

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Volume 13 Number 4 Winter 2013

ISSN 1474-7359

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Endorsed by



**National HIV Nurses Association**

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

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

Printed in England

Winter 2013

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# HIV in the international context: Two steps forward, one step back?

Ian Hodgson

Independent Consultant, HIV Education and Research

Welcome to this edition of *HIV Nursing*. One of the privileges of writing an end-of-year editorial is the opportunity for retrospection. Each year it's important to acknowledge advances against HIV, and major events in 2013 such as the International Congress on AIDS in Asia and the Pacific (ICAAP), held in Bangkok during November 2013, have reported significant improvements in access to HIV treatment in the region, and a reduction overall in the number of new infections. In addition, as another example, I've just returned from some participatory evaluation work in Zambia. Here, projects supporting HIV prevention for sex workers in a border town close to Malawi are having real impact at the community level. This is through effective joined-up thinking and planning involving both civil society and government agencies [1].

This year has also seen growing emphasis on treatment as prevention (TasP). The idea of providing treatment as prevention emerged following a landmark study [2], which included 1763 discordant couples in nine countries, suggesting that early initiation of antiretroviral therapy (ART) reduced HIV transmission and improved the overall health of affected individuals. TasP clearly has implications for both personal and public health, but ethical questions remain: Will there be pressure on a PLHIV who doesn't want to use TasP? What about the requirements of those with *symptomatic* HIV who still can't get treatment? And perhaps, most significantly, the nemesis of public health – the danger of complacency when there is a perceived reduction in HIV risk.

All this has to be seen against the backdrop of other recent developments around ART. The so-called Option B+ for example where, to prevent mother-to-child transmission of HIV, all HIV-positive mothers are given ART from diagnosis onwards, regardless of CD4 cell count and for life. In addition, new WHO HIV treatment guidelines emerged in June 2013 [3], recommending that any person living with HIV (PLHIV) with a CD4 count less than 500 cells/ $\mu$ L should begin treatment (a much higher threshold than previously). The outcome of this will be that, as of 2013, there are theoretically 26 million people now eligible for ART – leaving just 13 million of the estimated number of PLHIV globally (39 million) not on treatment. It's an ambitious target and, if implemented, could cause significant drain on stretched health budgets.

Arguably, however, these debates are indeed a sign of progress, but 2013 has also seen regression. There is continuing use of punitive drug legislation in Thailand [4], and varied responses to HIV prevention for sex workers and MSM in many countries, such as Botswana [5]. Russia has just reported a 7% increase in new HIV infections [6], and another key issue highlighted this month (November 2013) by the European HIV Testing Week is the 30–50% of people living with HIV in the European Region unaware of their status [7]. Fifty-four per cent (54%) of those testing positive are at an advanced stage of infection, and rates are especially high among heterosexual men (66%), individuals originating from Africa (65%) and patients receiving care in southern Europe (57%). What's going on here?

Perhaps it's not helped by continuing, and significant, problems with HIV stigma and discrimination. Insights are provided by the PLHIV Stigma Index [8] which, since its launch in 2007, has been documenting the experiences of PLHIV. In Europe, data have been collected so far from Estonia, Germany, Moldova, Russia, Poland, Turkey, Ukraine and the UK. Even a cursory glance at the results suggests HIV stigma still exists at multiple levels. In Moldova, for example, 13.6% of 403 respondents report denial of health or dental services. In Estonia, 17% reported avoiding visiting a clinic when they needed to. In Russia, 26% experience sexual rejection due to their HIV status, whilst 20% faced psychological pressure from a partner, with their HIV-positive status being used against them. In the UK, 31% of respondents have not had a constructive conversation with a health care provider. Perhaps of most concern – though all these instances are bad – is from Turkey where 55 people from a sample of 100 reported being tested for HIV without their consent.

But it's not all bad news, and initiatives such as the European HIV Testing Week promote heavily the need for people to be tested, making it acceptable and indeed desirable. If approaches like this can be rolled out – as they have been in many African countries – then the European context of HIV, though intense in places and, in comparison with other regions, rapid, may also be tamed in a relatively short time.

It's against this complex backdrop that this edition of *HIV Nursing* focuses on international perspectives. We have articles from three continents

and the content will hopefully demonstrate that, though there are significant differences in how HIV is perceived and managed, there are also similarities and lessons to learn.

Julie Pearson, a York-based Health Visitor, reflects on a trip to Uganda in 2012, working for a short time in a large HIV treatment centre outside of Kampala. She shares important insights into how mothers living with HIV cope with bringing up their children, and the most beneficial approaches for health care workers to provide care and support.

Taking a global policy perspective, Liz Williams provides a detailed discussion of the upcoming deadline for the Millennium Development Goals (2015), and the importance of national governance; no longer can the international community be fully responsible for national and local policy and funding.

Shifting the focus to Eastern Europe Bojana Delibašić Bjelić, a social worker based in Bosnia and Herzegovina, discusses approaches to supporting PLHIV in a country currently with low prevalence of HIV; how are health systems with limited capacity for this very specific group perceived by those affected? Or by healthcare workers? The article reports from a small pilot study describing how PLHIV perceive their needs and the effectiveness of formal and informal care systems in meeting them.

Africa, with the greatest burden of HIV, also has significant lessons for other regions in how to deal with the virus as we read in Janey Sewell's article about a trip to Kenya, Zimbabwe and South Africa. Here, great strides have been made in scaling up HIV testing, care and support. The discussion describes how these innovations can be applied in the UK context.

James and Gillian Meek discuss HIV in New Zealand, currently a low-prevalence country. Here, similar challenges to the UK exist, such as late HIV diagnosis and the need for effective antenatal screening. Additional issues, such as cultural and ethnic factors pose challenges for the health system, and the article describes community and health service initiatives to improve testing and access to care.

Iwona Wawer and Barbara Daniluk-Kula provide a summary of the evaluation of rapid HIV testing across nine European countries. This Europe-wide initiative aims to maximise community-led strategies to scale up testing, and here we see that rapid testing, though it has key benefits, is also perceived by some clients as problematic.

Finally, we turn to Kenya. Once a person is diagnosed, how is disclosure managed at the personal level? Wesley Too provides a detailed research report of a community-based study, and we see that PLHIV sometimes adopt very different approaches to disclosing.

As always, we invite feedback on these articles, and if you would like to comment please send a message to: [hivnursing@mediscript.ltd.uk](mailto:hivnursing@mediscript.ltd.uk)

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# A UK health visitor in Uganda: Personal reflections

Julie Pearson

Health Visitor, Children's Services, York Hospital Foundation Trust

In 2012 I was fortunate to spend some time based at Mildmay Hospital in Uganda, as part of my BSc in Specialist Community Public Health Nursing and Health Visiting. This was a real personal journey for me, and gave real insights into some of the challenges, and opportunities, working in an entirely different context to the UK.

Mildmay Uganda was established in Uganda in 1998 to provide quality HIV/AIDS care, treatment, training and education. Since then it has grown to be the biggest HIV care and treatment provider in central Uganda. Currently, around 45,200 people receive care and support from Mildmay Uganda every year – 19,440 adults and 4560 children from the central hospital, and 21,200 people at district level.

As of 2013, there are about 1.2 million people living with HIV in Uganda, and the prevalence rate is 6.5% of adults between 15–49. However, in the central region where Mildmay Uganda is based, only 15% of the population have been tested for HIV, and just 40.5% requiring treatment have access [1].

The central Mildmay Uganda Hospital cares for around 24,000 people at any one time. The main services provided include adopting a family-centred approach, children's ward, sexual and reproductive health services, prevention of mother-to-child transmission (PMTCT), family planning and research.

Health visitors in the UK support and educate families from pregnancy through to a child's fifth birthday. Their common tasks include offering parenting support and advice on family health and minor illness, new birth visits and providing advice on feeding, weaning and dental health, physical and developmental reviews, providing families with specific support on subjects such as postnatal depression. Some of the public health issues faced daily are childhood obesity, sudden infant death syndrome, and postnatal depression. None of these are recognised in Uganda: more commonly they face issues such as HIV, malaria, TB, poverty and malnourishment. Many children are in orphanages following parental death or through being abandoned.

Having worked previously in the UK HIV sector, I had some knowledge of the impact of HIV such as stigma, isolation, prejudice and struggles with treatment adherence. In the UK a continuing challenge is promoting and instigating

breastfeeding, which competes with several types of formula milk to tempt a new mum! As a result of poverty, and societal expectations, the majority of mothers in Uganda breastfeed. Malnourishment in babies is common, and can be a double-edged sword for an HIV-positive mother with an HIV-negative baby – there is a risk of vertical HIV transmission, though if she does not breastfeed the baby is at risk of malnutrition due to the lack availability and cost of formula milk. Sterilising equipment is not available and therefore if the baby is formula fed there is the risk of gastroenteritis.

## The challenges of parenting: Mercy and her baby

One Ugandan patient I met, Mercy (her name has been changed), was 27 years old and a single parent. Her husband left her during the pregnancy, and she lives in a rural area of Uganda. She was diagnosed HIV positive a year ago when her baby was 5 weeks old. She also has a toddler of 2 years. The toddler had been exclusively breastfed until 1 year old and is HIV negative. Her husband had left her when her HIV status was disclosed but the likelihood was that she had caught the virus from him.

Mercy engaged well with the antenatal service at the HIV clinic and commenced on antiretroviral treatment (ART) to reduce the HIV viral load and decrease the chance of transmission to her baby. Her baby commenced ART (syrup) at birth but her HIV status was unknown until an HIV test at 6 weeks. Her baby had been admitted into hospital at 5 weeks old with severe malnutrition and gastroenteritis. Mercy breastfed her for 4 days but had stopped, as she was concerned she would infect her baby. On stopping breastfeeding she fed her baby with water, cow's milk and porridge.

In hospital it was recommended that Mercy should try and reinstate breastfeeding: the risk of her baby dying of malnutrition outweighed the risk of dying of HIV. Staff discussed with Mercy the pros and cons of breastfeeding so she was able to make an informed choice.

Mercy was distressed with no support at home and unsure of what to do for the best. She was also dehydrated, exhausted, and malnourished herself. She agreed to attempt to restart breastfeeding.

Mercy was distressed and felt guilty, blaming herself for her baby's poor health. For her it was not

an option to resort to formula feeding as would be recommended in the UK. Sadly, due to the poor physical health of both mum and baby, the nurses did not think the prognosis was good, especially for the baby.

To combat this common scenario, a Baby Friendly Initiative (BFI) has recently been introduced into Uganda. Any maternity facility can be designated 'baby friendly' when it does not accept free or low-cost breast milk substitutes, feeding bottles or teats, and has implemented 10 specific steps to support successful breastfeeding [2].

## Stigma and treatment access

Stigma continues to surround HIV in Uganda, inhibiting progress tackling the virus. These confounding issues include extra-marital affairs, partners not disclosing their positive status and the unwillingness to use condoms. HIV continues not to be discussed in families, meaning they receive no emotional help or support.

Accessing ART can be difficult with patients having to travel long distances, mainly on foot. The hospital runs on a first-come, first-served basis, and has a waiting room full of patients as early as 6am. Mildmay takes a lot of time with patients, particularly around understanding the need for ART adherence. If a positive status is not disclosed within the family it is difficult to take medication secretly without other members of the family being aware. Government-run satellite clinics have some benefits at the community level, but these are generally poorly run due to low salaries, low staff morale and lack of organisation.

Uganda is blighted with poverty, politics, and many health issues apart from HIV. However, the patients, staff and people that I met and worked alongside were optimistic: friendly and warm, cheerful, resourceful, professional and eager to learn. Where a UK mum struggles with postnatal

depression, redundancy or poor diet, the benefit system is available for assistance. In Uganda, a mother can struggle with poverty, babies with malnutrition and HIV, with little outside help. In some ways I came home frustrated. As a nation we take things for granted – the NHS, a strong welfare state, and well-run charity organisations to offer emotional and practical support and in some cases financial support and travel expenses. New mothers in the UK also have freedom of choice whether to breast or formula feed without the threat of malnutrition or HIV transmission.

## Different context but the same challenges

I came back to the UK having grown on both a personal and professional level. I would recommend that, if the opportunity arises, every nurse should spend some time in clinical settings abroad. I have been able to bring new skills back to my health-visiting practice in the UK. It also became clear that, despite living miles apart, people affected by HIV face similar issues the world over, such as stigma, isolation, prejudice and the difficulties of treatment adherence. Whilst globally we still have a long way to go to tackle the effects of the virus, at the individual and community levels much has been learnt and achieved.

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# The Millennium Development Goals +15: What now for HIV?

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With the deadline for achieving the Millennium Development Goals approaching rapidly, policy-makers, academics and civil society actors are debating how successful the goals have been and what should replace them [1,2]. Success in meeting the goals has been at best patchy. Whilst targets on poverty, slums and water have been met [3] this has largely been attributed to the success of emerging economies, most notably China and India [2]. Other goals remain way off target and where progress has been made persistent levels of inequality are evident both within and across countries [3]. One school of thought is that the Millennium Development Goals reflect a flawed project that focused too narrowly on specific indicators of poverty and inequality rather than underlying sociological, political and economic factors. The argument follows that they should be replaced by an enhanced commitment nationally, internationally and globally to the broader goals of social justice, equity and good governance.

At a UN summit held in September 2013, world leaders met to discuss the MDG +15 agenda, as it has become known. It was noted that whilst great achievements had been recorded, the overall response had been too uneven, with significant gaps. Committing to scale up the response to extreme poverty, hunger and disease, a report published to coincide with the summit identified five 'big transformative shifts', cross-cutting themes, which participants argued should form a universal agenda for what comes next (see Panel 1).

The first of these shifts, *leave no one behind*, is described thus:

We should ensure that no person – regardless of ethnicity, gender, geography, disability, race or other status – is denied universal human rights and basic economic opportunities. We should design goals that focus on reaching excluded groups [4].

For those of us concerned with the health and well-being of people living with HIV this clearly resonates. A human rights-based approach to HIV has been the cornerstone of policy and programming since the earliest days of the epidemic. Of course it is too early to say for sure how these five shifts will translate into action. Much of the detail is still up for debate. But nurses do need to be thinking about where HIV will fit in to the bigger picture of development post 2015. What does seem to be emerging is that there are unlikely to be disease-specific goals; rather, the approach may be for increased integration of cross-cutting issues.

Given this uncertainty, this paper will focus upon MDG 6, *Combat HIV/AIDS, Malaria and Other Diseases* (see Panel 2), and explore what 'leave no one behind' might mean in relation to the emerging agenda for an 'AIDS-free generation,' with particular focus upon middle- and low-income economies. What does an 'AIDS-free generation' mean in contexts where there is pervasive inequality, human rights abuses and enduring poverty? How can we respond to the challenge of reaching key populations? Has the vitally important renewed focus on biomedical approaches, such as treatment as prevention and male circumcision, led to a shift in focus away from other approaches to prevention? And, importantly for us as a professional group, how should nurses respond to these challenges?

But first, I want to take the opportunity to offer a personal reflection on the changes wrought in the provision of treatment to people living with HIV since the setting of the MDGs. In the rush to criticise it can be easy to overlook the remarkable changes that have taken place over the past 15 years. In the summer of 2000 I was in West Bengal, India, researching how global guidelines for HIV prevention and control, and care and support were being translated into action by non-governmental organisations. As a nurse who had worked in HIV in

## Panel 1: Five big transformative shifts [4]

- Leave no one behind
- Put sustainable development at the core
- Transform economies for jobs and inclusive growth
- Build peace and effective, open and accountable institutions for all
- Forge a new global partnership

## Panel 2: Millennium development Goal 6: combat HIV/AIDS, malaria and other diseases [5]

- Halt and begin to reverse, by 2015, the spread of HIV/AIDS
- Achieve universal access to treatment for HIV/AIDS for all those who need it
- Halt and begin to reverse, by 2015, the incidence of malaria and other major diseases

the UK I was repeatedly struck by the contrast between what was available to people 'back home' – with respect to care and support – and the limited options available to the people I met during the course of my research. A World Bank document discussing the rationale for the approach to be taken in the next phase of Indian HIV programming gives a clear indication of the thinking at that time:

Providing Western-based treatment and care of AIDS cases for example triple therapy was rejected ... these treatments are hugely expensive, remain palliative and are unlikely to have an impact upon HIV transmission [6].

Instead, the focus of care and support was to be the development of Low Cost Models For Community and Home-Based Care and Support with some ring-fenced money for the treatment of opportunistic infections via the public health care system. The reality of this was made clear to me by an outreach worker for sex workers talking about the problem of trying to support HIV-positive women:

All of a sudden they disappear. One girl who was very close to us, she was gone for a few months ... and then we heard that she had died. When the girls know that they have HIV they give up [7].

At that time it was impossible to imagine the changes that the following decade would bring.

Against this background, the most recent figures published by UNAIDS show that there has been a 30% drop in AIDS-related deaths since the peak in 2005. By the end of 2012 antiretroviral therapy (ART) had been made available to 9.7 million people living in low- and middle-income countries. This represents an increase of 20% in just one year [8]. In India this means that a reported 570,620 people now have access to ART. To reflect rapid progress the target set for access to ART was increased in 2011 to 15 million people by 2015, and recently the WHO revised its HIV treatment guidelines to reflect treatment as prevention, increasing the estimated number of people in need of HIV treatment by a further 10 million. UNAIDS also announced a 33% reduction in new infections amongst adults and children since 2001. As such, using the criteria set by MDG 6, globally the AIDS epidemic has been halted and reversed.

Speaking at the launch of the latest global report into the HIV epidemic, Michel Sidibe, Executive Director of UNAIDS, clearly echoing the MDG +15 agenda, said:

Not only can we meet the 2013 target of 15 million people on HIV treatment – we must also go beyond and have the vision and the commitment to ensure that no one is left behind [9].

So there is undoubtedly much to celebrate. But it is too soon to be complacent. An estimated 1.6 million

people died from AIDS-related illnesses in 2012, and 2.3 million people newly acquired HIV (see Panel 3). The UNAIDS report also highlights that in a number of key areas, ensuring respect of human rights, enabling people most at risk of HIV infection (particularly people who use drugs) access to HIV services, and the prevention of violence against women and men, progress has been slow. Punitive laws, discrimination and gender inequality represent persistent obstacles to the scale-up of national responses. Worryingly, in some countries where there has been a significant decrease in rates of infection, sexual-risk behaviours amongst young people seem to be on the increase.

#### Panel 3: 2012 estimates [10]

- 35.3 million (32.2–38.8 million) people globally living with HIV
- 2.3 million (1.9–2.7 million) people became newly infected with HIV
- 1.6 million (1.4–1.9 million) people died from AIDS-related illnesses

## Behavioural interventions and structural interventions, as well as biomedical ones

The UNAIDS global report [8] highlights that prevention efforts aimed at men who have sex with men (MSM), sex workers and people who inject drugs (IDU) are insufficient and transmission rates remain stubbornly high. Men who have sex with men report a lack of availability of condoms and lubricants. Criminalisation and the very real threat of violence or even death continue to be major barriers preventing men who have sex with men and transgender people from accessing HIV services. Injecting drug users are similarly discriminated against, with many countries enacting punitive laws. Despite over 20 years of evidence for what works, people injecting drugs continue to be denied access to needle exchange services and opiate substitution therapy [8]. Pregnant women and children are also facing barriers to accessing HIV treatment services. A similar picture emerges for sex workers.

The common thread here is the importance of maintaining and increasing support for behavioural and structural interventions. There is a fear in some quarters that, with the possibilities of HIV prevention from ART and male circumcision, momentum may be lost on these vital programmes [11]. UNAIDS notes that:

There are worrying signs that social and behavioural programming might now have a lower priority ... however as new biomedical tools are rolled out, effective social-behavioural and structural programmes will not only remain



essential in their own right but will also be needed to maximise the efficacy of biomedical approaches, including averting the possible emergence of risk compensation ... behavioural and structural programmes also help to overcome barriers to service uptake, such as social exclusion, criminalization, stigma and inequality [8].

An associated theme is that of how to ensure community action, the bedrock of HIV prevention in low- and middle-income countries, is maintained and scaled up. With a funding base shifting from international donors (particularly in middle-income countries) to national level actors, non-governmental organisations and community-based organisations will need to develop new alliances with the public and private sectors in order to secure funding [12]. This may prove difficult if the national context is one of discriminatory laws and exclusionary social practices.

## Funding

The picture of funding for HIV globally has been a worrying one in recent years. The global economic downturn has affected the willingness or ability of both bilateral and multilateral donors to meet their funding commitments to aid and development programmes. The cancellation of Round 11 of the Global Fund for AIDS, Tuberculosis & Malaria in the autumn of 2011 led to a significant reduction in dedicated funding for HIV, TB and malaria. This was described by the UN Reference Group on HIV and Human Rights as presenting the international community with 'both a health and a human rights crisis' [13]. Fortunately, since September 2013 there has been a renewed commitment from some quarters to increased funding to meet MDG 6's target for treatment of HIV [14]. The UK Department for International Development has pledged to give £1 billion to the Global Fund over the next 3 years provided that other donors also meet funding commitments. To date, both the USA and France have responded positively with increased commitments. DFID estimates that the extra funding will provide ART for 750,000 people [15].

To put HIV and AIDS into the wider context of health service provision, global institutions are also beginning to change their thinking on funding. There is a growing recognition that health is an essential precursor to economic development as well as a human right. This signals a return to the values and ethos of the Alma Alta Declaration and 'health for all' [16]. The imposition of user fees is now being widely rejected as a strategy for health funding with a new commitment to raising funding from public financing mechanisms (including taxation). Activists have long argued that numerical targets for single disease have led to fragmentation of both health priorities and systems [17] and unduly diverted funding away from health service

strengthening. The WHO is promoting Health Service Strengthening by arguing for Universal Health Coverage and primary health care [18]. Research for universal health coverage is the theme of the WHO's 2013 World Health Report [19]. The World Bank is also on the record as rejecting user fees and promoting Universal Health Coverage:

The aims of universal coverage are to ensure that all people can access quality health services, to safeguard all people from public health risks, and to protect all people from impoverishment due to ill health [20].

Only time will tell how successful this new approach is in ensuring that the most vulnerable, impoverished and excluded people are able to access the health care that they need. Certainly, looking back again at my time in West Bengal in 2000, the one thing that project workers spoke of more than anything else was their desire to respond to the 'felt needs' of their project users. To care for their health in its totality and to provide access to wider health services.

## Implications for nurses and health workers

What then does all of this mean for nurses and health workers currently working in HIV/AIDS within resource-poor settings? One of the big stories in recent years has been the success of task shifting, where nurses or other health workers have taken responsibility for ART initiation and re-prescription. A study from 2012 found this could be done safely and improve health outcomes [21]. How nurses view this enhanced role is less well documented. What is clear is that nurses working in the field and in highly challenging situations need to be more engaged in the policy process and should be supported to actively shape health policy [22]. A paper exploring the experiences of nurses working in HIV prevention and care in six countries (Canada, Jamaica, Barbados, Kenya, Uganda and South Africa) found that respondents all reported a lack of involvement in policy development and the imposition of 'top-down' policies [23].

The need for nurses with experience of working in HIV to share their skills and expertise, and to train and support the development of colleagues, will become increasingly important as HIV treatment comes on stream and more and more people are living with HIV over the longer term. Indeed an emerging new challenge in HIV care is how to support an aging population who may have been taking ART for many years and have significant comorbidities. As access increases, and as a 'normalisation' of the epidemic takes place, country-level health services will need to adjust and change to meet the challenge. Health workers who may have no experience of caring for people with HIV will need to skill up and incorporate HIV care within the wider remit of their professional practice.

This inevitably raises the spectre of stigma and discrimination that originates from within the health sector. The most recent UNAIDS report on the global epidemic, discussed earlier in this paper, identifies an urgent need for men who have sex with men to have access to 'culturally sensitive HIV counselling and testing and antiretroviral therapy' [8]. Describing this as a global health priority the report highlights the fact that the fear of disapproval and discrimination by health workers is a significant stumbling block in achieving this aim [8].

## Concluding comments

The MDG +15 agenda is still under discussion. The exhortation to 'leave nobody behind' offers people living with HIV or AIDS, civil society actors, nurses and other health care workers an entry point into the global debate about where HIV should be situated in the new framework and what work still needs to be done. Globally, nurses have much experience to bring to this debate, not just in relation to HIV but to broader issues. Whilst acknowledging challenges faced by nurses in getting their voices heard in the policy arena, wherever possible nurses should endeavour to share their thoughts and experiences, their hopes and fears, and their aspirations for what HIV nursing will look like in the post-2015 world.

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# A study of adjustment by PLHIV in Bosnia and Herzegovina, and of requirements for psychosocial support

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## Introduction and background

**B**osnia and Herzegovina (BiH) is a small country (population: around 4 million) with low rates of HIV. Although an epidemic is not currently in prospect, various problematic social factors could combine to bring a marked rise in prevalence:

- Socioeconomic challenges
- Prevalence of human trafficking
- High unemployment
- High rates of prostitution
- Lack of HIV/AIDS education
- Immigration from high-prevalence areas
- Rising drug addiction
- Stigma/discrimination around HIV
- Limited testing and care for STIs
- Poor access to high-risk groups
- Low uptake of HIV testing

Between 1986 (when BiH registered its first HIV case) and the end of 2012, 221 people were registered as HIV positive, of whom 120 subsequently developed AIDS. Most are men (80.5%), with the main transmission route by heterosexual sex (52.1%), followed by homosexual-bisexual (28.5%). Most HIV patients are from the age groups 20–29 (33.8%) and 40–49 (26.3%).

Every society, including BiH, has an obligation to establish a comprehensive system for ensuring ethical, humane and individualised treatment, care and rehabilitation, and to confront stigma and discrimination against PLHIV. Psychosocial problems related to HIV/AIDS are increasingly present in BiH. HIV/AIDS is not only a medical but also a psychosocial problem. Social work as a profession is an appropriate framework through which society can improve quality of life and reduce suffering for PLHIV.

PLHIV face many problems and difficulties that they cannot solve alone and they need help and support from the communities in which they live, as well as input from services that can provide support for an acceptable quality of life. All welfare systems should include adequate measures for psychosocial assistance and support for PLHIV and their families. Unfortunately, this is not the case in BiH.

PLHIV receive medical assistance, which is funded by public health insurance. Clinical treatment is free and carried out at infectious diseases clinics in Sarajevo, Banja Luka, Tuzla and Mostar. Social and welfare institutions have little involvement in this area, and more input is needed. There is a steady rise in the numbers of people registered in the early stages of HIV, whose lives are being prolonged by antiretroviral therapy. However, because psychosocial problems are inextricably linked with HIV/AIDS, psychosocial support for PLHIV is key to improving life quality and preventing onward transmission. Specifically, these issues fall within the remit of the social work teams.

NGOs (non-governmental organisations) play a major role in providing psychosocial support to PLHIV. They also contribute significantly to raising awareness about HIV/AIDS among young people and have established effective partnerships with relevant stakeholders in tackling HIV/AIDS. These stakeholder groups include Governmental institutions, healthcare facilities, schools, the media, the police, other NGOs, UNAIDS [1], UNICEF [2], UNDP [3], WHO and other international organisations.

Both practising and trainee social workers and psychologists (and similar professions) lack adequate education about working with PLHIV. Addressing their own prejudices and attitudes towards PLHIV is not a part of their training or working routines. Tackling these issues through social work is key for current and future professionals in this field, but most of all for PLHIV.

## Policy and legislation

No legislation specific to HIV/AIDS exists in BiH. All citizens are automatically entitled to the highest attainable standards of human rights and values, to physical, mental and emotional wellbeing, and for their moral, cultural, religious and philosophical convictions to be respected. Fundamental human rights and freedoms are enshrined within the Constitution of BiH and other state legislation, as well as various declarations and charters which have been ratified by this country.

Respect of human rights is crucial in preventing the spread of HIV/AIDS and reducing the associated

stigma and discrimination. The Law of Population Protection from Communicable Diseases requires every citizen with a disease that may endanger the health of others to seek appropriate treatment, and to avoid exposing others to any risk of infection.

BiH has ratified the UN Declaration of Commitment on HIV/AIDS (2001), the UN's Millennium Development Goals (2000) [4,5], the European Council's Programme for Action (2001) [6], the Southeastern Europe Declaration on HIV/AIDS Prevention and Care (2002) [7] and other related international documents.

BiH has established a National Advisory Committee for AIDS comprising representatives of entities (The political divisions of BiH were created by the Dayton Agreement, which recognised a second tier of government in BiH comprising two entities – a joint Federation of Bosnia and Herzegovina [FBiH] and the Republika Srpska [RS]) and Brcko district governments, NGOs and international agencies. National Coordinators for HIV/AIDS have also been appointed, and a framework has been put in place for the prevention and treatment of HIV/AIDS, including centres for voluntary and confidential testing and counselling. BiH has initiated research on HIV/AIDS-related behaviour and service access among MSM (men who have sex with men), IDUs (injecting drug users) and sex workers (SW). Collection and analysis of epidemiological data around HIV/AIDS has been carried out by the Institute of Public Health of the Republic of Srpska and the Federal Office of Public Health. The BiH Council of Ministers has initiated a National Strategy to Prevent and Fight against HIV/AIDS (to be in place by 2016), while the Ministry of Civil Affairs has been appointed to coordinate activities related to HIV/AIDS issues.

The NGOs assigned to this problem have made significant progress in reducing the incidence of HIV/AIDS, cutting through the associated stigma and discrimination and providing psychosocial support for PLHIV through various activities and services aimed at young people and the general population. BiH recently completed a programme supported by the Global Fund in conjunction with the UNDP, which launched a national response to HIV/AIDS, with involvement from government departments such as the Ministries of Health, Social Welfare and Civil Affairs, along with infectious diseases clinics, hospitals, health centres, public health bodies, psychiatric clinics and specialised NGOs. The programme included a focus on post-conflict contexts, and was key in initiating improvements in HIV interventions from 2008–2011.

## The Study

*Aim:* To examine the mechanisms by which PLHIV adjust to their illness, and the requirements for appropriate psychosocial support.

*Objective:* Principally, to assess and record the needs of PLHIV, as seen by themselves and by the professionals who work with them.

*Sample:* Two sub-samples were employed: (a) people who living with HIV/AIDS ( $n=10$ ), and (b) professionals who deal with HIV/AIDS issues ( $n=10$ ).

*Method:* The study was exploratory, based on two semi-structured interviews of 14 questions, constructed specifically for this research. Interview content was then comprehensively analysed. Research was conducted in 2009 in four cities: Banja Luka, Sarajevo, Tuzla and Mostar.

*Results:* Presented below, by sample.

### Sample A: People living with HIV

#### 1. Background and profile

The PLHIV subjects comprised five males and five females in the 24–65 age bracket, based in urban (70%) and rural (30%) areas. Forty per cent of PLHIV questioned had high-school qualifications and all respondents reported having health insurance. The length of time they had lived with the disease ranged from 1 to 13 years. Sixty per cent had never had a break in antiretroviral therapy (ART), 30% had had a brief interruption due to lack of treatment availability, and 10% were not on treatment. Ninety per cent of respondents believed that regular medication alone was 'adequate therapy' and did not connect with or have expectations of psychosocial support alongside drug therapy as a comprehensive treatment for PLHIV.

#### 2. Usage and experience of services

All respondents used the services of infectious diseases clinics, which fulfil all physical healthcare requirements. Usage of health services outside of infectious disease clinics is rare. Fifty per cent of respondents rarely used other health services (e.g., family doctor, specialist clinics). Of those who did, 70% had not disclosed their status and 30% had (see also Relationships and Disclosure, below).

Forty per cent said that a social worker from the clinic fulfilled their social welfare needs and that they therefore did not attend the Centre for Social Work (CSW) (Table 1, Figure 1). Those who were

**Table 1: Respondents' use of other services**

Service	Centre for Social Work	NGO	Religious organisation
<i>Usage (%)</i>			
Use	50	60	20
Do not use	40	20	70
No response	10	20	10

using CSW services gave their main reason as financial and material assistance, but never their HIV status alone. Of those who had used or were currently using CSW services, just two were seeking psychosocial support, with the rest requesting only material assistance.

All respondents stated that lifestyle advice was something they received from their treating doctor, or through NGOs that included the Association for Supporting People Living with HIV (APOHA), and Action Against AIDS (AAA). Eighty percent reported adhering to instructions about diet, while only 30% undertook adequate physical activity.

The services of specialised NGOs – counselling centres for psychosocial support – were used by 60% of respondents. A religious organisation was used exclusively for the supply of food and clothing. Most respondents expressed satisfaction with services received from other sources (Figure 1).

Reasons given for dissatisfaction with other services were:

- financial and material support did not meet required level;
- generally poor standards of service;
- too few professionals interested in HIV issues.

### 3. Employment and the workplace

Most respondents believed that finding work is very difficult for those who are HIV positive. Respondents who were in work (30%) had not disclosed their HIV status to their employer. Problems faced at work varied according to job type (Figure 2), but the most significant issue recorded was working days missed (40%).

### 4. Emotional responses

Nearly all respondents (90%) were shocked when told that they were infected; only 10% were prepared for a positive test result.

It is very difficult for PLHIV to articulate their feelings in relation to the disease, and extended sessions with respondents were necessary to get a full picture of their emotional response.

Half the respondents (50%) felt that other people avoid PLHIV and reject them from the community,

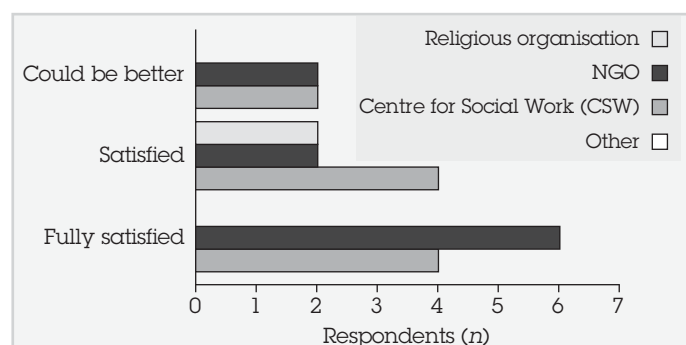


Figure 1: Satisfaction level – other services.

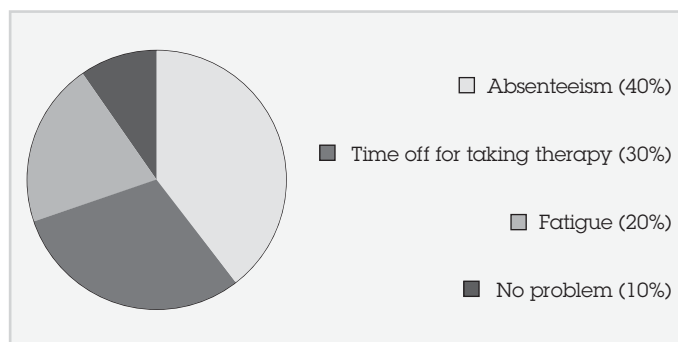


Figure 2: Problems faced at work due to HIV status.

possibly due to fear of infection. Half (50%) reported a negative experience with others in the community.

The majority of respondents (60%) reported that, before diagnosis, they had been energised, bright and cheerful individuals – who had since become withdrawn, lonely and demoralised. Respondents explained that the greatest fear arising from their HIV status was losing access to ART (Figure 3). Despite this, 70% claimed to be satisfied with their current life, while 30% said that they were not.

### 5. Relationships and disclosure

Respondents not in a relationship (60%) took the view that it is difficult to find a partner, while those in a relationship (40%) said they had not thought about it, and three-quarters of these said that they were satisfied with their relationship. When asked to rate their current relationships (immediate family, close relatives, friends or other people) the 'unchanged' category logged the greatest number of responses (Figure 4).

Eighty percent were against disclosing in a short-term relationship, while only 20% believed in disclosure to any/all partners. All agreed that condoms should be used with all partners, whatever the nature of the relationship. Regarding disclosure in other areas, the context where most respondents were against disclosure was the workplace, where 80% believed that, unless it is essential, one's HIV status should not be disclosed; although 20% were less adamant and considered that other workers might need the information in order to take appropriate protective measures if the

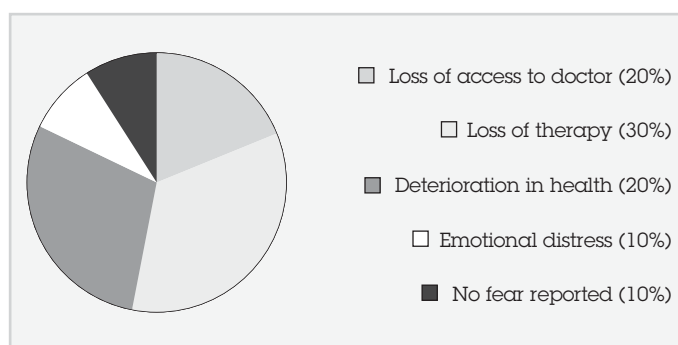


Figure 3: Reported fears relating to HIV.

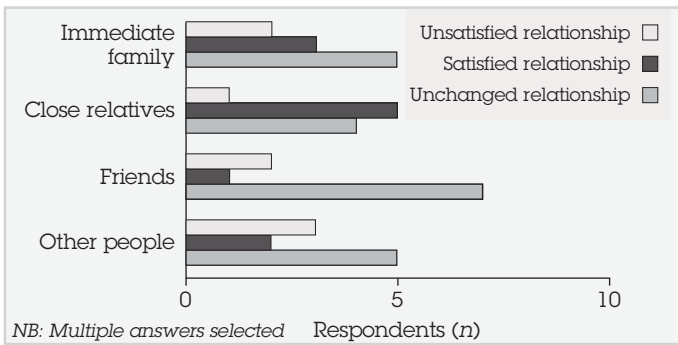


Figure 4: Satisfaction of PLHIV in relationships with others.

context arose. Respondents were split 40%–40% as to whether or not to disclose to a doctor (when seen outside of the context of HIV). Most respondents who did not disclose reported positive or neutral experiences with healthcare workers; whereas those who disclosed their HIV status reported unpleasant or negative experiences, such as cancellation of appointments, removal from the premises, impolite and insulting behaviour by doctors (Figure 5).

Other people aware of their HIV status were mainly (for 90%) their loved ones – parent, partner/spouse, sibling, close relatives – and the news produced a range of reactions (Figure 6). Only 10% had disclosed to a close friend.

### Sample B: Professionals working with PLHIV

#### 1. Background and profile

The ten professionals who were questioned (six women and four men) all lived in the cities where they worked: Banja Luka, Sarajevo, Tuzla and Zenica. Most respondents were university graduates (60%) and all had from 1 to 13 years' experience in the field. It is characteristic for these professionals to work in more than one job.

Forty percent of respondents had their first encounter with HIV through work in infectious diseases clinics (40%), while for 20% it was via the VCT (voluntary counselling and testing) service. Ten percent started this work at the Centre for Social Work (CSW) and 20% exclusively through NGOs. Most respondents (80%) had experience of working on various HIV projects through NGOs.

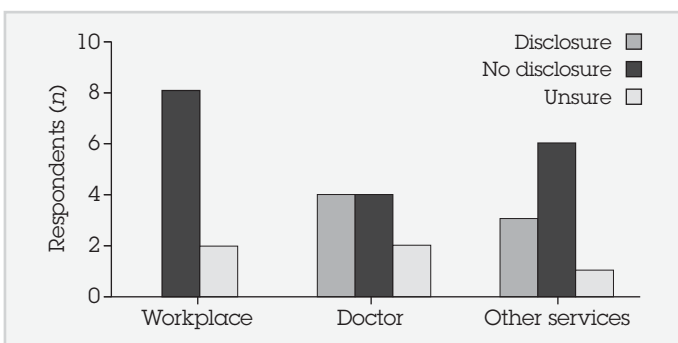


Figure 5: Formal contexts for disclosure/non-disclosure.

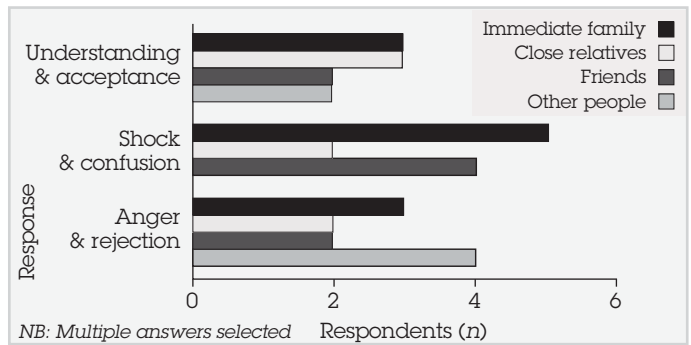


Figure 6: Perceived reactions of others to disclosure.

#### 2. Services provided

The respondents reported a range of services that they offered for PLHIV, recorded in Table 2.

#### 3. Perceptions of current treatment options

Half (50%) of professionals interviewed rated existing treatments for PLHIV as satisfactory, while 50% believed them to be inadequate. Typical answers are recorded in Table 3.

Table 2: Range of services undertaken for PLHIV

Respondents (n)	1	2	3	4	5	6	7	8	9	10
<b>Services provided</b>										
Information & education	✓	✓	✓		✓		✓			
Psychosocial counselling	✓		✓	✓	✓	✓		✓		✓
Medical support				✓						✓
Anti-discrimination activity	✓	✓			✓		✓			✓
VCT	✓	✓		✓		✓	✓			✓
Lobbying for rights/interests of PLHIV	✓				✓		✓			
Outreach with at-risk populations: MSM, prisoners, sex workers, IDUs	✓	✓			✓		✓			
Research & studies	✓	✓			✓		✓			✓
Developing programmes policies, laws	✓	✓			✓		✓			
Providing social welfare rights			✓		✓			✓		

#### 4. Scope and priorities for improvement

The respondents had a range of views on the most significant triggers for legal and social change, and the most effective ways to enhance treatment and services (Table 4). Thirty percent of respondents believed that BiH needs more powerful legislation, to regulate all areas of life and work for PLHIV, while 60% suggested further empowering those already working within the community, through improved networks and systems, to facilitate cooperation, mutual support and data-sharing. Just 10% felt that lobbying on all levels of government would be a key activity for change.

**Table 3: Assessments of current treatment of PLHIV**

Satisfactory	Inadequate
<ol style="list-style-type: none"> <li>In terms of choice, treatment offered is satisfactory, because PLHIV can access both free antiretroviral therapy and psychosocial counselling through clinic attendance.</li> <li>A comprehensive range of services and programmes is offered, with state bodies, governmental and non-governmental sectors all working together.</li> <li>Service is not dependent on wealth: testing, drugs and treatment are free at the point of use for all citizens; and there are also VCT services and various campaigns to support them and promote their rights.</li> </ol>	<ol style="list-style-type: none"> <li>Focus on the needs of PLHIV is not specific enough: clinics do not have dedicated units, some diagnostic equipment is lacking, current legislation is inadequate and social needs are not fully addressed.</li> <li>Despite progress made in setting up existing treatment and programmes, discrimination and stigma continue in all aspects of life, overshadowing many of the positives.</li> </ol>

**Table 4: Suggestions to enhance services for PLHIV**

Respondents (n)	1	2	3	4	5	6	7	8	9	10
<b>Suggested changes</b>										
Improve and advance existing services	✓		✓			✓	✓	✓		✓
Develop comprehensive HIV/AIDS treatment centres		✓		✓	✓					
Instigate laws and policies to regulate and protect										
Improve promotion of existing services		✓		✓						✓
Work on prejudice by service providers to PLHIV		✓							✓	
Increase budgets in various sectors	✓		✓		✓					
Enhance social worker involvement	✓	✓	✓			✓				✓

### 5. Required social worker services for PLHIV

The majority response was that social workers should have a key role in psychosocial support, securing the right to health and social welfare and broadly representing rights of PLHIV within society. Twenty percent of respondents felt that far more social workers should be deployed in the field of HIV/AIDS, although most did not see the social worker as an essential presence in the medical teams working with PLHIV, nor as being key in reducing stigma and discrimination.

The social worker was seen primarily as a provider of important practical input for PLHIV: 30% education, 10% motivation, 20% support and understanding from the community and employers.

Half the respondents (50%) were aware of how PLHIV can access their right to social and health welfare, while 30% did not have this information and 20% were unsure if their information was current. Forty percent of respondents knew that material assistance for PLHIV is part of the CSW

service, 20% of them knew that PLHIV received psychosocial support and 40% cited other social services provided by the public sector that might also apply for PLHIV.

## Results overview

On the whole, PLHIV are reasonably well catered for, because their status is not known within their social environment and most of their medical and psychosocial needs are addressed in a safe environment by staff at their infectious diseases clinic. The bulk of the psychosocial input is provided by NGOs, although these services are only a short-term solution because funding is mainly by overseas donors. Therefore the state needs to recognise the importance of these programmes and to provide support and funding for them to continue long term.

Those professionals with the dedication to engage in the fight against HIV and the care of those who are affected, and to develop appropriate programmes, should receive support and encouragement from government to realise these aspirations, so that a satisfactory national response to all these issues can be developed.

## Conclusion

One should not ignore the current evidence that PLHIV face stigma and discrimination at all levels of society: from family, friends, employers and, most disturbingly, within the social care and medical professions. All those with influence in society must work at reducing stigma and discrimination. Social workers and psychologists are particularly well placed to offer psychosocial support through institutions, as counsellors, and/or members of multidisciplinary medical teams working with PLHIV.

I believe that a social worker role is well suited for providing support and help for PLHIV, as well as working to develop programmes that enhance psychosocial responses around all aspects of HIV/AIDS. I hope that this overview, presented from the standpoint of a social worker, will encourage

others in my profession to seek greater involvement with PLHIV.

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# Overcoming barriers to HIV testing in the UK: Lessons from Kenya, Zimbabwe and South Africa

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## Introduction

In April 2012 I was awarded a Winston Churchill Travelling Fellowship – a grant that funds the recipient to travel abroad to gain experience and knowledge that can be shared and disseminated for the benefit of others back in the UK. Using this, I aimed to develop an understanding of the HIV services available, and people's attitudes towards HIV testing in Eastern and sub-Saharan Africa. I hoped this would enable me to characterise some of the barriers to HIV testing in the UK's Black African community in a step towards overcoming them. In the North London HIV service where I work, many of the Black Africans who use the service originate from Eastern and Southern Africa. This has developed my long-standing interest in how HIV/AIDS in Africa impacts on health-seeking behaviours and access to services in the UK. So, at the start of 2013 I spent 3 months visiting HIV clinics and testing centres in Kenya, Zimbabwe and South Africa. Here I reflect on and discuss the lessons that I learnt from this exciting opportunity.

## Background

In 2002, whilst volunteering as a teacher in a rural primary school near Gilgil, Kenya, I saw first-hand

the devastation caused by HIV/AIDS on the country. The highly traditional and superstitious community that I was working in met the onslaught of the epidemic with quiet resignation. There was a notable absence of the young adult and middle-aged generation; orphaned children lived with grandparents and relatives or became part of the growing number of street-children. This was part and parcel of the silence surrounding the virus. The columns in the daily newspapers were full of obituaries describing the lives of relatives cut short, but no explanation given. HIV was a highly taboo subject that was met with suspicious stares and an uncompromising silence; the public did not want to engage with this disease. During this time the rates of new infections and deaths were at their peak. Medication was widely unavailable and was far too expensive for the majority of the population. There was one HIV testing clinic attached to the hospital in Gilgil town that did not stock antiretrovirals (ARVs) as they were unaffordable. The majority of people regarded the clinic with deep mistrust as the disease was poorly understood and there was a great deal of social stigma. When I returned to the UK and enrolled as a student nurse, the amazing memories that I had from 6 months in Kenya were inextricably linked with the desperately sad experiences of people affected by HIV/AIDS.





**Picture 1:** *Myself and the clinical team at Ganjoni clinic, Mombasa, Kenya*

## HIV in the UK and access to services

In 2011, around 50% of adults diagnosed with HIV in the UK were at a late stage of infection. The majority of these were Black African men and women [1,2]. In an attempt to screen and reduce late diagnoses, the National Institute for Health and Clinical Excellence guidelines (2011) and the British HIV Association guidelines (2012) recommend that HIV testing services should be expanded in areas where HIV prevalence is greater than 2 per 1000 [3,4]. Public Health England further recommend that routine HIV testing should be commissioned as a priority for all general medical admissions in high-prevalence areas [5]. Research conducted within the UK's Black African community has informed these guidelines and recommended strategies to increase testing and service engagement within the population. A study in 2003 highlighted the need to determine whether social conditions that cause and facilitate high-risk behaviours and transmission in Africa persist or change after migration to the UK [6]. More recently a study in 2010 explored perceptions of 'risk environments' for immigrants in the UK and concluded that lack of knowledge and understanding of the epidemic in the UK resulted in serious misconceptions and risky sexual practice among the Ethiopian and Eritrean immigrant community in the West Midlands [7].

### Africa → UK, a transferable risk?

As a qualified nurse working in the HIV sector I often thought back to the time I spent in Kenya, and wondered whether the impact of HIV/AIDS in Africa changed the way that people would perceive the illness in the UK, and whether this in turn modifies their health-seeking behaviours. Furthermore, would the rapid changes seen in Africa in terms of scaling up of diagnostic and treatment centres have had any bearing on the social stigma towards HIV I saw in Kenya in 2002? And, in an increasingly mobile global population, how might the epidemic in sub-Saharan Africa impact on testing and engagement with healthcare services in the UK?

The Winston Churchill Travelling Fellowship granted me the opportunity to seek out contacts and clinics in Kenya, Zimbabwe and South Africa to explore these questions. To date, these three countries have responded to their HIV epidemics with different strategies and with varying degrees of success. Politically, they have faced multifaceted challenges in the last few decades, with different emphases and political agendas for HIV/AIDS in each country. All are still striving on a national level, aided by international and donor funding, to control the staggering consequences of this disease that threatens every sector of society.

## Kenya (January 2013)

The prevalence of HIV peaked at 13% across Kenya in 1999, and 180,000 people were dying from AIDS every year [8]. The average life expectancy at birth during the worst years of the epidemic was just 48 in 1998–2000. At this time the government of Kenya came under heavy criticism for not responding to the crisis as rapidly as neighbouring Uganda and there was no cogent strategy in place. Since then, Kenya has initiated a comprehensive response, with innovative programmes to strengthen and support existing healthcare facilities. Training and education is increasingly run by lay people, not healthcare professionals; resource and equipment supply has increased, including ART coverage which has been scaled up to improve national access; and extensive prevention and awareness programmes have created a network of peer educators, counsellors and HIV advocates to take HIV prevention to some of the most remote areas. ART is now fully subsidised by the Government of Kenya so HIV treatment is free for all those who need it.

In 2011, 83% of the eligible adult population were receiving ART, and the rate of new infections had fallen by around 40% since the peak of the epidemic [10]. The prevalence of HIV across the country is now between 6–7% and the national target to test 80% of the population by 2013 appears achievable, based on the commitment exhibited thus far. This target has been set in conjunction with others including: improved linkage to care for positive patients, initiatives for retention in care and adherence to treatment.



**Picture 2:** *An HIV clinic in a rural area of Kenya, built using old shipping container boxes, part of the community health centre.*



Picture 3: A workshop for volunteer workers on stigma in Zimbabwe.

## Zimbabwe (February 2013)

The political and economic troubles in Zimbabwe have been well documented over the last 10 years. More recently, a cholera and typhoid epidemic that left thousands of people dead, a near-total collapse of the public health service, and a mass exodus of trained health professionals out of Zimbabwe has placed increasing pressure on a country experiencing one of the most severe HIV epidemics in the world. As with Kenya, some of the major barriers to testing and treatment are stigma around HIV/AIDS and gender inequalities. Strict attitudes towards female sexuality are in contrast to the more lenient attitude towards men. This results in the acceptability of men having multiple sexual partners whilst women do not have the authority to instigate safe sex and condom use.

In Zimbabwe's extremely tense political environment, the government response to the HIV crisis has not been top of the agenda and has lacked organisation and resources. The National AIDS Council (NAC), local and international NGOs and faith organisations have initiated prevention programmes and treatment management for the population. The political situation in Zimbabwe has deterred foreign donors from providing international aid which other African nations have benefited from. However, prevention efforts at community level and the sheer scale of the epidemic have impacted upon safer sexual behaviour and awareness. HIV/AIDS is taught in schools and evidence of prevention messages are visible on billboards, TV and radio advertisements. Combined efforts by lay people and health professionals have helped the improvement in Zimbabwe's HIV/AIDS statistics. According to a recent survey, HIV prevalence has declined from 15.6% in 2007 to 13.9% in 2009 [11].

## South Africa (February/March 2013)

South Africa is the most developed country in sub-Saharan Africa, but the political leadership has floundered in its response to the HIV/AIDS crisis. Previous misguided healthcare policies have had a significantly negative impact on the epidemic. Doubt cast by the former government on the

science behind HIV and ART in 2000 caused confusion amongst the general population. This profoundly affected the population's perceptions and knowledge of the virus, transmission and risk factors at the time and the repercussions of this are still felt today. Thabo Mbeki, the second post-apartheid President of South Africa, was slow to join the global movement on HIV/AIDS amidst mounting pressure and advice from UNAIDS and WHO, and the current president, Jacob Zuma, famously declared a shower post sex with an HIV-positive person would minimise the chances of infection [12]. Such widespread misconceptions severely hampered the uptake of HIV testing and services when the scale-up finally started through a national adult treatment programme in 2004. HIV prevalence across the country remains around 17%, and in Kwa-Zulu Natal rates are as high as 40% [13].

As a result of the initial dearth of government action, a prolific number of national and international NGOs and faith-based organisations have long been a presence in South Africa and continue to play an important role in HIV service delivery. In more recent years the government has recognised the magnitude of the problem and the HIV response is now more focused and successful. In 2010 a media campaign was announced to increase awareness around HIV alongside the improvement and scale-up of HIV testing and counselling services [14], and South Africa is now home to the world's largest HIV treatment programme.

## Lesson from Kenya, Zimbabwe and South Africa:

There are a number of similarities in the strategies that the three countries have employed against HIV. The following is a summary of the notable themes that I believe affected people's access to services in sub-Saharan Africa and could be tailored for use in the UK.

- (1) Decentralisation of HIV care and integration into existing healthcare facilities:
  - Nurses and counsellors provide comprehensive HIV care, including the initiation and management of ART in small community healthcare sites. They employ simple but highly effective tools to test, link to care and initiate ART to their patients. This ensures access for those who do not have the means to travel to urban areas where the hospitals are. It also raises the awareness of HIV in the community and facilitates dissemination of HIV education to the local community.
  - Integration of HIV services in a setting that offers other healthcare services decreases stigma and increases attendance for testing. The Provide Initiated Testing and Counselling (PITC) model ensures that patients attending for an

illness/injury unrelated to HIV are also offered an HIV test as well as receiving treatment for the reason they attended.

Trust and confidentiality were hugely important to the patients in all the clinics that I visited. The use of community clinics means, by nature of their location, it is more difficult to maintain patient confidentiality. However, this was overcome through integrating the clinic with other community healthcare services so that it was not known as 'the HIV clinic'. Clinicians, nurses and counsellors also identified trust and confidentiality as specific indicators that ensured a minimal number of patients were lost to follow-up.

(2) Support groups and peer education are key for people who have tested positive and are heavily utilised:

- Support groups ensure that education and information is understandable and personal to the people attending groups run by people living with HIV. The use of peer educators to facilitate these support groups does not add to the work of clinic personnel and serves to empower those who take on this role. They discuss issues such as disclosure, adherence, risk reduction, and healthy living, and act as a platform to air individual opinions and fears that may be difficult to talk about with healthcare professionals.
- Peer education is highly valued as the educators are from similar socio-economic and educational backgrounds to the community.

(3) Stigma has decreased – 'if you are not infected, you are affected':

- As the epidemic engulfs sub-Saharan Africa with no preference for age, gender, tribe, socio-economic status or religion, it is rare to find someone who has not been affected by HIV. Everyone has a relative, friend or associate, or knows of somebody who is either HIV positive or has died from AIDS. The indiscriminate nature of the virus for any social characteristic has seemingly helped reduce stigma around the illness as people who are affected by it are able to talk more openly about it, knowing that almost everyone has some experience to relate to.

(4) Holistic approach to care for the individual:

- The focus on holistic care of the individual who attends for an HIV test was reflected in the time and coverage of the pre- and post-test counselling across all three countries. The counsellor discusses the outcome and impact of the test result on the individual, their partner and family. If the test is negative the post-test discussion focuses on how to remain negative and the importance of regular testing. If the result is positive then the counselling of the client is paid the same level of importance as the

prescription of ARVs. The counsellors report that if the client is psychologically not ready to commit to lifelong treatment, and does not have an understanding of the virus, treatment and prevention, then they are at higher risk of not returning to engage in care.

(5) Education and Information dissemination:

- Highlighted by my previous experiences in Kenya and the lack of education around HIV/AIDS where I volunteered in 2002, it was interesting to see just how much progress had been made in this area by 2013. In all three countries HIV/AIDS was taught at a primary school level and this has further increased awareness at a community level.

(6) Collaboration with community leaders to develop key messages and target at-risk groups of people within the community:

- Many of the clinics and services undertake work with key members of the community to develop and deliver information around available services. It is then possible to use existing communication structures to help disseminate this information. Furthermore, it is likely to be better received if it is sensitive to the target community.

## Discussion

The challenges in HIV testing, treatment and care delivery faced in sub-Saharan Africa are archetypal of the vast majority of people and healthcare systems affected by HIV/AIDS across the world. However, it is important to recognise that the generalised epidemic in sub-Saharan Africa is different to that of the UK where specific groups of the population are predominantly affected, particularly MSM and Black Africans.

Many of the HIV-positive Black Africans I meet through my work travel regularly back to their countries of origin. In my experience there is often a strong retention of cultural identities, traditions and beliefs among the Black African communities in the UK. The conservation of cultural identity is likely linked to close-knit communities found in specific London boroughs and big cities elsewhere in the



**Picture 4:** An outreach-worker in Mombasa, Kenya, delivering a health-education talk to sex-workers in their local bar.

UK, where cultural identity is strengthened through lifestyle, social spaces and places of worship. It may also be related to the ease with which today's travel network allows people to move more easily and economically around the world, meaning that home is never far away. Thus I believe it is important that healthcare professionals working with these communities are aware of people's different perceptions and expectations of a service and that the development of specific services to meet the unique and complex needs of this population is particularly important.

In contrast to the UK, the majority of HIV testing in Kenya, Zimbabwe and South Africa is initiated through a Provider Initiated Testing and Counselling (PITC) model. There has been a notable increase in uptake of HIV tests in all three countries since this model was implemented and it has undoubtedly reduced the number of late and missed diagnoses. Therefore HIV-specialist nurses and doctors working in cities with a high proportion of Black Africans should be aware that testing outside of a the GUM/HIV clinic setting is common across sub-Saharan Africa and may even be expected by Black Africans who access the NHS outside of a designated HIV service. PITC is certainly a strategy that requires further development in the UK to increase testing and opportune diagnosis.

Across the three countries that I visited, a decentralised HIV testing and care service, integrated into existing community healthcare, has helped to increase the number of people who test and engage in HIV services. In the UK, GP surgeries and community health clinics are prime examples of existing spaces where HIV services could be offered. Utilising the independent nurse prescribing course, HIV-specialist nurses could manage a caseload of patients in a decentralised community setting, should the UK move towards this model. There are examples of this happening in UK services but it is by no means the norm and is certainly an area that requires further consideration. The feasibility and acceptability of nurse-led clinics was demonstrated consistently in the clinics that I visited.

The use of peer-to-peer education and support groups has previously been underestimated and neglected in my experience working in HIV. This experience highlighted how valuable a non-healthcare professional can be at sensitising and educating individuals to HIV, treatment and management. Focusing on the impact that a positive diagnosis has both socially and culturally on an individual is of particular importance as this has implications on retention in care and adherence. These are topics that a peer educator or support group can address on a far more personal level than a healthcare professional. Additionally this could prove to be cost-effective as it detracts from the time spent with a specialist doctor or nurse

and can be addressed outside of a clinical environment. HIV nurses in the UK should be aware of what support groups are available in their areas and be proactive at referring patients to them.

It is important to bear in mind, when seeing patients from this population in the UK, that their experiences and expectations of the healthcare system are different to what we know and that this can lead to missed opportunities for HIV testing. Therefore ensuring that healthcare professionals across a wide range of services have the appropriate training to deliver an HIV test should be a priority.

As a nurse, some of the most important lessons I took from this experience were that we, as a profession, can play a key role in creating better access to services. Increasing services in the communities that are most at risk are key and, through training more HIV-specialist nurses to manage their own caseloads, this can be achieved and be cost-effective.

## Conclusion

The response to the HIV epidemic in the UK has been developed using a wealth of resources and finance. The countries that I visited in sub-Saharan Africa have limited access to both. The healthcare systems there have had to develop different and unique strategies that rely less on a biomedical approach and more on social and culturally sensitive interventions to face the challenges of HIV/AIDS. This is typified through access to care in the community, peer-to-peer education, prevention with positives, and extensive use of support groups. The decentralisation and integration of HIV testing and care in community healthcare services has meant that the available resources are accessible to a greater number of people and have played a vital role in the scale-up of services.

Valuable lessons from sub-Saharan Africa can inform the UK's future service development to improve meeting the needs of our own Black African community, if we utilise them. These lessons cannot be underestimated if the UK is to successfully overcome the existing barriers in HIV testing and care, to deliver an improved and accessible service to our Black African population.

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## HIV in New Zealand

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### Introduction

New Zealand has approximately 2000 people currently living with HIV. Records commencing in 1985 indicate that 3474 people have tested positive, with 170 people being diagnosed in 2012. This figure, while being an increase on the 2011 figure, is lower than for every year during the period 2003–2010. To date, 678 people who went on to develop AIDS have died. New Zealand is a popular tourist destination in the South Pacific, comparable in land mass to the size of the United Kingdom, but with a total population smaller than some cities around the world; this again has contributed to lower than expected levels of HIV [1].

Despite large numbers of travellers visiting the country each year and having an extremely mobile commercial and recreational population, the annual rates of HIV infection have remained low, with no significant crossover to the general population from those most at risk. Much of this can be attributed to: good access to advanced medical and diagnostic services, continual funding of targeted prevention campaigns and the geographical alignment of the population. This is evidenced by Auckland (as the largest city), which

has a significant proportion of people living with HIV in the region, and is home to a substantial number of men who have sex with men (MSM) [1]. Consequently, this assists with the containment of the spread of HIV infection. Legislation to legalise homosexual activity and prostitution have also predisposed to a low HIV prevalence, along with New Zealand legalising homosexual marriages in 2013.

### HIV testing

HIV testing in New Zealand is routinely offered in sexual health clinics as well as GP practices and from the New Zealand Aids Foundation (NZAF). NZAF offers the FASTest, Free, Anonymous, Simple, Test for HIV, syphilis and hepatitis C. This is a point-of-care test with results available within 10–20 minutes, undertaken by a trained member of staff who is competent in using the test. In contrast to the UK, NZAF does not recommend home-testing kits for HIV and instead recommends people access a service if they require testing. They argue that it is safer and more reliable to access a service offering testing instead as emotional and physical support will be available [2].

## Cultural diversity

New Zealand is a culturally diverse country with an estimated population of 4.6 million people. The four largest ethnic groups are: 67.6% Pakeha (European) descent, 14.6% Maori, 9.2% Asian and 6.9% Pacific Peoples [3]. Figures for March 2012 related to ethnicity at time of HIV diagnosis indicate that 49.4% of people, both male and female, infected with HIV are Pakeha, with the next largest group being those of African descent 18.8%, followed by Asian 12.5% and then Maori at 7.2% [4].

According to the New Zealand Aids Foundation, for the majority of people of African descent who are HIV positive in New Zealand, the infection occurred overseas [5]. The high number of Africans who are HIV positive can also be attributed to New Zealand social policy, as in 1987 it became the first country in the world to accept refugees under the Medical/Disabled category, many of whom were HIV positive. A large number of migrants who came into the country between 2002 and 2004, mainly from Zimbabwe and South Africa, were also HIV positive. HIV testing wasn't introduced for migrants until 2004; however, being HIV positive did not exclude potential migrants, with 75 places being kept for HIV-positive refugees each year [6].

As a population Maori, the indigenous people of New Zealand, have on average the poorest health status of all ethnicities and significantly lower life expectancy than non-Maori [7]. There are complex social and cultural reasons attributed to these health disparities; however, poorer access to healthcare and lower satisfaction rates with healthcare providers are known to contribute; along with lower socio-economic status and genetic factors [8]. As a consequence Maori show a reluctance to engage with mainstream healthcare providers and may be hesitant to approach Maori healthcare providers, for fear of stigma and discrimination. Many of these issues are shared with Pacific Islander people and also include a lack of leadership on HIV, differing world views on sex and poorer knowledge of their vulnerability to HIV infection [9].

## Late diagnosis

Late diagnosis of HIV has been reported as a major issue affecting not only the individual but the further spread of HIV within the population. Early diagnosis can help prevent the development of opportunistic infections and early antiretroviral treatment can decrease the level of infectivity on the individual [10]. A national study carried out between 2005 and 2010 in New Zealand found that 50% of those diagnosed were late presenters with a CD4 count below 350 cells/ $\mu$ L. MSM were least likely to be late presenters or to present with advanced HIV disease. There are higher rates of MSM testing for HIV within sexual health clinics and this possibly contributes to the reasons why MSM are less likely to present late.

Heterosexual Maori and Pacific Islanders were much more likely to present with advanced HIV. The article highlights that overall late presentation figures are similar to those of the UK and other northern European countries [11].

In 2012, 20 people presented with AIDS of whom 10 were MSM, five were heterosexual (two males and three females) and for five people the route of transmission was unknown. From this group, 11 (55%) of the people were of European/New Zealand decent, four (20%) were Maori, three (15%) were Asian and two African (10%). Three deaths were reported of people with AIDS in 2012 [4]. These figures show that if people presented earlier for HIV testing a reduction in the number of AIDS diagnoses could be achieved.

## Men who have sex with men

MSM are the group most affected by HIV in New Zealand, with over two-thirds of the infected presumed to be infected within New Zealand. The rate of HIV amongst MSM still remains low; however, a generalised increase in diagnosis since 1996 can be noted [12]. A study undertaken in Auckland in 2012 showed a prevalence rate of HIV amongst MSM of 6.5%, with 1.3% being unaware of their diagnosis. The HIV positivity rate was notably higher in men aged 30 years and over. The positivity rate by ethnic group amongst MSM was not significantly different; however, Maori and Pacific Islanders were substantially less likely to be aware of their diagnosis. The majority of the undiagnosed infection population also presumed themselves to be either definitely or probably uninfected [13].

Findings from the Gay Auckland Period Sex Survey showed that rates of MSM undertaking an HIV test had increased from 74.9% in 2002 to 79% in 2008. New Zealand/European MSM were statistically more likely to have tested for HIV at least once in the past and Pacific Islanders were least likely. The place of undertaking the HIV test showed that more than 50% tested with their GP or family doctor and 34% tested within a sexual health clinic. Almost 10% of tests were carried out by NZAF, the country's leading HIV charity. In total, 4.3% of the sample declared themselves as HIV positive when undertaking the survey [14].

New Zealand's HIV Prevention Plan 2009–2014 has set ambitious aims to reduce HIV transmission. Its primary goals are targeted at MSM and are to:

- Increase rates of condom use for anal sex between men
- Increase STI and HIV testing rates for gay and bisexual men
- Increase rates of condom use rate for first anal sex between men

These goals are supported by a network of plans to achieve these including: availability of condoms in

major towns' taxis, targeted online communications, online booking-in systems for sexual health services, rewards for STI/HIV screening, and the development of partnerships between education and youth services providers to normalise anal sex [15].

A 2008 study in New Zealand found a large proportion of gay and bisexual men do not disclose their sexuality or sexual practices to their GP. This may be potentially detrimental to the healthcare of MSM and work needs to be done to address this also [16].

## Pregnancy

HIV screening throughout pregnancy aims to reduce the onward transmission of HIV from mother to child. The risk of the child contracting HIV during pregnancy is estimated to be 15%–45%; however, this can be reduced to less than 5% with successful intervention [17]. HIV screening throughout pregnancy has been part of routine antenatal testing in all District Health Boards (DHB) since July 2010 in New Zealand. An initial site within the region of Waikato DHB introduced the programme in March 2006. They managed to have a success rate of HIV screening of 99.8% between October and December 2011. By the end of 2011 the HIV screening rate was 81.6% nationally; however, the report notes that issues with the collection of the data may mean this does not reflect true findings. The screening rate does vary drastically across the DHBs, from 56.0%–99.8%. Each DHB has a different set-up for offering HIV screening and the HIV test may be requested by the GP, midwife, obstetrician or other healthcare

professional. 'Other' is defined as the test being performed by family planning clinics, sexual health clinics, emergency departments or other doctors based within the hospital (see Table 1). It is interesting to note that the uptake rate amongst the GPs, midwives and obstetricians is almost identical across the country on average [18].

The ethnicity of the individual also has an impact upon uptake of screening within New Zealand (see Table 2). Maori, Pacific Islander and Asian ethnicities have a screening rate above 90% compared with other ethnicity, described as non-Maori, Pacific or Asian at 88.2%. The lowest rate of 15% uptake was observed in those who did not have their ethnicity stated on the request form. This was over 2500 tests performed and could have dramatically altered the uptake percentages if these tests had been completed [18].

There have been 18 women diagnosed HIV positive since the introduction of the screening programme. HIV testing amongst practitioners has been widely accepted and ongoing training alongside raising the profile of HIV testing are described as 'priority areas for action' in the HIV Progress Report [19].

A New Zealand study in 2013 showed the level of anxiety amongst women who have an initial screening test which reacts to HIV but on repeat testing is negative. The women interviewed all discussed having severe anxiety after receiving their result; however, all had positive feelings towards the screening programme. Anxiety should be anticipated by healthcare providers ensuring that they have all the relevant information ready for the women [20].

**Table 1**

Person requesting test	October to December 2011		
	Total antenatal screens	Antenatal screen with HIV test	Percentage uptake (%)
GP	13,736	11,154	81.2
Midwife	6400	5269	82.3
Obstetrician	576	475	82.5
Other	412	375	91.0
Not recorded	171	107	62.6
<i>Total</i>	21,295	17,380	81.6

**Table 2**

Ethnicity	October to December 2011		
	Total antenatal screens	Antenatal screen with HIV test	Percentage uptake (%)
Maori	4024	3682	91.5
Pacific	2167	2059	95.0
Asian	2533	2388	94.3
Other ethnicity	10,064	8874	88.2
Not stated	2507	377	15.0
<i>Total</i>	21,295	17,380	81.6

## Conclusion

This article has explored the HIV situation within a developed country in the Pacific Ocean with a low HIV prevalence rate. The cultural diversity, population and geographical set-up have been studied with explanations examining the reasons behind this. The interesting set-up with GPs, sexual health clinics and the voluntary sector undertaking HIV testing shows an established multi-agency approach at combating HIV. The large hub of MSM living within the country's largest city has helped control the spread of HIV around New Zealand. The introduction of antenatal HIV screening has further prevented HIV mother-to-child transmission but it would appear that further work needs to be undertaken to increase either screening uptake or reporting of HIV testing. Finally, as with most developed countries, further work needs to be done to address the issue of late diagnosis of HIV.

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# Acceptability, feasibility and impact of introducing the rapid oral HIV tests in the CBVCT network: the COBATEST project outcomes and recommendations

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On 27 September 2013 in Barcelona, the closing event of the COBATEST project was held: *HIV community-based testing practices in Europe* (Grant Agreement number 2009 12 11), co-funded by the Executive Agency for Health and Consumers (EAHC) (more information can be found at: [www.cobatest.org](http://www.cobatest.org)).

The project lasted for 36 months and aimed to promote early diagnosis of HIV infection in Europe by improving the implementation and evaluation of community-based testing practices. This objective was highlighted as well in the European public health agenda. The European Commission included access to HIV testing as a priority in *Community Action in the Field of Public Health Work Plan 2009*.

For the purposes of the project, the term Community Based Voluntary Counselling and Testing was precisely defined:

CBVCT is any program or service that offers HIV counselling and testing on a voluntary basis outside formal health facilities. It aims to target specific groups within the most-at-risk populations and is clearly adapted and accessible to those communities. Moreover, these services should ensure the active participation of the community with the involvement of community representatives either in planning or implementing HIV testing interventions and strategies.

Due to the fact that early diagnosis of HIV infection is essential to decrease mortality, morbidity and transmission rates, one of the primary aims of counselling is to assess suitability for treatment. The services of CBVCT are commonly recognised as a good model to improve access to most-at-risk populations. These centres are in an excellent position to advance all aspects of HIV testing and counselling – including access, offer, uptake and effectiveness – for those who are vulnerable and hard to reach.

Associated and collaborating partners from 19 countries were involved in the development of the project and in carrying out its work packages, the core being: work package 8 – acceptability, feasibility, and impact of introducing the rapid oral HIV test in the CBVCT network.

Ten CBVCT services from nine different countries participated in this particular study: AIDES

(France), AIDS FONDET (Denmark), LEGEBITRA (Slovenia), AIDS-Hilfe (Germany), Czech AIDS Help Society (Czech Republic), the National AIDS Centre (Poland, two CBVCTs), ARAS (Romania), Checkpoint LX (Portugal), BCN-Checkpoint (Spain), ACASC (Spain).



The oral rapid test used for the study was: OraQuick ADVANCE<sup>®</sup> Rapid HIV-1/2 Antibody Test 2004, which had the following characteristics:

- US Food and Drug Administration (FDA) approved it for use with oral fluid and detection of both HIV-1 and HIV-2.
- In 2007 it was labelled with the CE mark, confirming its safety.
  - *Simple* – Rapid HIV-1/2 antibody testing with oral fluid collection – results in 20 minutes
  - *Accurate* – Results with >99% sensitivity and specificity across all specimen types
  - *Versatile* – Testing platform suitable for both clinical and non-clinical settings using several specimen types



According to the manufacturer, the strategy of oral testing is simple and straightforward with many positive features, especially if we consider testing in a CBVCT: the method is non-invasive; it can be performed almost anywhere; there is no cost of training and equipment to perform blood extraction; the risks of manipulating biological materials and wastes are reduced.

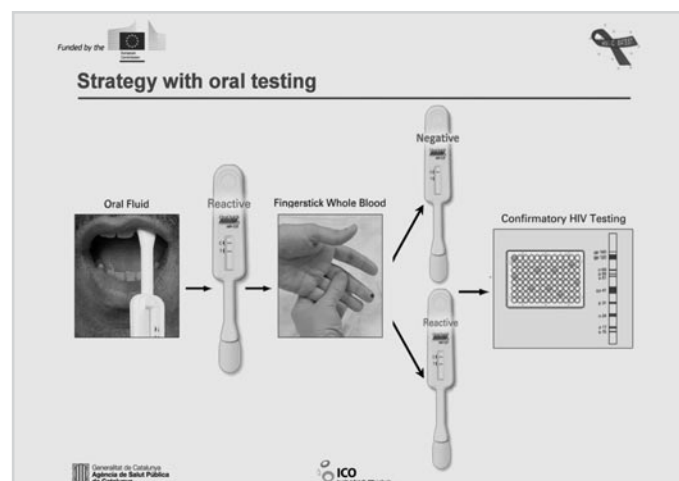


Figure 1: Strategy with oral testing.

In line with the project deliverables, oral testing was carried out during the pilot study of 3 months' duration in ten European CBVCT centres, and later assessed on the basis of two questionnaires, one filled in by the clients, the other by the providers (in the case of Poland by nurses).

**Panel 1: Quotes from Polish nurses who performed the test in two CBVCTS**

- 'Easy to use, no injection (many people do not like needles), short waiting time which reduces stress. A very good way of HIV testing, and can be performed in any situation. Clients liked OraQuick as well and many would like to buy them in pharmacies. Very good way of HIV testing.'
- 'The test does not detect early HIV infection, and this should be mentioned to the client. Rapid blood tests with p24 antigen have shorter window period.'

After data analysis it was discovered that the rapid oral testing was more comfortable for the clients than the conventional test. However, many people actually preferred and trusted the conventional test. The percentage of clients who chose the oral test instead of the blood test during the study period was really very low (9.5%). This selection could have been influenced by the following conditions:

- (a) The information given by the staff member performing the test could have been biased
- (b) Other multi STI testing (syphilis, HCV) could have been performed with the same blood sample
- (c) Reduced accuracy of the oral test versus the blood test in some cases
- (d) The requirement not to drink, smoke or eat 15 minutes before the test
- (e) For repeat testers it is possible that they prefer and have more trust in a known test than a new one

However, the test providers were happy performing the test due to the fact that the method is non-invasive, although they also noted the points mentioned above. It transpired that the acceptability of the oral tests depended on the kind of blood test usually performed in the centre (rapid or conventional). Oral tests were better accepted by the clients of centres where conventional blood tests are used (geographically in Central Europe). That was clearly visible in Poland where 936 oral tests were performed out of 1631 in all other CBVCTs taking part in work package 8.

## Recommendations

- In settings using conventional testing, the rapid oral test could be a good instrument to increase the number of people tested, encouraging periodical testing and attracting new users to the service.
- In settings using rapid blood testing, the rapid oral test could be a supplement also to attract new users, and for those cases where the client would not be able to give a blood sample for religious reasons.
- In addition, the rapid oral test could be a good instrument for outreach activities of the CBVCT services, as in saunas, clubs, sex venues or with a mobile unit.
- Rapid oral tests are good instruments to encourage periodical testing and to attract new users to the service.
- Rapid oral tests are good supplements to the rapid blood tests, but not as the only test in the service.
- However, it has to be remembered that in order to avoid false-negative results, oral testing has to be accompanied by pre- and post-test counselling to inform clients that it detects the antigens after 12 weeks of the high-risk behaviour.

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# HIV Status disclosure: Emerging strategies and experiences amongst HIV/AIDS patients receiving home-based palliative care in Uganda

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## Introduction

In Africa, palliative care initiatives have emerged and expanded as 'islands of excellence', yet are an absent feature in most African countries' national health policies [1]. Thus, home-based care (HBC) is by far the most common model of palliative care provision in sub-Saharan African countries, a resource-led decision by healthcare providers in response to provision of palliative care to increasing numbers of People Living With AIDS (PLWA) with limited resources [2]. Further, the HBC model has been reported to be flexible and to offer culturally appropriate care, and therefore this ensures sustainability of care among PLWA [2]. While this is the most common way of delivering holistic palliative care in sub-Saharan Africa, families and volunteers need to initiate palliative care intervention to PLWA as early as possible [2,3]. It is now recognised that palliative care should be incorporated and work alongside and within other programmes [3-6]. Such recognition has led to the development and promotion of a public health strategy for palliative care, promoted by the WHO [6]. The strategy recognises HIV disclosure as a critical point of entry to palliative care, yet there are still several psychosocial issues among PLWA which are commonly not addressed [7,8]. Disclosure amongst PLWA largely remains as an unmet need [9]. As part of a larger study, this paper only reports findings of qualitative study exploring the experiences of disclosing HIV status among patients with advanced AIDS in Uganda.

## Methods

This study employed qualitative interviews to collect data. Interviews were carried out in patients' homes. The study recruited patients who were newly referred at Hospice Africa Uganda. A consecutive sample of 22 patients participated in the study. All patients were in the advanced AIDS stage and were bed-ridden, so were unable to walk. Patients' interviews were digitally-recorded, transcribed and translated from Luganda (when Luganda was used in the interview) to English. Field notes recorded a broad summary of key issues in the interview and so could be used to cross check the broad meaning of the transcript. Field notes also offered an opportunity to check for inconsistency or missing points expressed in the interview, due to any interruptions at the time of interview.

Interviews were analysed and presented accordingly.

Ethical issues were paramount in this study and were addressed to ensure that patients' rights were protected. Before conducting research, approval was sought from Hospice Africa Uganda (HAU) and the Uganda National Council of Science and Technology (HS-805). In the study, I took necessary steps to ensure that there was no harm to participants, given their state of vulnerability. One of the strategies I adopted to overcome vulnerabilities was to include a third person, preferably a health professional, in assessing the patient. I also emphasised voluntary participation together with informed consent.

## Results

Fifteen participants in this study revealed that disclosure of their HIV/AIDS status was a particularly sensitive issue. Participants expressed difficulties associated with disclosure of HIV/AIDS to their family members and friends. This is because of fear associated with the HIV/AIDS stigma, the risk of losing the support of friends and family and, in many cases, the fear of blame or of losing one's livelihood or means of support. An examination of participants' views and experiences about disclosure clearly reveals that participants weigh up a number of issues before disclosing. Where disclosure was perceived to be leverage for support, participants sought to use several strategies to disclose. To illustrate this, I will use various participants' experiences of disclosures and identify the underlying factors influencing each strategy. Strategies commonly used were: indirect approaches, implied disclosure, disclosure to trusted confidants, and in some cases non-disclosure.

Where participants dreaded disclosing their HIV/AIDS status for fear of negative consequences, an indirect approach was often adopted or preferred. This was a common strategy among parents when they attempted to disclose to their children. Most parents expressed difficulties in the way in which disclosure to children should be handled, and this was among the most challenging of situations.

For example, Ssematimpa, a 44-year-old man introduced in Table 1 below, reported the difficulties he had in handling his children's curiosity. His wife also reported how she avoided the children's

questions and referred to Ssematimba as 'doing poorly'. Similarly, Agaba, a 40-year-old woman in stage IV (AIDS), did not openly break the news to her daughter. Instead she asked her daughter to accompany her to hospital when she was ill. While in hospital she left her daughter to be told by the health worker.

Disclosure to other family members was also experienced as challenging and complex. For example, the story of Lutalo, a 38-year-old man, who reported how he had to move to stay with his brother for fear of disclosing to his family members. His story is captured in the case scenario given in Table 1. In the case of Ssematimba, a 44-year-old man, an intermediary family member was asked to take the news to his family, because he found it hard and challenging to do it himself. He worked out a plan to request his brother to accompany him to hospital. While in hospital they both went to have voluntary counselling and testing (VCT) for HIV/AIDS. In the process, the brother learnt that Ssematimba had HIV/AIDS. The brother then acted as an intermediary to communicate to the rest of the family members. The following table depicts the experiences of disclosure among PLWA.

Some participants deliberately chose to avoid disclosing without giving a specific reason. Meanwhile, other participants chose to use overlapping terms which in a way avoided use of direct simple terms to express their health status. Participants instead preferred to trickle information slowly so as to imply they were not healthy. I have referred to this strategy as implied disclosure. In using this strategy, participants were careful in their choice of words when explaining their status while not using such terms as 'I have HIV/AIDS'. I noticed that use of silence was a coping strategy in order to avoid anticipated consequences. In doing so, participants succeeded in keeping information to themselves. For example, words such as 'they found me ill', 'I am not OK', 'weird disease making my legs swell', 'the leg has cancer' etc. In some cases, participants assumed that family members would observe physical symptoms (AIDS) and connect these to the reality of their diagnosis.

Among some other participants, the HIV/AIDS stigma influenced disclosure. For instance, Amandua a 20-year-old high school student described not only the fear of rejection due to the AIDS stigma but also the fact that his friends would gossip about him if he disclosed. Amandua cautioned me not to mention to anyone about his status when I visited him. He had told his colleagues that he had cancer rather than HIV/AIDS.

Amandua's experience was also voiced by Nafuna, an 18-year-old girl. While citing fear of gossip, stigma and questions around morality from family members, Nafuna decided to keep the information from some of her family members who were not showing support to her. However, she described

how, when she relocated to Kampala, she found a loving and caring sister-in-law who did not discriminate against her and, as a result, she felt able to disclose freely. Similarly, Nafuna's experience was also voiced by Kakiiza, a 23-year-old woman in stage III (AIDS). In my view, disclosure was a highly debatable issue and, where support was anticipated, disclosure was made with ease to ensure access to support. In contrast, where participants felt that there was no forthcoming support or that disclosure would damage access to support, they kept their diagnosis to themselves. Panel 1 describes experiences of disclosure by the participants.

As noted above, where patients perceived that they received spiritual support, counselling and guidance from their family members, friends or other supporters, the matter of disclosure was more easily pursued. Typically, patients told their relative(s) for material support, the pastor (for spiritual support), or the CHW (for community support). In such instances, participants were seen to benefit from psychosocial support activities such as frequent visits, access to medical support, counselling, or creating links with other support groups. For example, among the participants in this category were Adongo, a 40-year-old woman, and Amandua, a 20-year-old student. These examples show how anticipated support was leverage for disclosure. Where participants anticipated support, they easily opened up their status in order to access some form of support.

Some participants, especially those who had partners (wife or husband), attributed their reason for disclosure to having accessed support from their partners. However, where participants anticipated negative consequences, they chose not to disclose. Among them were participants who expressed fears related to their partner leaving them, being blamed, and/or uncertainties about whether support would continue to be forthcoming from the partner. Individuals who shared this experience expressed concerns around aspects of morality by their partners and blame for bringing the deadly disease into the family. The stories of Sempala, a 43-year-old married man, Gwandoya, a 32-year-old married man, and Nabirye, a 24-year-old, demonstrate the challenges which related to disclosure within marital relationships. Sempala's story in Panel 2, for instance, connected his story with possible stigmatisation in the community. He expressed his reservation on disclosure.

## Discussions

In this sub-section, I discuss the psychosocial issues surrounding experience of disclosure and non-disclosure as narrated by PLWA who participated in this study. Drawing lessons from various interviews, it became clear that disclosure is not an

### Panel 1: Disclosure experiences among PLWA

When I was ill, she came and I told her that let's go together [to hospital], so they told her when I was also around and she understood it. They also gave me the medicine [HAART] when she was there (*Agaba, KAF05 interview*).

I relocated to stay with my elder brother here (in Kampala) who knows my status... he (brother) gives me transport to Hospice and also some money to buy drugs (*Lutalo, KAM02 interview*).

I told my brother that my body is ill. So I first convinced him to go to hospital with me. We then actually tested with my brother and for him he was negative and he waited for me to get the results and later on I started on treatment... I told my family members that the last time they took off blood from me they found me ill and I need transport to go for treatment (*Sematimba, KAM01 interview*).

They ask me what is wrong with our father... what is our father suffering from? ... but I tell them that he is doing poorly (*Sematimba's wife, KAM01 interview*).

She would have spread the news to the village and not kept it to herself. I think she would have even told her daughters and I don't go along well with her daughters because whatever I do she still tell her daughters and would have laughed at me and among the daughters no one would help me. The only person who knew was my brother (*Nafuna, KAF21 interview*).

Almost all the family members know ... You see when I got sick they see your situation changing each day; they suspected that I have HIV. I told my children that they were treating cancer. I told my sister Jane they are treating me for cancer... But my brother knows from Nakasero. Since we were raised together I told him I am not OK (*Nabukwasi, KAF27 interview*).

I did not disclose to anyone in school ... they just knew that I was suffering from a weird disease which had made my feet swollen and was seeking medical attention. My colleagues would talk about me. Even here at the workshop they see me like anybody else, they look at the leg and I tell them that it is cancer (*Amandua, KAM11 interview*).

I told my brother – the one I live with – that I have been tested and I have HIV. My brother told me not to worry. My family here in Kampala knows that I am HIV positive but the ones in the village don't know. All my siblings in Kampala know that I am HIV positive. He doesn't give me much help but the help I get from him is that he sustains me from his home and he feeds me but he doesn't have much money (*Kakiiza, KAF08 interview*).

easy matter. Participants debated how to manage information relating to their status. I learnt from participants' narratives that disclosure takes different angles depending on the perceived consequences. Some participants who felt that disclosure would be detrimental or would stigmatise them kept it to themselves or adopted alternative ways/approaches to disclosure. The majority of participants preferred certain ways of disclosure that would limit provision of the information to

### Panel 2: Disclosure experiences among PLWA

No one knows, not even here at home ... In the hospital, we talk as patients, but for my friends no one knows. Someone don't understand what it is secret; if you tell someone, by two days you find someone says that one you see is sick. That is why I keep my promise of keeping it to myself (*Ssempala, KAM26 interview*).

He didn't tell me, now you would know what is going on because we have seen some people with HIV/AIDS. His mother and one relative told me you are seeing the situation: go and check yourself (test) and see if you are sick; you can begin to take the medication because you have seen how the things are. Then I went to the Hospital in X area, you know the hospital ... That is where I went ... They asked me what has pushed me to come here, I told them that my husband is bed-ridden and therefore I want to know my status so that I can start taking medication (*Gwandoya's wife, KAM24 interview*).

trusted confidants or to an individual who would give some support. Disclosure in some instances was support-motivated. In doing so, some participants felt that the trusted confidants would slowly play an intermediary role to convey the message to the rest of the family members. As seen in participants' interviews, it was perceived that the information regarding the HIV/AIDS status would be managed within the 'inside' circle of the family. This was meant to avoid stigmatisation or gossip in a communal setting of participants.

The findings of this research suggest that disclosure among PLWA was a sensitive issue. Studies performed on disclosure among HIV/AIDS patients report critical issues related to the decision to disclose [10–12]. The emphases of these studies are on sensitivity of disclosure among PLWA, which causes stress and apprehension due to uncertainty about how people will react to it as well as its role in coping with HIV/AIDS. While disclosure is seen to be imperative leverage for support [13,14], in a recent cohort study of PLWA in South Africa, Wouters and his colleagues (2009) reported disclosure as necessary for material and emotional support from significant others [15].

In contrast, another study suggests that disclosure does not guarantee an increased level of support, even from family members; instead, patients encounter difficulties related to stigmatisation, rejection and abandonment [13]. Other studies have reported prejudice and stigma [16,17]. Presented with such dilemmas, patients face challenges of disclosure with conscious acts of balancing consequential risks and benefits of keeping serostatus secret. However, a cross-sectional study seeking characteristics of psychosocial support of PLWA during their treatment suggests difficulties in accessing available and culturally-sensitive psychosocial care

amongst those patients who sought such support [13]. The present study further suggests enormous psychosocial distress, which varies across all stages of HIV/AIDS. However, in line with the findings of this study, other studies carried out in Uganda suggest use of diverse coping strategies, including spiritual and other social community agencies, to overcome psychosocial difficulties [8].

Some participants in the study used various strategies to disclose. Strategies used include use of indirect approaches, use of mediation, use of trusted confidants and, in some cases, non-disclosure for fear of rejection [7,10]. The studies performed in an African setting take into consideration the context of collective societies, which are more concerned with the harmony of the group. Therefore, some participants prefer an indirect approach in disclosing their status to avoid hurting other parties. The approach also takes into account the cultural background of communication in an African setting, which also emerged as influencing strategies of disclosure [14]. Participants who experienced difficulties disclosing employed different technical uses of language, which had overlapping meanings. The findings on communication issues related to disclosure were so sensitive that among those participants who disclosed were some who had received counselling. This finding is supported by a recent case-control study to explore factors influencing disclosure in one of the districts in Uganda [8]. The study suggests measures to empower PLWA to disclose, such as improved communication skills, should be reinforced during the counselling session.

## Acknowledgement

I wish to thank Prof Jane Seymour and Dr Michael Watson, at The University of Nottingham, for their contribution to this study and joint-funding opportunity from Aga Khan University and The University of Nottingham.

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# Third Joint Conference of the British HIV Association (BHIVA) *with the* British Association for Sexual Health and HIV (BASHH)

1–4 April 2014  
Arena and Convention Centre Liverpool

## Registration and Abstract Submission

You can register for the forthcoming conference and review instructions for the preparation of abstracts online. The deadline for standard registration and abstract submission is **Friday 17 January 2014**.

## Key conference themes

- ▶ 21st century prevention: vaccines for sexually transmitted infections, hepatitis and HIV
- ▶ Translating recent research into clinical practice
- ▶ Cardiovascular disease: risk assessment, risk reduction
- ▶ Management of sustained low level viraemia
- ▶ Enteric infections in men who have sex with men
- ▶ Strategies for retaining people living with HIV in care
- ▶ HIV testing: new technologies and new strategies for those at higher risk
- ▶ Partner notification for HIV: maximising positive outcomes
- ▶ Managing men with *M. genitalium* urethritis
- ▶ Investigating pyrexia of unknown origin
- ▶ Safeguarding and sexual health in HIV
- ▶ Syphilis: immunology and HIV
- ▶ HPV vaccination in men who have sex with men
- ▶ Hepatitis C: when to treat and when to wait
- ▶ Chem-sex: Why is it problematic and what can we do about it?

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