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Subjective experience in patients with brain injury and their close relatives before and after a rehabilitation programme

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This study reports results from 143 adult patients with cerebrovascular accident, traumatic brain injury or other acquired brain injury who underwent a neuropsychologically-based post-acute rehabilitation programme. Immediately pre- and post-programme, patients, as well as close relatives, completed the European Brain Injury Questionnaire (EBIQ) regarding patient symptoms, together with the impact of injury on the relative. Results for the three groups of patients were compared to those of 64 control subjects without brain injury. There were three major findings. First, significantly higher levels of symptoms were found in the patient groups at pre-programme evaluation, compared to the control group. Within the patient groups there were comparatively few differences between the self-reports of the patients and the reports of their relatives. Second, the patients showed significantly reduced levels of symptoms post-programme, both in their self-reports and in their relatives' reports. These levels

remained however above those of the control group. Third, the reported impact of the injury to the patient upon their relatives was significantly reduced post-programme. Thus, this study further documents that patient symptoms, and the impact of these on close relatives, may be broadly reduced, but perhaps not eliminated, as a result of neuropsychological rehabilitation.

INTRODUCTION

Recent years have witnessed a growing recognition that the evaluation of outcome following brain injury rehabilitation should involve measures that are ecologically valid and meaningful to the patient (Fleminger & Powell, 1999). Thus, Ponsford, Sloan, and Snow (1995b) have described how research has increasingly emphasised the use of outcome measures which relate directly to the daily life of the patient, rather than solely psychometric measures such as neuropsychological test results.

Correspondingly, the registration of symptomology has been extended from focusing primarily on physical symptoms and perhaps gross categorisations of mental functioning (Vapalahiti & Troupps study as cited in Brooks, 1984) to elaborations of cognitive, emotional, and social dimensions (Wade, 1992). In this context, however, questionnaires developed for psychiatric populations have proved to be of questionable validity when applied to patients with brain injury (Williams, Evans, & Wilson, 1999). Thus, in the last decade, a number of instruments have been specifically developed for use with such patients (e.g., the Brain Injury Community Rehabilitation Outcome, BICRO; Powell, Beckers, & Greenwood, 1998; the Dysexecutive Questionnaire, DEX; Wilson et al., 1996, and the European Brain Injury Questionnaire, EBIQ; Teasdale, Christensen, Willmes, Deloche, Braga, Stachowiak, et al., 1997b).

A particular difficulty with relying solely on the patient's subjective endorsement of symptoms is that he or she may lack awareness or have other cognitive deficits, such as memory difficulty, that make self-reporting unreliable (Port, Wilmott, & Charlton, 2002). A number of studies have shown that patients either under-report or over-report their symptoms compared to the ratings given by family member or clinician. Furthermore, patients tend to underestimate emotional and behavioural changes in particular (Brooks et al., 1987; McKinley & Brooks, 1984; Prigatano, Altman, & O'Brien, 1990; Thomsen, 1974). Other studies have found reasonable concordance between patients with brain injury and their relatives (Oddy, Humphrey, & Uttley, 1978a; Ponsford, Olver, & Curran, 1995a) and no difference in reports of changes within a given domain such as physical, cognitive, emotional or behavioural (Lannoo et al., 1998). In one study, Ponsford et al. (1995a) found that relatives tended to over-report the presence of anxiety in patients.

In an earlier study using the same questionnaire as in the present study, 905 patients with brain injury, from seven European countries and Brazil, were

found to underestimate cognitive difficulties compared to the report of their relatives (Teasdale et al., 1997b). In addition, patients with cerebrovascular accidents (CVA) had a different complaint profile from patients with traumatic brain injury (TBI). Patients with CVA and their relatives scored higher on scales relating to physical complaints and communication difficulties. The patients with TBI and their relatives scored higher on scales relating to cognitive dysfunction, impulsivity and social isolation. Comparing dysphasics and non-dysphasics showed that both patients and relatives in the dysphasic group (55% of sample) endorsed significantly higher problems regarding communication. Longer time since injury tended to be associated with increased levels of problems reported. This study also included 205 controls from France and Brazil. There was good agreement between self-report and relative-report in both control groups, although the Brazilian control group reported greater dysfunctioning on most of the EBIQ's nine scales.

Other studies have also shown that cultural factors can play a role in the extent and nature of the symptoms that are reported (Prigatano, Ogano, & Amakusa, 1997; Prigatano & Leathem, 1993). There is some evidence that time since injury (Godfrey, Partridge, Knight, & Bishara, 1993), severity of brain injury (Leathem, Murphy, & Flett, 1998), involvement in rehabilitation (Onsworth, McFarland, & Young, 2000; Port et al., 2002), and executive dysfunction (Port et al., 2002) can influence the level of insight as well as the consistency between raters. In a study of awareness after traumatic brain injury, Scherer et al. (1998) found that specific questions yielded better agreement than did general questions.

Within the field of rehabilitation, many different models and theories are in use, but the common basic aim of the process is to ameliorate, reduce or alleviate the patient's complex symptoms (Wilson, 2002). It is worth noting that symptoms are often strongly related to central aspects of social functioning, such as family relationships and employment (Voogt, Teasdale, Patrick, & Carman, 1998). Ponsford et al. (1995b) emphasise that the symptom perception of patients and their relatives represents the reality of their shared life experience after acquired brain injury. Symptoms must therefore be given serious consideration in the planning and evaluation of rehabilitation. A number of studies have shown that subjective symptoms decrease after rehabilitation (Fordyce & Roueche, 1986; Stilwell, Stilwell, Hawley, & Davies, 1999).

A related issue is the fact that brain injury has a significant impact on close relatives of the patient (Allen, Linn, Gutierrez, & Willer, 1994: Brooks et al., 1987; Lezak, 1988; Wood & Yurdakul, 1997). The neurobehavioural symptoms following brain injury correlate with the family's appraisal of the injury's impact on them. A particular frequent finding has been that problems in the areas of emotion, behaviour and awareness, rather than physical disability, are associated with the relative experiencing higher amounts of stress (Hillier & Metzer, 1997; Peters, Stambrook, Moore, & Esses, 1990;

Thomsen, 1992). Willer, Flaherty, and Coallier (2001) point out that the greatest needs of patients' relatives are for information and social and emotional support, as well as assurance that the patient is receiving the best possible treatment.

The present study has employed EBIQ questionnaire data derived from patients with brain injury, before and after a rehabilitation programme, together with corresponding data from non-brain-injured controls. We have done this in order to explore three issues and to examine some hypotheses relating to them.

First, we would predict that, prior to a rehabilitation programme, the level of reported complaints among patients with brain injury would be above that reported by a control group without brain injury. We wish further to explore the extent to which this is true for different injury types and for various aspects of complaints. Based on our earlier study (Teasdale et al., 1997b), we predict that patients with CVA would manifest more severe problems with regard to communication and physical complaints, and less severe problems with regard to cognition, impulsivity and social isolation than patients with traumatic brain injury. This is due to the CVA group suffering more frequently from aphasia and hemipareses than the TBI group. The presence of frontal lobe injury as an indicator of executive problems may correlate with discrepancies between self-reports and relative reports.

Second, from clinical experience we would predict that the level of reported complaints among patients with brain injury would fall subsequent to rehabilitation. We have been particularly interested to see how closely post-rehabilitation levels correspond to those found among non-brain-injured controls.

Third, we have examined the impact of injury on the relatives themselves. This impact would be predicted to decline over the course of rehabilitation, depending on the extent to which the rehabilitation programme has been successful in increasing the functioning and well-being of the patients. A further issue relating to the question of impact on relatives is to explore which areas of patient dysfunctioning following brain injury are most strongly related to the impact of that injury on the relatives.

METHOD

Our data stem from patients who had sustained an acute brain injury and who had completed the rehabilitation programme at the Center for Rehabilitation of Brain Injury (CRBI) in Copenhagen. The programme adopts an interdisciplinary, holistic approach, which is tailored to the individual in the light of neuropsychological assessments. Patients are admitted to the programme in groups of about 16, and the programme runs for about four months with day attendance at the centre. This is followed by close contact and monitoring of progress in the community for at least a further eight months. Exclusion criteria include alcohol and drug abuse, together with psychiatric or progressive

neurodegenerative illness. A degree of motivation and independence (ability to travel, feed, groom, etc.) is also required in order to participate. Details of the programme are presented elsewhere (Christensen, Piner, & Rosenberg, 1988).

For the purposes of the present study we initially selected all 204 patients who underwent the programme between January 1996 and December 2001, together with a 64-member control group without brain injury. The control group was recruited from acquaintances of colleagues at the Centre, and selected to be of approximately the same age and sex distribution as the patients.

The neuropsychological assessments at the start and end of the programme included the completion of the European Brain Injury Questionnaire (EBIQ). This instrument has been specifically designed in two parallel versions: a "self" version for use on individuals with brain injury, and a "relative" version to be completed by their close relatives (Teasdale et al., 1997b). It contains 62 questions relating to "problems or difficulties that people sometimes experience in their lives", as well as three questions regarding what impact the injury has had on the relative. Patients with brain injury complete the "self" version in which they are asked to indicate "how much (they) have experienced any of these within the last month". Their responses are coded on a three-point scale: "not at all" (1), "a little" (2) or "a lot" (3). Correspondingly, close relatives complete the "relative" version in which they give their perceptions of the person with brain injury. From both the patients' and the relatives' questionnaires, eight scales are calculated corresponding to complaints categorised as somatisation, cognition, motivation, impulsivity, depression, social isolation, physical symptoms, and communication. An additional "core" scale summarises complaints globally.

The scores on these scales are computed as the simple average of the scores (1, 2, or 3) for the questionnaire items pertaining to each scale. The scale scores can thus also range from 1.0 to 3.0. Reliabilities (Cronbach's coefficient alpha) for the nine scales ranged from .47 to .90 (median .63) for the patient self-reports and from .54 to .92 (median .66) for the relative reports. The reliability values for the corresponding scales derived from control samples are similarly generally high. The construct validity is regarded satisfactory since the instrument was able to discriminate between different injury types (CVA and TBI), particular symptoms (e.g., aphasia), time since injury, and between patients and controls. Further psychometric details are presented elsewhere (Teasdale et al., 1997b).

Three additional questions concern the impact of the injury on the relative him/herself. These are: the degree to which the relative's life has changed in consequence of the injury; the degree to which he/she is currently experiencing problems because of it; and the degree to which mood is currently affected by it. All three items were asked of both the relative and the patient, and were rated on the same three-point scale as above.

The 64 control subjects also completed the "self" questionnaire, and a close relative to each completed the corresponding "relative" questionnaire. In this case, however, we omitted the last three items, those concerning the effect of brain injury on the relative. The above scales were also calculated for the controls. Whereas the patients with brain injury and their relatives completed the EBIQs on two occasions, at the start and the end of the programme, the controls and their relatives completed the EBIQ just once.

Among the 204 patients, complete EBIQs, i.e. for patient and for relative at both pre- and post-programme, were obtained in 143 cases (70.1%). The attrition was primarily due to patients lacking a close relative who could complete the questionnaire. Table 1 shows basic demographic data for the 143 patients compared to the control group. It can be seen that the level of education was significantly higher among the control group. There were also significantly more non-partner relatives among the group with brain injury; the non-partner relatives were most often parents of a son or daughter with brain injury.

Table 2 shows a comparison of the 143 included patients with the remaining 61 excluded patients. The sole significant difference was a longer interval between injury and programme-start for the excluded patients. There was a noticeable general preponderance of males. The most common form of injury was cerebrovascular accident (CVA). This category consisted of 43 patients with haemorrhage and 42 patients with infarct and it contributed 29 of the 36 included aphasics. Classification of aphasic/non-aphasic was made on the basis

TABLE 1
Demographic characteristics of brain injured and control groups

Variable	Brain injured N = 143		Controls N = 64		Probability
Mean age # (SD)	41.4	(11.8)	40.2	(13.9)	.07*
Education level (SD)	4.1	(2.4)	5.4	(1.8)	<.01*
Sex					
Male (%)	83	(58)	28	(44)	.07†
Female (%)	60	(42)	36	(56)	
Sex of relative					
Male (%)	55	(38)	29	(45)	n.s.†
Female (%)	88	(62)	35	(55)	
Type of relative					
Partner (%)	105	(73)	62	(97)	<.01†
Other (%)	38	(27)	2	(3)	

* Mann–Whitney U test.
† Chi-squared test.
# At completion of EBIQ (pre-programme for the brain-injured group).

TABLE 2
Demographic and medical characteristics of included
and excluded brain injured patients

Variable	In sample N = 143		Not in sample N = 61		Probability
Sex *N* (%)					
Male	83	(58)	38	(52)	n.s.†
Female	60	(42)	28	(48)	
Type of injury *N* (%)					
CVA	85	(60)	32	(52)	
haemorrhage	43	(30)	13	(21)	.08†
infarct	42	(30)	19	(31)	
TBI	39	(27)	25	(41)	
Other	19	(13)	4	(7)	
Aphasic *N* (%)	36	(25)	15	(25)	n.s.†
Frontal lobe injured *N* (%)	14	(10)	2	(3)	n.s.†
Education level M (SD)	4.1	(2.4)	4.4	(2.6)	n.s.*
Age at injury (years) M (SD)	41.4	(11.8)	39.7	(12.7)	n.s.*
Injury to programme entry (years) M (SD)	1.2	(0.9)	1.7	(2.56)	.01*
Hospitalisation (days) M (SD)	70.5	(74.5)	66.5	(82.3)	n.s.*
Coma duration (days) M (SD)	2.1	(4.3)	4.3	(10.1)	n.s.*

* Mann-Whitney U test.
† Chi-squared test.

of clinical assessment. The "other" (OTH) diagnosis category includes anoxia following cardiac arrest, brain tumours and cerebral infections, e.g., meningitis. For purposes of subsequent analysis we have also noted the 14 (comparatively few) cases with pure frontal lobe injury, of which 8 had suffered a TBI. This group was identified from the peri-injury medical records.

Scores on the nine EBIQ scales and the three EBIQ items relating to impact on the relative proved to be approximately normally distributed. We have therefore employed repeated-measure analysis of variance to test our hypotheses. However, in some of these analyses, the assumption of sphericity was not met. In such cases the Greenhouse-Geisser epsilon correction was applied to the appropriate degrees of freedom. Post-hoc group comparisons were performed using Fisher's least significant difference test. This is particularly powerful and suitable for analyses involving few groups, as here (Howell, 2001). Effect sizes were calculated as Cohen's "d" (Howell, 2001). For some secondary analyses we employed stepwise linear regression. All analyses were performed using SPSS 11.5.

RESULTS

Comparisons of patient groups at pre-programme with controls

Table 3 shows the mean score on each of the nine scales, for patients and relatives separately, in each of the three patient groups alongside the control group. For this comparison we chose to employ the data for the groups prior to the rehabilitation programme. An overall repeated-measure analysis of variance revealed significant main effects of group $F(3, 203) = 24.8$, $p < .01$, and scale, $F(5.7, 1166.0) = 10.3$, $p < .01$. Significant interactions were also seen between scale and group, $F(17.2, 1166.0) = 4.6$, $p < .01$, and scale and respondent, $F(6.1, 1245.1) = 4.9$, $p < .01$. In order to investigate these effects more closely, we have run a series of separate analyses of variance examining the effects of group and respondent, on each of the nine scales. In all cases the effect of group was significant ($p < .001$). The effect sizes of the differences between the groups with brain injury and the control group varied as a function of diagnosis, scale and respondent. The effect sizes ranged from 0.32 to 1.92, with a mean of 0.95. The Cognitive scale uniformly had the greatest effect size (> 1.2).

There were invariably significant overall differences between the patient and control groups across all nine scales ($p < .01$). Notably, for all scales and for both types of respondents the means are 1.5 or over for the three patient groups. The control group had scores invariably under 1.5 for the control group. Post-hoc comparisons for overall group differences revealed that the control group had significantly lower scores than the three patient groups on seven of the scales ($p < .05$). On the Impulsivity and Isolation scales, the controls scored significantly lower than the TBI and OTH groups ($p < .05$). The difference between the controls and the CVA group approached significance ($p = .056$) on the Impulsivity scale. The CVA group scored significantly lower than the TBI and OTH groups on the Somatic and Impulsivity scales ($p < .05$). The same tendency was present for the Cognition, Isolation and Core scales ($p \le .07$).

For the Motivation scale there was an overall difference between responders ($p < .05$) and a near-significant interaction between responders and group ($p = .054$). Scores on the Motivation scale were higher for relative report than for self-report in the patient groups but not in the control group. The two categories of responders also gave significantly different scores on the Depression scale, ($p < .05$) with generally higher scores for self-report than for relative report. Table 3 shows that in the control group, the Depression means were the same for the self- and relative reports, even though there was no significant interaction between responder and group.

TABLE 3
Brain-injured pre-programme versus controls—EBIQ scales

| | CVA (n = 86) | | TBI (n = 38) | | OTH (n = 19) | | Controls (n = 64) | |
| | Self | Relative | Self | Relative | Self | Relative | Self | Relative |
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Somatic	1.61 (0.40)	1.66 (0.38)	1.79 (0.43)	1.77 (0.40)	1.82 (0.45)	1.79 (0.32)	1.44 (0.32)	1.39 (0.33)
Cognitive	1.75 (0.41)	1.84 (0.41)	1.92 (0.39)	1.90 (0.39)	1.98 (0.43)	1.99 (0.40)	1.33 (0.26)	1.30 (0.33)
Motivation	1.62 (0.47)	1.70 (0.45)	1.50 (0.40)	1.68 (0.50)	1.61 (0.41)	1.81 (0.36)	1.30 (0.33)	1.27 (0.39)
Impulsivity	1.51 (0.37)	1.57 (0.39)	1.70 (0.40)	1.83 (0.50)	1.71 (0.43)	1.72 (0.47)	1.45 (0.24)	1.42 (0.38)
Depression	1.61 (0.40)	1.56 (0.40)	1.71 (0.48)	1.70 (0.49)	1.78 (0.60)	1.60 (0.51)	1.32 (0.37)	1.32 (0.37)
Isolation	1.50 (0.39)	1.55 (0.42)	1.73 (0.42)	1.71 (0.50)	1.66 (0.47)	1.72 (0.46)	1.43 (0.36)	1.42 (0.39)
Physical	1.61 (0.36)	1.66 (0.35)	1.63 (0.42)	1.65 (0.47)	1.65 (0.44)	1.63 (0.44)	1.24 (0.28)	1.27 (0.36)
Communication	1.64 (0.50)	1.64 (0.51)	1.76 (0.43)	1.66 (0.53)	1.82 (0.61)	1.68 (0.48)	1.31 (0.37)	1.26 (0.38)
Core	1.62 (0.31)	1.66 (0.32)	1.74 (0.36)	1.79 (0.40)	1.79 (0.43)	1.78 (0.6)	1.35 (0.26)	1.32 (0.32)

Comparisons of patient groups pre- versus post-programme

In order to compare pre- with post-programme means, we uniformly transformed all scale scores within the three patient groups to z-scores normalised against the control group, separately for self and for relatives. Figures 1, 2, and 3 show, respectively, for the CVA, TBI and OTH groups the means, on each of the nine scales as a function of pre- and post-programme and respondent. An overall repeated-measure analysis of variance revealed significant main effects of diagnostic group, $F(2, 140) = 3.3, p < .05$, time, $F(1, 140) = 29.7, p < .01$, and scale, $F(5.6, 777.9) = 24.5, p < .01$. Significant interactions were seen between time and scale, $F(6.6, 918.7) = 3.7, p < .01$, respondent and scale, $F(6.1, 853.3) = 2.8, p < .01$, and time and respondent and scale, $F(6.5, 903.2) = 2.4, p < .05$.

In order to investigate further these effects, we ran a series of separate analyses of variance examining the effects of diagnosis, time and respondent, for each of the nine scales. Post-programme levels were significantly lower than pre-programme on all scales ($p < .05$) except Isolation and Physical which closely approached significance ($p < .065$). The effect size was greatest for the Somatic scale (0.4) and least for the Isolation scale (0.13). Notably, however, all but one of the z-scores post-programme are positive (range –0.07 to 1.71) with a mean of 0.74. This indicates that the post-programme scales remain on average more than half a standard deviation above those of the control group.

There were significant overall differences between the three patient groups for all scales ($p < .05$) except the Core scale, which approached significance
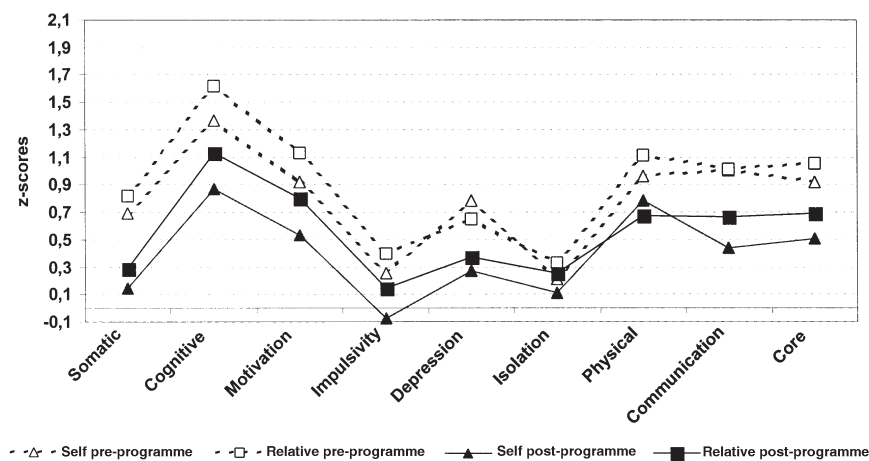

Figure 1. TBI-group: EBIQ scales pre- and post-programme.
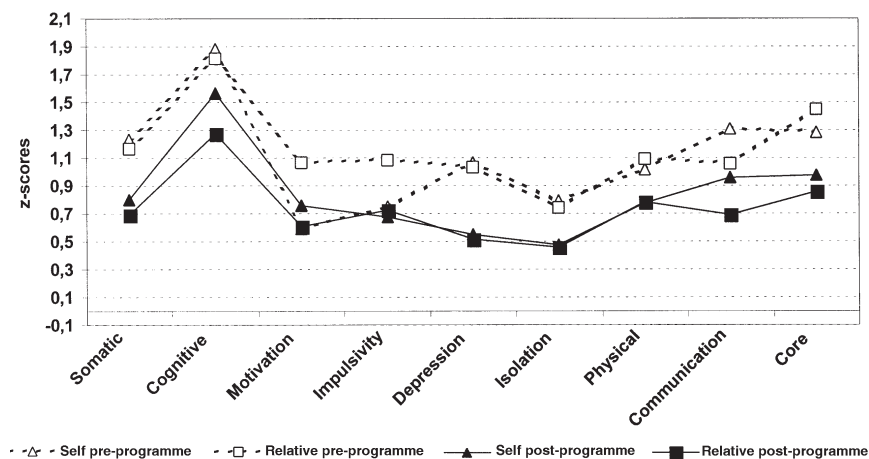
Figure 2. TBI-group: EBIQ scales pre- and post-programme.

(p = .053). Consistent with the above analysis, post-hoc comparisons here revealed that the CVA group had significantly (p < .05) or near-significantly (p < .072) lower means than the TBI and OTH groups on the Somatic, Cognitive, Impulsivity, Isolation and Core scales. There were no overall differences between the diagnostic groups for the Motivation, Depression, Physical or Communication scales.

Figure 3. OTH-group: EBIQ scales pre- and post-programme.

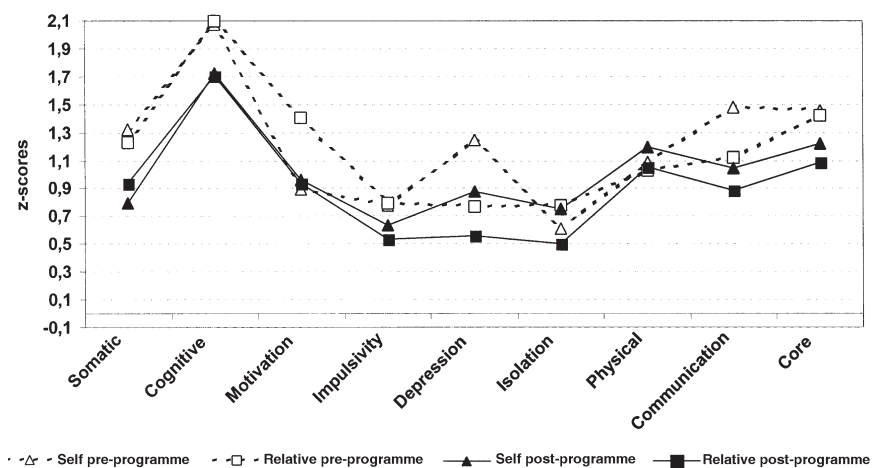There was only one significant overall difference between self-report and relative's report, namely in the Motivation scale ($p < .05$). Here the relatives reported higher levels of problems than the patients with brain injury themselves. The difference between self-reports and relative reports on the Depression scale approached significance ($p = .06$) with patients generally reporting higher levels than relatives. There were only three significant or near significant ($p < .1$) two-way or three-way interactions across all nine scales (i.e., 36 comparisons in all) and we therefore regard these as chance findings.

We further explored the extent to which patient characteristics related to the scales by including these as between-subject variables in a series of repeated measure ANOVAs otherwise as described above. The only significant effect of gender was in interaction with time-point, $F(1, 141) = 6.8$, $p = .01$. Although males and females were almost equal pre-programme, males registered greater improvement relative to females post-programme. Aphasia appeared only in a significant interaction with scale, $F(5.6, 792.0) = 4.8$, $p < .01$. Substantially, and unsurprisingly, this effect derived from a much greater difference between aphasics and non-aphasics on the Communication scale than on any other scale. In order to examine the effect of time since injury we defined two groups of patients: those who entered the programme at less than one year after injury ($n = 84$, 60%) and those who entered at one year or later ($n = 59$, 40%). Analysed in this way there was only a significant effect of time since injury in interaction with pre- to post programme, $F(1, 141) = 4.5$, $p = .04$. Reported problem levels were higher for patients who were one year or more post-injury, but this difference diminished from pre- to post-programme. We dichotomised the duration of hospitalisation at the median value of ≤ 50 days and > 50 days. However, we found no significant effect of duration of hospitalisation, either as a main effect or as interacting with any other independent variable. As noted above, only 14 of the patients with brain injury were recorded as having purely frontal-lobe injuries; we found no significant differences on any scales between this group and the remainder of the patients. There were no systematic differences in the scales for those relatives who were partners compared to those who had some other kind of relationship (e.g., parents).

In view of the differences between the patient groups and the controls with respect to educational level and type of partner we further explored this potential confounding factor. We first examined correlations between educational level and EBIQ scales separately for the three patient groups and for the Control group. No correlation was significant within the Control group and although several reached significance within the patient groups, only one of the 18 correlations involved exceeded .2. We similarly found that there were no significant differences between partner reports and non-partner reports, among the patient groups, either pre- or post-programme.

Impact of patient brain injury on relatives, pre- and post-programme

As stated above, the EBIQ contains three questions relating to the impact of the injury on the relative. Some patients felt unable to complete these items concerning their relatives, and we have thus only complete data for 118 cases. There were significant main effects of time, $F(1, 115) = 6.8$, $p < .01$, and item, $F(1.9, 213.2) = 56.6$, $p < .01$, but not for diagnosis group. There were also significant interactions between item and time, $F(2, 230) = 3.8$, $p < .05$, between diagnosis group and informant, $F(1, 115) = 3.28$, $p < .05$. Figure 4 shows that the reduction in reported impact of injury is less for the item "life changed" than for the items "current problems" and "current mood affected". Figure 5 shows there were greater discrepancies between patients' and relatives' reported impact among the TBI and OTH groups than among the CVA group.

We further explored the extent to which the relative's estimate of the impact of the injury on his or her own life related differentially to the distinct dimensions measured by the eight EBIQ scales excluding, for this purpose, the global Core scale. For both pre- and post-programme we calculated a total impact score by summing the relatives' own responses to the three impact items. We employed these in two stepwise linear regression analyses with the eight EBIQ scales also for pre- and post- programme respectively, as independent variables. At pre-programme evaluation, three scales entered the model,
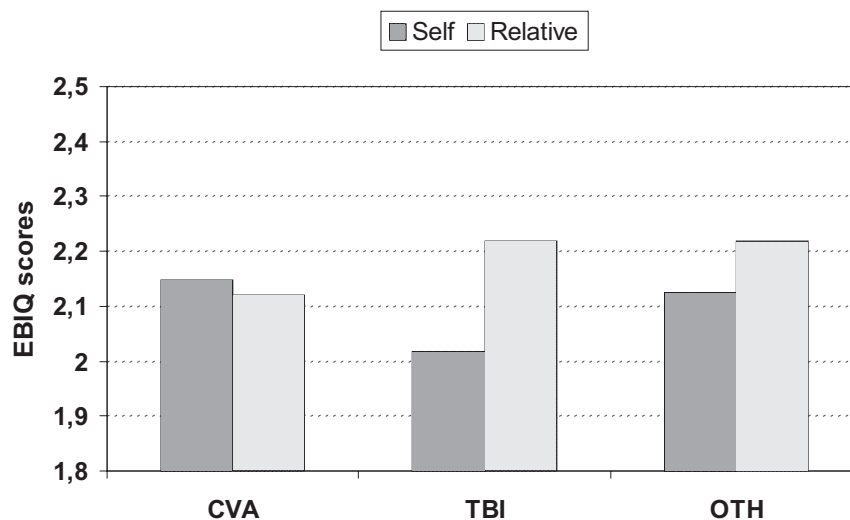

Figure 4. Impact item scores in relation to respondent and injury type.
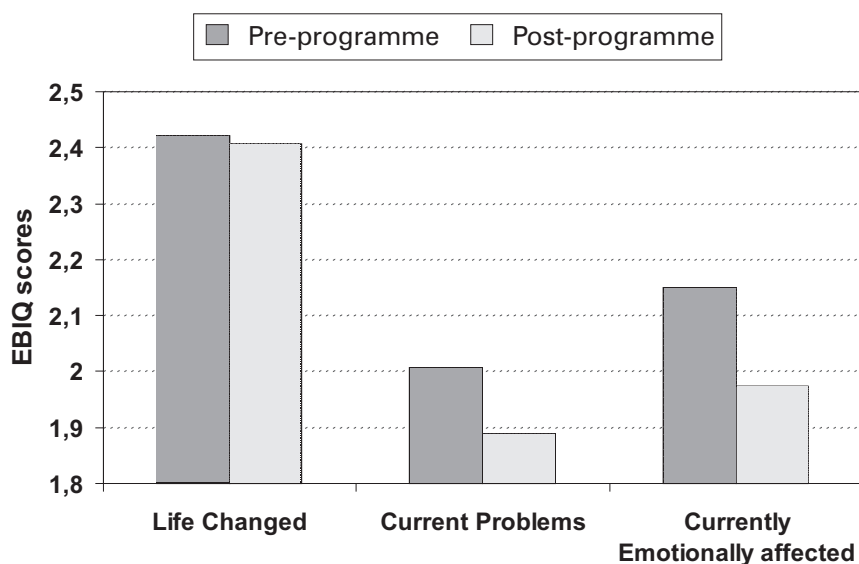
Figure 5. Impact item scores in relation to pre- vs. post-programme

Cognitive (beta = .29), Communication (beta = .26) and Impulsivity (beta = .16). The proportion of variance explained was 30%. The corresponding post-programme analysis yielded a very similar result, again with significant contributions from Cognition (beta = .25), Communication (beta = .24) and Impulsivity (beta = .25). The proportion of variance explained in this model was 32%.

DISCUSSION

The results presented here should be viewed in the light of a number of limitations. First, there are differences in demographic characteristics between our patient- and control groups. We are concerned here with the control group's higher educational level. Furthermore the control group was comprised almost entirely of partner relationships whereas in the patient group, more than a quarter of the relatives were not partners. If, for instance, higher levels of education were associated with lower levels of general symptomology, as assessed by the EBIQ, then this might account for the differences we have observed between the patient groups and the control group. Although there is evidence that people suffering traumatic brain injury often have lower levels of education than the general population (Haas, Cope, & Hall, 1987; Teasdale & Engberg, 1997), it seems likely that the difference here stems mainly from the

recruitment of a high educated control group. We relied on direct and indirect recruitment from among colleagues and acquaintances, leading to a bias towards higher education levels. The lack of correlation between educational level and the EBIQ scales, which replicate earlier negative findings (Teasdale et al., 1997b), suggests that this confounding factor has had relatively little effect on the results. Similarly, we did not find any systematic differences between the mean scales scores for relatives who were partners and those who were not. This again suggests that the different composition of the relatives among the patient and control groups was not a critical factor.

A second consideration is rather the large attrition from the study; only just over 70% of all potential patients could be included. A common reason for non-inclusion was the non-availability of an EBIQ questionnaire from a relative, at the pre- and/or post-programme stage. Thus, it might be the case that our sample is biased towards patients with comparatively strong social support and involvement from their close relatives, and perhaps therefore from a sub-group of better-functioning patients, which could have resulted in lower levels of reported symptoms. However, the excluded group also contains cases for whom EBIQ data were not obtained for diverse and non-systematic administrative reasons, a factor which would dilute any trend towards substantial differences. We found little evidence of systematic bias in the comparisons we were able to make between the included and non-included patients.

A third consideration is that the symptom ratings on the EBIQ are made on a scale having only three levels. Symptoms are reported as being present "not at all", "a little", or "a lot", during the preceding month. The three-point scale was originally chosen to minimise decision load on behalf of the patients, when they have to fill out the questionnaire. This provides limits for the range of possible judgements concerning symptomology. This may have biased results in the direction of masking subtle differences. However, this limitation becomes less grave at the level of the nine scales, which involve averaging rating across numerous individual symptom items.

Our first hypothesis concerned the expectation that patient groups at pre-programme evaluation would show greater levels of symptomology than the control group. This was substantially confirmed. Uniformly significant differences were found across all EBIQ scales, irrespective of self- or relative-reporting, and also substantially independent of type of injury. Since the EBIQ was constructed to be sensitive to the particular problems encountered by people with brain injury, this finding constitutes a further validation of the EBIQ instrument. It is also noteworthy that the effect sizes averaged above the 0.8 level, which is generally characterised as "large" (Howell, 2001). The greatest effect size was found in the cognitive scale. This reinforces the common finding that the predominant presenting symptoms of patients referred for holistic neuropsychological rehabilitation are indeed cognitive in nature (Trexler & Helmke, 1996; Wilson, 2000). As noted, every mean among

the patient groups lies at or above the value of 1.5. Every mean for the control group lies below that value, suggesting that 1.5 might be a useful cut-off in clinical applications.

The only effects of self-report versus relative-report were to be seen in the two interactions with patient and control groups concerning the motivation and impulsivity scales. That there were no differences between self-report and relative report among the control group is itself an important finding, replicating that of Teasdale et al. (1997b). It indicates the EBIQ scales are not inherently biased towards greater or lesser self-reporting of difficulties as compared to relative reporting of difficulties. Thus, the two interactions reveal that relatives are more sensitive to patient difficulties relating to apathy, lack of initiative and energy level on the one hand and impulse control and irritability on the other, than are the patients themselves. In both cases the effects are, however, quite modest. Taken together with the lack of difference on other scales, this suggests that the patients within our sample are not particularly lacking in awareness of their own deficits, as is otherwise so often noted among patients with brain injury (Prigatano et al., 1990). We have earlier found that patients reported significantly higher levels of depression than did their relatives (Teasdale et al., 1997b). Note that the pre-programme means in the present study also showed differences in this direction although not, in the present case, significantly so.

Our second hypothesis regarding reduced symptomology following rehabilitation was also substantially supported. In general, the pre- to post-programme changes show consistent and quite large improvements across all scales as reported by both patients themselves and by their relatives. Although we do not have a control group consisting of individuals with brain injury who did not undergo the rehabilitation programme, it does not seem unreasonable to attribute these changes, achieved across a comparatively short space of time, to the effect of the programme itself. At the same time it should be emphasised that the effect sizes were nonetheless clearly lower than the effect sizes of the pre-programme versus control group comparisons. Correspondingly the z-score means at post-programme were well above zero, at about 0.6. This shows that, improvements notwithstanding, patients at the end of the rehabilitation programme still register symptom levels clearly above those of the population without brain injury. Conversely, however, there is reason to anticipate that such improvements as are achieved can be sustained following the end of a rehabilitation programme. Although the present study does not include any longer-term follow-up, Teasdale and Caetano (1995), using a different assessment instrument, the SCL-90, did find that post-programme improvements were still fully present at a one-year follow-up.

The significant differences between patients and relatives on reported motivation and impulsivity replicate those noted above. Given the fact that there were no significant interactions between informant and time-point

suggests that two interactions that approached significance ($p < .1$) could be simply chance findings.

There were comparatively few patient characteristics that were related to the EBIQ scales. The significant difference on the Communication scale between patients with and without aphasia was to be expected, even though the scale is certainly also sensitive to subtler aspects of communication than the purely linguistic ability to produce and comprehend speech. The finding that pre-programme difficulties were reported as greater for those patients who entered the programme at more than one year post-injury than for those who entered it at less than one year concurs with the previous findings with the EBIQ (Teasdale et al., 1997b) and with earlier findings of Oddy, Humphrey, & Utley, (1978b) and Bond (1975) that difficulties related to brain injury do not typically diminish of themselves with time. It has been speculated that awareness of them actually increases with time as a function of cumulative experience of failure and fiasco for many patients with brain injury. In the light of that it is perhaps encouraging that the effect of time since injury diminishes at post-programme. This would suggest that, however desirable it might be to channel patients with brain injury into post-acute rehabilitation programmes as quickly as possible, nonetheless at least as much could be achieved for those patients who enter them later.

It might seem surprising that we did not find any effect of duration of hospi-talisation since we have often found this to be related to such outcome measures as return to employment (Teasdale, Skovdahl Hansen, Gade, & Christensen, 1997a) and cognitive test performance. We suspect that subjective well-being, as measured by the EBIQ, is possibly much more related to premorbid personality characteristics, such as resilience, coping and optimism, than to degree of injury itself (Elsass, 1993). It should, however, be noted that the criteria for entry into the programme limit the range of degree of injury; cases too severe to be able to take part in, or too mild to warrant, an intensive out-patient rehabilitation programme are excluded. A further limitation is that we unfortunately do not have potentially better injury-related predictors such as, for those with traumatic brain injury, duration of post-traumatic amnesia (Engberg, 1995).

The apparent lack of any distinct effect of localised frontal lobe injury with regard to differences between self and relative reports of symptoms was unexpected given that lack of insight into own dysfunctions is often found to be associated with a dysexecutive syndrome characteristic of frontal lobe injury (Prigatano et al., 1990). It may be that by the time of entry into the rehabilitation programme the frontal lobe injured patients had already achieved a realistic degree of insight. Alternatively it may be, as has been suggested by Port et al. (2002), that insight is as yet deficient in the relatives also.

The third objective of our study was to investigate the impact of brain injury on the close relatives of patients. With important exceptions (Brooks et al.,

1987; Lezak, 1988; Peters et al., 1990; Ponsford et al., 1995a) this issue has perhaps historically been under-investigated. The EBIQ itself was not designed primarily for that purpose. Nonetheless the analyses of responses to the supplementary items concerning impact reveal interesting trends. The overall greater response to the question concerning "life changed" subsequent to the injury, as compared to responses to the items concerning "current problems" and "current mood", is in itself perhaps not surprising, since it is formulated in the past tense in directly alluding to changes since the time of the injury relative to conditions before the injury. The two other questions, by contrast, concern, specifically, present circumstances. This probably also accounts for the greater improvement registered between pre- and post-programme on "current problems" and "current mood" than on "life changed". That the patients under-rated the "life changed" and "current mood" impact on the relatives was offset by their higher rating of "current problems" can be interpreted as suggesting that they may often be lacking in empathy, and that problems of a practical nature are therefore more easily perceived than more subtle, internal, emotions (Eslinger, 1998). Perhaps the most salient feature of these results is that they also bear testimony to the sensitivity of the patients to their relatives' situations. This again stands in contrast to reports of unconcern on the part of self-absorbed patients to the difficulties endured by their close relatives (Brooks & McKinlay, 1983).

It was quite striking that both at pre- and post-programme near-identical associations were found between the global rating of impact on relative and the relative-rated EBIQ scales. At both times degree of impact was related primarily to the cognitive, communication and impulsivity scales. The contribution of the communication scale may not simply reflect the particular burden for the relatives of patients with aphasia, but would also reflect breakdown of broader and qualitative aspects of close personal exchanges. The contribution of the cognitive and impulsivity scales suggests that failures of concentration and memory as well as poor impulse-control and irritability are especially burdensome for relatives.

In summary, the major clinical relevance of the present findings may be the demonstration that reductions in symptomology in patients with brain injury, and consequent burden on their relatives, can be achieved by rehabilitation, but that a goal of reducing such symtomology to "normal" levels found in the non-brain injured population is probably not realistic.

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