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Reintegration after severe brain injury: A retrospective study

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Abstract
Primary objective: The evaluation of school and work reintegration of patients following severe brain injury and of the relationship between the most common (early and late) prognostic indicators and reintegration itself.
Research design: A retrospective study on a population of 353 patients consecutively admitted to an intensive rehabilitation unit (S. Cuore Hospital, Negrar, Italy) from 1991–1999.
Methods and procedures: Evaluation of school and work outcome in this population up to December 2001 (follow-up from 2–10 years post-trauma). Data collection was made using the EBIS (European Brain Injury Society) protocol.
Results: In December 2001, 53% of those previously working had returned to competitive work; 76.5% of students were continuing with their studies or had progressed into work. There was a significant difference between employed and non-employed groups in terms of GCS, post-traumatic amnesia (PTA), in-patient rehabilitation length of stay (LOS) and GOS at 6 and at 12 months post-injury.
Conclusions: The data confirm the predictive value of the indices used regarding work reintegration in TBI patients. Nevertheless, prolonged and intensive rehabilitation programmes can lead to high re-employment rates in patients whose initial prognosis seemed very poor.

Introduction

Even though traumatic brain injury (TBI) is a major source of morbidity and mortality, in Italy there are very few epidemiological studies of post-traumatic disability in TBI patients. In absence of more detailed and specific surveys on the prevalence of brain injured people with disability, the Italian Superior Health Institute (ISHI) estimated a 2:1 ratio between disabilities and deaths due to TBI in year 1997 [1]. Table I reports number and rate out of 100 000 inhabitants of deaths, estimated disability and number of hospitalizations after TBI.

In another study published in 1998 by Pitidis *et al.* for ISHI, the cost of healthcare and 'human resource waste' due to TBI amounts to 20.134 million Euros per year [2].

Traumatic Brain Injury is the prime cause of disability under 40 years, with a deep impact on social and work reintegration and on quality of life [3, 4]. In spite of this, specific rehabilitation programmes and centres of training for vocational reintegration are not very numerous in Italy and there is no national data about how many brain-injured people go back to competitive employment.

The study is based on a population of severely brain-injured people, admitted and treated in the Rehabilitation Department from 1991–1999. The Don Calabria Rehabilitation Department, located in Verona (North Italy), consists of a hospital rehabilitation unit of 25 beds, admitting patients with acquired brain injury in the sub-acute phase and an external outpatient unit, devoted to social and vocational reintegration. The rehabilitation unit also includes a small intensive care unit (five beds), providing intensive medical and rehabilitation treatment to patients with severe respiratory problems or other complications. In the years under study, the patients admitted were on average 24 days post-injury. More than 85% has been in a coma for over 24 hours, needing substantial medical treatment and rehabilitation. After discharge, patients who

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Table I. Deaths, disabled and hospitalization due to TBI (Italy 1997).

	Number	Rate per 100 000
Dead	7 300	13
Disabled estimation	14 600	25
Hospitalized	146 000	253

need further rehabilitation are followed up in day hospital programmes, or they are referred to the social-vocational unit (out with the hospital), where they can take part in rehabilitation for extended periods.

Materials and methods

A retrospective study was carried out of 438 patients consecutively admitted to the hospital from 1991–1999. All patients were evaluated using the EBIS (European Brain Injury Society) protocol [5] and followed the same rehabilitation programme. The EBIS protocol is made up of 175 items, divided into two main parts:

- The first part (52 items) concerns the initial phase: pre-traumatic situation, types of injury and symptoms in the acute phase.
- The second part concerns post-acute and long-term outcomes considering: (a) neuromotor, cognitive, emotional and behavioural fields and (b) familial, social, educational and vocational reintegration.

From 1991–1996, data were collected on paper, while from 1996 a computerized version of the EBIS protocol was used which had been devised. This allowed the creation of a complete databank, with the possibility of immediate analysis of the data [6].

The first part of the protocol is completed during the first 2 weeks after admission. The second part is completed at the end of the intensive rehabilitation phase. Further evaluations are done at 6, 12, 24, 36 and 60 months post-injury. The main EBIS database, up to 1994, included 562 cases from various European countries, mainly from France ($n = 313$), Great Britain (120) and Italy (53).

For the present study, the following EBIS protocol items were considered:

3 : Sex;
6 : Age;
9 : Education in years;
10–11 : Activity before the trauma;
26 : Glasgow coma scale (GCS);
28 : Post-traumatic amnesia (PTA);
59 : Inpatient rehabilitation Length of Stay (LOS);
86 : Motor disabilities (hemiplegia, hemiparesis, double hemiparesis, ataxia, paraparesis);
143 : Level of dependence for cognitive problems;
144 : Level of dependence for physical problems; and
175 : Extended Glasgow outcome scale (GOS-E).

The Extended Glasgow Outcome Scale (GOS-E) was developed to address the limitations of the original GOS. The GOS-E increases to eight the original five GOS categories. The eight categories are: Dead (coded 7), Vegetative State (6), Lower Severe Disability (5), Upper Severe Disability (4), Lower Moderate Disability (3), Upper Moderate Disability (2), Lower Good Recovery (1) and Upper Good Recovery (0). A structured interview has been provided to improve reliability of rating. Good inter-rater reliability and content validity have been demonstrated for the GOS-E. Compared to the GOS, the GOS-E has been shown to be more sensitive to change in mild-to-moderate TBI [7].

Evaluation of educational and work outcome (EBIS items 10–11) and of the level of dependence due to cognitive (item 143) and physical problems (item 144) was made through periodical follow-up or by telephone interviews and is updated to December 2001 (follow-up from 2–10 years post-trauma).

Starting from a population of 438 patients, one was able to evaluate the outcome of 353 patients. Eighteen patients had died meantime for causes mostly not connected to the trauma and 67 patients were 'missing' (could not follow-up or reach them after discharge). The demographic and severity of injury data of the 353 individuals studied are presented in Table II.

In this population, through a frequency distribution, the relationship between GCS and GOS-E was studied at 12 months and between PTA and GOS-E at 12 months (Tables III and IV) to see the prognostic value of GCS and PTA on outcome. Then, people were selected who were on education or were employed prior to TBI, to identify the percentage who successfully returned to the previous activity and to compare the main clinical indices (GCS, PTA, LOS and GOS) of those who went back to education or work with those who did not (Tables V and VI).

Finally, in order to evaluate the importance of physical and cognitive impairment in preventing re-employment, the different distribution of motor and cognitive/ behaviour disabilities was examined among re-employed and not re-employed patients (Table VII). The assessment of motor and cognitive

Table II. Demographic and severity of injury data.

	Average	SD	Range	*n*	%
Males				275	78
Females				78	22
Age	32	15	5–77		
Years of school	9.9	3.7			
GCS	6.7	2.8			
PTA (days)	81.8	63			
0: 0–1 h				0	0
1: 1 h–1 day				7	1.9
2: 1–7 days				16	4.5
3: 8–27 days				69	19.5
4: 28–60 days				99	28.0
5: >60 days				162	45.9
LOS (days)	81.9	84.0	2–701		
GOS-E (6 months)	2.5	1.8	0–6		
GOS-E (12 months)	2.0	1.9	0–6		
Employment situation prior to TBI:					
Students				70	19.8
Workers				132	37.3
Employers				64	18.1
Managers				9	2.5
Freelancers				13	3.6
Housewives				5	1.4
Dealers				12	3.3
Unemployed				19	5.3
Retired				29	8.2
Motor disability at 12 months: *Hemiplegia, hemiparesis, double hemiparesis, ataxia,* paraparesis				167	47.3

Table III. Frequency distribution of the relationship between GCS and GOS-E at 12 months.

	Patients number	GOS-E 0–1		GOS-E 2–3		GOS-E 4–5		GOS-E 6	
GCS	*n*	*n*	%	*n*	%	*n*	%	*n*	%
3	16	4	25.0	6	37.5	4	25.0	2	12.5
4	53	21	39.6	8	15.1	23	43.4	1	1.9
5	76	33	43.4	20	26.3	21	27.6	2	2.6
6	65	41	63.1	10	15.4	13	20.0	1	1.5
7	65	54	83.1	8	12.3	3	4.6	0	–
8	17	15	88.2	1	5.9	1	5.9	0	–
9	11	7	63.6	3	27.3	1	9.1	0	–
10	10	10	100	0	–	0	–	0	–
11	14	13	92.8	1	7.1	0	–	0	–
12	7	4	57.1	2	28.6	1	14.3	0	–
13	6	6	100	0	–	0	–	0	–
14	7	6	85.7	0	–	1	14.3	0	–
15	6	6	100	0	–	0	–	0	–
Total	353	220	62.3	59	16.7	68	19.2	6	1.7

disability was made simply by evaluation of dependence level (score 0 = independent; 1 = partially dependent; 2 = always dependent) for cognitive disabilities (EBIS item 143) or physical disabilities (item 144). A score of zero for these items need not mean a complete absence of cognitive or physical problems, but only absence of dependence due to these problems.

Results

From study of the data in Table III, the following observations can be drawn:

a. The number of subjects with 'severely disabled' outcome (GOS-E 4 or 5) or 'moderately disabled' outcome (GOS-E 2 or 3) gradually decreases in relation to higher GCS values.

Table IV. Frequency distribution of the relationship between PTA and GOS-E at 12 months.

PTA	*n* patients	GOS-E 0–1		GOS-E 2–3		GOS-E 4–5		GOS-E 6	
		n	%	*n*	%	*n*	%	*n*	%
0: less than 1 hour	0	0	–	0	–	0	–	0	–
1: 1–24 hours	7	6	85.7	1	14.3	0	–	0	–
2: 1–7 days	16	16	100	0	–	0	–	0	–
3: 8–28 days	69	68	98.6	1	1.4	0	–	0	–
4: 29–60 days	99	82	82.8	15	15.2	2	2.1	0	–
5: more than 60 days	162	48	29.6	42	25.9	66	40.7	6	3.7
Total	353	220	62.3	59	16.7	68	19.2	6	1.7

Table V. Comparison among re-employed and not re-employed in patients previously working.

Patients employed before TBI *n* 230	Re-employed subjects		Not re-employed subjects		*t*-test	*p*
	n 125	54.3%	*n* 105	45.7%		
Mean age at the time of injury (range 18–68 years)	27.7	SD 10.8	29.7	SD 13.5	2.82	n.s.
Mean pre-injury education (range 1–20)	10.7	SD 3.2	9.5	SD 3.7	−3.16	n.s.
Mean GCS (range 3–15)	7.2	SD 2.6	6.0	SD 2.6	−4.65	<0.001
Mean PTA (range 1–180 gg)	49.4	SD 44.4	111.4	SD 63.9	10.7	<0.001
Mean GOS-E at 6 months (range 0–6)	1.3	SD 1.1	3.4	SD 1.8	13.8	<0.001
Mean GOS-E at 12 months (range 0–6)	0.1	SD 0.4	2.6	SD 1.9	16.9	<0.001
Mean LOS (range 2–701)	45.6	SD 39.7	117.3	SD 101.3	−6.4	<0.001

Table VI. Comparison among 're-engaged' and 'not re-engaged' patients previously studying.

Students before TBI *n* 64	Re-engaged (in education or work)		Not re-engaged (not in education or work)		*t*-test	*p*
	n 49	76.5%	*n* 15	23.5%		
Mean age at the time of injury (range 14–37 years)	17.8	SD 2.8	20.3	SD 5.6	2.34	n.s.
Mean pre-injury education (range 8–17 years)	11.4	SD 2.5	12.2	SD 2.8	−1.02	n.s.
Mean GCS (range 3–15)	6.4	SD 1.8	5.1	SD 2.9	−2.05	<0.05
Mean PTA (range 1–180 gg)	46.8	SD 34.5	169.3	SD 28.1	−12.5	<0.001
Mean GOS-E at 6 Range (0–6)	1.2	SD 1.1	4.5	SD 0.8	10.75	<0.001
Mean GOS-E 12 m (range 0–6)	0.2	SD 0.5	3.7	SD 1.2	16.78	<0.001
Mean LOS (range 4–381 days)	55.5	SD 60.5	175.1	SD 79.9	−6.2	<0.001

b. In this population, there are no persistent vegetative states (PVS) in patients with initial GCS greater than 6.
c. Patients with injury as severe as GCS 3 or 4 can, however, have a positive outcome: 25 patients out of 69 (36.2%) reached a good level of autonomy (GOS-E 0 or 1).
d. Moderate (GOS-E 2–3) or severe (GOS-E 4–5) disabilities in patients with moderate (GCS 9–12) or mild (GCS 13–15) brain injury were mostly due to old age, major orthopaedic problems, cognitive impairment and, in one case, to previous psychiatric pathology.

Table IV shows the relationship between PTA and GOS-E in this population. Obviously, most patients with short PTA duration ('mild' or 'moderate' TBI) have a good recovery (GOS-E = 0–1), but a

good recovery is also possible for very prolonged PTA values. As can be seen in Table IV, out of 261 patients having a PTA value of more than 4 weeks, 130 (49.8%) had a good recovery (GOS-E = 0–1). As is well known, GOS defines the residual disability level. According to the EBIS protocol, a 'good recovery' does not necessarily indicate vocational reintegration (because social and economic factors can play an important role in non-return to work), but simply estimates the level of autonomy.

Table VIII displays that there is a clear variation in GOS-E values between 6–12 months. Improvements take place for all outcome categories, confirming that the situation at 6 months is not definitive. It may be that further spontaneous recovery takes place and/or that outcome may be improved by intensive rehabilitation. Out of 13 patients in vegetative state at 6 months, seven (53.8%) arrived at a 'severe disability' (GOS-E 4–5) state by 12 months.

From the whole population (353 subjects), all the patients working before TBI (230 subjects) were selected and divided into two groups: re-employed and not re-employed. Table V shows means and standard deviations for the two groups concerning age, years of education, GCS, PTA, LOS and GOS-E at 6 and 12 months. In order to evaluate significant differences between re-employed and not re-employed group, *t*-tests were used.

Return to work does not necessarily mean return to the previous work and at the same level, but simply being in work at the time of the follow-up and also have been working for at least the last year or more (stable job reintegration). If these two groups are compared, a significant difference can be seen concerning GCS, PTA, LOS and GOS-E at 6 and 12 months. This is consistent with previous reports in the literature [8–16]. An interesting datum is the predictivity of GOS-E at 6 months as an indicator for the return to work, in accordance with recent literature that says that variables measured at 6 months and 1 year may add predictive power to earlier measures [17].

Then, those who were in education at the time of trauma (70 subjects) were considered, to evaluate their reintegration back into education or else into work. Those six subjects who were young enough to be in compulsory schooling (up to age 14 in Italy in 2001) were not considered as by law they were reinstated in school whatever their disability level. The remaining 64 subjects were divided into two groups: first, those who had re-entered education (or entered employment) and, secondly, those who had not. Both those who continued successfully their studies and those who left education and found paid employment were considered as 're-engaged'.

Table VI displays means and standard deviations for the two groups according to age, school years, GCS, PTA, LOS and GOS-E at 6 and 12 months. To evaluate significant differences between 're-engaged' and 'not re-engaged' groups, *t*-tests were applied.

From Table VI, one can see that there is again a significant difference between the two groups concerning GCS, PTA, LOS and GOS-E at 6 and 12 months. Compared to the data on employment (Table V), data on education showed a higher percentage reintegration (77% vs 54%). In the authors' opinion, this difference is due to greater social protection by Italian laws to younger patients, which makes reintegration in education easier than in work. Italian laws prescribe specific facilities and

Table VII. Level of dependence, comparison among re-employed and not.

	Re-employed ($n = 125$)	Not re-employed ($n = 105$)
Severe multiple disabilities (both motor and cognitive) Item 143: score 2 Item 144: score 2	0	73 patients: 15 hemiplegia 52 double hemiparesis 5 ataxia 1 paraparesis
Severe motor disabilities Item 143: score 0 Item 144: score 2	0	10 patients: 7 hemiparesis 3 paraparesis
Severe cognitive / behavioural disabilities Item 143: score 2 Item 144: score 0	0	11 patients
Mild motor disabilities Item 143: score 0 Item 144: score 1	8	3
Mild cognitive disabilities Item 143: score 1 Item 144: score 0	10	8

Table VIII. Variations of GOS-E values between 6–12 months from the trauma.

		GOS-E 0–1		GOS-E 2–3		GOS-E 4–5		GOS-E 6	
	n patients	*n*	%	*n*	%	*n*	%	*n*	%
GOS-E 6 months	353	144	40.8	94	26.6	102	28.9	13	3.7
GOS-E 12 months	353	220	62.3	59	16.7	68	19.2	6	1.7

specialized tutors as support for students with physical or cognitive impairment. Another point which emerges is the greater length of stay for those subjects not re-engaged (mean 175 days). This too seems to reflect a greater rehabilitation 'investment' in younger patients.

Finally, to evaluate the importance of physical and cognitive disabilities in preventing re-employment, those 105 subjects who were not re-employed were examined. Their level of dependence was considered due to cognitive problems (item 143 of EBIS protocol) and/or physical problems (item 144) and they were compared with the re-employed group ($n = 125$). Table VII shows the different distribution of motor and cognitive/behavioural disabilities among re-employed and not re-employed patients, whose level of dependence is defined as score 0 = independent; 1 = partially dependent; 2 = always always dependent for cognitive (item 143) or physical disabilities (item 144). An occasional need for assistance was considered as an indicator of mild or moderate disability not completely preventing autonomy and, on the other side, a continuous need for assistance as an indicator of severe disability and complete dependence. Nevertheless, also those patients who need no assistance at all can have minor motor or cognitive problems, which can be highlighted by clinical or neuropsychological examination.

Discussion

The data from the retrospective study show an encouraging level of reintegration, both as regards work and education between 2–10 years post-trauma. Although one did not investigate changes in role or kind of work in the analyses, reintegration percentages appear higher than in other reports [18]. This, as said above, is probably due to the laws [19] which make re-employment easier and to the socio-economic situation of the region, which has the lowest unemployment rate in Italy, because of the numerous small and middle-sized firms with great demand for non-specialized labour.

The number of patients who followed an employment retraining and job-coaching programme increased over the years in the Rehabilitation Department, extending the rehabilitation treatment over a longer period of time. As regards vocational rehabilitation, 45 re-employed patients out of 125 (36%) had followed a specific programme, including vocational retraining, job trials and job coaching. This programme, aimed at patients with milder disabilities, seemed to be a key element in their reintegration, consistent with recent studies [20, 21].

If one considers those subjects who were not re-employed, most of them (69.5%) were affected simultaneously by severe motor and cognitive disabilities and their level of dependence was so high as to prevent any kind of productive and competitive employment. A motor disability itself can bar access to employment, especially in the case of upper limb impairment and heavy dependence for everyday activities, incompatible with the autonomy level required to work. On the other hand, severe cognitive and behavioural disabilities can be by themselves an insuperable obstacle to work reintegration. Mild or isolated motor and cognitive disabilities requiring partial assistance did not preclude work reintegration, but there were no significant differences between the two groups (see Table VII).

Conclusions

The prognostic value of GCS and PTA was again confirmed. These indices, together with LOS and GOS-E, allow estimation of the prospects for social-vocational reintegration. The main obstacle to work reintegration is the presence of cognitive-behavioural disabilities and/or severe motor disability requiring a high level of assistance. Specific programmes of vocational rehabilitation and job-coaching can lead to the reintegration of subjects with mild or moderate motor and cognitive disabilities, if a partial autonomy is preserved.

The EBIS protocol is a well-defined and standardized instrument for data collection about epidemiology, acute phase, rehabilitation period, outcome and follow-up and it proved useful in this study. The authors' opinion is that a use of this system in different centres could permit periodical comparison of data between centres (perhaps via the Internet); an aid to research in the rehabilitation of TBI patients, because of the large amount of available data, and comparison of different rehabilitation programmes.

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