Patients with severe mental illness: A new approach to testing for HIV

John A Joska, Sean Z Kaliski, Solomon R Benatar

Background. The prevalence of HIV infection in South Africa is approaching 20% of young adults. In severely mentally ill people it is probably higher. Testing for infection is subject to stringent ethical principles. Undiagnosed HIV infection in people with severe mental illness increases costs and morbidity. Since effective treatments are available, it is imperative to diagnose HIV infection early in this high-risk population.

Methods. A literature review established the prevalence of HIV infection in inpatient populations with HIV infection. The pattern of testing for HIV over 3 years at a major psychiatric hospital was investigated. We surveyed public sector psychiatrists in the Western Cape to establish their attitudes to HIV in their patients.

Results. The reported HIV seroprevalence in psychiatric inpatients ranges from 0 to 59.3%, with a mean of 10%. Data show a clear trend towards an increase in prevalence: before 1996 the mean HIV seroprevalence was 7.4%, while after 1996 the mean was 15%. State psychiatrists in the Western Cape do not test routinely for HIV infection, mainly owing to ethical constraints: 14.6% of patients at Lentegeur Hospital were tested in 2006.

Conclusions. The high prevalence of HIV infection in South Africa, which is probably higher in patients with severe mental illness (most of whom are not competent to provide informed consent), and the availability of effective treatment require debate and a clear policy regarding testing for HIV infection to be implemented. We recommend a new approach to HIV testing in these patients.

S Afr Med J 2008; 98: 213-217.

The problem of HIV seroprevalence

The prevalence of HIV infection continues to rise in sub-Saharan Africa. In South Africa in 2005 the prevalence of HIV infection in the general adult population (aged 15 - 49 years) was 18.8%.[1] There was a continuous rise in prevalence from 2000 to 2005. In 2005 the prevalence was 30.2% in antenatal clinic attendees[2] and it was estimated that 5.5 million people were infected with HIV in South Africa. Much of the 79% rise in natural deaths in South Africa from 1997 to 2004 is attributed to HIV, and it is estimated that 2 million people do not know that they have HIV infection.[1]

Undiagnosed HIV infection is relevant to South Africans who live with severe mental illness (SMI) because they are at a greater risk of infection.[3] Furthermore, HIV infection can cause SMI. In the USA the HIV seroprevalence among people with SMI was estimated to be 13 - 76 times that of the general population.[4] We may then assume that the high and rising prevalence of HIV infection in South Africa is accompanied by with a similar (or higher) prevalence in patients with SMI.

Severe mental illness can be defined as the presence of a major psychiatric disorder (e.g. schizophrenia, bipolar disorder) with significant disability (e.g. impairment of judgement and insight), and a tendency to chronicity.[5]

Seroprevalence in psychiatric populations

We reviewed data on the seroprevalence of HIV in psychiatric inpatient populations. A MEDLINE and PsycINFO search for English language articles used the following terms: *Inpatients, HIV, Acquired immunodeficiency syndrome, Mental disorders, Mentally ill persons, Prevalence.* JJ screened the 257 articles that were retrieved. Studies on injectable drug users were not included, unless separate data on patients with SMI were available. Only studies that reported HIV seroprevalence were included, and 20 that were suitable for inclusion reported a range of seroprevalences (Table I).

The reported HIV seroprevalence in psychiatric inpatients ranges from 0 to 59.3%. Prevalences vary according to where the study was performed, the highest being from Zimbabwe. High prevalences were also found in patients with longstanding or co-morbid psychiatric disorders. Before 1996 the range of HIV seroprevalence was 0 - 22.9% (mean 7.4%), while after 1996 it was 2.6 - 59.3% (mean 15%). These data cannot be generalised but suggest an upward trend in the HIV seroprevalence in psychiatric inpatient populations.

HIV/Neuropsychiatry Service, Groote Schuur Hospital and Department of Psychiatry and Mental Health, University of Cape Town
John A Joska, MB ChB, MMed (Psych), FCPsych (SA)

Forensic Psychiatry Service, Valkenberg Hospital and Department of Psychiatry and Mental Health, University of Cape Town
Sean Z Kaliski, BA, MB ChB, MMed (Psych), PhD, FCPsych (SA)

Bioethics Centre, Department of Medicine, University of Cape Town
Solomon R Benatar, MB ChB, FFA, FRCP, FACP (Hon), FCP (SA) (Hon)

Corresponding author: *J A Joska (John.Joska@uct.ac.za)*

Table I. Seroprevalence of HIV in psychiatric populations

Author	Study site	Sample	Design	Main findings
Sacks *et al.*, 1990[14]	Acute psychiatric inpatients	205	Anonymous, cross-sectional	HIV seroprevalence 7.8%; 25% of patients had psychotic disorders
Coumos *et al.*, 1991[15]	USA, 2 state hospitals: inpatients	451	Consecutive anonymous and open	5.5% of patients were HIV+
Volavka *et al.*, 1991[16]	State hospital: inpatients	515	Anonymous	HIV seroprevalence 8.9%; 74.9% of patients had psychotic disorders
Lee *et al.*, 1992[17]	Non-profit hospital: inpatients	132	Anonymous	HIV seroprevalence 14.4%
Sacks *et al.*, 1992[18]	Private hospital, new admissions	132	Anonymous	HIV seroprevalence 7.1%; 20% of sample were injection drug users
Meyer *et al.*, 1993[19]	State hospital: homeless inpatients	87	Anonymous	HIV seroprevalence 5.8%
Empfield *et al.*, 1993[20]	State hospital: homeless inpatients	203		HIV seroprevalence 6.4%; 97% of patients had psychotic disorders
Meyer *et al.*, 1993[21]	State hospital: long-stay patients	199	Anonymous	HIV seroprevalence 4.0%; 80.4% of patients had psychotic disorders
Chen, 1994[22]	Taiwan: psychiatric hospitals	834		No HIV-positive patients
Dasananjali, 1994[23]	Thailand: forensic psychiatric hospital	325		HIV seroprevalence 1.85%
Silberstein *et al.*, 1994[24]	Municipal hospital: consecutive dual diagnosis admissions	118	Open	HIV seroprevalence 22.9%
Stewart *et al.*, 1994[25]	State hospital: new outpatient and inpatient admissions	533	Anonymous	HIV seroprevalence 5.8%; 40.5% of patients had psychotic disorders
Schwartz-Watts *et al.*, 1995[26]	Forensic inpatient unit for pre-trial detainees	223	Open	HIV seroprevalence 5.4%
Acuda and Sebit, 1996[27]	Zimbabwe: Harare psychiatric hospital	143	Cross-sectional	HIV seroprevalence 23.8%; HIV-positive diagnosis related to high education and unemployment
Chandra *et al.*, 1996[28]	India: psychiatric hospitals	2 139	Record review	HIV seroprevalence 3.4% in an at-risk sub-group; most of patients were tested due to clinical risk
Susser *et al.*, 1997[29]	Suffolk county, USA: first psychiatric admissions	320	Descriptive cross-sectional	HIV prevalence 3.8% in sample of 320 non-affective psychosis, but HIV NOT performed in all patients
Grassi *et al.*, 1999[30]	Italy: psychiatric hospitals	100	Questionnaire and record review	Adjusted HIV seroprevalence 5.8%
Hutchinson and Simeon, 1999[31]	Trinidad and Tobago: psychiatric hospital	1 227	Record review	HIV seroprevalence 6.9% in selected high-risk group, 1991-1994
Meyer, 2003[32]	Oregon, USA: chronic psychiatric inpatients	535	Record review following screening	HIV seroprevalance 2.6% among a sub-sample of HCV-positive patients; 23% not tested for HIV
Sebit *et al.*, 2003[33]	Zimbabwe: general hospital	194	Convenience sample using cross-sectional design	Point prevalence HIV 59.3%

HIV testing practice in psychiatric inpatients in the Western Cape

There are no published studies of HIV seroprevalence in psychiatric populations in the Western Cape. Presuming that the seroprevalence of HIV in psychiatric inpatients in this region may range between 18.8% (HIV adult prevalence in South Africa in 2003) and 30.2%,[2] we did an informal survey of the HIV testing practice of public sector psychiatrists in the Western Cape (J A Joska – unpublished data). A total of 14 psychiatrists were surveyed, 13 of whom returned replies (Table II).

Where patients were not routinely tested, psychiatrists are guided in their management decisions by clinical indications, such as physical or psychiatric features suggestive of HIV infection. This survey did not determine whether informed consent had been obtained for testing for these indications. A routine screening programme was not performed by 10 psychiatrists, most of who felt that it was unethical to test without informed consent, while many felt that limited access to antiretroviral therapy (ART) did not justify such testing. A discharge database audit at Lentegeur Hospital, Cape Town, over 3 years found that 11.9 - 14.6% of patients were tested for HIV infection (P Milligan – unpublished data). Psychiatrists feel that greater access to ARVs, improved staff numbers and skills, and clearer ethical guidelines would increase HIV detection.

A revised document outlining ethical guidelines for medical practitioners noted that in SMI, the patient either has capacity to give formal consent, or does not.[6] Testing in these patients follows the principles in the Mental

Table II. Western Cape public sector psychiatrists' views on HIV/AIDS

Total patients managed	43.8
Patients admitted per week	11.2
HIV-positive admissions per week	1.7
Psychiatrists routinely testing for HIV	2 of 13
Psychiatrists should test routinely for HIV	7 of 13

Health Care Act of 2002, which requires that formal consent be obtained where possible, or the patient restored to a state where he/she is able to consent. If a patient is unable to consent, a curator, spouse or family member may do so. The establishment head may give permission to test on the patient's behalf only if none of these persons is available. As they may not be medical practitioners, heads of health establishments may be reluctant to provide such consent unless they are satisfied that the situation constitutes a medical emergency.

The default position for clinicians is therefore to undertake a detailed counselling and consent procedure before testing for HIV. Where there are clinical features of HIV infection, some psychiatrists appear to test patients before obtaining formal consent in an attempt to unmask complications of HIV, delineate a clinical picture, or offer ART. The main barriers to screening all admitted psychiatric patients are pre-existing ethical rules and the purported limited access to ART. At best, HIV testing is haphazard. We question whether this is a rational approach.

Constraints of informed consent in psychiatric populations

In the struggle against HIV/AIDS the United Nations/World Health Organization policy document asserts that HIV testing and counselling remains of prime importance.[7] Furthermore, they estimate that only 10% of people in the developing world have access to voluntary counselling and testing (VCT). Other barriers to the identification and control of HIV/AIDS include individuals being unable to understand their illness or maintain healthy behaviours, and not having easy access to health services. Both these tend to apply to people with SMI. Even where active VCT programmes exist, up to half of patients with SMI do not get tested.[8]

The UNAIDS/WHO document refers to 'client-initiated testing' and also 'clinician-initiated testing', which includes diagnostic testing when HIV infection is suspected. People with physical or mental illness may therefore be tested for HIV infection, provided they give informed consent. Key elements of informed consent include the following: firstly, that the patient understands the clinical and prevention benefits of testing and the right to refuse; secondly, that they are made aware of follow-up services; and lastly, in the event of a positive test result, that they should anticipate having to inform sexual partners who would otherwise not suspect they were being exposed to HIV infection that they are at risk.[3]

In the context of SMI, these goals are very hard to attain. During the early admission period, psychiatric patients are extremely unwell and unable to make informed decisions. At this point the state, through the psychiatric hospital and treating team, has a duty to treat, care for and rehabilitate the individual. This involves drug treatments, restriction of movement and screening for medical conditions. These include diagnosable and treatable conditions such as hypothyroidism, anaemia and syphilis, for which consent to test is not required. Delay in diagnosing the mental health disorder or contributory medical condition leads to loss of valuable time before commencing effective treatments. In the case of HIV/AIDS, early investigation and management often includes performing a lumbar puncture and brain imaging to exclude opportunistic infection and/or tumours. Such tests are not necessarily done in the early treatment of mental disorders in patients without HIV infection. In addition, patients with significant neurodegeneration from HIV infection may be more vulnerable to the side-effects and toxicities of certain psychotropic medications.[9]

Current HIV testing guidelines aim to reach a point where residual symptoms of mental illness are few and the patient has the necessary insight and judgement to make an informed decision. In many cases, however, this point may never be reached.[10] Clinicians therefore, are reluctant to test patients for HIV/AIDS unless there is a clear clinical indication. Additional barriers to testing for HIV include passivity induced by perceived low true-positive rates, failure to detect risk behaviours at admission clerking, and concerns that a positive result may extend the already lengthy duration of admission.[6] Many patients may therefore never be tested for HIV infection, with dire consequences. It is increasingly realised that HIV infection presentation can masquerade as virtually any serious mental illness, and that ARVs, not conventional medications, are the treatment of choice. Not testing everyone who presents with a serious mental illness may therefore constitute a major error. By making HIV testing mandatory as part of any routine work-up the procedure will become 'normalised' and may reduce stigma associated with the illness.[11] It has been argued that the age of 'exceptionalism' in HIV has passed.[12] While resistance to widespread HIV testing without informed consent must still be respected, there is no longer justification for not testing because of the absence of effective treatments.

Different times, new approaches

We argue that the HIV/AIDS context has changed dramatically. Firstly, the epidemic advances almost unchecked and the prevalence of HIV infection is likely to be higher in psychiatric populations than in the general population.[13] Secondly, people with mental illness are at greater risk of becoming infected with HIV.[4,13] Thirdly, the number of individuals with mental illness complicated by HIV infection is rising alongside the

increase in HIV seroprevalence in the general population. This includes people with HIV-consequent disorders, as well as pre-existing disorders that become difficult to treat in the presence of HIV infection. Finally, access to ART continues to improve.

At the time of writing there are 42 accredited and well-funded ARV treatment sites in the Western Cape. With substantial facilities for providing ART and opportunities to treat people with SMI and HIV infection effectively, lack of access cannot be considered a reason not to test for HIV infection. Access may vary from province to province, and this needs to be taken into account when arguing that ARVs are equally accessible.

When effective treatment for HIV is absent, the ethical arguments for not testing routinely rest on the right to confidentiality (for all people) and the right to refuse (for those who are mentally competent to exert their autonomy), underpinned by notions that HIV/AIDS carries a stigma and a burden of knowing. We argue that this position is no longer appropriate. Many individuals with SMI lack the competence to refuse treatment or testing. Most admissions to psychiatric hospitals therefore occur under the 'involuntary' admission section of the Mental Health Care Act of 2002 (MHCA). This includes a duty to care, and admission for treatment, care and rehabilitation ought to include screening for all possible illnesses including HIV infection. This falls within the ethical principles of beneficence and the duty of care, which can justifiably over-ride autonomy when cognitive function is sufficiently impaired. Furthermore, patients have a right to effective treatment from the state or institution to which they have been admitted, including the need to know which treatment is required.

Psychiatric patients have always borne stigma, and ideas persist that mental illness is self-made; that the mentally ill should be separated from the rest of society due to dangerous or odd behaviour; that they are somehow dirtier, less successful and more difficult to relate to; and that mental illness is untreatable. While some attitudes to people living with HIV/AIDS are similar there are also differences, many of them brought about by ART. The stigma associated with HIV/AIDS has greatly diminished.

A proposed policy for testing for HIV infection in psychiatric inpatients

Given the scope of the problem of HIV, the fact that patients with SMI are a high-risk group, and the shift away from AIDS exceptionalism, we propose the following testing protocol in individuals with SMI who are admitted to psychiatric hospitals in South Africa.

1. All persons admitted to psychiatric hospitals should have their risk behaviour status and their knowledge and attitudes to HIV/AIDS and its treatment evaluated.
2. The patient and the accompanying relative or associate (the term used in the MHCA) should be counselled by a mental health care practitioner regarding HIV/AIDS (including risk behaviours), the test procedure and ART. This information should also be available as a pamphlet and handed to the patient and relative/associate.
3. As part of a psychiatric hospital admission, in terms of the MHCA, patients' ability to understand and comply with treatment, care and rehabilitation should be assessed. Patients with the capacity and ability to appreciate their need for treatment are admitted under the 'voluntary' section of the Act, those who do not have capacity, but who do not actively refuse treatment, are admitted under the 'assisted' section, and those who do not have capacity and who actively refuse admission and/or treatment are admitted under the 'involuntary' section. Patients with SMI usually fall into one of the latter two categories.
4. All persons admitted to a psychiatric facility with an SMI, or for the first time, should be informed that as part of routine psychiatric assessment and in their best interests as part of optimal investigation and treatment, an HIV test may be done, if it has not already been performed by the referring agent.
5. Patients should be given the opportunity to participate, wherever possible, in understanding the risks and benefits of HIV testing and in consenting to it. When patients with SMI have impaired capacity to consent to testing, but do not refuse, a senior clinician should be advised of the need to test and approve for testing. When patients with SMI either refuse HIV testing, or are too mentally ill to participate in deciding, the clinician must weigh up the potential harms and benefits of HIV testing. Where knowledge of HIV status may materially affect the clinical diagnosis, investigation and treatment, a senior clinician and/or the medical superintendent should be consulted to obtain approval for testing.
6. The clinical notes should record the discussion with the patient and consultation with a senior clinician, and the HIV status, when available. This information should be treated with the confidentiality afforded all patients with SMI who are admitted to psychiatric hospitals.
7. The counselling should be repeated when the patient's condition has improved and a full explanation given as to why investigations were performed and treatments instigated.
8. Referral to ARV clinics should be arranged as soon as possible according to the Department of Health guidelines.

Conclusion

Major advances have been made in understanding HIV, its psycho-social aspects and its treatment. Many local epidemics have been ameliorated. A national effort to provide effective ART is underway in South Africa, which is not being met by increased detection of HIV infection. It is in the best interests of those with SMI, who often lack the ability and means to engage in safe sexual practice, to test for HIV infection for prevention and treatment. These patients cannot be denied the opportunity to benefit from treatment

References

1. UNAIDS- Joint United Nations Programme on HIV/AIDS. http://data.unaids.org/pub/EpiReport/2006/04- Sub_Saharan_Africa_2006_EpiUpdate_eng.pdf (accessed 24 January 2008).
2. *National HIV and Syphilis Antenatal Sero-prevalence Survey in South Africa, 2005*. Pretoria: National Department of Health, 2006.
3. Blumberg SJ, Dickey WC. Prevalence of HIV risk behaviors, risk perceptions, and testing among US adults with mental disorders. *J Acquir Immune Defic Syndr* 2003; 32(1): 77-79.
4. Carey M, Carey K, Kalichman S. Risk for human immuno-deficiency virus (HIV) infection among persons with severe mental illnesses. *Clin Psychol Rev* 1997; 17(3): 271-291.
5. Walkup J, Satriano J, Barry D, Sadler P, Cournos F. HIV testing policy and serious mental illness. *Am J Public Health* 2002; 92 (12): 1931-1939.
6. South African Medical Association. *Human Rights and Ethical Guidelines on HIV and AIDS: A Manual for Medical Practitioners.* South African Medical Association, 2006.
7. UNAIDS Global Reference Group on HIV/AIDS and Human Rights. UNAIDS/WHO Policy Statement on HIV testing, June 2004. http://www.unaids.org/en/PolicyAndPractice/CounsellingAndTesting/default.asp (accessed 24 January 2008).
8. Meade CS, Sikkema KJ. Voluntary HIV testing among adults with severe mental illness: frequency and associated factors. *AIDS Behav* 2005; 9(4): 465-473.
9. Ferrando S, Wapenyi K. Psychopharmacological treatment of patients with HIV and AIDS. *Psychiatr Q* 2002; 73(1): 33-58.
10. Mokgoro Y, Gauntlett JJ, Hoexter CE, *et al*. *Assisted Decision-Making: Adults with Impaired Decision-Making Capacity.* Pretoria: South African Law Commission, 2004.
11. Bekker L-G, Wood R. Is it time to change our HIV testing policy in health care facilities? *S Afr Med J* 2006; 96(12): 1235-1236.
12. Bayer R, Fairchild A. Changing the paradigm for HIV Testing – the end of exceptionalism. *N Engl J Med* 2006; 355(7): 647-649.
13. McKinnon K, Cournos F, Herman R. HIV among people with chronic mental illness. *Psychiatr Q* 2002; 73(1): 17-31.
14. Sacks M, Silberstein C, Weiler P, Perry S. HIV-related factors in acute psychiatric inpatients. *Hospital and Community Psychiatry* 1990; 41: 449-451.
15. Cournos F, Empfield M, Horwath E, *et al*. HIV seroprevalence among patients admitted to two psychiatric hospitals. *Am J Psychiatry* 1991; 148: 1225-1230.
16. Volavka I, Convit A, Czobor P, Dwyer R, O'Donnell J, Ventura A. HIV seroprevalence and risk behaviors in psychiatric inpatients. *Psychiatr Res* 1991; 39: 109-114.
17. Lee HK, Travin S, Bluestone H. HIV-l in inpatients. *Hospital and Community Psychiatry* 1992; 43: 181-182.
18. Sacks MH, Dermatis H, Looser-Ott S, Perry S. Seroprevalence of HIV and risk factors for AIDS in psychiatric inpatients. *Hospital and Community Psychiatry* 1992; 43: 736-737.
19. Meyer I, Cournos F, Empfield M, *et al*. HIV seroprevalence and clinical characteristics of the mentally ill homeless. *Journal of Social Distress and the Homeless* 1993; 2: 103-116.
20. Empfield M, Cournos F, Meyer I, *et al*. HIV seroprevalence among homeless patients admitted to a psychiatric inpatient unit. *Am J Psychiatry* 1993; 150: 47-52.
21. Meyer I, McKinnon K, Cournos F, *et al*. HIV sero-prevalence among long-stay patients in a state psychiatric hospital. *Hospital and Community Psychiatry* 1993; 44: 282-284.
22. Chen CH. Seroprevalence of human immunodeficiency virus infection among Chinese psychiatric patients in Taiwan. *Acta Psychiatr Scand* 1994; 89: 441–442.
23. Dasananjali T. The prevalence of HIV infection among mentally ill offenders in Thailand. *J Med Assoc Thailand* 1994; 77: 257-260.
24. Silberstein C, Galanter M, Marmor M, Lifshutz H, Krasinksi K. HIV1 among inner city dually diagnosed inpatients. *Am J Drug Alcohol Abuse* 1994; 20: 101-131.
25. Stewart DL, Zuckerman CJ, Ingle JM. HIV seroprevalence in a chronically mentally ill population. *J Natl Med Assoc* 1994; 86: 519-523.
26. Schwartz-Watts D, Montgomery LD, Morgan DW. Seroprevalence of human immunodeficiency virus among inpatient pretrial detainees. *Bulletin of the American Academy of Psychiatry and the Law* 1995; 23: 285-288.
27. Acuda SW, Sebit MB. Serostatus surveillance testing of HIV-I infection among Zimbabwean psychiatric inpatients, in Zimbabwe. *Cent Afr J Med* 1996; 42: 254-257.
28. Chandra P, Ravi V, Puttaram S, Desai A. HIV and mental illness. *Br J Psychiatry* 1996; 168(5): 654.
29. Susser E, Colson P, Jandorf L, *et al* HIV infection among young adults with psychotic disorders. *Am J Psychiatry* 1997; 154(6): 864-866.
30. Grassi L, Pavanati M, Cardelli R, Ferri S, Peron L. HIV-risk behaviours and knowledge about HIV. AIDS among patients with schizophrenia. *Psychol Med* 1999; 29: 171-179.
31. Hutchinson GA, Simeon DT. HIV infection rates and associated factors in high risk patients admitted to a psychiatric hospital in Trinidad and Tobago. *West Indian Med J* 1999; 48: 129-131.
32. Meyer J. *Prevalence of Hepatitis A, Hepatitis B and HIV among Hepatitis C-seropositive State Hospital Patients*. Physicians Postgraduate Press, 2003.
33. Sebit M, Tombi M, Siziya S, Balus S, Nkomo S, Maramba P. Prevalence of HIV/AIDS and psychiatric disorders and related risk factors among adults in Epworth, Zimbabwe. *East Afr Med J* 2003; 80: 503-512.

Accepted 15 January 2008.