

# 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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# The changing face of palliative care

Ian Hodgson

Independent Consultant, HIV Education and Research

As we near the end of another year, World AIDS Day looms again on our horizon. A feature since 1998 in the calendar of HIV activities, selected themes generally reflect current issues around HIV, and looking back provides an intriguing overview of some of the history of HIV. Themes have included: men (2000); women and girls (1990 and 2004); stigma and discrimination (2002 and 2003); children and/or young people (1989, 1997, 1998 and 1999); and calls for increased political accountability, responsibility and the need for action (1995, 2004–2008) [1].

Technically, of course, the day should really be World *HIV* Day – the AIDS moniker being a legacy of what in 1998 was the key threat facing people living with HIV (PLHIV). However, the event's rapid branding soon 'locked in' the original label.

The theme for 2009 refers to what is now the dominant theme in HIV discourses – universal access, a catch-all term applying to the entire spectrum of HIV-related issues: treatment, prevention and care, harm reduction, equality and human rights. For incoming UNAIDS Chief Executive, Michel Sidibé, speaking earlier in 2009, universal access means: "saving lives and restoring dignity to people. It encompasses stopping mothers from dying and babies from being infected with the virus; stopping people living with HIV from dying of tuberculosis; and stopping drug users from becoming infected with HIV". He went on, "Universal access also entails curbing legislation that blocks an effective response to AIDS" [2].

This edition of *HIV Nursing* includes a selection of articles that are highly appropriate to the issue of universal access. The overarching theme in the issue is palliative care – caring for and supporting PLHIV from the point of diagnosis onwards, defined by the World Health Organization as: "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [3].

Two articles in the journal consider palliative care specifically. *Kathy Pickhaver* provides an essential overview, describing its history and development. *Dermott McDonald* describes a training programme for healthcare workers in Ukraine,

where the notion of palliative care has for many years – partly as a legacy of the Soviet health system – focused on *terminal* care. The article includes an evaluation of the programme, and confirms that following this training, perceptions of palliative care were broader and more empathetic to the various needs of PLHIV, both within and outside the clinical setting.

Two interesting and moving articles consider the care of PLHIV in hospital. The first, by *Carole Duff*, working in London, is intended to stimulate discussion and debate and considers another potentially challenging area of care – deciding on the appropriate level of engagement for a healthcare worker to adopt when caring for patients who are terminally ill. The second, from *Michelle Croston*, who is based in Manchester, describes difficulties faced by healthcare staff when a patient decides not to continue treatment. Respecting individual rights, whilst at the same time liaising with family members in the absence of advance directives, can be a challenging and traumatic experience for all concerned.

Other articles in this edition add an international context – *Caitlin Rose*, a registered nurse originally based in the United States, reflects on the perspective of non-HIV specialist nurses working in the general setting when caring for PLHIV. This personal reflection offers a starting point for addressing and overcoming instinctive and often negative responses, based on stereotypes and cultural constructions. Finally, *Rui Baptista-Gonçalves*, a nurse who qualified in Portugal, considers the landscape of HIV and implications for nursing care in the Portuguese health system, particularly stigma and discrimination.

As always, we invite and appreciate feedback. If you would like to comment on any of the articles in this issue of *HIV Nursing*, please send a message to: [hivnursing@mediscript.ltd.uk](mailto:hivnursing@mediscript.ltd.uk)

## References

1. Further information about World AIDS Day is available at: [www.avert.org-world-aids-day.html](http://www.avert.org-world-aids-day.html) (last accessed 13 November, 2009).
2. Universal access for HIV prevention, care top priority, says UN official. UNAIDS, 13th March 2009. Available at: [www.un.org/apps/news/story.asp?NewsID=30182&Cr=unaid&Cr1](http://www.un.org/apps/news/story.asp?NewsID=30182&Cr=unaid&Cr1) (last accessed 13 November, 2009).
3. World Health Organization. *Palliative Care*, WHO, 2002. Available at: [www.who.int/hiv/topics/palliative/PalliativeCare/en/](http://www.who.int/hiv/topics/palliative/PalliativeCare/en/) (last accessed 13 November, 2009).

# The evolution of palliative care in HIV and AIDS

Kathy Pickhaver

Palliative Care Physician, Chelsea and Westminster Hospital, London, UK

Palliative care had its origins in the British hospice movement but over the last 20 years has evolved in both concept and practice far beyond the original goal of improving terminal care, its terms of reference changing from 'terminal' to 'long-term supportive' care.

Defining and understanding palliative care for individuals living with HIV and AIDS remains a challenge as the divisions between curative and aggressive care, and between supportive and palliative care, are variable and not clearly defined.

Working in both the hospice and acute hospital settings for more than 10 years has for me highlighted the dramatic changes in the palliative care needs of patients with HIV and AIDS.

## The hospice setting

I first started working in this field as a palliative care physician at the Mildmay Mission hospital in 1995.

At that time, the majority of patients in the hospice were dying of AIDS (HIV dementia, disseminated Kaposi's sarcoma (KS), cytomegalovirus (CMV), *Mycobacterium avium-intracellulare* (MAI), HIV-related wasting). Hence, because of my background in palliative care, I felt confident in dealing with the terminal phase of illness – making sure patients were comfortable, setting up syringe drivers, talking to patients and relatives about death and dying, and working closely with the multidisciplinary team.

Some of the patients were in the hospice because of mental health problems. This was a steep learning curve for me and completely alien to the mental health problems I had encountered in my previous hospice job, where I had mainly been involved with cancer patients. There were also admissions arising purely for social reasons, for example, those who were socially isolated, or where a carer was going on holiday, or a flat being renovated.

With the advent of HAART, the disease course experienced by patients living with HIV and AIDS changed dramatically – the rapid decline from HIV diagnosis to death, once resembling that of untreatable cancers, shifted to a trajectory more typical of chronic progressive such as congestive cardiac failure (CCF).

Doctors and nurses in the hospice had to gain more knowledge of the disease itself, learn about

antiretroviral treatment, its potential side effects and potential drug interactions between commonly prescribed palliative care drugs and HAART, for example, carbamazepine and ritonavir.

The clinical assessment of prognosis and outcomes has also become more complex than was previously the case. The decision as to whether patients were suitable for resuscitation has needed to be clarified with the patient, the relatives and the HIV team involved. In the event of a patient becoming unwell with, for example, pyrexia or a chest infection, decisions have increasingly been required as to whether treating in the hospice setting was appropriate (given its limited resources for performing investigations and treating aggressively) or whether urgent transfer to an acute ward was needed.

As the disease changed, so also did the type of patients admitted to the hospice: more were being admitted for symptom control (for example, difficult pain syndromes such as peripheral neuropathy); for help with adherence to HAART and management of drug side effects; for substance misuse and other psychiatric illnesses; and for respite care (for example, after chemotherapy or an acute infection). As palliative care became recognised as a specialty in its own right, the issue of whether HIV patients admitted to the hospice had specific palliative care needs or would benefit from the specialist service, had to be addressed. Gone were the days of admitting patients purely for social reasons.

## The hospital setting

In 1997 I started working at Chelsea and Westminster hospital, as a palliative care doctor attached to the HIV and AIDS unit.

At that time there were two wards full of very sick patients, hence a significant proportion of my time was spent trying to manage pain and other symptoms (such as severe diarrhoea secondary to cryptosporidium using subcutaneous octreotide and diamorphine via a syringe driver), and in dealing with the terminally ill.

During the following years working on the HIV unit, it became apparent to me that there was often no clear transition from active curative treatment to palliative treatment – with patients often choosing active aggressive treatment right up until death. This setting also highlighted the importance of

investigating, and trying to identify, a cause of pain and other symptoms – as disease-specific antimicrobial treatment and other treatment (for example, intravenous amphotericin for the treatment of oral candida resistant to oral azoles) was often the best way to relieve the symptoms.

I also vividly remember the 'Lazarus syndrome', where patients would be moribund, bed-bound, cachectic and looked to me as if they were in the terminal phase. However, with what at the time appeared over-aggressive treatment (such as nasogastric feeding, intravenous antibiotics and invasive procedures), their condition would slowly improve, eventually enabling them to leave hospital and live for many more months, or even years.

At that time, in the absence of any curative treatment, I was struck by how the HIV team helped to empower patients by discussing treatment decisions in terms of quality of life, care preference and family – rather than making decisions for the patient. The patients' needs were complex, especially at the end of life, and were addressed very much in a multidisciplinary model of care.

With the arrival of HAART, much of the focus has shifted to a more curative therapy for which goals of treatment are more clear-cut, uniform and physician-directed. What is striking is the emergence of a new breed of HIV doctors and nurses, who have not lived through the pre-HAART era, who are medicalising care and less likely to be discussing goals of care or end-of-life decisions. The palliative care team is often not involved until a crisis occurs, such as life-threatening infection or loss of decisional capacity – and then addressing goals of care or end-of-life decisions seems inappropriate, when a patient is precipitously dying. As death is less common, so medical staff seem almost 'deskilled' in dealing with it, uncomfortable in discussing it – reluctant to undermine hope, and with death representing 'failure'.

## The outpatient setting

With the advent of HAART, a falling rate of progression to AIDS and closure of one of the wards, there has been a noticeable change in the role of the palliative care team – who are now dealing less with the terminally ill – and a shift towards symptom control in the outpatient setting. As the number of patients taking drug-complex HAART regimens increased, so more time was needed to deal with drug-related side effects. As a consequence a 'symptom control' clinic was set up – to assess patients with a variety of symptoms, such as nausea and vomiting, diarrhoea, myalgia and arthralgia.

With the development of the 'd' drugs (ddi – didanosine; ddc – zalcitabine; d4t – stavudine) the clinic soon became monopolised by patients with

drug-related peripheral neuropathy. As in the treatment of neuropathic pain in cancer patients and other conditions, a logical and stepwise approach to each neuropathic agent tried is the key to the most effective pharmacological treatment.

The picture is complicated by the high pill burden, possible drug interactions between HAART and various co-analgesics, and also by patients' co-morbidity: a significant percentage of patients are already on SSRIs (selective serotonin reuptake inhibitors) for depression, ruling out a trial of TCAs (tricyclic antidepressants) – except at low dose – for the treatment of neuropathic pain.

The majority of patients seen in clinic over the last few years are patients with symptoms of fatigue, anorexia, agitation and depression; and those with 'chronic' pain – such as back pain (secondary to degenerative changes or disc problems), osteoporotic crush fractures, arthralgia (secondary to hepatitis C, or HAART, or non-specific), pain in buttocks, or in soles of feet (secondary to lipodystrophy). It is possible to assess and treat pain effectively in patients with HIV and AIDS, including drug users, with standard drugs (the WHO pain relief ladder [1]), rational decision-making, evidence-based practice and common sense.

Given that adherence to HAART is so significant in determining the likelihood of success of the treatment regimen, it is not surprising that so much routine patient-doctor interaction is focused on adherence to therapy. However, the more the physician becomes frustrated with the patient's difficulty in adherence to HAART, or with their own inability to reverse the disease course, the less effective they are at accompanying the patient through their illness.

## Summary

The past two decades have seen both the emergence of AIDS as a new life-threatening infectious disease, and its conversion from a rapidly fatal illness into a manageable chronic disease. Although medical adherence is vital in stabilising the course of the disease, other factors can be equally important in optimising clinical outcome – relief from pain and other distressing symptoms, treatment for substance misuse, depression and other mental illnesses, adequate support from friends, family and carers.

The need for palliative care in HIV management is underlined by the high prevalence of pain and other symptoms, drug toxicity and side effects, emergence of co-morbidities, such as hepatitis B and C, continued high incidence of malignancies (both HIV- and non-HIV-related), late presentation of people with HIV and comparatively higher death rates among infected individuals.

Uncertainty about prognosis and the promise and limitations of rapidly evolving therapy have made

decision-making about advance care planning and end-of-life issues more complex than when the disease course was more uniform, rapid and predictable.

Palliative care is complementary care, *not* alternative care, and therefore should not be provided only when disease-directed therapy fails. Although the HAART era has prolonged life in the context of HIV, this extended trajectory as a manageable long-term disease comes with its own anxieties, burdens and challenges. For some, HAART has meant the possibility of full return to health, going back to work and minimal impact on daily quality of life; while for others treatment means conversion from death to chronic disability.

The availability of treatment does not give clinicians the luxury of ignoring important issues posed by a chronic progressive illness and its management over time. The more we focus on therapy, the less we tend to focus on the patient. It is the patient who must live with the illness, and goals of care are there for the patient and not for the physician.

Defining and understanding palliative care for individuals living with HIV and AIDS remains a challenge but what is clear is the false dichotomy of curative *versus* palliative care *must* be supplanted by a more integrated model to provide optimal care to all patients throughout the course of their illness.

## Reference

1. World Health Organization Pain Relief Ladder. Available at: [www.who.int/cancer/palliative/painladder/en/index.html](http://www.who.int/cancer/palliative/painladder/en/index.html) (last accessed 4 November, 2009).

## Recommended reading

Moss V. Palliative care in advanced disease: Presentation, problems and palliation. *AIDS*, 1990, **4**, S235–S242.

Kelleher P, Cox S, McKeogh M. HIV infection: The spectrum of symptoms and disease in male and female patients attending a London hospice. *Pall Med*, 1997, **11**, 152–158.

Selwyn PA and Arnold R. From fate to tragedy: the changing meanings of life, death and AIDS. *Ann Intern Med*, 1998, **129**, 889–902.

Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in non-malignant disease. *Pall Med*, 1998, **12**, 417–427.

Armes PJ and Higginson IJ. What constitutes high-quality HIV/AIDS palliative care? *J Pall Care*, 1999, **15**, 5–12.

Selwyn PA and Rivard M. Overview of Clinical Issues. In: *A clinical guide to supportive and palliative care for HIV/AIDS* (O'Neill JF, Selwyn PA and Schietinger H, eds). US Health Resources and Services Administration, 2003. Available at: [www.thebody.com/content/art34068.html](http://www.thebody.com/content/art34068.html) (last accessed 3 November, 2009).

Selwyn PA and Forstein M. Overcoming the false dichotomy of curative vs palliative care for late stage HIV/AIDS: "let me live the way I want to until I can't". *JAMA*, 2003, **290**, 806–814.

Harding R, Karus D, Easterbrook P *et al*. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect*, 2005, **81**, 5–14.

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# Training in palliative care for HIV and AIDS in Ukraine: the Mildmay experience

Dermott McDonald<sup>1</sup> and Ian Hodgson<sup>2</sup>

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## Background

Attention often shifts to sub-Saharan Africa when the global HIV epidemic is mentioned. However, there is a growing epidemic emerging on our doorstep in Eastern Europe, which is often overlooked and definitely under-resourced. Only a few UK non-governmental organisations (NGOs) for HIV training, care and support are active in confronting challenges in the region. Mildmay has been working for nearly 10 years in Eastern Europe – including the Russian Federation, Belarus and Romania, as well as Ukraine – training healthcare and drug rehabilitation workers in various aspects of HIV and AIDS care, using Mildmay's successful multidisciplinary, holistic approach pioneered over 21 years through its Mildmay UK and Mildmay International programmes.

A recent pioneering training programme led by Mildmay and funded by the UK-based International AIDS Alliance, focusing on palliative care and aimed at medical professionals in the Ukrainian HIV sector, is an example of how UK healthcare professionals with the right technical expertise can help build badly needed capacity and develop the skills of these European colleagues – who live just two hours way from the UK.

## HIV in Ukraine

Around 440,000 people in Ukraine were living with HIV in 2008, with 22,000 having died of AIDS since the beginning of the epidemic. Ukraine has Europe's highest adult prevalence rate, with 1.6% infected [1]. HIV is currently concentrated among injecting drug users (IDUs), sex workers and their sexual partners. The rise in HIV in the region is closely linked to increasing rates of injecting drug use in the mid-1990s during the socio-economic crisis following the break-up of the Soviet Union. A joint study by UNAIDS and the Ukrainian Ministry of Health estimated HIV prevalence among IDUs as somewhere between 17% and 70% [2]. HIV prevalence among sex workers ranges from 4% in the capital, Kiev, to 24% in Donetsk and 27% in Mikolayev [1]. Other identified at-risk groups include sexual partners of those at risk, prisoners and men who have sex with men (MSM).

Despite the fact that most healthcare professionals in Ukraine are well educated on HIV and AIDS

issues, a negative attitude towards people living with HIV (PLHIV) remains ingrained, due to issues around drug use and sex. Patients are often treated at AIDS centres which are segregated from the rest of the healthcare system. There is little training and awareness on the palliative care needs and rights of PLHIV, which greatly limits the ability of healthcare workers to deliver comprehensive HIV care and social support. Also of note is Ukraine's extremely low antiretroviral therapy (ART) coverage rate, at just 8%. This means that Ukraine lags severely behind the 33% global coverage average in low- and middle-income countries and far below several African countries with severe epidemics, including Botswana (79%), Zambia (46%) and South Africa (28%) [1].

Due to inadequate resources and lack of awareness, there has been a limited response to the wider, palliative care needs of PLHIV. The provision of palliative care does not currently focus on care needs, such as pain relief, diagnosis and treatment of HIV-related neurocognitive impairment, and various social care issues.

## Mildmay and palliative care education

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [3]. As such, "palliative care is an essential component of a comprehensive package of care for people living with HIV" [3], but a comprehensive definition of HIV care and support must include broader medical interventions as well as socioeconomic and legal support.

Mildmay's HIV and AIDS palliative care training course was developed in response to the need for a more comprehensive approach to palliative care in Ukraine. Mildmay responded in 2006 to calls from the Alliance Ukraine and Ukrainian National AIDS Centre for technical support in developing palliative care services in Kiev, Odessa and Crimea. A needs assessment was conducted by Mildmay medical and programme staff in 2007 and a

module-based training curriculum and programme was subsequently developed.

Four, week-long modular workshops were held during 2008. The 25 course participants were expected to be a combination of doctors, nurses, psychologists and social workers, although in fact the majority were either doctors or nurses, perhaps reflecting a health system still largely based on Soviet structures: hierarchical and doctor-led.

Mildmay ensured the training staff selected reflected its core holistic, multidisciplinary approach to care, and the curriculum included the following themes, based on the needs assessment:

- General understanding of palliative and hospice care, including 'holistic care'
- Palliative care as part of a seamless continuum of care
- Palliative care in the context of ART
- Pain and symptom control
- Care for IDUs and people on substitution therapy
- Recognition of the terminal phase; and terminal care
- Psychological care in general
- Adherence support
- Bereavement support
- Dealing with uncertainty about prognosis
- Dealing with difficult questions from patients and relatives
- Handling aggressive behaviour
- Facing death with the patients and relatives
- Disclosure
- Recognition and management of HIV-related dementia and psychiatric problems
- Spiritual care
- Burnout of staff and volunteers
- How to deal with patients co-infected with tuberculosis, hepatitis B, or C

The course also provided further information on developing and integrating palliative care into the care continuum for adults and children living with HIV and AIDS:

- Rehabilitation (physical, psychosocial and spiritual) for patients presenting with advanced AIDS, including AIDS dementia)
- The multidisciplinary team in practice
- AIDS-related cancers and how they can be managed
- The use of adjuvant or co-analgesic drugs or pain control

- Home-based care and all the possibilities of providing support in the home or through communities

## Post-training evaluation

A comprehensive evaluation was conducted after the training, which confirmed that the majority of participants considered the course beneficial to their practice. Sessions perceived as most useful were those focusing on AIDS dementia; aggression; teaching and learning; and pain and symptom control. Interviews with a selection of participating nurses and doctors suggested significant improvements in areas of symptom control. Communication, staff support, and HIV stigma were also identified as important by participants and it was encouraging that these 'non-medical' aspects of care have been given such prominence.

Quotes from participants included:

*"The course had led to a significant shift in perspectives on HIV and palliative care"*  
(Doctor)

*"The aim of palliative care is to bring the patient back to life"* (Nurse) [4]

All participants interviewed for the evaluation stated that the training had had a significant and positive impact on palliative care delivery in their clinical areas.

A key aim of the evaluation was to determine the impact of the training on perceptions of palliative care, and the findings suggested that this was significant. There was an understanding amongst participants that palliative care was not simply the care of people just before death (terminal care) – a common assumption of attendees prior to the course, and the prevailing view across the Ukrainian healthcare system. One participant who was interviewed said that her perception of the meaning of care had changed and that 'all care includes palliative care'. This reinforces the view that, prior to the course, care systems had been seen as a series of separate 'states'. Participants now appreciated that palliative care needed to involve an integrated and holistic approach to the planning and delivery of care, including a range of services offered to patients from the point of diagnosis. For one nurse respondent, as well as bringing patients "back to life", palliative care should make their lives "brighter" and should offer high-quality, holistic and comprehensive care along the entire continuum, from diagnosis to death [4].

During the evaluation, participants were honest about their lack of knowledge about palliative care before the training. One nurse with 5 years' experience said she had no real idea about palliative care, but after attending the course appreciated its holistic nature, and patients do not need to be "physically bad" to receive services. She confirmed that she now considered the inclusion of

physiotherapy, counselling, massage, and pain management in routine plans of care for PLHIV, and she also said she was "more aware of the psychological needs of patients", and acknowledged the need to listen to patients. She now made it a priority to meet patients, addressing their doubts and queries, because they "trust me sometimes more than their relatives, or the people in white coats". Indeed, other participants confirmed that engagement and dialogue with the relatives of patients had improved [4].

For the participants, therefore, palliative care is no longer preparing people for death, or "helping someone to die". It is rehabilitating, and helping patients deal with any problems they have living with HIV. Interviewees gave examples of the services they now consider appropriate within this area: massage; dentistry; physiotherapy; and counselling. The nurse participant in Poltava even confirmed that she had been able to "convince the Chief Doctor" at the AIDS centre where she worked that these services were necessary, highlighting that the masseur services they introduced were provided free of charge by a volunteer! Another participant described her enthusiasm for providing flowerbeds in the grounds of the AIDS centre where she worked, for use by patients as a form of occupational or 'garden' therapy – and how the "Chief Doctor" now realised that this was a valuable resource, contributing to patients' rehabilitation! [4]. Overall, 'carers' were now "more attentive to patient issues" and more willing to refer to other practitioners and specialists.

For the treatment of specific symptoms, medical staff confirmed their interventions are now more informed. Confidence in the use of assessment tools, for pain or for dementia, had increased for one doctor: prior to the course, he would often "refer to other doctors", whereas now, he felt able to initiate these approaches himself.

Regarding AIDS-related dementia or its more formal title, HIV related neurocognitive impairment, a specialism of Mildmay UK, and a diagnosis (if diagnosed at all) not commonly considered for rehabilitation in Ukraine, a nurse participant highlighted that she now had a much more positive approach to this condition. She is also now aware that it is amenable to therapy – something that can be improved, especially with the involvement of relatives. A doctor confirmed that they were now more aware of the tools to help identify and diagnose AIDS dementia, and the potential interventions for treatment.

Crucially, participants described how their attitudes towards PLHIV had changed. One nurse described how, prior to the training, she felt "challenged and uneasy" about their "chaotic" lifestyle, especially those injecting drugs. She now felt more confident about interacting with them – "understanding that they are people". Another respondent, a doctor,

confirmed that he now views PLHIV in a "more profound way – paying more attention" to the entirety of their needs, not just medical problems. He now considered "context", and was more "tolerant of patients who complain" [4].

## Relationships between course participants

A second component of the evaluation was to ascertain the nature of the professional interaction between participants: especially important, given the hierarchical nature of the health system in Ukraine, placing doctors at the forefront of executive planning, as the gate-keepers of all interventions, including those involving nursing care.

Respondents were unanimous in acknowledging that all course participants were treated as equals. One doctor said that, once in the classroom, there was "no need to know" whether a colleague was a doctor or nurse – a level of integration Mildmay can rightfully be proud of. Another respondent (a doctor) confirmed that he did not pay attention to whether other participants were nurses or doctors – they all "worked as a team", and there was a "mutual understanding" between course members [4]. Nurse attendees interviewed for the evaluation also confirmed this to be the case, although it would be interesting to undertake further research in this area.

Certain sessions and subjects were highlighted by participants as especially valuable. For nurses, these included sessions on pain control and hydration (including tools for assessment), which they confirmed are now part of their day-to-day care activities. For doctors, new insights into treatment and AIDS dementia were useful, and they felt in particular that the sharing of information and clinical insights had assisted them in expanding their expertise and confidence in certain areas. Course sessions addressing non-narcotic treatments for pain were considered extremely useful; and information about narcotic pain relief was especially enlightening, given that this was not available in some AIDS centres, due to local and national prohibitive legislation.

## Concluding comments

The context of HIV care in Ukraine is inherently more complex than in the UK – not just because of higher HIV prevalence, but also the demographics of PLHIV, many of whom are intravenous drug users (IDUs) in a country where this practice is heavily criminalised.

Also, as elsewhere, there is a need to ensure HIV care givers are supported in their work. The training participants in Ukraine no doubt find the work rewarding – one commented that it was "enriching". However, many outside the field are

wary of HIV care givers, thinking they are "crazy" to work in this specialised field, according to one participant. This component of the training could be enhanced, for the almost universal stigmatisation of care providers working in the field of HIV is as widespread in the Ukraine as in other countries, and needs to be addressed [5].

The scale-up of HIV and AIDS palliative care training is vital for the Ukraine to combat the growing impact of the epidemic on its population. Organisations such as Mildmay are equipped for and committed to sharing expertise and knowledge and building local capacity. The struggle for funding and donor interest remains a challenge for which, unfortunately, there is no easy answer.

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## References

1. UNAIDS. Report on the global AIDS epidemic, 2008. Available at: [www.unaids.org](http://www.unaids.org) (last accessed 2 November, 2009).
2. Kruglov YV, Kobyshcha YV, Saliuk T *et al*. The most severe epidemic in Europe: Ukraine's national HIV prevalence estimates for 2007. *Sexually Transmitted Infections*, 2008, **84**, i37-i41. Available at: [http://sti.bmj.com/cgi/content/full/84/Suppl\\_1/i37](http://sti.bmj.com/cgi/content/full/84/Suppl_1/i37) (last accessed 2 November, 2009).
3. World Health Organization. Palliative Care, 2002. Available at: [www.who.int/hiv/topics/palliative/PalliativeCare/en/](http://www.who.int/hiv/topics/palliative/PalliativeCare/en/) (last accessed 2 November, 2009).
4. Hodgson I, McDonald D. *Alliance Ukraine/Mildmay - HIV and AIDS Palliative Care Training Programme: End Of Project Evaluation*. Mildmay International, London, 2008. Available on request from: [www.mildmay.org](http://www.mildmay.org).
5. Hodgson I. Empathy, inclusion and enclaves: the culture of HIV care and nursing implications. *J Adv Nurs*, 2006, **55**, 283-290.

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# Professional boundaries: a reflection

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## Comment

Maintaining personal and professional boundaries between a nurse and patient is an ongoing challenge in health care. The reflection below highlights one particular case in the context of palliative care, where the nurse-patient interaction was especially close. It raises important questions about the nature of care, and essentially speaks for itself. It is presented here to stimulate discussion and debate about an area of health care that is perhaps one of the hardest and most challenging – supporting patients as they reach the end of their lives.

I hope that you will be as deeply moved as I am by this reflection, written by a nurse born and trained overseas, and who has been working with our team for the past five years. Working overseas, and with nurses not trained in the UK, has challenged and expanded my view of what nursing 'is' in broad terms, particularly in relation to professional boundaries between nurse and patient.

From the outset this nurse had great difficulty in grasping the more formal boundaries between nurse and patient. She saw caring as a form of loving, responding to need, limited only by her ability to meet those needs. This reflected her own great generosity of spirit and necessitated an agreement that she 'ran things by me' when she wondered whether they were professional and appropriate.

When she described this particular experience to me, I reflected that my own boundaries are often motivated more by a desire to protect myself from too much work and too much heartache than to protect the patient. I asked her to write her reflection so she could share it more widely. Her identity has not been revealed to protect the confidentiality of the patient.

**Carole Duff**

## Questions for discussion

1. Do the NMC directives provide sufficient clarity and detail regarding professional boundaries between patient and nurse?
2. How should we respond when the boundaries established by other nurses differ from our own, but break no *absolute* rules?

## John's story

John was a sad and lonely young man. When he came to our ward he had meningitis and anorexia. I liked him at first glance. His 'refusal of food' suggested a strong suffering, but the walls of the stronghold he had built around himself hid it. I cannot remember which one of my approaches was the magic one, but within a couple of weeks I had managed to make a breach in this stronghold. Sometimes I felt as if a transparent membrane lay between his 'inside' and me. In those moments, I imagined John behind a huge porthole, impervious to sounds, where he was floating and crying out words I could not hear.

He was alone in the world, living without any hope of a mum's love and with the memory of so much sorrow. His mother had abandoned him and his adoptive mother must have been really cruel, so he went to an orphanage. He then came to London where he lived a chaotic life for a while and eventually landed up in a hostel, where he tried to pull together all the pieces of himself that were left.

Every time I tried to delve into his heart, I felt something was growing between us; some of my words had what I used to call a 'hedgehog effect'; he felt touched by them but then withdrew into himself and showed the quills. I remember he refused all kinds of food, but he could not resist my homemade tiramisu, so I often prepared some for him when I was on shift. Sometimes I perceived that he was very far from us. He used to tell me about an island where inhabitants were only happy children. He had created this island in some part of his mind where he took refuge, and every time his own reality tried to peep out from that deep black well in which he had hidden it.

One day he told me I was allowed to know about that island and he would have let me in. I got really emotional on that day and felt that he really trusted me.

One night he asked me if I could caress his forehead like mums do with their children – he had had a bad dream and could not go back to sleep. He moved me so much. He went back to sleep with his thumb in his mouth ... while I was silently struggling to hold back my tears. On one of his last days, he did not want to let me go home. He was holding me by the hem of the skirt and asking if he could come with me, as an adoptive son, please... I laughed but suddenly stopped, embarrassed, because I felt that he actually meant it. I just walked away, really troubled.

I went on holiday for a few days with a storm of

emotions inside. When I returned to work, I found out that he had died and, having nobody, he was going to have a hospital funeral. I felt I needed to do something for him. I did not want him to vanish from this world leaving no imprints, as he had given me so much emotionally. I organised the funeral together with the lady from the bereavement office, the hospital chaplain and a few colleagues; we invited other carers, and the buddy, he had a lovely speech, lovely poems and songs. I went back a second time to scatter his ashes and I chose a place under a big weeping willow. Its branches were swinging in the wind and they reminded me of the arms of a mother rocking her baby, so I thought it was the right place for him. A poem came out of my pen... and I had the crazy instinct to steal some ashes and put a rose where I left the hole... And I took pictures – I do not know why – I kept them in a little blue marble box.

Three years later an agency contacted me because my name was mentioned in John's funeral papers. His natural mother was looking for him: she had been an unlucky, young single mother who fought for years to keep her child, against her parents as well as the courts, who decided to take the baby for adoption. She lost all her hope until last year, when the law changed and made it possible for natural

parents to find their adopted children. So, she had started the investigation: she wanted to have John back, to tell him that she did not abandon him, that she had never stopped thinking of her first child. She wanted to show him his brothers and sisters, for him to know what a big family he had.

Suddenly everything made sense to me: I had held John for his mother. My role, though I was unaware of it at the time, was probably to make a sort of bridge across the years to keep up the mother-son contact that difficult circumstances had tried to take away for ever. I feel I adopted John, in a way, and now I have closed a little bracket that was still open in my heart. I hope that, finally, John rests in peace.

Anon

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## How I want to be remembered: advance instructions

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### Introduction

Providing nursing care and support for a patient choosing not to take antiretroviral therapy (ART) is both challenging and demanding. This article highlights some of these challenges, and explores the provision of complex care and support, focusing on the use of advance directives and the role of psychological support at the end of life [1]. In order to maintain the patient's confidentiality, and in line with Nursing and Midwifery Council (NMC) Code of Conduct [2], the patient's name has been changed.

### Background

Joe was diagnosed with HIV in 2006; he was 30 years old. He was admitted to a local hospital with a variety of symptoms, including weight loss, fatigue, dry cough and feeling generally unwell. In an attempt to find a diagnosis, the medical team

suggested Joe should have a variety of tests, including one for HIV, which was positive.

Joe's HIV diagnosis was given with his family present. Family relationships had always been very complicated for Joe, and reflecting later on the way that his diagnosis was given, he says that, offered a choice, he would have preferred his parents not to be present, so he could decide when and where to tell them – if at all. It is difficult to gauge the impact his family's knowledge of the diagnosis had on Joe. Had they not been informed, it might have been more problematical for Joe and the multidisciplinary team subsequently involved in his care.

At the time of his diagnosis, Joe was very sick, so he transferred to a unit for specialist HIV services and additional counselling. Here, Joe and his family could be supported as they tried to make sense of what was happening. From onset, Joe had very

strong views about his status: he made it clear that he did not want treatment, or to live with HIV.

A key problem for Joe was that the diagnosis came as a complete shock: he claimed that it was the last thing he had expected, never thinking that he was at risk. As far as he was concerned, 30-year-old heterosexuals don't get HIV. Looking back on the years that followed, it seems that once Joe received his diagnosis he pressed the 'self-destruct button' and has never taken his finger off it. He soon decided that he did not want to take ART, and healthcare professionals battled at every opportunity to convince him of the benefits of treatment, but ultimately this resulted in Joe disengaging from services and only presenting when he was sick or in pain.

### Psychological care

Providing good psychological support for Joe was essential so he could begin to process some of the issues he faced as a result of his diagnosis. He was referred to an experienced HIV clinical psychologist, familiar with some of the issues that Joe raised. The therapeutic relationship Joe developed became invaluable, providing a safe, non-judgmental environment to express his thoughts, concerns, feelings and anxieties. It also enabled him to discuss issues around his death, as well as offering professionals dealing with Joe insight into a challenging area of care, so they could support him in his decision not to receive any active treatment for his HIV infection.

Support workers from George House Trust, a local agency providing support for people living with HIV (PLWH) provided invaluable help, support, counselling and education for Joe's family, especially with his decision not to take treatment, and with planning for his imminent death.

### Assessing capacity: the Mental Capacity Act (2005)

Joe is a well educated man, and demonstrated on numerous occasions that he had understood the implications of not taking treatment, and the impact that this decision would have on his future. Since Joe's decision, different consultants have highlighted at least four other patients opting not to take treatment. When dealing with emotive and challenging issues such as this, it is important that practitioners are aware of the Mental Capacity Act (2005) [3] which became law on April 1st, 2007. This legislation guides practitioners through the muddy waters of assessing a patient's ability to make health decisions.

The five key principles of the Act are:

1. A presumption of capacity: every person has a right to make decisions, and it must be presumed that they have capacity unless it is established otherwise.

2. Individuals should be supported where possible so that they can make their own decisions. Until all efforts have been made to help a person make a decision for themselves, they must not be seen as unable to make a decision.

3. People have a right to make a decision whether or not these decisions may seem eccentric or unwise to other people; and they should not be judged merely because their decision appears unwise to others.

4. Best interests: any decision made on behalf of another individual who lacks capacity must be done in their best interests.

5. A person's rights and freedoms must be restricted as little as possible. Before carrying out any act or decision on behalf of someone who lacks capacity, regard to how that can be achieved in a way that is least restrictive to their rights and freedoms must be considered.

Early in 2009, Joe was admitted onto the unit, confused, disorientated, agitated and unable to communicate; the implications of the act soon became apparent when Joe's decision-making capacity was brought into question.

On admission, Joe's speech was making no sense at all and he was finding it hard to express himself, which made him even more frustrated and agitated. The registrar gave Joe a full examination, performed a mini-mental state examination, booked Joe an urgent brain scan and arranged a lumbar puncture. He discussed what he felt the problem could be and suggested some differential diagnoses: progressive multifocal leukoencephalopathy (PML), dementia or meningitis.

There was dismay in the room when PML was mentioned. In the past a number of patients with PML had been nursed on the unit, prior to the availability of ART. PML is a rare and usually fatal viral disease characterised by progressive damage or inflammation of the white matter of the brain at multiple locations. There is no known cure, though possible treatments include *cidofovir* and *interleukin-2*, in addition to ART. Disease progression involves increasing weakness or paralysis, loss of vision, impaired speech and cognitive deterioration, and patients require intensive nursing interventions.

Blood tests revealed a low CD4 cell count and high viral load, also precursors to a range of serious opportunistic infections, which ultimately could be treated with ART. Joe was still finding it hard to communicate and was trying as best he could to express his wishes, but was unable to give a coherent response when asked what type of medical care he wanted and whether or not he wished to receive ART. The registrar felt that Joe no longer had capacity to make decisions and that, in the absence of an advance directive, the next of kin should be contacted.

## Advance directives and advance care planning

The fact that there was no formal advance directive led to much discussion within the healthcare team. It was argued that Joe had consistently made his wishes known about not wanting treatment, and there were concerns about the views of the next of kin, now that they were going to be involved. There was a fear that, naturally, Joe's father would want to do everything to prolong his son's life: what would be the legal repercussions if the healthcare team decided not to treat?

A doctor can only treat legally if there is permission from the patient to do so. If the patient withdraws that permission, the doctor is both *ethically and legally* bound to respect the patient's wishes, or to withdraw from the case [4]. Therefore, as long as the patient can direct their own care, there is no problem, as highlighted by the Mental Capacity Act [3]. However, the care of HIV patients is rarely as straightforward: due to disease progression, patients often become demented or comatose and can no longer give or refuse permission for care.

In the absence of advance care planning, advance directives or power of attorney, it is the next of kin who are in the position to make decisions about patients' care. This often results in family conflict and a lack of clear instructions for the doctor with duty of care [4].

Later Joe was diagnosed with herpes encephalitis, an acute inflammation of the brain caused by the herpes simplex virus. This was diagnosed through the examination of the cerebrospinal fluid obtained via lumbar puncture magnetic resonance imaging (MRI) scan. Joe responded well to acyclovir, and within a couple of days his cognitive function had returned to normal. He had very little recollection of his admission, so the writing of an advance directive was discussed with him, including the advantages and disadvantages of a formal document stating his wishes should he subsequently lack the capacity to make these decisions.

Advance directives indicate whom a person wishes to make treatment decisions on his or her behalf, and what treatment should be offered [5,6]. The completion of an advance directive requires that the writer fully understands the consequences of treatment decisions, and it is used when someone has become incompetent or incapable. Advance directives give patients the format and framework within which to organise their thoughts and articulate their preferences.

Advance care planning aims to prepare patients for death, providing them with a sense of control over the process. The Department of Health End of Life Strategy [7] states that all people approaching the end of life should have their needs assessed, their wishes and preferences discussed, and an

agreed set of actions reflecting their choices recorded in a care plan. Advance care planning needs to be patient led and can act as a catalyst for constructive dialogue between patients, family members and healthcare professionals [7–9].

Joe decided that he wished to put together an advance directive for care and treatment, and later said that this gave him the opportunity to maintain control of what was happening to him, and that he could make decisions about what he wanted and how he wanted to be remembered, without fear that these important decisions would be left to others not sharing his point of view.

## Palliative care and psychological support at the end of life

Advances in the treatment of HIV mean the disease is now seen as chronic and manageable. Literature on the use of advance directives dates mainly from the early to mid-1990s, when death was viewed as an inevitable outcome following an HIV diagnosis. As a result healthcare professionals were faced on a daily basis with providing end-of-life care for young people who had traditionally been viewed as part of our 'well society'.

Paradoxically, as the treatment for HIV has improved, so have provisions for caring for the terminally ill. The NHS has been committed to care for dying patients with its End of Life Care Programme (2004–2007), which has contributed to the roll-out of programmes such as the Gold Standards Framework (GSF), the Liverpool Care Pathway for the Dying Patient (LCP) and Preferred Priorities For Care (PPC) [7–12].

## Clinical supervision: the role of specialist nurses

The psychological effects of end-of-life issues can impact on the family and the healthcare team, as well as on patients themselves [13]. It is well recognised that clinical depression or anxiety are significant features of HIV following diagnosis, as with other life-limiting diseases, but it is equally important to recognise that carers are also at risk of developing psychological difficulties, during the time they are caring for the ill person and after their death [12].

Specialist nurses are well placed to help the patient and their family understand what is happening, as well as to support other members of the multidisciplinary team endeavouring to manage the complex situations which often arise. Good communication skills within the MDT are essential, with clear, accurate documentation and plans of care to ensure continuity of care.

Providing care for Joe could potentially touch on a professional's underlying fears, beliefs, behaviours and relationships with loved ones, as they contemplate their own mortality and perceptions of

what *they* would wish in a similar situation. It is hard to predict when patients or family members will experience powerful emotional reactions, and clinical supervision is an ideal forum in which to unearth and understand these feelings – often to the benefit of patient care.

## Final comments

Caring for patients who choose not to take treatment can be daunting, stressful and emotive. Good multidisciplinary support and care is vital to ensure a patient's wishes are both articulated and respected. This multidisciplinary collaboration also acts to safeguard the team involved, offering support and reassurance in the context of such complex care.

Caring for patients who are approaching the end of life is an important and rewarding field in which to work. Despite the challenges and emotional demands, healthcare professionals equipped with the necessary knowledge, skills and attitudes can find it immensely rewarding.

As for Joe, he finally left hospital with a full referral to palliative care services, but sadly did not engage very well with the community services, so still attends the hospital when he needs additional pain relief and symptom control. Recently, Joe has visited his local hospice, where he has decided to opt for care once his symptoms cannot be managed as an outpatient.

Joe is currently pain free, symptom free, and planning his last Christmas with his family.

## References

1. Gibbs G. *Learning By Doing: a guide to learning methods*. Further Education Unit, Oxford Brookes University, Oxford, 1988.
2. Nursing and Midwifery Council. *The Code: standards of conduct, performance and ethics for nurses and midwives*. NMC, London, 2007.
3. The Mental Capacity Act 2005. Available at: [www.dca.gov.uk/menincap/legis.htm](http://www.dca.gov.uk/menincap/legis.htm) (last accessed 18 October, 2009).
4. Hacker C, Watson J, Grimes R. Following the Patient's Wishes: Living Will and Power of Attorney. *Aids Patient Care*, 1995, **9**, 293–296.
5. Singer PAJ. Advance directives: are they an advance? *Can Med Assoc J*, 1992, **146**, 127–134.
6. Emanuel L. Advance directives: what we have learned so far? *J Clin Ethics*, 1993, **4**, 8–15.
7. National Health Service, Advance Care Planning, 2009. Available at: [www.endoflifecare.nhs.uk/eolc/acp.htm](http://www.endoflifecare.nhs.uk/eolc/acp.htm) (last accessed 18 October, 2009).
8. Dignity in Dying. Available at: [www.dignityindying.org.uk](http://www.dignityindying.org.uk) (last accessed 18 October, 2009).
9. Department of Health, Care Reforms Strategy. Available at: [www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/CancerReformStrategy](http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/CancerReformStrategy) (last accessed 18 October, 2009).
10. Liverpool Care Pathway for the Dying Patient (LCP). Available at: [www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway) (last accessed 18 October, 2009).
11. National Health Service, Gold Standards Framework. Available at: [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk) (last accessed 18 October, 2009).
12. National Institute for Health and Clinical Excellence (NICE). Improving supportive and palliative care for adults with cancer. NICE, London, 2004. Available at: [www.nice.org.uk/guidance/csgsp](http://www.nice.org.uk/guidance/csgsp) (last accessed 18 October, 2009).
13. The End of Life Care Working Party: British Psychological Society. The Role of Psychology in End of Life Care. Available at: [www.bps.org.uk/the-society/organisation-and-governance/professional-practice-board/ppb-activities/wpresources/theroleofpsychologyinendoflifecare.cfm](http://www.bps.org.uk/the-society/organisation-and-governance/professional-practice-board/ppb-activities/wpresources/theroleofpsychologyinendoflifecare.cfm) (last accessed 18 October, 2009).

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# HIV care in the United States: the general hospital setting

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## Introduction

Caring for people living with HIV (PLHIV) in a general hospital presents a number of challenges, due to staff lacking the appropriate level of experience to care for these patients socially as well as physically. Patients report feeling stigmatised and ostracised when admitted to non-specialist units [1]. This reflective article discusses ways in which non-specialist nurses can address their negative responses to PLHIV, and suggests that self-awareness is the key to ensuring optimum patient care in the general setting.

## Changing perceptions

Looking back 20 years, to the early days of the HIV epidemic in the United States, there was great fear and stigma surrounding the disease, not only in the general population, but also amongst healthcare providers. A survey conducted in 1990 [2] revealed that of the 323 nurses who responded, almost one-third contemplated career changes solely to avoid exposure to the virus, and more than half did not want to care for PLHIV.

Although some studies, such as the 2006 survey of Texas registered nurses [3], indicate that attitudes towards HIV-positive patients have improved, there are still many negative perceptions. A 2007 survey of American obstetrics nurses [4] found a startling disparity in nurses' intentions to care for women based on HIV status, as well as varying degrees of prejudice surrounding the alleged means of acquiring the virus. As this study concedes, nurses are human and will have personal biases that affect their views of patients and their illnesses, but it is important not to let these opinions compromise or diminish patient care.

In my personal experience, working as a nurse in the United States, it seems that the negative attitude toward caring for PLHIV still exists but has shifted somewhat with increased education about the virus. Now, stigma relates more to the associated social and economic factors than to any concern about contact with the virus. This is confirmed in further studies [5,6], noting strong correlations between nurses' desire to care for PLHIV and their religion and perception of homosexuality. I can see this in my own response at times: when assigned to care for an HIV-positive patient, my colleagues and I are generally less worried about the risk of contracting HIV, and more concerned about issues such as patient behaviour and compliance with

treatment. When HIV is only part of a laundry list of diagnoses and social problems, such as hepatitis, smoking, alcohol abuse and homelessness, we sometimes assume the patient has a history of drug abuse so is unlikely to cooperate with interventions while in the hospital or to follow up after discharge. This negative stereotype is far from the reality among PLHIV: according to the CDC, only 12% of newly diagnosed cases of HIV in 2007 involved intravenous drug use [7].

## Residual prejudice

The stereotyping of HIV patients by nurses is not always without foundation, often resulting from previous negative experiences caring for PLHIV. A recent study [8] includes drug users and uninsured patients among the most frequently hospitalised PLHIV. Even though they are not representative of the majority of PLHIV, these negative patient examples may be the most visible to hospital nurses. As a nursing student, my first HIV-infected patient was an African-American female drug abuser admitted for treatment of a very deep thigh abscess she had created, through the 'picking' behaviour common to crack-cocaine abusers. She told me that she was too afraid to find out whether she had transmitted the virus to her youngest child. In general areas, such as medicine and surgery, PLHIV are often admitted for unrelated complaints, but these may have similar underlying causes. On a predominantly surgical oncology floor where I worked for several years, there was often a correlation between PLHIV and homelessness, lack of insurance, and behaviours such as substance abuse. The same high-risk lifestyle that was responsible for their HIV status had also led to the disease for which they were being hospitalised, such as oral, facial or throat cancer, trauma or abscesses.

## Knowledge and practice

Despite increased awareness and understanding, nurses' knowledge deficiency in regards to HIV is still of great concern in the United States. One study [3] found a significant need for further education in this area, particularly among older nurses and those who worked in general areas of hospitals. This is partially attributable to the specialisation of the nursing profession and the subsequent tendency for nurses to become experts in a particular type of nursing, while often losing competency in and familiarity with other specialties. Most of what is taught in nursing school

creates a foundation for the specific skills and knowledge a new nurse will learn on the job. Therefore, even if a nurse has received some HIV education in school, working on a specialised surgical floor in a hospital is likely to result in more expertise surrounding that patient population and less on other diseases.

In most cases this specialisation is a good thing, allowing nurses to become more autonomous and skilled and to take pride in their work. However, I would argue that in the case of HIV, all registered nurses should be familiar with the disease, its treatments and the surrounding stigma. Although the HIV-infected population in the United States has only grown by 20% from 2001 to 2007, compared with the United Kingdom's 64% increase during the same period, the sheer number of those infected in the US, an estimated 1,200,000 people, is reason enough to compel nurses to become informed [9]. As medication regimens improve, PLHIV are living longer and are more likely to be hospitalised for other reasons; and nurses with no specific HIV training are more likely to be required to care for them.

In practice, the care of PLHIV should not differ from that of patients who test negative or whose HIV status is unknown. According to the American Nurses Association (ANA) Code of Ethics, all patients deserve equal medical treatment regardless of the ailment from which they are suffering, and its cause [10]. In reality, although many patients who are admitted to the hospital have tested positive for HIV, the majority of inpatients have not been tested, and unless an HIV test is medically indicated or a needlestick or other injury occurs during their stay, they are likely to be assumed negative and be discharged without testing. It is for this reason that we follow the CDC's universal precautions whenever there is possible contact with blood or other infectious body fluids, using the same provisions with each patient, because anyone could be unknowingly infected [11].

## Where to go from here?

Although much research was conducted about American nurses' perceptions and knowledge of HIV early on in the HIV epidemic, this has tapered off in the last few years, making it difficult to draw conclusions about any progress we may have made. Despite the fact that the number of AIDS-related deaths in the United States peaked in 1995, the number of people living with HIV in the US is steadily increasing, as is the mortality rate: in 2007, the greatest number of people died of AIDS in the US since the late 1990s [9]. If the disease itself is not abating, and knowledge of treatments is expanding, why are we not holding nurses increasingly accountable for quality treatment? And how can we assist nurses in being better equipped to care for an escalating number of PLHIV being admitted to hospital?

A study from 2004 [12] suggests that adding a personal component to nursing school HIV education fosters a more empathetic attitude toward PLHIV. In this study, significant differences arose between the views of nursing students who were randomly assigned to a class featuring an HIV-positive speaker and a control group class with traditional lecture and discussion.

Webb *et al.* [13] similarly recommend increasing nurses' knowledge and interpersonal communication to improve the care they provide to HIV-infected inpatients. Many of the other studies found positive relationships between increased levels of education or knowing someone with HIV, and a nurse's willingness to care for HIV-positive patients [3–6].

Mandatory continuing education programmes should be focused on HIV and AIDS, not only for older nurses who may not have had any exposure to this information in nursing school, but for all nurses, as the pathology and treatments for the virus continue to evolve. However, we can only learn so much from lectures and textbooks in a profession that is so hands-on, so there must also be an element of personal experience. Therefore, it seems that fostering a positive relationship between nurses or nursing students and PLHIV benefits both parties by decreasing fear and stigma and creating a mutual respect and empathy. And that is exactly the role that nursing should assume in the HIV epidemic: as well as an obligation to provide comfort and safe high-quality healthcare, the ANA's Code of Ethics demands that nurses facilitate social reform and reduce stigma [10]. We as nurses hold the power to revolutionise the way patients with HIV are treated, both in the hospital and in society.

## References

1. Hodgson I. Empathy, inclusion and enclaves: the culture of HIV care and nursing implications. *J Adv Nurs*, 2006, **55**, 283–290.
2. Wiley K, Heath L, Acklin M *et al.* Care of HIV-infected patients: nurses' concerns, opinions, and precautions. *Appl Nurs Res*, 1990, **3**, 27–33.
3. Watkins S and Gray J. Human immunodeficiency virus/acquired immune deficiency syndrome: a survey of the knowledge, attitudes, and beliefs of Texas registered nurses in the 21st century. *J Nurses Staff Dev*, 2006, **22**, 232–238.
4. Tyler-Viola LA. Obstetrics nurses' attitudes and nursing care intentions regarding care of HIV-positive pregnant women. *J Obstet Gynecol Neonatal Nurs*, 2007, **36**, 398–409.
5. Preston DB, Forti EM, Kassab C, Koch PB. Personal and social determinants of rural nurses' willingness to care for persons with AIDS. *Res Nurs Health*, 2000, **23**, 67–68.
6. Wang JF. Attitudes, concerns, and fear of acquired immune deficiency syndrome among registered nurses in the United States. *Holist Nurs Pract*, 1997, **11**, 36–49.
7. Centers for Disease Control and Prevention (US Department of Health and Human Services). HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States and Dependent Areas, Volume 19. Atlanta, 2007.

8. Yehia BR, Fleishman JA, Hicks PL *et al*. Inpatient health services utilization among HIV-infected adult patients in care 2002–2007. *J Acquir Immune Defic Syndr*, 16 October 2009 (epub ahead of print).
9. UNAIDS/WHO. *Epidemiological Fact Sheets on HIV and AIDS*, 2008 Update. Available at: [www.who.int/hiv/pub/epidemiology/pubfacts/en/](http://www.who.int/hiv/pub/epidemiology/pubfacts/en/) (last accessed 9 November, 2009).
10. The American Nurses Association. *Code of Ethics for Nurses with Interpretive Statements*. ANA, Maryland, 2005. Available at: [www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses.aspx](http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses.aspx) (last accessed 9 November, 2009).
11. Division of Healthcare Quality Promotion (DHQP), National Center for Preparedness, Detection, and Control of Infectious Diseases. *Universal Precautions for Prevention of Transmission of HIV and Other Bloodborne Infections*. Centers for Disease Control and Prevention (US Department of Health and Human Services), Atlanta, 1999. Available at: [www.cdc.gov/ncidod/dhqp/bp\\_universal\\_precautions.html](http://www.cdc.gov/ncidod/dhqp/bp_universal_precautions.html) (last accessed 9 November, 2009).
12. Cornelius JB. Senior nursing students respond to an HIV experiential-teaching method with an African-American female. *J Natl Black Nurses Assoc*, 2004, **15**, 11–16.
13. Webb A, Pesata V, Bower DA *et al*. Dimensions of quality care: perceptions of patients with HIV/AIDS regarding nursing care. *J Nurs Adm*, 2001, **31**, 414–417.

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# HIV/AIDS in Portugal: current trends and nursing perspectives

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Portugal has the highest incidence of HIV infection in the Western European region, with a reported cumulative number of 34,888 cases in 2008 [1]. The majority of cases (42.5%) were transmitted through injecting drug use, followed by heterosexual contact (40%) and men who have sex with men (MSM) (12.3%). Injecting drug use has traditionally been the major route of transmission, up until around 2006, as a result of the country's move away from penalising drug use. This earned the country an international reputation in drug policy, as it is *"arguably the European country that has moved farthest in decriminalizing drug use"* [2]. From being responsible for more than 30% of all intravenous drug use (IVDU) HIV diagnosis in Europe, the most common route of transmission is now heterosexual contact (57.6% of all new diagnoses in 2008) [1]. This article will summarise the country's response to the epidemic, as well as reviewing this response with regards to patient satisfaction and nursing care.

## Historical and political background

The first case of infection by HIV in Portugal was detected in October, 1983 [2]. Two years later, the Ministry of Health created the Working Group on AIDS, which aimed to gather new information on the growing epidemic, as well as implement strategies for prevention. In 1990, as the epidemic continued to spread, this working group was reformed, and the National Commission for the Fight against HIV/AIDS was created. This was responsible for drawing up the national plan for the fight against HIV/AIDS that was approved by the Ministry of Health in 1993. Amongst other things, the plan called for the decentralisation of the Commission's various functions, and thus 20 Regional Delegations of the Commission were created.

In 2000, the National Commission updated its Strategic Plan for the Fight Against HIV/AIDS, which informed its activities until 2003. It was also only after 2000 that Portugal started officially to report HIV cases to UNAIDS and the World Health Organization (WHO) [3]. In 2002, Portugal was nominated for the Presidency of the UNAIDS Coordination Council.

In 2004, the Commission ceased its operations, and the National Coordination for the Infection of HIV/AIDS was created, to better articulate the goals of that plan, as well as to develop new partnerships

and strategies for the improvement of overall health outcomes directly linked with HIV infection. Currently, the Coordination is developing a range of programmes and interventions, as well as supporting research, providing surveillance on the epidemiology of the infection in Portugal and offering information regarding HIV infection to public and private institutions, communities and individuals. It also draws up all policies regarding care of the HIV-positive population, and their social support, rights and wellbeing, ensuring these policies are effectively implemented and applied [4].

## Current trends, healthcare provision and HIV

The EuroHIV Index of 2009 placed Portugal in 22nd position [5]. This index assesses public policy and best practice regarding HIV, based on patient satisfaction and expert consultation. Yet, however comprehensive its analysis, the EuroHIV Index fails to include any trend-of-infection measurement. Despite its high prevalence by Western European standards, Portugal has seen a considerable decrease in the number of new cases, from 2731 in 2000 to 1201 in 2008 [1].

When it comes specifically to HIV-related care, this tends to occur only at hospital level. A pan-European study [6] looking at the involvement of GPs and specialist care in HIV concluded that Portugal had Europe's lowest percentage of reported involvement of GPs in HIV care, with 29% of respondents saying they had not visited their GP at all in the 6 months prior to the survey. The same study concluded that the majority of HIV-positive people in Portugal received all their care from a specialist infectious disease/HIV physician. The reasons that were highlighted for this indicated higher levels of patient satisfaction with the specialist physician than with the care received from GPs, as well as concerns that the GP would not know enough or was not sufficiently experienced in the field of HIV.

These results corroborate the way in which HIV care is organised in Portugal. Most people tend to be diagnosed by their GPs, during routine check-ups or even pre-natal check-ups. They are then referred on to an HIV specialist unit, from where all subsequent care is accessed, including free antiretroviral therapy and further healthcare and social support.

Several hospitals offering HIV care in Portugal have, since 1998, offered a combined service that treats

people for HIV and offers methadone for those willing to stop using injecting drugs [2,7]. This may be another reason why people prefer to visit a specialist unit, an area which was not documented in the study mentioned above. In any case, the reported low take-up of GP services, which can be associated with anecdotal evidence of stigma and discrimination experienced in primary care, affects the articulation of care that should be in place, according to the constitution of the Portuguese NHS.

A recent assessment undertaken by the Portuguese National School of Public Health [8] revealed that people who live with HIV tend to prefer receiving their care from one place, as this reduces frequency of exposure to situations where disclosure is needed. Moreover, some of the respondents interviewed related instances of discrimination from healthcare providers, as expressed by this female participant:

*"I received a letter from the lab where I had done my blood tests asking me to go back to the hospital immediately. I did, and at the reception when I asked what was going on, the person that saw me yelled – It's because of the HIV! – and everyone in reception looked at me. I was shocked!"*

Another participant refers back to the time when she went to the maternity ward to deliver her baby:

*"I was asked to do an HIV test by my obstetrician, to which I replied that I had none of those issues. The result was positive, and I cried a lot. One of the nurses then told me – 'You're going to be transferred to that room where the whores stay'."*

Discrimination within healthcare institutions is thus a reality in Portugal, and this sort of behaviour certainly violates any professional codes of conduct applying to health workers, given that such codes generally seek to emphasise social justice and equity. Despite these two accounts, the preliminary findings of a study on the sexual and reproductive rights of HIV-positive men in Portugal [9] has found that most instances of discrimination and/or stigma occur outside the remit of specialist HIV units. All men in this study received specialist HIV care from a hospital-based health team, with which they all seemed very satisfied, and the health team was perceived to offer excellent care, as one participant explained:

*"The support is better than in many other places. I've used hospitals in which they told me not to tell anyone I was HIV positive. Now, in the hospital I go to, nothing like this happens. The whole ward works in a fantastic way. In some hospitals you have to wait 2 or 3 hours to see a doctor. I have never waited to see my doctor, and it has always worked like this."*

The healthcare experience was described as centred around one person, the main doctor, who

was perceived as being the pillar of care. As one man put it:

*"Dr X is almost the miracle man, he is a saint! (...) when it comes to my health, I hand it all in onto science and Dr X."*

Only one man referred to the other health professionals involved in the care:

*"Nurses and healthcare assistants do a very multifunctional job, they do a bit of everything and sometimes what they do is even outside their remit. Sometimes I talk to nurses about aspects that go beyond their functions. They do the role of psychologists or doctors, they do that quite often."*

The medical profession is seen here as representing science and knowledge, and holding the power within the institution, a view which in many ways highlights the power of medicalisation<sup>1</sup> in Portuguese society. This last quote reflects well the nature of HIV nursing in Portugal. As most HIV units exist within larger infectious diseases wards, nurses are required to care for patients with a wide range of diagnoses, not just HIV. Moreover, there is no specific training on HIV and sexual health as part of the core nursing degree, which deeply impairs the knowledge acquired and potentially affects the ways in which most nurses will care for HIV-positive people, whether within or outside an infectious diseases ward. There is, however, some light at the end of the tunnel: a number of universities have created postgraduate programmes in HIV, which are mostly attended by nurses across the country. As nursing research and knowledge improves, let us hope it translates into better HIV nursing care, and increased visibility of good practice.

## References

1. Ministério da Saúde Português, A Infecção por VIH em Portugal: situação em Portugal a 31/12/2008, Instituto Nacional Dr Ricardo Jorge, 2008. Available at [www.aidsportugal.com/recursos/VIH-SIDA\\_Dezembro\\_de\\_2008.pdf](http://www.aidsportugal.com/recursos/VIH-SIDA_Dezembro_de_2008.pdf) (last accessed 2 September, 2009).
2. Godinho J, Veen J. Illicit drug policies and their impact on the HIV epidemic in Europe. In: *HIV/AIDS in Europe: moving from death sentence to chronic disease management*, Matic S, Lazrus JV and Donoghoe MC (eds). WHO, Copenhagen, 2006.
3. Matic S. Twenty-five years of HIV/AIDS in Europe. In: *HIV/AIDS in Europe: moving from death sentence to chronic disease management* (Matic S, Lazarus JV and Donoghoe MC, eds). WHO, Copenhagen, 2006.
4. Coordenação Nacional para a Infecção VIH/SIDA, Breve Historial. Available online at [www.sida.pt/](http://www.sida.pt/) (last accessed 2 August, 2009).

<sup>1</sup> *Medicalisation refers to the form of social control that "denotes the spread of the medical profession's activities, such as their increasing involvement in the processes of birth and dying. Greater power is usually assumed to follow increased pervasiveness. For that reason, the term may also be used to imply expansionist, imperialist strategies" [10].*

5. Health Consumer Powerhouse. The EuroHIV Index 2009. Available online at [www.aidsportugal.com/imagens\\_artigos/Euro%20HIV%20index.pdf](http://www.aidsportugal.com/imagens_artigos/Euro%20HIV%20index.pdf) (last accessed 26 October, 2009).
6. Tomlinson DR, Colebunders R, Coppieters Y *et al*. Primary care involvement in human deficiency virus infection – a pan-European view. *Family Practice*, 2008, **17**, 288–292.
7. Wiessing L, van de Laar MJ, Donoghoe MC *et al*. HIV among injecting drug users in Europe: increasing trends in the East. *Euro Surveill*, 2008, **13**, pii 19067. Available at: [www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19067](http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19067) (last accessed 15 April, 2009).
8. Costa C. Os melhores hospitais para cada doença – doenças infecciosas, Sábado, 27/11/2008.
9. Baptista-Gonçalves, R. Sexual and reproductive rights of HIV-positive men in Portugal, unpublished preliminary report, University of London: Institute of Education, 2009.
10. Scott J, Marshall G. *A Dictionary of Sociology*. Oxford University Press, 1998. Available at [www.encyclopedia.com/doc/1O88-medicalization.html](http://www.encyclopedia.com/doc/1O88-medicalization.html) (last accessed 10 November, 2009).

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## NHIVNA update

The web-learning programme 'hivinsight' has proved very popular, with more than 300 people accessing the site and over 500 completed modules to date. If you are not familiar with this educational programme, please do have a look via the NHIVNA website. The aim of the programme is to support nurses who are working towards Level 2 of the NHIVNA National HIV Nursing Competencies, whether based in a hospital or community setting. It is free to register and use this programme, and its flexibility allows users to work at a time and pace that suits them.

The NHIVNA Competency Framework has now been in circulation for two-and-a-half years. We have started work on an audit to evaluate the use of the framework in practice – its strengths and its limitations. The questionnaire is about to be piloted. You should all then receive a questionnaire in the New Year. Please do take a few moments to complete it. Your views are critical to how this initiative is to be used and developed in the future.

The NHIVNA study days continue to run very successfully. The theme of Health Promotion was the focus in October in London,

with the day being repeated in November in Edinburgh, and participation by delegates has been excellent. The presentations for these workshops will be available to you on the website, to use as a reference and resource.

Do remember to look out for information coming up soon about the next NHIVNA Conference. This will be held in Brighton on 29 and 30 June, 2010; however, now is the time to start thinking about abstracts and posters! Look out also for scholarships supporting conference attendance – all conference and scholarship information will be available as from early next year, both on the website at [www.nhivna.org](http://www.nhivna.org) and in the First Announcement. Dates and content for next year's Study Days will shortly be finalised, so keep an eye on the website, where details will be available as from early next year,

And lastly, a reminder to renew your NHIVNA membership! The Executive Committee wish all NHIVNA members a very happy Christmas and a successful 2010.

**Juliet Bennett**  
 NHIVNA Executive Committee

# Research round-up:

## Alternative therapy use, non-disclosure and nurse-led clinics

Catrin Evans

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**Bormann J, Uphold C, Maynard C. Predictors of complementary/alternative medicine use and intensity of use among men with HIV infection from two geographic areas in the United States. *J Assoc Nurs AIDS Care*, 2009, **20**, 468–480.**

A descriptive, correlational study on the use of complementary and alternative medicine (CAM) was conducted among 301 HIV-infected men in Florida and Georgia, USA. The objective was to identify factors influencing CAM use, which was categorised into three modalities: alternative care services (for example, massage), psychospiritual therapies (for example, meditation) and drug or dietary supplements (for example, herbal remedies). The majority of participants (69%) reported CAM use. The most frequently cited modalities were dietary supplements (71%) and spiritual therapies (66%). CAM use was significantly associated with a greater frequency of depressive symptoms and with health-promoting behaviours (such as exercise).

Interestingly, CAM use was not significantly associated with other stress-management strategies. The majority of CAM users were white men who have sex with men (MSM). The authors conclude that more research on the efficacy of CAM use in people living with HIV/AIDS (PLWHA) for symptom management and quality of life is needed, particularly in women and ethnic minority groups. Given the frequency of CAM use, the authors suggest that nurses need to discuss and promote CAM use explicitly during consultations as a potential form of HIV self-care, and assess whether any existing CAM strategies may be influencing adherence to, or efficacy of, antiretroviral therapy (ART).

**Sullivan K. Male self-disclosure of HIV infection to sex partners: a Hawaii-based sample. *J Assoc Nurs AIDS Care*, 2009, **20**, 442–457.**

This study reports on a cross-sectional survey with self-report that was designed to (i) describe serostatus disclosure to recent sex partners among a multi-ethnic group of HIV-infected men; (ii) explore factors influencing disclosure; and (iii) examine relationships between condom use and disclosure. Respondents recalled their sexual experiences, with up to three most recent sex partners, in the last 3 months. The men ( $n=93$ ) reported a disclosure rate of approximately 50% with 228 sex partners. Based on the findings, more than two-thirds of the respondents' sex

partners could be classified as at risk of HIV infection on the basis of the self-reports given, due either to non-disclosure, lack of discussion, or false reports of being HIV negative. There was a high rate of non-discussion.

A direct correlation was identified between the level of commitment to a sex partner and likelihood of disclosure (disclosure being more likely in committed partnerships and decreasing as the numbers of sexual partners increased). There was a positive association between disclosure and safer sex but this association could not be assumed to have causal significance. Disclosure was significantly more likely in men who (i) discussed their sexual partner's serostatus; (ii) were in more committed relationships; (iii) had higher incomes; and (iv) had higher self-efficacy scores for knowing when it was safe to disclose. Less likely to disclose were men who were recently infected, with multiple partners or using cocaine before sex.

The author suggests that qualitative research is necessary to explore social contexts of disclosure or non-disclosure in more depth, concluding that nurses are well placed to discuss issues of disclosure with sensitivity, while presenting other self-care strategies that enhance self-efficacy and highlight the clients' central role in addressing HIV management. In addition, she states that equipping healthcare providers with tools and techniques for exploring sensitive topics related to sexual communication with clients is essential in all healthcare settings.

**Nurse prescribing of ARVs: evidence of success in Rwanda and Lesotho, October 28, 2009, *NAM Aidsmap News*. Available at: [www.aidsmap.com/en/news/6E49B0BE-0B3C-4434-B2DE-207EADBB67CD.asp](http://www.aidsmap.com/en/news/6E49B0BE-0B3C-4434-B2DE-207EADBB67CD.asp).**

Aidsmap recently highlighted more studies of nurse-led HIV clinics in sub-Saharan Africa that have adopted task shifting – the delegation of HIV treatment management and ART prescription from doctors to nurses, in order to increase healthcare system capacity. The evaluations of Cohen *et al.* (Lesotho) and Shumbusho *et al.* (Rwanda) found that the programmes had achieved overall success, despite some study limitations. For more information on these studies, see the NAM Aidsmap website.

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