

Patients' and relatives' experience of difficulties following severe traumatic brain injury: The sub-acute stage

Sara Holm¹, Michael Schönberger^{2,3}, Ingrid Poulsen¹,
and Carla Caetano⁴

¹*Brain Injury Unit, Copenhagen University Hospital Hvidovre, Hvidovre, Denmark;* ²*School of Psychology, Psychiatry and Psychological Medicine, Monash University, Melbourne, Australia;* ³*Monash-Epworth Rehabilitation Research Centre, Epworth Hospital, Melbourne, Australia;* ⁴*Centre for Rehabilitation of Brain Injury, University of Copenhagen, Denmark.*

The present study aimed to (1) identify the difficulties most frequently reported by individuals with severe traumatic brain injury (TBI) at the time of discharge from a sub-acute rehabilitation brain injury unit as well as difficulties reported by their relatives, (2) compare patients' and relatives' reports of patient difficulties, and (3) explore the role of injury severity, disability and other factors on subjective experience of difficulties. The primary measure was the European Brain Injury Questionnaire (EBIQ) administered to patients and to one of their close relatives at discharge. Results from 52 patients and 50 relatives indicate that the most frequent complaints in both groups related to somatic and cognitive problems. Relatives reported significantly more difficulties than patients on all subscales of the EBIQ. However, the level of complaints in both patients and relatives was low compared to other studies using the EBIQ. Furthermore, the effects of injury severity and general level of

Correspondance should be sent to Sara Holm, Department of Neurological Rehabilitation, 354 Hvidovre Hospital, Kettegård Allé 30, 2650 Hvidovre, Denmark.

E-mail: sara_holm@hotmail.com

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functioning had limited impact on the subjective experience of difficulties. Implications of these findings, specifically as they pertain to the sub-acute stage are discussed.

Keywords: Subjective experience; Traumatic brain injury; European Brain Injury Questionnaire; Quality of Life; Sub-acute treatment.

INTRODUCTION

During the past few decades, the subjective perception of disease and treatment has received growing attention in several areas of medicine. Increasingly, the patients' own description of well-being and difficulties is assessed in addition to the professionals' accounts of symptoms (Bullinger et al., 2002). This is also the case in the field of brain injury. Hart and Evans (2006) note that an important benefit of assessing the subjective experience of resources and difficulties in relation to brain injury and other illness, is the opportunity to identify personally relevant goals for treatment and rehabilitation, thereby enhancing patients' chances of a successful outcome. In addition, a goal planning approach may address multiple levels of functioning across multiple domains with multiple subsystems (Wilson, Evans, & Keohane, 2002). Information about patient's and significant others' subjective experience contributes to the establishment and maintenance of the therapeutic alliance, helps to identify the psychosocial systems that pertain to the patient (such as the treatment and family subsystems), and is informative on issues pertaining to awareness, e.g., Lustig, Strauser, Weems, Donnel, and Smith (2003) and Schönberger, Humle, and Teasdale (2006a) who explore working alliance in brain injury rehabilitation and outcome and Ownsworth and Clare (2006) and Schönberger, Humle, Zeeman, and Teasdale (2006b) who discuss issues of awareness and rehabilitation gains.

However, measurement of subjective experience in patients with brain injury poses considerable problems. The most common tools for assessing subjective well-being have been developed for other patient groups, where the validity for patients with brain injury is questionable (Teasdale et al., 1997; Williams, Evans, & Wilson, 1999). For instance, Teasdale and Caetano (1995) pointed out that the widely-used Symptom Checklist-90-R (SCL-90-R) may show misleading results regarding the level of psychopathology from samples of persons with brain injury, because cognitive components such as concentration and memory deficits load on some of the psychopathology scales of the questionnaire. Another major problem in assessing the subjective perception of difficulties is that patients with brain injury may lack awareness of their difficulties or may have other cognitive deficits that can make their own evaluation of problems unreliable (McKinlay & Brooks, 1984; Svendsen, Teasdale, & Pinner, 2004). Finally,

a challenge that specifically pertains to the measurement of the subjective experience in persons with severe brain injury in early stages of rehabilitation is the variation in level of cognitive functioning in this group. For instance, after acute and sub-acute rehabilitation of patients with severe traumatic brain injury, some patients may have regained full consciousness and can be discharged to their homes, while others need further in-patient rehabilitation due to persistent, severe disturbances of consciousness and/or severely restricted levels of cognitive functioning. In cases of severely impaired level of consciousness, it may not be possible to obtain a valid and reliable description of patients' perception of injury-related changes.

Specific instruments for measuring subjective experience in patients with traumatic brain injury (TBI) are scarce. However, the European Brain Injury Questionnaire (EBIQ) (Teasdale et al., 1997; Teasdale & Engberg, 2005), has been used in several studies addressing consequences after TBI (Martin, Viguier, Deloche, & Dellatolas, 2001; Svendsen & Teasdale, 2006; Svendsen et al., 2004; Teasdale et al., 1997; Teasdale & Engberg, 2005). It has also been used as one of the measures for evaluation of the effect of rehabilitation programmes (Schönberger et al., 2006a, 2006b; Svendsen & Teasdale, 2006; Svendsen et al., 2004). These studies focus on patients' and relatives' reports of brain injury related difficulties at various times after TBI. However, few studies are found concerning the subjective experience in patients and relatives in the sub-acute phase and in the early phase after severe TBI, i.e., less than one year post-injury. This is, therefore, the focus of our study.

In the present study, using the EBIQ, we had the following aims:

1. To identify the most frequently reported self-experienced difficulties at this very early stage after severe traumatic brain injury, i.e., at time of discharge from a sub-acute rehabilitation brain injury unit.
2. To compare patients' and relatives' reports of difficulties.
3. To explore the relationship, (a) between subjective experience of brain injury related problems as viewed by patients' and relatives' and (b) between patients' severity of injury, disability, gender and age.

METHOD AND MATERIALS

Design

During the period from 2000 to 2004, a consecutively referred sample of severe TBI patients as well as their relatives rated the subjective experience of patients' brain injury related problems at time of patient discharge from a

centralised, highly specialised brain injury unit for early intensive rehabilitation after severe TBI in Denmark.

Setting

Time from injury to admission to the unit was on average 18 days ($SD = 13$). At the brain injury unit, rehabilitation takes place 24 hours per day, and is staffed by an interdisciplinary team of neurologists and rehabilitation doctors, neuropsychologists, physiotherapists, occupational therapists, nurses, social workers and, when needed, speech therapists and health care workers. Each discipline is equally involved in the treatment planning, which takes place at regular interdisciplinary team conferences. Patients have ongoing contact with neuropsychologists who rate patients' level of consciousness and describe patients' cognitive functioning. Depending on the patient's level of consciousness, cognitive functioning and emotional state, neuropsychological interventions may be supportive (e.g., counselling in regard to psychosocial issues), or may focus on insight and/or coping strategies. However, neuropsychological rehabilitation that consists of group sessions and structured cognitive training is often not applicable at this stage of treatment. Significant others are offered regular and ongoing contact with neuropsychologists. Depending on the relatives' emotional states and other individual factors, the focus is on emotional themes, relatives' coping strategies and/or discussion of the patient's behaviour. Further details about the unit are presented elsewhere (Engberg, Liebach, & Nordenbo, 2006).

Participants

All patients and relatives were recruited from the brain injury unit described above. Exclusion from the study was based on (1) persistent, seriously impaired level of consciousness, and/or (2) severely impaired cognitive functioning, (3) severe language deficits, (4) inadequate pre-existing Danish skills in either patients or relatives, and (5) cases where a close relative could not be identified. The exclusion of patients based on these criteria was made by a neuropsychologist in each case.

Measures

Subjective description of difficulties: The European Brain Injury Questionnaire. The EBIQ was specifically developed for brain-injured patients, based on a large, international multi-centre study in 1995 and was found to be both a reliable and valid measure for the subjective experience of difficulties in brain-injured patients (Teasdale et al., 1997). Svendsen and colleagues (2004) have collected EBIQ results from a group of 64 non-brain-injured Danish subjects. The questionnaire has been translated into

several languages including Danish. The EBIQ assesses the patient's own perception of difficulties after brain injury, and a parallel version of the questionnaire is given to a close relative who also rates the patient's difficulties. In this respect, the EBIQ explores the concordance between patients' and relatives' evaluation of difficulties. In the Danish version of the EBIQ used in this study, the questionnaire consists of 62 questions about brain injury related problems that people may encounter in their lives. From the 62 questions, eight scales can be calculated relating to different aspects of problems, i.e., "soma-tisation", "cognition", "impulsivity", "depression", "isolation", "physical", and "communication". In addition, a "core scale" can be calculated referring to problems in general (Teasdale et al., 1997). The response alternatives are "not at all", "a little" or "a lot", coded as "1", "2", and "3", respectively. (The English version of the EBIQ includes 63 items but minor changes were made in the Danish version by excluding item 49, "Needing to be reminded about personal hygiene", and item 20, "Needing help with personal hygiene" was changed to "Not being occupied with your physical appearance". The English version of the EBIQ is available at www.psy.ku.dk/teasdale.)

Severity of injury: Post traumatic amnesia (PTA) and length of hospitalisation. Duration of post traumatic amnesia (PTA) is considered to be an important predictor for general outcome after TBI, and PTA can therefore, be seen as an indicator of the severity of the injury (Hall & Johnston, 1994; Levin, O'Donnell, & Grossman, 1979; van Baalen et al., 2003). The duration of PTA was measured with the Galveston Orientation and Amnesia Test (GOAT) which assesses the degree to which a patient is oriented regarding time, place and own data and is able to account for relevant information about circumstances regarding the accident and hospitalisation (Levin et al., 1979). An additional measure for injury severity, namely, length of hospitalisation (i.e., time span from time of injury to discharge from the brain injury unit) was also included.

General level of functioning: The Glasgow Outcome Scale (GOS) and the Functional Independence Measure (FIM). At the time of discharge from the brain injury unit, the patient's general level of functioning was measured on the GOS (Jennett, Snoek, Bond, & Brooks, 1981) and the 18-item ordinal FIM-scale (van Baalen et al., 2003). The GOS categorises patients in one of five major categories, namely, death, vegetative state, severe disability, moderate disability, and good recovery. Although the GOS has been criticised for lacking unambiguous criteria for distinguishing between the different categories, it is, nonetheless, a widely used measure of outcome after brain injury (Teasdale, Pettigrew, Wilson, Murray, & Jennett, 1998). The FIM examines different aspects of functioning, i.e., self-care, sphincter control, mobility, locomotion, communication, and social cognition. Scores range

from 18 to 126, where a high score indicates a high level of functioning. The FIM is used relatively frequently with brain injured patients (Hall, 1999) and good reliability is reported (Kidd et al., 1995; Ottenbacher et al., 1997; van Baalen et al., 2003).

Procedures

The EBIQ was administered at time of discharge from the brain injury unit. Discharge was chosen as the most reliable time point for obtaining data as few patients have a sufficient level of consciousness and/or cognitive functioning before discharge. The majority of the patients completed the EBIQ questionnaire alone, without any further instruction than the short introduction written on the questionnaire. However, a neuropsychologist assisted patients with substantial visual or motor problems in questionnaire completion. The respondents were encouraged to give immediate responses to the questions and not spend too much time on any item. Patients and relatives were asked to answer separately without discussing the answers with each other before responding.

Determination of injury severity and level of general functioning were made by the interdisciplinary staff. Rehabilitation doctors rated patients on the GOS. Nurses, physiotherapists and occupational therapists rated patients on the FIM, and neuropsychologists assessed the duration of PTA.

Of note is that not all data were available for all subjects. Missing data include cases where (1) relevant variables were not registered in the central database at the unit, (2) the relevant information was registered in an unclear manner, and where (3) relatives' gender and relation to a patient did not appear on the EBIQ questionnaire.

Informed consent was obtained from patients and/or relatives and the study was approved by the local ethical committee in Copenhagen/Frederiksberg (J.no.07328453).

Statistics

Since the EBIQ can be treated as an interval scale (Svendsen et al., 2004; Teasdale et al., 1997), parametric statistical procedures for the comparison of EBIQ ratings were used. Since the GOS and the FIM are ordinal scales and the distribution of FIM scores, PTA, and length of hospitalisation were skewed in the present study, nonparametric statistics for the comparison of EBIQ scales with demographic and injury variables were computed. Alpha was set at .05 (2-tailed). Statistical analyses were performed using Statistical Package for Social Sciences, SPSS 13.0.

Results

EBIQ responses were obtained from 52 patients and 50 relatives. As such, of the 162 TBI patients discharged from the brain injury unit over a period of

four years, 32.1% were included in the study. The study sample represented a severely injured group based on duration of unconsciousness, duration of PTA and length of hospitalisation. In all cases PTA exceeded one week (as assessed by the GOAT). However, compared to patients in the same unit not included in this study, our sample had a shorter duration of PTA and hospitalisation and had a higher general level of functioning, as measured both by the FIM and the GOS (see Table 1). As can be seen from the table more patients were excluded than included when PTA was more than 9 weeks, when hospitalisation was up to 468 days, when FIM scores were lower, and GOS scores were in the severe disability range. Thus, the patients included in this study, although severely injured, represented a group with a higher level of functioning than the patients excluded from the study.

Aim 1: To identify self-reported difficulties most frequently experienced in the sub-acute stage of traumatic brain injury rehabilitation. As shown in Table 2, complaints on the somatic and cognitive sub-scales of the EBIQ were most frequently reported by the patients. At the single item level, these were: "Trouble remembering things" ($M = 1.8, SD = 0.65$), "Having to do things slowly in order to be correct" ($M = 1.8, SD = 0.65$), "Trouble concentrating" ($M = 1.7, SD = 0.58$), and "Lack of energy or being slowed down" ($M = 1.7, SD = 0.63$).

Aim 2: To compare patients' and relatives' reports of difficulties. As with the patients' own reports, relatives reported that patients had most problems on the somatic scale and the cognitive scales. However, the relatives reported significantly more symptoms than patients on most scales, i.e., the somatic, cognitive, motivation, impulsivity, physical, and the core scale. As for the patients, the most frequent complaints were: "Trouble remembering" ($M = 2.1, SD = 0.65$), "Having to do things slowly in order to be correct" ($M = 1.9, SD = 0.74$), "Lack of energy or being slowed down" ($M = 2.0, SD = 0.60$), and "Trouble concentrating" ($M = 1.9, SD = 0.64$). However, additional items to these were frequently reported by the relatives, such as patients being viewed as finding everything to be an effort ($M = 1.9, SD = 0.68$), and as being confused ($M = 1.9, SD = 0.74$).

Aim 3: To explore the relationship between (1) subjective experience of brain injury related problems as viewed by patients and relatives and (2) patients' severity of injury, disability, gender and age. Patients' experience of brain injury related difficulties on the EBIQ was not related to patients' sex and age. Few significant correlations were found between measures of the patients' general level of functioning and their subjective reports of

TABLE 1
Characteristics of participants

	<i>Patients in sample (N = 52)</i>	<i>Patients not in sample (N = 97)</i>
Gender		
Female	35%	26%
Male	65%	74%
Age		
Mean (<i>SD</i>) years	34.46 (17.47)	46.27 (18.9)
Severity of injury		
PTA:		
Median/Mean (<i>SD</i>) days	38.5/44.65 (29.56)	
1–2 weeks	5 (10%)	3 (4%)
3–4 weeks	9 (17%)	8 (10%)
5–6 weeks	17 (33%)	10 (12%)
7–8 weeks	12 (23%)	8 (10%)
9–16 weeks	6 (12%)	15 (19%)
> 16 weeks	3 (6%)	37 (46%)
Hospitalisation:		
Median/Mean (<i>SD</i>) days	86.5/82.6 (48.5)	101.0/137.1 (101.5)
Range	18–206	11–468
General level of functioning at discharge		
FIM-score		
Median	120.0	84.0
Percentiles 25	114.0	35.0
75	122.0	114.0
GOS-score		
Dead or vegetative	0 (0%)	12 (15%)
Severe disability	3 (6%)	37 (47%)
Moderate disability	27 (57%)	25 (32%)
Good recovery	17 (36%)	5 (6%)
Relatives (N = 50)		
Gender		
Female	72%	
Male	28%	
Relation to the patient		
Partner	49%	
Parent	38%	
Child	4%	
Other	9%	

difficulties: Patients' GOS-scores were moderately related to patients' EBIQ scores of cognitive complaints, complaints regarding isolation, and overall complaints (EBIQ-core scale) (see Table 3). Patients' FIM-scores were moderately related to patients' cognitive complaints (EBIQ cognitive scale). No other correlations between patients' EBIQ ratings and measures of level of functioning were found (see Table 3).

TABLE 2
EBIQ scale descriptives

<i>EBIQ subscales</i>	<i>Rater Self</i>			<i>Relative</i>		
	<i>Mean (SD)</i>	<i>Minimum</i>	<i>Maximum</i>	<i>Mean (SD)</i>	<i>Minimum</i>	<i>Maximum</i>
Somatic	1.53 (0.32)	1	2.38	1.66 (0.32)**	1	2.38
Cognitive	1.51 (0.35)	1	2.38	1.71 (0.38)***	1	2.69
Motivation	1.31 (0.36)	1	2.50	1.52 (0.43)**	1	2.80
Impulsivity	1.42 (0.21)	1	2.25	1.54 (0.43)*	1	2.62
Depression	1.35 (0.33)	1	2.29	1.43 (0.37)	1	2.14
Isolation	1.44 (0.35)	1	2.75	1.55 (0.46)	1	3.00
Physical	1.43 (0.34)	1	2.30	1.64 (0.40)**	1	2.60
Communication	1.33 (0.37)	1	2.50	1.44 (0.42)	1	3.00
Core	1.40 (0.26)	1	2.03	1.56 (0.30)**	1	2.36

1 = "Not at all", 2 = "A little", 3 = "A lot". *Patient–relative difference is significantly different from 0 at the .05 level (paired-samples *t*-tests, 2-tailed); **Patient–relative difference is significantly different from 0 at the .01 level (paired-samples *t*-tests, 2-tailed); ***Patient–relative difference is significantly different from 0 at the .001 level (paired-samples *t*-tests, 2-tailed).

For the relatives' ratings of patients' brain injury related difficulties on the EBIQ, no gender effect was found (see Table 4). Correlations between patients' age and relatives' reports of difficulties were found only on the isolation scale, which refers to the feeling of being misunderstood, hiding one's emotions, and mistrust of other people. No effect was found for length of hospitalisation. However, relatives' ratings were moderately related to PTA-length on the EBIQ-cognitive scale and the EBIQ-motivational scale. As for the general level of functioning for the patients, significant correlations were found between GOS-scores and the relatives' reports of difficulties on the cognitive scale, the motivation scale, the communication scale, and the core scale. In addition, significant correlations between FIM-score and the physical scale were found.

DISCUSSION

Methodological considerations

The subjective experience of difficulties after severe TBI in the sub-acute phase using the European Brain Injury Questionnaire (EBIQ) was investigated. About one third of patients completed the questionnaire as did their relatives. While low, this level of participation from a severely injured group of brain injury survivors in the early stage of recovery is arguably acceptable. This method of investigation, however, has several limitations. Firstly, a standardised questionnaire only allows subjects to state their

TABLE 3
Patients' EBIQ ratings in relation to patients' demographic and injury characteristics (Spearman's correlations)

<i>Patients' demographic and injury characteristics</i>	<i>EBIQ scale</i>								
	<i>Somatic</i>	<i>Cognitive</i>	<i>Motivation</i>	<i>Impulsivity</i>	<i>Depression</i>	<i>Isolation</i>	<i>Physical</i>	<i>Communication</i>	<i>Core</i>
Sex	.02	-.10	.17	.22	.27	.04	.25	.14	.23
Age	-.04	-.00	.13	-.18	-.01	-.02	.05	.08	-.00
PTA length	.05	.18	.25	.10	.13	.25	.02	.06	.21
Hospitalisation	.21	.18	.16	.16	.17	.20	-.00	.20	.25
GOS score	-.24	-.35*	-.23	-.17	-.19	-.49**	-.24	-.24	-.38*
FIM-score	-.20	-.37**	-.14	-.22	-.11	-.24	-.20	-.19	-.24

Spearman's correlation is significant *at the .05 level (2-tailed); **at the .01 level (2-tailed); ***at the .01 level (2-tailed).

TABLE 4
Relatives' EBIQ ratings in relation to patients' demographic and injury characteristics

<i>Patients' demographic and injury characteristics</i>	<i>EBIQ scale</i>								
	<i>Somatic</i>	<i>Cognitive</i>	<i>Motivation</i>	<i>Impulsivity</i>	<i>Depression</i>	<i>Isolation</i>	<i>Physical</i>	<i>Communication</i>	<i>Core</i>
Sex	-.17	-.16	.04	-.16	-.03	.10	-.14	-.17	-.06
Age	.10	-.13	.01	-.23	-.20	-.34*	-.03	-.07	-.14
PTA length	-.10	.29*	.35*	-.19	.01	-.04	.17	.18	.14
Hospitalisation	-.07	.26	.26	-.21	.01	.10	.19	.09	.09
FIM score	-.15	-.25	-.17	-.17	-.16	-.04	-.32*	.23	-.20
GOS score	-.26	-.37*	-.36*	-.11	-.17	-.13	-.31	-.35*	-.30*

Spearman's correlation is significant *at the .05 level (2-tailed); **at the .01 level (2-tailed); ***at the .01 level (2-tailed).

experience concerning the specific items listed in the questionnaire. It is therefore possible that patients and relatives experience difficulties other than those listed in the EBIQ. Moreover, as the EBIQ was not specifically developed for the in-patient sub-acute rehabilitation phase, some of the items are superfluous to patients and relatives in this setting. For example, questions concerning problems with household chores, lack of interests in hobbies outside of home, and loss of sexual interest or pleasure do not seem appropriate to hospitalised patients and their relatives. Secondly, the limited response alternatives of the EBIQ, i.e., “Not at all”, “A little” or “A lot”, also appear to be a possible shortcoming, as informal feedback from patients and relatives suggests that some respondents would have preferred additional response alternatives to nuance answers. Thus, paradoxically, it can be argued that the EBIQ response alternatives in some cases may be too circumscribed to capture the subjective experience of patients and relatives while in other cases may pose too many demands on the patient’s level of cognitive functioning, as demonstrated by the inability to complete the questionnaire. This would seem to suggest that the EBIQ may not provide an optimal measure of subjective experience for those patients with very limited cognitive resources or for those with serious language problems, as is often found in the sub-acute stage of post-acute rehabilitation. However, it is disputable if the use of another method, e.g., interviews, would provide a valid description in patients with a very poor outcome or significant language problems. It could be argued that interviews may place an equally high or even higher demand on patients’ language and cognitive functioning (e.g., executive skills), than a questionnaire would. Further studies could employ an item-response theoretical approach in order to further investigate the scale properties of the EBIQ in patients with different cognitive and language problems and in both in-patient and out-patient settings.

Aim 1: Self-reported difficulties

Somatic and cognitive difficulties were most frequently reported by patients. This is partly consistent with other evidence found in later stages of rehabilitation, namely that the subjective complaints of TBI patients primarily concern cognitive functioning (especially attention, concentration and memory) (Gordon, Haddad, Brown, Hibbard, & Sliwinski, 2000; Teasdale et al., 1997; Thornhill et al., 2000). However, compared to EBIQ studies of survivors after TBI at a later point after injury (Teasdale et al., 1997; Teasdale & Engberg, 2005), the level of complaints by patients in the sample under investigation is surprisingly low. Apart from the three most elevated scales in our sample, the level of patient’s complaints on most EBIQ scales in our study is only slightly higher than the level of complaints reported by a non-injured sample of 64 Danish subjects (mean age = 41.4

years; male/female ratio = 38/62) (Svendsen et al., 2004). In addition, the patients in our sample also rated fewer problems on all EBIQ scales compared to the moderate to severely injured TBI participants in Svendsen et al.'s (2004) study who were on average 1.2 years post-injury.

These findings seem to be in contrast with the professional evaluation of patients' disabilities on both the FIM and the GOS, which indicate moderate disability in this sample. There can be several explanations for this finding. One possible explanation is that the severely brain injured patients in our sample lack the ability to recognise their problems (i.e., suffer from anosognosia). A second possible factor is that psychological defence mechanisms prevent patients from recognising the consequences of their brain injury. A third explanation is that patients, at this early point in time after the injury, lack experience with many demanding situations of daily life, where the brain injury related difficulties would be more explicit. Thus, at time of discharge from the hospital, patients might not yet have been confronted with a broad range of difficulties in more complex settings. A contributing factor might be that patients have been in a very supportive and structured environment at the rehabilitation unit. For example, regarding the latter, patients have regular contact with staff who are supportive and specifically trained to work with the sequelae of brain injury, patients have private rooms, and the number of visitors is restricted in order to protect patients who are disoriented and confused. Furthermore, all activities during the day are written down for each patient in order to provide as much clarity as possible.

Our findings also seem to support the argument that patients with acquired brain injury might experience more problems when they are surveyed later rather than earlier post-injury. As Engberg and Teasdale (2004) point out, it may take several years before the full impact of the brain injury is recognised.

Finally, it should be taken into consideration that patients in this study were asked to evaluate their problems just as they were being discharged from a long period of hospitalisation (range 25–243 days) during which time they had recovered from very critical conditions. Discharge from hospital might, therefore, be associated with an inflated sense of optimism regarding outcome in general. Thus, it may be that evaluations based on subjective experience of functioning should take place at various time points and not just at the time of discharge, e.g., when patients have achieved a criterion level of consciousness or level of cognitive functioning.

Aim 2: Divergence between patients' and relatives' reports of difficulties

The results show divergence between patients' and relatives' reports of difficulties. Although the most frequently reported difficulties correspond to those

of the patients, it is noteworthy that relatives reported significantly more symptoms on most scales of the EBIQ than did patients. In contrast to the patients' own reports, the relatives' reports of the patients' difficulties are elevated on all subscales compared to results from relatives in the non-injured group (Svendsen et al., 2004). The discrepancy between patients' and relatives' reports of difficulties on the EBIQ in our study (understood as more difficulties reported by relatives) is consistent with findings from Martin et al. (2001) and Teasdale et al. (1997). In addition, several studies using other measures to evaluate the concordance between patients' and relatives' experience of difficulties also reveal discrepancies, i.e., more cognitive, behavioural and emotional complaints reported by relatives than by TBI patients (Hart et al., 2003; Sbordone, Seyranian, & Ruff, 1998; Sherer et al., 1998). However, even the relatives in our sample report a lower level of complaints on all EBIQ subscales compared to the patients' relatives in Teasdale et al.'s (1997) and Svendsen et al.'s (2004) studies. The reasons for the comparatively positive EBIQ ratings given by the relatives in our study may be the same as for patients' own ratings. Relatives are supported by neuropsychologists and other professionals who have knowledge and understanding of the consequences of TBI and of the emotional impact of the injury on relatives. Other possible reasons for the relatively positive evaluations may be due to psychological factors and lack of experience with the patients in demanding situations that may prevent a full realisation of patient difficulties.

Aim 3: Effect of injury severity, disability, gender, and age on subjective experience

The results of the present study suggest that patients' subjective experience of difficulties after severe TBI in the sub-acute phase of rehabilitation are relatively independent of both injury severity and professionals' ratings of patients' general level of functioning. This is to some degree inconsistent with findings from brain injured patients studied 5–10 years post-injury where correlations between duration of PTA and the motivation, isolation, physical, and communication scale of the EBIQ are identified, as are correlations between GOS-score (at discharge from hospital) and the cognition and physical scale (Teasdale & Engberg, 2005).

However, a much stronger relationship to injury severity and disability is seen in relatives' experience of difficulties in the patients. Thus, it seems that there is more agreement between the professional rating of disability in patients and the relatives' evaluation of problems, than between the professional rating and the patients' own evaluation. It would be tempting to conclude that the relatives' reports of difficulties give a more valid picture of the existing problems after severe TBI. However, in the study of subjective

experience, determining who is more accurate is of little value. What is of importance, is that there is a discrepancy between the patient's own view on his or her situation and the judgement of both professionals and relatives. The implication of such a discrepancy has relevance for brain injury rehabilitation as this pertains to treatment planning and interventions.

Considerations about implications for clinical practice and future studies

The results of the present study are relevant for rehabilitation of severe TBI patients in the following ways: First, both during the sub-acute stage and at discharge planning, the patient's own experience of difficulties and rehabilitation needs may differ from professional evaluations. Such differences are useful not only in providing additional information as regards patient functioning but also as regards treatment, specifically in goal setting and facilitating motivation. Thus, identifying the patient's subjective view should be considered integral to the assessment, planning and treatment process. Second, the findings of this study and previous studies indicate that divergent views typically exist as regards patients' and relatives' experiences of difficulties. Investigating why these differences exist can provide valuable information as regards patient/significant other's perceptions, interactions and motivations and how these affect treatment. In addition, such differences require active intervention by treatment staff to establish a common framework for understanding the sequelae of brain injury and to maximise contributions from the patient's social network in treatment. Third, in comparison to studies of the subjective experience of brain injury related difficulties conducted later than sub-acute in-patient rehabilitation, our results suggest that patients may initially acknowledge less brain injury related difficulties than later on. Thus, in order to further explore the similarities and differences of subjective experience of difficulties at different stages of brain injury rehabilitation, we plan to conduct a further study comparing subjective experience of difficulties in the same group of brain injured patients and their relatives at the sub-acute and post-acute stages of rehabilitation.

In conclusion, the subjective evaluation of brain injury sequelae by both patients and their relatives appears to be as relevant for the sub-acute stage of rehabilitation as for later stages of rehabilitation. While the nature and scope of subjective experiences may be achieved more comprehensively by measures other than the EBIQ, the following applications are possible: (1) using contrasting perspectives from the patient and other sources (i.e., patients, relatives, staff) to further qualify treatment planning and outcome; (2) facilitating goal setting and motivation for treatment by giving explicit acknowledgement to the subjective experience of patient and relatives, and

(3) providing a more comprehensive assessment of functioning by the combined use of subjective and objective measures, which include normative criteria and more phenomenologically based individual perspectives.

Future studies might more systematically address how the subjective experience of difficulties is related to premorbid factors such as personality traits, coping style, etc., and how these and other variables may affect rehabilitation outcome. Similarly, analysis of the interactions and perceptions between subsystems during treatment (for example, patients' and relatives' subjective experience of brain injury sequelae) could also be explored as this contributes to outcome. Finally, the impact of subjective experience of functioning on rehabilitation efforts (e.g., goal setting, creating motivation for treatment, etc.) at different phases of treatment could also be further explored.

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