

HIV NURSING

Volume 4 Number 4

Winter 2004

Inside this issue:

Editorial

- Can HIV be a model for patient involvement?
Jane Bruton 1

Interview

- Constructively stropky
Paul Clift, as interviewed by Jane Bruton 3

NHIVNA update

- Nicky Perry* 5

Features

- The model of developing expert patients: Living Well and the Positive
 Self-Management Programme
Shaun Watson 6

- Patient and public involvement (PPI) as an employment opportunity
 for patients
Robert James 8

- The argument for patient and public involvement (PPI) as an innovation
Eileen Nixon 10

- Patient and public involvement (PPI) in HIV care: innovation or
 tokenism – reflections
Ian Hodgson 11

Peer-reviewed article

- HIV education in Botswana
Susan MacDonald 13

Now listed in **CINAHL** database

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Volume 4 Number 4 Winter 2004

ISSN 1474-7359

Editorial Board

Jane Bruton
HIV Nurse Manager
Chelsea and Westminster Hospital
London

Ian Hodgson
Lecturer
School of Health Studies
University of Bradford
Bradford

Eileen Nixon
Senior Nurse HIV
Brighton and Sussex University Hospitals
Brighton

Advisory Panel

Roy Brazington
HIV Mental Health Nurse Specialist
Maudsley Hospital, London

Margaret Clapson
Paediatric Clinical Nurse Specialist
Great Ormond Street Hospital, London

Ian Jones
HIV Dietitian
Royal London Hospital, London

Judith Sunderland
HIV Specialist Midwife
Newham General Hospital, London

National HIV Nurses' Association



Disclaimer

Although great care has been taken in compiling and checking the information given in this publication to ensure that it is accurate, the authors, publisher, sponsor and its servants or agents shall not be responsible or in any way liable for the continued currency of the information or for any errors, omissions or inaccuracies in this publication whether arising from negligence or otherwise howsoever or for any consequences arising therefrom.

The opinions expressed in this publication are, where named, those of the individual authors, and do not necessarily represent those of the publisher or sponsor.

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.

Now listed in CINAHL database.

HIV Nursing is supported by an educational grant from the following companies:

Abbott Laboratories

Boehringer Ingelheim

Editorial Office

Editorial Director: Fatima Patel
Managing Editor: Ayse Abdullaha
Mediscript Limited
1 Mountview Court
310 Friern Barnet Lane
London N20 0LD
UK

Printed in England
Winter 2004
© Mediscript, 2004

All rights reserved. No part of this publication may be translated, reproduced, stored in a retrieval system, or transmitted in any form, by any means, electrical, mechanical, photocopying, recording or broadcasting or otherwise, without prior permission from the publisher.

Can HIV be a model for patient involvement?

Jane Bruton

HIV Nurse Manager, Chelsea and Westminster Hospital, London

I was awoken by the sound of rustling plastic and opened my eyes to be confronted by a nurse in boots, plastic apron, hat and rubber gloves. I wanted to die there and then' [1].

Introduction

HIV care in the early days of the epidemic grew out of a partnership between patients, their significant others and healthcare workers. It was shaped by an underlying outrage at the stigma and discrimination surrounding HIV. Fuelled by the media hysteria, patients like Terry Higgins, whose plight inspired the Terrence Higgins Trust (THT) and underlined the need for specialist units, were dumped in a hospital side room that no one would enter unless in full protective clothing. Dying and acutely ill patients were stripped of their basic human dignity and treated as outcasts by society and the NHS. It was understood within the specialist units that the patient must be at the centre of care. There was little room for the traditional medical model of paternalism. Looking back, the concept of 'public and patient involvement' (PPI) was embedded in the philosophy of care from the very beginning in the specialist units.

PPI

PPI has taken many forms from the bedside through to the governmental level: from the decision around whether to start palliative care to decisions about what the HIV public health campaign should look like. HIV care has challenged many assumptions about the doctor/patient relationship. The controversy surrounding the issue of the right to patient consent to take an HIV test was unprecedented for blood and other non-invasive tests. It caused much disdain and disagreement within the medical profession. One of the most significant victories for patient and public involvement was when the British Medical Association (BMA) in 1995 recognised Advanced Directives, stating that the fundamental aim of them is 'to provide a means for the patient to continue to exercise autonomy and shape the end of his or her life' [2]. This came after years of using Living Wills within the service and tireless campaigning by THT. Interestingly, they are still not widely used within the rest of the NHS.

From the beginning gay activists and clinicians shared platforms at meetings of activists. It was a united response and essentially it was from the bottom up. This alliance between activists and clinicians was described by Berridge [3] as the

'policy community' seeking ways to force a formal government response to what they saw as an impending crisis for the whole of society.

Self-help and campaigning organisations sprang up to plug the gaps that existed in the community by enlisting volunteers or buddies to provide the basic holistic care that was not being provided by the statutory services. They set up support groups and hospital visitors' groups, gave legal advice, and provided safer sex information.

At every level clinicians, patients and the community worked together: a model for PPI. This predated the introduction of the Patients' Charter in 1991, seen as the first formal step along the road of patient involvement. The Charter heralded the idea of patient as 'consumer', talking about the rights of patients, the right to a named nurse, the right not to wait for treatment etc. Nearly ten years later, in 2000, came the NHS Plan which set out a vision of a service 'designed around the patient'. It set out plans for establishing a new system of PPI to replace the Community Health Councils as part of the modernisation of the NHS. A year later, in the wake of the Bristol Royal Infirmary Inquiry, the Kennedy Report recommended representation of patients' interests 'on the inside' of the NHS at every level. The NHS should put the patient at the centre of everything that it does and recognise that to embed this there would need to be a change of attitude and a new approach. The government embodied this notion of PPI in legislation. The Health and Social Care Act 2001 places a duty on Strategic Health Authorities (SHAs), Primary Care Trusts (PCTs) and Health Trusts to make arrangements to involve and consult patients and the public. In practice we have seen Patient Advisory and Liaison Services (PALS) being set up in every Trust, Patient Public Forums organised and a number of high profile national consultations about the future of the NHS, the growth of patient expert programmes and local initiatives to consult and involve patients and the public. Gradually, the concept of PPI has been refined; the emphasis quite rightly has shifted from the concept of patient as consumer to one of the patient being in partnership with clinicians. The onus now on clinicians, patients and the public is to make this a reality.

PPI and the challenge

Today PPI has to be part of every clinician's thinking and yet the Department of Health Research Programme [4] suggests that in practice shared decision making is rare and its character is elusive.

Within HIV and sexual health the main guidelines and policies have been jointly developed through partnerships and place PPI at their heart. The Strategy for Sexual Health and HIV emphasises that the planning and provision of services benefit from involving service users and their representatives. The Medical Association for AIDS and Sexual Health (MedFASH) Guidelines talk of the principle of empowerment being the key to effective management of patients' own health care [5].

There is a huge challenge for those working in HIV. Despite the embeddedness of patient involvement we cannot be complacent that we have got it right. HIV has changed from an acute terminal condition to a chronic illness. More and more of our patients are coming from socially isolated and vulnerable groups with a weaker voice and less support in the community. There are serious problems regarding rights and access to treatment. With the complexity and ever changing nature of antiretroviral treatments, it is critical that patients are kept fully informed to enable them to make the right choices for their future care. We cannot forget that knowledge is power. An imbalance in the knowledge and understanding can lead to an imbalance in the partnership and the danger of a slippage back to paternalism. The September 2004 conference sponsored by the UK Coalition, Positively Women and National AIDS Trust was the first conference for people living with HIV for five

years. The message from this conference was loud and clear: people living with HIV must be involved from the beginning in planning and developing services.

Conclusions

The challenge is to take forward the concept of the patient expert and to further involve patients in the decisions about service provision. This issue of *HIV Nursing* is devoted to looking at these issues: from Paul Cliff's experience of being a patient representative on the Management Committee of Brighton's HIV clinic to the Living Well initiative to develop patient experts. HIV services have grown upon solid foundations of patient involvement but there is still much to do.

References

1. Adler MW. ABC of AIDS, London: *BMJ*, 2001, **322**, 1226–1229.
2. British Medical Association (BMA). *Advanced Statements About Medical Treatment*. BMA Professional Division Publications, London, 1995.
3. Berridge V. *AIDS in the UK. The Making of Policy 1981 to 1994*, Oxford University Press, Oxford, 1996.
4. Department of Health (DOH). *Patient and Public Involvement in Health: the Evidence for policy implementation*, DOH, London, April 2004.
5. The Medical Association for AIDS and Sexual Health (MedFASH). *Recommended Standards for NHS HIV Services*. MedFASH, London http://www.medfash.org.uk/publications/documents/Recommended_standards_for_NHS_HIV_services.pdf (accessed on 10 December 2004).

NHIVNA workshops and study days for 2005

18 February	NHIVNA/Gilead Co-infection Workshop	Scotland
16 March	NHIVNA/GSK Developing Knowledge and Skills	London
8 April	NHIVNA/Gilead Co-infection Workshop	London
13 April	NHIVNA Sharing Good Practice	Newcastle
April	Pre-BHIVA Nurses Meeting	Dublin
23–24 June	'Mind, Body and Soul' NHIVNA Annual Conference	Bristol
14 September	NHIVNA/GSK Developing Knowledge and Skills	Manchester
14 October	NHIVNA/Gilead Co-infection	Bristol
16 November	NHIVNA/GSK Developing Knowledge and Skills	Birmingham
1 December	NHIVNA Sharing Good Practice	London

Constructively stropo

Paul Clift, as interviewed by Jane Bruton

HIV Nurse Manager, Chelsea and Westminster Hospital, London

Paul Clift has been the patient representative at the Lawson Centre in Brighton for the last 4 years. Paul is no stranger to activism. He was a trade unionist at the British Museum, marched with Gay Pride in the days when the whole demo could fit in the Student Union at ULU, and supported the miners' strike in 1984. Since being diagnosed 16 years ago, and losing his partner in 1993, he has contributed to HIV organisations in Brighton and nationally. He has been a service user representative at Open Door, regularly wrote articles for Body Positive (BP) and sat on the BP Editorial Board. But when managers at the Lawson called a meeting for patients to discuss the idea of a patient representative the response was not promising.

The following interview was conducted at Victoria clinic on 3 November 2004. It has been edited.

Interview starts

'True to form no more than half a dozen people turned up, at least that's true-to-form in Brighton. Getting people together at any kind of meeting in Brighton is usually really difficult: the commonly cited reason is fear of disclosure.'

'From that meeting we formed a steering group which met a number of times, with Jane Carnadine, the Services Manager. She was very good at bringing common sense and practicality into things. There were some ideas being thrown up like the idea that the patient representative when it gets going should advertise their home phone number and address and visit people at home. Thankfully Jane said no and I most definitely said no! We put together a job description for a post that's voluntary, part time and not paid. The basic job description is something like 'Elicit the views of the broad range of service users and from that inform and influence the clinic managers'. The key word there is influence. It's a voluntary post because we didn't want the patient representative to be suspected of working his or her own career or being in some way a management lackey.'

So it's about being seen more as the voice of patients?

We thought that it was imperative to retain the credibility of the whole exercise and to do that it was really important to demonstrate independence. So closely working with, but independent of, clinic management, which is more or less what goes on now.

A shortlist of candidates were interviewed by a panel of Lead Consultant, the Services Manager and one person with HIV.

What does the role involve?

A lot more than the basic remit. That's because I've chosen to broaden it for my own interest and because of certain frustrations on my part. For example, I don't think Brighton has got to grips with the African issue yet and I have been going round to conferences here – and one in Africa – trying to get some movement on the issue. They are beginning to now but it has taken over a year or so, to get things moving.

We thought it would be a good idea to have a patient survey as a kind of thorough snapshot of how people experience the clinic. I got solid support and encouragement from senior clinicians at the Lawson and we brought in the Clinical Effectiveness Team at Trust level. We had a number of brainstorming sessions about what questions to ask and it's given us enough data of good enough quality to base things on for another two to three years, we hope.

What is your relationship to the Management Committee?

I go to the monthly heads of department group: all the consultants including nurse consultant, senior nurse, pharmacist, patients' representative, all the key people really. We discuss the big strategic issues and things such as the evening clinic. We look at staffing issues, trying to make sure, that the number of staff is commensurate with the number of patients.

Have you been able to take issues from the patients' survey into the management committee?

I am not sure that I have, actually. I have taken it via my main working relationship, which is the senior nurse, sitting down together, going through it, picking out what trends are there, what can be done.

Are you based in the clinic at certain times?

Every Thursday morning I am actually in the clinic, one of the consultants' rooms was made over to me. Patients can just walk in and see me, not many do, but they can walk in and see me. I have also set up a patient's email address to try and get round this disclosure problem, not wanting to be seen in public in here. But funnily enough not many people use that either, but then it does seem that a lot of people down in Brighton are pretty happy with the quality of care and treatment they're getting overall.

What expectations did you have of the role?

I didn't, and I don't think the clinicians did either because there was no other model to go on at that point. It turns out, that there was something [similar] going on at Mortimer Market but we didn't know that at that time. So we were just trying to explore and develop something new, really. All my expectations were that I wanted to develop something substantial, something worthwhile, but I didn't know what it was going to look like.

What do you think you've achieved?

Well, I've got a slight qualification: that is, I don't think enough people make use of it, but you just say that's up to them and leave that to one side. I am more than pleased with what we've got; as we've got the basic mechanism that is far reaching and it is effective and is trusted by both sides, by clinicians at quite a high level really and patients, and I think that's a major thing for a start.

What is the best thing about what you are doing?

Patients having a voice. Or perhaps me being a mouthpiece for that in helping to shape services and hopefully keeping them up to an acceptable level and pushing for more change occasionally. I also enjoy the personal achievements, I put in abstracts at Barcelona, Bangkok and NHIVNA this year and, as I don't have an academic background, on a personal level those achievements mean a lot to me.

What are the challenges?

In some ways it is probably not dissimilar to yours as a clinician, that's things like bashing your head against the wall asking for some decent resources to work with and, from my point of view, I see that impacting on patients. At the same time I know what a room looks like when you have half a dozen nurses pretty much hot desking all day. I think that is disgraceful. That's the sort of ongoing low point.

One where I will probably be lynched by fellow patients is, well we hear UK-born patients complaining about what can be petty things, not all the time, but just occasionally, and I am thinking now hang on, there are people in Africa dying, just put it in perspective.

There is a concern about tokenism. Do you think your role is there so that the NHS can tick the patient involvement box?

It is not tokenism at the Lawson in the slightest; it's a real and substantial thing. It has been token on some occasions within the Trust outside of the Lawson, where the Trust has been more than happy to trot me out as a shining example of how this particular Trust has involved patients or slapping me onto one of the committees. No I am well aware of the difference between tokenism, which I won't accept, and meaningful involvement, which is what the Lawson exercise is.

Can what has been built at the Lawson be used as a model for other centres?

That is what one of the abstracts at Barcelona and Bangkok was about. I think that certainly with the kind of healthcare system we've got in the UK the only hurdle, and it can be a big one, depending on particular hospitals, is professional arrogance from senior clinicians. We are lucky in Brighton within HIV, but I think within HIV we are lucky anyway. There is a rather more democratic outlook on the part of HIV clinicians and there was a paper at NHIVNA by Ian Hodgson [1] that explains, at least partly, why that is.

In theory I don't see why our practice cannot be the model for practice in other departments, certainly HIV, and chronic diseases. I have had some meetings with the renal department and met some of their patients, although it is interesting that their patients weren't so constructively stropic.

HIV has a history of 'constructive stropicism', if you like, of people really wanting to get involved to make a change and being able to walk into meetings with doctors, nurses and managers and speak with them on a level, if you like. Whereas in the group of renal patients that I met with a couple of years ago, now they didn't have that confidence, not to say that they can't have it or that they can't get it but they didn't have it there and they were all daunted by the whole sort of exercise. So I am currently having another stab at renal to see if we can get something going there.

Interview ends

Reference

1. Hodgson I. HIV stigma: is the battle lost? *NHIVNA Conference 'Diversity in HIV Nursing'*, Manchester, 2004.

NHIVNA update

It is hard to believe that another year is drawing to an end. It has been a busy one for the NHIVNA committee but very rewarding to see the Association continue to grow and develop. Each year more people join and our activities continue to increase. You should have all received your renewal forms for 2005, which I hope you will return. You will notice that we have increased the membership fee by £5.00 next year, the first increase for 3 years. With the benefits of membership including monthly *AIDS Treatment Update*, *NHIVNA Newsletter* and access to free study events, we hope that you agree that it is value for money.

In 2005, we will be bringing you more study days and workshops with events nearly every month. It has been very rewarding to hear about the changes in practice that people have implemented after attending one of the 'Developing Skills and Knowledge' workshops and these are continuing in 2005. A full diary of events can be found in this journal. We are also holding two study days next year on 'How to Get Started' focusing on audits and research and 'Sharing Good Practice' which will give examples of nurse-led audits and research and how these have changed or improved practice. We are finalising venues so put the dates in your diaries and you will receive further information soon.

The programme for 'Mind, Body and Soul' NHIVNA's 2005 annual conference, is finalised and speakers are being approached. The conference, on 23 and 24 June in Bristol, will

include, amongst others, topics on current mental health issues, cultural diversity, managing dispersal of asylum seekers and a key note presentation from a representative for the All Party AIDS Parliamentary Working Group. There will also be sessions on resistance and implications for practice, workshops on setting up nurse-led clinics and HIV competencies in line with the Knowledge Skills framework and of course an evening of entertainment. For further information contact nhivna@conass.co.uk

The NHIVNA committee had the opportunity to reflect on where we are at and where we are going and we have already made a start to look at how we can continue to develop as an Association. Some of the projects include: raising our profile so that we can, as a group of nurses, add our voice at a national level; developing knowledge and skills through workshops and developing national HIV competencies; increasing our membership by appointing Sheila Morris as membership officer; supporting and encouraging nurse-led research by study days, grants and encouraging collaborative working. We will keep you informed on how these and many other projects progress over the next 12 months.

I want to thank the NHIVNA Executive Committee for all their hard work and commitment in 2004 and wish you all a happy and peaceful festive period.

Nicky Perry, Chair, NHIVNA, Brighton

National HIV Nurses Association (NHIVNA)

NHIVNA Subscription and Membership Enquiries

UK NHIVNA Membership £35 annually

Benefits of membership

- Free subscription to the *NHIVNA Newsletter* (bi-annual)
- Discounted registration to NHIVNA conferences and study days
- Free subscription to *AIDS Treatment Update*[†] (monthly)
- Discounted membership to BHIVA
- Full published list of members of NHIVNA

[†] Provided by *National AIDS Manual (NAM)*.

All enquiries to:

NHIVNA Secretariat

Mediscript Ltd, 1 Mountview Court, 310 Friern Barnet Lane, London N20 0LD
Telephone: 020 8446 8898 Fax: 020 8446 9194 Email: mailbox@mediscript.ltd.uk



The model of developing expert patients: Living Well and the Positive Self-Management Programme

Shaun Watson

Treatment Support Nurse Specialist, Living Well

Introduction

Who or what are expert patients? It is a phrase that may strike dread and fear into many healthcare professionals. Does it put the balance of power firmly in favour of the patient? Surely not! I have worked in the HIV speciality since 1991 and soon realised that, on the whole, patients were empowered not only with knowledge but also with confidence to ask questions, challenge and facilitate change. Without this patient empowerment many of today's HIV services would not exist. I suppose this is why I love HIV nursing; the patients challenge me. They keep me up to date with new developments and I utilise my communication, negotiating and diplomacy skills on a daily basis.

Expert patients

So, back to the original question, who or what are expert patients? The Expert Patients Programme describes them as people living with a long-term health condition who are able to take more control over their health by understanding and managing their conditions, leading to improved quality of life. This is further expanded by the Expert Patient task force, who state that they:

- Feel confident and in control of their life.
- Aim to manage their condition, in partnership with professionals.
- Become informed about their condition and its treatment.
- Communicate effectively with professionals and are willing to share responsibility with them.
- Make best use of professional advice, support and treatment.
- Are realistic about the impact of the disease on themselves and on their family.
- Use the skills and knowledge to lead a full life [1].

Being diagnosed and living with HIV/AIDS can be very difficult and may result in a variety of feelings. Maintaining a 'normal life' may be the aim but juggling clinic appointments with full time education/family life/work or socialising with friends whilst dealing with medication regimes, side effects and erratic health can prove very challenging. An important issue for people living with HIV/AIDS may be just dealing with it in a way that means HIV is a small part of their lives not a

huge all-encompassing illness. But who tells you how to live with chronic ill health? Snatched conversations with your GP or consultant, visits to a clinical nurse specialist, a myriad of websites or sitting in the clinic waiting room talking to other people living with HIV? Many of the support groups for people living with HIV have folded and structured support has not been available until recently. It is, therefore, important that programmes exist which offer help with emotional and practical issues that HIV frequently throws up.

The Living Well programme

The Living Well programme is an NHS-funded community HIV/AIDS healthcare initiative. First developed and implemented in London in 1998, it is a 'multi-disciplinary, client-centred treatment, support and health promotion programme for and led by people living with HIV disease'. During its first 4 years it was perceived by users, facilitators and commissioners as a successful intervention and was runner up in the 2001 Health Service Management Awards. Living Well was designed to help those living with HIV/AIDS by providing support, information and coping skills in a structured group environment. The organisation offers the Positive Self Management Programme (PSMP) and weekend residential; this is called Living Well 1. Living Well 2 then offers the chance to join a participant steering group, life coaching sessions and PSMP facilitator training. Running alongside these two Living Well structures are theme days and study sessions, access to complementary therapies, specialist counselling and treatment/adherence support.

Expert patients and the Positive Self-Management Programme

Living with a long-term chronic illness does not automatically make expert patients. The 'Expert Patient Programme (EPP)' for people living with chronic illness such as asthma, diabetes etc. has proved to be a very popular way to develop effective self-managers (expert patients). The benefits of self-management have been well documented. The EPP defines effective self-managers as those who have;

- Improved confidence
- Less pain
- Increased exercise and relaxation

- Experience less depression and anxiety.

And that they are:

- Less likely to suffer acute episodes that require hospitalisation.
- Make fewer visits to the doctor
- Are more selective about the way they use healthcare services.
- Can communicate better with professionals.
- Are more likely to take medicines as prescribed
- Many are able to return to work [2].

Living with any chronic illness will raise similar issues and problems. People living with HIV/AIDS can access EPP training. However, it was felt that there needed to be further development of this concept for people living with HIV. It may be relatively easy to disclose living with asthma, diabetes or arthritis but disclosure of HIV may raise prejudice, stigma and discrimination. A new programme was needed to cover these issues, as well as the more sensitive areas of confidentiality, sex, intimacy and disclosure. The 'Positive Self-Management Programme' for people living with HIV and AIDS was devised in the USA at Stanford University in 1994 after successful self-management programmes were developed for other chronic illnesses such as rheumatism and asthma. In the US, research on the PSMP was part based on the successful results of a 5-year project of the generic 'Chronic Disease Self-management Programme'. It was found that people who undertook this programme (compared to those who did not) improved their health behaviours such as symptom management; exercise and communications with healthcare professionals improved their health status (self-reported health, fatigue, disability, social/role activities and health distress) and decreased their days in hospital.

The Positive Self-Management Programme's aim is to enable people with HIV/AIDS to enhance their health and sense of wellbeing by taking greater control of their lives, developing new social networks and making better-informed decisions about managing their condition. Living Well holds a licence from Stanford University to run the PSMP in the UK.

The 7-week PSMP (3 hours a week) teaches and demonstrates strategies to enable participants to effectively live with HIV. It provides a safe, confidential setting for participants to get to know other people in similar circumstances, to share thoughts, ideas and anxieties; to give and receive support, to socialise and make new friends. Each week, the programme focuses on action planning and goal setting with action plan development, feedback and problem solving built into each session. To aid success it is important for participants to have a realistic aim for the programme. The aims are then broken down into smaller goals whereby the achievability is key. Aims are varied and have

ranged from getting back into work, entering education/training, socialising, starting or re-starting a project (such as decorating a room or writing a book) to joining a gym, exercising and disclosing HIV status to a family member.

Once participants have completed the programme there is an opportunity to access a weekend, countryside residential, which aims to strengthen and develop areas discussed on the programme such as communication issues, sex and relationships, disclosure and the development of future plans.

Future planning

Future planning can be taken further with the introduction of life coaching and the opportunity to undertake sessions with a qualified life coach. Life coaching is a one to one, interactive relationship where a coach guides and facilitates the client's progress towards defined goals. These goals may concern career, relationships or financial matters and is a further strengthening of the action planning and goal setting developed on the PSMP.

John Clarkson sums this up more effectively in an article in *Positive Nation* on his experiences of life-coaching: 'HIV can lead you to reassess your life. Things that you thought important seem silly, and paths you have ended up on may now seem like dead-ends. And if you're feeling great after thinking you were going to die, you've got some pretty fundamental decisions to make. If you need pointing ... in the right direction then coaching could get you where you want to be' [3].

Once Living Well 1 is complete participants become eligible to join Living Well 2, which, as well as being a supportive structure, offers participants the opportunity to become involved in the way Living Well is structured and delivered in the future by taking part in a steering group. This steering group looks at developing Living Well through developing new programmes or by devising theme/study sessions. Past sessions have looked at complementary therapies, going back to work and benefits advice. Some participants decide to undertake training to become an accredited facilitator on the PSMP. The program has been running for a year and so far approximately 8 participants have undertaken the training to co-facilitate the PSMP.

So who can access Living Well? We are currently open to anyone who has been diagnosed HIV-positive and lives in, works in or attends a treatment centre within the area covered by the following London Primary Care Trusts: Hammersmith and Fulham, Ealing, Hounslow, Hillingdon, Brent and Harrow, Westminster, Redbridge and Waltham Forest, Tower Hamlets, City and Hackney, Newham, Barking, Havering and Dagenham. Prospective participants are referred by their health professional or contact Living Well directly.

Once a referral is received, Living Well contacts the participant to make an informal assessment. This is an opportunity to answer any questions about the programme and to get to know the needs of the participant, establishing how Living Well can link into their life.

Conclusions

The EPP and PSMP are relatively new but are proving to be a popular concept in chronic HIV disease management. Evaluation is ongoing. I conclude this article with the following question: With expert, empowered, self-managers accessing our services, who will develop the healthcare team to be able to work effectively with this empowered client group? Expert staff, anybody?

If you have any queries about the program or wish to refer someone to it please contact Shaun Watson

on shaun.watson@chelwest.nhs.uk or call Living Well on 020 8746 2274 (West) or 020 8521 8631 (East).

References

1. Expert Patients task force definition. EPP Update: Conference Special, *Department of Health*, London, 2004.
2. Kennedy A, Gately C, Rogers A and EPP Evaluation Team. National Evaluation of Expert patients programme: Assessing the process of Embedding EPP in the NHS Preliminary Survey of PCT Pilot Sites. *National Primary Care Research and Development Centre*, 2004.
3. Clarkson, J. Therapy of the month: life coaching. *Positive Nation*, **103**, July/August, 2004.
4. www.the-coaching-academy.com (accessed 20 November 2004).
5. www.expertpatients.nhs.uk/what.shthl (accessed 20 November 2004).
6. Jones S and Miller J. Living Well Today & Tomorrow. *Living Well Programme & Thames Valley University*. Abstr. 2004.

Patient and public involvement (PPI) as an employment opportunity for patients

Robert James

Patient Consultant, NHS Modernisation Agency, London

Introduction

I work as a Patient Consultant at the NHS Modernisation Agency. If you consider having Nurse Consultants and Management Consultants, Patient Consultants are the obvious next step. I work for the Modernisation Agency as part of the Performance Development Team that provides support to NHS Trusts that are rated as zero stars. My job is to provide a patient perspective on the work of the team and to help nil star trusts on Patient and Public Involvement (PPI). This means my work ranges across all the types of NHS Trusts, Acute Hospitals, Primary Care Trusts, Mental Health Trusts, Care Trusts and Ambulance Services.

PPI in HIV services

It has ranged from running a whole programme of focus groups for service users of a mental health trust in order to develop and rank their priorities to provide some input to the future planning by the trust, helping an acute trust review the involvement of community groups in their strategic decision making to bringing Ambulance Services PPI leads together to exchange good practice. Much of my work is actually doing consultancy, talking to staff about PPI and suggesting ideas that have worked in other places or supporting them to do the things they have already thought of and giving them a chance to think about how they would like their service to work.

I joke that I got the job by virtue of having more diseases than anyone else who applied; I was

coming back to work after some elective surgery on my elbow, and I have haemophilia, hepatitis C and HIV. However, this collection of conditions has given me a range of experiences of many different bits of the health service and with different patient groups. I also attend two hospitals; a foundation Trust for my haemophilia care and a zero starred one for my HIV care! So I get to see the good and bad in Trusts at both ends of the star ratings scale.

NHS managers' fear of their patients is something that has surprised me and it is sad that so much of previous patient involvement was seen to be about apologising to complainants. Every survey of patients or poll in papers shows how much people value the patient-seeing staff in the NHS, with results a private company would kill for, and so I find it remarkable how little impact this seems to have on staff morale sometimes. I am also surprised that I have not seen any PPI done in a truly cynical way, as a justification for re-modelling trusts in the way the senior managers want them – it seems more likely to provoke cunning schemes to avoid involvement in decision making.

From my perspective PPI in HIV services starts from an easier place in that the patient group is well defined and, as with other chronic conditions, patients and the service are in contact for some period of time. It is much easier to model services around the needs of patients that build a relationship with a clinic over a long period of time, than one that only sees patients in a one-off

situation and for whom everyone is a potential patient. The nature of the patient group, being mainly people already discriminated against in society and often within their own local communities, makes it more complicated in providing appropriate services. However, if you wished for a simple life, then working with HIV-infected patients would not have been an option.

PPI in the HIV sector is much like that in the mental health sector, which is perhaps not very surprising given that the service provision for both is so strikingly similar (e.g. drop-in centres, reintegration to work schemes and living wills or 'advance directives', as they are called in mental health). PPI has a generally good reputation and some outstanding things were achieved; proper attention was paid to patients' needs and there was lots of scope for patient involvement. On the other hand, I have the impression that some clinics would prefer for patients to be compliant and silent.

The unusual fact about PPI is that it is written into statute, yet there is no mention of clinical governance in the *Health and Social Care Act 2001*. However, Section 11 specifically requires NHS trust authorities to involve patients and the public. This is not to suggest that you should abandon risk management and refuse to audit anything to see if it works, simply because clinical governance is not the law of the land. The desire was to get to a situation where there was an ongoing debate between service providers and those receiving the service, in order to make care more focussed on patients' needs and less on bureaucratic comfort. This ongoing debate is not meant to be only about proposals for service change, but also about how the service operates presently. It is perfectly plausible to involve patients in a discussion about maintaining a service as it is.

PPI in the NHS

But what impact has PPI made in the NHS? A number of reports have specifically looked at how it has developed and impacted on the NHS. Ridley and Jones [1] have reviewed recent literature but the impacts are hard to evaluate because of the nature of the way large organisations change. It is obvious that a patient making a suggestion that will save a trust's money and does not involve changing the responsibilities and staff workload is much more likely to see it implemented, than a patient suggesting a complex series of changes requiring significant up-front investment and major changes to workload and responsibilities. The same goes for proposals by staff, as I am sure you all know well! The Department of Health review [2] of 12 projects, that they funded, highlights small-scale changes and ongoing improvements instigated by patients and tended to say that large-scale changes have not yet been seen, although much work has gone into involving patients. The Healthcare Commission gave a general review about PPI in the

NHS and its major feeling was that the NHS had improved its listening skills but was less able to do things with the findings [3]. On the one hand I could see this as disappointing but then I have seen audits of all types produce striking results requiring change that have not been acted upon. I wonder if this is as much to do with a system that struggles to change when confronted with evidence that current structures and processes are inadequate.

I have not discussed public involvement in great detail in this article, because I consider patient involvement to be of greater importance in the HIV sector. The notion that large numbers of the general public are going to come and give up time to be involved in commenting on and designing parts of the health service that they currently have no interest in and may never use strikes me as completely fanciful. In my opinion, public involvement can be better utilised as a measure of transparency in decision making and the involvement of interested parties such as the PPI Forum, the Local Authority and voluntary and independent sector groups in the process.

Conclusions

In general, PPI will soon undergo some significant structural changes. The Commission for PPI, informally nicknamed 'Chippy' will be abolished in April 2005 and an alternative body will take on its organisational role. If you have any suggestions about how it should work, the Department of Health would like to hear from you as they are currently discussing what should replace it. Within this discussion, there are also some expectations from the Department of Health about what they would like PPI Forums to do for the Trusts they work with: specifically, to be aware of not just the views of the Forums' members but also gain an understanding of how prevalent a concern is within the patient body or local population. There will also be a centre of excellence for patient and public involvement, which will, hopefully, be a useful resource for clinics wishing to identify methods and models of involvement. It will be interesting to find out whether patient involvement gets drowned out by patient choice. Even if all that PPI does is change the NHS definition of 'consultation' from a three-month pause before implementation to asking people to be involved in drafting proposals to consult on, then it will have made a significant difference.

References

1. Ridley J and Jones L. *User and Public Involvement in Health Services: a Literature Review*. 2003. See <http://www.show.scot.nhs.uk/involvingpeople/readinglist.htm> (accessed 30 November 2004).
2. Farrell C. *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. 2004. See <http://www.dh.gov.uk/assetRoot/04/08/23/34/04082334.pdf> (accessed 30 November 2004).
3. Commission for Health Improvement (CHI). *Involvement to Improvement*. 2004. See http://www.chi.nhs.uk/patients/ppi_report_0204.pdf (accessed 30 November 2004).

The argument for patient and public involvement (PPI) as an innovation

Eileen Nixon

HIV Nurse Consultant, Brighton and Sussex University Hospitals

Introduction

Is PPI an innovation? Innovation means novelty, modernisation, improvement and, in terms of general health policy, PPI is most certainly an innovation. Since the birth of Clinical Governance in 1998 [1] and more recently the formation of the Commission for Patient and Public Involvement in Health (CPPIH) in January 2003, patient involvement has theoretically risen to the status it has long deserved. While some of us might find it disturbing that health policy needs to dictate the fundamentals of involving and working in partnership with patients, we need to remember that many mainstream healthcare services have evolved very differently from the relatively recent HIV speciality.

Historically, HIV services have matured within a true patient/clinician partnership where negotiation about care and respect for patient choice has dominated (Table 1). This culture has largely been influenced by a number of sociological issues that have contributed to the uniqueness of the HIV speciality, which has often been put forward as a model for healthcare provision.

philosophy translates into practice across a range of healthcare settings.

Patient involvement at the front line of care

I think we have seen many examples of successful PPI involvement in HIV care, evident in the current edition of this journal and in recent HIV conferences. At the 6th Annual Conference of the National HIV Nurse Association Conference, 36% of oral presentations and 50% of poster presentations demonstrated that patient knowledge, feedback and information needs were key areas for nursing intervention [2]. At the previous year's conference, the research award was given to the author of a qualitative study on patient stories and their impact on service delivery [3]. While this may be more reflective of the priorities of HIV nurses, I believe it also represents more reliance on validated patient feedback for the delivery of innovative nursing care.

As HIV nurses, we are well practised in engaging in patient feedback while delivering nursing care, but the real power lies in how we process this feedback to inform service improvements. An example of this is introducing a booked system for blood tests in response to informal patient feedback about waiting times for a walk-in service. Likewise, addressing and directing complaints in a constructive and proactive way can highlight difficulties in service delivery to managers and fund holders. Whether this can result in more money on the table of local services remains to be seen, but the stakes are undoubtedly raised when patient feedback is unleashed.

Patient surveys

Patient surveys are very in vogue. But are they innovative or just another patient satisfaction exercise that gathers dust in bulging in-trays? The National NHS Patient Survey has greatly assisted in identifying key healthcare issues that matter to service users [4]. One example is the hot topic of hospital cleanliness that has now been pushed to the top of the 'to do' pile, particularly for the new Chief Nursing Officer in England. Whether addressing this is a role for modern matrons or for hospital administrators is another debate. Quite clearly, the views of patients have forced this rather embarrassing thorn deep into the flesh of healthcare infrastructure and given rise to new priorities.

Table 1: Factors in the growth PPI in HIV services

- Patient activism and patient advocacy early in the the HIV epidemic.
- Predominantly younger group of patients.
- More defined community of people with HIV compared with other illnesses.
- Generally very well-informed group of patients with easy access to a range of patient information.
- Mutual goals shared by health professionals and patients at a time when stigma and discrimination were significant in general society.
- More recently an established cohort of people with chronic HIV disease.

So while PPI may be an innovation for some healthcare settings, the public/patient involvement agenda may be more affirming for HIV services than groundbreaking.

Does PPI translate into practice?

Whatever the cultural differences that exist between mainstream healthcare and HIV services, in practice there are many facets to the successful implementation of PPI. The real test is whether this

Patient surveys can be tokenistic if not treated seriously and not fed back to patients. Equally, they can be innovative and proactive when the following principles are applied, whether locally or nationally (Table 2):

Table 2: The process of patient surveys

- Representative patient sample.
- Validated questionnaire which has been piloted.
- Patient involvement in identifying survey questions.
- Validated data analysis tool.
- Implementation and publication of findings.
- Action plan to address concerns.
- Repeat surveys to measure progress.

Patient representatives

Patient representatives come in all shapes and sizes from representatives on the hospital inspection committee to service user representatives. We can never expect patient representatives to epitomise a cohort of patients, as the essence of this initiative is to communicate a diverse and patient-focussed perspective on care and service delivery.

In the words of Green and Hart [5] when writing about qualitative research methods, 'generalisability tends to be more conceptual than numerical'. Patient representatives are the start of clinician/patient working relationships and given the right support and infrastructure can facilitate effective patient feedback on behalf of a number of patients.

Involving patients in service planning

The growth of community PPI forums has been varied across the country and is intended to replace Community Health Councils by involving patients at a more strategic level of service planning. There are concerns about whether patients will volunteer for these groups and if their views will be

incorporated in the healthcare planning cycle. The concept of working in partnership is about respecting patients' choices at being involved in PPI and, as long as a mixture of methods for public involvement are utilised, patients can become involved in a way that is suitable for them, if they choose to do so. Public consultation is another mode of involving patients at this level and we have very recently seen the success of public consultation on public health as £300 million has now been targeted at the 'sexual health crisis' in England. In addition, evidence is slowly coming to light on the outcomes of PPI in terms of patient satisfaction and service planning and gives credence to the essence of working alongside patients in new ways [6].

Conclusions

In conclusion, as healthcare professionals it is a shame that we needed PPI directives to facilitate working in partnership with patients. Now that it is here, it is an innovative opportunity to formalise and modernise patient feedback with a range of tools and continue to build on the unique model of HIV service delivery.

References

1. Department of Health. *A First Class Service*, Department of Health, London, January 1998.
2. National HIV Nurses Association (2004) Conference Handbook, 24th & 25th June, Manchester www.nhivna.org.uk (accessed 30 November 2004).
3. Tapia G, Nixon E and Carter P *et al.* Are patient stories a useful tool for feedback on service provision? *HIV Nursing*, 2003, **3**, 8-10.
4. Healthcare Commission. *Patient Survey Report 2004 - Overview*. www.healthcarecommission.org.uk (accessed 30 November 2004).
5. Green J and Hart L. Children's views of accident prevention: A Qualitative Study. *Injury Prevention*, 1998, **4**, 14-21.
6. Department of Health. *Patient and Public Involvement in Health - the Evidence for Policy Implementation*. Department of Health, London, May 2004.

Patient and public involvement (PPI) in HIV care: innovation or tokenism – reflections

Ian Hodgson

Lecturer, School of Health Studies, University of Bradford, Bradford

Introduction

Patient and public involvement (PPI) in the context of healthcare services has affected significantly the 'place' of the service user in healthcare delivery. In what has been in the health services a traditionally unequal relationship, with

medical and nursing staff adopting a patriarchal position towards the vulnerable 'patient', HIV care has over the past years been much more amenable to encouraging a more equal partnership. This is epitomised in the growth of PPI and accompanying activities, such as patient surveys, public consultation and a much more collaborative

approach to care planning. This is covered in depth by the related article in this edition of *HIV Nursing* on pages 10 and 11.

PPI issues considered

More broadly, there are issues regarding PPI that must be considered to ensure the initiative is properly critiqued. These are:

- Who is best placed to facilitate PPI?
- How should the content of PPI be shaped?
- Is PPI a universal initiative, applicable in all HIV contexts?

1. Who is best placed?

This may seem like an obvious and unnecessary question, but in the context of HIV care, nothing is straightforward. Much research suggests that the stigmatisation of people living with HIV or AIDS (PLWHA) is endemic in many healthcare systems [1]. With HIV, as with all heavily stigmatised pathologies, the people best placed to facilitate PPI must be those who are comfortable and able to integrate with the context of HIV care. Otherwise, the risk of stigmatisation and subsequent discrimination is very real and indeed inevitable according to extant studies. Carers with extensive experience, or who chose to work in the field, generate an alternative cultural milieu that does not stigmatise, and encourages service user/healthcare worker engagement [2].

2. How should the content and context of PPI be shaped?

This is perhaps a more complex question than the first, but no less significant, for it requires a level of reflexivity on the part of the healthcare worker that is by no means an obviously natural position. Much of Foucault's post-modernist critique of medical 'power' [3] identifies how the shift of 'person' to 'patient' is inevitable in the healthcare context. This occurs not least because of the level of knowledge accumulated in medicine, and the power that accrues from this. For Foucault, 'each society has its regime of truth.... types of discourse it accepts and makes function as true' [4].

In applying this to the PPI initiative, how is the discourse managed? Who decides in the final analysis the essential framework of healthcare services, or indeed a service user's care trajectory? A Foucauldian analysis would suggest a real danger of an entropic drift towards (for the service user) a state of relative inadequacy,⁸ in the face of a powerful healthcare system. PPI will never truly work unless the underpinning infrastructure of HIV knowledge is addressed.

Perhaps, it is here that the accusation of 'tokenism' can be readily invoked. Arguably, it could be said that by involving service users, healthcare workers

can claim to be encouraging involvement, but in reality maintain a position of control which becomes by default theirs because of the vast amount of knowledge forming the backdrop of care delivery. This includes: medication and treatment, care management, short and long term care systems and the like. How can all this be focused meaningfully upon a context in which a service user is able to fully participate in planning healthcare services?

Consulting and involving service users is no doubt a good thing morally. However, care providers must always be aware of the culture they are 'plugged in' to, one that could lead to the manipulation of service users. The problem is not insurmountable, of course, and the issues may be overstated here, but a similar debate around informed consent (do service users ever truly consent?) has been troubling ethicists for a while.

3. Is PPI a universal initiative, applicable in all HIV contexts?

The third and final point to be raised here concerns context. Is PPI simply a way of involving the 'converted' – those who are already activists engaged in contributing to the debate around healthcare planning? Integrating the medical context with the broader social and cultural context is always a challenge, as is being found with the current '3 x 5' World Health Organisation project as discussed by Furber [5].

In addition, any PPI initiative must endeavour to reach service users who are not currently engaged, those who feel that they have nothing in common with other service users, apart from a particular pathology. How can they be encouraged to contribute? This is of particular concern in the developing world, where HIV has meshed at a much more profound level with the everyday lives of millions of people. How can people not normally classed as 'activist' be encouraged to 'speak their world'? A first step, and one that is certainly consistent with the underpinning principles of PPI, is to provide specific mechanisms for those affected by HIV to openly debate health issues directly affecting them.

The use of electronic forums (eForums) managed and moderated by Health and Development Networks (HDN: www.hdnet.org) is one example. HDN is a non-government organisation that aims to mobilise a more effective response to HIV/AIDS and other health and development-related issues by improving information, communication and the quality of debate. It takes a critical, objective and non-partisan perspective on current issues, and through eForums, publications and reports endeavours to provide a mouthpiece for those in society, especially in the developing world, often not heard in health-related discussions and

initiatives. HDN has around 20,000 people and organisations associated in some way with its activities, and serves as a useful example for one way of ensuring there is an appropriate level of debate around health. Recent discussions have led to hundreds of contributions from many parts of the world, people 'living' the world of HIV sharing their experiences. This allows HIV-affected people to talk of their own world, outside of the influences of academia, medicine, healthcare systems; a valuable approach because it circumvents the risk that discussion or analysis in the social scientific setting is undertaken by those who are not stigmatised themselves [6].

In relation to PPI, this and similar attempts to reach the broader, HIV-affected populace is a necessary precursor to a more wide-ranging level of service user involvement

Conclusions

- PPI must be facilitated by carers with an appropriate level of expertise and a wish to be involved.

- These carers must be cognisant of their context; they are part of, and do represent, a power-base that traditionally tends to be unsympathetic to the individual/user perspective.
- Lastly, broadening the principle of PPI to other contexts should provide the opportunity for individuals not normally able to engage with consultation-type initiatives to 'speak their world'.

References

1. Foreman M, Lrya P and Breinbauer C. *Understanding and Responding to HIV/AIDS Discrimination in the Health Sector*. Pan American Health Organisation, Washington, 2003.
2. Hodgson I. Stigma reduction: what can be learnt from the context of HIV care? *15th International AIDS Conference, Bangkok, 2004*, Abstr. MoPeD3857.
3. Foucault M. *The Birth of the Clinic*. Tavistock, London, 1973.
4. Foucault M. *Power/Knowledge*. Harvester, Brighton, 1980.
5. Furber AS, Hodgson IJ, Desclaux A and Mukasa D. Barriers to better care for people with AIDS in developing countries. *Br Med J*, 2004, **329**, 1281-1283.
6. Kleinman A. The Social Course of Epilepsy - Chronic Illness As Social Experience in Interior China. *Soc Sci Med*, 1995, **41**, 451.

Evaluation of pre- and post-HIV training questionnaires to assess input of a training programme on learning in Botswana

Susan McDonald

Senior Staff Nurse, Kobler clinic, Chelsea and Westminster Hospital, London

Introduction

St Stephen's AIDS Trust seconded HIV-specialised nurses from the UK to work for an organisation called African Comprehensive HIV AIDS partnership (ACHAP) in Botswana. This programme started in March 2002. The main purpose of their visit was to educate local health professionals, in their designated areas, on issues relating to HIV and antiretroviral (ARV) therapy. The teaching sessions delivered by two of the seconded nurses were assessed by using pre- and post-training questionnaires. The purpose of this study was to evaluate how effective these questionnaires were at assessing learning, following a HIV training programme. Although there were limitations in this study, it did show that participants' knowledge improved following the training. Results suggested that pre- and post-training questionnaires could be an effective tool for educators to assess short-term effectiveness of a training programme. Areas for improvement are discussed.

HIV in Botswana and the ARV therapy programme

Botswana has been recognised as having one of the highest rates of HIV in the world, affecting approximately 40% of the 1.68 million population [1]. Currently it boasts the highest GDP per capita in Africa [2]; however, the life expectancy in Botswana is estimated at 39 years. This is attributed to the epidemic and, in the absence of HIV, would be approximately 72 years [3]. The Botswana Government initiated an ARV therapy programme in 2002, collaborating with the Bill and Melinda Gates foundation and the Merck Drug Company to form the organisation called ACHAP. Their aim, primarily, is to provide ARV therapy free of charge to citizens of Botswana. Nurses from the UK were seconded by St Stephen's AIDS Trust to work for ACHAP. The nurse preceptor's role is predominantly to educate indigenous nurses to enable them to support the ARV therapy services in Botswana.

HIV training programme

In August 2003, two nurses were sent to two rural health sites in Botswana, Mahalapye and Tutume, for 6 months. Each site included a hospital and sub-district health facilities. An HIV training programme was devised, which was an adapted version of the Botswana Government's KITSO model. Kitso means knowledge in Setswana, the language spoken in Botswana. KITSO is a collaboration of the Botswana Ministry of Health and the Botswana Harvard Institute partnership for HIV, research and education, which is supported by ACHAP. It consisted of 12 interactive lectures. The teaching material was used in each site but the duration of course and time of presentation differed. There are many ways of evaluating a training programme; however, for the provider of education it can be difficult to assess their effectiveness. A literature search failed to identify any studies specifically looking at the use of pre- and post- education questionnaires to assess learning. However, there has been a variety of studies discussing questionnaires to evaluate a training course. According to Shepard [4], one of the most difficult challenges using questionnaires for evaluation purposes is determining what to measure. Assessors must be focused on what they want to achieve. Therefore, the design of the questionnaire should reflect the desired information; for our purposes, collecting information that will guide nurse educators to improve an HIV training course. The results should be able to determine what did and did not work. Used within this context pre- and post-training questionnaires have research qualities [5]. However, designing questionnaires that participants find easy to understand, unambiguous and, therefore, able to answer the question, is challenging. There are many studies examining the design of questionnaires [6–8] that have highlighted concerns regarding question interpretation and comprehension. Conrad and Blair [9] identified and classified five categories of response problems. One of these, referred to as lexical problems, is associated with meaning, use of words and context, suggesting that some words have different meanings to different groups of people.

This could certainly affect the response to a questionnaire. Collecting data using questionnaires is not always reliable due to non response or completion of questionnaires [10]. This again has to be considered when designing the questionnaires.

Twenty seven questions, based on course content, were completed by nurses before and after attending the training. The aim of the study was to determine if pre- and post-training questionnaires were valuable tools to assess learning. Did the results of the questionnaires demonstrate learning improvement and areas of misunderstanding? Could this evaluation tool be used effectively to assess an HIV training programme?

Methodology

Nurses in Botswana are educated in English, hence the questionnaires were in English. The questionnaires were not piloted and were not culturally specific. Their initial intent was to evaluate the training programme, by focussing on what was learned rather than questions related to other aspects of a training course. They were based on the 12 lectures that were presented to all of the participants.

Permission to use the information gathered from the questionnaires, in the context of research, was granted by the Botswana government Ministry of Health and ACHAP. The questionnaires completed were from nurses who volunteered to participate in the evaluation.

Twenty seven questions were completed pre- and post-HIV training programme by nurses who attended (Table 1). The allocated time given to each participant was 15 minutes. The sample size altogether was 201 from both sites. From Mahalapye the sample size was 107 and from Tutume the sample size was 94. Although some participants had previously received HIV training from the Botswana Government on Prevention of Mother to Child Transmission Programme (PMTCT), they still received the same questionnaires. The intention of the questionnaires was to assess improved learning.

The 12 lectures were presented to both sites but duration and time of day differed between sites. Mahalapye lectures were presented over a 12 hour period, 3 hours on four afternoons a week per

Table 1: Examples of questions on the Questionnaire

Q2	What is the MASA programme?
Q3	In which country was AIDS first diagnosed?
Q4	Name 3 ways HIV is transmitted
Q6	What is the first line therapy for TB in Botswana?
Q8	What does the diagnostic test for HIV look for?
Q13	Does ARV therapy cure or treat HIV?
Q15	Which drug can cause anaemia?
Q16	Why is adherence so important in ARV therapy?
Q17	Name 2 factors that could influence adherence
Q18	Why should ARV drugs and TB drugs not be started together?
Q19	What is your understanding of the work resistance to HIV treatment?
Q20	Why does resistance matter in relation to HIV and ARV therapy?
Q23	At what week would a pregnant woman with HIV start PMTCT – prevention of mother to child transmission?
Q24	What drugs are used to prevent MTCT in Botswana?
Q27	What specific test would be required to detect HIV in a baby of 12 months?

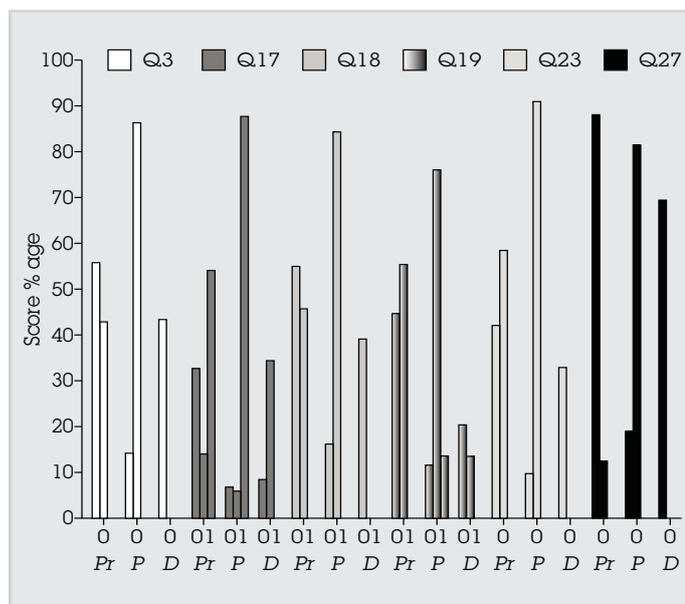


Figure 1: Mahalapye site with significant improvement. Pr, pre-training; P, post-training; D, difference.

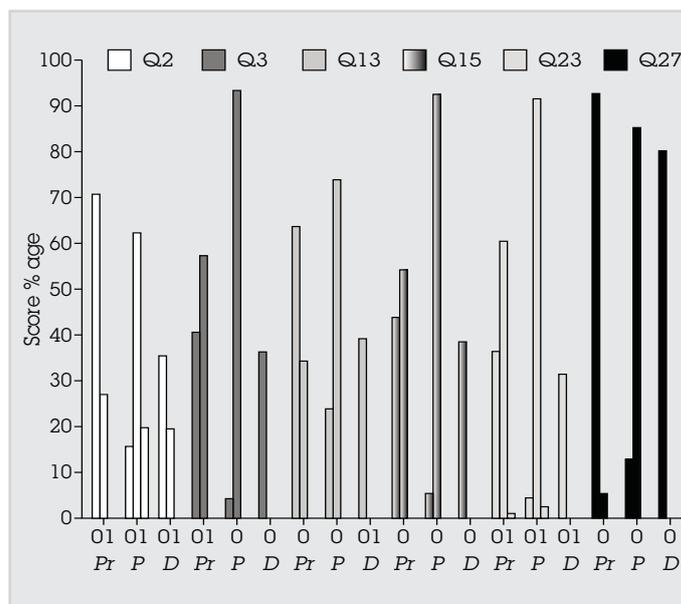


Figure 2: Tutume site with significant improvement. Pr, pre-training; P, post-training; D, difference.

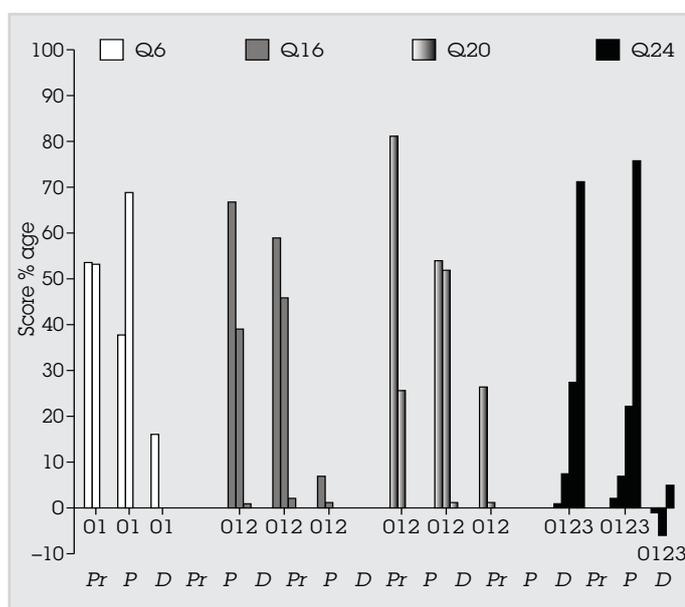


Figure 3: Mahalapye site with no significant improvement. Pr, pre-training; P, post-training; D, difference.

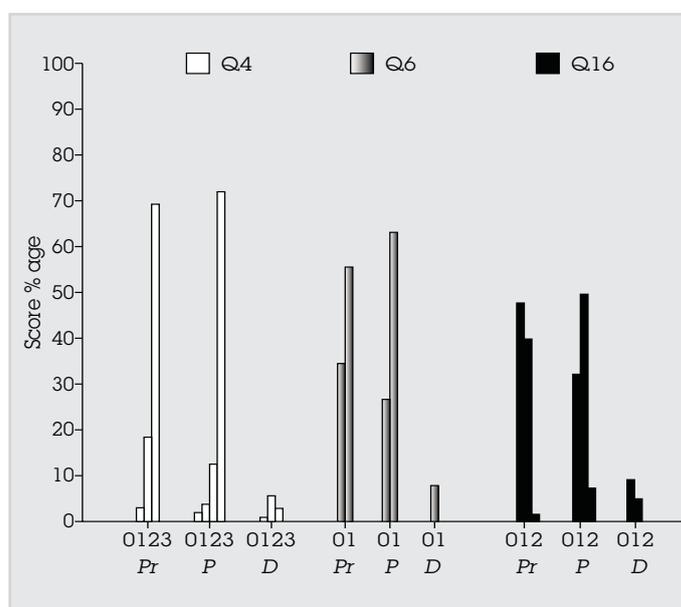


Figure 4: Tutume site with no significant improvement. Pr, pre-training; P, post-training; D, difference.

participant. Tutume lectures were presented over a 15 hour period, one third over 2 full days (7.5 hours a session) and two thirds over 4 mornings. The questionnaires were marked using a guide devised by pre- and post-questionnaires following completion of the training course. The marks allocated to each question ranged from 1 to 3. Each nurse marked their own site questionnaires. Reliability and validity will be discussed with the results.

Results

To assume reliability and validity, 20% of the questionnaires were second marked by an HIV clinical nurse lead at Chelsea and Westminster Hospital. The results showed no significant difference between initial and second markers. This was proven using the Wilcoxon test (see Table 2)

[11]. A chi square test showed that the higher scores from the Tutume sample were significant.

The questionnaire

Figures 1 and 2 show the questions where there was a marked improvement in both sites (questions cited in Table 1). Figures 3 and 4 show the questions where there was no significant improvement in each site (questions cited in Table 1). The marks ranged from 1 to 3, depending on each question.

There were common questionnaire answers between each site indicating both improvement and no improvement (Figures 1-4). However, the results also revealed differences. It is difficult to ascertain what could have contributed to these differences and the marked improvement from Nurse 2 participants. Factors that may have

Table 2: The Wilcoxon test

	Mahalapye Nurse versus Second Marker	Tutume Nurse versus Second Marker
Pre:	$P = 0.900$	$P = 0.939$
Post:	$P = 0.0831$	$P = 0.955$

contributed to the improved marks from Tutume sample are motivation, duration of education and training schedule.

The Mahalapye site nurse explained to participants that the questionnaires were for research purposes, to evaluate the training. Results were discussed after each group submitted the questionnaires. The Tutume site nurse explained to participants that it was to evaluate the training but that marks would be allocated to each participant. This may have been interpreted as a test and self interest may have motivated participants.

As previously mentioned, although the same training programme was used in each site, the Tutume site nurse spent three hours longer teaching than the Mahalapye site nurse. This extra time may have influenced sustainability of information

Botswana has an extremely hot and dry climate with temperature soaring up to 40 degrees. There was no air conditioning in the designated teaching areas. Nurse 1 conducted her sessions in the afternoon, after most nurses had already been working in the morning. Nurse 2 taught in the morning, when it was cooler and nurses had not already been on duty. This may have affected the students' concentration.

The answers to question 16 (Table 1), why is adherence important, suggest that the question was misinterpreted by a high proportion of all participants. Many of the participants' answers were related to why is an adherence assessment important. During the training there seemed to be misconceptions regarding modes of transmission. The results from data collected have not suggested this.

Conclusions

Results have shown that overall the participants trained in both sites demonstrated improved knowledge after training. Variables that may have influenced the significant higher scores in Tutume participants could be motivation, duration and timing of training. This is valuable information that could be used to improve training schedules. This information could be used to re-assess training programmes. The answers to Q16 suggest that the question was misinterpreted by a high proportion of the sample. During training, there appeared to be misconceptions regarding modes of transmission, but the results from the data collected did not suggest this.

Limitations

Although 20% of questionnaires re-marked showed

no significant difference, interpretation of answers may have varied among markers. As discussed previously, each nurse marked their own questionnaires with the lead nurse re-marking 20%. Although the Wilcoxon test was a successful indicator of reliability, there might have been misinterpretation of answers between the two original markers, suggesting bias, thus unreliable data. The response to Q16 suggests there were interpretation and comprehension difficulties, highlighting the limitations of this questionnaire.

An area that has not been highlighted in this study is cultural differences between the UK teachers and the local nurses. Perhaps a qualitative study, exploring the Botswana culture and effective ways of teaching, could follow on from the data gathered from this study. This would be a far more holistic way of assessing an HIV training programme.

Recommendations

Pre- and post-questionnaires could be used as an evaluation tool to assess short-term effectiveness of learning. This could be particularly useful for nurse educators, when determining duration and environment of a training programme. It would be interesting to re-assess the same sample 6 months post-training, to evaluate sustainability of information learned. Finally, although questionnaires have research qualities, it is important to complement them by considering other evaluation tools, to assess training programmes, perhaps by using assessments, or by interviewing participants on areas of learning.

References

- UNAIDS 2003 online, <http://news.bbc.co.uk/1/hi/health/3436200.stm> (accessed 20th November 2004).
- United Nations Development Programme, 1999 online, http://www.undp.org/hdr2001/indicator/indic_13_1.html (accessed 20th November 2004).
- US Agency of International Development of Press Release. *Washington DC 20523 Press Office*, 2002, **202**, 712-4320.
- Shepard R. Questionnaires for Evaluating On-Farm Field Days. *Journal of Extension*, 2001, **39**. <http://www.joe.org/joe/2001/february/tt5/html> (accessed on 14 December 2004).
- Van den Ban AW and Hawkins HS. Cited in Shepard R. Questionnaires for Evaluating On-Farm Field Days. *Journal of Extension*, 2001, **39**, 1.
- Tourangeau R. Cognitive science and survey methods. In: *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines*. National Academic Press, Washington. 1984, pp73-100.
- Jobe J and Mingay D. Cognitive research improves questionnaires. *Am J Public Health*, 1989, **79**, 1053-1055.
- Goldbloom R, Kim R, Hodder-Mallory C *et al*. Design and reliability of paediatric health quiz: preliminary report of a comprehensive, computerized, self administered child health assessment. *Clin Pediatr*, 1999, **38**, 645-654.
- Conrad F and Blair J. From impressions to data: increasing the objectivity of cognitive interviews. In *Proceedings of the Survey Research Methods Section of the American Statistical Association*. American Statistical Association, Alexandria, VA. 1996.
- Drenman J. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *J Adv Nurs*, 2003, **42**, 57-63.
- Wilcoxon F. Individual comparisons by ranking methods. *Biometrics*, 1945, **1** 80-83.

Instructions to Authors

1. **Manuscript submission:** Articles to be considered for publication and other correspondence relating to the journal should be addressed to:

Kruna Vukmirovic
Mediscript Limited
1 Mountview Court
310 Friem Barnet Lane
London N20 0LD
Telephone: +44 20 8369 5381
Facsimile: +44 20 8446 9194
E-mail: kruna@mediscript.ltd.uk

Articles are accepted on the understanding that they have been approved by the Editorial Board and may be subject to revision. One hard copy of the manuscript should be supplied together with an emailed version.

2. **Manuscript format:** Authors should include with their manuscripts full affiliation, address, telephone and facsimile numbers and e-mail addresses. Where there is more than one author, the author to whom proofs should be sent should be indicated. For article length, please refer to commissioning letter. Manuscripts should be typed double-spaced using English spellings. Subheadings should be used wherever possible, and abbreviations defined when first used.
3. **References:** in the text should be cited consecutively, including tables or figure legends, as they fall in the text. Each reference should be numbered in square parentheses and listed at the end of the article in numerical order, according to the following style:

Wu AW, Rubin HR, Mathews WC *et al*. Functional status and well-being in a placebo-controlled trial of zidovudine in early symptomatic HIV infection. *J Acquir Immune Defic Syndr*, 1993, **6**, 452-456.

Miller D. *Living with AIDS and HIV*. Macmillan Press, London, 1987.

Corey L. HIV vaccine: update on science and policy. 14th International AIDS Conference. Barcelona, 2002, Abstr. TuOr143.

4. **Illustrations and tables:** These should be provided wherever appropriate. All figures sent with the hard copy of the manuscript should be clear and supplied at larger than the final printed size. In general, figures supplied by the author are redrawn to the Journal style. Where this is not possible, the illustration supplied should be of sufficiently high quality to ensure good reproduction. Colour reproduction is available at the author's expense (cost available on request). All hard copies of illustrations should be clearly labelled with the author's name, figure number and orientation. Where appropriate, magnification figures or scale bars should be supplied. Illustrations and tables must be cited in the text in numerical order. Figure captions should provide an adequate description of the figure without discussing it. When required, it is the author's responsibility to obtain permission to reproduce illustrations or tables, and to include the appropriate credit in the figure or table legend. All photographs are returned to authors on publication.
5. **Proofs:** will be sent to the author shortly before publication for correction of errors.
6. **Copyright assignment:** Authors are assumed to transfer to Mediscript copyright of their words. Copying of articles should only be made following permission from Mediscript. However, requests by authors wishing to make copies of their own articles for personal use will be treated sympathetically. A personal copy of the issue in which the author's article appears will be sent to the author on publication.

Prescribing Information (UK) Tablets and Suspension

VIRAMUNE™ ▼

Tablets containing 200mg zalcitabine, and suspension containing 10mg/ml. **Action:** Non-nucleoside reverse transcriptase inhibitor (NNRTI) of HIV-1. **Indication:** Combination therapy for the antiretroviral treatment of HIV-1 infected patients with advanced or progressive immunodeficiency. **Dose & administration:** 2 months-8 years (suspension): 4mg/kg once daily for 14 days, then 7mg/kg twice daily. 8-16 years (suspension): 4mg/kg for 14 days, then 4mg/kg once daily. Over 16 years: 200mg daily for 14 days, then 200mg twice daily. This dosage must be strictly adhered to, especially the 14-day loading period. If rash occurs during loading period do not increase dose until rash has resolved. Maximum daily dose: 400mg. Combine with at least two other antiretroviral agents to which the patient has not previously been exposed. After treatment interruption > 7 days start with loading dose for 14 days. **Contra-indications:** Hypersensitivity to any component. Previous Viramune-associated severe rash, rash with constitutional symptoms, hypersensitivity reactions, or clinical hepatitis. Severe hepatic impairment; pre-treatment ASAT or ALAT > 5 ULN. Recurrence of liver function abnormalities on re-administration after previous increase in ASAT or ALAT > 5 ULN. Co-administration with St. John's Wort or shagrin. **Warnings & precautions:** Monitor for skin and hepatic reactions during the first 16 weeks. The greatest risk is in the first 6 weeks. Observe and patients with high pre-treatment CD4 cell counts are at greater risk of hepatic events; the greatest risk is in women with CD4 cell count > 250 cells/mm³. Monitor liver function every 7 weeks during the first 6 weeks of treatment, at 12 weeks, and then regularly. Perform UFTs if patients present with a Viramune-associated rash. **Discontinue Viramune if ASAT or ALAT > 5 ULN.** The greatest increased ASAT or ALAT levels > 2.5 ULN and/or co-infection with hepatitis B or C increase risk of hepatic adverse reactions and require close monitoring. Advise patients to promptly notify their doctor if they develop any of the following symptoms of hepatitis: a general feeling of illness, or discomfort, or pain in the upper right part of the abdomen, loss of appetite, loss of weight, darkening of the urine, or yellowing of the skin or whites of the eyes. **Adverse reactions:** Rash, pruritus, or skin eruptions may be reduced by strong CYP inducers. **Pregnancy and lactation:** Not recommended. **Undesirable effects:** Most common: fatigue, fever, SJS/TESS or serious hypersensitivity reactions associated with rash & constitutional symptoms eg fever, arthralgia, myalgia, lymphadenopathy, plus visceral involvement such as hepatitis, eosinophilia, granulocytopenia - more common in children than adults - and renal dysfunction. Rash, nausea, fatigue, fever, headache, sore throat, dizziness, abdominal pain, myalgia, abnormal liver function tests, jaundice. Rare reports of neutropenia, anaemia, arthralgia. Allergic reactions (angioedema, angioedema, urticaria). **Pack sizes and NHS price:** 50 tablets £168.00. 240ml suspension £51.40. **POM Marketing Authorisation Holder:** Boehringer Ingelheim International GmbH, D-55216 Ingelheim am Rhein, Germany. **MA numbers:** Tablets: EU/1/97/055/04. Suspension: EU/1/97/055/002. For full prescribing information please see Summary of Product Characteristics. Prepared in February 2004.

References:

1. Virelli F, *et al*. *Journal* 2004; 363: 1253-1263.
2. Finkelstein D, *et al*. XIV International AIDS Conference, Barcelona, 2002; abstracts, TuP04443.
3. Raff F, *et al*. *HIV Clin Trials* 2001; 2: 317-322.
4. Thior U, *et al*. *International Journal of STD & AIDS* 2002; 14: 71-77.
5. Shan JQ, *et al*. XIV International AIDS Conference, July 7-17, 2002, Barcelona, Spain; abstract 130r15.
6. Timpone JJ, Kaplan AL. *AIDS* 2002; 16: 1708-1715.
7. Nathardul BK, *et al*. 2nd International AIDS Society Conference on HIV Pathogenesis and Treatment, Paris, July 2003. Poster 552.

BI/Viramune

PI Information

**DO NOT
DISTURB**



BI/Viramune

Full-colour Advertisement

Because life carries on after HAART starts

- Proven efficacy and durability¹⁻³
- Well-defined tolerability profile^{1,2,4,5}
- Few adverse events affecting the Central Nervous System^{6,7}

Prescribing information can be found on opposite page


viramune[®]
nevirapine

 **Boehringer
Ingelheim**

TRIED. TESTED. TRUSTED



Abbott/Kaletra

Full-colour Advertisement

*Undetectable,
five years on.*



The success of Kaletra as a first-line antiretroviral is now supported by 5-year data.¹

These data continue to confirm that Kaletra helps keep viral loads undetectable. And reinforces that not a single case of primary PI resistance has been detected in any patient initiated on a Kaletra-based HAART regimen.^{1,2}



...and not a single case of primary PI resistance in the ARV-naive.

