Disability after severe head injury: observations on the use of the Glasgow Outcome Scale

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SUMMARY The nature of the neurological and mental disabilities resulting from severe head injuries are analysed in 150 patients. Mental handicap contributed more significantly to overall social disability than did neurological deficits. This social handicap is readily described by the Glasgow Outcome Scale, an extended version of which is described and compared with alternatives. Comments are made about the quality of life in disabled survivors.

Some of the patients who now survive severe head injury due to intensive therapy in the acute stage make a satisfactory recovery. Others are left with sequelae which range from the inconvenient to those which render the patient totally dependent. Many of these survivors are young and they face many years of disability, which commonly affects both mental and physical function. Although the separate components of handicap after brain damage have frequently been described, particularly those which can be measured by psychometric tests, what matters to the patient is the net effect of all his separate disabilities on his functioning as a person, which includes the extent of his dependency on others. This may be termed the overall social outcome, and it is often described in poorly defined terms such as: "good," "fair," "poor," "acceptable," "practical," "worthwhile," or "tolerable"—the last two involving value judgements about the quality of life.

Some years ago we devised a simple scale for describing overall social outcome,¹ mainly in order to facilitate two multicentre studies on outcome from coma due to structural brain damage. One of these dealt with severe head injury,² the other with coma due to non-traumatic conditions;³ the purpose of both was to evolve a system of predicting outcome six months after the ictus. The need was for a limited set of outcomes which had to be sufficiently clearly defined to be used reliably by observers in several centres, some of whom were in different countries.

Subsequently, a leading American neurosurgeon suggested that the Glasgow Outcome Scale should be adopted world-wide for reporting series of severely head injured patients, at least for a period of five years, in order to facilitate comparison between different studies.⁴ In the event most recent publications reporting recovery after head injury from North America and Europe have used this scale, and the multicentre studies of severe head injury and of ruptured aneurysm recently initiated in the USA by the NINCDS require participants to classify survivors on the Glasgow scale.

It is timely therefore to review the practical application of the scale, to compare it with alternative systems of assessing outcome, and to describe the components of physical and mental disability in patients who reach the various points on the scale. This paper discusses these matters by reference to a series of severely head injured patients who were prospectively studied during their recovery. It also proposes sub-division of the original scale to allow more sensitive measures of recovery in patients who regain consciousness.

THE ORIGINAL GLASGOW OUTCOME SCALE

The scale proposed four outcome categories for surviving patients as follows:

(a) *Vegetative state*: This was defined by Jennett and Plum⁵ in rigorous terms which limited it to patients who showed no evidence of meaningful responsiveness. Patients who obey even simple commands, or who utter any words, are assigned to the better category of severe disability. Vegetative patients breathe spontaneously, have periods of spontaneous eye-opening when they may follow moving objects

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Accepted 20 November 1980

with their eyes, show reflex responses in their limbs (to postural or painful stimuli), and they may swallow food placed in their mouths. This non-sentient state must be distinguished from other conditions of wakeful, reduced responsiveness—such as the locked-in syndrome, akinetic mutism and total global aphasia. Although the vegetative state indicates lack of function in the cerebral cortex, this may be structurally intact; for this reason Jennett and Plum argued that the term “apallic syndrome” was inappropriate.

(b) *Severe disability*: This indicates that a patient is conscious but needs the assistance of another person for some activities of daily living every day. This may range from continuous total dependency (for feeding and washing) to the need for assistance with only one activity—such as dressing, getting out of bed or moving about the house, or going outside to a shop. More often dependency is due to a combination of physical and mental disability—because when physical disability is severe after head injury there is almost always considerable mental deficit. But a few patients who have little or no physical deficit are unable to organise their day-to-day lives effectively, and must be classified as severely disabled. The worst of these requires the care and protection which only a mental hospital can provide, while others cope at home with the support of attentive relatives, but could not be left overnight because they would be unable to plan their meals or to deal with callers, or any domestic crisis which might arise. The severely disabled are described by the phrase “conscious but dependent.”

(c) *Moderate disability*: These patients may be summarised as “independent but disabled,” but it is perhaps the least easily described category of survivor. Such a patient is able to look after himself at home, to get out and about to the shops and to travel by public transport. However, some previous activities, either at work or in social life, are now no longer possible by reason of either physical or mental deficit. Some patients in this category are able to return to certain kinds of work, even to their own job, if this happens not to involve a high level of performance in the area of their major deficit.

(d) *Good recovery*: This indicates the capacity to resume normal occupational and social activities, although there may be minor physical or mental deficits. However, for various reasons, the patient may not have resumed all his previous activities, and in particular may not be working.

Patients and methods

Characteristics of the patients

A data bank of over 1000 severely head injured patients from three countries has been accumulated prospectively

in Glasgow over the last ten years. The minimum severity of injury was a period of coma of at least six hours (coma is defined as not opening the eyes, not obeying commands, not uttering understandable words). Post-traumatic amnesia (PTA) in survivors was at least two days, and in 94% exceeded a week. Many initial features of the patients in each of the three countries were similar, as were the mortality rates (about 50%) and the distribution of outcomes on the Glasgow scale six months after injury (2:6).

For a more detailed analysis of disability a series of 150 conscious adult survivors in Glasgow were called to a special clinic for the purpose of this study, at least one year after injury (range 1–14 years, mean 5.2, SD 2.6), where they were assessed by a neurologist (JS). These patients had a similar distribution of outcome categories six months after injury as the remaining Glasgow cases, and as the cases from other centres (table 1). Their mean age was 28 years, 44% being under 20 years and 5% over 60 years; males predominated (5:1). PTA was over 28 days in 61%, 15–28 days in 9% and 2–14 days in 30%. An acute intracranial haematoma had been evacuated in 52% of these patients.

Table 1 *Conscious survivors 6 months after injury*

	<i>Other data bank centres</i> 191	<i>All Glasgow cases</i> 314	<i>Glasgow detailed follow-up</i> 150
Severe disability	21%	19%	20%
Moderate disability	35%	34%	40%
Good recovery	44%	47%	40%

Results

1 RELIABILITY OF THE SCALE

The outcome category at six months and at twelve months was assigned by JS for the 150 patients whom he saw in the clinic. These assessments were compared with those already made by BJ, as part of the ongoing data bank study. For both times there was agreement between these two observers in more than 95% of patients; each observer scored a few patients higher and a few lower than the other.

2 HOW MANY CATEGORIES?

Several sizeable reports in recent years have recognised only two categories of survivor after severe head injury,^{7–11} and one made no distinction between the disabled and the recovered.¹² The categories in these classifications are seldom clearly defined but their probable equivalence to the practical scale under discussion is set out in table 2. Considering the range of disability which occurs, it does seem important to recognise at least the difference between disabled patients who are dependent and those who are not. Even the three-category Glasgow scale is considered by some to be over-compressed, and

Table 2 Classification of disability of head injury survivors who became conscious.

Jennett and Bond (1975)	Carlsson (1968)	Pazzaglia et al (1975)	Heiskanen and Sipponen (1970)	Vigorous et al (1979)	Overgaard et al (1973)	Vapalhati and Troupp (1971)
Severe disability	Persisting Dementia	Partially Re-integrated	Permanent invalid	Serious sequelae	Severe deficit	
Moderate disability						
Good recovery	Mental restitution	Recovered	Recovery	Nil/slight sequelae	Good recovery	Recovery

Figure Distribution of disability of conscious survivors on the 6-point Glasgow scale (from *Management of Head Injuries—Jennett B and Teasdale G. F A Davis: Philadelphia 1981*).

therefore to be insensitive to degrees of improvement which occur within one of its categories. For this reason we divided each of the 150 conscious survivors in this study into a better and worse level within each of the original categories to which they had been assigned. The proportional distribution along the six-point scale for conscious survivors at six and twelve months after injury showed only small numbers of patients at the extreme ends of this scale (figure). Including dead and vegetative this makes eight outcome categories. For some purposes, however, it may be more appropriate to contract the original five point scale to two or three outcomes (table 3); for example, for statistical calculations of probable outcome at six months on the basis of data collected in the first week after injury.

A number of outcome scales have been published with more categories than the original Glasgow scale¹⁵⁻¹⁹ but none of these scales has its categories as evenly spread across the range of disability as the extended Glasgow scale (table 4). More than half of the aggregate of categories from five published scales refer to patients whom we would classify as severely disabled and who make up less than a fifth of survivors six months after severe head injury.

Table 3 Outcome after severe brain damage (variations on Glasgow Scale)

Dead	Dead/Vegetative	Dead/Vegetative	Dead	Dead	Dead
			Dependent	Vegetative	Vegetative
		Severely Disabled		Severely Disabled	Disability:
					5
					4
Survivors	Conscious			Moderately Disabled	3
		Independent	Independent		2
				Good Recovery	1
					0
No. of categories	2	3		5	8

Table 4 Classification of disability due to brain damage (conscious survivors)

Acute brain damage (traumatic or not)		Head injury			Stroke	
Glasgow Scale Jennett and Bond (1975) 3 point	(1981) 6 point	Najenson (1974)	Stover and Zeiger (1976)	Roberts (1979)	Rankin (1957)	Adams (1963)
	5		2	4		
Severe Disability		2	3		4	3
	4		4	3.5	3	2
			5	3		
Moderate disability	3	3		2.5		
	2	4	6	2	2	1
				1.5		
Good recovery	1		7	1		
	0	5	8	0.5	1	

3 WHEN TO ASSESS OUTCOME

When patients from the international data bank who were conscious three months after injury were re-assessed later there were fewer who improved between six and 12 months than between three and six months. Of those who by 12 months had made a good recovery, or who were by then moderately disabled, almost two thirds had already reached this level within three months of injury and 90% had done so by six months. This corresponds with the pattern of recovery for many aspects of cognitive function.²⁰⁻²³

Examination of the 150 patients in the present study confirmed that 10% of patients who were severely or moderately disabled at six months were in the next better category by one year. When re-assessment was made using the six point scale it was found, as expected, that 20% had improved by one subcategory between six months and 12 months. Only 5% of 82 patients, followed for more than 18 months improved sufficiently after 12 months to reach a better category. It was exceptional for a patient who was severely disabled at three months after injury ever to reach the category of good recovery.

4 NATURE OF DISABILITY

Physical (neurological) disability

Four main deficits were recognised: in descending order of frequency these were signs of continuing dysfunction in the cerebral hemisphere, deficit in one or more cranial nerves, post-traumatic epilepsy, and ataxia (table 5). No neurophysical disability was detected in a quarter of these survivors after severe injury. Patients who had had an intracranial haematoma evacuated during the acute stage of

injury more often had neurophysical sequelae; as expected they more often developed epilepsy and fewer of them had ataxia. Although those survivors who had had a haematoma more often had dysphasia than other patients, fewer of them had hemiparesis; after head injury hemiparesis is probably quite frequently due to damage to deep central white matter rather than to cortical and subcortical lesions. In about half the patients with epilepsy there was no hemiparesis, dysphasia or hemianopia.

The most commonly affected cranial nerve was the optic (13% of all survivors); 9% had one or more of

Table 5 Neurophysical sequelae

	All cases 150	After intra- cranial haematoma 70	No intra- cranial haematoma 73
<i>(a) All features</i>			
Signs of continuing cerebral hemisphere dysfunction*	59%	52%	66%
Cranial nerve palsy	32%	36%	27%
Epilepsy	15%	21%	5%
Ataxia	9%	3%	10%
No signs	26%	35%	16%
<i>(b) Cerebral hemisphere dysfunction</i>			
<i>Hemiparesis</i>			
as only hemiplegic sign	28%	18%	38%
total incidence	49%	38%	60%
<i>Dysphasia</i>			
as only hemiplegic sign	9%	13%	4%
total incidence	29%	32%	26%
<i>Hemiparesis + dysphasia</i>	21%	19%	22%
<i>Hemiparesis and/or dysphasia</i>	57%	51%	64%
<i>Homonymous hemianopia</i>			
as only hemisphere sign	1%	1%	1%
total incidence	5%	5%	5%

*Excluding those with only epilepsy.

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Table 6 Frequency of physical sequelae in each outcome category

		Good recovery 60	Moderate disability 60	Severe disability 30
Hemiparesis	{ Mild Severe	25% 0	40% 20%	37% 40%
Dysphasia	{ Mild Severe	10% 0	32% 12%	17% 30%
Both Hemiparesis and Dysphasia	{ Either severe Both severe	0 0	27% 2%	60% 17%
Cranial nerve	{ Mild Severe	20% 0	32% 15%	23% 30%
Only CN ($\pm$ epilepsy)		20%	15%	7%
Epilepsy		17%	10%	30%
Ataxia		2%	13%	17%

the nerves to ocular muscles affected and 8% had sensorineural deafness. Anosmia was noted in only 5%—possibly an underestimate because assessment in severely damaged patients can be difficult. Dysarthria was present in 4% and facial weakness in 2%. Deficits in patients judged to have made a good recovery most often consisted of mild hemiparesis, cranial nerve palsies, or epilepsy (table 6). The severely disabled had a higher incidence of severe hemiparesis or severe dysphasia, one or other of which affected a third of these patients; half of these patients were both severely paralysed and severely dysphasic. Epilepsy was also more frequent in the severely disabled.

Psychological and social disability

The nature and time course of the cognitive deficits and disorders of personality found in severely brain damaged patients (as defined here) has been described in several previous reports from this Institute.²⁰⁻²⁶ In the present series the neurologist made a clinical assessment of the degree of personality change from questioning of the patient and a close relative. Formal tests of cognitive function were carried out independently on as many patients as possible by a psychologist who did not know the neurologist's rating of outcome category for the patient. The test battery comprised verbal and non-verbal learning and memory, verbal and performance intelligence, and measures of perceptual/constructional function. In these severely injured patients it was often impractical to carry out full cognitive testing; for this reason the totals vary for different tests in the tables.

The overall severity of the cognitive deficit was graded (in 3 categories) by the neurologist, who had access later to the psychologist's reports, and the relationship to the outcome category was explored

(table 7). None of the nine patients with severe cognitive deficit was judged to have made a good recovery, and only two were in the moderate disability category. Of the 45 patients with good cognitive recovery, none had an outcome category of severe disability, while of the seven patients with a moderate cognitive disability, four were in the outcome category of moderate disability. The picture for personality change was very similar, with no patients with moderate or severe personality change being placed in the good recovery category, and only 13% of those with a mild degree of personality change being severely disabled.

Table 7 Frequency of deficits in each outcome category

		Good recovery 29	Moderate disability 23	Severe disability 9
Physical (as a whole)	{ Mild Severe	29 0	23 0	6 2
Personality	{ Mild Severe	12 0	15 3	1 7
Cognitive (as a whole)	{ Mild Severe	29 0	21 2	2 7
Verbal IQ	{ Mild Severe	3 0	9 0	2 4
Performance IQ	{ Mild Severe	13 0	13 1	1 8
Verbal memory	{ Mild Severe	11 1	12 5	1 8
Non-verbal memory	{ Mild Severe	16 0	11 5	2 7

Combination of mental and physical deficits

Some deficit was detected, albeit sometimes mild, in 97% of these 150 patients. Two thirds had personality change which in almost 30%, was the only deficit. It was found to a marked degree in over 60% of patients whose physical deficit was nil or mild, and in the same proportion of those with nil or minimal cognitive deficit. By contrast, most patients with marked cognitive or physical deficits also had definite deficits in either of the other two components of disability.

The relative severity of physical, cognitive and personality disorder in patients in each outcome category was assessed for the 61 patients who had completed the full psychological test battery (table 7). The table shows the number of cases judged by the psychologist to have deficits in each cognitive area. Disorders of verbal intellect were found to be relatively infrequent, while disorders of learning and memory, and of performance intelligence were found to be severe and persistent; these findings are in

accord with several psychological studies of severe head injury.²⁰⁻²⁸

Although some neurophysical deficit (including epilepsy) occurred in three-quarters of the patients, mental handicap was judged by the examining neurologist to be more significant than physical sequelae in contributing to the overall disability in over half the cases; physical features were more significant in less than 30% (table 8). This dominance

Table 8 Contribution of mental and physical features to overall disability in each outcome category

Balance of disability	Good recovery n 55	Moderate disability n 60	Severe disability n 30	Total n 145
Mental worse	56%	48%	63%	54%
Physical worse	27%	30%	23%	28%
Equal	17%	22%	13%	18%
Mental > physical	73%	70%	76%	72%

of mental sequelae, which was similar in each of the three categories of outcome, confirms an early observation on the interaction between components of the disability after head injury.²⁷ A more detailed study of psychosocial disability has shown that when relatives were questioned about the frequency of a wide variety of deficits, physical deficits were felt to be infrequent during the first year after injury.²⁸ However, emotional personality and memory disability were all rated as frequent, and disorders of emotional control and affect were still very common 12 months after injury.

Relationship of PTA to disability

Almost all the patients with severe disability had more than four weeks of PTA; but so did the majority of those with moderate disability and more than a third of those who had made a good recovery (table 9). Less than a third of patients with more than a month's PTA were left severely disabled, whilst over 80% with less than two weeks PTA made a good recovery (table 9b). This relationship between PTA and outcome also holds for the six point scale, although the numbers in some categories are small (table 10). It follows from this that if a patient has emerged from PTA in less than four weeks he is almost certain to become independent, although he may be left moderately disabled.

Discussion

Classifying the outcome after severe head injury commands much less attention than does characterisation of the initial damage and early complications. Yet there is a need for a simple, reliable means

Table 9 PTA and outcome (486 data bank cases on 3 point scale)

(a) PTA duration for each outcome category			
PTA	Good n 226	Moderate n 170	Severe n 90
< 7 days	12%	2%	
8-14 days	25%	8%	
15-28 days	28%	18%	3%
> 28 days	35%	72%	97%

(b) Outcome categories for different PTA durations				
	< 7 days n 30	8-14 days n 71	15-28 days n 96	> 28 days n 289
Good	90%	80%	66%	27%
Moderate	10%	20%	31%	43%
Severe	0	0	3%	30%

Table 10 PTA and outcome (148 Glasgow cases on 6 point scale)

(a) PTA duration for each outcome category						
	Good		Moderate		Severe	
	0 n 5	1 n 54	2 n 34	3 n 24	4 n 21	5 n 9
< 7 days	2	9	1	0	0	0
8-14 days	1	21	7	2	0	0
15-28 days	0	9	6	2	0	0
> 28 days	7	15	20	20	21	9

(b) Outcome categories for different PTA durations				
	< 7 days n 12	7-14 days n 31	15-28 days n 17	> 28 days n 88
Good	0 1	3 9	1 21	0 15
Moderate	2 3	0 0	7 2	6 20
Severe	4 5	0 6	0 0	21 9

of describing the degree of recovery. Assessing the relative efficacy of alternative therapeutic measures depends on valid comparison of the outcomes in patients differently treated. Prediction of outcome, on which both management decisions and advice to the patient and his family depend, requires the relationship between early features and ultimate outcome to be established; that is possible only if well-defined outcome categories are recognised. In the later stages of recovery the rate of improvement in individual patients may be important in assessing the need for, and the effectiveness of, rehabilitation; this calls for a scale by which to measure change. When disability is prolonged or permanent, appropriate arrangements for continuing care demand that the degree and nature of the disability be readily categorised.

Disability after severe head injury

The Glasgow Outcome Scale, either in its original form, or in the expanded version described here, allows the overall social outcome of most patients to be assessed reliably on the basis of a structured interview which concentrates on social and personal functioning, without the need for detailed neurological and psychological evaluation. Indeed we have found that attempting to summate the deficits in neurological and psychological functioning is cumbersome and is also liable to overestimate the functional deficits experienced by patients in everyday life. This is not to deny the value of discovering the nature of physical deficits (for example: dysphasia or hemianopia, or hearing loss) or of psychological dysfunction (for example of memory or learning) as a means of understanding why a given person is disabled, and as a guide to how rehabilitative efforts might best be directed. What this scale does is to indicate the degree of disability without analysing the factors contributing to handicap.

Realistic versus optimistic or pessimistic assessment

It is, however, possible to exaggerate or to underestimate the effect which the injury has had on the patient's life-style, unless relatives or close associates are also interviewed—both to corroborate the patient's account of his present state, and in order to assess his pre-traumatic state as a basis for comparison. Many patients who suffer head injury prove to have been psychosocially maladjusted before injury;²⁹ if this is not appreciated then socially deviant behaviour afterwards may be mistakenly ascribed to brain damage. Sometimes a patient was just able to cope with life before injury (for example a chronic alcoholic in remission), but the additional insult of the head injury tips the balance, and he either begins to drink again, or else becomes dependent socially. On the other hand, disability may be underestimated when a patient makes light of his deficits, usually because of lack of insight; it can also occur when a patient claims to have returned to work, and independent enquiries are made as to what he is in fact doing there.

Social markers such as return to home or to work, can frequently be misleading—in either direction. Severely disabled patients may be at home rather than in institutions, because of exceptional family efforts. Moderately disabled patients, on the contrary, may be in hospital because of deprived home circumstances. On the other hand disabled patients may be in their previous jobs because it happens that their particular work and their disability makes this possible; for example, we had a shepherd who was almost completely aphasic, but because he could still whistle to his dog he had resumed work. Sometimes employers are unusually tolerant of the inadequacies

of a former staff member, at least for a time and particularly if he has long service and has managerial or supervisory status. Such a patient may claim to be back at work, when in truth he is being covered or cushioned to a considerable extent. On the other hand, patients who have made a good recovery may not return to work, for a variety of personal or socioeconomic reasons. For these reasons classification of outcome which rely too much on whether or not a patient is in care or at home, or has returned to work or not, may be misleading in a number of cases.

Another source of bias in assessing overall outcome derives from judging this in the light of the known severity of the injury. The comment may be made that the patient has made a good recovery "considering how bad he was". This is especially likely to occur when outcome is judged by those who were responsible for the early management. It must be remembered that the patient and the family judges the outcome by comparison with the pre-traumatic state. In the early months, however, the family may share the optimism of members of the therapeutic team (with whom they share the memory of how bad the patient initially was) and may thus tend to over-estimate the degree of recovery. During the stage of relatively rapid improvement a month or so after injury assessment may prove to include an element of expectation or prediction (or hope) about the ultimate degree of recovery rather than being a true appraisal of the state at the present time.

Most conscious survivors after severe injury (more than six hours in coma) have some deficit, even those judged to have made a good recovery. However, marked neurological deficit is relatively uncommon; only 16% of these severely brain damaged patients had persisting, marked hemiplegia. Unlike survivors after stroke, who have suffered major focal damage, head injured patients have mostly sustained widespread damage which has more effect on mental than on neurological function. Personality change is the most consistent finding, and this can constitute an appreciable deficit even in patients without significant cognitive or physical sequelae. Mental deficits contribute more significantly to social disability than do persisting neurological signs, as previously reported in a smaller series.²⁷ Mental deficits also contribute more to the burden reported by caring relatives than does physical handicap.²⁸

Time scale of recovery

Recovery is a dynamic process. How long it may continue is a matter of controversy, partly because of the lack of agreed criteria by which to measure changes in the overall degree of recovery with time; and partly because different components of recovery

may plateau at different periods after injury.^{21–23 27} Isolated reports of continued improvement over years, and of occasional cases of delayed late recovery, have led to the generalisation that assessment of ultimate outcome should be postponed for years in those who are disabled; moreover, clinicians may therefore remain optimistic about further substantial improvement for longer than is realistic. It is our experience that maintaining unrealistic expectations for further substantial recovery may impede the acceptance of disability by the patient and his family; this in turn will postpone the time when practical steps are taken to adjust to the new circumstances of planning the future in the light of the disability. Another aspect of the persistence of disability in many severely injured patients is that the prevalence of patients in the community who are suffering from head injury is considerable. Even severely disabled younger patients have only five years reduction in expectancy of life over the next 20 years, according to Roberts;¹⁷ thus many disabled patients live for 20–40 years after head injury.

Our studies emphasise that the proportional distribution of patients among the outcome categories of the Glasgow Scale does change considerably as time passes during the first year after injury. Valid comparisons between the results of treatment in series of severely head injured patients therefore requires adequate information about when outcome was assessed. But our studies also show that the majority of patients have reached their final outcome category (on this scale) within six months of injury, and that very few change category after a year. This is not to deny that there may be considerable improvement without this being sufficient to justify reclassification. This later improvement in overall social functioning may not be associated with any measurable change in neurological deficit or in mental performance on tests. Instead it may reflect a passing of the phase of denial of disability through which many patients pass and that hinders their making appropriate adjustments in their mode of life. What is subsequently recorded as improvement may therefore represent adaptation or acceptance of a disability which is in fact fixed and will not become any less.

Quality of life

Much is heard nowadays about the importance of quality of life in patients rescued from life-threatening situations; when it is judged that the life saved seems to be hardly worth living then doubts are sometimes raised about the wisdom of having expended such efforts to achieve survival. Such doubts are particularly likely to arise in regard to head injured youths—previously fully normal and with so many years

ahead of them. But discussion about the quality of life tends to remain unfocused; it may therefore be helpful to consider six aspects of living as a basis for reviewing a given patient's disability.

(1) Activities of daily living (ADL) are widely used by geriatricians when analysing the degree of dependence of victims of stroke. Scores are evolved to indicate whether the patient can feed, dress and toilet himself, or requires varying degrees of aid from others; mobility—from bed to chair, or around the room, is another vital activity. An elderly patient may regard a degree of partial independence for some of these activities as a reasonable achievement; a man in his twenties may take a different view.

(2) Mobility beyond the sick room—about the house and outside of it—is essential if the patient is to have the possibility of organising his life himself, either hour to hour or day to day. It may be that mental handicap prevents this, the patient requiring someone else to plan every part of the day lest he forgets to start, or fails to finish, even simple tasks, like preparing a meal.

(3) Social relationships depend on initiative and response—the patient who must wait to be visited or is limited entirely to the company of his own family may feel limited and frustrated.

(4) Work or leisure activities represent the next stage in the hierarchy of returning to normal life, and are important for most people's sense of purpose—once the struggle for survival, and then to achieve the activities of daily life, is over.

(5) Present satisfaction and future prospects are difficult to measure, and depend to some extent on pre-traumatic personality. Some patients seem to have such blunted insight that they may not seem to suffer; others are only too well aware of their plight and are frustrated by their limitations. It is unfeeling to pretend that the initial satisfaction at achieving certain milestones of recovery will be lasting, if the recovery is arrested far short of that patient's previous performance. Doctors need to guard against glib judgements such as “practical or worthwhile recovery,” which often prove to be euphemisms for severe disability. Similarly it is doubtful whether outcome scales that have many subdivisions within the category that we have termed severe disability, are helpful in reflecting the true degree of disability. Thus the eleven point scale of Roberts¹⁷ recognised severe and profound disability as well as total dependence, and then subdivided the latter into four more categories. This may be of some use in indicating the amount of physical support required on an hour to hour basis, but in terms of survival over many years it does not seem to us useful to have as many subdivisions.

More important is to recognise the burden borne

by the families of patients who do become independent, but who have serious mental deficits, particularly of personality. Such patients may seem to be functioning at a satisfactory level when compared with the population in general, even on formal psychological tests—but their relatives and close friends know that they are changed persons. Previously quiet and kind, they may now be talkative and tactless, liable to outbursts of temper, forgetful and irritable. This is much harder for relatives to bear than hemiplegia or even paraplegia—and it is unfair to draw comparisons with severe physical disability and the courage and resourcefulness with which it is dealt with by patients and their families. After brain damage the ability to cope and to adapt is affected, as part of the disability, whilst the nature of the mental disability is more likely to cause exasperation than to provoke pity or to elicit sympathy.

These studies formed part of a programme of research into head injury supported by the Medical Research Council.

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