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Children and young adults in a prolonged unconscious state after severe brain injury: Long-term functional outcome as measured by the DRS and the GOSE after early intensive neurorehabilitation

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Abstract

Objective: To investigate the long-term (2–15 years) functional outcome of children and young adults who received an early intensive neurorehabilitation programme (EINP) after a prolonged period of unconsciousness due to severe brain injury; to differentiate between traumatic brain injury (TBI) and non-traumatic brain injury (nTBI); and to compare the results on two different outcome scales: the Disability Rating Scale (DRS) and the Glasgow Outcome Scale Extended (GOSE).

Subjects: One hundred and forty-five patients, who were admitted to EINP between December 1987 and January 2001.

Outcome measures: The Post-Acute Level of Consciousness scale (PALOC-s), the DRS, including categorized scores (DRScat), and the GOSE.

Results: The long-term functional level of 90 patients could be determined, of whom 25 were deceased. The mean DRS-score of the surviving patients was 6.8 (SD = 6.6); the mean score on the GOSE was 4.5 (SD = 1.7). There was a significant difference in the outcome amongst traumatic and non-traumatic patients ($t_{(88)} = 4.21$; $p < 0.01$). The correlation between the DRS and the GOSE was high (Spearman rho = 0.85; $p < 0.01$), as well as the correlation between the categorized scores of the DRS and the GOSE (Spearman rho = 0.81; $p < 0.01$). The distribution of outcome scores on the DRScat is more diverse than on the GOSE. Especially item 7 of the DRS, measuring functional independence, showed considerable variance in discriminating between different outcome levels.

Conclusions: More patients with TBI than expected reached a (semi-) independent level of functioning, indicating a possible effect of EINP. Patients suffering from nTBI did not demonstrate these outcome levels. Only a few patients stayed in a vegetative state for more than a couple of years. In this cohort of severe brain-injured young people, the DRS offered the best investigative possibilities for long-term level of functioning.

Keywords: *Consciousness, brain-injured children, functional recovery, long-term functioning, minimally conscious state, neurorehabilitation, severe brain injury, vegetative state, youngsters*

Introduction

Severe brain injury in young people, with a prolonged period of unconsciousness of several weeks or months, results in an extensive loss of function regarding almost all capabilities. This usually leads to a decreased level of independence, and results in the majority of cases in a lower level of social participation [1]. A number of patients do not regain consciousness and continue to remain in a vegetative state (VS) or minimally conscious state (MCS) for many years, even resulting in death for some patients [2]. For those children remaining in a

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vegetative state three months after suffering severe traumatic brain injury, the probability of remaining in a vegetative state for at least one year was calculated by the Multi-Society Task Force on Persistent Vegetative State (MSTF) at 30% ($CI_{99} = 13–47$) and the probability of death was calculated at 14% ($CI_{99} = 1–27$) [3]. For children who suffered a non-traumatic brain injury the probability of remaining in a vegetative state was calculated at 97% ($CI_{99} = 89–100$) and the probability of death was calculated at 3% ($CI_{99} = 0–11$). Since the 1960s treatment programmes have been developed, focusing on the recovery of consciousness and on an early start of recovery of functions in non-responsive patients [4, 5]. The different programmes vary considerably in terms of content, target group, intensity, duration, location, and finances [6, 7]. It is extremely difficult to investigate the effects of these rehabilitation programmes because of a range of methodological difficulties, a lack of sound treatment theories [8] and ethical limitations [9]. As a result, the efficacy of these kind of programmes has remained unproven [10]. A few studies, however, do support the beneficial effects of early intensive neurorehabilitation of non-responding patients [11, 12]. Earlier investigations [13, 14] show that only one quarter of patients who were still in VS or MCS one month after injury regain self-care independency, implying that three quarters of the patients require aid from either family members or a health care facility. Patients who remained dependent and who required a full-time care facility often expressed their anguish and demonstrate a low level of experienced quality of life [15]. The close relatives of these patients are also often distressed, especially when they have to deal with behavioural changes [16]. Therefore, each treatment programme that can contribute to better outcome levels will ultimately reduce emotional problems for both the patient and their family.

In 1987 a comprehensive early intensive neurorehabilitation programme (EINP) for children in VS or MCS was developed at the Rehabilitation Centre Leijpark (RCL) in the Netherlands, aiming at recovery of consciousness and ultimately at ameliorating the level of independence. The outcome upon discharge of 145 patients, aged 0–25 who were admitted between December 1987 and January 2001, showed that 62% of the patients had reached full consciousness, 27% were in MCS, 6% were in VS, and 5% deceased [17]. Most of the conscious patients were discharged to a regular rehabilitation facility, indicating potential for a reasonable recovery of long-term function. The question remains whether the recovery of function achieved at the time of discharge indeed led to higher levels of independence in long-term functioning.

This study therefore focuses on the long-term functional recovery of the patients mentioned above, after receiving EINP. This is the first large-scale Dutch study concerning long-term disability in young patients with severe brain injury and with a known long period of disturbed consciousness.

Other objectives of this study include the comparison of outcome amongst traumatic and non-traumatic patients given that it is to be expected that the latter group has fewer possibilities for recovery than the first [3].

Finally, a comparison of results will be made concerning the two different and widely used outcome measures; the Glasgow Outcomes Scale Extended (GOSE) [18, 19], and the Disability Rating Scale (DRS) [20].

Outcome after severe brain injury can be examined at different levels of functioning: neuropsychological functions [21], quality of life [22] or the level of disability [23]. In an overview of some frequently used outcome measures for clinical trials in neurotrauma, Bullock et al. [24] concluded that the Glasgow Outcome Scale (GOS) [25] or its extended form (GOSE), and the DRS are the most widely used outcome measures. They recommend that the GOSE be further evaluated, especially in relation to the higher sensitivity of this instrument for the middle outcome categories. The structured nature of the interview should protect against inter-observer variability. They also concluded that the concordance between the DRS and the GOS is moderate, with an underestimation by the DRS of the severity of outcome related to the GOS. Others however, showed a higher sensitivity of the DRS in the most severe outcome levels. Hall et al. [26] stated in 1985 that 'the DRS more sensitively reflects improvement during in-hospital rehabilitation than the GOS, 71% to 33%, respectively' (p. 35). The latter effect is in all probability a reflection of the sensitivity of the DRS to changes in seriously impaired patients. Therefore, for a population concerning high probability of low outcome (VS or MCS), the DRS seems to be more useful in differentiating between outcome levels.

Method

Patients

Subjects included in this study were all patients ($N = 145$) admitted to the EINP between December 1987 and January 2001. Criteria for admission were: age between 0–25 years, in a vegetative or minimally conscious state subsequent to severe brain injury, admission date between 2 weeks and 6 months after injury.

Admission took place between 0.7–7.6 months (Mean (M) = 2.3, Median = 2.1, SD = 1.2) after injury. One patient was admitted more than a half year after the injury due to a waiting list. Of the 145 patients admitted to the EINP programme, 107 patients suffered severe brain injury, with an initial Glasgow Coma Scale (GCS) [27] score less than or equal to eight. One patient with a GCS-score of 9 was admitted because of the extended vegetative state. For 37 patients the initial GCS-score was unknown.

In Table I the most important characteristics of the participants are presented.

The cohort is divided into two groups: 104 patients who suffered traumatic brain injury (TBI: 91 of the cases was caused by a traffic accident, 12 caused by a fall, and in 1 case caused by a blow to the head) and 41 patients who suffered a non-traumatic brain injury (nTBI). In this group different kinds of causes are represented more or less equally: near-drowning ($n = 11$), encephalitis ($n = 10$), cardiac arrest ($n = 7$) and other causes of anoxia ($n = 10$). Three patients suffered a stroke. There are two main differences between the TBI group and the nTBI group. Firstly, the mean age at time of injury of the nTBI group is significantly lower ($t_{(143)} = 5.74$; $p < 0.01$), and secondly the level of consciousness (LOC) at the time of discharge from EINP is significantly less encouraging in the nTBI group, as compared to the TBI-group ($t_{(143)} = 3.51$; $p < 0.01$).

Table I. Demographic characteristics.

	Traumatic injury	Non-traumatic injury
Total number	104[1]	41
Age at admission to EINP		
0–5 years	12 (12)	23 (56)
6–10	17 (16)	5 (12)
11–15	25 (24)	5 (12)
16–20	38 (37)	5 (12)
21–25	12 (12)	3 (7)
Mean (SD)	14.8 years (5.8)	8.0 years (7.5)
Gender		
Male/Female	76/28 (73/27%)	28/13 (68/31%)
GCS[2] at admission to hospital		
Mean (SD)	3.9 (1.9)	3.2 (2.2)
Unknown	20 (19)	17 (42)
LOC at admission to EINP[3]		
Vegetative state	45 (43)	18 (44)
Minimally conscious state	59 (57)	23 (56)
LOC at discharge from EINP		
Deceased	3 (3)	4 (10)
Vegetative state (VS)	4 (4)	5 (12)
Minimally conscious state (MCS)	24 (23)	15 (37)
Conscious state (CS)	73 (70)	17 (42)

[1]Numbers and (between brackets) are the column percentages in each category, except for the Mean and SD scores.
[2]GCS = Glasgow Coma Scale score.
[3]LOC = Level of consciousness.

Outcome measures

The PALOC-s is a newly developed observation scale to investigate the level of consciousness in patients with a prolonged loss of consciousness after severe brain injury. The PALOC-s is a one item rating scale including eight levels of consciousness: 1 = coma, 2 = hypo-responsive vegetative state, 3 = reflexive vegetative state, 4 = high (re-)active vegetative state, 5 = transitional minimally conscious state, 6 = inconsistent minimally conscious state, 7 = consistent minimally conscious state, and 8 = conscious state. Preliminary results show that the PALOC-s is reliable ($0.85 < r < 0.94$) and valid ($0.88 < r < 0.93$) [28]. In this study, the scores on the PALOC-s were reduced to class scores: coma (PALOC-s score of 1), vegetative state (VS, PALOC-s score 2–4), minimally conscious state (MCS, PALOC-s score 5–7), and conscious state (CS, PALOC-s score of 8).

The Disability Rating Scale (DRS) [20] consists of eight items, either scored on a four, five or six-point scale. A high score on an item indicates a low level of functioning on that aspect. The scores on the eight DRS items can be summed up to values from 0–29. A score of 30 is given when a patient has deceased. The DRS is reliable and valid [20, 29] and is able to track a patient from the lowest level of unconsciousness up to independent functioning in the community. The DRS has proven to be sensitive to improvement until at least five years after injury [30], especially in patients who are still (partly) dependent one year after injury. The DRS was translated into Dutch by the first author, in a forward-backward procedure [31], and adapted to be filled out by a proxy of the patient.

The GOSE is an extension of the Glasgow Outcome Scale (GOS) [18, 19]. The GOSE is a one-item rating scale including eight outcome categories (from 'deceased' to 'upper good recovery', see Table II) and can be administered through a structured interview. Compared to the GOS, the GOSE has proved to be more sensitive to changes in the mild-to-moderate range of TBI [32, 33]. The GOSE was translated into Dutch in an earlier research programme at the Erasmus University of Rotterdam and was administered in a structured interview with a proxy of the patient, as proposed by Wilson [19].

Table II. Disability Rating Scale category levels (DRScat), as converted from the raw scores of the Disability Rating Scale, and GOSE category levels.

Raw DRS score	Categories DRS (DRScat)	Level	GOSE
0	No disability	8	Upper good recovery
1–3	Mildly to partially disabled	7	Lower good recovery
4–6	Moderately disabled	6	Upper moderately disabled
7–11	Moderately severe disabled	5	Lower moderately disabled
12–16	Severely disabled	4	Upper severely disabled
17–21	Extremely severe disabled	3	Lower severely disabled
22–29	Vegetative state	2	Vegetative state
30	Deceased	1	Deceased

Procedures

This study was carried out following a one-group archived pretest-posttest design.

The local medical ethics committee gave ethical and lawful approval of the study.

The first author, an experienced neuropsychologist, investigated the patients' medical files to collect their demographic and injury-related characteristics, and to determine the level of consciousness (LOC) upon admission and discharge to the EINP, using the class scores of the PALOC-s. The procedure has been previously described in detail [17].

Next, all subjects were contacted in writing and asked for informed consent. When no reaction was received, contact was made by telephone. After having received the informed consent from the patients or their family, the outcome scales were administered with a proxy of the patients (usually one of the parents). All assessments took place between November 2002 and June 2003 by the second author, a neuropsychology trainee, generally at the rehabilitation centre. Some assessments were done at the patients' home. In one case concerning an emigrated patient, the administration was fully executed in a telephone interview. The assessment was carried out in one session, and completed in 20–30 minutes. The GOSE was always administered first.

Statistical analyses

To be able to compare the DRS and the GOSE properly, the scores on the DRS were transformed into category scores. The possibility of categorization was already proposed in the first publication of the DRS by Rappaport et al. [20]. Gouvier found that the inter-rater reliability of this ranked DRS was slightly less than that of the summed score, but still very high (0.95 vs. 0.98 in a study with three raters and 40 patients) [34]. Gouvier concluded that deriving category scores from raw DRS-scores did not result in losing much information, ensuring that the categories represent meaningful levels of recovery in their own right. Therefore, we used this eight-level categorized DRS-scoring method (DRScat, see Table II). To avoid negative correlations, the raw scores were converted to category-scores in the same means as the GOSE: a DRScat-score of 1 reflects the worst outcome category (deceased) and a score of 8 reflects the best outcome category (no disability). This combination of scores on the DRS and GOSE is represented in Table II.

The raw scores on the last two items of the DRS were treated individually during the analyses. These two items present most likely the best possibilities to differentiate between the outcome levels. Item 7 reflects the 'Level of Functioning' on six levels: 0 = completely independent, 1 = independent in a particular environment, 2 = mildly dependent, 3 = moderately dependent, 4 = noticeably dependent, and 5 = totally dependent. Item 8 reflects the 'Employability' or 'Educationability' on four levels: 0 = not restricted (for labour or education), 1 = selected, competitive jobs; or can perform most school tasks on a regular basis, 2 = sheltered, non-competitive workshop; or requires assistance for all school tasks, 3 = not employable; or education is not possible [35].

Data analyses were performed with the Statistical Package for the Social Sciences (SPSS 11.0.1, © SPSS Inc.). Descriptive statistics such as frequency tabulations were used to describe the population and the scores on the scales. Association between variables was established by calculation of the Spearman rho correlation coefficient. Curve fitting was done using polynomial regression models containing first-, second-, and third-order terms. To obtain a quantitative measure of how well these models predicted the dependent variable R^2 was used. Group differences were tested by the *t*-test or by the χ^2-test.

Results

Participants

Out of the total 145 patients, 90 patients could be included in this study, of which 25 (19% of the TBI

Table III. Characteristics of the participating and the non-participating groups of patients. Except for the first two variables, all data are with exclusion of the deceased patients.

Variable	Participating	Non-participating
Number	90	55
Deceased	12 TBI (19%) 13 nTBI (48%)	n.a.
Gender	70.8% male	72.7% male
TBI/nTBI	78.5% TBI	74.7% TBI
Age at injury (yrs)	M = 12.6, SD = 6.2 Range: 0.6–25.0	M = 13.3, SD = 7.3 Range: 0.7–23.7
Current age (yrs)	M = 18.6, SD = 6.3	M = 19.6, SD = 8.6
Level of consciousness at admission	VS = 51%, MCS = 49%	VS = 69%, MCS = 31%
Level of consciousness upon discharge	VS = 0%, MCS = 23%, CS = 77%	VS = 4%, MCS = 25%, CS = 71%
Time since injury (yrs)	M = 7.5, SD = 3.4 Range: 2.4–15.7	M = 7.9, SD = 3.1 Range: 2.6–13.9

VS, Vegetative State; MCS, Minimally Conscious State; CS, Conscious State.

Table IV. DRScat scores and GOSE scores of the surviving patients ($n = 65$), individually for the traumatic patients (TBI) and for the non-traumatic patients (nTBI) presented in number and in percentages per column.

	DRScat		GOSE	
Level	TBI	nTBI	TBI	nTBI
8	6 (11.7%)	0	3 (5.9%)	0
7	15 (29.4%)	2 (14.3%)	12 (23.5%)	0
6	21 (41.2%)	4 (28.6%)	4 (7.8%)	0
5	1 (2.0%)	1 (7.1%)	4 (7.8%)	1 (7.1%)
4	5 (9.8%)	1 (7.1%)	3 (5.9%)	1 (7.1%)
3	2 (3.9%)	4 (28.6%)	25 (49.0%)	8 (57.1%)
2	1 (2.0%)	2 (14.3%)	0	4 (28.6%)
Total	51 (100%)	14 (100%)	51 (100%)	14 (100%)

group and 48% of the nTBI group) were deceased. Twelve patients (8%) had moved and could not be located and 43 patients or their families (30%) did not return the informed consent. The time between injury and the determination of the long-term functional outcome varied between 2.4 and 15.7 years (M = 7.2, Median = 6.7, SD = 3.3). The mean age of the surviving patients was18.6 years (range 5–35, SD = 6.3), and 71% were male.

The main characteristics of the participating patient group ($n = 65$) and the non-participating patient group ($n = 55$) were compared to investigate whether the groups differed (see Table III).

No differences in the two groups were found in age ($t_{(118)} = 0.72$; $p = 0.47$), time since injury ($t_{(118)} = 0.49$; $p = 0.63$), cause of injury (TBI vs. nTBI) ($\chi^2_{(1)} = 0.26$; $p = 0.61$), or gender ($\chi^2_{(1)} = 0.06$; $p = 0.81$). Further analysis showed no association between group membership (participating vs. non-participating) with level of consciousness at admission (VS or MCS) ($\chi^2_{(1)} = 1.45$, $\phi = 0.11$, $p = 0.23$), nor with the level of consciousness upon discharge (VS, MCS, or CS) ($\chi^2_{(2)} = 2.58$, $\phi = 0.15$, $p = 0.28$). Therefore, with regards to different essential aspects related to functional capacities, the studied group was representative for the total population that participated in EINP.

Long-term outcome

The mean DRS-score of the total group, including the deceased ($n = 90$) was 13.4 (SD = 11.8). For the surviving group ($n = 65$) the mean DRS-score was 6.8 (SD = 6.6), for the TBI patients ($n = 51$) it was 5.4 (SD = 5.3), and for the surviving nTBI patients ($n = 14$) the score was 12.1 (SD = 8.1). The mean GOSE-score of the total group was 3.5 (SD = 2.1). For the surviving group ($n = 65$) the mean GOSE-score was 4.5 (SD = 1.7), for the TBI patients ($n = 51$) it was 4.9 (SD = 1.7), and for the surviving nTBI patients ($n = 14$) the score was 3.3 (SD = 0.9).

Table IV shows the distribution of the scores on the DRScat and on the GOSE. There was a significant difference between the TBI and the nTBI patients on both the DSRcat ($t_{(88)} = 4.36$; $p < 0.01$) and the GOSE ($t_{(88)} = 4.37$; $p < 0.01$). The TBI group, with 83.3% of the cases in the upper three categories of the DRScat, scored clearly better compared to the nTBI group (only 42.9% in the upper three categories).

Comparison between scores on the DRS and GOSE

The distribution of the scores over the categories differed between the GOSE and the DRScat. On the DRS the majority of the patients scored in the upper

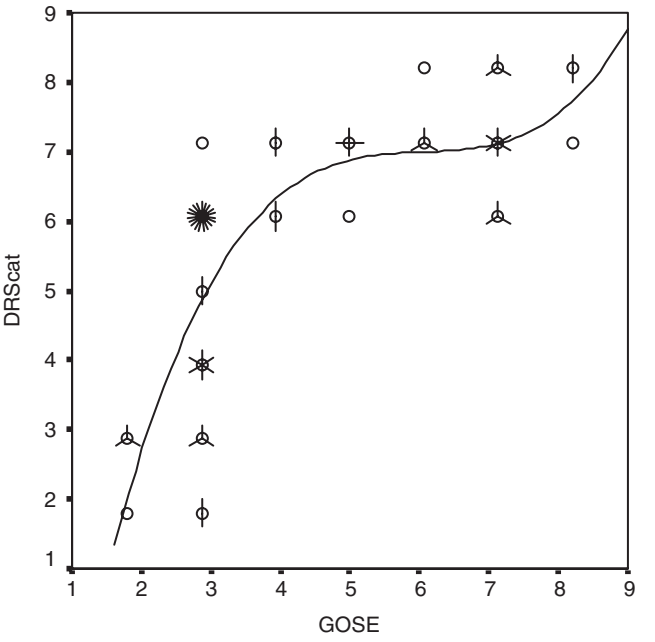

Figure 1. Scatter plot of the scores on the GOSE and on the DRScat, with a cubic curve fitted to the data. An open dot represents one case; the number of lines connected to the other dots represents the total number of cases.

three levels, whereas on the GOSE the majority of the patients scored in the lower three levels, especially in level 3.

The correlation between the DRS and the GOSE was high (Spearman rho $= -0.84$; $p < 0.01$), as well as the correlation between the DRScat and the GOSE (Spearman rho $= 0.81$; $p < 0.01$). As Figure 1 shows, the scores on the DRScat seemed to be more differentiated in the lower levels of functioning, whereas the GOSE-scores were more differentiated in the upper levels of functioning. Level 6 (containing 25 patients) and level 7 (containing 17 patients) of the DRS were differentiated in six GOSE levels, and in return, level 3 (containing 33 patients) of the GOSE was differentiated in six DRS levels. Although there was a clear linear trend in the data ($R^2 = 0.47$), a cubic curve fitted the data better ($R^2 = 0.58$; test for significance of the difference: $F(2,61) = 6.14$, $p = 0.00$).

Functionality and employability/educationability

The scores on the two separate items of the DRS concerning functionality (item 7) and employability/educationability (item 8) showed considerable variations. In particular the variance on item 7 in the TBI group was high (see Table V). The scores were more or less equally distributed among the six categories, showing that one third of the TBI patients were moderately independent, one third were mildly or moderately dependent and one third were noticeably or totally dependent. A majority of 64% of the nTBI patients was noticeably or totally dependent.

Table V. Distribution of the traumatic (TBI) and the non-traumatic (nTBI) patients on Item 7 (functionality) of the DRS.

Level	TBI	nTBI
Completely independent	13 (25.5%)	1 (7.1%)
Independent in a particular environment	4 (7.8%)	0
Mildly dependent	9 (17.6%)	1 (7.1%)
Moderately dependent	8 (15.7%)	3 (21.4%)
Noticeably dependent	8 (15.7%)	2 (14.3%)
Totally dependent	9 (17.6%)	7 (50%)
Total	51 (100%)	14 (100%)

Table VI shows the distribution of the scores for both groups among the four levels of the employability item 8 of the DRS, indicating that almost half of the surviving TBI group was able to participate in work or school activities, compared to one quarter of the nTBI group.

Discussion

This study describes the long-term outcome of children and young adults with severe brain injury who had been in a vegetative state or a minimally conscious state for a considerable period. The results showed that, though full recovery is rare, the majority of patients eventually reached a (semi-) independent level of functioning. For the patients

Table VI. Distribution of the traumatic (TBI) and the non-traumatic (nTBI) patients on Item 8 (employability/education-ability) of the DRS.

Level	TBI	nTBI
Not restricted	6 (11.8%)	0
Selected competitive jobs/can perform most school tasks on a regular basis	16 (31.4%)	4 (28.6%)
Sheltered non-competitive workshop/requires assistance for all school tasks	22 (43.1%)	4 (28.6%)
Not employable/ education is not possible	7 (13.7%)	6 (42.9%)
Total	51 (100%)	14 (100%)

with traumatic brain injury 37% (GOSE) to 82% (DRS) recovered to partly or total independency. Forty-three percent were able to perform substantial work or accomplish most or even all school tasks without help. No TBI-patients seemed to be in VS several years after injury. When we compare the results of this study to the results of our discharge study concerning the same population [17], we can conclude that almost all the patients who were in a vegetative state upon discharge from EINP died in the period following release. Also, approximately one quarter of the patients in MCS deceased. It can be assumed that most of them were in the lowest level of the MCS, the transitional state. Eventually almost 50% of the nTBI patients died, compared to 12% of the TBI patients. The more encouraging outcome of TBI patients is in full accordance with other outcome studies [3], and with our expectations. Furthermore, one can conclude that patients who are still in VS 12 months after injury are likely to die within a couple of years.

To assess the effect of a treatment programme like EINP, a controlled group study design is needed. In this study, there were no possibilities to execute such a study design. Nevertheless, it is wished for to compare the results of this study with the results of earlier outcome studies, although differences in study design and sample characteristics will exist. In doing so, it appears that some of the results of this study suggest that more TBI-patients than presumed recovered to a reasonable level of independence. Firstly, at admission to EINP none of the patients had an indication for rehabilitation with a poor prognosis for substantial recovery, however eventually 50–67% of all traumatic patients reached a level of at least partial independence. Of the 25 patients who were in VS for three months or more, 11 (44%) reached this level. This is substantially more than described by Kriel et al. [36]. They studied a cohort of 188 young patients (0–20 years) who suffered a severe brain injury, of whom 60 were in VS for more than 90 days. Kriel et al. found that 1–20 years (Median = 8 years) after trauma, only 10% of the patients were verbal communicators and 30% had reached some level of motor independency. Secondly, comparing the results of this study with the earlier mentioned calculations of recovery probability made by the Multi-Society Task Force (MSTF) [2, 3], and with the results of the study of Groswasser and Sazbon [13, 14], in our study the long-term outcome of patients who suffered a traumatic brain injury seems to be more encouraging, therefore indicating possible therapeutic effects of the early intensive neurorehabilitation programme. The MSTF calculated a probability of 30% remaining in a vegetative state with an estimated survival of 7.4 years (±1.8) for children 7–18 years old [3]. In our study none of the TBI-patients were in a vegetative state within one year of the injury. Groswasser and Sazbon found that 11% of patients who were unconscious for more than one month were able to resume working in the open job market and 49% were engaged in sheltered non-competitive workshops [13]. In this study these percentages were respectively 43 and 43.

In this study, half of the patients were classified in the 'lower severe disability' category of the GOSE, mainly because they needed some kind of physical help during daily life. In scoring the GOSE it is not possible to take into account the level of mental independence. As it is generally accepted nowadays that social participation is a function of mental capacities rather than of physical capacities, it seems worthwhile to use other measures for the classification of the level of disability. In this study especially item 7 of the DRS, which requests functional independency, showed a substantial variation in the scores. Demonstrating that in the studied population, the level of functioning is more diverse than the results of the GOSE suggested. The use of the DRS as a whole, and item 7 especially, can contribute to a better insight in the need for different kinds of specialized facilities and care. This is in accordance with the latest views regarding what is important in the long-term care for persons with severe brain injury. For example, Lollar et al. underlined the use of outcome measures in children and young adults which reflect the dimensions of the International Classification of Functions (ICF), in terms of functions, capabilities and participation [37]. As we have demonstrated, the DRS offers more possibilities to do so than the GOSE and should preferably be used in long-term outcome studies in young patients with severe brain injury.

Limitations

The dropout rate in this long-term outcome study was considerable. However, compared to other studies, the participation in this study was relatively high [38], possibly because we asked cooperation and participation of family members as a replacement for of the patients themselves. Furthermore, the results showed that the studied group did not differ significantly in important injury and demographic variables from the group of patients that did not participate. All in all, the effects of the dropout rate on the results seem to be negligible.

The time since injury varied widely in this study: between 2.4 and 15.7 years. The longer the time, the greater the possibilities that all kinds of other life events have had influence on the recovery process. This might result in a lessening, but also in a worsening of the effects of brain injury per se. It is not possible to control this variability. Only in a prospective longitudinal study fixed measure points are possible, but even then, life events will differ amongst participants, making it difficult to control.

Conclusions

In conclusion, this study proved that patients who suffered a severe traumatic brain injury might have reasonable chances for long-term independency, when early intensive neurorehabilitation is applied even when the patient is still in an unconscious state. It is supposed that the application of a structured early intensive neurorehabilitation programme contributed to the recovery. Patients with a non-traumatic brain injury who were in a vegetative state for more than two months did not demonstrate these possibilities for long-term recovery.

The comparison between the GOSE and the DRS of measuring the long-term level of social participation showed that the DRS has advantages above the GOSE in patients with severe brain injury. Especially the single items concerning functionality (item 7) and employability/educationability (item 8) were able to differentiate between different levels. Suggestions for future research are, above all, longitudinal prospective multi-centre outcome studies in which severe brain-injured patients are followed from admittance in the hospital up until five to ten years after the injury.

Competing interests

HE was the clinical psychologist of most of the patients during their treatment period at the rehabilitation centre, but had no contact with them in this study.

No other competing interests were present.

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