

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Editorial Board

Juliet Bennett

Independent Nurse Advisor

Ian Hodgson

Independent Consultant
HIV Education and Research

Shaun Watson

Clinical Nurse Specialist
(HIV Community)
Hammersmith and Fulham
Primary Care Trust, London

Advisory Panel

Nathaniel Ault

Consultant HIV Nurse
Barts and the London
NHS Trust

Margaret Clapson

Paediatric Clinical Nurse
Specialist
Great Ormond Street
Hospital, London

Zoë Sheppard

Ward Manager
St Mary's Hospital NHS Trust
London

Judith Sunderland

Lecturer in Midwifery
City University, London

Psychosocial issues

Editorial

Mental health: a question of degree

Shaun Watson 1

Features

Psychological outcomes in children and young people
living with HIV

*Jennifa Miah, Annette Eneberi, Margaret Clapson,
Jacquie Flynn, Tarryn Klotnick* 2

Efavirenz-induced psychosis: a case study

Nicola Galbraith 4

Standards for psychological support for adults living
with HIV: a review (Part 1)

Dennis Dobbin 7

Who's afraid of the Big Bad Wolf? Mental health for
general HIV nurses

Shaun Watson 12

Health workers living with HIV in Kenya: challenging
stigma through support groups based in health facilities

Catherine O'Keeffe 15

HIV update

Antiretroviral treatment as prevention: considerations for
nursing practice

Juliet Bennett 20

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

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Volume 12 Number 1 Spring 2012

ISSN 1474-7359

Endorsed by



National HIV Nurses Association

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

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

Editorial Office

Editorial Director: Fatima Patel

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

Printed in England

Spring 2012

Copyright © Mediscript, 2012

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.

Mental health: a question of degree

Shaun Watson

Clinical Nurse Specialist (HIV Community), Hammersmith and Fulham Primary Care Trust, London, UK

The issues surrounding psychological and mental health associated with HIV are many and complex. We have all experienced patients with psychological or emotional distress, or those who have mental health problems predating or brought on by HIV – whether they are newly diagnosed or living with a long-term diagnosis. For me, psychological and mental health issues are some of the most concerning, interesting and challenging areas of HIV care, and witnessing the reactions to the psychological/mental health sessions at NHIVNA's Study Days, I am clearly not alone in this interest.

On a daily basis I work with patients experiencing emotional/psychological/mental health difficulties, at a variety of levels of severity. I have worked in HIV for the past 20 years and have learned a lot through experience. In 1988 I had an 8-week mental health placement as part of my general nurse training in Hull, based in an outreach/drop-in service for people who, from what I could tell at the time, suffered from drug and alcohol issues, mild depression, personality disorders and phobias. Our days were spent helping them to adjust to 'normal' life, going shopping, playing snooker and making cakes. In 1997 I moved to London and worked in a small unit for people living with HIV-related dementia, which was like working in a slightly crazy guest house with the occasional trip to the HIV clinic and heavy emphasis on adherence. Residents had long histories of drug and alcohol misuse and some had severe mental health issues but, on the whole, they were fairly pleasant and the situations were challenging, manageable and frequently hilarious – rarely did I feel out of my depth.

It was when I started as ward manager in a specialist HIV unit that I realised my introduction to HIV and mental health had so far been a delightful one! I was soon managing and supporting severely depressed, suicidal patients or those with increasing dementia or acute schizophrenia. It was the day that a patient scrubbed his face red raw and

shaved his eyebrows off that I realised I lacked the necessary skills – as I tried to manage and support a team of general nurses who were struggling alongside me. Something had to change.

HIV nurses, wherever they are based, will at some point have to manage severe emotional distress, adverse reactions to diagnosis or ARV treatments, HIV-related or senile dementia, severe mental health difficulties or patients so deeply disturbed that they may be suicidal. Our general training may have equipped us with good listening skills, the ability to calm stressful situations, assess health and provide holistic care – but do we need more?

It is incredible to note that that only now, after 30 years of HIV, do we have the *Standards for psychological support for adults living with HIV* to inform and support us in our work. In this issue of *HIV Nursing*, Dennis Dobbin presents Part 1 of a two-part paper looking at the rationale behind the development of these new standards. This issue also offers an interesting range of articles on managing mental health and HIV. Efavirenz-induced psychosis is hopefully a rare occurrence, and Nicola Galbraith gives us an insightful case study on some of the challenges involved. Catherine O'Keeffe's article focuses on stigma and discrimination among people living with HIV in Kenya and the use of group support. Jennifa Mich takes a look at the psychological outcomes for young people living with long-term HIV, while I have aimed to pass on some useful experience for tackling mental health issues among HIV patients.

Finally, in a new strand for *HIV Nursing* journal Juliet Bennett looks at news and developments for nurses in the field, starting with an article on the use of antiretroviral treatment as prevention.

Correspondence: Shaun Watson
Clinical Nurse Specialist, 4th floor
56 Dean Street
London W1D 6AQ, UK
shaun.watson@chelwest.nhs.uk

Psychological outcomes in children and young people living with HIV

Jennifa Miah Principal Clinical Psychologist,
Annette Eneberi Volunteer Assistant Psychologist,
Margaret Clapson Senior Clinical Nurse Specialist,
Jacquie Flynn Clinical Nurse Specialist
and Tarryn Klotnick Social Worker

HIV Family Clinic, Great Ormond Street Hospital (GOSH), London, UK

Introduction

Whilst there have been huge medical advances in HIV therapy and management, relatively little is known about psychological outcomes for the UK cohort of children and young people with vertically acquired HIV.

Changing demographics

In the UK there are reportedly just under 1300 children and young people up to 19 years of age living with HIV, and 97% of this group were vertically infected [1].

Improved antenatal testing and management in pregnancy has (as at March 2011) reduced vertical HIV transmission rates to less than 1%. The largest proportion of the UK paediatric cohort is now over 10 years of age (70%), with the median age being 12.4 years. Seventy-two per cent are on combination HIV therapy, and with 79% being of black African origin. The total number of children and young people still alive and reported by CHIPS as attending London clinics is just over 600, as this includes some non-London residents [2].

The GOSH cohort

The HIV Family Clinic at GOSH has a cohort of 118 children and young people, with a 62/56 male/female split. Over 80% are of black African origin, and more than 17 African countries are represented. Over the last decade, the success of preventing mother-to-child transmission in the UK has been reflected in our clinic figures: whereas more than half the children seen were previously below the age of 11, today 87 of our 118 total are between 11 and 18 years of age.

Improvements in HIV therapy and diagnostic tests have impacted greatly on morbidity and mortality, with only three deaths in the period 2004–2011, compared to 37 deaths between 1996 and 2003. However, 23 children and adolescents have had one parent die (9 mothers and 14 fathers); and five children are presently in foster care.

Adherence remains one of the major challenges, and out of the 94 children and adolescents on HIV therapy, 23 have adherence issues.

Psychological challenges

Research indicates that children and young people living with HIV are at greater risk of poor psychological outcomes. They face stressors which include the trans-generational impact of the condition, and the stigma, isolation and secrecy surrounding HIV. Young people face physical and psychological upheaval and the task of managing sexual health demands in addition to coping with a chronic health condition [3].

Additional difficulties

A number of children and young people face additional hardship, such as: carer change; living in foster care due to the loss of parents [4]; or physical or emotional neglect or abuse. Children placed in care are vulnerable to attachment difficulties [5,6], which can further complicate their relationship with health and ability to self-care and adhere, and their relationship with adults caring for them. This group of children and young people are known to have poorer outcomes across a range of areas [7] than peers without the diagnosis of HIV.

Adherence challenges

This group also face the challenge of managing the demands of taking medicines on a daily basis, and for a lifetime. It can be particularly difficult for parents to manage when their child does not know the name of the illness or understand why they have to take medicines. There are different challenges for adolescents who may be aware of the name of the condition. During adolescence the task of developing both individual and group identity takes on great importance. The process of adjustment to living with a chronic health condition surrounded by stigma and secrecy is especially complex during this stage of life.

'Naming of the illness'

The literature suggests that children's concepts of illness develop over time, through experience and with maturity. There is some variability between children in the way that they deal with new information, such as a diagnosis [8]. There is evidence that partial disclosure, in the context of providing age-appropriate building blocks of information, can be as helpful to the child's emotional wellbeing as full disclosure, as long as it is based on the truth [9]. Proactively engaging children and young people in their healthcare is vitally important in order to promote adherence and facilitate better psychological outcomes.

Measuring concerns

Melvin conducted a multi-centre study investigating parental concern about emotional and behavioural difficulties in school-aged children living with HIV. Fourteen per cent of children scored within abnormal or significant concern range, and another 14% were within borderline range. Adolescents scored higher than primary school children. Seventy per cent of 13-year-olds scored in problem categories [3]. These findings are consistent with norms for children living with chronic childhood illnesses and slightly higher than norms for the general population [10]. Given the multiplicity of risk factors in this population, it was expected that higher levels of difficulties would be reported. The authors concluded that perhaps it was more helpful to use measures looking at quality of life, adjustment and psychological wellbeing, rather than mental health.

Promoting resilience

It is also important to consider that there may be a range of resilience or protective factors which might help moderate the influence of risk factors on outcomes [4]. Eisler reflects on the focus shift in the psychological literature on chronic childhood conditions, from risk factors that impact on psychological functioning to protective factors that promote resilience [11]. Yeo and Sawyer argue that building competence in young people, strengthening connectedness within the family, school and peer group, and building the capacity of the healthcare team in different settings will all provide opportunities to enhance resilience in young people with chronic illness [12].

Why look at psychological outcomes?

The Children's National Service Framework (Department of Health), stresses that, 'all children and young people who are ill will have timely access to appropriate advice and to effective

services which address their health, emotional social, and educational needs throughout the period of their illness' [13]. Moreover, the Standards for Psychological Support for Children and Young People Living with HIV highlights, 'the psychological wellbeing of children and young people should be routinely considered to examine or better understand the impact of treatment' [14].

Measures used

We decided to pilot the use of Paediatric Index of Emotional Distress (PI-ED) and the Child or Young Persons Rating Scale. PI-ED is a paediatric version of the Hospital Anxiety and Depression Scale (HADS) [15]. It is a brief, valid and reliable self-report measure that screens for emotional distress in children aged between 8 and 16 years of age. It can provide an index of clinical change and is suitable for use with children and young people with health issues [16].

The Child or Young Persons Rating Scale [17] requires the child to indicate on a Likert scale, with a smiley face at one end and a sad face at the other, how things are going in relation to themselves, family, friends, school and health. This measure provides qualitative information to help us contextualise responses on the PI-ED.

Screening for emotional distress

We are currently collecting data to better understand the impact of naming the HIV diagnosis for children and young people, and of starting or interrupting treatment. In addition, we will be considering the impact of other factors such as coping at school, managing peer relationships, dealing with the transition to secondary school, family breakdown, parental ill-health or death, and living with a chronic health condition.

Conclusion

With the Paediatric Review of services pending, it seems more important than ever to fully examine and understand the impacts, both of treatment and of wider factors, that lead to poor psychological outcomes for children and young people living with HIV.

It is equally important to continue learning about protective factors that promote resilience, in order to offer preventative work [8,18] including screening for potential psychological vulnerability [19], which can inform interventions to build resilience [20]. In planning for the future, we need to ensure that the psychological needs of children and young people are addressed in order to facilitate better psychological and health outcomes.

References

1. Health Protection Agency (HPA). HIV in the United Kingdom: 2009 Report. HPA, London, 2009. Available at: www.hpa.org.uk/hiv (accessed February 2012).
2. Medical Research Council (MRC). Collaborative HIV Paediatric Study Annual Report 2010/11. Available at: www.chipscohort.ac.uk (accessed February 2012).
3. Melvin D, Krechevsky D, Divac A *et al*. Parental reports of emotional and behavioural difficulties on the SDQ for school aged children with vertically acquired HIV infection living in London. *Psychology, Health & Medicine*, 2007, **12**, 40-47.
4. Melvin D, Biggs R, Warrington S. Monitoring neurological and developmental outcomes in the UK paediatric HIV cohort 2011. Available at: www.chiva.org.uk (accessed February 2012).
5. Department of Health (DH). Statutory guidance on promoting the health and well-being of looked after children. DH, London, 2002.
6. Followfield J. Attachment theory and social work with 'looked after' children and their families, 2009. Available at: www.goodenoughcaring.com (accessed February 2012).
7. House of Commons Children, Schools and Families Committee. Looked-after children. Third Report of Session 2008-09. HC111-I. The Stationery Office, London, 2009. Available at: www.publications.parliament.uk/pa/cm200809/cmselect/c/mchilsh/111/111i.pdf (accessed February 2012).
8. Melvin D. Pediatric HIV – psychological issues: challenges and achievements. *J HIV Therapy*, 1999, **4**, 77-81.
9. Miah J, Waugh S, Divac A *et al*. Talking with children, young people and families about chronic illness and living with HIV. National Children's Bureau, London, 2004.
10. Meltzer H, Goodman R, Ford T *et al*. Using the strengths and difficulties questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *British Journal of Psychiatry*, 2000, **177**, 534-549.
11. Eisler C. Effects of chronic illness on children and their families. *Advances in Psychiatric Treatment*, 1997, **3**, 204-210.
12. Yeo M, Sawyer S. Strategies to promote better outcomes in young people with chronic illnesses. *Annals of the Academy of Medicine Singapore*, 2003, **32**, 36-42.
13. The Children's National Service Framework, Department of Health, London, 2004.
14. Melvin D. Standards for psychological support for children and young people living with HIV (in preparation for publication in 2012).
15. Zigmund AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 1983, **67**, 361-370.
16. O'Conner S, Carney T, House E *et al*. The Paediatric Index of Emotional Distress Manual, GL Assessment, London, 2010. Available at: shop.gl-assessment.co.uk/home.php?cat=466 (accessed February 2012).
17. Duncan BL. The Child/Young Person Rating Scale. Adapted from the Heart & Soul of Change Project. See: www.heartandsoulofchange.com (accessed February 2012).
18. Miah J, Collins K, Campbell T. All about me: a group for children living with HIV. Poster presentation, *XIV International AIDS Conference*, Barcelona, Spain, 2002.
19. Prince-Embury S. Introduction to the special issue: assessing resiliency in children and adolescents. *Journal of Psycho-educational Assessment*, 2010, **28**, 287-290.
20. Gurney K, Peake T, Yungman E. An overview of TEAM psychology and TEAM clinic 2011. Presentation, GOSH HIV Business Meeting, 2012 (contact: tabitha.peake@nhs.net).

Correspondence: Jennifa Miah
Principal Clinical Psychologist
HIV Family Clinic
Great Ormond Street Hospital
London WC1N 3JH, UK
jennifa.miah@gosh.nhs.uk

Efavirenz-induced psychosis: a case study

Nicola Galbraith

Clinical Nurse Specialist for HIV in Hammersmith and Fulham, Central London Community Healthcare, London, UK

Introduction

Antiretroviral therapy (ART) has proven to be invaluable in the treatment of HIV infection, as it delays the progression of AIDS and prolongs survival by means of viral suppression and restoration of immunological function [1].

While the non-nucleoside reverse transcriptase inhibitor (NNRTI) efavirenz is clinically effective in its capacity to suppress the virus and secure the health of the individual by way of immunological integrity and strength, its use can be associated with a number of side effects which have been well reported and documented over many years. This drug, which has been described as 'potent' [2], can cause dizziness, insomnia and unusual dreams among other effects [3], but fortunately patients can

be reassured that these typically resolve after the first 2-4 weeks [2].

However, in certain cases the situation is more complex: for some patients, particularly those with a history of psychiatric disorders, there appears to be a greater risk of side effects such as severe depression, suicidal ideation, aggressive behaviour, paranoid reactions and/or manic reactions [4,5]. In such settings, proactive history taking, ongoing review and information sharing are all key components of care provision, alongside medication.

In the following case study, where the patient's previous underlying mental health issues were unknown, commencing efavirenz could have had serious, perhaps even fatal consequences.

Case study: Tony

Background

Tony is a 32-year-old MSM (man who has sex with men) who was diagnosed HIV positive in July 2010 after a routine sexual health screen. His last negative HIV test had been in September 2009. As a clinical nurse specialist (CNS), I became involved in his care 2 weeks after his diagnosis following a referral to our community team from his clinic doctor. Tony seemed accepting of his diagnosis and did not appear overly anxious or distressed at this point. With the exception of mouth ulcers, he felt very well. He reported a good appetite and no other physical symptoms. His CD4 cell count was 426 cells/mm³ with a percentage of 34. His viral load was 59,545 copies/ml.

Tony lived with his partner, whose HIV test was negative; he was working as a receptionist. He reported smoking socially, drinking low to moderate amounts of alcohol, and had previously but not recently used recreational drugs including cocaine, ecstasy, MDMA, mephedrone, ketamine and marijuana.

Tony was reviewed again by his clinic doctor a month after diagnosis. He was well apart from some stress at work. He told his clinic doctor that being overly stressed by small things at work was causing him to develop mouth ulcers and he requested a referral for counselling. At this point Tony had declined input from the CNS team as he had felt it unnecessary but had our contact details should he require them.

Tony was referred to the health advisors for ongoing support in terms of coping with his diagnosis and agreed to be referred back to our service.

4 months later

Tony was seen in clinic. He appeared very well despite having had a viral cold. His latest CD4 cell count was 316 cells/mm³, percentage was 27 and his viral load was 17,358 copies/ml. He had stopped work due to stress. He continued to see health advisors but had telephone contact only with our team, preferring to avoid community input due to confidentiality concerns.

Commencing ART

Tony commenced ART 6 months after diagnosis in accordance with BHIVA guidelines, which recommend starting treatment when a CD4 cell count falls below 350 cells/mm³ [6]. His CD4 count was 327 cells/mm³ with a viral load of 34,000 copies/ml. He started Kivexa and efavirenz, following full discussions on side effects and adherence with his doctor and the clinic pharmacist. I also increased my level of contact

with him at this point for additional monitoring and support. However, this proved difficult at times as Tony regularly did not want to engage due to his confidentiality concerns.

Five days after starting his regimen, Tony was admitted via A&E to an inpatient mental health unit voluntarily after presenting in an acute anxiety state with thoughts of deliberate self-harm and suicidal ideation. The mental health team were informed, by the HIV team, of Tony's medication and advised of its potential associations with mood disturbance and possible role in this context.

The diagnosis given here was adjustment disorder arising from a number of factors. Tony had recently separated from his partner, resulting in him having to move back in with his parents who were unaware of his HIV status. In addition, job concerns and worries over starting ART were also thought to have contributed to his current mental instability.

There had been no reports of psychiatric ill health during any of his HIV clinic appointments; however, at that point, Tony reported feeling depressed over the previous 4 months and attempts at self-harm – for example, stabbing his wrists.

It then came to light that Tony only commenced his new ART regimen the day before presenting to A&E. This fact, and his background of pre-efavirenz psychiatric disorder, meant that the association between his ART and psychiatric morbidity was far more likely to be co-incidental than causal. He was advised to continue with his regimen and remained in the mental health unit.

Follow-up

Tony was seen a month later in clinic, following discharge from the mental health unit. He reported mood swings since starting treatment and said the efavirenz was making him feel 'crazy'. He dreaded taking the medication and reported feeling stressed and pressurised, convinced that it was exacerbating his problems. He felt as if he had lost control and that 'medication has sent me over the edge'. Tony's behaviour in clinic was diagnosed as cyclothymic (bipolar), and he was difficult to manage, varying from being very excitable to tearful and at times aggressive – all of which were out of character for him. His medication was switched due to severe efavirenz toxicity and he commenced Kivexa and etravavirine.

In severe cases such as Tony's, efavirenz has to be discontinued. [7]

The community CNS team stayed in close contact with Tony during this period, providing as much support as we could; however, this proved

Case study: Tony *continued*

challenging at times as he would only accept telephone communication yet regularly failed to answer the phone or respond to messages.

A week later Tony reported to be feeling 'back to normal'. Having discontinued efavirenz, he felt overall better but did remain anxious and stressed and was therefore referred for psychological support. It was at this point thought that there had, after all, been a causal link between his commencing ART and his psychiatric morbidity, because of his dramatic improvement since switching.

However, less than a month later Tony was arrested by the police because it was alleged he had physically attacked his sister and threatened to damage the family property. He was again admitted voluntarily to the mental health unit but later sectioned after attempting to hang himself. He

was diagnosed with severe depression and an adjustment disorder. He was commenced on the anti-depressant mirtazapine by the treating psychiatrist and remained an inpatient for 3 weeks.

A positive outcome

Recently Tony's mood has improved considerably although he reports taking his anti-depressants intermittently. Reassuringly he has no ongoing thoughts of self-harm. He is not receiving any formal follow-up from the mental health team because he was discharged from their service. Therefore, we have asked for a formal assessment and re-evaluation of this.

Tony tolerates and adheres to his treatment well with a current CD4 cell count of 627 cells/mm³ and an undetectable viral load. He has a new job and is moving in with some friends.

Reflection

This case study demonstrates how severe antiretroviral-induced psychiatric side effects can be, and the detrimental impact they can have on an individual's life.

It can be argued that, in this particular case, the patient's psychiatric symptoms predated the introduction of ART and thus did not arise specifically from it; however, the evidence strongly suggests that the initiation of efavirenz precipitated his psychotic behaviour and the exacerbation of his condition.

Side effects have been described in patients without psychiatric antecedents, but those with a previous psychiatric history are more vulnerable and should be monitored very closely [7].

It is difficult to predict or indeed avoid such adverse effects if comprehensive health records are not available centrally and/or a patient does not divulge information on request about their past mental health history prior to commencing ART. However, effective monitoring and patient education on potential side effects allows us to pinpoint detrimental effects before they become unmanageable – and when necessary, switch treatment promptly.

The regrettable events that Tony suffered will have a lasting impact on my future practice. As a team we have now developed a more detailed mental health assessment to be carried out on all patients, not just when initially referred but also as a means of regular reassessment within their care plan. A copy of this will be shared, if the patient consents, with the clinic doctor, nurses, GP and any other members of the multidisciplinary team involved.

We have also found that improving communication and links with our local community mental health teams provides valuable support and expertise to us in managing the mental health issues that we experience regularly within our cohort of patients.

References

1. Deeks D, Perry CM. Efavirenz/emtricitabine/tenofovir disoproxil fumarate single-tablet regimen (Atripla®): a review of its use in the management of HIV infection. *Drugs*, 2010, **70**, 2315–2388.
2. De Santis M. Periconceptional exposure to efavirenz and neural tube defects. *Archives of International Medicine*, 2002, **162**, 355.
3. Summary of product characteristics, efavirenz 200 mg, revised June 2011 (section 4.4, p. 3), available at: www.cpps.who.int/prequal/whopar/whoparproducts/HA438Part4v1.pdf (accessed February 2012).
4. Aberg J. Efavirenz (EFV) well tolerated: IAS Report. Re: International Aids Conference, July 2003, Paris [Abstr. 53 and 54]. Reported for NATAP by Judith Aberg, MD, Washington University, St Louis, Missouri and the ACTG, Available at: www.natap.org/2003/IAS/day15.htm (accessed February 2012).
5. Puzantian T. Central nervous system adverse effects with efavirenz: case report and review. *Pharmacotherapy*, 2002, **22**, 930–933.
6. British HIV Association (BHIVA). Guidelines for the treatment of HIV-1-infected adults with antiretroviral therapy 2008. *HIV Med*, 2008, **9**, 563–608. Available at: www.bhiva.org/TreatmentofHIV1_2008.aspx (accessed February 2012).
7. Peyriere H, Mauboussin J-M, Rouanet I *et al*. Management of sudden psychiatric disorders related to efavirenz, *AIDS*, 2001, **15**, 1323–1328.

Correspondence: Nicola Galbraith
West London Centre for Sexual Health
Charing Cross Hospital
Fulham Palace Road, London W6 8RF, UK
nicola.galbraith@chelwest.nhs.uk

Standards for psychological support for adults living with HIV: a review

Part 1: background, rationale and approach (levels of care)

Dennis Dobbin

Team Manager and Clinical Nurse Lead, HIV and Mental Health Service (CASCAID), (Maudsley Hospital), South London and Maudsley NHS Foundation Trust, London, UK

Introduction

This is the first of two papers reviewing the Standards for psychological support for adults living with HIV, published in November 2011 [1]. It looks at the rationale for setting these standards, the first of their kind for people living with HIV (PLHIV). Discussion follows on the psychological difficulties associated with HIV, the psychological interventions used, and the skills and knowledge required to deliver them. The paper concludes with a guide to the Step care model, which provides a framework to the standards.

Background

Thirty years into the HIV pandemic, there were still no standards to provide a reference point for the psychological care and support of PLHIV. Organisations such as the British HIV Association (BHIVA) and the National HIV Nurses Association (NHVNA) had published guidelines on treatment and competencies on delivery of care, in 2008 and 2007 respectively [2,3], while various guidance and briefing papers had been issued by the National Institute for Health and Clinical Excellence (NICE) [4].

However, an increasing population presenting with psychological need in the HIV field, and pressure on budgets made it evident that definitive standards were needed to provide a treatment framework and guide commissioning policy. The multidisciplinary expert seminar convened in 2010 by the National AIDS Trust, which I attended, demonstrated a strong consensus that standards for HIV psychological support were required to improve the quality and consistency of care across the country.

Development

My initial response was to establish a small working party of psychiatrists and nurses working in HIV mental health teams, and I invited a psychologist working on my team. Following our first meeting, he informed the group that he was instrumental in establishing a similar working party within the Faculty for Sexual Health and HIV at the British Psychological Society (BPS). The team agreed that it would be beneficial to join forces and several

workshops and meetings followed over a period of 5 months, as the standards were developed. In this document, psychological support is defined as 'any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing' [1].

For a moment, consider how difficult it can be to get a nurse and doctor to agree; how difficult it is to get two nurses and doctors to agree. Then consider a room with psychiatrists, psychiatric nurses, psychologists, service users and representatives from the voluntary sector. There would be long discussions over, for instance, the definition or placing of single words. It was at times difficult but this working group had the professionalism to ensure that every word, every sentence was correct: once it had gone to print, there would be no turning back – but more importantly it mattered for the patients. The over-arching aim of this process was to establish standards for PLHIV that were recognised across our profession and fit for purpose.

Applicability

The standards represent current best practice and are intended to apply to all services providing psychological support for adults living with HIV. These services may be provided by the statutory, voluntary or independent sectors and are mostly funded by the NHS or local authorities, although the standards are equally relevant for services funded by charities or by service users themselves [1].

The standards are intended to apply to all parts of the UK. While the systems and structures for planning and funding services differ between England, Scotland, Wales and Northern Ireland, all PLHIV are entitled to expect the same standards of care. It is recognised that some services providing psychological support in the UK are currently not meeting these standards, and thus mental and physical health outcomes for PLHIV are below requirement. It is intended that the standards should act as a catalyst for improvement where needed [1].

Rationale

The number of PLHIV in the UK continues to rise, with an estimated 86,500 infected at the end of

2009 [5]. MSM and black African heterosexuals are the groups with the highest prevalence. The proportion aged 50 or over is rising [5] while young people account for one in ten new diagnoses [6]. Late diagnosis is a major problem, with one in four new infections being diagnosed late [5].

However, alongside dramatically improved treatment options, depression remains prevalent and is the most common psychiatric disorder for which HIV-positive individuals seek treatment [7]. The incidence of psychological and psychiatric problems among PLHIV is substantially higher than in the general population [8–10]. HIV infection tends to be concentrated in vulnerable and stigmatised populations who are already at greater risk of mental health problems than the general population [11], and HIV exacerbates this health inequality. Psychological difficulties can also result from receiving an HIV diagnosis and the challenges of living with HIV [12,13].

Whatever their causes, psychological problems in PLHIV complicate care and clinical management through decreased adherence to antiretroviral therapy (ART), loss to follow-up, reduced quality of life and poorer health outcomes including clinical decline and mortality [14–16]. HIV is now considered a long-term health condition in the UK, characterised by periods of good health punctuated with bouts of illness. However, despite improved life expectancy and physical health, HIV continues to be a difficult and stressful condition for many. Recent research identified a complex array of concerns about quality of daily life and other personal, social and medical issues, with widespread reports of discrimination and social isolation. Such experiences, along with other psychosocial factors, have a negative impact on health outcomes [17], leading to longer and more frequent hospital admissions and other costly interventions. It is estimated that the prevention of one new HIV infection saves the public purse between £280,000 and £360,000 in direct lifetime healthcare costs [5]. Cognitive impairment is also more common amongst PLHIV than in the general population [18] and is an independent risk factor for earlier death [19]. It can contribute to reduced adherence to medication [20], poorer functioning in daily life, and loss of employment [21].

It is important to highlight that risky sexual behaviour is often associated with depression and substance misuse [22]. When combined with low adherence to ART, which raises viral load, the risks of onward transmission are substantially increased by such behaviours. Therefore, psychological interventions which address self-efficacy and behavioural skills training are key in improving adherence as well as enabling changes to HIV transmission risk behaviour [23]. It is apparent that good psychological support can strengthen the safer sex message, reduce transmission rates and improve psychological wellbeing. In these times of

usterity and challenging healthcare budgets, the associated cost saving is also significant.

Psychological interventions

Over the last 15 years, increasing attention has been given to the psychological welfare and management of people living with long-term health conditions. There is evidence that a range of psychological interventions can make a considerable difference to the long-term health and wellbeing of someone living with HIV, including how well they manage their condition and adhere to treatment [24].

Cognitive behaviour and stress management interventions in particular, whether delivered through individualised or group methods, have been shown to enhance coping among PLHIV [25]. Interventions directly targeting anxiety have also been effective, especially psychological interventions [26]. A range of approaches, in particular those incorporating a cognitive behavioural component, have reduced depression [24]; while cognitive rehabilitation can improve adherence and day-to-day functioning in those with HIV-related cognitive impairment [27–28].

Although improving mental health and psychological wellbeing is a valuable outcome in itself, interventions which achieve such improvements in PLHIV also play an important role in improving physical health and reducing onward transmission risk. Critically, this means that investment in psychological support for PLHIV is a way of preventing avoidable ill-health, and avoidable costs, through appropriate early intervention. Thus, despite competing claims on tight budgets, the provision of timely and appropriate psychological support for PLHIV supports the objectives of the NHS Quality, Innovation, Productivity and Prevention (QIPP) programme [29].

Psychological and cognitive difficulties are often underestimated by healthcare practitioners. As a result, it is possible that many PLHIV are not offered access to the services they need [30–33]. If needs are underestimated or the health and economic benefits of psychological support are not recognised, there is a risk that commissioners may fail to invest in services providing psychological support, with a resulting negative impact on health outcomes and associated costs.

The standards therefore provide evidence-based recommendations to guide commissioning and service provision, using a stepped care model with relevance for all practitioners. This approach aims to ensure that appropriate psychological support is available to meet the diverse needs of PLHIV.

Table 1: Components of the four levels in the Step care model.

Level	Assessment	Interventions
1: Information and support	Understanding psychological needs Understanding of risk of harm to self and others Recognising overt psychological distress	Provision of relevant information in accessible formats Supported self-help Signposting and referring to appropriate providers Response to overt distress Supportive communication and general psychological support Signposting self-management strategies, e.g. books and computerised resources, newly diagnosed courses Peer support
2: Enhanced support	Screening for cognitive difficulties Assessing risk of harm to self and others	Discussions aimed at acceptance and adaptation to living with HIV Signposting and referral to more appropriate services and peer support Education sessions around the nature of psychological and psychiatric problems and how to cope with them Brief interventions aimed at behavioural change, e.g. sexual risk behaviour and substance misuse
3: Counselling and psychological therapies (HIV specialist)	Assessing and formulating of psychological problems Identifying of psychiatric problems Screening for cognitive impairment Assessing risk of harm to self and others	Counselling and psychological interventions based on explicit theoretical frameworks for specific psychological difficulties such as: <ul style="list-style-type: none"> ▪ moderate or severe anxiety ▪ substance misuse ▪ moderate or severe depression ▪ psychosexual or relationship problems ▪ sexual trauma / PTSD Interventions for cognitive impairment Psychological interventions based on explicit theoretical frameworks to develop and enhance positive psychological processes such as adaptive coping strategies which increase resilience
4: Specialist psychological intervention; and mental health intervention (general or other specialist)	Psychiatric diagnosis Neuropsychological assessment Assessment and formulation of complex psychological problems Assessment for cognitive impairment Assessment of risk of harm to self and others	Specialist psychological and psychiatric interventions for severe, and complex psychological problems, cognitive impairment, PTSD or co-morbid psychiatric problems such as: <ul style="list-style-type: none"> ▪ psychosis ▪ severe depression ▪ mania ▪ eating disorders ▪ personality disorder ▪ cognitive impairment ▪ specific situations, e.g. complex adolescent and family issues Cognitive rehabilitation

The need for specialist HIV knowledge

Frameworks developed for psychological support for the general population, or for those with other long-term conditions, do have content that is relevant for PLHIV. However, certain aspects of HIV and its care also mean that different assessment and intervention methods may be appropriate. Given these unique aspects of living with HIV, additional competencies are also needed by practitioners at all levels [1]. Services providing psychological support for PLHIV need to recognise the impact of the stigma associated with HIV and understand the experience of the UK population groups most affected by HIV, i.e. MSM and black Africans. People from black and minority ethnic (BME) communities are less likely to be offered or to take up, and more likely to drop out of, talking

therapies [34–37]. Talking therapies can be defined as counselling or psychological therapy. There is reason for concern about the ability of mainstream psychology, counselling and psychotherapy providers to meet the needs of lesbian, gay, bisexual and transgender (LGBT) communities [38].

It is important that services are able to provide appropriate, culturally sensitive and effective support in relation to sexual behaviour and reducing the risk of transmission. Practitioners without specific expertise in this area are often not comfortable or experienced in discussing issues of sex and sexuality, including the specifics of sexual practices or issues of disclosure with sexual partners. It is also important to introduce behavioural interventions to reduce transmission risk. Practitioners need an understanding of the physical impact of HIV infection and HIV therapy, how this may affect psychological and cognitive

functioning, and the implications of this for the use of assessment and intervention methods. It is also important to have a working knowledge of specific psychological side effects of HIV treatment.

The care pathway

The Step care model (see Figure 1) was used in the Standards to address issues specific to the care of this patient group:

- the skills and materials required for neuropsychological assessment in HIV are usually only available in HIV specialist centres;
- physical care and psychological support should, as far as possible, be combined into a single care package;
- all levels of provision need to be within the same care pathway.

People with HIV are often treated for HIV outside their own catchment area, especially in the bigger centres. It is difficult for HIV treatment services to liaise effectively with mental health services in a different area, sometimes at significant distance, let alone develop effective pathways. Having HIV-specialist provision more easily available may allow faster and smoother access to psychological support than referral to general psychological support services. Faster access reduces negative outcomes, such as non-adherence to ART, clinical complications and hospital admissions, and their associated costs [1].

The four steps

A PLHIV may progress through the four steps in order, or enter the system via any one of them; equally, they may only require interventions provided by Step 1. As indicated, self-help and informal support has a place at all levels, while greater complexity of treatment and lower patient numbers apply as one moves up the levels. Table 1 lists the components of each step in detail.

Step 1: The type of intervention associated with Step 1 is the least specialised, and for some patients no more is needed. When first diagnosed, if a person has a supportive partner, family and friends, all they may require is signposting to clinics and appropriate agencies.

Step 2: If, following diagnosis, the individual finds that their life is not going according to plan, then the interventions indicated in Step 2 would be more appropriate. This is enhanced support – for example, discussions around adjusting to the diagnosis and possible referral to peer support groups.

Step 3: This level involves specialist interventions that go beyond enhanced support, where the patient needs support for more pronounced difficulties.

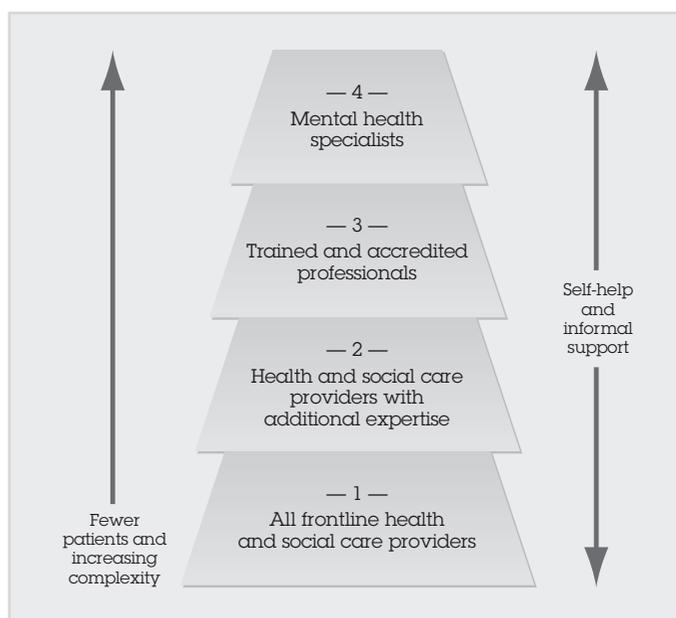


Figure 1: Step care model: different levels of psychological support for PLHIV.

Step 4: In this context, for example, the PLHIV may have been diagnosed while on an acute mental health ward; or a manic presentation requiring a hospital admission may indicate an underlying HIV cognitive impairment. Here, the involvement of highly specialised professionals is needed to deliver the appropriate care and treatment [39].

Conclusion

This standards document should be a key resource for service providers, commissioners, health boards and other local service planners; as well as enabling PLHIV to define minimum service expectations. It is designed to facilitate equitable access to psychological support of consistent and high quality, regardless of location or provider. In the context of decision-making about the availability and configuration of local services, psychological support services for this group should be planned and adequately resourced in accordance with these standards [1].

This paper (Part 1) has included discussion of the background and rationale for the standards, and of HIV-associated psychological problems/best interventions. We have looked at skills and knowledge of benefit to the practitioner and at the step care model that works effectively with the standards. Part 2 will review the standards with particular reference to nursing care.

Acknowledgements

Grateful thanks are due to the following individuals: Elizabeth Shaw, Consultant Clinical Psychologist and Standards Working Party Chair; Stuart Gibson, Chair of the Faculty for Sexual Health and HIV, Division of Clinical Psychology, British Psychological Society; Ruth Lowbury, Chief Executive Medical Foundation for AIDS & Sexual Health (MedFASH).

References

- British Psychological Society (BPS), British HIV Association (BHIVA) and Medical Foundation for AIDS & Sexual Health (MedFASH) [joint publication]. Standards for psychological support for adults living with HIV (2011). Available at: www.bhiva.org/StandardsForPsychologicalSupport.aspx (accessed February 2012).
- British HIV Association (BHIVA). Treatment of HIV-1-infected adults with antiretroviral therapy (2008) (Addendum 2009). Available at: www.bhiva.org/PublishedandApproved.aspx (accessed February 2012).
- National HIV Nurses Association (NHVNA). National HIV Nursing Competencies (2007). Available at: www.nhivna.org/Introductiontocompetencies.aspx (accessed February 2012).
- More information on NICE Pathways, Guidance, Seminars and Briefings at: www.nice.org.uk (accessed February 2012).
- Health Protection Agency (HPA – 2010a) HIV in the United Kingdom: 2010 Report. Health Protection Agency, London, 2011.
- HPA (2010b) Young Adults: United Kingdom New HIV Diagnoses to end of December 2010. Health Protection Agency, London, 2011.
- World Health Organization (WHO). HIV/AIDS and Mental Health. WHO, Geneva, 2008. Available at: http://apps.who.int/gb/ebwha/pdf_files/EB124/B124_6-en.pdf (accessed February 2012).
- Bing EG, Burnham AM, Longshore D *et al.* Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Archives of General Psychiatry*, 2001, **58**, 721–728.
- Petrak J, Miller D. Psychological management in HIV infection. In: *The Psychology of Sexual Health* (Miller D, Green J, eds). Blackwell Science, Oxford, 2002.
- Harding R, Liu L, Catalan J *et al.* What is the evidence of interventions to enhance coping among people living with HIV disease? A systematic review. *Psychology, Health & Medicine*, 2011, **16**, 564–587.
- Ciesla JA, Roberts JE. Meta-analysis of the relationship between HIV infection and the risk for depressive disorders. *American Journal of Psychiatry*, 2002, **158**, 725–730.
- Power R, Tate H, McGill S *et al.* A qualitative study of the psychosocial implications of lipodystrophy syndrome on HIV positive individuals. *Sexually Transmitted Infections*, 2003, **79**, 137–141.
- Fumaz CR, Muñoz-Moreno JA, Moltó J *et al.* Long-term neuropsychiatric disorders on efavirenz-based approaches: quality of life, psychological issues, and adherence. *Journal of Acquired Immune Deficiency Syndromes*, 2005, **38**, 560–565.
- Smart T. Mental health and HIV: a clinical review. HIV & AIDS Treatment in Practice, 2009, 145. NAM, London, 2009. Available at: www.aidsmap.com/Mental-health-and-HIV-a-clinical-review/page/1330115 (accessed February 2012).
- Leserman J. Role of depression, stress and trauma in HIV disease progression. *Psychosomatic Medicine*, 2008, **70**, 539–545.
- Gonzalez JS, Batchelder AW, Psaros C, Saffren SA. Depression and HIV treatment nonadherence. *Journal of Acquired Immune Deficiency Syndromes*, 2011, **58**, 181–187.
- Bravo P, Edwards A, Rollnick S *et al.* Tough decisions faced by people living with HIV: a literature review of psychosocial problems. *AIDS Review*, 2010, **12**, 76–88.
- Heaton RK, Franklin DR, Ellis RJ *et al.* HIV-associated neurocognitive disorders before and during the era of combination antiretroviral therapy: differences in rates, nature, and predictors. *Journal For Neurovirology*, **17**, 2011, 3–16.
- Vivithanaporn P, Heo G, Gamble J *et al.* Neurologic disease burden in treated HIV/AIDS predicts survival: a population-based study. *Neurology*, 2010, **75**, 1150–1158.
- Hinkin CH, Castellon SA, Durvasula RS *et al.* Medication adherence among HIV-positive adults: effects of cognitive dysfunction and regimen complexity. *Neurology*, 2002, **59**, 1944–1950.
- Heaton RK, Marcotte TD, Mindt MR *et al.* The impact of HIV-associated neuropsychological impairment on everyday functioning. *Journal of the International Neuropsychological Society*, 2004, **10**, 317–331.
- Harding R, Lampe FC, Norwood S *et al.* Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse. *Sexually Transmitted Infections*, 2010, **86**, 520–524.
- Kalichman SC. Co-occurrence of treatment nonadherence and continued HIV transmission risk behaviours: implications for positive prevention interventions. *Psychosomatic Medicine*, 2008, **70**, 593–597.
- Sherr L, Clucas C, Harding R *et al.* HIV and depression – a systematic review of interventions. *Psychology, Health & Medicine*, 2011, **16**, 493–527.
- Harding R, Liu L, Catalan J, Sherr L. What is the evidence for effectiveness of interventions to enhance coping among people living with HIV disease? A systematic review. *Psychology Health & Medicine*, 2011, **16**, 564–587.
- Clucas C, Sibley E, Harding R *et al.* A systematic review of interventions for anxiety in people with HIV. *Psychology Health & Medicine*, 2011, **16**, 528–547.
- Ranka JL, Chapparo CJ. Assessment of productivity performance in men with HIV-associated neurocognitive disorder (HAND). *Work*, 2010, **36**, 193–206.
- Stephenson J, Woods S, Scott B *et al.* HIV-related brain impairment: from palliative care to rehabilitation. *International Journal of Palliative Nursing*, 2000, **6**, 6–11.
- See: www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index.htm (accessed February 2012).
- Muñoz-Moreno JA, Prats A, Nieto-Verdugo I *et al.* Distinct detection of HIV-associated neurocognitive dysfunction according to clinician and patient perception: findings from the NEU study. *6th IAS Conference on HIV Pathogenesis, Treatment and Prevention*, July 2011, Rome, Abstr. TUPE205.
- Rao R. 'Sadly confused'. The detection of depression and dementia in medical wards. *Psychiatrist*, 2001, **25**, 177–179.
- Bushnell J. Frequency of consultation and general practitioners' recognition of psychological symptoms. *British Journal of General Practice*, 2004, **54**, 636–642.
- Parry G, Richardson A. NHS psychotherapy services in England: review of strategic policy, Department of Health, London, 1996.
- Cole E, Leavey G, King M *et al.* Pathways to care for patients with a first episode of psychosis: a comparison of ethnic groups. *British Journal of Psychiatry*, 1995, **16**, 770–776.
- Rathod S, Kingdon D, Smith P *et al.* Insight into schizophrenia: the effects of cognitive behavioural therapy on the components of insight and association with sociodemographics – data on a previously published randomized controlled trial. *Schizophrenia Research*, 2005, **74**, 211–219.
- Rathod S, Kingdon D, Phiri P *et al.* Developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority patients by exploration and incorporation of service users' and health professionals' views and opinions. *Behavioural and Cognitive Psychotherapy*, 2010, **38**, 511–533.
- Neale J, Worrell M, Randhawa G. Reaching out: Support for ethnic minorities. *Mental Health Practitioner*, 2005, **9**, 12–16.
- Bartlett A, Smith G, King M. The response of mental health professionals to clients seeking help to change or redirect same-sex sexual orientation. *BMC Psychiatry*, 2009, **9**, 11.
- Ungvarski PJ, Trzcianowska H. Neurocognitive disorders seen in HIV disease. *Issues in Mental Health Nursing*, 2000, **21**, 51–70.

Correspondence: Dennis Dobbin

CASCAID (Maudsley Hospital)

5 Windsor Walk, Camberwell, London SE5 8BB, UK

dennis.dobbin@slam.nhs.uk

Who's afraid of the Big Bad Wolf? Mental health for general HIV nurses

Shaun Watson

Clinical Nurse Specialist (HIV Community), Hammersmith and Fulham Primary Care Trust, London, UK

Background

Mental health and HIV are natural partners. Since the start of the epidemic in the 1980s, HIV and mental health services have worked side by side but today many mental health services have been drastically cut, are threatened with closure or have closed down permanently. However, mental health remains a huge issue, perhaps now more than ever, as people are living longer with HIV yet the discrimination and stigma continues; meanwhile, new health threats such as neurocognitive disorders and cancer are increasing, which may lead to more psychological problems.

'What do you need?', a survey report from social research group Sigma Research, found that 72% of people living with HIV surveyed had had problems managing depression or anxiety in the previous year, and a third of those had not received any help to address these problems. A similar proportion of people living with HIV reported troubles with self-confidence and self-esteem – and an even higher number had not received any help for these issues. The same research highlighted that anxiety and depression, self-esteem, sleep and sex are the areas of life that pose problems to the greatest number of people living with HIV in the UK [1].

For some, their mental health problems predate their HIV diagnosis, with issues such as personality and bipolar disorders and depression. In some cases, it is these mental health problems that have led them to become HIV positive, especially if accompanied by drug or alcohol addiction. For others, mental health issues have resulted from their HIV diagnosis, or from antiretroviral therapy or other medication. People living with HIV can lead healthy lives; however, many have some degree of psychological or emotional troubles. Think about the people you care for ... how many of them at times have shown emotional distress or depression? How many have ongoing mental health issues that may be obvious or hidden? For any general nurse in HIV, working with patients with mental health issues is a daily occurrence – yet do we even think about it? Do we feel skilled and able to manage? Or is it now a fact of HIV care that, unless there is an acute mental health episode or a patient is so depressed they become suicidal, we rarely think about how we will react and manage the situation?

Where to start?

Barker [2] claims that mental illness and mental health are 'two expressions fundamental to psychiatric and mental health nursing – [but they] possess no clear, accepted definition', and he suggests that nursing should be geared to focusing on human responses to some very special human problems. We all go in for stereotyping, and being told that a patient is low in mood, depressed, suicidal or has schizophrenia, bipolar or personality disorder can bring up a lot of thoughts, emotions and anxieties before we even meet them. Obtaining as good a history as possible and researching the issues is an important start. There is a wealth of information out there. Clinic letters from psychology or psychiatry services, or speaking to those involved in caring for the patient's mental health, can help you put the illness into some perspective. Is this what we, as general nurses, would call holistic nursing? – that is, treating the patient as an individual with unique problems. It has been stated that general nurses ignore mental health factors in patient care and that psychiatric nurses neglect physical aspects of health [3]. It has also been observed that general nurses often feel unsure what to do when faced with patients with psychological problems and often withdraw from interaction with them. What can we do to reverse this tendency?

The issues and where they began

HIV is complex and can impose a significant psychological burden. In a meeting of South African Mental Health Services in 2007 Professor Melvyn Freeman stated, 'a number of studies from across the globe suggest that mental health issues are on the rise in people who have HIV and AIDS', adding that twice as many people with HIV have mental health issues than people without the disease. Freeman also commented, 'When you look at the higher rates among HIV-infected people, you have to ask the question: is this because they had a prior condition and their vulnerability led to their infection or is it that, because they have contracted HIV, it has mental impact on them, and, therefore, this raises the numbers of people living with HIV who have mental disorders. This is a complex issue and I would like to suggest that both are true: that it's very likely that mental disorder is both a risk factor and a consequence of HIV'.

As patients adjust to the impact of their HIV diagnosis, they can suffer from depression and anxiety as they face the difficulties of living with a chronic life-threatening illness, such as a perceived shortened life expectancy, potentially complicated drug regimens, stigma, and the potential loss of social support, family or friends. A third of HIV-positive gay men have post-traumatic stress disorder: events including starting treatment, HIV-related illness, and witnessing an HIV-related death were all linked to the development of symptoms associated with post-traumatic stress disorder. Emotional responses to such events – rather than actual physical threat – were associated with the development of symptoms of post-traumatic stress [4].

HIV infection can also have direct effects on the central nervous system and cause neuropsychiatric complications including HIV encephalopathy, depression, mania, cognitive disorder and dementia. Throw in drug and/or alcohol use and the problems become heightened. However, at times patients find themselves being batted between services. Perhaps because healthcare staff are not always sufficiently trained, or able to see the big picture, HIV services may place the onus onto mental health, whereas mental health think that HIV services are at the forefront of care – while the patient is stuck in the middle and may feel unsupported by all involved.

The significance of psychological support has finally been highlighted with the publication of the Standards for psychological support for adults living with HIV (2011) [5] which, instead of focusing upon the physical manifestations of HIV and mental health, now gives a clear framework and guidance for supporting people living with HIV with their psychological and mental health issues.

What can you do?

What are our concerns about HIV and mental health? What are we afraid of? Could it be the fear of the unknown, of dealing with people who have the potential to be unpredictable, aggressive or emotionally labile? Or is it that fear of not knowing what to say? As general nurses, we should be good listeners but sometimes this may not be enough. General nurses are mostly terribly practical people, offering a pill to take away the pain, a dressing for a wound or a comforting hand – but how do we mend a broken mind or help those who are so depressed they want to end their lives? Our fear may lie in not knowing what the next course of action is, whether the patient will be safe, or what therapy they can access to enable them to lead healthier, emotionally stable lives.

Conclusion

The following pointers can be used to help:

Be prepared and know your limits. As much as

possible, avoid situations that make you wary or anxious, as this may be obvious to the patient. On occasions where this cannot be avoided, try to be as prepared as you possibly can. If there is any doubt, see the patient with a nursing colleague present or arrange a joint visit with a mental health professional. Bouncing ideas off others and checking whether you were reading the situation right is important. One person's 'manic' is another person's 'excited', so being able to discuss your thoughts and share experiences is vital. If you are seeing a patient at home, find out who else will be there, and whether or not they are aware of the diagnosis and history – we have all had stilted, covert conversations when we avoid naming the condition and talk with raised eyebrows and knowing nods, and such situations are best avoided.

Treat everyone as a person first. Common sense?

Yes! Approach adults with mental health issues in the same way you would relate to anyone – holistically with respect, with appropriate boundaries, and with an understanding of that person's life. Assess the patient as thoroughly as possible and be as inquisitive as possible without causing anxiety to the patient. If they are happy for you to talk to their partners, family or friends, then utilise this resource, as they may be able to give you the bigger picture. Think about how you phrase questions – the 'mental illness' tag is a hard one to bear. Asking if a patient has had a mental health issue in the past may not elicit an honest response. However, getting to the bottom of someone's emotional state is vital – how many people have had adverse reactions to medications because they failed to disclose a past history of depression or mental illness?

Don't jump to conclusions. It may be easy to put every incident down to mental illness but there may be other causes, including obvious ones like excessive drug or alcohol use, or a new recreational drug. Equally, other causes that can cause signs and symptoms of confusion, slurring, or hallucinations could include blood toxicities, side effects of new medications or overdosing with medication, for example, double-dosing with Fentanyl patches or confusion over Oramorph doses. Explore obvious possibilities first and, if there is no clear cause, consider other options.

Be open, honest and non-judgmental. Adults with mental illness have long been the victims of severe social stigmas, based on the assumption that they had a moral deficiency [6]. It should therefore be a given for any nurse to work in a way that is open, honest and non-judgmental. However, we all have stereotypes and fears that may impinge on how we work with patients.

Although it may be hard to shake our preconceptions, for us to be effective we must try to put these aside. While some patients will amaze you, some will strengthen what you felt before – so acknowledge this. Being honest may also mean admitting that you are unsure what to do next and need to seek expert advice; or that you are anxious or worried about a patient, and sometimes this is all that needs to be said.

Take HIV out of it. For some patients their mental health issues were around long before the HIV diagnosis, so getting to know their history and what has worked and not worked before is important. Take advice from professionals, even though it may go against what you have been taught as a general nurse and may be hard to work with. For example, some people with personality disorders may respond better to very clear-cut boundaries, such as setting tight timings for meetings, not answering the phone out of hours or offering only objective, practical advice. However, for others, antiretroviral therapy or HIV itself may be the root cause of the mental health issues and may feature large in the patient's life – so have an awareness of how HIV fits into the whole picture.

Seek help and education. Get to know your local mental health service and what they offer. Do they have a crisis resolution team and how do you access the emergency psychiatric unit? What are their referral criteria and how do you refer to them? There may be a clinical nurse specialist or a psychiatric nurse with an interest in HIV. Look to see if there are sessions offering an introduction to mental health, or a module at the local college/university. Or you could offer some reciprocal training with local mental health staff, such as HIV awareness or HIV update sessions. In the late 1980s and 1990s, HIV training was part of statutory training within many NHS trusts but now it may only be of interest if a unit has had an issue with a patient, so be on hand to offer support and they may do the same for you.

Network and collaborate as much as you can. Most trusts will have statutory training on the management of aggression or conflict resolution which may give you the tools you need.

Know the law. The Mental Health Act can be scary so get to know what the main points are, what are 'sections' and what do they mean? Even a basic knowledge will better equip you to know when a patient may require more structured help.

And finally ... Yes, on some occasions you may feel that you have failed a patient or situation, or be concerned that you have put yourself at risk. However, try to use this experience and learn from it. Formulate strategies and use the support of colleagues, clinical supervision and your appraisal to move forward.

References

1. Weatherburn P, Keogh P, Reid D *et al.* *What do you need? 2007–2008: findings from a national survey of people diagnosed with HIV.* Sigma Research, London, 2009. Available at: www.sigmaresearch.org.uk/go.php/reports/report2009b (accessed February 2012).
2. Barker P. *Psychiatric and Mental Health Nursing.* Arnold, London, 2003.
3. Castledine G. General nurses must ensure they have mental health skills. *British Journal of Nursing*, 2004, **13**, 683.
4. Theuninck AC, Lake N, Gibson S *et al.* HIV-related posttraumatic stress disorder: investigating the traumatic events. *AIDS Patient Care and STDs*, 2010, **24**, 485–491.
5. British Psychological Society/British HIV Association/Medical Foundation for AIDS and Sexual Health. *Standards for psychological support for adults living with HIV.* Published November 2011, available at: www.medfash.org.uk/publications/documents/standards_for_psychological_support_for_adults_living_with_HIV.pdf (accessed February 2012).
6. Lin AMR. Mental health overview. In Edwards R ed.) *Encyclopedia of Social Work.* National Association of Social Workers, Washington DC, 1995.

Correspondence: Shaun Watson
Clinical Nurse Specialist, 4th floor
56 Dean Street
London W1D 6AQ, UK
shaun.watson@chelwest.nhs.uk

Health workers living with HIV in Kenya: challenging stigma through support groups based in health facilities

Catherine O'Keeffe

Senior Lecturer in Clinical Education, Institute of Education, University of London, UK

Introduction

Stigma and discrimination are thought to be significant factors preventing health workers living with HIV from openly accessing treatment and care [1]. Even though they are often subject to the same kind of gender and cultural norms that predispose community members more generally to infection, health workers are broadly seen as role models with knowledge and resources to protect themselves from HIV infection – a view that partly derives from their own understanding of 'professionalism'.

There is evidence from Kenya to suggest that stigma and discrimination within the health system, as well as from communities, often prevents health workers living with HIV from accessing treatment and care. To address this problem, support groups have been established within Ministry of Health facilities [2].

This article describes the findings of a study that aimed to explore relationships between models of professionalism and social capital associated with support groups for health workers, where social capital can be defined as: '... active connections among people (including the trust, mutual understanding, and shared values and behaviours) that bind members of human networks and communities and that also empower them to make cooperative action and participation possible' [3]. The study was guided by the central research question: what role, if any, can support groups for health workers living with HIV play in the professional development of their members? The article presents a literature review; a summary of study methods used; then highlights the study's main findings and suggest further developments in policy, practice and research.

Literature review

What is known about health workers living with HIV?

Several small-scale qualitative studies in sub-Saharan Africa have reviewed the care of health workers living with HIV. In South Africa, for example, a qualitative study found that nurse managers considered key aspects of their role to be: ensuring physical care for nurses with HIV, so that

they can continue to work effectively [4], and also providing them with psychosocial support [5].

An ethnographic case study of six HIV-positive nurses working in a rural clinic in Uganda [6] found that they were unable to access treatment in their place of work due to stigma. However, they could access treatment at facilities run by non-governmental organisations. A particularly worrying finding was that nurses might self-prescribe antiretroviral therapy. Nurses in this study felt overlooked by workplace programmes, and as a result set up their own informal 'secretive' support group, a response observed previously in Uganda [7].

In Zambia a mixed-methods study was conducted in 2007 to explore the impact of the HIV epidemic from the perspectives of health workers and managers in two districts [8]. Participants were reluctant to discuss their own HIV status, or that of colleagues, due to fear of being stigmatised. Whilst managers demonstrated a wish to help health workers deal with HIV, their ability to do this varied according to individual skills and expertise because no workplace policies were in place.

Another mixed-methods study in Zambia in 2009 [9] concluded that comprehensive programmes were urgently needed to care for health workers, including: options to access care from a trusted provider within the workplace and a central comprehensive healthcare clinic for staff, providing both antiretroviral therapy and general care. All the above studies commented that well-developed workplace policies needed to be in place if care initiatives for health workers were to be successful.

Stigma and health professionals

Stigma related to HIV within health systems is acknowledged to be a common problem internationally [10–12]. High levels of stigma and discrimination within the Kenyan health system were reported in recent surveys of health facilities [13,14]. The Kenya National Health Workers Survey noted that health workers expressed considerable interest in self-testing for HIV [15]. It was subsequently observed [16] that this suggested high levels of stigma and discrimination within the Kenyan health system.

Policy

The WHO commissioned a survey of policy practices in 17 countries, six of which were within Africa [17]. The study found that policies tended to be spread through a variety of documents and were often inconsistent. Gaps existed in relation to HIV and TB workplace policies in many countries. Some policies were difficult to apply in practice or were not widely disseminated so that health workers were not informed of their rights and entitlements. Programmes and guidelines to implement policies to improve health worker access to services were found to be inadequate. The survey's recommendations [18] included:

- ensuring priority access to HIV and TB services for health workers and their families (through review of existing national policies and/or development of new ones);
- including strategies for reducing stigma and discrimination;
- addressing gender issues;
- promoting meaningful involvement of people living with HIV.

The available literature suggests that little is known about the experiences of health workers living with HIV in sub-Saharan African, or how to help them access treatment and care. HIV-related stigma and discrimination within health systems appears to arise from complex social factors, preventing health workers from openly accessing treatment. Workplace policies are seen to be important mechanisms for addressing stigma and discrimination in health systems, although currently such policies are not well developed or effectively implemented.

Methods

The study used a qualitative case study approach within a constructivist paradigm, a theoretical approach that enables the interpretation of subjective meanings that people use to understand their world and behaviour [19]. Data were collected in Kenya in May 2009. Narrative interviews were undertaken with 22 support group members from three support groups based within public hospitals (17 women, five men). Semi-structured interviews were also conducted with 13 key informants, including senior officials from the hospitals where the support groups were based, and from provincial and national level authorities (11 women, two men). All interviews were fully transcribed and a detailed content analysis was undertaken to identify categories and emerging themes.

Ethical approval for the study was granted in writing from the Provincial Medical Office in the province where the study was to be undertaken in Kenya and also from the Institute of Education, University of London. All participants provided written informed consent.

Theoretical framework

The study was guided by a theoretical framework comprising three components from social theory:

- the understanding of HIV-related stigma and discrimination as a product of structural injustices [20];
- the concept of the 'professional project', which argues that traditional models of professionalism can exclude disadvantaged groups from joining or progressing within a given profession [21];
- theories of social capital, which was defined for the purpose of this study as: 'relationships within and between different social groups that may influence health outcomes' [3,22,23].

Main findings

Nature and purpose of the support groups

The nature of the support groups appeared to be influenced by location (the hospital names given here have been changed to maintain confidentiality). The Huruma group and the Same group were both based in district hospitals, had between 20 and 25 members and consisted mainly of administrative and support staff. One support group, Kisubi, was based in a large provincial hospital. The Kisubi group was larger than the other two with approximately 40 members, mostly nurses or other health professionals. Doctors, dentists, pharmacists and senior managers did not join any of the groups.

All three groups were based in health facilities experiencing severe staff shortage and high demand, placing staff under considerable pressure. In the district hospitals, however, HIV-related stigma due to gender inequalities and cultural beliefs was particularly evident in the surrounding communities, suggesting that levels of stigma within these hospitals may be higher.

A key factor in the formation of the groups was the active interest and support from senior management in the hospitals where they were based. In addition, specialist HIV nurses based in these hospitals played an important role, that of negotiating permission from individual HIV-positive staff to introduce them to group members. They also guided group members on how to access treatment and supported group leaders.

The findings consistently revealed that members considered the aims of the support groups to be providing emotional and practical help, as well as financial assistance, to members. Helping members to access the care and treatment they needed to live and work without stigma was seen as the main aim of each group. All three groups considered involvement in educational activities within the health facilities and the surrounding communities to be important. However, the focus appeared to be on meeting the specific needs of individuals rather

than challenging the underlying factors that perpetuate stigma within the health system.

Influence on members' personal lives

The support group members interviewed reported the benefit of being a member of a group on their personal lives. Of the 17 women interviewed, 12 were widowed and viewed the groups as a valuable source of social help in times of need:

'... the group is very friendly to us ... in case I fall sick, my friends will care ...'

Interviewees reported that joining a support group had significantly improved their physical and mental health, helping them to come to terms with their status, access treatment and adopt a more optimistic perspective on living with HIV:

'... first of all when I was tested I had a problem ... actually it was disturbing me, I was wondering ... I needed to know how long. Because ... I thought that death is just next door. But when I joined, a discussion was made, I realised that I have more time ... and I accepted I can access medicine, and feed well. So now psychologically I am not disturbed.'

'... it's because of the support group that we have been able to really aggressively access care and that has positively maintained my health.'

The relationships that developed in the support groups also enabled members to help each other as they tried to talk to their children about HIV. A nurse spoke of how the group had enabled her to talk to her 10-year-old daughter:

'It has helped me because, when we joined the support group, I had not told my child, she didn't know that the drugs she is taking is because she is positive. She just knew the drugs should be taken at six in the morning and six in the evening ... But now when I joined the support group ... we encouraged each other to reveal to our children ... even the children, now they know ... even my daughter now knows. She knows why she is taking the drugs and they are for life ...'

The ability of the group members to help each other towards improved health and social wellbeing suggest that the supports groups represent a form of social capital.

Influence on members' professional practice

Membership of the groups was associated with a marked improvement in professional knowledge, due to learning within the groups and the opportunity to take part in courses related to HIV

care, management and prevention. Group members directly linked their improved professional knowledge to the ability to provide better-quality care. Examples included awareness of the importance of administering antiretroviral therapy on time to babies born to HIV-positive mothers, and the ability to teach outpatients about caring for relatives with HIV.

Key informants observed that the formation of the support groups improved work performance:

'... after this support group I think ... [the Medical Superintendent] ... is happy ... those olden days when a nurse would just be too sick to attend to a patient, today they can work for one week without complaint. They can do night duty because they are on care.'

Support group members spoke of how their own experiences enabled them to empathise better with patients:

'... you want to attend to that person as if you were doing it to yourself or to a colleague of yours, so that the person also feels the comfort that you would have wished too. It has really changed ... the way I see other patients. And whenever somebody comes with a problem I really have to understand that problem, because most of these things that they go through are the things that I go through ...'

Key informants also recognised that health workers living with HIV have a particularly good understanding of the needs of patients with the same condition, and attributed improved attitudes amongst staff to this:

'... you see like the attitude ... you know we've always had problems with the attitude of the nurses, the attitudes even of other staff, to other patients or even to colleagues but it's now improving ... because you see those people who are infected themselves, at least they get to know how to relate to others and the other people are now seeing that many people are coming to be open and accept their status and they also need to support them. So this is improving their attitude towards patients and towards caring for people living with HIV.'

An important finding from the study is the challenge that health workers may encounter as they return to normal duties, as their health improves after starting treatment. Group members expressed considerable pride in relation to their ability to work normally and spoke of being keen to work in all wards including those caring for patients with active TB. As a consequence, they did not always give adequate consideration to protecting their own health.

Emotional distress

The ability of support group members to empathise with patients with HIV was, on occasion, accompanied by emotional distress. Members spoke of how upsetting it could be to see the suffering of patients with HIV, as they often related such suffering to what might happen to them:

'Sometimes ... it really touches you to the extent that you feel like it has really touched you so much. Emotionally you feel so affected. It puts yourself like it was you ... and you really feel that pain.'

Seeing deterioration in patients who had been adhering well to antiretroviral therapy was reported to be particularly disturbing:

'... and worst of all, somebody who has been taking drugs when they go down it really affects me so much, it really affects me and sometimes I just wonder why they should not improve ... It's something that has really been disturbing me psychologically. Because once somebody has been taking his drugs so well, somebody who you think must be adhering so well, and then he starts going down. It really disturbs me.'

This response suggests that the groups need to focus more on strategies to help members cope with the emotional effects of caring for patients with HIV.

Influence on stigma and discrimination

Support group members and key informants alike considered the groups to be a useful tool to challenge stigma and discrimination within the health facilities. Many group members were able to talk openly about their status to colleagues, and even take part in educational events. However, not all support group members felt able to disclose their status in public, often for fear that family and/or community members might judge them or consider that they were about to die and were therefore 'not worth' supporting. A student health worker, for example, said that her family would not pay for her to finish her training if they knew she was HIV positive:

'... because you know if somebody just sees that someone is HIV positive, you know that this one is automatically going to die so why throw my money into her? ... My father will be knowing that he is just throwing money and automatically I am going to die. That's why I didn't tell him, that is why I didn't tell my mother.'

This is just one example of how stigma and discrimination within health facilities arise from social processes. The support groups were able to influence some but not all of these social processes.

Influence of models of professionalism on stigma

Tensions were evident in the support groups due to differences in social status. A support worker explained how she used to be frightened of talking to staff who she considered to be of a higher social status:

'What we fear when you are at a low place, approaching somebody who is ahead of you becomes a problem ... You may go, but you may fear that because I'm of a low grade, he will start saying why have I approached or ... why has she come to me?'

Through being a member of the support group, however, this participant was able to overcome her fear to the extent that she felt able to help nursing staff in the groups:

'I see even these nurses ... you know, we feared them but, when they come to the group here, we find that because of somebody's life they are behind and we come to be strong, to tell them, 'No, you do this and this, just be strong, just take [the] drugs, don't miss your drugs.' Some of these nurses, they have read these pamphlets on drugs, they know the effects of a certain drug and they know the benefit, so mostly they fear the drug. Some take drugs or sometimes they leave. And now at the group we encourage them not to stop ...'

Support staff and mid-level professionals such as nurses may initially not have strong social links with their workplace. However, the findings suggest that membership of the support groups can help to strengthen these links and therefore build social capital.

A key finding, however, was that there were no doctors, pharmacists, dentists or senior management staff living with HIV in any of the three groups. Of significance here is that professionals in these groups tended to be men (generally perceived as reluctant to take part in group activities), and were thought to be especially concerned about losing social status if joining a support group caused others to assume they were HIV positive. In addition, it was felt that they may be reluctant to share personal problems with support group members who they may also have to manage or treat. A key informant observed:

'... so far, we have not been able to have the very senior staff, like the doctors [joining the support group] ... it would be a bit difficult for them, because most of the senior staff would also be people in management ... they will still feel kind of vulnerable to be open because maybe the people in the support group are people they have some kind of authority over.'

Separate initiatives for doctors and senior staff were suggested as one way to meet their needs.

However, it appears that conventions of professional stratification itself may prevent such staff from joining support groups. Alternative strategies, to re-examine understanding of professionalism within the health system, may therefore be of use to address this issue.

Conclusions

The findings from this study suggest that support groups for health workers living with HIV in Kenya, that are based in health facilities, can help members address personal challenges and promote their professional development. The support groups were also seen as instrumental in reducing stigma and discrimination within health facilities. However, the support groups were limited in their ability to challenge structural factors that perpetuate stigma within health systems. Hierarchical models of professionalism appear to underpin the HIV-related stigma and discrimination that exist within the health facility – this was observed within this study in relation to gender and social class.

Suggestions for policy, practice and further research

A more enabling policy environment is needed to ensure that workplace interventions intended to support health workers living with HIV are effective – for example, specific policy-making should protect the rights of health workers living with HIV, with particular consideration of gender inequalities so that women living with HIV in the health workforce cease to be disadvantaged in comparison to their male counterparts. In addition, the occupational health needs of health workers living with HIV, and protection of their right to confidentiality, would also need to be considered. The findings from the study suggest that improved mechanisms would be required to ensure that any new policies were implemented effectively across the health system.

Mechanisms to further promote the professional development of health workers living with HIV need to be explored and could include forms of clinical supervision for support group members and nurses specialising in HIV.

Opportunities for health workers, through participatory research, to examine how models of professionalism influence their personal and professional lives, would be particularly useful. Such exploration could help determine how best to encourage doctors, dentists, pharmacists and senior managers living with HIV to access treatment and care openly.

Acknowledgements

I am grateful for support from a NHIVNA/Boehringer Ingelheim Travel Scholarship/Research Award. Grateful thanks are also due to all the participants who kindly agreed to take part in

this study and also to Mildmay and the Provincial Medical Officers of Health (PMOH) in Kenya, for their support and guidance.

References

1. World Health Organization (WHO). *Treat, train, retain: the AIDS and health workforce plan*. WHO, Geneva, 2006. Available at: www.who.int/hiv/pub/meetingreports/tr/en/index.html (accessed February 2012).
2. O'Keeffe C. Exploring the challenges faced by health workers in relation to their personal and professional identities in the context of high HIV prevalence [unpublished Institutional Focus Study, Institute of Education, London, completed 2008].
3. Putnam R. Bowling alone: America's declining social capital. *Journal of Democracy*, 1995, **1**, 65–78.
4. Minnaar A. Caring for the caregivers: a nursing management perspective. *Curationis*, 2001, **24**, 19–26.
5. Minnaar A. HIV/AIDS issues in the workplace of nurses. *Curationis*, 2005, **28**, 31–38.
6. Kyakuwa M. Ethnographic experiences of HIV positive nurses in managing stigma at a clinic in rural Uganda. *African Journal of AIDS Research*, 2009, **8**, 367–378.
7. O'Keeffe C. An exploration of cross-cultural understanding in HIV/AIDS care in Uganda and applications to teaching and learning [unpublished Manchester University MPhil thesis, completed 2005].
8. Dieleman M, Biemba G, Mphuka S *et al*. 'We are also dying like any other people, we are also people': perceptions of the impact of HIV/AIDS on health workers in two districts in Zambia. *Health Policy and Planning*, 2007, **22**, 139–148.
9. Kruse GR, Chapula BT, Ikeda S *et al*. Burnout and use of HIV services among health care workers in Lusaka District, Zambia: a cross-sectional study. *Human Resources of Health*, 2009, **7**, 55.
10. Brown L, Macintyre K, Truillo L. Interventions to reduce HIV/AIDS-related stigma: what have we learned? *AIDS Education and Prevention*, 2003, **15**, 46–69.
11. International Council of Nurses. *Nurses: fighting AIDS stigma, caring for all* [published for International Nurses Day]. International Council of Nurses, Geneva, 2003.
12. Holzemer WL, Uys L, Makoe AE *et al*. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 2006, **56**, 541–551.
13. Taegtmeier M, Suckling RM, Nguku PM *et al*. Working with risk: occupational safety issues among healthcare workers in Kenya. *AIDS Care*, 2008, **20**, 304–310.
14. Kamau J, Odundo P, Korir J, for the Kenya Treatment Access Movement (KETAM). *Measuring the degree of S&D in Kenya an index for HIV/AIDS facilities and providers*. USAID Health Policy Initiative, Washington DC, 2007. Available at: www.healthpolicyinitiative.com/Publications/Documents/26_2_1_Measuring_SD_Final_July_2007.pdf (accessed February 2012).
15. National AIDS and STD Control Programme (NASCO), Ministry of Health, Republic of Kenya. *The 2005 Kenya Health Worker Survey*. NASCO, Nairobi, 2006. Available at: www.popcouncil.org/pdfs/horizons/KenyaHealthWorkerSurvey.pdf (accessed February 2012).
16. Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? *Journal of the International AIDS Society*, 2009, **12**, 15.
17. Petit-Mshana EJ, Nabitulya F. Health workers' access to HIV and TB prevention, treatment, care and support services [unpublished draft WHO report, concluded 2009, of a survey of policy practices in 17 countries].
18. Petit-Mshana EJ. *International consultation on policy guidelines on improving health workers' access to prevention, treatment and care services for HIV and TB*. Report on the proceedings and compilation of presented papers. World Health Organization, Geneva, 2010.

19. Cohen L, Manion L, Morrison K, Morrison KRB. *Research Methods in Education*. Routledge, London, 2008.
20. Parker, R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 2003, **57**, 13–24.
21. Larson MS. *The rise of professionalism: a sociological analysis*. University of California Press, Berkeley and London, 1977.
22. Woolcock M. The place of social capital in understanding social and economic outcomes. *Canadian Journal of Policy Research*, 2001, **2**, 1–17.

23. Islam MK, Merlo J, Kawachi I *et al*. Social capital and health: does egalitarianism matter? A literature review. *International Journal of Equity in Health*, 2006, **5**, 3.

Correspondence: Catherine O’Keeffe
The Institute of Education
20 Bedford Way
London WC1H 0AL, UK
c.okeeffe@ioe.ac.uk

Antiretroviral treatment as prevention: considerations for nursing practice

Juliet Bennett

Independent Nurse Advisor

Introduction

The use of antiretroviral treatment (ART) for prevention of HIV infection has been carefully examined in the last two decades. It was initially used in the treatment of HIV-positive mothers to prevent mother-to-child transmission; and exploration then followed of its preventative potential for uninfected individuals post exposure to HIV. More recently the plausibility of pre-exposure prophylaxis has been investigated, followed by the use of ART to reduce viral load, with the specific aim of preventing onward transmission. The journal *Science* even bestowed its ‘Breakthrough of the Year 2011’ award on the concept of HIV treatment as prevention.

Better than cure

In the last few years, we have edged a little closer to our goal of bringing the pandemic under control, with the arena of biological prevention publishing some interesting developments. A series of Africa-based studies revealed that circumcising heterosexual men could reduce risk of infection by up to 75%. The mathematical models exploring this intervention are less optimistic, especially in relation to the benefits of this strategy for MSM and women, but still conclude that circumcising men should start to produce significant and sustained decline in female HIV prevalence, as prevalence among men declines [1,2].

At the XVIII International AIDS Conference in July 2010, the CAPRISA 004 study [3] reported encouraging findings for the use of a vaginal microbicide containing tenofovir. The risk of HIV infection was reported to be reduced by 39% for women who received the topical gel in a randomised placebo-controlled study. However, last autumn a large study known as VOICE [4], which had been investigating both oral pre-

exposure prophylaxis and the vaginal gel, was halted when study monitors established that HIV incidence was almost identical in women using tenofovir gel when compared to those using the placebo. Thus at present the use of topical agents as an HIV prevention strategy appears to be a considerable way off.

Several researchers have also published findings suggesting that a significant reduction in transmission rates could be achieved with ART where an undetectable viral load was achieved and sustained [5]. In 2008, *The Lancet* published a mathematical model exploring the potential for universal (voluntary) testing, with immediate ART for those testing positive. It illustrated that this strategy could cut HIV incidence and mortality to less than one case per 1000 people per year by 2016, or within 10 years of full implementation, and reduce the prevalence of HIV to less than 1% within 50 years [6].

Then followed the results of the HPTN052 study, released in July 2011 [7], showing conclusively that early initiation of ART significantly reduces rates of sexual transmission of HIV-1. A relative reduction of 96% was demonstrated in the number of transmissions (as a result of early initiation of ART), compared with those for whom therapy was delayed until the CD4 count dipped below 350 cells/mm³. The study indicated benefits both for those with HIV and their uninfected partners – as well as the potential for a wider public health benefit, as a pre-exposure method of preventing the spread of HIV.

The end of AIDS ...?

Whilst it is currently a minority view, there are some who feel that we may not need novel approaches or new interventions such as these to significantly reduce HIV transmission. Certainly, many experts and advocates now believe that the provision of



Figure 1: The Economist front cover, June 4, 2011, celebrating a possible end to the AIDS epidemic.

Cover reproduced by kind permission
© The Economist
Newspaper Ltd.

ART may be one of the most important elements of any strategy to end the HIV epidemic. During last summer's International AIDS Conference in Rome, the front cover of *The Economist* raised the question, 'The end of AIDS?' (Figure 1). Without doubt there is cause for optimism at what has been achieved so far – but have we really found a solution to this escalating epidemic?

Even assuming resource limitations and political and logistical factors can be ironed out, so that ART is made available for all HIV-positive people, the question remains: how can we optimise the impact of this obviously valuable intervention? The future of HIV incidence depends on many other factors, including:

- coverage and frequency of testing;
- detection in the primary infection phase;
- effects on the individual of early ART initiation;
- treatment adherence;
- development and transmission of drug-resistant virus;
- sustainability of viral load suppression;
- potential change in risk-taking behaviours following diagnosis;
- potential change in risk-taking behaviour following viral suppression;
- social, cultural and religious influences.

In addition, the stigma and discrimination associated with HIV, which continues to be deeply entrenched worldwide, will inevitably impact on people's ability and willingness to present for testing, to access and take treatment, and to change their sexual behaviours.

Prevention in practice

While the debate continues, for us as nurses working on 'the front line', the immediate concern is how such information impacts on our practice, promoting health at an individual patient level. First, we can certainly further advocate the benefits

of testing (in the UK where ART is widely accessible) now that there is an additional advantage to knowing one's status and starting treatment earlier. Some clinicians are willing to commence ART for the sole reason of reducing risk of onward transmission, even in those with CD4 counts above 350 cells/mm³. However, this practice varies considerably from clinic to clinic, and cost implications are inevitably taken into account. We may therefore find ourselves caught up in the politics and human rights issues related to access to treatment. We must, as always, act as well-informed advocates with our patients' best interests central to the cause.

In terms of preventing onward transmission, for as long as we can remember, 'use condoms' has been the cornerstone of our health promotion strategy. However, we all recognise that, in reality, this has been far from straightforward to implement – and new infections continue to rise, even in the UK where condoms are readily available. One study [8] found that only 5% of GUM clinic attendees used condoms every time they had intercourse in the year following a clinic visit, and HPA figures from 2011 show the highest-ever annual increase of new HIV diagnoses in men who have sex with men (MSM), with the majority of infections believed to be newly acquired [9].

Data such as this, along with our learned experience from dialogue with patients, and recent scientific revelations, require us to think about prevention in a different way. It is now not simply about advocating consistent condom use, but also about helping people make knowledgeable and empowered choices, considering whichever combination of prevention methods best suits their own circumstances and priorities. We will have to learn how to better communicate issues of risk and risk reduction in order to support our patients in this complex and changing 'minefield'. Since it is well established that condoms do not eliminate risk entirely, most of us already feel comfortable with a risk-reduction, rather than a risk-elimination approach – and this must remain the backdrop for any advice given, rather than being swept away by the wave of current optimism.

Serodiscordant couples and HIV-positive seroconcordant couples should receive detailed and expert counselling in relation to their risk-reduction options. This may include discussions around issues such as sero-sorting, pregnancy planning and sperm-washing. In some settings sexual health advisors are an integral part of the multidisciplinary team and take on this role. In other areas we as nurses are best placed to provide this intervention – but obviously we require training, regular clinical knowledge updates and resources to do this well.

The draft BASHH/BHIVA United Kingdom National guideline on safer sex advice [10] recommends

that, whilst advising that taking ART and having an undetectable viral load reduce risk of onward transmission, we should state clearly that a residual risk remains. We should also stress that this risk is likely to be greater for anal sex compared to vaginal and oral sex and that it is increased with reduced ART adherence. (The presence of STIs in either partner also increases risk of HIV transmission.)

The big picture

We now need to think more broadly than ever of the implications for real lives, taking time to explore these with our patients as individuals and, where appropriate, together with their sexual partners. For example, if ART is being considered as the method of prevention, other significant commitments would also be required. We must facilitate discussion around the practicalities and motivation for undertaking these, such as the ability and willingness to attend clinic regularly, have regular blood tests, avoid STIs and have regular STI screening; plus reliable treatment adherence and an ability to be open and honest with sexual partners. We also need to keep in mind that knowledge of ART as prevention may lead to 'risk compensation', both among people living with HIV, and those at risk, and be alert in particular to the possibility of decreased or less consistent condom use.

Furthermore, there may be risk of so-called 'super-infection' with another strain of HIV, perhaps with resistance to ART. The Centers for Disease Control (CDC) in North America states, 'super-infection can have a negative effect on the course of HIV. There have been cases in which it has caused the disease to progress more quickly, or caused treatment problems' (because the additional strain was resistant to some antiretroviral drugs). If both partners are taking effective ART, the chance that super-infection will occur is probably decreased; however, the risk can never be zero for all of the reasons mentioned earlier. The CDC advises, 'to protect against super-infection, couples should consider using proven prevention methods (such as condoms) even if both partners have undetectable viral loads' [11].

In sexual relationships condom use is mutually agreed and it is usually obvious when the method has failed. In contrast, the viral load of an individual is an 'unknown quantity' at any given point in time: even where blood test results are very recent, only one party has access to this information, and the same applies to the level of their ART adherence. Negotiating the use of antiretroviral therapy to prevent transmission between partners involves very differing levels of trust and openness. Complex issues of love and trust arise, plus for many the need to unlearn years of internalised stigma. The National AIDS Trust gave some interesting case studies at a

seminar [12]. They reported that some couples are happy to rely on this method entirely but for others the debate felt much more complex. In some cases the negative partner was happy to trust this method but the positive partner felt too fearful. How individuals respond to this information clearly depends on the degree of risk that they are prepared to accept. These decisions are very individual, and complex personal and interpersonal dynamics are at play. It is clear that counselling for prevention entails not just practical advice – the significant psychological and emotional elements also need in-depth exploration.

Starting ART earlier than would otherwise be recommended on clinical and symptomatic grounds clearly prolongs the period during which an individual needs to adhere to a medication regimen and therefore the period of risk of viral load rebound. For some people in this situation the desire to prevent those they care about from infection may be a strong motivating force to adhere. However, for others, taking ART without obvious personal clinical or symptomatic benefit may undermine motivation, especially over time, and particularly if they also experience treatment-related side effects.

Nurses who take on this advisory role will also need familiarity with the issues relating to criminal liability for transmission of HIV and recent case reports, and feel equipped to discuss this area. To date, successful prosecutions in England and Wales have been made under the Offences against the Person Act 1861, with the charge being 'recklessly inflicting grievous bodily harm'. In these cases it must be proved that:

- it was the defendant who infected the complainant/sexual partner;
- the defendant was aware of the risk of transmission;
- the complainant did not explicitly give informed consent to sex with an individual they knew had HIV;
- the defendant did not take steps to protect their partner.

Noteworthy here is that consistent condom use is considered a strong defence and it would be logical (but not yet tested) to argue that reliably taking ART, along with all other known measures to ensure a sustained undetectable viral load, would also prove a robust defence but we will need to 'watch this space'.

Conclusion

According to Montaner [13], 'the evidence is in' and we are now at a turning point where we must move from 'from hypothesis to implementation priority'. Certainly it would appear unethical not to offer ART immediately to serodiscordant couples when they present, and as nurses we must feel well informed and equipped to advocate to this effect. We need to

re-evaluate the entire care pathway, seeking innovative ways to normalise and roll out HIV testing, then to treat and support those testing positive to take ART effectively for sustained viral load suppression. We must continue to improve our skills in opening up effective dialogue with our patients and their partners, to provide informative and supportive risk-reduction strategies in light of these research findings. Finally, as always, we must continue to keep abreast of new developments in what is undoubtedly a fast-moving, exciting and optimistic time.

References

1. Bailey RC, Moses S, Parker CB *et al.* Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. *Lancet*, 2007, **369**, 643–656.
2. Auvert B, Taljaard D, Lagarde E *et al.* Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 Trial. *PLoS Med*, 2005, **2**, e298 [epub Oct 25 2005].
3. Abdool Karim A, Abdool Karim SS, Frohlich JA *et al.* (CAPRISA 004 Trial Group). Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women. *Science*, 2010, **329**, 1168–1174.
4. VOICE (Vaginal and Oral Interventions to Control the Epidemic; also entitled MTN-003). National Institutes of Health study update available at: www.nih.gov/news/health/nov2011/nicid-25.htm (accessed February 2012).
5. Garnett GP, Gazzard B. Risk of HIV transmission in discordant couples. *Lancet*, 2008, **372**, 270–271.
6. Granich RM, Gilks CF, Dye C *et al.* Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. *Lancet*, 2009, **373**, 48–57.
7. Cohen MS, Chen YQ, McCauley M *et al.* Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine*, 2011, **365**, 493–505. Available at: www.nejm.org/doi/full/10.1056/NEJMoa1105243 (accessed February 2012).
8. Peterman TA, Tian LH, Warner L *et al.* Condom use in the year following a sexually transmitted disease clinic visit. *International Journal of STI & AIDS*, 2009, **20**, 9–13.
9. Health Protection Agency. *HIV in the United Kingdom: 2011 Report*. Health Protection Services, London, 2011. Available at www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317131685847 (accessed February 2012).
10. British Association for Sexual Health and HIV/British HIV Association. The United Kingdom National guideline on safer sex advice, Consultation Draft, January 2011. Available to view at: www.bhiva.org/documents/Guidelines/SaferSex/BASHH_BHIVA_Safer_Sex_Advice_FEB_2012.pdf (accessed February 2012).
11. Centers for Disease Control and Prevention website: www.cdc.gov/hiv/topics/treatment/index.htm (accessed February 2012).
12. National AIDS Trust (NAT). *HIV treatment as prevention*. Report of the NAT expert seminar, Towards a UK consensus on the Impact of HIV Prevention Strategies. NAT, London, 2011. Available at: www.nat.org.uk/Media%20library/Files/Policy/2011/NAT_TreatmentasPrevention2011.pdf (accessed February 2012).
13. Montaner JS. Treatment as prevention – a double hat-trick. *Lancet*, 2011, **378**, 208–209.

Correspondence: Juliet Bennett
jv_bennett@yahoo.co.uk

Call for Papers 2012

HIV NURSING welcomes all research papers, case reports, audit reports, literature reviews, editorial letters and other contributions relevant to healthcare professionals working in HIV.

If you have recently completed a dissertation or degree, set up a project that has improved care for your patients or conducted some research, please let us know.

One of the best ways to raise our profile as nurses is by demonstrating innovative work that improves the lives of patients, family and staff within the field of HIV care.

Whether you wish to contribute a full-length feature article (up to 2,500 words), a current issues/opinion piece (minimum 500 words) or send in a letter or comment, the Editorial Board of HIV Nursing will be pleased to hear from you.

Themes during 2012 include: **12.2** Women and HIV · **12.3** Patient participation · **12.4** International perspectives
Copy date: 20 April Copy date: 20 July Copy date: 19 October

Need some help? If you feel you have a contribution to make to HIV Nursing but are unsure how to go about it, help is at hand from a member of the Editorial Board. We are delighted to offer a 'writing buddy' service to guide both first-timers and old hands through any aspects of the writing process. Please contact the Mediscript editorial team (naomi@mediscript.ltd.uk) in the first instance with a brief description of your proposed contribution, and your query will be forwarded to the person best qualified to support you.

Please remember: not all items carried in an issue have common subject matter – so don't be put off if you have a contribution that is not within the themes mentioned above.

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Instructions to Authors

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

The Editor, Mediscript Ltd
 1 Mountview Court
 310 Friern Barnet Lane, London N20 0LD
 T: +44 (0)20 8369 5389 E: naomi@mediscript.ltd.uk

Articles are accepted on the understanding that they have been approved by the Editorial Board and may be subject to revision. Contributions regularly accepted are: research papers (for peer review), case studies and audit reports. In addition, submissions such as current issues/opinion pieces, editorial letters and 'day in the life' items are also welcome and will be considered for publication.

2. **Guidance:** If you would like help with any aspect of the writing process, please contact the Mediscript Editorial team in the first instance with a brief description of your proposed contribution, and your query will be forwarded to the person best qualified to support you (email: naomi@mediscript.ltd.uk).
3. **Manuscript format:** Authors should include full affiliation, address, telephone number and email 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 use English spellings. Subheadings should be used wherever possible, and abbreviations defined when first used.
4. **References:** References 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.

5. **Illustrations and tables:** These should be provided wherever appropriate and be captioned. Any illustrations supplied should be of sufficiently high quality to ensure good reproduction. Colour reproduction is available at the author's expense (cost available on request). Where appropriate, magnification figures or scale bars should be supplied. Illustrations and tables must be cited in numerical order. 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.
6. **Proofs:** will be sent to the author for correction of errors and approval.
7. **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.

