

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Editorial Board

Jane Bruton

HIV Nurse Manager
Chelsea and Westminster
Hospital, London

Ian Hodgson

Lecturer
School of Health Studies
University of Bradford, Bradford

Eileen Nixon

Senior Nurse HIV
Brighton and Sussex University
Hospitals, Brighton

Advisory Panel

Roy Brazington

HIV Mental Health Nurse
Specialist
Maudsley Hospital, London

Margaret Clapson

Paediatric Clinical Nurse
Specialist
Great Ormond Street Hospital,
London

Judith Sunderland

HIV Specialist Midwife
Newham General Hospital,
London

HIV and mental health

Editorial

- The role of mental healthcare in HIV nursing today
Roy Brazington 4

Features

- A cognitive perspective of HIV-related mental health issues
Angela Lavery 6
- The Mental Capacity Act (2005): an HIV case review
Eileen Nixon 10
- Care issues for inpatients – HIV and mental health
Flick Thorley 13

Peer-reviewed article

- Chronic illness and sexuality needs: HIV-positive
homosexual men
May McCreddie 16

Conference report

- HIV and Metabolic Complications Study Day
Candy Duggan 21

NHIVNA update

- Nicky Perry* 27

Now listed in **EMBASE, EMNursing, Compendex, GEOBASE,**
Mosby Yearbooks, Scopus and CINAHL databases

IFC
BMS/Sustiva
Full-page Advert

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, EMNursing, Compendex, GEOBASE, Mosby Yearbooks, Scopus and CINAHL databases

HIV Nursing is supported by an educational grant from **Gilead Sciences Ltd.**

Editorial Office

Editorial Director: Fatima Patel

Managing Editor: Jayne V Carey

Editor: David Shaw

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

Printed in England

Spring 2006

© Mediscript, 2006

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.

AIDS Care Handbook

To order your copies, complete and return this form.

AIDS and its related diseases have changed almost every aspect of medicine. This genuinely readable handbook provides a comprehensive and up-to-date insight into AIDS and its management.

The AIDS Care Handbook is written by a team from the Chelsea & Westminster Hospital, an internationally renowned centre for the treatment of HIV-associated disease. The expert authors, led by Professor Brian Gazzard, introduce this complex disease by first explaining the underlying epidemiology, immunology, and virology of HIV infection.

The central sections of this handbook discuss the clinically important areas of opportunistic infection and malignancy, before detailing how bodily systems can be affected by HIV infection and AIDS. Current diagnostic and therapeutic techniques are carefully explained for those unfamiliar with this field.

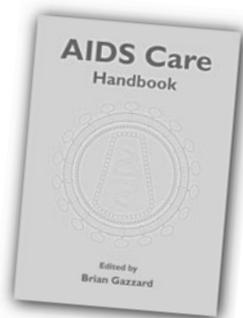
Further sections focus on treating AIDS in a District General Hospital in isolation and on the requirements for treating coinfection with hepatitis.

Antiretroviral treatment is a constantly changing area of medicine. The authors present optimal treatment regimens based on the latest clinical evidence as well as a realistic interpretation of current surrogate marker trials and clear explanations of drug toxicity. To end the book, an appendix lists the indications, dosages, adverse reactions, and interactions for the more commonly encountered drugs used in HIV-related disease.

Of interest to:

- Medical and nursing staff in HIV units
- Hospital doctors
- Genitourinary physicians
- Those living with HIV infection
- General practitioners
- Carers of those living with HIV infection

Published by Mediscript Ltd · Editor: Brian Gazzard
Size A5 · 360pp · Stiff cover ISBN 1-871211-55-7



Boehringer I
half-page
(PI Information)
Viramune

ORDER FORM

AIDS Care Handbook New Edition

Quantity	RECOMMENDED RETAIL PRICE £20.00 Price per copy* £
1 - 9	20.00
10 - 99	15.00
200 - 499	13.50
500 - 999	12.00
1,000 - and more	10.00

* Prices are exclusive of carriage and VAT thereon.

I would like to order _____(qty) copies of the above publication at £ _____
(price) per copy, shown above.

Total £ _____

Name: _____

Institution/Company Name: _____

Address: _____

Telephone Number: _____

Fax Number: _____

E-mail Address: _____

Delivery/Invoice instructions (if different from above address)

NB We cannot deliver to a PO Box Number.

Signed: _____ Date: _____

Please print name: _____

PLEASE RETURN THIS ORDER FORM TO:
Mediscript Ltd, 1 Mountview Court,
310 Friern Barnet Lane, London N20 0LD.
Telephone: +44 20 8446 8898 Facsimile: +44 20 8446 9194

Page 3

Boehringer I/Viramune

Full-page colour Advert

The role of mental healthcare in HIV nursing today

Roy Brazington

HIV Mental Health Nurse Specialist, Maudsley Hospital, London

HIV infection has long been associated with stigma and fear. Its effects on the psychological well-being of an HIV-positive person are sometimes ignored because of the complexity of this infection. However, the psychological distress surrounding an HIV diagnosis and the ongoing difficulties of coping with HIV are receiving increasing levels of recognition among clinicians. It is apparent that, in the initial period following an HIV diagnosis, the majority of people experience an adjustment disorder, which for many is self-limiting in the background of good support from family, friends and others. However, there are a number of people diagnosed with HIV who experience isolation and rejection by those closest to them, making the adjustment process far more difficult to cope with. One example of this, which we are seeing frequently in practice, is that of an asylum seeker who has recently been diagnosed and is not aware of the local support available. For instance, the asylum seeker may be too scared to access his/her local support services because of perceived worries about meeting others from their own community.

The most common symptoms of psychological distress among people with HIV are depression and anxiety. This issue of *HIV Nursing* explores some of the difficulties that patients experience upon diagnosis and living with HIV in the long term.

CASCAID: an HIV and mental health service

Currently, I am a Community Psychiatric Nurse working for CASCAID, an HIV and mental health service based in south London. The CASCAID team is multidisciplinary, comprising psychiatrists, psychologists, nursing staff and administrators. We work within the London boroughs of Lambeth, Southwark, Lewisham and Croydon. These areas of London have a high prevalence of HIV infection: 13–17% of HIV-positive patients in England reside in the boroughs of Lambeth, Southwark and Lewisham. In these boroughs, patients can be referred to CASCAID by their treatment centres, social services or voluntary services. Patients can also choose to refer themselves to CASCAID or, rarely, are referred by their local GPs.

The CASCAID team then assesses the patient in a venue that is convenient for him/her, which can be in a treatment centre, psychiatric outpatient setting, GP practice or in the patient's own home. The

different disciplines – psychiatrists, psychologists and nurses – of CASCAID use a number of approaches to treat the patient, which can include medications, psychological therapies, and practical support and counselling. The CASCAID team liaises with statutory and non-statutory agencies, for example, the patient's treatment centre, social services, Mildmay Hospital, Terrence Higgins Trust services (such as Lighthouse, Kings and Lighthouse South), Body and Soul, and Positively Women, to enable patients to obtain as much benefit as possible from their local services.

At present, the main challenges for CASCAID include the difficulties working with patients who are seeking leave to remain in this country on compassionate grounds or because of political affiliation. This is becoming increasingly more complex as a result of the UK government policy changes to immigration and healthcare access for asylum-seeking patients. These problems are further compounded by a lack of social capital and a system that is designed to meet the needs of a population that has lived in the UK for a significant period of time.

Mental health problems are culture bound and, for many people who have recently arrived in the UK, the concept of mental health is not that of the population at large. The patients who are being assessed may have witnessed atrocities in their country of origin and it may not be appropriate for them to engage in long-term work to explore their psychological distress. Hence, support in the immediate periods may be far more useful in these cases.

Asylum seekers: a different approach is needed

An increasing number of the patients we are seeing in the team today are not originally from the UK, but have recently arrived in the country for work or study. This particular population has different needs from patients who grew up here in the UK. The question is how can the healthcare community improve the situation for asylum-seeking HIV-positive patients because these patients are often not aware of how the NHS functions or how to access the services offered. One example is that the healthcare professional involved could help by providing a letter of support for a charity hardship application or submit a letter to the patient's solicitor to support his/her need to stay in the UK.

Sometimes, a letter to the local MP to contact the Home Office on the patient's behalf to speed up a decision based on the individual's circumstances has also proved helpful in the past.

Patients may also come from a culture where 'active forgetting' of difficult experiences is encouraged or where talking to strangers about your problems is an alien concept. However, we must be aware that we may lack the traditional structures of support in the UK for these patients and, therefore, a much more flexible approach is needed where clarity of our professional roles can become blurred. An example of this 'blurring' could be that the patient may see you as a 'one-stop professional' who can address all their needs, both health and social needs. Other patients perceive you to become part of the family and, at times, the healthcare professional may adopt more of a mentoring role rather than a defined healthcare role. This is often fostered by patients who have complex needs. A general explanation of how the country functions and how healthcare is managed can be of benefit to such patients.

HIV and the law

Recently, in the media, there has been a great deal of discussion about the reckless transmission of HIV, which has a significant impact upon the discussions between clinicians and patients. It is apparent that reckless transmission has a basis in both ignorance and the actions of a few people with HIV who have found themselves in a difficult situation of experiencing a police investigation because of a complaint brought against them by a partner. Indeed, this area is made more difficult to assess when the patient involved has a mental health problem.

Reckless transmission of HIV has created ethical dilemmas for clinicians and those who have consulted their professional bodies have found that there is no clear guidance on this issue. The need for guidance is paramount to enable clinicians to give clear information to patients in their care.

Further education in mental health

My own interest in mental health is driven by how a person's early childhood experiences and environment play an important part in creating the person they are today. I am currently studying for an Advanced Diploma in Mental Health Dynamics at Bethlem Royal Hospital, Kent (in association with South London and Maudsley NHS Trust, and Tavistock and Portman NHS Trust, London), to develop my skills further in order to assist my work with patients who have difficulties in coping with their daily lives. In particular, this diploma will enable me to develop therapeutic relationships with patients, which are enabling and supportive in the long term.

Providing help and support to patients who have HIV are both important components of mental healthcare. Indeed, an awareness of mental health problems and the availability of local non-statutory services to provide emotional support will enable nurses to better meet the needs of their patients.

In terms of maintaining adherence to medication, it would be pertinent to treat underlying mental health problems before commencing antiretrovirals. In this background, it is recommended that nurses continue to develop their awareness of the problems encountered by patients with HIV, particularly with respects to asylum seekers who may present with complex needs. In conclusion, the psychological problems associated with HIV infection will remain for as long as the stigma and fear remain in the general population.

Correspondence to: Roy Brazington, HIV Mental Health Nurse Specialist, Maudsley Hospital, Denmark Hill, London, SE5 8AZ, UK.
(email: roy.brazington@slam.nhs.uk)

A cognitive perspective of HIV-related mental health issues

Angela Lavery

Clinical Nurse Specialist (HIV and Mental Health), Leeds General Infirmary, Leeds

Introduction

HIV is predominantly viewed as a physical illness and, consequently, there is often limited awareness or recognition of the psychological and psychiatric aspects of the disease. This feature article aims to raise awareness of these issues, providing an overview of the most common mental health difficulties experienced by people living with HIV. These are then discussed in greater depth, with reference to the cognitive and behavioural aspects of the development and maintenance of such difficulties.

Psychological and psychiatric aspects of HIV/AIDS

The impact of HIV can be viewed on a continuum, starting from the decision to undertake an HIV antibody test to the development of AIDS and death. During this time, an individual is likely to experience profound psychological threats, some of which are phase-specific, and others that are common across different phases (phases relate to different stages of HIV infection from HIV diagnosis to death; for example, being diagnosed, becoming symptomatic, starting treatment, experiencing opportunistic infections and receiving AIDS diagnosis) [1]. Such major life events challenge an individual's view and may require readjustment of personal beliefs.

HIV infection has been associated with a broad range of mental health problems, even where HIV is well controlled [2]. Psychiatric disorders are common in HIV and the stressors associated with living with HIV can contribute to psychiatric illness. Mental health problems may even pre-exist an HIV diagnosis, and patients with serious mental illness are at increased risk of HIV infection [3].

Studies vary in their estimates of the prevalence of different mental health problems in people living with HIV, such as depression [4]. In one study of outpatients with HIV infection, 54% were found to be suffering from a psychiatric disorder [5]. Despite the variation in estimates of prevalence, there seems to be clear agreement that 'a substantial proportion of people with HIV experience mental health problems, the main diagnoses are adjustment disorder, major depression, panic disorder, personality problems and sexual dysfunction, with organic brain syndromes and new onset psychotic illnesses being rare' [6].

HIV is associated with a number of taboos including sexuality, drug misuse and death. These taboos contribute to the complexity and diversity of emotional and psychological problems experienced by this patient group, which in turn can impact upon every aspect of their life. Responses to an HIV-positive diagnosis have been likened to the stages of grief [7]. These reactions are often regarded as an understandable emotional response to a potentially fatal illness that has a substantial stigma attached to it. However, it is important to recognise the risk of normalising such responses; for example, depression in HIV/AIDS is often considered logical and inevitable and, consequently, is often undertreated [8].

Depression

The incidence of depression in people with HIV is generally estimated to range from 22% to 38% [9], although a more recent study estimates 22–45% [10]. The rate of depression in the general population is 12–13% [11]. Several studies suggest that major depressive disorder is the most frequent psychiatric condition seen in patients with HIV [12], with increased rates of ideation, attempts and completion of suicide reported in people with HIV. Factors such as uncertainty about the future, fears about incurable illness, multiple bereavements, isolation and stigma may increase the risk of suicide. Such hopelessness is a key feature in those contemplating suicide [13]. Consistent with this is recognition of an increased risk of suicide in people with HIV compared with that in the general population [14].

There are numerous factors that may contribute to depression in people with HIV. HIV may become their central focus, with self-criticism and perceptions of the world as generally negative and the future as hopeless, as described in the depressogenic cognitive triad [15], where self, others and the world are viewed negatively. Negativity may focus on losses and changes, resulting in feelings of loss of control, helplessness and hopelessness. This can result in cognitive distortions and biases in information processing, which influence how an individual experiences the world and serves to maintain their negativity and discounting of possible options or solutions. It is important to assess the degree of distortion in a person's appraisal of the situation, particularly as high levels of dysfunctional attitudes have been reported in people with HIV and are associated with

psychological distress [16]. Ruminative thinking about mortality may lead to an increased sense of vulnerability. People with HIV have often experienced multiple bereavements and losses; this may be compounded by loss of social support, survivor guilt and concerns about their own health, which conspire to and can lead to unresolved and complex grief reactions [17].

Anxiety

Anxiety is almost universal in people with HIV and even in those who have adjusted to their diagnosis. Episodes of anxiety may be triggered by incidents such as the death of others, illness or simply reading about the virus [18]. Anxiety is neither inappropriate nor uncommon in people with serious chronic illness [19]; again, this may be viewed on a continuum ranging from tension to panic. People with HIV often experience uncertainty about their condition and worries about this may escalate to overwhelming worry and intense anxiety, which results in a sense of hopelessness and loss of control [20]. HIV may become the central focus, with the self perceived as being vulnerable, the future uncertain and the world as threatening, as indicated in the anxiogenic cognitive triad [21]. The nature of such anxiety may result in excessive worry and the development of generalised anxiety disorder. Here, worry is the central theme, with type 1 worry concerning daily internal and external events, and type 2 worry focussing on the nature and occurrence of the thoughts themselves [22].

Vulnerability of the self often focuses on the physical aspects of HIV infection, with worries about illness, uncertainty, disfigurement, disability, loss and death. Worries about death may pertain to the process of dying, which may be influenced by previous negative experiences of the death of others with HIV or worries about the afterlife. A particular concern may relate to anxiety about developing mental illness, with HIV dementia being particularly feared – the double jeopardy of HIV and mental illness. Stigma often arises from the misrepresentations of the mass media and can result in private shame and societal scorn [23]. The stigma, prejudice and discrimination associated with HIV/AIDS results in a great deal of secrecy about diagnosis. This creates isolation and anxiety about disclosure, breach of confidentiality and fear of rejection. Because HIV is an infectious disease, there may be unique anxieties about infecting others or fear of contagion by others, perpetuated by a significant amount of ignorance about the modes of HIV transmission. This type of fear may result in rejection, avoidance and a range of safety behaviours. Such stigma and prejudice can also contribute to low self-esteem.

Health anxiety is particularly common in people with HIV infection. Whereas worries about health

originate from their diagnosis, it is not unusual for these worries to be disproportionate to their actual health situation. The nature of treatment for HIV serves to maintain focus upon their condition and monitoring of disease progression. This can result in preoccupation with blood results and achieving an undetectable viral load. Hypervigilance may also develop in response to somatic complaints, with these often misinterpreted as evidence of disease progression.

Low self-esteem

Body image can be affected in numerous ways in HIV-positive patients. Body image has three components: (i) body reality; (ii) body presentation; and (iii) body ideal [24]. Body reality pertains to the areas of the body that are altered. Alterations to the hands, face and genitals cause the most distress. It is common for all of these areas to be affected in HIV; disfiguring conditions, such as Kaposi's sarcoma, are particularly distressing. Body presentation relates to how the body functions; in HIV, this may be affected both physically and mentally, with a sense of loss of control as a result of conditions such as diarrhoea. Body ideal relates to personal expectations of how an individual believes their body should look and function; again, this is often compromised by HIV infection.

The side effects of HAART may significantly affect body image, with lipodystrophy being a particularly feared consequence. Problems such as lipodystrophy and weight loss are often perceived as 'hallmarks' of HIV and, if experienced, therefore inevitably disclose HIV status, along with all the feared consequences related to stigma, prejudice, discrimination, rejection and persecution. In addition, side effects of HAART that impact upon body image can be contributing factors to poor treatment adherence.

Cognitive behavioural therapy has both strength and utility in its application. This type of therapy has the ability to identify proximal factors that precipitate and maintain body image concerns, such as distorted patterns of thinking and behaviours (for example, attentional biases such as selectively attending to disliked body areas) and a biased interpretation of this (for example, others will now see that I am HIV positive), and avoidance [25]. Cognitive restructuring can be used to reframe dysfunctional thoughts that contribute to low self-esteem, which can be pervasive among people with HIV [26].

Sexual dysfunction is common in HIV-positive people. It can have numerous origins including the physiological impact of the virus, side effects of HAART and side effects of antidepressants. This can also arise as a result of psychological factors, such as secondary to depressive illness, low self-esteem, poor body image and anxiety about infectivity. Sexual dysfunction can therefore be a factor in

altered body image and in turn may contribute to low self-esteem. Experiences that involve sexual guilt, humiliation and rejection can also impact upon sexual self-esteem and sexual functioning, which may be particularly pertinent in patients with HIV [27]. Shame has been demonstrated to significantly correlate with low self-esteem [28].

Depressive illness may develop in response to altered body image and therefore contribute to low self-esteem. In turn, this may adversely affect body image as depression distorts body image due to negative evaluations, perceptual distortions and attentional biases, which develops into a vicious circle maintained by cognitions and behaviours.

Trauma

Cognitive models are a steady state but, when dealing with adjustment, reactions to loss and trauma are a continuum [29]. The reality of HIV infection and its associated illnesses is a chronic stressor, which may result in chronic hyper-vulnerability to hopelessness, helplessness and self-blame. The therapist should be mindful that this could create obstacles when challenging negative automatic thoughts and core beliefs, possibly making cognitive therapy for this patient group more arduous and prolonged. People with HIV are in a constant state of flux with numerous critical incidents; these critical incidents relate to any significant event; for example, experiencing opportunistic infections, starting treatment, treatment failure and an AIDS diagnosis. Hence, the cognitive model of trauma may be beneficial for working with patients in this situation.

The diagnosis of HIV can itself be seen as a trauma. It is also important to recognise the high incidence of other types of trauma in this patient group, such as rape, torture, war, abuse, violence and separation. Not surprisingly, there is a high level of post-traumatic stress disorder recorded in asylum seekers and refugees [30], a group of people who are disproportionately affected by and infected with HIV. Trauma experiences can impact upon mood resulting in depression and anxiety, with specific types of trauma leading to low self-esteem, guilt, shame and self-blame. Primary cognitive components or determinants of guilt in trauma often relate to numerous cognitive distortions, resulting in individuals drawing faulty conclusions about their role in the trauma [31]. Body image may also be adversely affected if mutilation, rape, sexual abuse and/or humiliation have occurred. The use of a cognitive model for trauma [32] may be of particular benefit for such patients, with treatment interventions directed at exposure with cognitive restructuring. Therapists should be aware of possible difficulties in therapy relating to trust, and potential cultural differences associated with the type of trauma and an individual's background.

Conclusion

This article has hopefully raised awareness of the psychological and psychiatric impact of HIV/AIDS, with particular reference to the cognitive and behavioural elements of such problems. It is not within the scope of this article to discuss psychiatric or psychological intervention for these problems, or the particular benefits of cognitive behavioural therapy. However, increased awareness should improve detection and recognition of such problems by non-mental health workers who are caring for people living with HIV/AIDS (PLWHA), and increase their ability and confidence in referring such difficulties to specialist mental health services.

Despite the significant body of literature documenting high levels of psychiatric and psychological morbidity in PLWHA, nationally there is limited provision of specialist psychological services for this patient group. With the UK Government and policy focussing primarily upon serious and enduring mental illness, people with HIV are often dismissed as experiencing 'normal reactions' to a significant life event and therefore perceived as not requiring specialist psychological intervention. Please refer to Panel 1 for recommendations for practice.

Cognitive processes are clearly significant in the development and maintenance of both psychological and psychiatric disorders in people living with HIV. There is a clear role and responsibility for all healthcare professionals working with this patient group to ensure such difficulties are detected and managed appropriately.

References

1. Chesney M and Folkman S. Coping with HIV infection. *Chronic Diseases* (Stein M and Baum A, eds), Lawrence Erlbaum, New Jersey, 1995, 11-133.

Panel 1: Recommendations for practice

- Be able to demonstrate effective listening and questioning skills.
- Demonstrate an empathetic, non-judgemental and approachable manner.
- Further training for non-specialist mental health workers in recognising and referring HIV-related mental health problems.
- Increased provision of specialist mental health services for people living with HIV/AIDS (PLWHA).
- Knowledge and skill development for mental health workers to provide psychological therapies that have been shown to be effective for HIV-positive patients, for example, cognitive behavioural therapy.
- All healthcare professionals working with PLWHA must take shared responsibility for raising awareness of these needs and advocating services responsive to such individuals, which are proven to be effective and maximise the use of resources.

2. Zinkernagel C, Taffe P, Rickenbach M *et al*. Importance of mental health assessment in HIV infected outpatients. *J Acquire Immune Defic Syndr*, 2001, **28**, 240–249.
3. Coumos F, Empfield M, Horwath E *et al*. HIV seroprevalence among patients admitted to two psychiatric hospitals. *Am J Psychiatry*, 1991, **148**, 1225–1230.
4. Bing EG, Burnam MA, Longshore D *et al*. Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Arch Gen Psychiatry*, 2001, **58**, 721–728.
5. Lyketsos CG, Hanson A, Fishman M *et al*. Screening for psychiatric morbidity in a medical out patient clinic for HIV infection: the need for a psychiatric presence. *Int J Psychiatry Med*, 1994, **24**, 103–113.
6. Catalan J. *Mental Health and HIV Infection*. University College London Press, London, 1999, pp 21–41.
7. Kubler-Ross E. *On Death and Dying*. Tavistock, London, 1970.
8. Silversides A. Depression often undertreated in HIV/AIDS. *Canadian Med Assoc J*, 1998, **158**, 391–392.
9. Brown GR, Rundell JR, McManis SE *et al*. Prevalence of psychiatric disorders in early stages of HIV infection. *Psychosom Med*, 1992, **54**, 588–601.
10. DeSilva KE, LeFlore D, Marston BJ and Rimland D. Serotonin syndrome in HIV infected individuals receiving antiretroviral therapy and Fluoxetine. *AIDS*, 2001, **15**, 1281–1285.
11. Murphy JM, Sobol AM, Neff RK *et al*. Stability of the prevalence of depression and anxiety disorders. *Arch Gen Psychiatry*, 1984, **41**, 990–997.
12. Blanch J, Rouscaud A, Hautzinger M *et al*. Assessment of the efficacy of a cognitive behavioural group psychotherapy programme for HIV infected patients referred to a consultation liaison psychiatry department. *Psychother Psychosom*, 2002, **71**, 77–84.
13. Beck AT, Kovacs M and Weissman A. Hopelessness and suicidal behaviour. *JAMA*, 1975, **234**, 1146–1149.
14. Mitchell C. Suicidal behaviour and HIV infection. In: *Mental Health and HIV Infection* (Catalan J, ed), University College London Press, London, 1999, pp 114–131.
15. Beck AT. *Depression: Causes and Treatment*. University of Pennsylvania, Philadelphia, 1967.
16. Penedo FJ, Antoni MH, Schneiderman N *et al*. Dysfunctional attitudes, coping and depression among HIV seropositive men who have sex with men. *Cogn Ther Res*, 2001, **25**, 591–606.
17. Sherr L, Hedge B, Steinhart K *et al*. Unique patterns of bereavement in HIV: implications for counselling. *Genitourin Med*, 1992, **68**, 378–381.
18. Green J. Dealing with anxiety and depression. In: *Counselling in HIV Infection and AIDS* (Green J and McCreaner A, eds), Blackwell, Oxford, 1989, pp 174–197.
19. Pratt R, Stephens T and Gibson K. The individualized care of patients with HIV disease. In: *HIV and AIDS: A Foundation for Nursing and Healthcare Practice* (Pratt RJ, ed), Arnold, London, 2003, pp 264–318.
20. Cote JK and Pepler C. Cognitive coping intervention for acutely ill HIV positive men. *J Clin Nurs*, 2005, **14**, 321–326.
21. Blackburn IM and Davidson KM. *Cognitive Therapy for Depression and Anxiety: A Practitioner's Guide*. Blackwell, Oxford, 1990.
22. Wells A. *Cognitive Therapy of Anxiety Disorders: A Practice Manual and Conceptual Guide*. Wiley, Chichester, 1997.
23. Corrigan P. The impact of stigma on severe mental illness. *Cogn Behav Prac*, 1998, **5**, 201–222.
24. Price B. *Body Image: Nursing Concepts and Care*. Prentice Hall, Hemel Hempstead, 1990.
25. Reas DL and Grilo CM. Cognitive behavioural assessment of body image disturbances. *J Psychiatr Prac*, 2004, **10**, 314–322.
26. Thomson BT, Bachanas PJ and Campos PE. Cognitive behavioural interventions with persons affected by HIV/AIDS. *Cogn Behav Prac*, 1996, **3**, 417–442.
27. McCarthy BW. The effects of sexual guilt, humiliation and rejection in sexual functioning. *J Sex Educ Ther*, 1987, **13**, 25–28.
28. Yelsma P, Brown NM and Elison J. Shame focused coping styles and their associations with self-esteem. *Psychology Rep*, 2002, **90**, 1179–1189.
29. Moorey S. When bad things happen to rational people: cognitive therapy in adverse life circumstances. In: *Frontiers of Cognitive Therapy* (Salkovskis P, ed), The Guilford Press, New York, 1996, pp 450–469.
30. Van der Veer G. *Counselling and Therapy with Refugees and Victims of Trauma: Psychological Problems of Victims of War, Torture and Repression*. Wiley, Chichester, 1998.
31. Kubany ES and Manke FP. Cognitive therapy for trauma related guilt: conceptual bases and treatment outlines. *Cogn Behav Prac*, 1995, **2**, 27–61.
32. Ehlers A and Clark DM. A cognitive model of post-traumatic stress disorder. *Behav Res Ther*, 2000, **38**, 319–345.

Correspondence to: Angela Lavery, Clinical Nurse Specialist, Department of Liaison Psychiatry, Leeds General Infirmary, Great George Street, Leeds, West Yorkshire, LS1 3EX, UK.
(email: angela.lavery@leedsth.nhs.uk)

HIV NURSING INCLUDED IN ONLINE DATABASES

The editorial team is pleased to announce that *HIV Nursing* has been selected for inclusion by Elsevier Bibliographic Databases.

This means that you will now be able to search for specific journal articles on EMBASE, EMNursing, Compendex and GEOBASE, as well as Mosby Yearbooks and Scopus. Scopus was launched only last year, and is already the largest abstract and indexing database of scientific literature in the world.

We hope that our inclusion on these databases will prove useful to our readership.

For more information, visit:

http://www.elsevier.com/wps/find/bibliographic_browse.cws_home

<http://www.info.scopus.com>

The Mental Capacity Act (2005): an HIV case review

Eileen Nixon

HIV Nurse Consultant, Brighton and Sussex University Hospital Trust, Brighton, UK

Case scenario

The following is based on an actual case, although names and some details have been changed to protect anonymity.

Joseph is a 42-year-old man from North Africa who was diagnosed HIV-positive on hospital admission following a presentation of pulmonary tuberculosis (TB). His CD4 count was 17 cells/ μ L with a viral load of >750,000 HIV-1 RNA copies/mL. Following a short period of induction therapy for TB, he started on antiretroviral therapy in line with British HIV Association guidelines [1].

After three weeks of hospitalisation and some improvement in his health status, Joseph began to refuse all nursing and medical interventions, including his TB and antiretroviral therapy. He also refused all meals and personal care from the

nursing team, but remained too unwell to undertake any care for himself.

Joseph did not engage in any discussions regarding his treatment, care or prognosis, and gave neither explicit nor implied consent for any investigations or procedures to improve his health status. He had no next of kin or significant other in the UK. He was fluent in English, his preferred language of communication on admission and with any visitors from his own country.

The HIV team involved in Joseph's care decided to surgically insert a percutaneous endoscopic gastrostomy (PEG) tube without consent from Joseph, in order to ensure administration of TB and antiretroviral medication.

Introduction

When patients are not able to consent to treatment or interventions, it raises a number of questions about our professional role of protecting and caring for patients and how to act in their best interests. This article examines how The Mental Capacity Act 2005 [2] can be effectively utilised where capacity to consent is impaired, and how the clinical team can ensure that decisions are made within legal and professional frameworks.

The process of consent

Consent, as defined by the Department of Health, is 'a patient's agreement for a health professional to provide care' [3]. Consent can be non-verbal, verbal or written.

The Nursing and Midwifery Council (NMC) Code of Professional Conduct (2004) states in Section 3 that nurses should respect patient autonomy with regard to consent, even if refusal to consent could result in harm or death of a patient. The code also states that care can be given without consent in order to preserve life, provided this is in the best interests of a patient [4].

In a clinical situation such as Joseph's (see Case scenario), what informs our judgement that a patient is making an autonomous decision regarding his refusal to consent to treatment and care?

By the time a patient's refusal to consent has been raised as an issue within a clinical team, we have already made a number of judgements about that particular patient. Our duty of care may have been compromised by a refusal of treatment and we may not agree with a patient's decision to end his or her life when we believe that treatment and care could alter that path. It is important to put our personal judgements aside and be certain that all necessary actions and assessments are undertaken in order to ensure that the right decision is made for each individual. We must presume that all patients have capacity to consent unless there is evidence to the contrary [2].

The most obvious initial course of action is to ensure that every opportunity has been taken to communicate effectively with a patient regarding the implications of his or her refusal of care. It is important to be realistic about prognosis and the chances of recovery with and without treatment, and quality of life should also be discussed in detail. Utilising members of the multidisciplinary team, including medical and counselling professionals as well as a named nurse, can offer different perspectives. A holistic and balanced approach is important.

In view of Joseph's co-infection with TB and advanced HIV disease, it was difficult to pitch the urgency of his clinical needs against the time that he might require to adjust to his new health status

and all the psychosocial facets associated with his diagnosis. Ability to consent can be affected by shock and illness and Joseph had a very complex asylum issue that may also have influenced his refusal to consent.

In circumstances where there is no next of kin or significant other, it is important to offer a patient the opportunity to talk to someone outside the clinical team such as a hospital chaplain, patient advocate or member of a similar ethnic group. This was arranged for Joseph, but he declined to communicate with anyone.

Unfortunately, the crucial factor in Joseph's case was that he had a notifiable infectious disease and refusal to consent to TB therapy could therefore have resulted in compulsory detention under Sections 37 and 38 of the Public Health Act, where compulsory treatment is not permitted and the patient is likely to die [5]. In view of Joseph's continuing refusal to communicate with the clinical team or any other individual, his capacity to consent was assessed in order to identify the optimum management for his individual circumstances.

Establishing capacity to consent

The Mental Capacity Act (2005) [2], which replaces Part 7 of The Mental Health Act (1983), gives health professionals clear guidance regarding capacity to consent. Although this act will not be fully implemented until 2007, and some aspects are currently being consulted upon, the legislation became an Act of Parliament on 7th April 2005. The Royal College of Nursing (RCN) produced an online briefing of The Mental Capacity Act for members and other nurses in March 2005 [6]. The five key principles of The Mental Capacity Act are shown in Panel 1.

The Mental Capacity Act states that a person lacks capacity if he or she is unable to make a decision for himself or herself because of an impairment or disturbance in the functioning of the mind or brain (Panel 2).

Panel 1: The five key principles of The Mental Capacity Act (2005) [2]

- A person must be assumed to have capacity unless it is established that he or she lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Of particular relevance to Joseph's case was the absence of communication regarding any aspect of his care including his refusal of even basic assistance with the activities of daily life. A psychiatric opinion was urgently requested in order to independently assess Joseph's capacity to consent. The psychiatrist assessed Joseph as lacking capacity to consent to refusal of treatment and care, in view of the absence of verbal and non-verbal communication with the HIV team, non-clinical individuals and during the psychiatric assessment. No mental health illness was identified, although this would not necessarily impinge on capacity to consent unless the illness was inadequately treated. The psychiatrist agreed to treatment proposals and prescribed mild sedation to enable the team to administer treatment and care with minimal resistance from Joseph. When the Act is fully implemented, the use of an independent mental capacity advocate will be recommended and, in the absence of any significant others in Joseph's case, the role of this advocate might have been beneficial in representing the patient's interests more holistically. In the absence of an advocate, the clinician in charge of the patient's care assumes that responsibility.

Deciding on the best interests of patients

Decisions concerning the best interests of patients should be based on whether the patient is likely to regain capacity in the future. These decisions need to be made across the multidisciplinary team and all team members should be involved in reaching an agreement regarding the best interests of a patient. Given the potential benefits of TB and HIV therapy for Joseph, a gastrostomy tube was inserted for the administration of medications and nutrition. It is permissible under The Mental Capacity Act to administer a treatment that is 'reasonable in the circumstances' [6] and the goal of this treatment plan was to improve the patient's

Panel 2: Four criteria for incapacity: The Mental Capacity Act (1995) Part 1, Section 3 [2]

- Inability to make a decision is defined as being when a person:
- Is unable to understand the information relevant to the decision;
 - Is unable to retain that information;
 - Is unable to use or weigh that information as part of the process of making the decision; or
 - Is unable to communicate his or her decision (whether by talking, using sign language or any other means).

health status so that he was able to communicate his wishes effectively in the near future. In the meantime, it is essential that the team continues to encourage the patient to be actively involved in all aspects of his care.

Conclusion

Nurses have a key role to play in obtaining consent from patients and in reporting when refusal of consent is likely to result in harm to the patient. The Mental Capacity Act (2005), although not yet implemented, gives clear guidance in assessing capacity to consent and in the processes required to reach decisions in the best interests of patients.

The HIV field is no stranger to patient choice, particularly with regard to patient decisions to stop treatment or care. The key questions for nurses and other HIV professionals should be whether this choice is informed, whether the patient has capacity to consent and whether the patient has an adequately treated mental health illness.

Postscript: One month after the administration of TB and antiretroviral therapy, Joseph made a significant recovery and was discharged from the

acute inpatient unit for convalescence. As his health improved, he was able to communicate that he wished to continue with treatment.

References

1. Posniak, AL, Miller RF, Lipman MC *et al*. BHIVA treatment guidelines for tuberculosis (TB)/HIV infection. *HIV Medicine*, 2005, **6** (suppl 2), 62-83.
2. Department of Constitutional Affairs. The Mental Capacity Act (2005). Department of Constitutional Affairs, 2005.
3. Department of Health, *Good Practice in Consent Implementation Guide*. Department of Health, 2001.
4. Nursing and Midwifery Council. *The NMC Code of Professional Conduct: Standards for Conduct, Performance and Ethics*. Nursing and Midwifery Council, 2005.
5. Joint Tuberculosis Committee of British Thoracic Society. Chemotherapy and management of tuberculosis in the UK: recommendations 1998. *Thorax*, 1998, **53**, 536-548.
6. Cox C. Legal Issues for Nurses: Capacity and Consent including The Mental Capacity Act 2005. <http://www2.RCN.org/management>

Correspondence to: Eileen Nixon, HIV Nurse Consultant, Brighton and Sussex University Hospital Trust, Eastern Road, Brighton, BN2 5BE, UK. (email: Eileen.Nixon@bsuh.nhs.uk)

Endorsed by the British HIV Association (BHIVA)

What we should all know about HIV & AIDS

To order your copies, complete and return this form.

What we should all know about... is a series of patient-oriented booklets produced by Mediscript in conjunction with leading medical experts. Written in easy-to-understand terms, the facts of the condition are explained and issues frequently raised in consultation are addressed in a questions and answers section.

First published in 1995, *What we should all know about HIV & AIDS* has been fully revised and updated in consultation with Dr Martin Fisher who is based at The Elton John Centre in Brighton, a leading specialist unit for the treatment of HIV/AIDS patients. The 2000 edition of this handy-sized book reflects the latest developments in understanding and treatment of HIV infection and its complications (medical, psychological and social) and is an invaluable guide to General Practitioners, patients and carers involved in the management of HIV.



In such a fast-changing field of medicine, sources of up-to-date information are the key to good practice. Therefore, in addition to a comprehensive list of support groups, this new edition includes useful websites where more details on specific aspects of HIV disease can be found.

Published by Mediscript. Size 122 x 185mm. 80pp (approx). Stiff cover. Price £4.50 (RRP). ISBN: 1-871211-66-2

Essential information on:

- Avoiding infection
- Anti-HIV treatment
- Legal and financial issues
- Virus & immune system
- HIV complications
- Support groups & counselling
- Having an HIV test
- Women & children & HIV

ORDER FORM

What we should all know about HIV & AIDS (Second Edition)

RECOMMENDED RETAIL PRICE £4.50

Quantity	Price per copy* £
1 - 99	4.50
100 - 249	4.25
250 - 699	4.00
700 - 999	3.75
1,000 - 2,000	3.50

* Prices are exclusive of carriage and VAT thereon.

I would like to order _____ (qty) copies of the above publication at £ _____ (price) per copy, shown above. Total £ _____

Name: _____

Institution/Company Name: _____

Address: _____

Telephone Number: _____

Fax Number: _____

E-mail Address: _____

Delivery/Invoice instructions (if different from above address)

NB We cannot deliver to a PO Box Number.

Signed: _____ Date: _____

Please print name: _____

PLEASE RETURN THIS ORDER FORM TO:
Mediscript Ltd, 1 Mountview Court, 310 Friern Barnet Lane, London N20 0LD.
Telephone: +44 20 8446 8898 Facsimile: +44 20 8446 9194

Care issues for inpatients – HIV and mental health

Flick Thorley

Clinical Nurse Specialist HIV and Mental Health,

Chelsea and Westminster NHS Trust, Central and North West London Mental Health NHS Trust, London

In the Western world, most major HIV events and experiences can be divided into two eras: the pre-HAART era (before 1996) and the post-HAART era (after 1996). People who work in the field of HIV often identify themselves in the same way: were they there in the beginning pre-HAART or did they enter the field of HIV in the post-HAART era? (It is interesting that you can still be 'new' to something having already been doing it for ten years.)

My personal experiences and reflections are in the context of working in central London, either with access to specialist HIV mental health services or being involved in providing them. When I was asked to write this article, I started thinking about all the situations I have experienced in relation to people living with HIV who also had various mental health problems. As I am one of those old dinosaurs who were around before 1996, I immediately started defining and differentiating these individuals by the pre- and post-HAART era cut-off point. But then I thought: is it important? Does it matter what was going on prior to 1996? Does what happened in 1996 affect how we manage inpatients with mental health problems now? I believe the answer has to be yes, because many of the ways we do things now have been informed by the way we did things then. Before the availability of HAART, psychological difficulties in an HIV setting were significantly different from those we see today. We regularly saw individuals with no previous psychiatric histories presenting with severe depression, manic episodes (often requiring hospitalisation), severe cognitive impairment and damage as the result of deliberate self-harm. We also saw many more patients with brain disorders such as HIV dementia, progressive multi-focal leukoencephalopathy (PML), cytomegalovirus (CMV), encephalitis and toxoplasmosis. These patients often needed psychiatric intervention to help with medication and management, but still had poor prognoses and outcomes. If someone with HIV presented with mental health problems in the pre-HAART era, the cause of the mental health problem could sometimes be seen as irrelevant. The symptomatic treatment options were the same – psychotropic (anti-psychotics), anxiolytic or antidepressant medication and/or psychological intervention (talking therapy and/or crisis management).

The difference now is that if the brain infection and resulting mental health problem are the direct result of an HIV-related opportunistic infection, the underlying cause can be treated with antiretrovirals, and an improvement in immune

response could resolve the mental health problem. Psychiatric medication has also improved, with newer drugs possessing reduced toxicities and side effect profiles, making the symptomatic management of these illnesses easier for all. The significant change between the pre- and post-HAART eras has been the reduction in the number of people presenting with end-stage disease-related issues such as HIV-related dementia, mania, psychotic presentations and suicidal behaviours, and the attendant reduction in acute stress disorders and the complexities of coping with terminal illness. Unfortunately, when this does happen (and it does), we are often less prepared, less skilled and more poorly resourced to deal with the problem than we were in the pre-HAART era. Although the numbers are far fewer, people still get sick as a result of late diagnosis and presentation, previous lack of access to antiretrovirals, inability to or personal choice not to take antiretrovirals, or exceptional circumstances. The issues pertaining to more patients now are how to help them live with HIV and not die from this disease.

Mental health

Mental health problems can affect anybody, but they do affect a substantial number of people living with HIV [1]. The reasons for this are complex and can include many factors, such as HIV-related stressors, individual social circumstances, psychiatric history, personality traits, adverse life events such as bereavement and demographic influences. Most statistical data regarding HIV and mental health were collected before the availability of HAART. Although these facts and figures are still used, there are some anecdotal differences between the pre- and post-HAART eras.

Patients can present with mental health difficulties in different ways. Many people can cope without any external intervention. Some people have severe and enduring illnesses such as schizophrenia, repetitive episodes of depression and bipolar affective disorder (BAD or manic depression), which impact on their everyday lives and activities. In a general hospital, whether it is a designated HIV ward or a general medical ward where people with HIV happen to be, you are less likely to see severe and enduring mental health problems, and more likely to see people with HIV-related mental health problems such as mood disorders, adjustment disorders, sleep disorders, substance dependency and organic brain syndromes. However, HIV-related mental health

problems may seem both severe and enduring to the individual experiencing them.

Being admitted to an HIV ward can be a terrifying experience for an HIV-positive individual. Sometimes it is the first port of call following their diagnosis. A hospital admission tends to be stressful for anyone, but to be HIV-positive and surrounded by people with varying HIV related infections can potentially leave a person frightened that they are staring at their own fate. There may be patients with advanced disease, undergoing chemotherapy (a common sight in an inpatient setting), or displaying 'odd' or frightening behaviour due to neurological illnesses. Why are we then surprised that some patients display psychological difficulties, for example they cannot sleep, display signs of anxiety, become withdrawn and uncommunicative, appear sad and tearful, or at times just disappear and do not come back? (Okay, I can only think of one person who did that.) These symptoms are generally only of psychiatric concern if they are severe or sustained over more than a few weeks.

It is important to fully assess HIV-positive patients. Try to understand their premorbid state prior to admission, and ascertain their normal coping strategies and perception of their own situation before crash-calling the psychiatric team. Develop a relationship with him or her. Having an empathic approach and actively listening to someone can sometimes be all that is necessary to alleviate someone's fears and anxieties.

If your assessment raises concerns, further assessment and support from a psychiatric colleague may be appropriate, where he or she will thoroughly assess mood, cognitive function, risk and abnormalities in thinking and perception. When you have concerns about someone's safety, do not hesitate to get help. Psychiatric liaison nurses or psychiatrists are the people to call.

Remember that everyone is an individual and communication with patients about their needs is essential. It is never okay to describe someone as mad no matter how unusual they may seem to you. How would you feel if you heard someone talking about you like that?

Psychopharmacological treatments

Some HIV-positive people appear to be more sensitive to drugs than the HIV-negative population [2]. Because there is the same potential for interactions between HAART and psychiatric medication that exists between many other drugs, it is useful to know what is less likely to cause problems, and since nurses look at drug charts very frequently, you are often best placed to flag up a problem.

Antidepressants that are generally safe to use with HAART are from the newer classes, which include selective serotonin re-uptake inhibitors (SSRIs) such as citalopram, and also mirtazapine, venlafaxine and reboxetine. Some of the older antidepressants

(known as tricyclics) are used in HIV to manage the symptoms of peripheral neuropathy. These are commonly amitriptyline and lofepramine.

It is very important that a person is not on one of the newer antidepressants and a tricyclic at the same time. If they need the pain-killing properties of tricyclics and are clinically depressed, it may be better to increase the dose of the tricyclics to a therapeutic psychiatric dose and get the benefit of both properties. This is associated with potential risks because the tricyclics can be lethal in an overdose (whereas the newer drugs are not) and is important to assess a patient's mood and suicide risk before considering increasing the dose.

The newer antipsychotics such as risperidone and olanzapine are better tolerated than the old drugs (such as haloperidol and chlorpromazine) with fewer side effects in general, but they can still cause difficulties. Again, HIV-positive people tend to be more susceptible to side effects and generally need lower starting doses. Caring for someone in an inpatient setting gives valuable assessment opportunities over each 24-hour period.

The Mental Health Act

The Mental Health Act (1983) [3] is designed to support and manage individuals detained by psychiatric services, not general hospitals (Panel 1). One of the complicating factors of caring for someone under the Mental Health Act (1983) (MHA) in a general hospital is that the responsible medical officer (RMO) is the Consultant in charge of the detained patient. This is the physician on the ward, not a psychiatrist. Many general hospitals have access to advice from a local psychiatric unit or direct support from liaison psychiatry (liaison psychiatry being mental health provision associated with physical illness and within non-mental healthcare settings), but as this service is often provided by a separate mental health trust, the psychiatrist might not be the RMO or responsible for the legal documentation. This is worth clarifying in your own workplace.

The MHA is a huge and complex document and, if you wish to understand more about it, there is a very accessible guide available on the internet [4].

The MHA is divided into sections. This is where the term 'being sectioned' appears to come from: it means being compulsorily admitted to hospital. When a patient is either transferred to your ward on a section, or is sectioned while there, there are legal requirements regarding the paperwork involved. Most hospitals will have designated either one person or a team of people to be responsible for accepting section papers on behalf of the hospital managers. In my experience, this is usually either the clinical site manager or the bed manager. Please check who this designated person is in your own trust.

We often come across people who we think are making bad decisions and disagree with their

Panel 1: The Mental Health Act (1983)

There are specific issues relating to someone who needs assessment and/or detention under the Mental Health Act (1983) in a general hospital:

- The Mental Health Act (1983) is an act of Parliament which applies to England and Wales.
- The Mental Health Act (1983) governs:
 - Admission to hospital against a person's will;
 - A person's rights while in hospital;
 - Discharge from hospital;
 - Aftercare following discharge.

Panel 2: The most commonly used sections in a general hospital

- Section 5(2). People who are already patients in hospital can be detained by a doctor (either their HIV consultant or their representative) pending a further assessment. Section 5(2) lasts for 72 hours and a formal psychiatric assessment must be arranged within this timeframe. This constitutes an assessment by a psychiatric Approved Social Worker (ASW) and at least one psychiatrist legally trained to assess for section, and another doctor (often their GP).
- Section 2. Admission for assessment for up to 28 days [often the section following an assessment on a general ward while someone is detained under a 5(2)].
- Section 3. Admission for treatment for up to 6 months (initially).

choices. This does not mean they are sectionable, or most of us would have been sectioned at least once. If an individual is deemed to have capacity, no-one has the right to make decisions for them or detain them against their will; to do so would constitute assault. To have capacity, patients must:

- Understand the decision and possible consequences;
- Understand any alternative courses of action;
- Assess which course of action would be reasonable;
- Retain memory of the decisions and reasons for them;
- Be able to communicate their intent.

People detained under section on a general ward (Panel 2) often require one-to-one nursing by either a Registered Mental Nurse or sometimes an experienced B-grade nurse. This is not a legal requirement but a decision based on the individual circumstances or local policy.

Mental health treatment can be given against someone's will under the MHA (refer to Consent to Treatment); physical treatment cannot. For example, if someone is detained under the MHA and suddenly refuses to take their antiretrovirals, there is nothing you can do other than devote time, patience and perseverance. The only exception to this is in the case of a physical illness which gives rise to a mental illness, or a specific opportunistic infection where the antiretroviral treatment could

improve the physical condition of the patient (which would then directly have a positive impact on the mental illness). This is an unusual situation but it does occur.

Training and support

One of the biggest concerns for inpatients with mental health problems is feeling that they are safe; contained by their environment and by the attitude and skills of the staff caring for them. General nurses are frequently frightened of people who display mental health difficulties (in the same way a psychiatric nurse might panic at the thought of a temperature or diarrhoea), which can lead to them avoiding contact with patients. This can be for a multitude of reasons which include patients who are: disruptive, time consuming (time which is not available), frightening, demanding, inappropriate or in the wrong place ... (add your own). But all of these will probably lead to the same outcome: the patient will feel more isolated and alone.

Inpatient psychiatric units can be inappropriate places for someone with a physical illness, particularly for someone who may be frail or have acute physical health needs. Sadly, in my own experience, they are also often places where homophobia, ignorance and prejudice about HIV are alive and well. This means that a patient with mental health problems may remain under your care even if it seems that it is not the best place for them. Adult mental health services are also very reluctant to take on young people with illnesses such as dementia, which can lead to extended hospital stays, delayed discharges and placement problems. It is important to use whatever local psychiatric support you have available to try to address this if it occurs.

Training for HIV-related mental health is available in a variety of settings, and many specialist nurses such as myself are keen to teach and share experiences which may make your job easier, and patients' experiences better. It can be very challenging caring for someone with mental health problems in a general health setting, but it is worth remembering that no matter how difficult it is for us, the chances are that it is much harder for them.

References

1. Catalan N J (ed). *Mental Health and HIV Infection*. UCL Press, London, 1999.
2. Catalan N J and Thornton S. Mental Health. In: *AIDS Care Handbook* (Gazzard B, ed), Mediscript Ltd, London, 2002, pp 199-212.
3. Department of Health and Welsh Office. *The Mental Health Act (1983) Code of Practice* (3rd edition). The Stationery Office, London, 1999.
4. Nigel Turner's *Hyper Guide to the Mental Health Act*. www.hyperguide.co.uk/mha

Correspondence to: Flick Thorley, Clinical Nurse Specialist HIV/Mental Health, Thomas Macaulay Ward, Chelsea and Westminster Hospital, 369 Fulham Road, London, SW10 9NH, UK.
(email: flick.thorley@chelwest.nhs.uk)

Chronic illness and sexuality needs: HIV-positive homosexual men

Mary McCreaddie

Senior Lecturer (Research), University of Paisley, UK

Sexuality needs are considered a fundamental part of healthcare provision [1,2]. The evidence suggests, however, that nurses continually neglect to provide their patients with adequate sexual healthcare [3] and are reluctant to be proactive in discussing sexuality needs with patients [4]. Despite this, Waterhouse and Metcalfe [5] stated that, in a sample study, 92% of patients considered a nurse as the most appropriate individual with whom to discuss sexuality needs.

Nurses may not consider themselves 'qualified' to discuss sexuality needs and issues, particularly with homosexual patients [4], and patients do not wish to see or be referred to a specialist [6]. Indeed, knowledge and a degree of comfort are both essential when discussing potentially sensitive issues with patients [1]. Matocha and Waterhouse [7] claimed that the provision of education on sexuality issues for nurses does impact upon nursing interventions in this area.

This article provides a brief introduction to the issue of sexuality needs and chronic illness, and reports on a grounded theory study looking at the sexuality needs of HIV-positive homosexual men.

Chronic illness and its impact on sexuality needs

Shover and Jensen's integrative model of sexual healthcare demonstrates the totality of sexuality needs as it encompasses psychological, biological and social needs [6]. Figure 1, for example, shows how a single problem in testicular cancer can have an impact across the wide spectrum of sexuality needs. In order to gauge the true impact of a chronic illness on an individual's sexuality needs, it is important to be aware of the person's previous norms, such as sexual activity. In addition, individuals may have 'sexual baggage' in terms of a negative outlook on sexuality issues, for example, 'sexual intercourse is dirty' [8]. Moreover, patients may be misinformed and could harbour certain myths, such as 'cancer is contagious' [9].

Hospitals tend to be rather asexual places with name tagging, regulation of daily living and activities, in addition to a lack of autonomy and privacy. Thus, healthcare staff need to be aware of the consequences of the chronic illness on an individual, as well as potential impact of the hospitalisation process. There is also a degree of subtlety required in assessing when, how and where it is appropriate to discuss sexuality needs of patients [10].

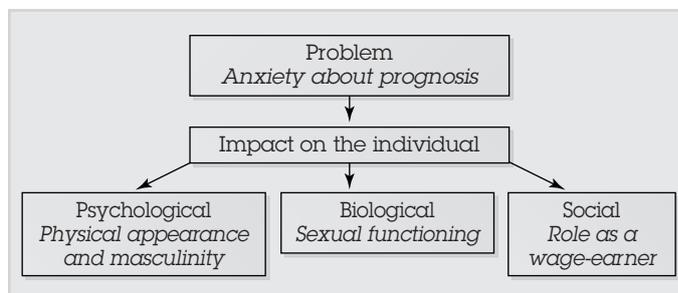


Figure 1: The different effects chronic illness has on sexuality needs in men with testicular cancer.

HIV and testicular cancer as chronic illnesses

Male patients with testicular cancer and homosexual men with HIV are now living longer as a result of advances in treatment [11,12]. In testicular cancer, the cure rate for those with early detection of the disease is reported as being in the region of 95% [11]. For HIV, however, a cure is yet to be discovered. Nonetheless, the life expectancy of an HIV-positive person with an AIDS-defining illness has increased from 2.5 to 5.5 years [12] and is expected to increase further. Both illnesses and their treatments, whether short or long term, do have an effect on the sexuality needs of the individuals concerned. Whereas cancer and HIV are both priority health topics for primary health promotion in Scotland [13], it is becoming increasingly recognised that secondary and tertiary health promotion (health promotions covering post-diagnosis stage to chronic illness) also need to be addressed [14].

Study design and structure

Following informal discussions with colleagues working in cancer care, it was clear that chronic illness and sexuality needs are an under-developed and poorly managed aspect of healthcare. Therefore, it was decided to investigate the issue of sexuality needs further by comparing and contrasting the needs of two different groups – men with testicular cancer and HIV-positive homosexual men. We then obtained funding for the study from the National Board Scotland (now NHS Education Scotland) through the small grants scheme.

The study was based on a qualitative design in order to assess the information obtained from the recruited participants. A grounded theory [15] approach was used because this design is based on the belief that knowledge is socially constructed

[16]. Given that sexuality can be, to a large extent, a socially and culturally constructed entity, a holistic qualitative design seemed the most appropriate approach.

A semi-structured interview schedule derived from academic literature was used (see Panel 1 for the topics covered as part of the semi-structured interview schedule). The interview schedule was initially tested in four pilot interviews, the only refinement being the addition of a checklist. Three participants were then randomly selected to verify a transcript of their respective interviews to indicate their agreement with the interpretation of the data. In addition, face validity was undertaken with colleagues, patients and through a conference presentation (face validity is the extent to which a measure appears on the surface to measure what it is suppose to measure).

Ethical issues

An information sheet was provided to participants who met the criteria for the study. Issues such as anonymity and confidentiality were included, and were later expanded upon by the researcher. Numbers were used to protect individuals' identities and any references that may identify participants, such as partner's name and places of note, were deleted. A signed consent form was then obtained from the participant before starting the interview process. Ethical approval for the study from the local ethics committee proved to be a protracted process, but was eventually obtained.

Method of sampling and data collection

The sampling method of any study should be appropriate, adequate and aimed at generating enough information to answer the questions posed [17]. The criteria for inclusion in this study are summarised in Panel 2. Participants were then recruited through their outpatient clinics. The interviews lasted for approximately one hour and were undertaken in a private room, with the exception of one interview that was carried out in the participant's home.

The interviews were transcribed verbatim and initial themes or concepts noted. Further reading of relevant literature was then undertaken to ensure

Panel 1: Topics covered in the semi-structured interview schedule

- Tell me a bit about yourself.
- How was your health (including sexuality needs) pre-diagnosis?
- Impact of diagnosis on life in general.
- How is your health now (including sexuality needs) post-diagnosis?
- Sexuality needs and healthcare provision.

Panel 2: Sampling criteria

- Self-identified homosexual male with a diagnosis of HIV or male with a diagnosis of testicular cancer.
- Non-ethnic origin.
- Aged between 16 and 50 years.
- Non-illegal drug use.
- On antiretroviral therapy or on chemotherapy.

constant comparison of the data analysed (the emerging data were informed by existing literature). Each interview was compared with the preceding interview, thus enabling constant comparison [18]. This was initially undertaken with both groups, but the failure to recruit in the testicular cancer group left the process of constant comparison incomplete. Core categories were assembled and more reading was carried out, but based only on the information available from the group of HIV-positive homosexual men. The core categories arranged around the basic social process 'fear of contagion' are depicted in Figure 2.

The cohort

The twelve participants recruited for the HIV-positive homosexual men group were aged between 22 and 48 years, with a mean age of 36 years. Three participants were still employed on a full-time basis, two attended college and the remainder were 'benefit-disabled' [12]. Benefit-disabled is a term applied to individuals who are financially better off in benefit than in paid employment, thus discouraging individuals from returning to work [12]. The earliest diagnosis of HIV status was in 1985, the latest 1996. All except two of the cohort were currently on antiretroviral therapy.

One participant was teetotal, whereas the remaining eleven consumed alcohol on a regular basis. Four of the eleven consumed significant amounts of alcohol. It transpired during the interview that only four of the participants did not use illegal drugs on a regular basis. One participant was on a methadone prescription and also took non-prescribed drugs. The main drug of choice among the cohort was cannabis.

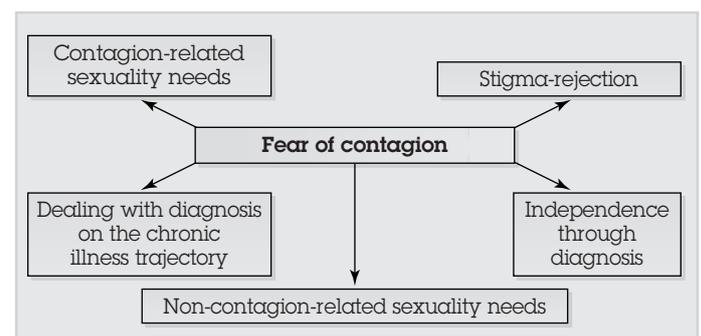


Figure 2: The basic social process including the core category and subcategories emerging from the data.

General health

All but four of the cohort had symptoms related to their HIV disease or antiretroviral therapy. This ranged from being confined to a wheelchair, nausea, diarrhoea, insomnia, weight loss to skin problems. One participant had a significant mental health problem that required medication, but this condition was unrelated to HIV or antiretroviral therapy. Seven of the cohort had taken antidepressants at some point following diagnosis, with three of the seven continuing to do so.

Results

Fear of contagion

The fear of contagion was reported as the core category that linked all other constructs. This fear was described by the HIV-positive participant or was reported by the participant as being an issue for his partner. Sexual transmission of HIV to or from a partner was the main concern. For some participants and their partners, there also existed a fear of contagion from casual contact or through open cuts or wounds.

'It's silly things like if you scratch yourself, he's there saying make sure you cover that up and he's spraying the work surface with Detox or something.'

Contagion-related sexuality needs

The fear of infecting a partner with HIV was a significant concern and an impediment to penetrative sexual intercourse (PSI) for seven out of the twelve participants. One participant had infected his current partner, having previously been infected by his former partner. Although extremely unhappy within his current relationship, he was determined not to leave his partner as:

'It would be just be like getting a woman pregnant and leaving her. I should be there for him'.

There was, therefore, a tremendous amount of guilt in infecting a partner and significant ongoing implications for the relationship. Thus, this contagion fear had a direct psychological impact upon sexual functioning:

'There was an instant attraction there between the two of us. After he moved in, I thought oh ... He was obviously looking for more in the sexual side of things and I thought ... I tried and just couldn't? The erection just disappeared and I thought, no this is wrong. I cannae do this'.

Partner support or, alternatively, the lack of partner support, could resolve these difficulties or make them a permanent feature of the relationship. Non-penetrative sexual intercourse was often the outcome of an ongoing fear of contagion (see Table 1).

Table 1: Current sexual activity within the cohort, with or without a partner

Sexual activity	n
PSI, NPSI and MMM	5
NPSI and MMM	3
MMM only	4

MMM, masturbation and/or mutual masturbation; NPSI, non-penetrative sexual intercourse; PSI, penetrative sexual intercourse.

Non-contagion-related sexuality needs

The disease process and medication both have an impact on the sexuality needs of participants, including a lack of physical energy and/or decreased sexual desire.

'There's lots of times where the desire is there, but you just can't be bothered. You want it, but you go, oh no, I would rather just go to my bed. It's not worth the hassle.'

Disability as a result of HIV disease was also an impediment to expressing sexuality needs for two of the participants.

'[My partner has] never been a particularly cuddly person but, before I was disabled, I could go to him and get the cuddle. Now I've got to lie here and I've got to depend on him coming to me for the cuddle and, of course, it doesn't happen and I've begged for it and begged for it.'

Relationship needs

Ten members of the cohort had current partners, although three of these partners could be designated practical partnerships. A practical partnership describes a partnership that may have originally been a sexual and emotional relationship, and had subsequently become a partnership based on the need to maintain a home and/or joint mortgage. These partnerships/relationships had been established for a minimum of 6 months to over 18 years within the cohort. The average length of the partnerships/relationships within the cohort was 7.4 years. All except one of the ten cohabited with their partner.

Stigma-rejection

The stigma associated with being infected with HIV was clearly felt by the participants. The enduring presence of stigma perhaps assisted in enforcing the issue of contagion and its impact upon sexuality needs. The fear of being stigmatised was also linked to the potential for rejection to follow. Thus, the potential for stigma-rejection did appear to influence an individual's decision to disclose their HIV status. Participants reported feeling stigma-rejection at work, from their family and from hospital staff. For example, one participant

explained his thoughts on stigma-rejection and the workplace:

'It sounds a dreadful thing to say, but sometimes I wish I had cancer because then people think it's okay, because they talk to you, but if you are HIV positive or have AIDS, they don't want to know'.

Another quote regarding stigma and family:

'I was really angry at my mum when she said, how did you get the virus, who gave you it and I said "if it makes any difference to you, they're dead".'

With respect to hospitals, one participant commented:

'I don't like coming to the hospital. I don't like coming. I think it's ... I just don't like it. I don't like it when people say your name out loud. I don't like that. I don't like anybody knowing any of my business. I just don't like coming to the hospital'.

Dealing with diagnosis

The diagnosis of a chronic illness can have various effects on an individual. Central to an individual's response to a diagnosis is the manner in which the diagnosis is made. For some people, diagnosis of an illness may come as a welcome relief following months or even years of uncertainty. Nine of the twelve participants had presented themselves for testing following a period of illness. For most of the cohort, the immediate impact of the diagnosis provoked extreme reactions, ranging from a dependence on alcohol:

'For the first year after it, I was drinking about a half bottle of whisky a night. Probably for about a year, I drank far too much ...',

– to one participant who described his response as:

'I went AWOL in my head'.

Following the initial post-diagnosis impact, the participants reported adopting a longer-term outlook such as gaining a perspective following diagnosis:

'The things you thought were important before are no longer important. A lot of people put a lot of importance on trivial things'.

In most instances, this perspective was attributed to the impact of the diagnosis. One participant however, offered a contrasting view, relating the diagnosis to becoming mature:

'I think my life was changing anyway before I was diagnosed. It's not to do with the HIV issue. I think it's just to do with life in general'.

Gaining perspective may lead to a number of decisions being made, such as sorting out finances, planning holidays, change of career or making plans.

'When I'm told I've got AIDS, I'm going to commit suicide because I just do not want to look not well, I don't want people to remember me being.'

One participant reported that he continued living on a day-to-day basis:

'The most I'll plan for the future now is maybe 6 months. I've just sort of grabbed life and got on with it now. Whatever happens, happens, you know?'

Independence through diagnosis

The above themes expressed the participants' perspectives and possible eventual coping strategies following diagnosis. There were, however, other sub-themes identified that were clearly mediating influences on the participants' holistic response such as being a burden (for example, the concern of having to be cared for by a partner). This sub-theme led to two specific coping strategies in order to avoid this scenario: (i) by building barriers (emotional and social barriers prevent the participant from becoming too close to a new or current partner); and (ii) by streamlining the social circle (friends, family and work colleagues were streamlined on the basis of support or lack of support they had given to the individual). One participant quoted:

'Something I've noticed about myself is that I tend to do a lot on my own now. Maybe it's just this thing that people weren't there for me when I needed them'.

In addition to the sub-themes, a further related theme demonstrated an important coping mechanism or a personal indicator that was significant, namely, looking well and feeling well (see also Figure 3). This theme indicated that

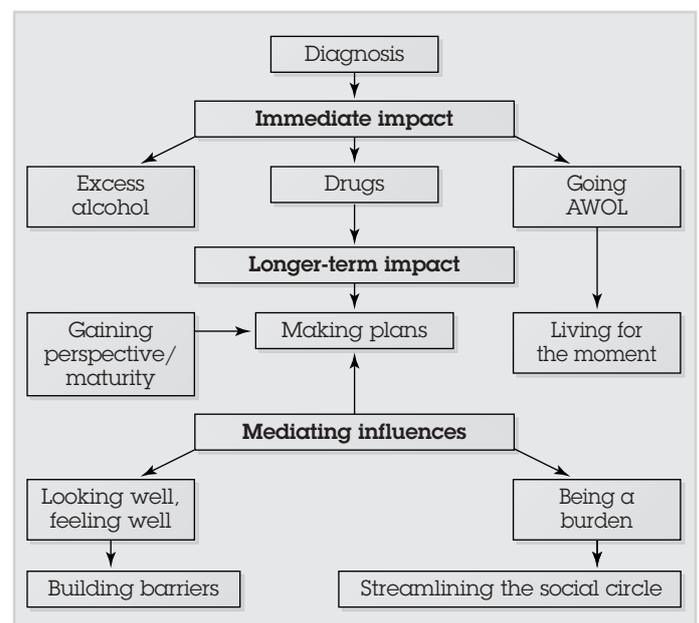


Figure 3: The context and process of sexuality needs following diagnosis.

participants were aware of the importance of markers such as CD4 counts (immune function) and viral load (viral replication). However, participants often went on much more overt and personal indicators of health:

'When your immune system is run down, your piercings start to smell sickly and when it smells like that, you know there's something wrong'.

'A lot of how I feel goes on actually how I feel'.

Sexuality needs and care provision

Participants reported that they were rarely asked about their sexuality needs within the context of their clinical consultation. Indeed, only two of the twelve participants had been specifically asked about their sexuality needs.

'I brought [sexuality needs] up a couple of times and it kind of gets pooh-pooed.'

A majority of the cohort inferred that medical staff saw sexual health and sexuality needs as separate issues from general health and/or HIV health. The suggestion was that if sexuality needs were raised then the likelihood was that the participant would be referred on, possibly to a genitourinary medicine clinic. Three participants went as far as to suggest that medical staff held the view that HIV-positive patients should not be sexually active.

Limitations of the study

It must be highlighted that this is a small study of one specific group and the findings, therefore, cannot be generalised. The failure to recruit men with testicular cancer and to compare and contrast the two separate groups augments this limitation. In addition, the participants are a self-selecting sample and may not be representative of HIV-positive homosexual men.

Discussion and conclusion

HIV is rapidly being re-classified as a chronic illness. Individuals who are HIV positive have to face living with their illness, rather than dying from it. It follows, therefore, that sexuality needs, as a basic human function, are a challenging and complex part of the life of an HIV-positive individual. This study stresses the importance of the fear of contagion to an HIV-positive person's sexuality needs. This fear may have a direct impact on their needs and their relationships. In addition, like many other patients with a chronic illness, dealing with the diagnosis and adapting to it provides an additional strain upon needs and relationships.

This small study also indicates that the sexuality needs of HIV-positive patients are not being fully addressed and may even be ignored, despite it

being a central part of an individual's identity and being. It is important that healthcare staff, including nurses, are given the information, skills and support to provide this important aspect of caring for the HIV-positive individual.

Acknowledgements

I would like to thank the participants of the study and Joan McDowall (University of Glasgow) for her comments.

References

1. Gamel C, Hengeveld M W, Davis B *et al*. Factors that influence the provision of sexual health care by Dutch cancer nurses. *Int J Nursing Studies*, 1995, **32**, 301-314.
2. Van Ooijen E. How illness may affect patients' sexuality. *Nurs Times*, 1995, **91**, 36.
3. Lewis S and Bor R. Nurses' knowledge of and attitudes towards sexuality and the relationship of these with nursing practice. *J Adv Nurs*, 1995, **20**, 251-259.
4. Wilson ME and Williams HA. Oncology nurses' attitudes and behaviors related to sexuality of patients with cancer. *Oncol Nurs Forum*, 1988, **15**, 49-53.
5. Waterhouse J and Metcalfe M. Attitudes towards nurses discussing sexual concerns with patients. *J Adv Nurs*, 1991, **16**, 1048-1054.
6. Schover ILR and Jensen SB. *Sexuality and Chronic Illness: A Comprehensive Approach*. Guilford Press, London, 1988.
7. Matocha L and Waterhouse JK. Current nursing practice related to sexuality. *Res Nurs Health*, 1993, **16**, 371-378.
8. Hart G and Wellings K. Sexual behaviour and its medicalisation: in sickness and in health. *BMJ*, 2002, **324**, 896-900.
9. Flannagan J and Holmes S. Social perceptions of cancer and their impacts: implications for nursing practice arising from the literature. *J Adv Nursing*, 2000, **32**, 740-749.
10. Waterhouse J. Nursing practice related to sexuality: a review and recommendations. *NT Res*, 1996, **1**, 412-418.
11. Scottish Intercollegiate Guidelines Network. *Management of Adult Testicular Germ Cell Tumours*. Royal College of Physicians, Edinburgh, 1998.
12. Ostrow DG and Kalichman SC. *Psychosocial and Public Health Impacts of New HIV Therapies*. Kluwer Academic, New York, 1999.
13. The Scottish Office Department of Health. *Working Together for a Healthier Scotland*. The Stationery Office, Edinburgh, 1998.
14. Indicators for Health Education in Scotland: Summary of Findings for 1997. Health Education Board for Scotland, Edinburgh, 2003.
15. Glaser G and Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine, New York, 1967.
16. Holloway I and Wheeler S. *Qualitative Research for Nurses*. Blackwell Science, Oxford, 1996.
17. Morse J (ed). *Completing a Qualitative Project: Details and Dialogue*. Sage Publications, London, 1997.
18. Strauss AL. *Qualitative Analysis for Social Scientists*. Cambridge University Press, Cambridge, 1987.

Correspondence to: May McCreddie, School of Health, Nursing and Midwifery, University of Paisley, Paisley, PA1 2BE, UK.
(email: may.mccreddie@paisley.ac.uk)

HIV and Metabolic Complications Study Day

Candy Duggan

South Park Clinic, Ilford, Essex

9 December 2005

London, UK

The aim of the HIV and Metabolic Complications Study Day was to explore and discuss current issues in managing patients with HIV and lipodystrophy syndrome (LDS). Our knowledge of the pathogenesis, risk factors and clinical definitions of LDS is evolving, and this short report cannot cover all the information presented at this meeting. The meeting began with presentations from Mervyn Tyrer (Royal Free Hospital, London) and Jonathan Cartledge (Camden Primary Care Trust, London) which were followed by presentations about the roles of the dietician, pharmacist and psychologist in relation to LDS. The meeting concluded with workshops using case studies and the launch of the booklet *What we can do to reduce our risk of Heart Disease: Key facts for people living with HIV* (2005) by Robert Fieldhouse [UK Coalition of People Living with HIV & Aids (UKC)].

An overview of the history of LDS

LDS is a complex issue and the syndrome has been difficult to define. The term lipodystrophy is widely used to describe the body fat changes and metabolic disturbances observed in HIV-infected patients treated with highly active antiretroviral therapy (HAART). The main features of this syndrome include fat loss (lipoatrophy) in the face, arms, legs and buttocks, and fat gain in the abdomen, over the back of the neck and in the breasts. Metabolic abnormalities linked to HAART-associated lipodystrophy include increased total and low-density lipoprotein cholesterol (LDL-c) and triglyceride levels in addition to reduced high-density lipoprotein cholesterol (HDL-c) levels. Less commonly, insulin resistance, type-2 diabetes mellitus and lactic acidemia can also be found simultaneously in these patients.

Lipoatrophy is now thought to be caused by toxicity of the thymidine analogues (TAs) stavudine and zidovudine. The risk of lipoatrophy differs between TA drugs, and available data for abacavir and tenofovir indicate that these nucleoside reverse transcriptase inhibitors (NRTIs) are not associated with risk of lipoatrophy. 'Switch studies' have examined the effect on lipoatrophy of replacing TAs with abacavir or tenofovir, or of discontinuing all NRTIs via a switch to a nucleoside-sparing regimen and have shown that switching from a TA also partially reverses lipoatrophy and can lead to significant incremental increases in body fat over

time [1-3]. Factors predictive of lipoatrophy have included baseline lipid values and changes in triglyceride, cholesterol and insulin values, as well as greater age and lower CD4 lymphocyte count.

Specific drug therapy for treatment of LDS

Mallon *et al.* [4] investigated approaches to increasing limb fat, and showed an encouraging 0.72 kg increase in limb fat at 12 weeks with pravastatin. Growth hormone and metformin, both of which help fat accumulation [5,6], can be used in treating age-related fat accumulation and so may not be effective. Patients taking rosiglitazone showed no difference in recovery of limb fat whether the patient continued with zidovudine or stavudine or took a placebo [7].

Recently, it has been proposed that toxicity is the result of intracellular depletion of pyrimidine precursors, rather than depletion of mitochondrial DNA. Uridine is a pyrimidine precursor and so might replenish plasma uridine levels. In two small studies, patients who received NucleomaxX[®] (a dietary supplement which increases serum uridine) showed an increase in the amount of subcutaneous fat [8,9]. It is unclear whether this treatment will provide long-term fat restoration. A larger US study sponsored by the US AIDS Clinical Trials Group is underway.

Repairing facial fat loss is difficult and a variety of cosmetic procedures has been tried to treat facial wasting. Solutions often involve injecting materials under the skin, including: collagen, which is biodegradable, meaning the benefit will disappear over time; BIO-ALCAMID[®], a synthetic biopolymer; NuFill[™], which is composed of a synthetic substance (poly-L-lactic acid); and silicon implants. Fat liposuctioned from one area of the body and then injected into the areas of concavity in the face has also been used, although the transferred fat seems to be absorbed.

Non-pharmacological approaches to treatment of LDS

Michelle Phillpot (Specialist HIV Dietician, Chelsea and Westminster Hospital, London), Ysobel Gourlay (Senior Pharmacist, Gartnavel General Hospital, Glasgow) and Tomás Campbell (Psychologist, Newham University Hospital, London) presented approaches to the prevention and management of LDS including diet, exercise and psychological interventions.

LDS is visible and stigmatising. It can affect the patient's self-esteem and sex life and have negative emotional and social consequences. Controlling HIV infection is paramount, but confidentiality issues related to changes in body shape lead to increased worry and treatment adherence problems [10]. People with lipodystrophy may self-manage the condition by interrupting their therapy to prevent changes and this can be dangerous for them. The Strategies for Management of Antiretroviral Therapy (SMART) study was designed to compare episodic use of anti-HIV treatment with continuous therapy, based on CD4 cell count [11]. The trial was stopped after an excessive number of AIDS-defining events was observed among patients taking a break from treatment. Patients in the treatment-interruption arm were advised to restart therapy immediately.

All of the presentations stressed that more attention should be paid to the psychological and emotional effects of LDS. All healthcare professionals should ask patients how LDS affects them and how they perceive differences in their own appearance. It is important to provide accurate advice, act as an advocate and give treatment adherence support. Appropriate referral for psychological help should also be part of the management strategy.

Diet and exercise

'When diet therapy is used alone, lipid levels may not reach desired goals but a significant reduction can be observed' [12]. Dietary and exercise-based intervention was shown to be effective in lowering cholesterol in HIV-infected patients by 11% in one study. Exercise has a role in disguising limb fat loss, particularly in male patients, although it has limitations for female patients. Exercise in general, however, is of benefit in reducing cardiovascular disease (CVD).

Recommendations include having a 'Mediterranean diet' with an increase in the use of olive oil, omega-3 fatty acids, oily fish, fruits, vegetables and soluble fibre and plant sterols, all of which help to reduce total serum cholesterol.

The workshops reviewed and discussed case studies, looking at the implications of LDS for the patient and the role of healthcare professionals in helping to prevent and manage LDS.

Conclusion

LDS is of great concern to many patients, has a negative impact on their quality of life and is a threat to treatment adherence. Lipodystrophy is not just trivial and cosmetic. It is stigmatising and distressing and impacts on all areas of life. It is difficult to reverse body shape changes and metabolic complications once they occur. What is becoming increasingly clear is that there is no single mechanism by which LDS arises. Rather, there appears to be a number of factors influenced

by medication choice, family history and HIV disease state, all of which influence the development of LDS.

The multidisciplinary HIV team is increasingly concerned with the increase in CVD risk that will probably emerge over time for individuals on HAART [13]. Risk reduction for CVD needs to be actively addressed in patients being treated for HIV infection. Patients' weight, blood pressure, smoking history and family history should be systematically recorded in the notes and British Hypertension Society guidelines should be followed [14]. The meeting suggested that clinicians should work to an agreed set of criteria to facilitate early diagnosis of LDS. Patients should be screened for metabolic syndrome and CVD risk. Non-pharmacological interventions such as stopping smoking, diet modification and increased exercise can result in significant reductions in CVD. LDS can be a particularly dangerous adverse effect because it evolves slowly and is difficult to measure. Although it is disturbing to many patients, it is an adverse effect that can be avoided now that the mechanism is better understood. Prevention is the best option.

Acknowledgements

This meeting was endorsed by the National HIV Nurses Association (NHVNA), HIV Pharmacy Association (HIVPA) and Dieticians in HIV/AIDS Group of the British Dietetic Association (DHIVA), and sponsored by an unrestricted educational grant from Gilead Sciences Ltd.

References

1. McComsey GA, Ward DJ, Hestenthaler SM *et al.* Trial to Assess the Regression of Hyperlactatemia and to Evaluate the Regression of Established Lipodystrophy in HIV-1-Positive Subjects (TARHEEL; ESS40010) Study Team. Improvement in lipodystrophy associated with highly active antiretroviral therapy in human immunodeficiency virus-infected patients switched from stavudine to abacavir or zidovudine: the results of the TARHEEL study. *Clin Infect Dis*, 2004, **38**, 263-270.
2. Martin A, Smith DE, Carr A *et al.* (Mitochondrial Toxicity Study Group). Reversibility of lipodystrophy in HIV-infected patients 2 years after switching from a thymidine analogue to abacavir: the MITOX Extension Study. *AIDS*, 2004, **18**, 1029-1036.
3. Moyle G, Sabin C, Cartledge J *et al.* Lipid changes in a randomised, 48-week, open label comparative study of tenofovir DF vs. abacavir as substitutes for a thymidine analog in persons with lipodystrophy: the RAVE study. *45th Interscience Conference on Antimicrobial Agents and Chemotherapy*, Washington DC, 2005, abstr. H-340.
4. Mallon PWG, Miller J, Kovacic J *et al.* Changes in body composition and cardiovascular measures in hypercholesterolaemic HIV-infected men treated with pravastatin: a randomised, placebo-controlled study. *Antiv Ther*, 2005, **10**, L15.
5. Kotler DP, Muurahainen N, Grunfeld C *et al.* Effects of growth hormone on abnormal visceral adipose tissue accumulation and dyslipidaemia in HIV-infected patients. *J Acquir Immune Defic Syndr*, 2004, **35**, 239-252.
6. Hadigan C, Corcoran C, Basgoz N *et al.* Metformin in the treatment of HIV lipodystrophy syndrome: a randomized controlled trial. *JAMA*, 2000, **284**, 472-477.

7. Carr A, Emery S, Law M *et al*. HIV Lipodystrophy Case Definition Study Group. An objective case definition of lipodystrophy in HIV-infected adults: a case-control study. *Lancet*, 2003, **361**, 726–735.
8. Sutinen J, Walker UA, Sevastianova K *et al*. Uridine supplementation increases subcutaneous fat in patients with HAART-associated lipodystrophy (HAL) – a randomized, placebo-controlled trial. *Antiv Ther*, 2005, 10 (suppl 3), Abstr 7.
9. McComsey GA, O’Riordan M, Setzer B *et al*. Effect of NucleomaxX[®] on fat and blood mitochondrial DNA in d4t-treated subjects with clinical lipodystrophy. *Antiv Ther*, 2005, 10 (suppl 3), Abstr 82.
10. Gallant JE, Staszewski S, Pozniak AL *et al*. Efficacy and safety of tenofovir DF vs. stavudine in combination therapy in antiretroviral-naïve patients: a 3 years randomized trial. *JAMA*, 2004, **292**, 191–201.
11. SMART (International Study Group on CD4-monitored Treatment Interruptions). The National Institute of Allergy and Infectious Diseases (NIAID) Press release 18/01/06, <http://www3.niaid.nih.gov/news/newsreleases/2006/smart06.htm>
12. Batterham MJ, Brown D and Workman C. Modifying dietary fat intake can reduce serum cholesterol in HIV-associated hypercholesterolemia. *AIDS*, 2003, **17**, 1414–1416.
13. Grinspoon SK and Carr A. Cardiovascular risk and body fat abnormalities in HIV-infected adults. *N Engl J Med*, 2005, **352**, 48–62.
14. Williams B, Poulter NR, Brown MJ *et al* (the BHS guidelines working party for the British Hypertension Society). British Hypertension Society guidelines for hypertension management 2004 (BHS-IV): summary. *Br Med J*, 2004, **328**, 634–640.

Correspondence to: Candy Duggan, Clinical Nurse Specialist HIV, Redbridge PCT, South Park Clinic, 100, South Park Drive, Ilford, Essex IG3 9AN, UK. (email: candy.duggan@redbridge-pct.nhs.uk)

The 8th Annual Conference of NHIVNA

Nicky Perry, *Chair of NHIVNA*

The 8th Annual Conference of NHIVNA will take place on 29 and 30 June in Leeds, the fastest-growing city in the UK. This energetic city is the perfect location for our latest conference, which promises to be the most engaging and cutting-edge yet. The event will take place at the Royal Armouries conference venue, which also hosts a museum housing the national collection of arms and armour.

This year’s keynote lecture is entitled: *The sexual health strategy: where are we five years on?* Among the other highlights of the conference will be the plenary sessions. We are delighted to confirm a number of eminent speakers, including: **Professor Peter Aggleton** and **Dr Helen McColl** (University College London); **Masheeda Downing** (East Kent Hospitals NHS Trust); **Norma Williams** and **John Allen** (National Asylum Support Service); and **Dr Valerie Delpech** (Health Protection Agency).

The wide variety of topics covered in these sessions includes:

- Towards universal access for HIV prevention, treatment and care.
- The CHIVA initiative in KwaZulu-natal (case study).
- Asylum seekers and issues in managing eligibility for HIV treatment.
- Treatment issues in pregnancy.
- Community nursing and development of roles.
- Occupation exposure to HIV and PEP.
- Update on PEPSE.
- CHAPS project feedback.
- Nurse-led clinics.

As well as the plenary sessions, the conference will also feature two symposia; one on toxicity and side-effects management, and one on novel approaches to adherence. There will also be lectures covering new therapies and modes of action, and the management of treatment-experienced patients.

Overall, the conference will provide an invaluable insight into innovation in the field of HIV nursing. It is not to be missed and we hope that you will be able to make it to Leeds for this event.

For more information, please contact the NHIVNA conference organisers:

Mediscript Ltd, 1 Mountview Court, 310 Friem Barnet Lane, London, N20 0LD.

Telephone: 020 8446 8898. Fax: 020 8446 9194. Email: nhivna@mediscript.ltd.uk



National HIV Nurses Association

Page 24 + 25

Aptivus

DPS colour Advert

Page 24 + 25

Aptivus

DPS colour Advert

Page 26

Abbott/Kaletra

Full-page colour Advert

NHIVNA update

■ The first announcement for this year's NHIVNA conference is hot off the press and should be with you very soon. The NHIVNA Executive Committee has come up trumps again with a programme that promises to be informative, interactive, engaging and exciting. We have taken your feedback on board and included sessions that you requested, specifically on post-exposure prophylaxis and the complex issues of asylum seekers and managing eligibility for treatment. Here is the interactive bit: we would like you to provide us with some case histories. Have you been involved in cases that you would like to share with other delegates and receive feedback from a panel of experts? Do not be put off if you do not want to present your case, because the Chair of the session can help. There will also be plenty of opportunities to ask questions during the session. You will find details in the conference announcements. The conference will also cover treatment updates, and we are currently finalising the programme and speakers to ensure we cover the issues that nurses are interested in. An important date for your diary is the abstract deadline of 21st April 2006.

■ Unfortunately, we have had to cancel the 'Research – How to get started' workshop, the aim of which was to encourage nurse-led research and audits; only five people registered. We will try to run another one later in the year but meanwhile, do not forget that the NHIVNA/Boeringer Ingelheim grants and scholarships are available throughout 2006 if you are undertaking a project. These are also available to help you to attend a conference where you will give an oral or poster presentation (so put in an abstract for the NHIVNA conference this year and apply for a scholarship to cover attendance). There are also travel grants available from NHIVNA/BI for expanding your knowledge and skills. The submissions will be reviewed at our quarterly committee meetings so you can apply throughout the year. For further information, contact Jacqueline English at Mediscript (jacqueline@mediscript.ltd.uk).

Nicky Perry, Chair, NHIVNA, Brighton

Abbott
half-page
(PI Information)
Kaletra

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

Published by Mediscript www.mediscript.ltd.uk

SUBSCRIPTION ORDER FORM

HIV NURSING

Volume 6, 2006 Numbers 1 – 4

Subscription rates:	Personal (£)	Institution (£)
UK, Four issues	52.00	80.00
Europe, Four issues	60.00 (€ 90)	90.00 (€ 135)
Rest of the World, Four issues	65.00 (€ 98)	105.00 (€ 158)

Please charge my MasterCard / Visa / American Express* card in the amount of
....., inclusive of post and packing.

I enclose a cheque / banker's draft, drawn on a UK bank, to the value of,
payable to: **Mediscript Ltd** (all bank charges are the responsibility of the remitter).

Card Number: Expiry date: /

Cardholder's Name: Title:

Mailing Address:

.....
.....

Cardholder's address, if different from above:

.....
.....

Cardholder's signature:

* Please delete whichever is not applicable.

Special rates are available for bulk subscriptions.

PLEASE COMPLETE AND RETURN THIS ORDER FORM BY FAX OR POST TO:

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

Telephone: +44 20 8446 8898 Facsimile: +44 20 8446 9194 E-mail: mailbox@mediscript.ltd.uk

12th
Annual Conference
of the
British HIV Association
29 March – 1 April 2006
The Dome, Brighton

BHIVA
Autumn Conference
13 – 14 October 2006
Queen Elizabeth II
Conference Centre,
London

*For further information on
these events,
please contact:*

BHIVA Secretariat
Mediscript Ltd
1 Mountview Court
310 Friern Barnet Lane
London N20 0LD

Tel: 020 8369 5380

Fax: 020 8446 9194

E-mail: bhiva@bhiva.org

Web:

<http://www.bhiva.org>

BMS
half-page
(PI Information)
Reyataz

BMS/Reyataz
Full-page Advert