

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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Aims and Scope

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

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

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The quest to win the war – without losing the battle

Ian Hodgson

Independent Consultant, HIV Education and Research

Welcome to this edition of *HIV Nursing*. As we reach the end of another year, the battle against HIV infection remains constant. One highlight of the last 12 months was the International AIDS Conference (IAC), this year held in Washington, DC – its first time in the US since 1990, and largely a product of lifting travel restrictions for people living with HIV (PLHIV) by the Obama administration in 2010.

As usual, there were gazillions of presentations, proposals, and announcements, but for this writer two things stood out. The first was what became a mantra for the event – the quest for an ‘AIDS-free generation’. It is the hope of major donors (such as the Global Fund and PEPFAR), and international HIV agencies, that strategies with proven effectiveness such as TasP (treatment as prevention), prevention of vertical transmission and male circumcision, really will herald a day when HIV is finally under control. This is very different from the 1990 San Francisco IAC, when the very idea of restraining HIV and AIDS was a pipe dream.

‘We invest so much in keeping children alive in the first decade of life. We must not lose them in the second.’

There is much debate of course, not least from activists concerned that the shifting focus towards treatment and biomedical approaches will divert attention (yet again?) from the many structural drivers of HIV, such as punitive legislation against drug users in Thailand and Ukraine, or men who have sex with men (MSM) in many African countries. Prevention is certainly key, and campaigns such as ‘What’s Preventing Prevention?’ seek to promote combination prevention, maintaining focus on a rights-based approach to HIV prevention, in addition to maximising access to treatment [1].

Two monoliths

The second feature standing out from the IAC was a focus on adolescents living with HIV. In many countries, due to better antiretroviral treatment access, many HIV-infected children are surviving into adolescence (ages 10–19). Much of the conference thus attempted to raise awareness of this new, challenging, demographic which over the years has often been neglected, falling between the two monoliths of paediatric and adult HIV care.

They experience significant gaps in services and facilities, even three decades into the HIV pandemic – largely because it is not always clear where to put them! Are they just big children? Or young adults?

Also, in stretched health systems, limits on all patient resources simply push adolescent-friendly services outside available capacity [2]. Throw into the mix complex phenomena such as transactional sex (more common amongst young people who are primary caregivers of parents living with HIV, according to one study presented), forced early marriage, nascent sexuality, and dealing with stigma and discrimination in school (often from teachers) ... and we see that the nine years of adolescence require more consideration in treatment and care programming than perhaps any other developmental stage. As UNICEF Executive Director Anthony Lane reminds us, ‘We invest so much in keeping children alive in the first decade of life. We must not lose them in the second.’

Turning to the contents of this edition of *HIV Nursing*, a number of international issues are addressed by contributors. As mentioned above, the ban on PLHIV entering the US was lifted only in 2010, and continues in many other countries, restricting the human rights and dignity of many affected people. In her *HIV Update* Juliet Bennett writes of the many other nations with such restrictions, and what is perhaps more shocking than the 46 (yes, forty-six) countries that refuse or limit entry, are the restrictions placed on affected people following arrival.

Huge improvements

Learning about the HIV response in other countries is also valuable, salutary, and reminds us of the many differing contexts in which people are supported. Iwona Wawer provides a detailed and intriguing insight into Poland’s approach to HIV care, and how a significant shift in attitudes, preparation of healthcare workers (paid a fraction of those in the UK), and strong PLHIV networks, led to huge improvements in the quality of care and support.

Preparing healthcare workers is indeed an important part of improving care, and Martin Jones writes about a successful programme of mentoring HIV nurses in South Africa. Kirstie Weeks and Heather Wharrad also focus on nurse preparation,

describing the benefits and positive outcomes of an innovative online teaching resource on HIV. An evaluation confirmed that nurses' knowledge did improve, suggesting this tool could provide an important component in advancing nurses' skill sets.

Continuing the focus on supporting healthcare workers, Mary Morris and colleagues share details of their work in Lesotho, a landlocked country surrounded by South Africa and with high HIV prevalence. This paper is important, for it provides insights into the implications of task-shifting – where nurses provide frontline care in locations where doctors are not available. A priority is maintaining consistent quality of care, and the article discusses ways to apply a quality management approach.

Gathering data – especially on how the world is seen by an individual – is vital to supplement alternative data, such as those gathered by quantitative-based surveys. Rui Baptista-Gonçalves' article on ethnography in HIV research discusses how this methodology can provide key insights into social and cultural realities. Those of us in the HIV sector spend much time preparing and planning programmes based on what we perceive to be a

person's problems – but what is it that they see? How is their world experienced? Are we presumptuous in what we think we know about them?

Finally, Robert Fieldhouse reports on what he found during a recent trip to Kenya, where strategies spearheaded by huge corporate investment are maximised and carried forward by government initiatives and a legion of community workers manning hundreds of counselling and testing sites.

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

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Three decades on: how Poland has tackled HIV

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Background

During nearly 30 years of the HIV epidemic in Poland, responses have been required to a range of situations and challenges connected with changing epidemic trends, the most striking changes being around transmission. As depicted in Figure 1, the last 25 years has seen transmission related to intravenous drug use (IDU) fall to almost zero – whereas there has been a sharp increase of HIV cases among men having sex with men (MSM). Two decades ago it was just the opposite.

Containment strategies

Current estimates and recorded trends are summarised in Panel 1 – and in general the HIV epidemic in our country is considered stable. However, future social and behavioural changes, including the increase of migration from Eastern Europe – primarily the Russian Federation – may have a negative impact.

In order to prevent a worsening scenario, and control the current HIV epidemic in Poland, the National AIDS Centre (an agency of the Ministry of Health) was established in 1993. Its main role is to define and follow up implementation of the state policy on HIV prevention and combating AIDS.

One of its most important functions is the programme entitled 'Antiretroviral (ARV) treatment of people living with HIV in Poland', which covers all those with HIV who fulfil the medical and legal criteria, including HIV-infected pregnant women and infants born to HIV-infected mothers.

Panel 1: Key statistics up to 2012

HIV/AIDS in Poland: 1985 to 2012:

- At present, the heterosexual infection rate is also higher than before, confirming that HIV is a problem facing all people: on average, each day, two Poles learn of their HIV infection.
- Cumulative data obtained from the National Institute of Public Health – the National Institute of Hygiene (NIZP-PZH) show that from the beginning of the epidemic (1985), to 30 April 2012, there were 15,602 cases of HIV infection recorded.
- Between 1985 and 30 April 2012, 2745 cases of AIDS were noted, and 1154 deaths.
- According to current estimates, there are around 30,000–35,000 people living with HIV in Poland, 25% of whom are women.

As well as offering antiretroviral treatment to people living with HIV (PLHIV), the programme includes post-exposure prophylaxis, both for healthcare staff exposed to HIV at work, and for accidental, non-occupational exposure. In September 2012, 119 children and 6127 adults were treated in 16 highly specialised centres and penitentiary institutions around the country.

They are not isolated from other patients, and hospital staff treat them on an equal basis, because in Poland individual staff members carry responsibility for their own and their patients' security and must follow universal precautions, treating any and every patient as potentially infected with HIV.

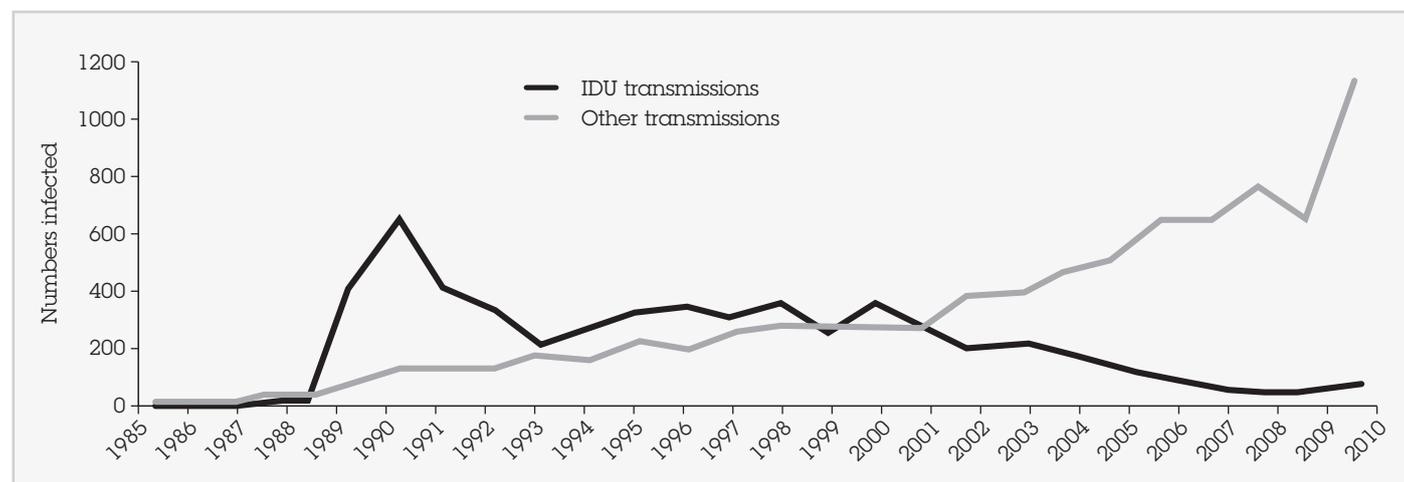


Figure 1: HIV transmission modes in Poland, 1985–2010

Early days

Warsaw's Hospital for Infectious Diseases (pictured), one of the referring centres providing complex healthcare of infectious diseases (including HIV, hepatitis A/B/C and tropical diseases), admitted one of the very first Polish patients with HIV in 1985. A woman who had returned from work abroad was sent to the hospital directly from the international Okęcie Airport, accompanied by her luggage.

The nurses were asked to turn a multi-room into a single, intended exclusively for her. All furniture and equipment was taken out, the room disinfected, and only the essential pieces of equipment remained. The patient received new personal belongings for her sole use, such as cutlery and towels, which were cleaned and disinfected individually. A separate WC and shower was put at her disposal and she was not allowed to leave her room or have contact with other patients.



Hospital for Infectious Diseases, Warsaw



This was because in 1985 everyone, including healthcare workers, was so scared of HIV transmission. Times have changed, however, and nowadays many HIV patients are admitted to this same Warsaw hospital. They are able to make friends with one another and form a strong social group whilst in hospital.

Changing times

Mutual support among PLHIV has a very positive influence on both psychological state and treatment outcomes. Nobody living with HIV feels lonely or isolated at the hospital. Unfortunately, some acts of discrimination from other, non-HIV, patients still occur because of a lack of understanding among certain members of the public. Generally, however, stigma and discrimination have markedly decreased in the last ten years.

These changes are well illustrated if we recall how things were in the 1990s. A priest, Arkadiusz Nowak, was trying to establish hospices for people with AIDS, but was prevented by protests from the local population. Meanwhile, medical and nursing personnel who took care of the ill had to cope with stigma themselves, preferring not to state where they worked, or in which ward of the hospital.

However, ten years later a hospice for people with AIDS was opened in 2000 at Otwock, near Warsaw, in a peaceful and positive way. Now, the local population are keen to offer support – and kindness – to medical and nursing staff who commute in to Otwock every day.

For some people, this is the most inspiring of all the changes Poland has seen in HIV and AIDS over the last 30 years.

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Mentoring HIV nurses overseas ... a rough guide

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Since returning to the United Kingdom from an overseas assignment mentoring nurses in South Africa, I've regularly been asked: How did you go about it? There are two different answers to this that I'll tackle in turn. Both answers offer a personal perspective – a 'rough guide' to my own experience of mentoring overseas.

From formless ambition – to overseas placement

Inspiration

Firstly, so how did I go about setting up an overseas assignment? The idea of nursing in a developing nation was a long-held, if rather formless ambition that came into focus through a blog for *Nursing Times* that reflected on my mid-career uncertainties [1]. A reader commented:

'Just a suggestion. There are millions of people in the world in need of your expertise. Why not do as I did 12 years ago and go to Africa, and teach and work there with an NGO (non-governmental organisation)? The satisfaction of helping people who are really in need of your skills far outweighs any discomfort caused by heat, bugs, etc.'

That was an inspiration. There I was, an experienced clinical nurse specialist in HIV with knowledge and skills that could be shared in developing countries, some of which have very high rates of HIV incidence.

Groundwork

I carried out some exploratory research; found that I had too little overseas experience to be considered by some aid agencies and that many ask volunteers to commit to a significant amount of time, generally more than 2 weeks. Having agreed the plan at home, I discussed my ambition with my manager who was enthusiastic and supportive, granting a sabbatical of up to 3 months including 2 weeks' study leave. As he pointed out, I would be learning from the experience.

Application

I was familiar with the work of Global Medic Force (GMF) [formerly known as International Centre for Equal Healthcare Access (ICEHA)], through their participation at previous NHIVNA conferences. I filled out their online application, had a telephone

Panel 1: PD Suggested Reading List

(comments from a letter to mentors written by Dr Fritz Kinkl, FPD, 2010)

- > Liz Walker, Graeme Reid, Morna Cornell
Waiting to happen: HIV/AIDS in South Africa: the bigger picture

Lynne Reinner Publishers Inc, Colorado, USA, 2004

'An excellent social scientists' view on HIV/AIDS in South Africa (history, labor migration, gender roles being a child in South Africa).'

- > Jonny Steinberg
Three-Letter Plague: a young man's journey through a great epidemic

Vintage Books, London, 2008

'The journalist Jonny Steinberg explores the reasons why people do not seek HIV testing despite easy accessibility of ART clinics, even in far rural areas.'

- > Lewis Nkosi
Mandela's Ego: a novel

Umuzi, Cape Town, SA, 2006

'Fiction. Nkosi interweaves the growing-up of a young boy in rural South Africa in the 1960s with the history of Mandela.'

interview with their office in New York ... and waited.

GMF placed me with the Foundation for Professional Development (FPD), an NGO providing technical support and training in South Africa's health service. I was to act as a mentor to nurses initiating and managing antiretroviral therapy (NIM-ART) in primary care clinics in South Africa. My base was to be the Umasizakhe Clinic in the town of Graaff-Reinet, in the Eastern Cape.

Guidance

I sought practical advice from a friend who works for Médecins Sans Frontières, read the reports of previous GMF volunteers, devoured a reading list provided by FPD (see Panel 1) and visited a recently returned NIM-ART mentor in London – my wife found it helpful to talk with her husband about 'being left at home'. I gained precious insight into NIM-ART mentoring in South Africa and practical guidance on living and working in the country.



The view from Umasizakhe Clinic

Getting set up

The second angle, on that same question, is a response to people seeking to find out about the actual business of being a nurse mentor in South Africa. Three principles are central:

- *Understanding theoretical background*

One needs to observe the theoretical framework and balance the three key elements of effective mentoring: support, challenge and a vision for the future [2]. This is no different from mentoring in the UK National Health Service.

- *Observing national guidelines*

South Africa's national guidelines for NIM-ART mentoring were clearly required reading [3].

- *Learning ways of adapting*

Most important of all, there's the issue of how to work effectively in an unfamiliar environment.

Critical to my approach here was being open to my new environment and reflecting on my experiences within it. In a 12-week assignment there is time to assess and plan, to allow the host country to get under the skin. As South Africa geared up for the Rugby World Cup I joined in, watching a sport that I'd never followed at home. The referees' mantra at the scrum, new to me, encapsulated an approach that I took to the clinics: **'crouch, touch, pause, engage'**.



From **L** to **R**: Martyn, with colleagues Maryna (HIV mentor nurse), Dolly and Vicky (lay counsellors) and Henry (professional nurse attached to the clinic)

Crouch — By this I mean the importance of getting into position to work effectively, and taking a measured approach to this. The scrum has its different team members – props, hooker, lock and so on – each of whom plays a role. So it is in healthcare. I needed to become integrated with the key personnel in the local South African health service, the Primary Care Clinics (PCC), and especially the HIV team; to understand their systems, relationships, roles, ways of working, attitudes to NIM-ART.

Touch — Besides 'touching base' with many people, FPD's local HIV team was mobilised to get their hands on patient files and HIV registers. We audited HIV care in three PCCs and identified gaps [4]. We assessed pharmacy stock rooms, gauging their capacity for stocking antiretroviral medicines. We identified NIM-ART-trained nurses who required mentoring. We sat in on PCC consultations – listening, observing, considering how to integrate HIV care to PCC care, hearing from and talking to patients. We identified patients lost to HIV follow-up and deployed lay counsellors who went out into the community and recalled them to clinic [4].

Pause — As an outsider it was important to check my assumptions with those around me. This involved practice nurses and their teams, pharmacists, locality managers, the HIV programme manager and others. Did everybody understand my purpose? Had I understood things properly? Would they support the implementation of NIM-ART? My weekly reports to GMF and FPD and their feedback acted as a form of supervision.

All of us in FPD's HIV team agreed upon our approach and prepared to implement it. We would improve the clinics' systems whilst increasing HIV attendances through the recall exercise, maximising opportunities for mentoring during the second 6 weeks of my assignment.

Engage — Engagement was an important process from the outset: meeting, explaining and integrating. After careful preparation, this was the true purpose of my assignment. Could we introduce to extremely busy PCCs the additional, challenging NIM-ART programme? Reading the weekend newspaper I found local inspiration from jazz trombonist Jonas Gwangwa:

'When you plant a seed, it decays a little bit before it grows. We achieved so much following the end of apartheid. Now we are going through some rot. It is this that bothers us: how long is it going to stay this way before we sprout?' [5]

The manner of engagement was also important. The 80th birthday of Archbishop Desmond Tutu provided another guiding light:

'My biggest mistake in life was being cocky because I was right. Had I remembered that you catch more flies with honey than with vinegar I might have been less self-righteous.' [6]

As a role model I was prepared to challenge where necessary: assertively not aggressively, honey not vinegar.

Lasting change

Part of my role as an overseas mentor was to plant seeds, establishing systems for high-quality HIV care, ensuring that eligible patients receive uninterrupted antiretroviral therapy and that this would continue after my departure. From the outset we planned for my withdrawal so that HIV care in the PCC would continue. FPD's HIV team has remained in place for another year, completing the mentoring process, encouraging growth in PCC nurse numbers and in services provided.

FPD's HIV team is now well established in local PCCs:

- All the sub-district's PCCs now provide HIV services following national guidelines.
- They all stock antiretroviral drugs.
- All the sub-district's PCC nurses have received NIM-ART mentoring and are initiating antiretroviral therapy for increasing numbers of patients.
- Patient records and registers are up to date.
- Systems are in place for ensuring that patients with HIV receive timely and appropriate HIV care.

On reflection

I look back with satisfaction. I cannot claim that the assignment was all that I expected; but that is because I travelled with an open mind. I was prepared to take some time establishing myself and my role; to listen and observe; to crouch, touch, pause, engage. I tried to avoid pre-conceptions. I had hoped that it would be enjoyable and that any impact would be sustained after my departure – and am satisfied on both these counts.



Maryna (HIV mentor nurse) with Martin

And the question that started it all has certainly been answered: there is plenty of opportunity for change and challenge for an HIV nurse over 50.

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Mabel Pieterse (professional nurse attached to the Horseshoe Primary Care Clinic, Graaff-Reinet) [left], and Marlene van Zyl (HIV mentor nurse)

Improving nurses' knowledge about HIV: development and evaluation of an innovative online resource

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This article documents research carried out at the University of Nottingham as part of the author's Undergraduate Nursing Science Master's degree

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Introduction and background

HIV is now seen as a chronic condition in western societies, with many people living into their 70s [1]. Those over 50 are the fastest-growing group of people living with HIV (PLHIV) in the UK [2]. This presents a challenge to health professionals, as this group needs to be cared for by generalist nurses due to the number of comorbidities that accompany HIV infection [3]. This shift in care means there is a need to develop educational programmes to increase generalist nurses' HIV knowledge and skills in caring for PLHIV.

Many studies have concluded that educational interventions are effective in increasing nurses' HIV knowledge [4–9]. However, there is debate over whether traditional/lecture-based delivery is appropriate and some studies have recommended the development of innovative delivery methods for HIV education [4–10].

To date, there has only been one published study on the use of e-learning to increase nurses' HIV knowledge [11]. This comparative study found that both e-learning and traditional face-to-face methods increased nurses' HIV knowledge, with no statistical difference between the methods [11], suggesting that e-learning is suitable for this purpose.

Reusable learning objects (RLOs) are one form of e-learning. These short online learning modules utilise active learning through interaction and self-assessment [12–14]. Evaluative research of RLOs is minimal [15]. Studies carried out suggest that RLOs can improve knowledge [16–19]; however, no quantitative research has so far been carried out with nurses.

Given the lack of data, this study was designed to provide quantitative evidence regarding the use of RLOs. A short RLO entitled 'HIV for nurses' was developed for the purpose, and the research comprised two stages: RLO development and RLO evaluation.

RLO development

Due to the cost constraints of an undergraduate research project, the RLO was developed by the

author. The Agile Framework (Figure 1) was used to ensure a high-quality, credible RLO was developed. HIV experts, including HIV specialist nurses and HIV charity professionals, were asked to provide guidance to ensure content was accurate and up to date. Two independent HIV experts peer-reviewed the media content of the RLO. The RLO was also reviewed by an e-learning consultant.

Each section of the RLO incorporated images or interactions to ensure user engagement. Quizzes at certain intervals in the RLO ensured revision of the information, thus enhancing educational value; while patient experience scenarios allowed relation to nursing practice by incorporating situated learning (Figure 2).

Study aim and objectives

The aim of this study was to develop and evaluate an RLO on HIV designed to increase the HIV knowledge of nurses in non-HIV settings. The research question was: 'Does an RLO about HIV increase the HIV knowledge of nurses working in a non-HIV setting?' Objectives were:

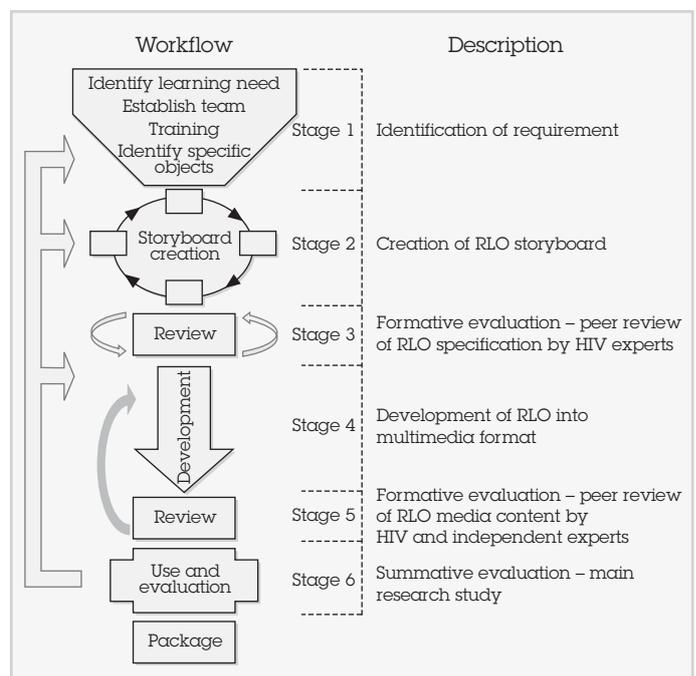


Figure 1: Agile Framework flow diagram [20]



Figure 2: Screenshot showing different design elements of the RLO's interactivity, quiz and patient experience scenarios [21]

- consult with experts on the content of the RLO;
- evaluate the RLO by comparing HIV knowledge scores from two questionnaires, both completed by the intervention (exposed to RLO) and non-intervention (no-RLO) groups.

It was hypothesised that exposure to the RLO would cause the intervention group to show a greater change in HIV knowledge score than the non-intervention group.

Methodology

Design

A quasi-experimental method was used with a pre-RLO/post-RLO comparison design. A quantitative methodology was utilised as it provided numerical data which could be analysed to establish whether an RLO increased nurses' HIV knowledge.

Intervention

The 'HIV for nurses' RLO formed the intervention in this study.

Instrument

A multiple-choice questionnaire was the research instrument. Previous questionnaires used to establish nurses' HIV knowledge were inappropriate due to the specific nature of the RLO. An initial questionnaire and a second questionnaire were developed on HIV nursing, in consultation with HIV specialists. The required answers derived from the RLO content, using the principles of constructive alignment [22].

Identical content in both questionnaires allowed maximally effective comparison:

Section 1 contained demographic questions, seeking information about previous HIV training and experience in caring for PLHIV; and asked about perceptions of stigma and discrimination against PLHIV in healthcare.

Section 2 contained 12 knowledge questions on HIV in general.

Section 3 contained 8 knowledge questions on HIV nursing.

The only difference was that, for the intervention group, the second questionnaire contained an extra section with evaluation questions of the RLO.

A pilot study ($n=5$) established a correlation coefficient of 0.9, indicating good test-retest reliability of the questionnaire. Content validity of the HIV nursing questions was established through consultation with HIV experts. The pilot study ($n=5$) also established face validity (validity at face value) by seeking participants' feedback and adjusting content accordingly.

Ethics

Ethical approval was granted by the Nottingham University Medical School Research Ethics Committee.

Sample

Learning Beyond Registration (LBR) students from a regional teaching hospital who had not worked within HIV settings were selected to evaluate the RLO. They were an accessible population of nurses

which represented the target population – nurses in non-HIV settings. The participants were selected using convenience sampling (taking samples/subjects from a group readily accessible to the researcher/s).

Data collection

The study took place at a regional teaching hospital between September 2011 and November 2011. Two groups of LBR students undertaking the same module on separate occasions were utilised. The first group formed the intervention group (RLO group) and the second the non-intervention group (no-RLO group). Both groups were asked to complete the initial questionnaire about HIV knowledge before leaving. The intervention group was given the RLO's web address and asked to complete the RLO within 2 weeks. Each group, 2 weeks after completing the initial questionnaire, completed the second questionnaire. Participants were assigned an identification number to allow matching of each person's initial and second questionnaires, for analysis. An independent observer was present throughout and kept the list of numbers, along with the names assigned to them, which protected anonymity.

Data analysis

The HIV knowledge test had a maximum score of 20, with each question scoring 1 point. 'Don't know' responses scored 0. Data were entered into SPSS Version 19.0 for analysis. Data-checking was undertaken to ensure that only numerical values in the coding scheme were entered into the scoring.

Descriptive statistics were used to display the key characteristics of the participants within the two groups for comparison. Statistical analysis included Chi square test, Shapiro-Wilk test, Independent T-tests, Pearson's product-moment correlation coefficient and the Kruskal-Wallis test. Statistical significance was set at $P < 0.05$.

RLO evaluation

Results

In total, 24 nurses out of 61 completed the study: $n=12$ in the intervention group and $n=12$ in the non-intervention group. Analysis showed no statistical differences between the basic characteristics of the groups. However, Chi square tests determined that the differences between the intervention and the non-intervention groups were

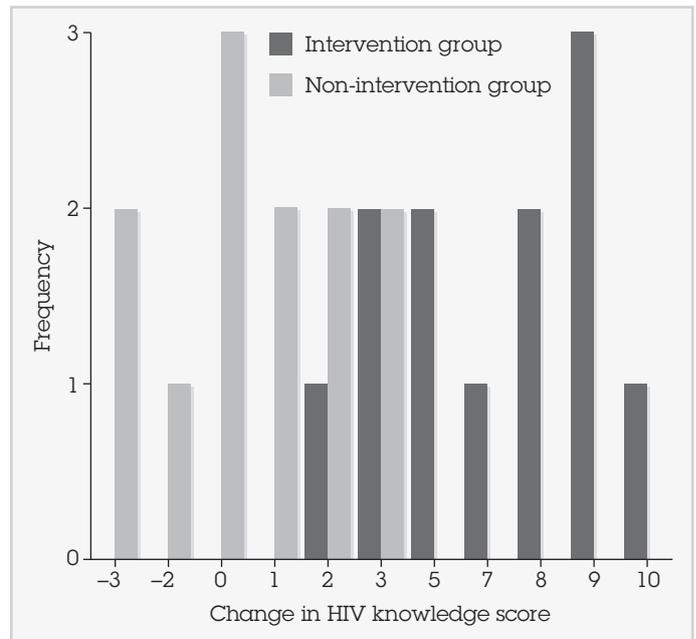


Figure 3: Distribution frequency of change in HIV knowledge scores for the intervention ($n=12$) and non-intervention groups ($n=12$).

statistically significant in respect of:

- a) participants' previous HIV training: [$\chi^2(1, n=24)=6.0, P=0.01$];
- b) the year of qualification: [$\chi^2(2, n=24)=7.0, P=0.03$].

Independent T-tests established no significant differences in initial-questionnaire HIV knowledge scores for the following variables:

- previous HIV training ($P=0.544$);
- care of PLHIV ($P=0.321$);
- year of qualification ($P=0.862$).

Initial-questionnaire knowledge

The initial questionnaire showed both groups to have poor HIV knowledge. The intervention group's mean initial-questionnaire HIV knowledge score was $9.4/20 \pm 2.4$, while the mean score for the non-intervention group was $8.6/20 \pm 2.2$. An Independent T-test established no significant difference between mean HIV knowledge score in the initial questionnaire for the intervention and the non-intervention groups: $t(22)=0.897, P > 0.05$.

Change in knowledge

Change in HIV knowledge score for each participant was calculated by subtracting their initial-questionnaire result from their second-questionnaire result. The intervention group's score

Table 1: Statistical analysis (Independent T-test) of the mean change in HIV knowledge score of the intervention group ($n=12$) compared with non-intervention group ($n=12$)

Group	Mean change in HIV knowledge score	Standard deviation (SD)	Minimum	Maximum	P value
Intervention	6.5	2.8	2	10	<.001
Non-intervention	0.3	2.1	-3	3	<.001

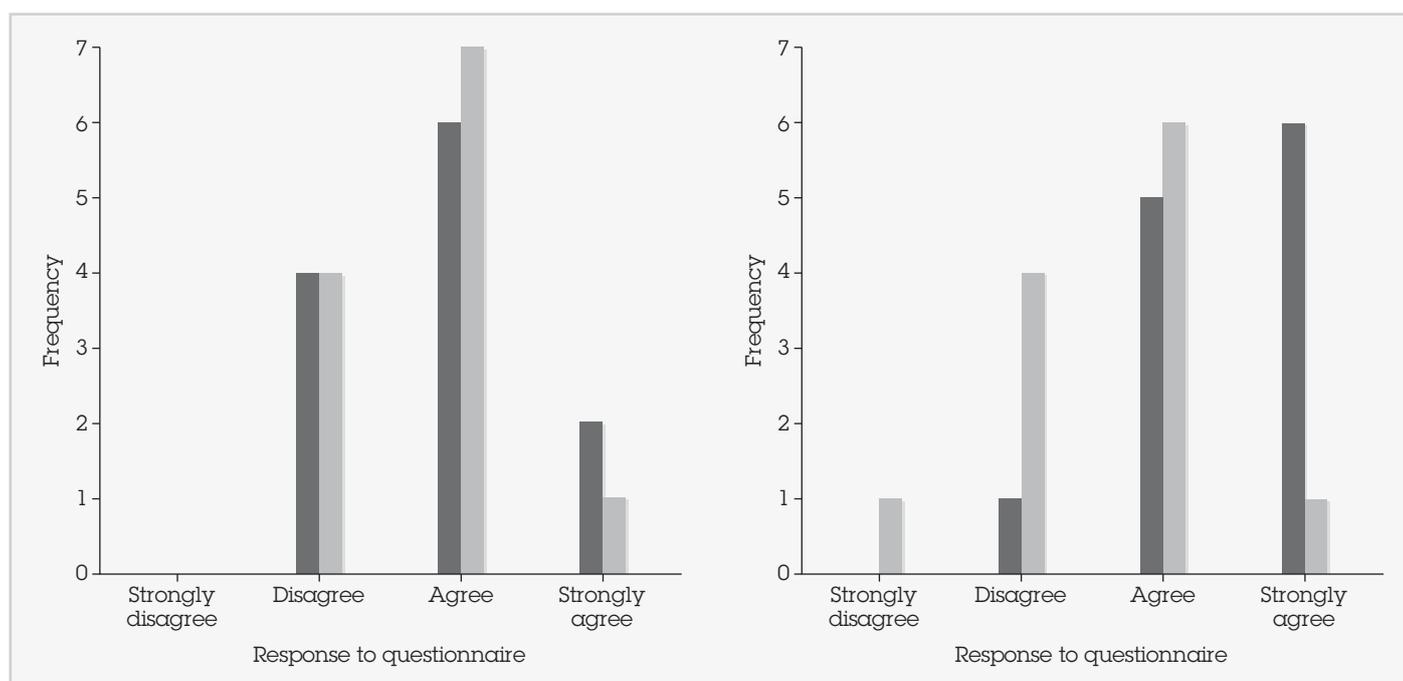


Figure 4a: Frequency distribution of initial-questionnaire perceptions of stigma and discrimination experienced by PLHIV, for intervention (■) and non-intervention (□) group

Figure 4b: Frequency distribution of second-questionnaire perceptions of stigma and discrimination experienced by PLHIV, for intervention (■) and non-intervention (□) group

change ranged from 2 to 10, while that of the non-intervention group ranged from -3 to 3 (Figure 3). In the intervention group all participants' ($n=12$) HIV knowledge scores increased. However, in the non-intervention group six of the participants' second-questionnaire HIV knowledge scores were either lower or the same.

Perceptions

The initial-questionnaire perceptions for both groups were similar, mainly agreeing or strongly agreeing with the statement, 'Patients living with HIV experience stigma and discrimination in healthcare settings' (Figure 4a). However, second-questionnaire perceptions for both groups were different (Figure 4b). The Kruskal-Wallis test confirmed that the distribution shift for the intervention group to the agree/strongly agree pole was statistically significant [$H(2)=6.121$, $P=0.013$]. This shift did not take place in the non-intervention group.

Overall, the evaluation of the RLO was positive, with all participants ($n=12$) stating that they would recommend it to others. Participants who elaborated stated that they would recommend the RLO to other nurses, student nurses and colleagues.

Conclusion

This study is the first of its kind, to date, that has evaluated the ability of the RLO to increase nurses' knowledge. Results showed poor knowledge overall, and that the RLO was effective in significantly increasing it. This outcome provides important additional evidence to support the use of RLOs, which is currently minimal [15].

The RLO is currently being used by HIV specialist nurses as an educational resource and is freely available for use [21].

It is hoped that, with further evaluation of the RLO, the conclusions of this study could lead to the implementation of e-learning into post-registration HIV education, increasing nurses' HIV knowledge and potentially improving the care that PLHIV receive.

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• Discussion follows overleaf

Discussion

Improving HIV knowledge

The results suggest that the RLO was effective in improving nurses' HIV knowledge, with a significant difference between the intervention and non-intervention groups' mean change in HIV knowledge score. However, there is no way of determining whether confounding factors contributed to the intervention group's change in HIV knowledge score – for example, participants having used other means to further increase their HIV knowledge after completing the initial questionnaire.

Like other research in this area, these results support the effectiveness of educational interventions in increasing nurses' HIV knowledge [4–9]. However, the variation in questionnaire content between this and other studies means that direct comparison of HIV knowledge score changes, attributed to educational interventions in this study and others, is questionable and requires caution. Most significant here is the correlation in findings between this study and the only other study undertaken on increasing nurses' knowledge through e-learning [11].

These results provide empirical evidence supporting the specific proposition that e-learning is viable as an alternative HIV education method which may help address difficulties in disseminating new developments in HIV care to nurses. However, the results do not determine whether e-learning is more effective than traditional/lecture-based delivery methods. Further research is required comparing the two approaches.

Urgency for education

This study's results provide an up-to-date picture of UK nurses' poor HIV knowledge. The average score from this study is similar to those of others carried out in the early 90s [23], suggesting that nurses' HIV knowledge in the UK is still poor despite the issue being raised over two decades ago. This highlights the need for education, and in turn for study outcomes establishing the RLO's effectiveness for this purpose.

It is paramount that, with these results confirming nurses' poor HIV knowledge, HIV education becomes a priority for nurse educators.

Nurses' perceptions

The shift in the intervention group's perceptions regarding stigma suggests that the RLO changed this group's views. This is encouraging as it suggests that the RLO's use within post-registration HIV education would both increase knowledge and also raise nurses' awareness and understanding of these

key issues. However, further research is required to establish whether this change is permanent and/or has any impact on attitudes and behaviours within nursing practice.

Strengths of study

- Despite the small sample size, the large size effect ($\eta^2=0.79$) indicated a strong relationship between completing the RLO and increased score, suggesting these results are generalisable with caution.
- Use of a comparison group surmounted limitations attributed to previous research in this field [24,25].
- The application of the Agile Framework enabled formative evaluation during RLO development – also cited as a limitation in previous research [24,25].

Limitations of study

- The main limitation was the small sample size.
- The voluntary nature of the study meant that voluntary response bias is likely to have occurred.
- Lack of randomisation in selecting participants for the two groups affected the internal validity of the study.
- The sample population, LBR students, was a limitation as they may have been more willing than others to take part in a study relating to nurse education.
- The use of LBR students from a single site affected the study's rigour.
- The study did not collect follow-up data to determine whether the increased HIV knowledge endured: further research is required on long-term effects of HIV knowledge increase on nursing practice.

Implications of study

The main implications of this research are that:

- increasing nurses' HIV knowledge must become a priority for nurse educators, to improve the care that PLHIV receive in hospital;
- all nurses should receive post-registration HIV education;
- RLOs may be one suitable method to enable the above;
- more study is needed, with larger samples using the RLO and further research, to establish the long-term effects on practice of greater HIV knowledge among nurses and of changes in their attitudes.

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Quality improvement at work: outcomes in Lesotho in 2011

Mary Morris, Mamorapeli Tsoeu, Appolinaire Tiam, Tony Isavwa, Leopold Buhendwa, Ashley Thompson, Shabbir Ismail

Elizabeth Glaser Pediatric AIDS Foundation

Introduction and background

In April 2012, representatives from the World Health Organization (WHO), health ministries in 33 countries, and international leaders in quality improvement and patient safety, convened in Salzburg to address critical gaps between current professional awareness of interventions to improve population health – and the healthcare actually provided to patients. The outcome was a statement urging international, regional and national stakeholders to promote improvement in population health by using quality improvement methods [1]. This objective of this article is to discuss the effects of implementing quality improvement strategies to increase access to antiretroviral therapy for HIV-positive children in resource-limited settings in Lesotho – where the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has been working with the Ministry of Health (MoH) to implement programme improvements in family health since 2004.

Lesotho, a landlocked, mountainous kingdom surrounded by South Africa, is divided into ten administrative districts, comprising about 30,355 square kilometres [2]. Lesotho's two official languages are Sesotho and English [2] and 23% of its 1.9 million population live in urban areas [2]. Lesotho has the third highest HIV prevalence in the world [2], with 2009 estimates of 23.6% for the 15–49 age group [3], an increase of 0.6% from 23% in 2007 [3]. Under-5 mortality has increased from 90 to 117 deaths per 1000 live births from 2002 to 2009 [2].

The 2009 infant mortality rate (IMR) was 91 deaths per 1000 live births, an increase from 85 deaths per 1000 births in 1986, one of the major causes being mother-to-child transmission of HIV [3]. Revised antiretroviral therapy guidelines issued by the government in 2008 estimated a rise in numbers of people living with HIV (PLHIV) in need of ART. Nevertheless, coverage of ART therapy increased from 16% in 2005 to 54% in 2009 [3]. Improving access to, retention and quality of HIV care is a priority for Lesotho's Ministry of Health, to reduce HIV-related mortality and improve social development outcomes [2,4].

Supply versus demand

From October 2007 to March 2012, in health facilities supported by EGPAF, approximately 25,000 women received antiretroviral prophylaxis

to prevent mother-to-child-transmission; and during the same period EGPAF supported the initiation of 46,000 adults and 2800 children on ART. At the end of March 2012, 76,000 adults and 7300 children were receiving ART services in EGPAF-supported health facilities [5] [out of an estimated 118,000 in need of ART in 2010 (3)]. Critical human resource gaps mean that health services fall short of meeting demand, particularly for HIV care and treatment. In a baseline assessment conducted by EGPAF in 2012, 31% of health facilities had a physician on staff and 65% of health facilities had at least one registered nurse [6].

Nurses are trained at one of four accredited nursing schools in Lesotho. The nursing education levels are:

- Nurse Assistant – a 2-year certificate;
- Registered Nurse – a 3-year diploma;
- Registered Nurse/Midwife – a 4-year diploma;
- Registered Nurse Clinician – requires a Nurse Midwife diploma plus a diploma or degree in primary healthcare;
- Clinical Mentor – requires a first degree or Master's in nursing;
- Nurse Educator – requires a first degree or Master's in nursing;
- PhD Level Nurses – requires a first degree or Master's in nursing and a PhD.

Registered nurses and registered nurse midwives provide the bulk of HIV care and treatment services, including outpatient consultations and prescribing essential medications [7]. Registered nurse midwives conduct antenatal, maternal, neonatal and child health services, including deliveries, patient consultations in health centres, prescribing ART and other medications. Nurse clinicians and mentors provide comprehensive health services including prescribing, in addition to mentoring registered nurses on service delivery and compliance with standards.

Quality management

In developing countries, lack of investment in health infrastructure and human resource development diminishes quality of care through inadequate service coverage, poor physical and professional working environments and staff shortages [8].

Despite healthcare advances in a number of low- or middle-income countries, reducing maternal and

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Themes for 2013

13.1	13.2	13.3	13.4
Men and HIV	Community and collaboration	Health promotion and adherence	International perspectives
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infant mortality remains a challenge, particularly where HIV prevalence is high. However, even where resources are limited, quality improvement strategies can help providers strengthen operating systems and care delivery [9].

Health outcomes are affected by multiple processes in health service delivery [10,11]. Assessing and improving processes and structure of service delivery – such as adherence to national guidelines, standards of care, communicating and building trust with patients – can influence health outcomes [10,11]. Recognising how each component contributes to the whole, and to the end result, constitutes the structure-process-outcome framework of 'quality of care' [10,11].

For the Institute of Medicine (IOM), quality healthcare is 'the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge' [12]. The WHO defines quality healthcare as 'effective, efficient, accessible, acceptable, equitable and safe' [13].

While the Lesotho MoH recognises that quality management methods enhance healthcare service provision, lack of funds has slowed their application. The National Quality Assurance unit is developing its policy and strategic plan, including quality management standards, a patient charter and quality management training materials. EGPAF works to support the MoH in the use of quality management methods to improve care in the 202 health facilities where it has involvement.

▪ Targeting problems

In collaboration with the MoH, EGPAF provides training to district and facility healthcare workers in quality improvement, focusing on defining healthcare quality, dimensions of healthcare

quality, measuring quality and implementing quality improvement cycles. Once they are trained, healthcare workers form quality improvement teams to work on improving quality of care provision. The Model for Improvement (developed by Associates in Process Improvement in the US) [14] is used as a framework for implementing quality improvement (QI) efforts.

This framework uses three initial questions to frame any QI activity at facility, district or national level, after asking the questions. The teams:

- select and agree on targets after identifying gaps in quality care;
- determine how to measure the impact of improvement efforts; and
- implement Plan-Do-Study-Act (PDSA) cycles of change (Figure 1).

At a number of EGPAF-supported facilities in early 2011, healthcare teams identified that starting eligible HIV-infected children on ART was challenging. Some eligible children aged 0–14 years were not being prescribed ART or cotrimoxazole (CTX) as indicated by the national treatment guidelines. To determine what the next steps should be to improve, it was imperative to understand the problem and its causes. EGPAF used a number of tools, such as cause-and-effect diagrams and process mapping, to focus on the problem rather than apportion blame, to investigate and summarise the team's knowledge of the problem, and to focus on causes rather than symptoms. Below are examples of such tools in use:

i. Cause-and-effect diagrams (or fishbone diagrams) were first devised by Professor Kaoru Ishikawa at Tokyo University in the 1960s, to help teams to focus and to think through all the causes of problems, logically and thoroughly [15]. Improvement teams identify a problem, such as long waiting times, then consider it in detail: who is involved, when and where it occurs. They identify the main categories of potential causes and then work through all potential causes of problems under each category (Figure 2).

ii) Process mapping [16] consists of mapping a patient's journey when s/he comes to the clinic for a particular service and is a way to understand the process in order to change it. It identifies bottlenecks, unnecessary steps, duplication and gaps in a process, showing what actually happens rather than what should happen, and helps to inspire improvement efforts (Figure 3).

EGPAF worked with facility teams to create cause-and-effect (fishbone) diagrams and conduct process mapping to outline the actual steps in the process of initiating eligible children on ART (Figure 4). The teams then determined what was happening at each stage, and where the gaps and bottlenecks arose.

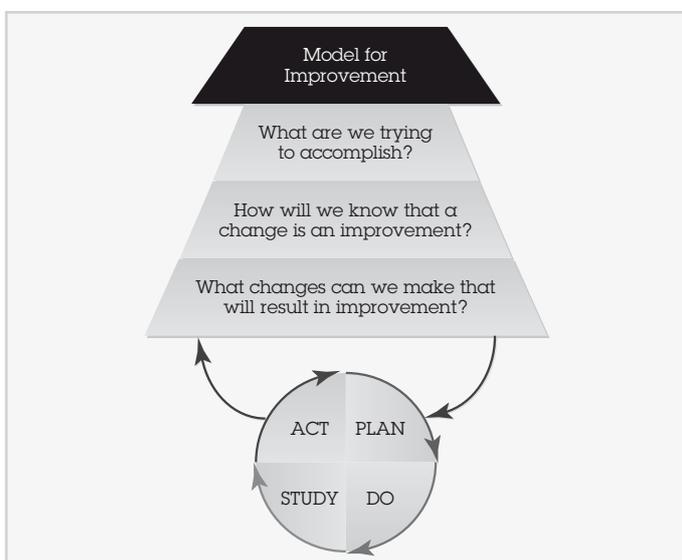


Figure 1: Model for improvement [14] (reproduced with permission from Associates in Process Improvement)

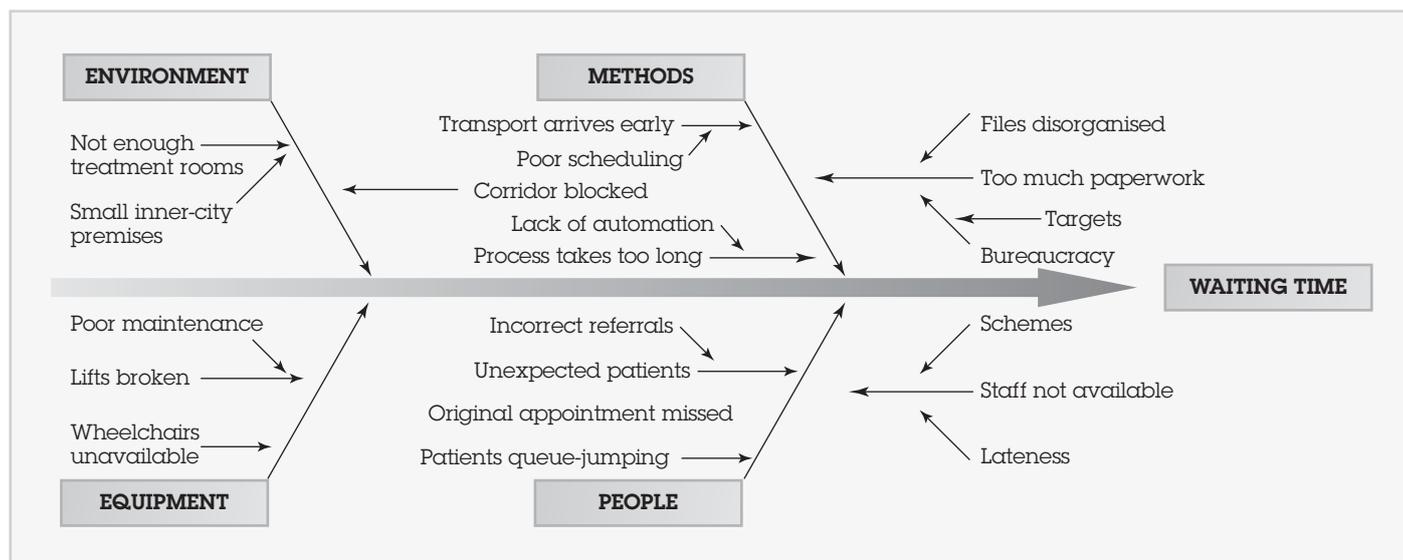


Figure 2: Cause-and-effect (fishbone) diagram [15] (reproduced with permission from NHS Institute for Innovation and Improvement)

■ Tackling barriers

These approaches identified the following barriers to prescribing ART in children:

- In some busy clinics, only absolute CD4 count testing (rather than WHO staging combined with CD4 count) was performed on children to determine ART eligibility – because nurses lacked confidence in clinical HIV disease staging.
- Some children were not prescribed ART or CTX because the recorded WHO clinical stage did not reflect their nutritional status; hence children who were chronically moderately to severely underweight were missed, or erroneously diagnosed as WHO stage I or II.
- Lack of confidence and skill in taking CD4 blood samples in young children led to reduced testing, with a resulting lack of data for clinical decision-making.
- Long waiting times meant that caregivers were reluctant to return to the clinic for care.
- Nurses, although trained, were not confident in

conducting WHO clinical staging and lacked adequate tools for nutritional assessment.

EGPAF's fundamental package of support includes provision of extensive training and mentoring for doctors, nurses and allied healthcare workers (HCW) in HIV prevention, care and treatment. This is accompanied by printing/distribution of posters, information sheets and instructions to guide nurses in WHO clinical staging, ART eligibility, and the correct dosing of medication for paediatric patients. Moreover, all facilities are provided with all relevant national guidelines.

Following identification of these issues, improvement PDSA cycles were implemented. These cycles involved providing clinical mentoring to nurses to increase their confidence in clinical staging of HIV disease and in prescribing ART and CTX. Nurse clinicians and physicians from EGPAF distributed WHO growth monitoring tools at all supported facilities; provided clinical mentoring in nutrition assessment using WHO weight-for-age Z-score charts; and mentored in clinical staging, ART prescription, and diagnosis/treatment of opportunistic infections (OI). Training in paediatric phlebotomy was provided to help nurses increase their skills and confidence in taking blood samples for CD4 testing in small children. In some facilities, the patient flow was changed to increase efficiency, avoid duplication and remove unnecessary procedures.

Monthly children's clubs were set up at each health facility to counsel and support HIV-infected children and provide opportunities for peer support and encouragement. Defaulter tracing to follow up children late for appointments was conducted by community-based organisations.



Figure 3: Process mapping [16] (reproduced with permission from NHS Institute for Innovation and Improvement)

Outcome and discussion

Following implementation of clinical mentoring,

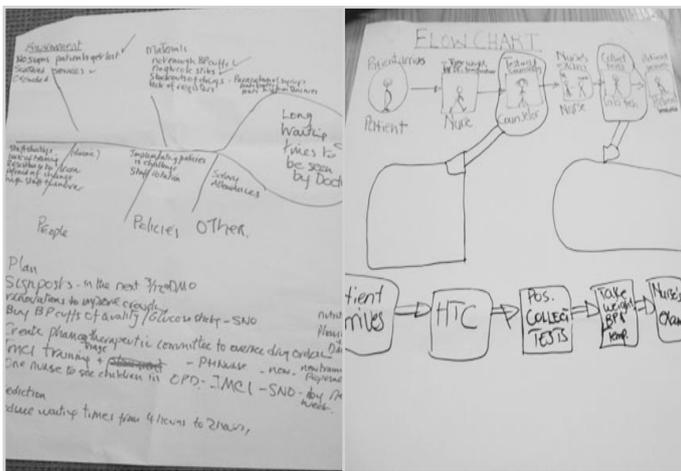


Figure 4: Cause-and-effect (fishbone) diagram and process mapping at facility level

training in paediatric phlebotomy, and efforts to follow up children, the numbers of eligible children who were appropriately commenced on ART or CTX increased.

■ *Positive responses*

In busy antenatal and mother/child health and HIV treatment clinics, teams of nurses embraced quality management concepts to improve the care they provided to patients. They appreciated the methodology and tools to help identify causes of problems and develop ideas for improvement. They identified that teamwork using routinely available data, testing changes, and focusing on systems and processes, were critical to improve. Taking the time to review and analyse their performance as a team was important as they sometimes realised that the problems and their causes were very different from what they had thought. In addition, the focus on quality helped teams see that, although they rated customer service as highly important when seeking quality services themselves, it was not always central in their own service provision.

■ *Roles and ramifications*

The shortage of physicians in Lesotho has resulted in nurses providing the bulk of health services including HIV prevention, care and treatment services in hospitals and health centres. This extended scope of work, 'task-shifting', evolved out of necessity, and was recommended by WHO, UNAIDS, and the President's Emergency Plan for AIDS Relief (PEPFAR) [17]. Task-shifting programmes have been employed successfully to scale up ART access for people living with HIV (PLHIV), even in countries with limited resources [18]. The WHO defines task-shifting as 'extending the scope of practice of existing cadres of health workers to allow for the rational distribution of tasks, to make better use of human resources and ease bottlenecks in the service delivery system' [19].

Given the extended role of nurses and the challenges of treating adults and children with HIV

and multiple comorbidities, it is vital to ensure that nurses, as the majority of healthcare providers in Lesotho, are trained and mentored to provide these crucial services. The minimum essential activities needed to prepare competent nurses to prescribe include continuous provision of advanced pre-service and in-service training, mentoring, guidelines, job aids and referral support – along with systems to ensure that quality is continuously assessed, gaps in quality are identified and improvements are seen through [18].

As increasing numbers of nurses assume extended roles, using quality improvement methodologies can assist with demonstrating their added value. Systematic use of data through continuous assessment enables providers to show they can improve care within a structured process, using tools and strategies to identify problems and causes, and implement changes. Utilising Quality Improvement methods enlightens healthcare providers on what works and what does not work, allowing recognition of excellence, or early identification and correction of problems. Through this cyclical process, providers assess themselves and build an evidence base to demonstrate their effectiveness and the quality of their service provision, reviewing their service alongside guidelines and standards and closing any gaps that become evident.

■ *Supportive policy-making*

National leadership, policy and governance is vital to the success of task-shifting and quality improvement efforts: it influences health providers at all levels of the system to focus on providing quality services. Such leadership can ensure continuous evaluation and improvement of quality, along with support for interventions that are evidence-based, patient-centred, effective, efficient, safe, equitable and accessible. It is important that national policies, frameworks, quality guidelines, care standards and a patient charter are implemented at all levels in collaboration with consumer groups and civil society, so that care provision is responsive to patient needs. This focus and cooperation should enable all necessary training materials, job aids and guidelines to be readily available so that healthcare workers have the resources, information, education and tools to provide quality care.

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Ethnography and HIV research

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Introduction

As an approach to research, ethnography is rooted in both traditional British anthropology and the Chicago School of Sociology. With its commitment to cultural interpretation, ethnography is widely used across a range of fields of enquiry and has gradually become more popular amongst nurses and other healthcare professionals. Major journals have recently devoted special issues to reports from hospital-based ethnographies, confirming an increased concern in work within this setting and its potential to shed light on broader social and cultural realities [1].

What is ethnography?

Broadly speaking, ethnography seeks to understand how people live their lives in their sociocultural worlds [2]. Ethnography is unique in social scientific enquiry in that it is committed to making sense of the way informants naturally talk and act when they are doing ordinary activities [3]. Ethnographic research is based on the assumption that understanding any culture requires studying all its aspects. Thus it combines research design, fieldwork and methods of inquiry to generate historically, politically, and personally situated accounts, descriptions, interpretations and representations of human lives [4].

A further characteristic of ethnography concerns the cyclic nature of data collection. Researchers can revisit data and reach new and deeper conceptualisations. Ethnography is also used to generate theory from an emic perspective. This means that the ethnographer reflects and interprets the conceptualisation, beliefs and values of a given group of subjects, after being immersed in that group [5].

A dual meaning

The word 'ethnography' denotes a process as well as a product, and researchers sometimes use the term rather loosely so that a clear distinction is not always made. It means both:

- the process of formulating, then applying, a specific research design onto a culture and its characteristics;
- the field study/case report that results from this research [6].

Moreover, an ethnographic study may use a range of methods beyond the interview process or the observation of participant/s; and generally involves a period of fieldwork when the researcher is immersed in the culture to be studied [7].

Use in healthcare

Types of activity

Within healthcare research, two types of ethnographic activity have been described – traditional and focused [8].

Traditional: a large-scale, comprehensive study of the general and particular features of a culture, often undertaken to obtain a comparative understanding of the universal and relative aspects of human behaviour.

Focused: often presented as a case study on a specific area of inquiry, focusing on a specific problem area and the aspects of group life that impact upon it.

Both methods seek to understand health and illness, and most studies in this field focus on the patient's views and experience of either illness or service delivery [7].

Key considerations

Four key themes have been identified [9] when applying ethnography in health and healthcare (with the first three encompassing most aspects of this discipline). More detailed review follows below of these themes, which are:

- symbolic interaction in medical institutions;
- socially constructed character of medicine;
- experience of illness/sociology of the body;
- challenges facing health ethnography.

1. symbolic interaction in medical institutions

Most representative here are studies of the doctor-patient relationship, although it is not the only instance of interaction within a clinical setting: hospitals are unique settings, not only as centres of advanced technological and scientific knowledge, but also for:

'Harbouring some of the most miraculous achievements as well some of the most worrying risks, and they are the most likely place where we are born and where we die' [10].

Here the authors point out that few studies look at the day-to-day realities of hospital medicine; most seem to focus on issues of patient safety and hygiene. Hospitals have traditionally been regarded as unappealing to ethnographers, and a difficult setting to access [11]; however, a recent increase in published hospital ethnographies suggests that the richness and complexity of hospital life can be effectively explored through this methodology.

One example was the use of an ethnographic approach to explore personal identity and HIV/AIDS within an HIV day centre [12]. The author described how the relationship between physician and patient can sometimes be contentious, particularly when it challenges the traditional authority of doctor over patient – for example, by means of the ‘expert patient’ role.

2. socially constructed character of medicine

Social constructionist studies view the practising of medicine as a form of social action, drawing on realities of human social existence and activities entrenched by behavioural and symbolic conventions of medical institutions – just as the patient’s response to a diagnosis, for example, is also informed by social prepositions that can be explored. Early ethnographies have focused extensively on medical conduct, leaving the subject of medical work little studied [9]. Medical work can be defined [9] as medical diagnoses and prognoses that are tangible demonstrations of medical authority, as well as a range of other activities and notions that are shaped by society itself (social constructs).

A number of ethnographers have focused on this social constructionist character of medical work, particularly in the last 50 years. One explored the notion of death – both from social and clinical points of view [13], based on fieldwork in two hospitals in the United States. This close, focused research aimed to describe what constituted death for the staff at the hospitals, and how this differed from one hospital to another; concluding also that clinical death is less institutionally organised than social death, the latter having more impact on routines and on the work of doctors, nurses and other staff.

Medical talk is another area of analysis relevant to ethnographers, and widely explored in the literature. One take on medical language [14] explored the power of language within a medical encounter and how it both contributed to – and defined – the doctor–patient relationship. Medical discourse therefore works both as a surveillance tool and a means to exercise power and control.

Other theorists have explored medical talk from the perspective of social constructionism. Research looked at material from nursing home conferences and activity on a haematology ward [15,16], agreeing that discourse is shaped according to the audience and medical terminology is used as a demonstration of status. It has also been observed that junior doctors and medical students, and their clinical competence, is highly related to the way in which they describe and present different cases to peers and seniors; and that the process of becoming a competent doctor involves mastering the vocabulary used by those already considered to be competent by remaining members of the group [16,17].

3. experience of illness/sociology of the body

Health sociology research has benefited greatly from the use of ethnography [18], and an important area of study focuses on the experience of chronic diseases and/or the study of pain. Particularly significant was the account of chronic illness as social deviance, introducing concepts such as ‘patient career’ and exploring issues of identity, normalisation and coping strategies to deal with illness on the one hand, and with discrimination and exclusion on the other [19].

A classic account is the report by a TB patient on his experience, at a time when patients were hospitalised for several months. As well as keeping a detailed diary, the writer also joined the hospital staff shortly after discharge, to explore the experience of illness among other patients [20]. Another important study explained how intravenous infection is symbolically understood by patients by imagining the body as a ‘battleground against HIV’ [12]; while a further paper concluded that an HIV-positive diagnosis can be transformed, from a negative and stressful event into a tool for self-reflection and introspection [21].

4. challenges facing health ethnography

For a number of reasons, health ethnography sometimes receives a mixed reception, which can bring its validity into question. The issues and challenges that arise most often are:

(a) maintaining appropriate perspective

This relates to the appropriateness or otherwise of the author/researcher perspective on the material researched. In contrast with the approach of medically trained hospital professionals, ethnographic writing can often be perceived as unscientific, which gives rise to criticism of ethnographers and their approach to research [9]. Also, certain aspects of the health ethnographer’s role can create extra challenges during the research process. One study author was both a ‘native’ (the anthropological term for someone born in a specific place and/or associated with that place) and a professional (a medical doctor) in the fieldwork of the study, and this is a good example of how the researcher’s identity and role can be difficult to pin down, both from their own perspective and from that of others. He observed: ‘I admit that for many doctors at the hospital, my identity was ambiguous’ [1]. Ambivalence about role and identity can lead to a skewed approach, eg, where data that should be observed specifically by a researcher are reported from a nurse’s perspective.

(b) compromised validity for policy-making

This is one of the key challenges facing the application of ethnography within the health

sciences. Whilst quantitative research may offer policy-makers relatively simple and straightforward criteria to underpin executive actions [9], qualitative and ethnographic studies can be regarded as scientifically suspect because they derive partly from individual perceptions and thus cannot claim generalised accuracy. It has been suggested that, as long as limitations on generalisation remain embedded, ethnography will never gain gold-standard recognition [9].

Nevertheless, a number of ethnographic studies have contributed to policy-making, particularly around injecting drug use and HIV infection. It has been reported that understanding of how injecting drug use facilitates transmission of HIV and other blood-borne viruses was initially derived from ethnographic studies in this field, with the data soon in use for harm-reduction campaigns and interventions [9,22].

Another contribution to policy-making was the role of ethnography in understanding male involvement in reproductive health, which facilitated the planning and implementation of culturally appropriate interventions [23].

On a general level, it has been widely acknowledged that many health practitioners take into account the findings from ethnographic studies to inform their practice [9].

(c) impact of challenges from subject

The 'revolt of the subject' (the person on whom the research is focused) is widely documented in the health sciences literature, and can become an ethical issue in itself. It takes several different forms, one of the most obvious types of revolt occurring when subjects feel poorly represented or even betrayed by the researcher – often because the ethnographer is not a member of the group being studied or does not endorse the subject's versions of the facts [24]. A key area of relevance is disability studies in which the ethnographer is not disabled: can s/he interpret the complex realities faced by disabled people without being 'one of them'? Equally, however, some authors stress that an outsider's interpretation can enhance understanding of a group's reality [25].

Conclusion

This article explored the definition and scope of ethnographic research, and how it can be useful in teasing out rich and complex data surrounding experiences and perspective on a given aspect of someone's life. Although its applicability, or otherwise, to hospital-based and healthcare research presents significant challenges, certain areas of HIV research and care can benefit greatly from an ethnographic approach, and its observations on what informs and shapes the experience of people living with HIV.

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Partnerships in action

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Robert Fieldhouse reports on prevention, testing and treatment initiatives in Kenya

Introduction and background

It is ten years since Abbott launched its Access to Care programmes in Africa. Over the past decade the Abbott Fund has invested more than \$250m in programmes to support HIV/AIDS education, prevention, testing and treatment roll-out, as well as to strengthen healthcare systems and build local capacity. The key to success and sustainability has been to facilitate lasting partnerships. Over five days in June 2012 I witnessed first hand the incredible impact such investment is having in Kenya and Tanzania.

Kenya, in eastern Africa, is a country of some 39 million people. Life expectancy is just 55.3 years. Half the population lives below the poverty line. The first cases of HIV were described in 1983 and HIV was declared a national disaster in 1999. Unlike England, Kenya has a National AIDS Strategic Plan.

At around 8%, HIV prevalence among Kenyan women is twice the rate among men. Prevalence among injecting drug users in Mombasa exceeds 20%.

HIV burden is greatest in the western part of the country. Close to both the Congo and Uganda, this is where HIV first began to spread in Kenya. It is also a region where male circumcision rates are below the national average: historically, only 15% of men in the Lake Victoria region were circumcised. This, along with cultural practices such as wife inheritance, has played a part in allowing HIV to spread.

Kenya was the first country in Africa to develop a policy on male circumcision. Even around Lake Victoria, where circumcision was not a cultural norm, 50% of men are now circumcised and Kenya is regarded as the 'leading' country in Africa for circumcision.

However, by 2015 Kenya anticipates being able to close its male circumcision programme and make the procedure routine for boys at a young age.

The intention is to bring about universal access to HIV treatment by 2015 but there is still a way to go.

Towards universal access

In 2006 Kenya's President announced that HIV treatment would be free in public hospitals.

Kenya was awarded US\$ 345,103,870 from the Global Fund to fight AIDS, TB and malaria. In total

\$40m is managed by the Red Cross on behalf of civil society organisations. The Ministry of Finance on behalf of the Kenyan Government manages the remaining \$305m. The intention is bring about universal access to HIV treatment by 2013. But there is still a way to go.

Current estimates suggest that just 500,000 of the 1.4 million people living with HIV in Kenya are taking antiretroviral drugs, meaning a substantial unmet need in the population. However, to put this in perspective, only 10,000 people were receiving HIV treatment in 2004 – a scale-up of phenomenal force.

Here people typically initiate treatment at a CD4 cell count around 200. The Global Fund monies are intended to assist Kenya in being able to implement World Health Organization guidelines which recommend people begin treatment at 350 CD4, the same as here in the UK.

The Kenyan Government distributes 15–20 million condoms each month, believing that, 'you only need a small proportion (5–10% of the population) to use condoms to affect the epidemic', according to Dr Peter Cherutich, Head of Kenya's National AIDS and STI Control Programme (NASCOP).

'The middle classes don't access testing; they see it as beneath them to go for an HIV test.'

Condom use within marriage remains a challenge. The condom was first introduced into Kenya as a protective mechanism for HIV prevention. 'It should have been marketed as family planning; there's no stigma around that,' Dr Cherutich told me.

Testing times

Five million Kenyans take an HIV test each year. Population surveys asking if you have been tested in the past 12 months show rising testing rates, up from 10% in 2003 to 50% in 2009. By the end of this year NASCOP estimates testing rates will hit 70%.

The offer of an HIV test in antenatal clinics is taken up by 95% of women. Vertical HIV transmission (mother to child) has fallen dramatically as a result. The current rate is 10–15% and the aim is to bring it below 5% by 2015. In some regions vertical transmission has been eliminated completely.

Since last year people seeking treatment for malaria and typhoid will have also been offered HIV testing.

Abbott recently donated its 20 millionth HIV test in developing countries across Africa and Haiti in the Caribbean.

Coming forward for HIV testing can still be a challenge: 'Around 65% of those who have ever tested are women. The middle classes do not access testing; they see it as beneath them to go for an HIV test.' Dr. Cherutich said, continuing, 'The best way to fill the gap is to have testing kits that can be distributed through pharmacies.'

Though Dr Cherutich acknowledges Kenya is still 'trying to develop a plan to roll out home-based testing', he sees it as pivotal in closing the gap on the undiagnosed. Home-based testing is being done on a large scale in western Kenya, and it is possible this strategy has played a role in reducing vertical transmission rates.

Other strategies

Since 2009 it has become clear that most HIV transmissions occur within discordant couples. In recognition of this, perhaps, the government has grabbed the concept of Treatment as Prevention by the horns and has already begun dialogue to roll out pre-exposure prophylaxis (PEP) to people at high risk of HIV acquisition.

Introducing a medical insurance scheme for middle-class people at least is a hot topic right now in Kenya. A scheme for civil servants, and a number of employer contribution schemes, are already up and running.

Voluntary input

However, right now HIV services are free. During my trip I visited the Liverpool Care and Treatment (LVCT) centre, a not-for-profit non-governmental organisation, with 270 staff across four distinct geographical regions: Nairobi, the Eastern Region, the Central Province and Western Province. Liverpool is Kenya's largest provider of voluntary counselling and HIV testing outside of the country's government.

Liverpool was set up in 1998 as a research study from Liverpool School of Tropical Medicine to assess the feasibility of scaling up HIV testing in Africa. Since 2001, LVCT has established more than 500 voluntary counselling and testing sites.

As well as providing HIV testing and counselling, Liverpool provides treatment and care to 13,000 people with HIV and currently manages 6500 people on antiretroviral therapy.

'Ten years ago when all this started, we did not have capacity to treat most of the population so we needed to manage the number of people who came into testing,' explained Dr Lilian Otiso, Director of Services.

Strength in numbers

The clinic uses a network of community workers who are paid a small stipend, equivalent to 10% of

the minimum wage. In the future the plan is to have 400 of these workers: in Rwanda volunteerism works, whereas in Kenya the cost of living is higher.

Having developed a partnership with leading Kenyan mobile network operator Safaricom, and sought funding from the Elton John AIDS Foundation and Comic Relief, Liverpool operates what is now the largest telephone helpline in eastern and central Africa.

Being a man who has sex with men is illegal in Kenya. Liverpool has established good working relationships with non-governmental organisations working with MSM. 'We had to house the Gay and Lesbian Association of Kenya,' Dr Otiso said. 'We built their capacity in terms of financial management. Now they are on their own and advertise for their own jobs. We are more tolerant than our neighbours' (meaning Uganda and Malawi).

MSM are recognised as a 'most at risk' population in the Kenyan National AIDS

Strategic Plan, giving the clinic a green light to provide prevention and care services to them.

Exactly like the UK, there is an emphasis on 'doing more with the same budget or less'.

Maximising funds

Similar to the UK, the approach to HIV testing has radically evolved over the past 5 years. Exactly like the UK, there is an emphasis on 'doing more with the same budget or less'. Pre- and post-test discussion is now completed in 20 minutes.

Despite huge investment from companies like Abbott, its philanthropic foundation, the Abbott Fund and other global health foundations, it has become increasingly difficult to keep up: 'funding is plateauing when we need to expand,' Joshua Olang, Liverpool's Operations Director, told me.

'Getting testing, treatment and care services out into the community is a must, it saves time and money. If there is a country that will roll out home testing, it will be Kenya,' NASCOP's Dr Cherutich assured me. Judging by Kenya's impressive scale-up of condoms and HIV treatment over the past 5 years, he is likely to be right.

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Road to nowhere?

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People living with HIV should be able to travel freely in today's global community – but some countries are notoriously reluctant to align public health policy with human rights

Introduction

There are countless laws and policies in place restricting people living with HIV (PLHIV) from entering, staying or seeking residence in specific countries. The justification given for such laws is, in general, public health – to protect public health or minimise risk of incurring costs associated with care and treatment. This is neither an evidence-based nor a rights-based way of preventing HIV transmission; and whatever the reasons given, these restrictions are clearly discriminatory and raise fundamental questions regarding human rights. Some would argue this approach effectively criminalises PLHIV.

The list ...

Table 1 lists all the countries imposing restrictions on PLHIV in 2012. In total UNAIDS [1] lists 46 countries and territories; 11 out of 30 countries in Eastern Europe and Central Asia have legislation placing restrictions on entry, residence or stay – ranging from refusal of work, study and residential permits and, although less frequently, tourist visas.

... the impact ...

We all recognise from our work that PLHIV are vulnerable, often more so in other countries than here in the UK. Through their HIV diagnosis, PLHIV are at constant risk of losing employment, financial

status, housing, friends and family and – of course – their health. Testing in many countries with restrictions is effectively mandatory, in stark contrast to the World Health Organization (WHO) guidelines and joint UNAIDS/WHO policy statement on HIV testing [2], which stipulate voluntary testing in all circumstances. In many instances these tests are done without appropriate counselling, or systems to safeguard confidentiality.

Such prohibitions limit opportunities significantly for PLHIV. As the world becomes increasingly 'mobile', freedom to travel is more important than ever to many of us. For those seeking to migrate, gain asylum, visit family, work outside their country of origin or study overseas, these restrictions can be devastating. If an HIV test taken in these circumstances is positive, the individual may face, simultaneously, the diagnosis, potential loss of employment, deportation and loss of family contact.

Restrictions then imposed on travel may further expose confidentiality, leading to self-stigmatisation and fuelling negative perceptions of PLHIV.

'Everyone has the right to leave any country, including his own, and to return to his country.'

... the response

Not surprisingly, this forced disclosure leads some people to 'disappear', hiding from immigration officials and unable to access healthcare or support. In extreme cases, these laws and policies encourage violence and discrimination against the most vulnerable, often directed at women. Paradoxically, this then undermines the country's intended strategy to reduce public health risk.

From a business perspective, at AIDS 2012, this year's International AIDS Conference in Washington [3], a group of 20-plus chief executives from multinational corporations called upon the countries still imposing restrictions to lift them. The business leaders opposed what they believe to be discriminatory 'laws' which are bad for business in today's competitive global landscape. For Sir Richard Branson, 'treatment has allowed people with HIV to live fully productive lives and these laws are downright archaic' [4].

Table 1: Countries expelling foreigners who test HIV positive

Bahrain	Korea (North)	Saudi Arabia
Bangladesh	Korea (South)	Singapore*
Brunei*	Kuwait	Solomon Islands*
Egypt	Lebanon	Sri Lanka
Equatorial Guinea*	Malaysia	Syria
Hungary	Mongolia	Taiwan
Iraq*	Oman	Turkmenistan
Jordan*	Panama	United Arab Emirates*
Kazakhstan	Qatar*	Uzbekistan
	Russian Federation*	Yemen*

*categorically refuse entry to PLHIV

Bahamas, Papua New Guinea and Sudan also categorically refuse entry.

Personal histories

UNAIDS reveals some disturbing experiences which demonstrate the true impact of such restrictions [5]:

- Immigrants are forced into illegal employment and economic activities to stay in the country. 'Many people living with HIV reportedly buy forged medical certificates to enjoy a stable life in the Russian Federation and avoid deportation,' reports Andrei, an HIV-positive Ukrainian based within the Russian Federation. He will not buy one of these certificates as he wants to respect the law but is forced to work illegally because he cannot prove that he is seronegative. Lack of residency status also means he cannot access medical insurance in the Russian Federation: 'Compulsory HIV testing does not prevent the entry of foreign nationals living with HIV,' Andrei says.
- Harjeet, an Indian migrant worker, was jailed and then deported from Saudi Arabia when a blood test, required for the conversion of his tourist visa to a work visa, showed he was HIV

positive. HIV tests are required as part of the application for a work visa in Saudi Arabia, and PLHIV are deported. Harjeet was left destitute after a futile journey that he would not have undertaken if his doctor in India had told him he had been found positive on a recent test for HIV. Harjeet reported trying to hide his 'social blemish' following his return. He did not seek treatment and became seriously ill. His family disowned him when they discovered his HIV status.

- For a student, a denied visa shatters academic dreams. In 2005 Huang was denied a visa to study for his PhD in Australia. He was offered a conditional visa that he believed would have jeopardised the chances of completing his studies. His right to privacy was compromised in the visa application process, and the developments that followed forced Huang to leave his work and home in Singapore. He believes his career development was irreparably damaged.

Realistic strategies

We know that the HIV epidemic is largely driven by undiagnosed infection and not, on the whole, by those who know their status. Singling out HIV, just one of several communicable diseases, causes long-term harm to health, perpetuates stigma and discrimination and enhances the risk that people will not present for testing or seek treatment.

It is part of our role as nurses to support and facilitate behaviour change promoting health and wellbeing. It is our experience that criminal laws do not change behaviour, which is rooted in complex social issues – especially behaviour that is so greatly influenced by stigma and discrimination [6].

Furthermore, the Oslo Declaration, prepared by international civil society [7], states that 'relying on disclosure to protect others and prosecuting people for non-disclosure can and does lead to a false sense of security'. A better approach would be legislating to create an environment where people can seek testing, support and treatment and safely disclose their status without incurring penalties.

Human rights

Some countries in Eastern Europe and Central Asia, for example, the Russian Federation, enforce restrictions on a large scale. The European Court of Human Rights announced in March 2011 that the Russian Federation was in violation of the European Convention on Human Rights for denying a residence permit to an Uzbek national because of his HIV status [8].

The United Nations, established after World War II, recognised the importance of freedom of movement through documents such as the Universal Declaration of Human Rights (1948) [9] and the International Covenant on Civil and Political Rights (1966) [10].

The first reads: 'Everyone has the right to leave any country, including his own, and to return to his country.'

However, the International Covenant is more specific, stating that this is subject to the requirements by law in order to: 'protect national security, public order, public health or to protect the morals or freedom of others'.

Freedom of movement as a human right asserts that individuals have the right to move freely within their state of origin and to leave and return to that state at any time, 'within the limits of respect for the liberty and rights of others'. Some immigrants' rights advocates also assert that human beings have the right to mobility between states.

Whilst there is no human right specifically to enter or remain in a country, there are human rights to *non-discrimination* and *equality* before the law. These, together with the human right to *freedom of movement* and *privacy*, all apply in the context of HIV and travel. To withhold these rights, governments must show just cause, and withhold in the least restrictive manner possible. By restricting PLHIV from entering, and/or remaining in a country, governments have clearly not met these requirements. HIV-specific and blanket restrictions

violate the right of *non-discrimination* and *equality*. Mandatory testing and confidentiality lapses also breach rights to *liberty* and *privacy*.

UNAIDS' position

UNAIDS is clear on its stance regarding the imposition of such restrictions on PLHIV [5]. The key points of its argument against such prohibitions are:

- Every individual should have equal access to freedom of movement (regardless of HIV or any other health status).
- A large number of countries do not have HIV-related restrictions and have not found a need for them.
- Such restrictions are discriminatory and therefore in breach of Human Rights law.
- There is no evidence that such restrictions protect public health.
- Such restrictions fuel stigma and perpetuate ignorance, which may in turn increase risk to public health.
- An exclusion based on economic risk of allowing entry by PLHIV presupposes that these individuals are not financially self-sufficient.
- Valid human rights or humanitarian claims should take priority over economic considerations in determining freedom of movement for individuals.
- Governments should not let other governments impose such restrictions on their HIV-positive citizens.

Protest power

Recent years have seen some encouraging developments. There are now 19 countries in Eastern Europe and Central Asia without restrictions, and some have introduced anti-discrimination legislation.

Furthermore, there is evidence that advocacy efforts may yield favourable results, a good example being the Czech Republic. In May 2009 the republic specified ten countries whose visa applicants needed to present for an HIV test in order to enter the country. The new legislation applied only to citizens from Congo, Kenya, Moldova, Mongolia, Nigeria, Pakistan, Tajikistan, Turkmenistan, Ukraine and Vietnam. However, after a mass protest by the HIV community throughout Europe, the proposition was withdrawn.

Restrictions lifted

In the last few years a number of countries, including China and the US, have lifted travel restrictions for PLHIV – although not without a struggle. The US first imposed restrictions during President Reagan's administration in the late 1980s, and this was upheld in 1992 when Congress added it to immigration law. Astonishingly, it was not until



Access all areas: freedom of movement for all was embraced by the UN following World War II.

2008 that things started to change, when Congress voted in favour of lifting restrictions, as part of the legislation approving funding for PEPFAR (a major US source of international funding for HIV care and treatment initiated by President Bush) [11]. In 2009 President Obama took the final step needed, by signing the Ryan White HIV Treatment Extension Act [12], bringing an end to the 22-year ban on travel and immigration imposed by the US [13].

Work in progress

The work continues by several organisations including UNAIDS, the European AIDS Treatment Group (EATG) and the HIV Justice Network. The HIV Justice Network is an advocacy organisation striving to end inappropriate criminal prosecutions of PLHIV. The group reports a growing body of evidence, suggesting that 'criminalisation of non-disclosure of HIV is doing more harm than good in terms of its impact on public health'. The network launched its Oslo Declaration in February this year [7], providing a clear roadmap for policy-makers and the criminal justice system, and with a view to ensuring a 'proportionate, evidence based, cohesive, restrained and appropriate' application of criminal law.

Conclusion

All people should be equal in their enjoyment of human rights, and human rights expectations need to accompany public health considerations to ensure that laws, policies and programmes do not increase vulnerability or result in further human rights violations.

More investment is clearly needed in human rights programmes that raise awareness. There are still

reports that, even in countries where bans have been lifted, customs officials continue to interrogate and degrade HIV-positive people – thus it is essential both to ensure comprehensive training for law enforcement officials and healthcare professionals; and to facilitate access to legal support and justice for PLHIV.

It is also essential that the pressure is maintained on countries which continue to impose restrictions.

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Writing for the *NHIVNA* Newsletter – why not give it a try?

Your article needs to be informal and provide a report, comments or opinions on experiences – rather than being a formal account of research and/or audit. You might like to contribute one of the following:

- ◆ News of innovations in practice (clinical or community) which may relate to physical, psychological or social issues
- ◆ Reviews of conferences and events, both local and national
- ◆ Opinion pieces around current HIV issues, which might spark some dialogue and debate!
- ◆ Or you might like to write a 'Day in the Life' piece, based around the journeys in our lives and in our daily routines. How does your day compare with PJ, who wrote for us in this issue? There's more information in the Newsletter section of the *NHIVNA* website.

Send in
your
articles

Articles should be between 500 and 800 words and will be edited by the Newsletter working group.

The final decision on publication will rest with the working group.

Please submit within the deadline to be considered for publication.

Deadlines for 2013 are: April issue **15.2.13** · August issue **21.6.13** · December issue **18.10.13**

Please contact Editor Jayne Churchill with any thoughts or queries, on jchurchill261@gmail.com

We look forward to hearing from you!