Psychiatric Bulletin (1992), **16**, 638–639

Personal columns

Learning disabilities and the HIV epidemic

NEIL BRENER, Senior Registrar in Psychiatry, Charing Cross Hospital, Fulham Palace Road, London W6 8RF; and DANITZA JADRESIC, Senior Registrar in Psychiatry, The Maudsley Hospital, Denmark Hill, London SE5 8AZ

Antecedents of HIV infection in those with learning disabilities

It has been said that there is little likelihood of risk contact between people with learning disabilities in institutions and HIV infected people in the community and also that the shift of patients with learning disabilities from large institutions towards the community does not augur well for the prevention of HIV infection. There is little evidence for either of these views.

Potential sources of HIV infection for those with learning disabilities are already recognised. Two per cent of the prison population suffer from learning disabilities. Attention has already been drawn to the sexual exploitation of these offenders. When a rumour went around a prison that a person with learning disabilities had AIDS, 50 inmates requested an HIV test.

The epidemiology of HIV infection in adults with learning disabilities is unknown. A survey of state departments in the USA in 1987 yielded 45 cases of "mentally retarded" adults with HIV infection from 11 of 44 states.

No prevalence studies of HIV infection have been carried out among those with learning disabilities in this country. As yet no cases of HIV infection have been reported from the Learning Disabilities Unit which covers patients in the North West Thames Region and cares for just under half the cases of AIDS in Britain. Nor have cases been reported from the liaison HIV psychiatry team of Riverside Health District.

European studies have yielded no cases of HIV infected individuals in samples of learning disabilities patients. One Spanish study screened 102 adult residents of an institution for mentally handicapped (Buti *et al*, 1986). An Italian study of 58 institutionalised adults with learning disabilities contrasts the absence of HIV antibodies in this population compared to the 41% prevalence of markers for hepatitis B infection.

Management issues

Testing for HIV infection in those with learning disabilities

Some authors have suggested that routine screening might be justifiable in hospitals and residential homes (Bayer *et al*, 1986). But it appears that the question of HIV testing may spring from staff anxieties about dealing with potentially infected patients. Some have argued that doctors screen for hepatitis B in those patients with learning disabilities, so why not HIV? (Bayer *et al*, 1986).

A high rate of false positive is likely to result from screening a low-prevalence population for HIV antibodies. Current anonymous screening programmes use two alternative assay methods to reduce the likelihood of false positive or false negative results. One Italian study found one false positive and no true positives in a survey of 112 residents from two hospitals for patients with learning disabilities.

There is a delay between exposure and seroconversion of about three months, and occasionally as long as one year. It is therefore of little use to propose HIV testing in order to deal with staff anxieties about handling physically aggressive and potentially infected patients.

Consent to testing

It is now more accepted that patients with learning disabilities have the right to choose whether to be tested or not. It has been suggested that if they are able to consent to HIV tests after comprehensive counselling, they can be tested (Kastner *et al*, 1989). All patients who have counselling should also have an independent advocate, such as a social worker, to advise them. Counselling and support for carers should also be considered (Kastner *et al*, 1989).

If a person with learning disabilities is unable to make considered judgements, prevention of transmission of HIV becomes a priority. When such a person is unable to comprehend, and so give valid consent, the health authority should perhaps go to

the High Court. A person under the age of 18 should be made a Ward of Court. A Declaration should be required for every case. These suggestions have been supported by the Mental Health Act Commission.

Rarely, a clinician may feel that the situation is urgent and there is no time to go to Court. In this case the clinician should be prepared to justify carrying out the test later in Court (General Medical Council, 1988). Multidisciplinary hospital ethical review committees could be useful in the decision-making process around the issues (Bayer *et al*, 1986).

Social contact

Management issues are at present centred on preventive aspects. Health care workers are concerned to prevent an HIV positive patient from transmitting the infection to others. Much of this controversy has arisen elsewhere and hinges on the extent to which society is justified in overcoming the rights of an individual in favour of preventing the spread of a life-threatening infection?

It is widely agreed that a HIV positive person with learning disabilities who engages in unprotected sexual intercourse should be treated like a non-learning disabilities person who engages in similar behaviour. Often a lack of knowledge in both groups is the cause for this behaviour. In one case, a patient thought that by "passing on" the virus to others, he would "get rid of" all of his own virus.

The General Medical Council (1988) has given cautious approval to doctors informing spouses of the HIV status of their partners. The identity of sexual partners cannot or will not be revealed to carers. Some have seriously suggested "locking them up" as the answer to the spread of HIV infection. If screening of individuals with learning disabilities is considered, then extra supervision and resources for those found to be HIV positive is the management implication. Closer supervision of all people with learning disabilities would be impractical. In prison, increased supervision would perhaps be a more valid proposition in order to prevent prison rape.

Education

The cornerstone of management should be education, but Government educational campaigns about HIV infection have serious limitations in reaching those with learning disabilities and the mentally ill (Centre for Disease Control, 1988). The Centre for Disease Control in America (1988) has recommended the development of AIDS education programmes to address the special needs of minorities, including those with learning difficulties.

Education on HIV infection must be easily available to staff and patients. For the staff the method of spread, sexuality of patients, and having an easily available condom supply have to be addressed. Each hospital should have an appropriate forum for the development of policies related to HIV. These should be multidisciplinary with practical and ethical issues open for discussion.

The HIV epidemic has brought about a profound change in the way we consider sex education. Most persons with learning disabilities can distinguish "good and bad". Training in the use of condoms for sexual intercourse should become part of training programmes, alongside personal hygiene and socially acceptable behaviours. The greatest obstacle is not the feasibility of such an educational programme but taboos surrounding the subject of sexuality (Kastner *et al*, 1989). Ethical and practical guidelines to promote sex education for those with learning disabilities people have been approved by the British Medical Association but no mention was made of HIV related issues.

Support has been given for the greater availability of prison condoms; this could extend to residential and community services for those with learning disabilities. Others are apprehensive that such programmes might be an encouragement for sexual behaviour, especially homosexuality.

Comments

The AIDS epidemic has brought to the fore a number of unresolved conflicts. If ethical considerations have proven intricate in individuals without learning disabilities, it is not surprising that such discussion in those with learning disabilities should be fierce. Different health workers are likely to arrive at differing ethical conclusions depending on their priorities and values. It is important that further discussion takes place before the clinical problems arise.

References

BAYER, R., LEVINE, C. & WOLF, S. (1986) HIV antibody screening. An ethical framework for evaluating proposed programs. *Journal of the American Medical Association*, **256**, 1768–1774.

BUTI, M., ESTEBAN, R., SANJOSE, R. *et al* (1986) Prevalencia de marcadores de infeccion de los virus dela hepatitis B, Delta Y HTLV-III en deficientes mentales. *Revista Clinica de Espana*, **179**, 175–177.

CENTRE FOR DISEASE CONTROL (1988) Guidelines for effective school health education to prevent the spread of AIDS. *Morbidity & Mortality Weekly Report*, **37** (suppl S-2), 1–14.

GENERAL MEDICAL COUNCIL (1988) *HIV Infection and AIDS: the ethical considerations*. London: General Medical Council.

KASTNER, T. A., KICKMAN, M. L. & BELLEHUMEUR, D. (1989) The provision of services to persons with mental retardation and subsequent infection with human immunodeficiency virus (HIV). *American Journal of Public Health*, **79**, 4914.

Further references can be obtained from the authors.

https://doi.org/10.1192/pb.16.10.638 Published online by Cambridge University Press