We’re just in time – AIDS, brain damage and psychiatric hospital closures: a policy rethink

By Dr CHARLES TANNOCK and Dr CAROLINE COLLIER

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In the autumn of 1989, Drs Tannock and Collier, of the Bow Group, published the report We’re Just in Time which argued that “as many as 2,500 additional mental hospital beds” would be required to look after AIDS patients with severe dementia. As a result of the estimate, the authors recommended that “as a measure of a strategic contingency reserve between two and eight long-stay hospitals be kept open or ‘mothballed’ for this purpose”.

We wish to comment on their paper and reject the recommendations made by Tannock and Collier, on the following grounds: (a) their conclusions are based both on inaccurate data and on a misunderstanding of and lack of familiarity with the literature on HIV disease, (b) impractical assumptions about the possible role of long-term psychiatric hospitals in relation to HIV disease, and (c) apparent ignorance of the range of services already being provided by statutory and voluntary bodies.

(a) The report contains inaccurate information and shows a misunderstanding of the literature in HIV disease

While it is true that a majority of people with AIDS are found at post mortem to have evidence of CNS abnormalities, only a minority show clinical evidence of significant cognitive impairment. Studies based on unselected AIDS patients suggest that up to 16% may develop severe dementia, which in most cases lead to rapid deterioration and death (WHO, 1988). Tannock and Collier have made the serious mistake of taking neuropathological abnormalities to mean chronic brain damage in a clinical sense, so that their assumptions about the prevalence of chronic organic brain syndromes lead them to over estimate the expected number of patients with dementia by about seven times.

We are not aware of any studies suggesting that up to 15% of patients with AIDS and neuropsychiatric complications may require a contained psychiatric facility as claimed by Tannock and Collier. The authors base their predictions for the number of beds required on this estimate, and therefore before their arguments can be accepted, supporting evidence has to be produced. Similarly, we are not aware of any work which would support their statement that AIDS patients with neuropsychiatric complications “are best kept in separate facilities due to the special nursing and containment facilities required for their disturbed behaviour”.

Tannock and Collier claim, quoting a personal communication, that the “neuropsychiatric complications of AIDS are rising, possibly because patients are living longer due to better treatment of previously life threatening complications of AIDS”. In fact, what evidence there is contradicts this statement. Open and double blind placebo control studies of Zidovudine in AIDS patients (Schmitt et al, 1988) show that Zidovudine has important and statistically significant effects on neuropsychological performance. It has also been argued that Zidovudine may contribute to a reduction in the prevalence of AIDS dementia (Portegies et al, 1989).

It is also untrue to say that “asymptomatic HIV positive patients have a much increased survival time when taking AZT”: the American studies referred to have shown that Zidovudine (AZT) delays progression to AIDS or ARC when given to asymptomatic subjects or those with early ARC if their CD4 cell count is less than 500 cells/cm (BMJ, 1989). No data are available regarding survival.

(b) The report makes impractical assumptions about the possible role of long-term psychiatric hospitals

We are baffled by the suggestion that a model of care which is now regarded as undesirable
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for most psychiatric patients should be preserved for a group of patients who, in addition to neuropsychiatric problems, suffer from a serious and rapidly progressing physical disorder which affects many organs and systems, therefore requiring access to expert medical care.

The report recommends that between two and eight long-term psychiatric hospitals should be "mothballed" for this purpose. It is difficult to imagine how these supra-regional centres would be able to meet the needs of the patients they are supposed to help. For example, it is difficult to envisage how relatives and friends of the patients could visit or how expert medical care as well as specialised laboratory, radiological or endoscopic investigations could be provided. The practicalities and cost-efficacy of providing sophisticated medical care in the rather spartan and dilapidated surroundings provided by long-term psychiatric institutions would in themselves be a considerable, if not insurmountable obstacle.

It is also difficult to follow the argument that "there would be massive political and public opposition to setting up local AIDS dementia hospitals, as opposed to keeping existent facilities to which the public are already accustomed". There is something unsavoury and rather disturbing about suggesting that AIDS patients could be somewhat smuggled into the old psychiatric hospitals without public disquiet, while the setting up of special facilities would lead to political and public opposition. The example of centres like the Lighthouse or the Mildmay Mission Hospital proves that the possibility of local opposition can be seriously over-estimated.

The report ignores successful collaboration between statutory and voluntary services

Anyone familiar with the range of medical, psychological and social problems experienced by people with HIV disease will know of the many examples of successful collaboration between hospitals, social services, and voluntary groups.

Similarly, anybody working in the field will know that the majority of patients would prefer to be either at home, provided the necessary home care supports are available, or in residential facilities within easy reach of relatives and friends, and with good access to intensive medical care. Many people with advanced HIV disease, whether they have neuropsychiatric problems or not, are already being cared for in the community and with the support of voluntary agencies, and this is the form of care that is generally perceived by the users of the services as appropriate. What is required is an expansion of the range of facilities available and a better co-ordination of services, rather than the resurrection of outmoded forms of care which have not proved successful even when dealing with a population with fewer medical problems.

Conclusions

The neuropsychiatric problems seen in a proportion of patients with advanced HIV disease, will not be adequately tackled by placing these patients in outmoded and remote long-term psychiatric hospitals.

The majority of AIDS patients with chronic organic brain syndromes will also be suffering from serious physical disorders resulting from HIV infection, and so will require access to expert medical care for diagnosis, treatment and prevention of other complications. The majority of these patients will require a medical bed, and liaison psychiatrists should play an important role in their care while they are in hospital and be involved in planning their aftercare. Other AIDS patients with chronic brain syndromes will be in the terminal stages of their illness, and maybe more appropriately nursed either at home (provided the necessary home-care support is available) or in a hospice. Access to a psychiatric opinion and, where appropriate, community psychiatric care would be desirable. A few patients with chronic brain syndromes may be, for short periods of time, well enough not to require an acute medical bed or ill enough to be in a hospice for terminal care, but still require supervision 24 hours a day. As it is the case with other demented patients, provision of adequate community support in addition to the assistance given by relatives and friends would seem the best option both in terms of the patients own needs and from the financial point of view.

At present it is not possible to have accurate information on the prognosis of patients with chronic organic brain syndromes who require this form of home based care, and whether some will indeed require admission to a residential facility, but the evidence provided by the literature and clinical experience suggests that numbers are likely to be much smaller than anticipated. Further research into both the prevalence of these problems and the best way to support patients and their carers along the lines outlined above, is needed, before launching into alarmist and misguided responses.

References


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June 1990

President’s Essay Prize

The President’s Essay Prize will be offered for the first time in 1991, as part of the College’s 150th Anniversary celebrations. Depending on the success of this award, consideration will be given to establishing the Prize for future years.

The Prize, value £200, will be offered for an essay of 2,000–3,000 words. The topic for 1991 is the assessment of the therapeutic effects on psychiatric patients of a pleasant and congenial environment, both in and out of hospital.

Applicants are expected to include a critical review of the current relevant literature and on this to base some original comments and conclusions.

Entry is open to all Members and Associates* of the College, without restrictions as to age or seniority. Entrants should include a brief curriculum vitae and send their submissions to the President, at the College, by 31 January 1991.

Judges for the Prize will be the President, the Dean and the Chairman of the Public Policy Committee.

*“Members and Associates of the College” means that applications can be received from “registered Members and Fellows of the College” as well as the “registered Affiliates, Honorary Fellows, Corresponding Fellows, Corresponding Associates, Inceptors, New Affiliates and New Associates”.

Senior registrar numbers in general psychiatry and old age psychiatry

As a result of the College’s submission to the Joint Planning Advisory Committee at the end of last year, the Department of Health has agreed to increase the allocation of senior registrar posts in the above specialties. This increase of 90 posts brings the number of posts allocated to general psychiatry and old age psychiatry as a whole to 480.

In view of the establishment of old age psychiatry as a separate specialty of psychiatry, the Department of Health has assigned one third of the new total (480) to higher training in old age psychiatry.

In its future assessment of higher training schemes in general and old age psychiatry the Joint Committee on Higher Psychiatric Training will expect sufficient training opportunities in old age psychiatry to be available.

Professor A. C. P. Sims
President

Overseas Doctors’ Training Scheme

The Overseas Doctors’ Training Scheme (ODTS) has been in operation for just over a year. During this time we have placed nearly 40 doctors in posts throughout the UK.

The scheme now has a rapidly lengthening waiting list of doctors who have been accepted by the College for sponsorship but for whom no post has yet been identified. We are consequently hoping to expand our list of training offers to accommodate the increasing number of applicants whom we hope to place in post in February 1991.

I would be very grateful to hear from any psychiatric tutors who would like to reserve an SHO or registrar post on their general professional training scheme for an overseas trainee sponsored by the College. Interested tutors should contact me at the College for further information.

I should also like to take this opportunity to thank all tutors and consultants currently involved in the scheme for their help and support in developing the ODTS.

Dr Fiona Caldicott, Dean
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References
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