

# *Institutional Care for Patients with Huntington's Chorea*

## *Is there a better alternative?*

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Despite recent advances in the understanding of Huntington's Chorea, treatment remains, at best, symptomatic and many sufferers end their days in institutional care. A recent survey<sup>1</sup> established the prevalence of Huntington's Chorea in South Wales as 7.65 per 100,000. From this figure, 4,000 or more sufferers of this condition are living in the United Kingdom at present of whom 20% are in hospital or other institutional care. Although some studies<sup>2</sup> have looked in passing at the degree of disability of Huntington's Chorea sufferers in hospital and found it to be considerable, staff and relatives often feel that long stay psychiatric wards are inappropriate or unnecessarily restrictive settings for these patients. This study looks at the disability of Huntington's Chorea sufferers in hospital and other institutions in order to determine the suitability of their placement and to see whether their physical and psychological needs are being met.

### **The study**

Over six months an exhaustive search of all hospitals and institutions around Birmingham (population 1.2 million) found 20 patients with Huntington's Chorea of whom 12 were in hospital and 8 in residential care. Each patient was then visited to assess the degree of disability using a modified Crichton questionnaire.<sup>3</sup> Staff and where possible relatives were then interviewed.

### **Findings**

(a) *Population details.* The mean age of the hospital group was greater (53.4 S.D. 20.5 years) than the age of

the group in residential care (47.9 S.D. 13.2 years). There were 12 males and 8 females. Hospital patients had been symptomatic for 9.9 (S.D. 6.0) years compared to only 6.8 (S.D. 3.6) years in the residential group. A diagnosis of Huntington's Chorea had been made earlier in the hospital group than in the group in residential care (8 years versus 3.3 years). Patients in the hospital group had been permanently resident longer than those in residential homes (2.9 years versus 1.8 years).

(b) *Disability.* Using the modified Crichton scale disabilities for the two groups were assessed separately (see Table I). It can be seen that all disabilities were more severe amongst patients in the hospital group. Chorea was regarded as the biggest disability in both groups followed by speech disturbance and mobility problems.

(c) *Management difficulties.* Aggression was a commoner problem among patients in hospital, with a third being described as aggressive at times. Although staff in both settings felt that they could generally cope there was often insufficient time to give patients the attention they needed, particularly in hospitals where staff shortages caused difficulties in dealing with the physical needs of Huntington's Chorea patients. In residential homes staff appeared to have had little advice on how physical problems could be overcome and would have liked advice on whether specialists aids would have been of help. Staff in both hospital and residential homes appeared to be inadequately informed about the nature of Huntington's Chorea.

(d) *Living conditions and availability of resources.* Patients in both hospital and residential homes were allowed unrestricted visiting and personal possessions. However, those in residential homes lived either in private rooms or shared with one or two other people whereas those in hospital were housed largely in dormitories. Home visits or day outings were made very rarely by patients from either setting due largely to a lack of adequate supervision and the problems caused when the patients became unwilling to return.

Occupational therapy, speech therapy, physiotherapy and supportive counselling were available both in hospitals and in residential homes. In general, however, facilities were limited and patients frequently did not attend. The main reasons given for this were a lack of staff to supervise the patients and a widespread feeling that these patients were too handicapped to benefit because of the progressive nature of their disease.

(e) *Counselling services.* Genetic counselling is available

TABLE I  
Mean disability scores on the modified Crichton

Disability	Hospital group (n = 12)	Residential group (n = 8)
Cognitive	2.00	1.25
Behaviour	1.58	0.88
Speech	2.58	1.38
Chorea	2.75	1.88
Mobility	2.58	1.25
Bathing	2.33	0.65
Feeding	2.41	0.50
Incontinence	1.58	0.63

(Maximum disability scores 4 per item)

from the Department of Clinical Genetics at the University of Birmingham. Relatives were asked if they had been offered such counselling and staff and relatives were asked if they had heard of Combat (Association to Combat Huntington's Chorea) as a way of assessing how successful these services were at reaching their targeted clientele. Most families were aware of Combat and all had been in contact with the organisation. Information was principally requested on the genetics and course of the illness. Over half these families had also received some counselling and support from the local Combat branch and social worker. Surprisingly almost half the staff questioned had not heard of Combat. Genetic counselling had been offered to nearly three quarters of the relatives most of whom expressed satisfaction at the service offered.

(f) *Suitability of placement.* Staff, relatives and where appropriate patients were asked if they felt that the placements were satisfactory or not. For individual patients there was good agreement between staff and relatives. In general residential placement was thought to be satisfactory. Hospital staff, however, felt that over half their patients were unsatisfactorily placed. Seven staff and four relatives thought that their staffing levels were too low. Three staff and four relatives thought that a special unit should be made available for Huntington's Chorea patients. Seven staff and five relatives thought that these patients should not be kept with the mentally ill.

#### Comments

In this study patients, staff and relatives have been questioned to find out whether an adequate service is being provided for sufferers of Huntington's Chorea.

It appears that there is a matching of disability with the type of placement in that patients more advanced in the course of their illness and showing greater disability were to be found in hospital. Only limited resources are available particularly in residential homes. It was also shown, however, that staff apathy often prevented patients from taking advantage of the limited services that were available. Everywhere in hospitals there appeared to be staff shortages. Generally residential homes were thought to be more suitable than psychiatric wards for the care of Huntington's Chorea patients, with over half of the hospital patients being considered unsuitably placed. The main reasons given were the lack of privacy and the distress patients and their relatives felt about their being nursed along side people with severe mental illness. It was also felt that staff shortages prevented adequate physical nursing care at times. There are indications that where genetic counselling<sup>4,5</sup> and general supportive counselling<sup>6</sup> are available patients and relatives benefit. Judging from the high rate of referral to the Clinical Genetics Department of Birmingham University and Combat this message is slowly getting through.

In and around Birmingham it has been estimated that 1.653 per 100,000 of the population are in some form of institutional care because of Huntington's Chorea, of

whom 60% are in hospital; 1.24 per 100,000 are in permanent care and this figure is in agreement with research findings from South Wales.<sup>7</sup> Extrapolating from our survey the West Midlands Regional Health Authority (with a population of 5.18 million) should have 394 patients in various stages of Huntington's Chorea. Of these, 16 will probably be in permanent residential care and 48 in permanent hospital care. Allowing for an average cost of £238.00 per week per hospital bed<sup>8</sup> the cost to the NHS for providing long-term hospital care in the West Midlands would be approximately £600,000 per year. This survey suggests a general dissatisfaction with the level of care provided for patients requiring long term care in psychiatric hospitals. Allowing that there are some patients who through their aggressive behaviour require a secure containing environment, a case could be made for each region providing a small specialist unit for some 30 patients. Disadvantages of such a scheme might be the long distances some relatives would have to travel and the mixing of people with relatively mild and advanced forms of the disease. However, there would be considerable advantages such as the presence of trained and knowledgeable staff, a close liaison with Combat, the absence of unsuitable fellow patients and a more accepting and understanding attitude among staff and visitors. The general feeling among those questioned was that these advantages would make this proposal worthy of serious consideration.

#### ACKNOWLEDGEMENTS

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