

Needs and Opportunities in Rehabilitation

Rehabilitation after head injury: 2—Behaviour and emotional problems, long term needs, and the requirements for services

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Psychiatric symptoms and less stable patterns of behaviour are common after severe head injury.¹ Character change and difficult behaviour are among the most tragic consequences. Sometimes they represent not so much a change of personality as exaggeration of previous adverse traits. In a family they cause immense stress and depression,¹ calling at the least for careful counselling and support.² Behavioural disorders clearly may sabotage rehabilitation as well as jeopardising the future quality of life.

Behaviour problems and behaviour modification

Aggressive types of behaviour¹ bar people from most rehabilitation units and most forms of residential care, and manipulative behaviour is also said to create great problems. The "negative" disorders of apathy (lack of arousal) and loss of motivation make people unresponsive to rehabilitation as to everything else. Psychological methods to help head injured people make the most of the abilities they have left may be a major need,³ not confined to those with obvious behaviour disorders. The success of a comprehensive rehabilitation programme being carried out in New York and Israel⁴ (p 367), it was said to me, is attributed in part to this factor—patients have previously performed well below their potential—as well as to help with problems of behaviour and socialising.

Behaviour modification using reinforcement appears to offer a way forward for some patients with behaviour problems,^{1,4,5} especially as there may be also a "learned" version of the disturbed behaviour; for example, aggressive outbursts similar to those caused by the brain damage may be learned as a way of getting attention.¹ If the damage is of epileptic type behaviour modification and drugs combined are said to be better than either alone. Even those with learning deficits may profit if enough time and effort go into helping them, with the use of more concrete types of reinforcement.

The aims of behaviour modification are to get rid of unwanted behaviour, to shape existing behaviour into more socially acceptable or otherwise appropriate forms, and to encourage activity where the drive to do anything is absent.⁵ Breaking the problem behaviour down into small components and tackling these in a very precise way may be the starting point.^{3,6} Behavioural techniques are not widely available but are used in some specialised rehabilitation units and in at least one long term workshop, while experiments in behavioural approaches in transitional living and outpatient programmes have been reported from the United States and Canada.⁴ As an example of reinforcement used successfully in a rehabilitation unit, a young man who had the habit of yelling and was doubly incontinent was praised when quiet (and ignored while yelling); attempts at continence were rewarded at first with sweets and cigarettes and later with plastic tokens to be exchanged for treats⁶ (p 262).

A "token economy"⁷ operates in the Kemsley Unit at St Andrew's Hospital, Northampton.^{1,5,8} This was set up in 1979 for brain injured people with severely disturbed behaviour, who go there usually three to five years after injury and stay 12-18 months. Positive reinforcement for appropriate behaviour consists of plastic tokens, which are needed for meals and other everyday items. In the face of inappropriate behaviour tokens are withheld (at worst Complan replaces some meals) or "time out" is briefly operated—the person is totally ignored or is taken into the corridor or a small bare room with the minimum of attention, "like a piece of furniture." The token economy combined with "social" reinforcement is not intrinsically more effective than the latter alone but being more structured is easier for nurses and other staff to carry out properly. The method is unsuitable in "dissociative" (hysterical) disorders, and difficult to use in "negative" disorders as rewards mean little to someone with low arousal or motivation.

The token economy may be very effective, but the important issue is whether it can have a lasting effect on these people. With behaviour modification in general the main difficulties are maintaining learned behaviour after the programme ends and generalising it to other settings, but ways around the difficulties have been devised.⁷ Brain damaged people have especial problems here but may manage quite well beyond the programme if the reinforcements are gradually separated in time from the behaviour concerned and tapered off, and if there is adequate "overlearning."¹ Some 70 patients have so far been treated in the Kemsley Unit, all of them described as "no hoppers." Twenty four patients with severe brain injury (head injury in 21) were followed up six to 33 months after discharge.⁹ Of the seven who failed to benefit, five had very diffuse damage from anoxia, ischaemia, or hypoglycaemia and another was a life long psychopath who had had a stroke. The others had become able to live in settings or in ways that had not been open to them before; four lived at home independently and 12 with family supervision but without help. Improvements in odd behaviour and in drive and motivation were not well maintained after discharge from the unit, but ratings for activities of daily living did not drop significantly. Clearly this approach should be regarded not as a panacea but as one possible stage on the road of rehabilitation; at the least, conclude the authors, the token economy had made rehabilitation possible despite behaviour disorders that had previously made it impossible.

"I find the methods distasteful but they seem to work in head injury," a consultant said to me. Against the charge that behavioural methods may be seen as "mechanistic, degrading, and inhuman" Wood argues that with desperately handicapped people who would otherwise end up in psychiatric or subnormality units these methods "rather than being a hard line may offer many patients a lifeline."¹ A joint working party has produced guidance for the use of behaviour modification.¹⁰

If special treatment is to be given, would it not be better at an early stage instead of after years of suffering with worsening problems? If patients with serious brain damage were all rehabilitated in special regional centres and those with behavioural disorders separately within such centres, that might be feasible. Moreover,

behavioural rehabilitation, for reducing aggressive behaviour and improving self care, need not be confined to special units.¹ Directors of neurological rehabilitation centres, it was suggested to me, should be trained in behavioural management so that disruptive patients are not unnecessarily rejected for rehabilitation. Beyond this, a more widespread knowledge of behavioural principles in hospitals, residential homes, and families might do a lot. For example, it is natural to give a lot of attention while someone is creating a disturbance but not while he is quiet, thus reinforcing the disturbed behaviour and failing to reinforce the acceptable behaviour. But there is a broader problem: while a very small minority need special facilities for their behaviour problems many more, it has been emphasised to me, need expert psychological help for themselves and their families (see below); far too often they do not get it.

More help for the head injured

Animals are said to recover better from brain lesions in a stimulating than an impoverished environment⁶ (p 54). This might well apply to man; but many people with severe head injury have a long spell in hospital followed by inactivity at home with some outpatient rehabilitation. It has been pointed out that when patients are beginning to recover but not fit to go home a rehabilitation centre provides a cheaper and more appropriate setting; thus hospital savings would partly pay for more places at such centres¹¹—but many parts of Britain have none accessible. Problems needing particular attention are the provision of rehabilitation programmes and their content; emotional needs of sufferers and relatives; and long term help and opportunities, including work.

The integrated team approach to rehabilitation is constantly emphasised, even more so for head injury than for other problems; what each therapist teaches must be reinforced by all staff,



Rock climbing with an occupational therapist during an adventure training course in Snowdonia for patients from the head injury unit of the Joint Services Medical Rehabilitation Centre.

including nurses, all day. The "colocation" system of the Joint Services Medical Rehabilitation Unit was one attempt to achieve this: physiotherapists and occupational and speech therapists would supplement their individual work with patients by taking part in the group work of other therapists.¹² It is said to be best suited to the more severely affected patients.¹³ Now many units have more than one therapist working with patients at a time, and perhaps common treatment areas. This kind of system and the need for intensive rehabilitation mean that adequate programmes cannot usually be provided in the course of the normal work of local hospitals but call for more specialised units (see below).

Anxiety and depression are inevitably common after head injury.¹⁴ Neurotic disturbance moreover is more common with mild and moderate than with severe disability—possibly because of the effort of trying to cope with simple tasks that have become difficult¹ (pp 96-9, 103), together with the fact that the worse affected tend to be unaware of the magnitude of their problems. So very specific counselling may be needed here. Relatives may be just as wretched,² and perhaps near the end of their tether, though many do manage wonderfully; the focus needs to be on "the head injured family."¹¹ Recent work in Glasgow has shown considerable psychiatric and social dysfunction among relatives that persisted throughout the year after injury.¹⁵ For head injured people themselves what counts most in the long run is cognitive impairment and personality changes rather than physical disability.¹⁶ Rehabilitation centres, it was suggested in 1980, "should relinquish their emphasis on physical recovery," and as well as developing more effective retraining for those with mental changes should seek better ways of helping patients and relatives to adjust to what cannot be mended.¹⁷ One psychologist emphasised the importance of exploring with the patient what has happened to him and to his family and where he is going. Some units are attending to these aspects, but on the other hand there are all the people who get to rehabilitation units only after long delay or for too short a time, or not at all, who also need to be considered in this way.

Children are not well catered for.¹ They appear to have an even longer recovery period and need even longer follow up than adults, but after the acute phase there is a lack of specialised facilities and they may go to adult centres. As long separation from their parents is bad a peripatetic remedial service has been recommended to advise families and schools on their management—including the provision of cognitive and behaviour therapies—and to counsel parents about problems of discipline and overprotection.¹ Investigations of specific measures are needed.

The long term outlook is often though not inevitably grim—family life and especially marriage, work, social life (including friendships), and leisure activities all being vulnerable, particularly where there is personality change and intellectual impairment. But there are many successful adjustments.^{17 18} A follow up study of groups of ex-patients who had had 12 and 24 weeks on average at two different rehabilitation centres showed that, while the longer course did not give more functional independence than the other, it did produce modest improvement in personality and behaviour (A Tyerman, M Humphrey, paper presented to Headway International Conference, July 1983). But at follow up, some 35 weeks after discharge, emotional state was worse than at discharge in both groups. Some 80% had been expected by staff at discharge to become independent in self care and capable of work but many belied this hope, probably for want of suitable opportunities. Both this and an earlier study¹⁷ showed that many people stay at home doing nothing after rehabilitation had ended, much distress going with the lack of work. Long term psychological help as well as special work opportunities appear to be a great need.

With work, not many are as lucky as the aphasic shepherd who could still whistle to his dog, or the man with a low score on performance testing due to wartime brain injury who was nevertheless a successful surgeon.¹⁸ As well as more sheltered work and specially modified jobs, and also suitable day centres, systematic skills analysis and job training for the badly impaired should offer a way forward. This is happening in a very few centres. A recent "vocational development" programme based on systematic analysis has won recognition in the United States⁴ (p 222).

Headway

Mutual support and activities for victims of brain damage (mainly head injury) and their families are offered by Headway (200 Mansfield Road, Nottingham NG1 3HX), which has over 40 branches. In Gloucester there is an exciting new project, Headway House—an activity centre, open two and a half days a week, in a bungalow in the grounds of Gloucestershire Royal Hospital that had been due for demolition and was renovated largely by the group. The coordinator, Roger Fitzsimmons, who has produced a report on the first year's work, is a speech therapist seconded to work half time with the project (aided by volunteers), thanks to a private trust fund. The centre has electronic and other equipment, TV and other games, art and workshop materials, and a kitchen and is saving for another computer. Once a week language and other academic activities are pursued. Some inpatients and outpatients as well as people not having NHS rehabilitation attend (there is no rehabilitation centre in the region). The social interaction is felt to be therapeutic, and there is much self help and mutual help: "Helper and helped are frequently interchangeable." Two attenders after being helped to recover communication skills then worked intensively with a man who had had stroke, which helped them as well and led to very supportive relationships between the three.

A few long term workshops are devoted to head injured people. One has been going for a year at Rivermead Medical Rehabilitation Centre, Oxford; and another, the Selly Oak Head Injuries Rehabilitation Centre in Birmingham, started in 1963.¹⁹ This now uses behavioural methods tailored to each individual and payment based on a token economy. A few hours a week are given to special activities for some—activities of daily living, social skills, clerical tasks (with microcomputer training) for some with mental impairment, newspaper discussion, and a keep fit class for exercise and interaction. Some clients move on to jobs, and some stay for many years. "Retirement" is prepared for by encouraging leisure activities and suggesting suitable outside groups. Staff believe that a rehabilitation hostel is badly needed for some of those attending.^{19a}

Those with empty hours, or activities lost beyond recall, may need someone to explore with them possibilities of new interests and help get them started. This is especially important after head injury, with the hypoactivity it often causes: truly successful rehabilitation should have an impact on how the person spends his time, say Diller and Gordon.²⁰ Different people, including the family, may be able to help here, during rehabilitation and later; but professionals, and not just those in a rehabilitation centre, must surely look into the matter. Among the most exciting "rehabilitation" activities are special adventure training courses in Snowdonia (figure) and sailing for the disabled through the Jubilee Sailing Trust. I also met a man who 20 years after his accident was doing a menial job but was writing and printing his own poetry.

The Medical Research Council coordinating group that reviewed research in rehabilitation after acute brain damage points out that the need is for more facilities and procedures of proved effectiveness, which means a lot of sound work on evaluation, using standardised methods.²¹ The group will give advice on research. Diller and Gordon,²⁰ Newcombe,^{13,22} and Miller³ are among those who have spelt out some of the requirements for research. One is the use of independent assessors.²² Ideas and methods proposed for tackling many of the problems of head injury, which I have looked at briefly in these articles, are plentiful, and so are enthusiastic staff; but the recurring theme is that reliable data on the real value of the various methods are scanty. Moreover, some approaches may require time and effort out of all proportion to the good they do,³ and so cost effectiveness may need to be considered as well.

Meanwhile there are the general needs for care with provision for rehabilitation: more acute head injury units; more long term accommodation and community support services suitable for the accumulating numbers head injured people with the difficult combination of physical and behavioural problems,²³ for whom a psychiatric or mental handicap ward is often an unhappy last resort (see also 2 February, p 369); and acceptance of the needs of those close to a persistent vegetative state, where small and hard won gains, such as rudiments of communication, may lighten a family's burden. The Swedish documentary film *Beyond Sorrow, Beyond Pain* (BBC2, 9 February) shows something of the problems from the inside, portraying a man who was written off as regards rehabilitation but who was helped to the beginnings of communication by his girl friend, who made the film as part of her campaign for a better deal for such people.

The MRC coordinating group proposes the development of assessment and therapeutic units, perhaps for five days a week, for the early months, with special units for those with serious behaviour problems in a few mental hospitals—beds for 10-15 patients plus day facilities serving more than one region.²¹ But too few doctors are concerned with head injury rehabilitation and interest in such patients might grow, suggests the group, if additional consultants were appointed with a responsibility for rehabilitation in the "acute" specialties concerned with the conditions leading to permanent brain damage. Little progress, however, has so far been made in following up the group's recommendations.

As Headway (see box) with its family support groups knows only too well, there is so much unmet need among the estimated 70 000 sufferers. In addition to the more obvious short and long term needs, the scope for continued remedial teaching and other activities after rehabilitation courses have ended presents a challenge. This could be met only by imaginative exploration of largely non-medical resources in the community, including the family with the right help, to suit each individual.

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Addresses

Action for Dysphasic Adults (ADA) Northcote House, 37A Royal Street, London SE1 7LL
 Association to Aid the Sexual and Personal Relationships of the Disabled (SPOD) 286 Camden Road, London N7 0BJ (holding study day on sexual consequences of brain damage on 3 April)
 Headway (National Head Injuries Association) 200 Mansfield Road, Nottingham NG1 3HX
 Jubilee Sailing Trust Atlantic Road, Eastern Docks, Southampton SO1 1GD

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Clinical Algorithm

Suspected thyrotoxicosis

A S M KHIR

A useful approach when dealing with a patient with suspected thyrotoxicosis is to ask the two questions, "Is the patient thyrotoxic?" and, "What is the underlying condition?" The answers can, in most cases, be easily found by clinical examination and a few simple investigations. The algorithm illustrates the steps towards establishing a functional and aetiological diagnosis and gives brief notes on the appropriate treatment of the underlying disorder.

Presentation

The clinical manifestations of excess circulating thyroid hormones are abundant. The box shows the main clinical features of thyrotoxicosis. It is common for dysfunction of one or two systems—for example, the cardiovascular or the neuropsychiatric—to dominate the presentation, but careful interview and examination will show most of the elements of the syndrome.

Unusual modes of presentation deserve special mention. This is especially likely in the elderly, in whom cardiovascular features predominate over the aforementioned classic symptoms and signs or, indeed, may occur alone. Hyperthyroidism should be suspected in elderly patients with refractory cardiac failure, especially if atrial fibrillation and a high cardiac output state are present. Also suggestive is failure of cardiac glycosides in usual dosage to control rapid heart rate. Older patients may also present with a retarded rather than the usual hyperactive physical and mental state; this is called apathetic thyrotoxicosis. Diagnosis may be less obvious if myopathy is the dominant presenting feature mimicking neuromuscular disease (such as carcinomatous myopathy) or if diarrhoea and weight loss seem to point to a gastrointestinal malignancy.

Main clinical features of thyrotoxicosis

SYMPTOMS

nervousness—irritability, emotional liability—
increased sweating,
intolerance of heat, palpitations,
undue fatigability ± muscular weakness,
weight loss usually with increased appetite,
dyspnoea or exertion ± ankle swelling,
eye complaints—prominence, "grittiness" (Graves)—
diarrhoea, thirst, menstrual irregularities,
dermatological—hair loss, pruritus

SIGNS

tachycardia, hyperkinesia, goitre ± bruit,
warm moist skin, tremor
eye signs—lid retraction, lid lag, and signs of
Graves' ophthalmopathy—
atrial fibrillation, myopathy,
signs of heart failure (high output)

Occasionally a patient with hyperthyroidism may present with thirst, polyuria, weight loss, and glycosuria; diabetes mellitus and thyroid overactivity may, however, coexist.

Although thyrotoxicosis can be readily confirmed by carrying out biochemical tests as outlined below, differential diagnosis may pose problems in the following clinical circumstances:

(1) Euthyroid goitre or ophthalmic Graves' disease, especially if associated with other causes for weight loss or tachycardia.

(2) Anxiety neurosis. The difficulty here may be compounded as this is often seen in young women who may be taking the combined oestrogen and progestogen contraceptive pill, which can affect the results of certain in vitro thyroid function tests.

(3) Occult neoplasm or infections such as tuberculosis.

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