.

The opening session incorporating the Chairman's welcome and the Patron's address was swiftly followed by the keynote presentation by Neil Gerrard MP, Chairman of the All Party Parliamentary Group on AIDS (APPG). He provided a great insight into the activities and plans of the APPG around the Sexual Health Strategy, and immigration and asylum issues. He closed his session, leaving the audience feeling hopeful towards confronting these two significant issues affecting today's society.

The remainder of the morning was spent addressing the 'Mind of HIV nursing'. This began with Roy Brazington, South London and the Maudsley NHS Trust, providing a comprehensive overview of 'Mental health issues in HIV – UK perspective', followed by Dr Derek Summerfield, St George's Hospital Medical School, London, who delivered an extremely animated and thought-provoking presentation on 'Mental health issues – international issues'. Lisa Power of the Terrence Higgins Trust (THT) provided an overview, and the plans of the THT, on the 'Criminalisation of HIV: disclosure of confidentiality'. The main focus of the THT is to assist in providing clarity in this extremely topical area of HIV. The next presentation was 'Asylum seekers: the law and your role', Janis Nwokoro, an immigration solicitor from Lighthouse, delivered this. She provided a very informative insight into the issues with which asylum seekers are confronted, on top of dealing with their HIV. Christina Hanley, of St Mary's Hospital, London, provided a captivating review of child protection, highlighting the complexities involved in the care of children.

The afternoon concentrated on concurrent sessions. There were many sessions to choose from, with a great diversity of topics, and one had to choose the ones of greatest interest.

As always, the evening was something to look forward to, with dinner, drinks and entertainment, and we were not disappointed – Topping and Butch (an entertainment double act) kept the audience on their toes. Along with the hilarities came the presentation of awards to very worthy winners.

It was quite coincidental that day 2 began with the 'Body of HIV nursing', considering the night before appeared to be still hanging over some heads. David Stainer of the Royal Free Hospital, London, had the challenge of drawing the attention of the audience with 'TDM (therapeutic drug monitoring): why, when and how', and he was successful. The overwhelming area of HIV resistance was very eloquently presented by Dr Simon Portsmouth of St Mary's Hospital, London, and Kieran Sharkey of Bristol Hospital presented a very comprehensive case study entitled 'M184V what does it mean to me?'

After lunch the issue of the 'Soul of HIV nursing', was addressed, during two 'Professional Practice Development Workshops' – 'Competencies' and 'Nurse Led Clinics'. Both of these sessions were very informative.

'Whose needs are they anyway?' was addressed by three service users, using 'Mind, Body and Soul' as the backbone, reflecting on their experiences of living with HIV. This was a powerful session.

Overall, a fabulous conference, a great time for networking and a wonderful time had by all. We look forward to next year.

2nd South African AIDS Conference: The end of the affair – and is it all about mixed messages?

Ian Hodgson

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The 2nd South African AIDS conference, in Durban on 7–10 June, 2005, closed not with a bang, perhaps but at least with a brave whimper.

At the closing ceremony – a relatively low-key and reflective event, as these things go – there was a determined effort to highlight the dominant theme of the conference: the need for unity – of message, and action. Prof Hoosen (Jerry) Coovadia, Centre for HIV/AIDS Networking, Durban, South Africa, speaking at the very close of the conference hoped that the gathering had helped delegates in their 'daunting job' of facing and dealing with the HIV epidemic. There is no doubt that the conference this week has given a vital snapshot of the state of HIV and AIDS in South Africa, and also served as a window into the complex and multi-layered characteristics of how the virus manifests in this region, and the challenges that remain if HIV and AIDS are ever to be contained.

It is common knowledge that currently South Africa has the greatest number of people living with HIV/AIDS (PLWHA) in a single country, but it also has one of the most sophisticated national strategies for tackling the virus – the Operational Plan for Comprehensive HIV/AIDS Care and the Treatment Plan for Africa. The operational plan was praised by a number of people (not just government representatives) for being a robust and potentially highly effective strategy. Dr Françoise Venter of the University of Witwatersrand, South Africa, no government lackey, and who plays a central role in the support and treatment of PLWHA, praised it as 'the best HIV plan in the world'.

Of course, there is still much to do, and the conference has also revealed the continuation of what has always been a uniquely South African phenomenon – the mixed and confusing messages about HIV/AIDS. This point was duly emphasised by Dr Mamphele Ramphele, of the University of Cape Town, South Africa, when giving the Nkosi Johnson memorial lecture in the opening ceremony. She demanded that 'scientists must stand up more... to say no to those bent on misleading the public'.

One of those accused of misleading the public is the current Health Minister, Dr Manto Tshabalala-Msimang. Her comments at the beginning of the conference, strongly promoting the benefits of

nutrition prepared in the way delegates' 'mothers and grandmothers' used to do, was part of what seems a personal campaign to downgrade the priority of antiretroviral (ARV) provision and offer other interventions as equally effective in tackling HIV/AIDS, including nutrients and nutritional supplements.

This emphasis is seen by many as allowing undue prominence to nutritionists such as Matthias Rath (Matthis Rath Research, CA, USA), known for discrediting the benefits of ARVs in favour of his own products. Condemned as being an opportunist and 'beneath contempt' by Dr Venter, this disagreement well illustrates – in addition to AIDS denialists – key problems in the discourse of HIV in South Africa: an apparent obfuscation of the truth that undoubtedly adds to the misery of PLWHA.

Prof Coovadia took this further, by highlighted the need for addressing the confusion surrounding HIV and AIDS, and for targeting the 'charlatans, hypocrites and criminals, who are trading on AIDS misery' – and uniting in the battle against the virus. However, what else needs to be done, on the evidence of this conference? At least three major factors were evident:

First, the need for all initiatives must be embedded within a framework of human rights, as argued convincingly by Fatima Hassan of the AIDS Law Project, South Africa, during her plenary session on Wednesday, 8 June 2005. This must include: the provision of ARVs; dealing with denialism; correcting problems around intellectual property rights; and ensuring reproductive autonomy and rights for women are not eroded, but enhanced. In particular, she suggested, we should be concerned that the United States' 'global gag' may be 'seeping into our policies'.

Second, in its ongoing review of the Comprehensive Plan, the Treatment Action Campaign (TAC) released during the conference their most recent report, 'Let them eat cake'. While calling for a rapid scaling up of the ARV roll-out, the TAC also highlighted the lack of proper monitoring systems 'leading to misinformation and misunderstanding about the ARV roll-out' – especially by the Health Minister. Clearly, therefore, there is a need to address current HIV/AIDS discourses in South

Africa, around treatment, but also in the broader advice that should be available for PLWHA, in order that they can stay healthy as long as possible, during the inevitable delay between recognition that somebody requires ARVs, and actually receiving them.

Third, and connected with this, Coovardia in the closing ceremony stated that 'biomedicine is not the major part of this disease'. There does remain a huge number of quality-of-life issues that, apart from the provision of ARVs, need urgent consideration. The day-to-day challenges facing PLWHA are numerous, and one difficulty in particular, which was discussed in Durban, is the current concern around the disability grant – a fund for PLWHA provided according to the CD4 count, but withdrawn if the count goes above a certain level. This is clearly inequitable, and according to Prof Nicoli Natress of the AIDS and Society Research Unit, South Africa 'there is something deeply wrong with a society that... forces PLWHA to choose between income [disability grant] and health [ARV therapy]'.

HIV stigma remains as potent a force as ever. Progress has been made in bringing HIV into the open, but there remains a need for further action protecting the rights of PLWHA, and opening up the public awareness still further. As was clear from many presentations, the fact that HIV is more prevalent in one region does not mean the virus is necessarily 'normalised' – there are just more people who are stigmatised.

This conference attempted to combine the multi-faceted nature of HIV in South Africa into one event. ARVs clearly remain prominent in the discourse of HIV in South Africa, though given the inevitable

delay in provision – of the 600,000 who require access, only around 30,000 currently receive treatment – it is vital that quality-of-life issues stay on the agenda, as well as the provision of non-ARV medications as required. It is also essential that the 'message' of HIV is clarified – internecine disagreements simply make the prevention and treatment of HIV a more daunting task than it already is.

All this will depend on unity: and only time will tell if this conference has generated sufficient concordance in tackling HIV and AIDS in South Africa.

The next South African AIDS Conference is to be held 5–8th June 2007.

Further sources

Operational Plan for Comprehensive HIV/AIDS Care and Treatment Plan for Africa is online at: www.mrc.ac.za/publications/arvrollout.htm

Information about TB in South Africa can be found at: www.stoptb.org

Additional information and details about the South African AIDS Conference can be found at: www.sa-aidsconference.com

Treatment Action Campaign information can be found at: www.tac.org.za

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14–15 October 2005

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12th Annual Conference of the British HIV Association

29 March –
1 April 2006

The Dome,
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13–14 October 2006

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NHIVNA update

Thank you if you attended the 7th Annual Conference in Bristol last month (23–24 June, 2005, Marriott City Hotel). This year's conference was well attended and everyone seemed to enjoy themselves. The feedback we have received about the speakers and content was very positive. It was amazing how many people said it was the first time they had attended a NHIVNA conference and they were impressed at the high standard of speakers and overall quality of the conference. Planning for next year is already under way.

We try to have representation from most disciplines on the executive committee and we now have a vacancy for someone with an interest in, or whose role includes, education and training of HIV nurses. If you are able to commit to attending the committee meetings every 3 months, and taking on the additional workload that being part of a growing association entails, then send a short biography outlining your experience, areas of interest and what you can bring to the committee. Access to e-mail on a regular basis is essential. E-mail your biography to nicky.perry@bsuh.nhs.uk by Monday, 5 September, 2005.

At the conference we also asked for volunteers to work on the HIV nursing competencies' subgroups. We are looking for nurses across the country and from all areas of HIV nursing. If you interested then please contact Jacqueline English from Mediscript at Jacqueline@mediscript.ltd.uk. Jacqueline will forward your details to the steering group.

NHIVNA's programme of study days will commence again in September 2005. On 14 September we will be holding a workshop on 'Nurse-led Services and Resistance Update' in Manchester. The workshop will also be run on 16 November in Birmingham. On 14 October there will be a co-infection study day in Bristol. For NHIVNA members these study days are free and you will receive notification. For the first time, in December, we will be running a 'Getting Started in Research' workshop, which will include how to write an abstract and article for publication. Again, attendance will be free to NHIVNA members, and will be on 1 December in London.

Nicky Perry, Chair, NHIVNA

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