

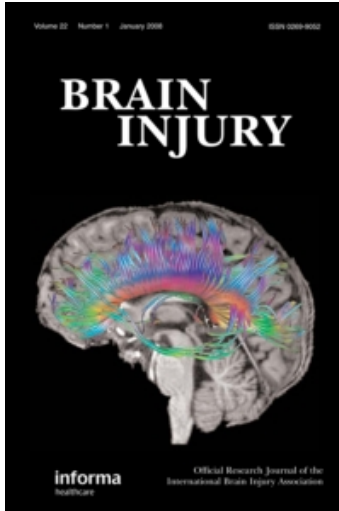
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Subjective experience in brain-injured patients and their close relatives: A European Brain Injury Questionnaire study

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Results are reported from an international project the aim of which has been to develop and validate a wide-ranging questionnaire suitable for administration to brain-injured patients and their relatives. A self-report questionnaire concerning subjective experience of cognitive, emotional and social difficulties (The European Brain Injury Questionnaire, EBIQ) was administered to a group of 905 brain-injured patients, and close relatives to these completed a parallel version of the questionnaire concerning the brain-injured person. The sample was drawn from seven European countries together with Brazil. The same questionnaire was also administered to a group of 203 non-brain-injured controls, similarly in self-report and relative-report versions. Scales relating to eight specific areas of functioning, together with a global scale, are derived from the questionnaire and their internal reliability was estimated in the present data. Analyses of the 63 items of the questionnaire showed consistently greater levels of problems for the brain-injured group, especially as indicated by relatives. This pattern was substantially replicated among the nine scales. The scales discriminated well between stroke patients and those who had suffered a traumatic brain injury. There was also a tendency for reported problems to be greater for patients who were surveyed later post-injury (≥ 19 months) rather than earlier. Comparison of sets of controls derived from two countries (France and Brazil) showed small but important differences. It is concluded that the questionnaire has an acceptable reliability and validity, but that it will be necessary to obtain culturally relevant non-brain-injured control data when employing it in different countries.

Introduction

Historically two dominant strands can be seen in neuropsychological studies of brain injury and its consequences. In one strand, the focus has been on the objective specification of degree and type of cognitive functioning and dysfunctioning. In such studies, neuropsychological tests, whether quantitative or qualitative, have been employed to explore such traditional areas as attention and concentration, memory, and language [1,2]. In the second strand, the focus has been on the broadest aspects of the life of the brain-injured person. Often termed 'psychosocial', these aspects cover such areas as independence in everyday activities, employment, accommodation and family relations [3–5].

In contrast to the extensive work that has been done in these two areas, the subjective experience of brain-injured persons themselves has long been somewhat overshadowed. The past decade has, however, seen a growing attention to the issue of their subjective well-being. In particular aspects of emotionality have been increasingly studied, as has subjective experience of cognitive difficulties. One frequent finding has been that whereas objectively measured cognitive deficits may diminish with time following an injury (albeit not necessarily resulting in a complete return to pre-injury levels) the subjective distress felt by brain-injured person can be more resistant to amelioration [6,7].

Neuropsychology has developed an imposing armarium of objective tests [8] and the psychosocial outcome areas listed above, employment etc., are similarly readily recorded objectively. With regard to subjective experience, the most common assessment tool has been the questionnaire. In part, use has been made of pre-existing standardized questionnaires and self-report instruments, one methodological advantage being that population norms are typically available. For instance, Teasdale and Caetano [9] used the SCL-90 [10] in showing a sustained improvement along several dimensions of psychopathology following rehabilitation for brain-injured persons. Similarly, Tuokko *et al.* [11] have used the Millon Clinical Multiaxial Inventory to assess psychiatrically defined personality disorders in head-injured patients.

A major disadvantage of such standardized questionnaires is that, in being developed for other patient groups, they may lack validity for people with brain-injury [12]. In common with earlier literature [8], Teasdale and Caetano [9] pointed out that the psychopathology scales of the widely-used SCL-90 may yield misleading results from samples of brain-injured persons. Thus, for instance, it showed an apparent elevation on the obsessive-compulsive dimension owing to this scale's loading with questions on attentional and memory problems. Woessner and Caplan [13] have also recently underlined this deficiency. Another self-rating instrument, the Minnesota Multiphasic Personality Inventory [14] has been extensively used with brain-injured populations, but in reviewing the literature Lezak [8] concludes with the observation that it 'was not constructed for neuropsychological assessment and may be inherently inappropriate for this purpose'. An alternative approach which avoids these difficulties has been to study emotionality and affect using instruments constructed *ad hoc* for the study in question. Although this may have a greater degree of validity, comparability across studies becomes more difficult and comparison with the general population is impossible unless time and effort has been expended in gathering control group data.

There is a second issue which needs to be addressed with respect to the use of self-reporting questionnaires with brain-injured persons, namely that of insight. It is a common observation that brain-injured persons, perhaps especially in the first period of time after the injury, may not show a full realization of the effects of their injury. The degree to which this represents true unawareness, 'anosognosia', 'denial', or disordered self-awareness, has been the topic of much discussion [12,15]. At all events, however, it points to the merits of eliciting information from an independent reliable source regarding the status of the brain-injured person, i.e., a close relative. Oddy *et al.* [5] have shown that even seven years after injury the reporting of symptoms is higher for close relatives to brain-injured persons than among the latter themselves.

The Katz Adjustment Scale (KAS-R1) [16] is a typical and commonly used questionnaire to assess general psychological functioning in patient and population groups. It comprises 127 items and is completed by a relative to the proband person. Thirteen scales are derived from it and norms, albeit perhaps somewhat dated, are available. However, Fabiano and Goran [17,18] have subjected KAS-R1 data, obtained from a group of relatives to brain-injured patients, to principal component analysis which yielded scales differing considerably from those originally identified by Hogarty and Katz [16].

In general one may conclude that the scales derived from standardized questionnaires, whether administered directly to brain-injured patients (e.g., the SCL-90) or to their relatives (e.g., the KAS-R1) tend to be of doubtful validity. The present authors have therefore conducted an international collaborative study, the aim of which has been to develop and validate a questionnaire specifically designed for use with brain-injured populations. We have gathered data on a large sample of such patients and their relatives and also on a corresponding non-brain-injured control group. Preliminary French results have been reported elsewhere [19] but we here report for the first time on findings from all participating countries, and including controls.

Method

Patient and control sample

The brain-injured patients and control subjects in the present study were drawn from a number of participating centres in seven European countries together with Brazil. Table 1 shows the basic demographic and medical characteristics of the sample. As can be seen the large majority of the brain-injured patients, and all of the controls, were derived from centres in France and Brazil. For the latter countries, the controls were drawn largely from hospital staff and their spouses, or indirectly via such staff. In virtually all cases the brain-injured patients were recruited from out-patient departments in hospitals or other post-acute treatment facilities. For both groups, the relative-form was most often completed by a partner, but in some cases by a parent or a child. For 36 of the brain-injured patients, no relative-form was obtained.

As a group, the brain-injured patients were on average older than the controls, and had a larger age variance. The age range among patients was 16–93 years and in the controls the range was 19–74 years. Over 60% of the patients were male, whereas the sex distribution among the controls was approximately even.

Table 1. Demographic and medical characteristics

Country	Brain-injured	Controls
Belgium	30	
Brazil	200	53
Denmark	47	
Finland	9	
France	521	150
Germany	57	
Portugal	19	
Spain	22	
Total	905	203
Mean age (SD)	47.6 (17.8)	41.8 (11.9)
Sex: male—female	62%—38%	48%—52%
Mean education level (SD)†	4.6 (1.7)	5.4 (1.4)
Mean months since injury (SD)	31.8 (40.1)	
Type of injury (%)		
CVA	571 (63)	
TBI	258 (29)	
Other	76 (8)	
Dysphasic—Non-dysphasic		55%—45%

†7-point scale 1=illiterate, 7=completed university education.

Educational level was recorded for the French, Belgian and Brazilian samples, using a uniform 7-point scale ranging from 1=illiterate to 7=completed university education. On this scale the controls were somewhat better educated than the brain-injured group.

For the patients, the time since their injury showed a strongly positively skewed distribution, with a median of 18 months (range 1–278 months). Cerebrovascular accidents (CVA) formed the largest diagnostic group and thereafter Traumatic Brain Injury (TBI). Among the remainder (<10%) are included tumours, anoxias and cerebral infections. Over half of the patients (over 60% of the CVA group and 40% of the TBI group) were dysphasic, i.e., had some degree of language dysfunctioning, as defined by local clinical criteria. It should be noted that the dysfunctioning would not in all cases reach levels which could be characterized as frank aphasia. Sixty-five percent were hemiplegic and about 50% were noted as having attention and/or memory deficits.

The European Brain Injury Questionnaire (EBIQ): construction and scale reliability

As stated above the questionnaire used in the present study was developed by the present authors specifically for use with brain-injured patients, and their relatives. It comprises 63 questions regarding diverse 'problems or difficulties that people sometimes experience in their lives' and it is requested that answers should concern the preceding month. The final question concerned 'problems in general'. The response alternatives are 'not at all', 'a little' or 'a lot' and these are subsequently coded numerically as 1, 2, and 3 respectively. There are two parallel versions of the

EBIQ, one to be completed by the patient him/herself and the second to be completed by a close relative reporting about the patient.

Recognizing the importance of brain injury for the relative themselves, both versions of the questionnaire have three supplementary questions regarding the consequences for the relative of the patient's brain injury. Specifically these items concerned whether the relative's life had changed since the injury, whether they currently experienced problems in relation to the patient's injury, and whether their mood had changed due to the patient's present situation. The brain-injured patients usually completed the questionnaire in the presence of, and if necessary with the assistance of, a clinician. Relatives usually completed the questionnaire at home.

The EBIQ was particularly tailored to the special circumstances of brain-injured patients. It was deliberately brief to avoid excessive exertion and tiring effects, and efforts were made to avoid double negative formulations which could be especially problematic for dysphasics. Since the EBIQ was from the outset a multinational collaboration, questions which were highly culture-specific, or which would present serious translation difficulties, were also avoided.

The original intention had been to develop a questionnaire which tapped aspects of emotionality, but it became apparent to the group that it would be more in keeping with our generally holistic view of brain injury to incorporate cognitive and social dimensions, together with basic ADL functions. Initial statistical analyses based on 395 patients using nonmetric multidimensional similarity scaling [20] were carried out to study the intercorrelations among the 63 items of the EBIQ. Based on various studies assessing quality of life [21] a so-called 'radex hypothesis' from facet theory [22,23] was put forward about the structure of the similarity relations among items. The expectation was that the general item 63 should be located in the centre of the spatial representation of the nonmetric scaling solution. Different wedge-like sectors emanating from that centre should contain only items belonging to one particular aspect of the sequelae of brain injury (e.g., cognitive, emotional, etc.). It emerged that the questions could be grouped into eight quite readily interpretable domains or scales. These eight scales are listed in Table 2 together with the number of items in each and representative items from the questionnaire.

In addition, a second aspect of structuring the spatial representation is with respect to the distance from the central item 63 'Problems in general'. Within each sector an inner circle can be distinguished from an outer circle. All 34 items falling within the inner circle were combined to form one additional scale which we have termed the 'Core' scale, also shown in Table 2. This scale can be used as a single measure to assess the general severity of the restrictions in quality of life.

It should be noted that facet analysis and nonmetric scaling differ conceptually and mathematically from the conventional principal components analysis from which were derived the scales which we have earlier reported [19]. Nonetheless the Cognitive, Impulsivity and Depression scales are essentially the same as the three factors derived from the earlier analysis.

For each of the nine scales, scores were computed from the simple average of scores for all relevant items. Reliabilities (Cronbach's Coefficient Alpha) for the nine scales for the data included in the present study are also shown in Table 2. It can be seen that the values range from 0.47 through 0.90 (median 0.63) for the brain-injured self-reports and from 0.54 through 0.92 (median 0.66) for the brain-injured relative-reports. As is usual for Cronbach's coefficient alpha, the reliability values correlate strongly with the number of question items entering the respective scales

Table 2. Questionnaire item domains/scales

Domain/Scale	Number of items	Representative items	Scale reliability†	
			Self	Relative
Somatic	8	Headaches Lack of energy	0·63	0·66
Cognitive	13	Trouble concentrating Difficulties in planning activities	0·83	0·85
Motivation	5	Lack of interest in hobbies in the home Feeling unable to get things done	0·58	0·66
Impulsivity	13	Annoyance or irritation Behaving tactlessly	0·81	0·87
Depression	9	Feeling sad Feeling hopeless about the future	0·79	0·82
Isolation	4	Thinking only of oneself Mistrusting other people	0·49	0·54
Physical	6	Needing help with personal hygiene Problems with household chores	0·50	0·58
Communication	4	Difficulty in conversation Difficulty in communication	0·47	0·59
Core	34	Problems in general	0·90	0·92

† Reliability calculated from Cronbach's Coefficient Alpha using data from 905 brain-injured patients and their relatives.

(for self-ratings, $r = 0\cdot79$, for relative ratings $r = 0\cdot77$). It is noticeable that the relative rating scale reliabilities are consistently greater than those derived from the self ratings. Although no control data had been used in the initial multidimensional scaling analyses, the reliabilities for the corresponding scales derived from the control data in the present study were similarly generally high.

In calculating the scale values for individuals, missing responses were replaced with the modal value for the item in question, separately for self-report and relative-report, but across both the brain-injured and control groups (except for the 36 cases of a missing relative-form for a brain-injured patient). In fact, non-response was comparatively rare. The response rate among the controls for both self-report and relative-report was never below 95% for any of the 63 items. Among the brain-injured, one item concerning sexuality produced markedly lower response rates, 85% among self-report and 70% among relatives. In some cases the item was, for discretionary reasons, not presented to the brain-injured patients (this happened for some dysphasics where the administering clinician was a speech pathologist rather than a psychologist). Nonetheless the response rate was above 90% for all but three self-report items and all but six relative-report items.

Results

We have performed an extensive series of statistical analyses with the broad aim of exploring the construct validity of the EBIQ questionnaire and the derived scales.

Analyses of questionnaire items

Comparisons of brain-injured and control groups: On the self-report questionnaire, there were significant differences (Mann–Whitney U test, $p < 0.05$) between the brain-injured and control groups on 45 of the 63 items, of which 40 were in the ‘positive’ direction of greater reported problems in the brain-injured group. Table 3 shows the 10 items on which there was the greatest positive difference between the two groups, together with the five items which showed a significant difference in the opposite direction. Applying Bonferroni’s correction for multiple comparisons ($\alpha = 0.05/63 = 0.0008$) still yields 28 significant comparisons, only two of which are negative. All of the ten positive items shown in Table 3 were significant at the 0.0008 level.

The pattern of mean differences were more marked in the relative-report questionnaire, with 50 significant positive differences (Mann–Whitney U test, $p < 0.05$) and only two significant negative differences (42 and 1 respectively after Bonferroni). There was, however, otherwise a high degree of agreement concerning the rank order of the magnitude of the group mean differences. Thus for instance, the first three items on the positive list in Table 3 also showed the greatest positive group differences on the relative-report, and similarly the two most extreme negative differences in Table 3, were also most extreme on the relative-report. Overall the rank order-correlation between mean differences on the self-report and relative-report was 0.93.

Table 3. Items showing greatest differences between brain-injured and control individuals on self-report

Item†	Brain-injured		Control		p ‡
	Mean	SD	Mean	SD	
Positive differences§					
Having to do things slowly in order to be correct	2.11	0.80	1.25	0.52	< 0.01
Difficulty participating in conversations	1.89	0.82	1.32	0.52	< 0.01
Feeling unable to get things done	1.84	0.77	1.32	0.52	< 0.01
Everything is an effort	2.02	0.78	1.52	0.66	< 0.01
Feeling of worthlessness	1.76	0.79	1.33	0.56	< 0.01
Having problems in general	1.87	0.73	1.46	0.58	< 0.01
Forgetting the day of the week	1.63	0.78	1.23	0.47	< 0.01
Feeling inferior to other people	1.75	0.81	1.37	0.58	< 0.01
Trouble concentrating	1.85	0.77	1.49	0.58	< 0.01
Trouble remembering things	2.02	0.76	1.66	0.64	< 0.01
Negative differences					
Mistrusting other people	1.67	0.72	1.77	0.65	< 0.05
Hiding one’s feelings from other people	1.81	0.80	1.93	0.69	< 0.05
Shouting at people in anger	1.56	0.75	1.69	0.65	< 0.01
Headaches	1.50	0.69	1.73	0.67	< 0.01
Feeling critical of others	1.59	0.73	1.87	0.68	< 0.01

† coded as 1=not at all, 2=a little, 3=a lot.

‡ Mann–Whitney U test.

§ Brain-injured > Control.

|| Brain-injured < Control.

Comparisons between brain-injured patients and their relatives: That there were more brain-injured versus control differences from the relative-report than from the self-report is also confirmed by the direct comparison of self versus relatives within each of the two groups. Among the controls only five items showed significantly (Wilcoxon signed-rank test, $p < 0.05$) greater reported problems in self-report and a further seven showed significant greater problems in the relative-report. By contrast among the brain-injured there were 42 items showing significantly greater problems in the relative-report and only four significant differences in the reverse direction (28 and 1 respectively after Bonferroni, $\alpha = 0.05/63 = 0.0008$). The ten items showing the greatest mean difference between self-report and relative-report are shown in Table 4. All of these ten items were significant at the 0.0008 level. As can be seen, there is only a single overlap between these items and those appearing in Table 3 ('trouble concentrating'). Thus the items which most distinguish the brain-injured and their relatives from the controls are not the same as those on which they differ most between themselves.

Supplementary questions regarding the relatives

The distribution of responses for the three supplementary questions concerning the relatives themselves (for the brain-injured group only) is shown in Figure 1. For all three variables response levels were significantly higher (Wilcoxon signed-rank test, $p < 0.01$) for the relatives than for the brain-injured patients.

Analyses of scales

Comparisons of brain-injured and control groups: The nine scales were approximately normally distributed and were therefore analysed using analysis of variance. For each scale a two-way ANOVA was performed using brain-injured versus control as a between-subject variable and self-report versus relative-report as a repeated measure. Table 5 shows the means and standard deviations from each of the scales. It can be seen that almost all comparisons are statistically significant, and most remain so, even after correcting for multiple comparisons (Bonferroni, $\alpha = 0.05/27 = 0.002$). The means are also shown graphically in Figure 2.

Table 4. Items showing greatest differences between brain-injured individuals and their relatives

Item†	Brain-injured		Relatives		$p‡$
	Mean	SD	Mean	SD	
Acting inappropriately in dangerous situations	1.50	0.71	1.80	0.72	< 0.01
Being unsure what to do in dangerous situations	1.54	0.75	1.83	0.75	< 0.01
Loss of sexual interest or pleasure	1.56	0.76	1.85	0.71	< 0.01
Problems with household chores	1.65	0.79	1.91	0.77	< 0.01
Thinking only of oneself	1.35	0.63	1.55	0.74	< 0.01
Difficulty making decisions	1.68	0.73	1.88	0.76	< 0.01
Trouble concentrating	1.85	0.77	2.04	0.73	< 0.01
Being unable to plan activities	1.74	0.78	1.93	0.81	< 0.01
Feeling hopeless about the future	1.63	0.76	1.81	0.77	< 0.01
Lack of interest in hobbies in the home	1.53	0.74	1.71	0.77	< 0.01

† coded as 1=not at all, 2=a little, 3=a lot.

‡ Wilcoxon signed-rank test.

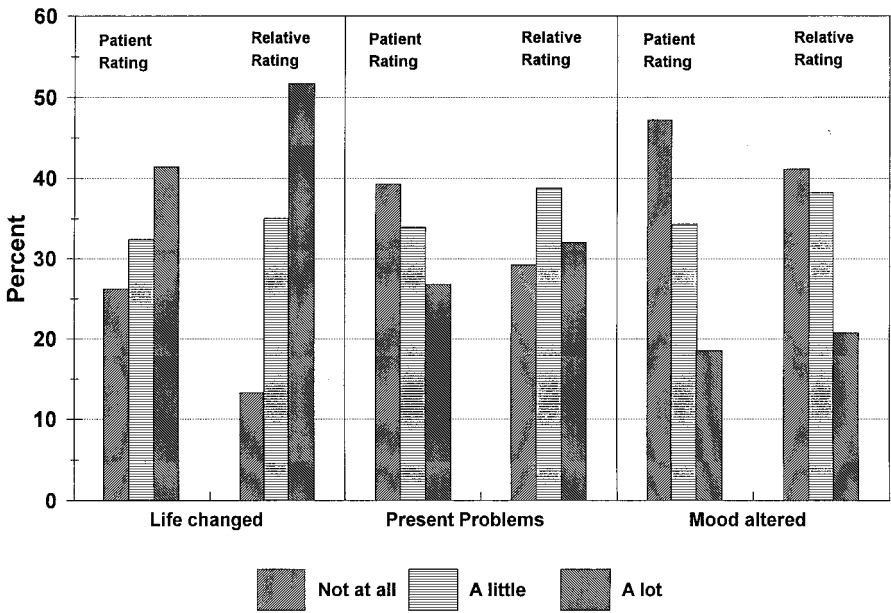


Figure 1. Distribution of responses to questions concerning relatives.

Table 5. Mean scale scores for brain-injured versus control groups

	Self		Relative				Significance of Comparisons [†]				
	Brain-injured		Control		Brain-injured		Control		SvR [‡]	BI v C [§]	Interaction
	Mean	SD	Mean	SD	Mean	SD	Mean	SD			
Somatic	1.65	0.38	1.54	0.38	1.68	0.39	1.48	0.31	ns	< 0.002	< 0.001
Cognitive	1.71	0.43	1.41	0.31	1.84	0.46	1.40	0.30	< 0.002	< 0.002	< 0.002
Motivation	1.59	0.45	1.34	0.32	1.70	0.49	1.38	0.35	< 0.002	< 0.002	< 0.05
Impulsivity	1.62	0.40	1.61	0.37	1.72	0.46	1.63	0.42	< 0.002	ns	< 0.05
Depression	1.70	0.47	1.43	0.38	1.74	0.48	1.36	0.33	ns	< 0.002	< 0.01
Isolation	1.70	0.46	1.65	0.41	1.73	0.48	1.61	0.40	ns	< 0.01	< 0.05
Physical	1.50	0.38	1.30	0.26	1.69	0.41	1.32	0.28	< 0.002	< 0.002	< 0.002
Communication	1.95	0.50	1.61	0.45	1.97	0.52	1.49	0.41	< 0.05	< 0.002	< 0.002
Core	1.68	0.36	1.45	0.30	1.78	0.38	1.43	0.29	< 0.01	< 0.002	< 0.002

[†] Derived from 2-way analysis of variance (Bonferroni correction $\alpha = 0.05/27 = 0.002$).

[‡] S v R=overall comparison of Self versus Relative.

[§] BI v C=overall comparison of Brain-injured versus Control.

^{||} Interaction=interaction term.

Essentially three patterns may be discerned among the scale means. For the Cognitive, Motivation, Physical and Core scales, rather large differences in the brain-injured group between self and relative means are matched only by smaller or nonexistent differences among the controls, which means are furthermore below the brain-injured group values. Thus on these scales the brain-injured group shows clearly greater levels of problems, particularly as reported by the relatives, whereas among the controls there are only small differences between self- and relative-

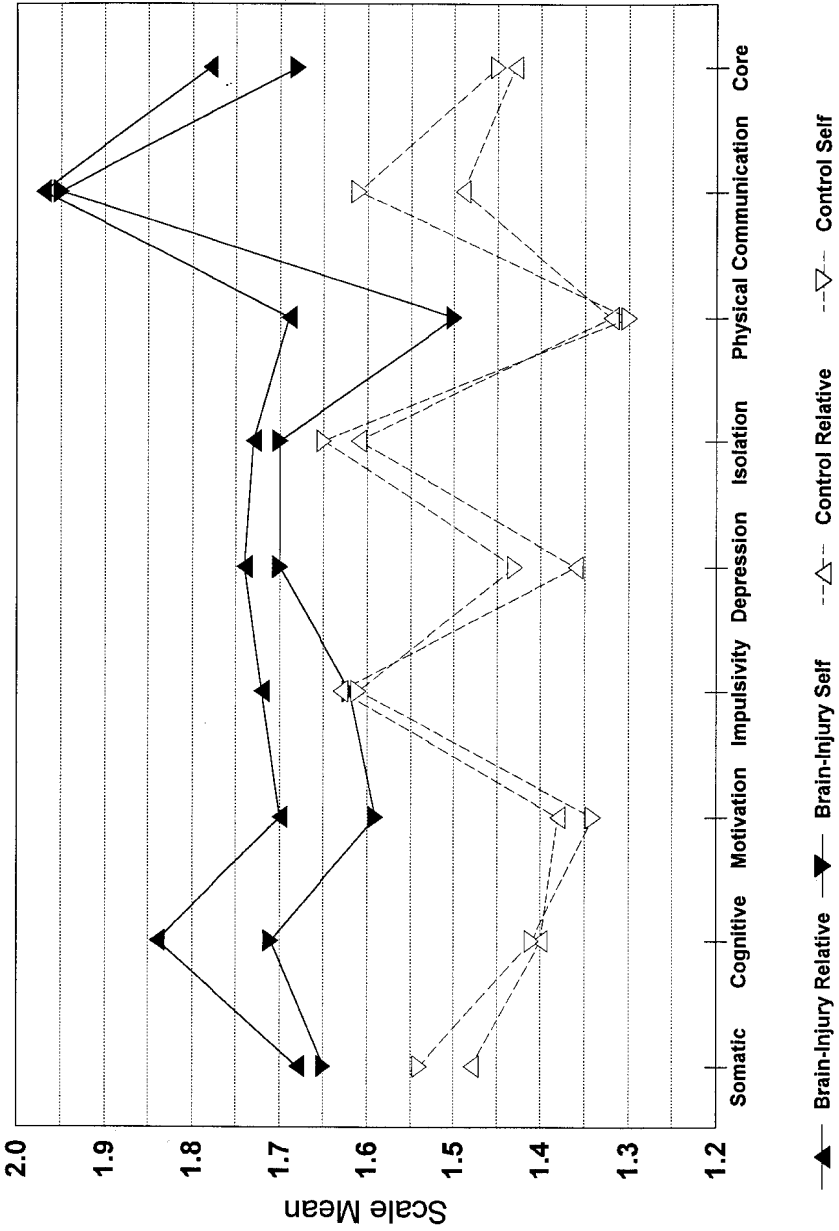


Figure 2. Mean scale scores for Brain-Injured and Control groups, relatives and self.

reports. For the Somatic, Depression, Isolation and Communication scales a reversal is seen such that whereas among the brain-injured group levels are reported as somewhat higher by the relatives the reverse is true among the controls. In these four scales therefore the general tendency among controls for reporting to be higher for self than for relatives is reversed in the case of brain-injury where the problems are perceived as being greater among the relatives than among the brain-injured themselves. The pattern for the Impulsivity scale is quite distinct in that there is essentially no difference between three of the means, i.e., reported levels of problems for the control group and the brain-injured self-report.

For all nine scales the mean level is highest for the relatives of the brain-injured individuals, followed in all but one case (Impulsivity) by the means for the brain-injured individuals self-report (see Figure 2). The most substantial differences between the brain-injured and control groups are seen in the Cognitive and Communication scales and differences are perhaps smallest in the Isolation scale.

Comparisons between countries: Since the data on brain-injured patients and their relatives were derived from eight different countries, we have examined the potential effect of country on each of the nine scales separately for the brain-injured patients themselves and for their relatives. For this purpose we employed a set of one-way analyses of variance with Bonferroni's correction for post-hoc examination of all pairwise comparisons between countries (of which there are 28). Among the comparisons of the nine scales for the brain-injured patients only five were significant of a total of 252 such comparisons (9×28). Similarly there were only six significant comparisons among the nine scales for the relatives. We have taken this broadly negative finding to justify the pooling of the data for the eight countries. There is, however, evidence of some subtle differences between the two largest datasets, i.e., those from France and Brazil, an issue which is addressed below.

Comparisons between dysphasics and non-dysphasics: Since so many among the brain-injured group in the present sample were dysphasics (55%, see Table 1), we have compared them with the remainder of the brain-injured group on all of the nine scales for both self-report and relative-report using *t*-tests for independent groups. Not surprisingly, there were significant differences on the Communication scale for both self-report (mean for dysphasics 2.04, mean for non-dysphasics 1.84, $p < 0.01$) and for relative-report (mean for dysphasics 2.09, mean for non-dysphasics 1.86, $p < 0.01$). These comparisons remain significant after applying Bonferroni's correction ($\alpha = 0.05/18 = 0.003$). There were, however, almost no other significant differences, the single exception being a significantly lower ($p < 0.01$) Somatic mean for dysphasics on self-report which, among 16 comparisons may be a type 1 chance finding.

Comparisons of brain injury type: We have also examined the overall differences between the two largest groups of injury type, namely Cerebrovascular Accident (CVA) and Traumatic Brain Injury (TBI). Table 6 shows the means for the nine scales as a function of injury type and these means are also shown graphically in Figure 3. The pattern of significant findings in this case is relatively similar across the nine scales. For all scales except Communication a significantly higher reporting of problems was found for the relatives than for the brain-injured individuals themselves. This, of course, replicates the above finding in relation to the controls. In the

Table 6. Mean scale scores for CVA versus TBI groups

	Self		Relative				Significance of Comparisons [†]				
	CVA		TBI		CVA		TBI		SvR‡	CVA v TBI§	Interaction
	Mean	SD	Mean	SD	Mean	SD	Mean	SD			
Somatic	1.64	0.38	1.67	0.39	1.67	0.38	1.70	0.40	< 0.05	ns	ns
Cognitive	1.68	0.41	1.76	0.46	1.81	0.45	1.88	0.47	< 0.002	< 0.05	ns
Motivation	1.59	0.45	1.61	0.46	1.70	0.48	1.69	0.50	< 0.002	ns	ns
Impulsivity	1.59	0.39	1.68	0.41	1.68	0.44	1.83	0.49	< 0.002	< 0.002	< 0.05
Depression	1.71	0.46	1.70	0.48	1.74	0.47	1.75	0.49	< 0.05	ns	ns
Isolation	1.67	0.45	1.78	0.48	1.70	0.46	1.83	0.49	< 0.05	< 0.002	ns
Physical	1.52	0.40	1.45	0.35	1.71	0.42	1.61	0.38	< 0.002	< 0.002	ns
Communication	1.97	0.49	1.90	0.50	1.99	0.51	1.92	0.54	ns	< 0.05	ns
Core	1.67	0.35	1.71	0.38	1.77	0.37	1.81	0.39	< 0.002	ns	ns

[†]Derived from 2-way analysis of variance (Bonferroni correction $\alpha = 0.05/27 = 0.002$).

[‡]S v R=overall comparison of Self versus Relative.

[§]CVA v TBI=overall comparison of CVA versus TBI.

^{||}Interaction=interaction term.

present comparisons, however, there is only a single case of a significant interaction between injury type and self- versus relative-report, namely the Impulsivity scale. In this case (in fact not significant following Bonferroni) the self versus relative discrepancy appears greater among the TBI group than among the CVA group. The pattern of overall differences between the two diagnostic groups is rather more differentiated. The TBI group are, at some level, significantly higher on the Cognitive, Impulsivity and Isolation scales, whereas the CVA group are significantly higher on the Physical and Communication scales.

Interpretation of these findings on five scales between the two groups is potentially complicated by a large difference in their ages. The mean age for the CVA group was 55 years (SD=16) and for the TB group it was 32 years (SD=11). Less than 20% of the CVA group were less than 40 years old whereas over 75% of the TBI group were. It is therefore conceivable that some part of the above group differences could be the result of general age effects. In each of the two groups taken separately, however, and in the Control group, none of the five scales in question showed any substantial correlation with age, either for self-report or for relative-report (all correlations were within the range ± 0.17). Furthermore, the scale differences between the CVA and TBI groups are consistent with clinically derived information. Thus 63% of the CVA group were recorded as being dysphasic, against 40% of the TBI group. Conversely, cognitive problems regarding attention and memory were more commonly noted among the TBI group (68% and 75% respectively) than among the CVA group (36% and 37% respectively).

Time since injury: Table 7 and Figure 4 show the mean scale scores in relation to the time since injury. For purposes of these analyses we divided the brain-injured group at its median for months post-injury, i.e., 18 months. Necessarily the comparisons of self versus relative show again the consistent tendency to reporting of higher levels of problems by the relatives. Five of the scales also show a significant (after

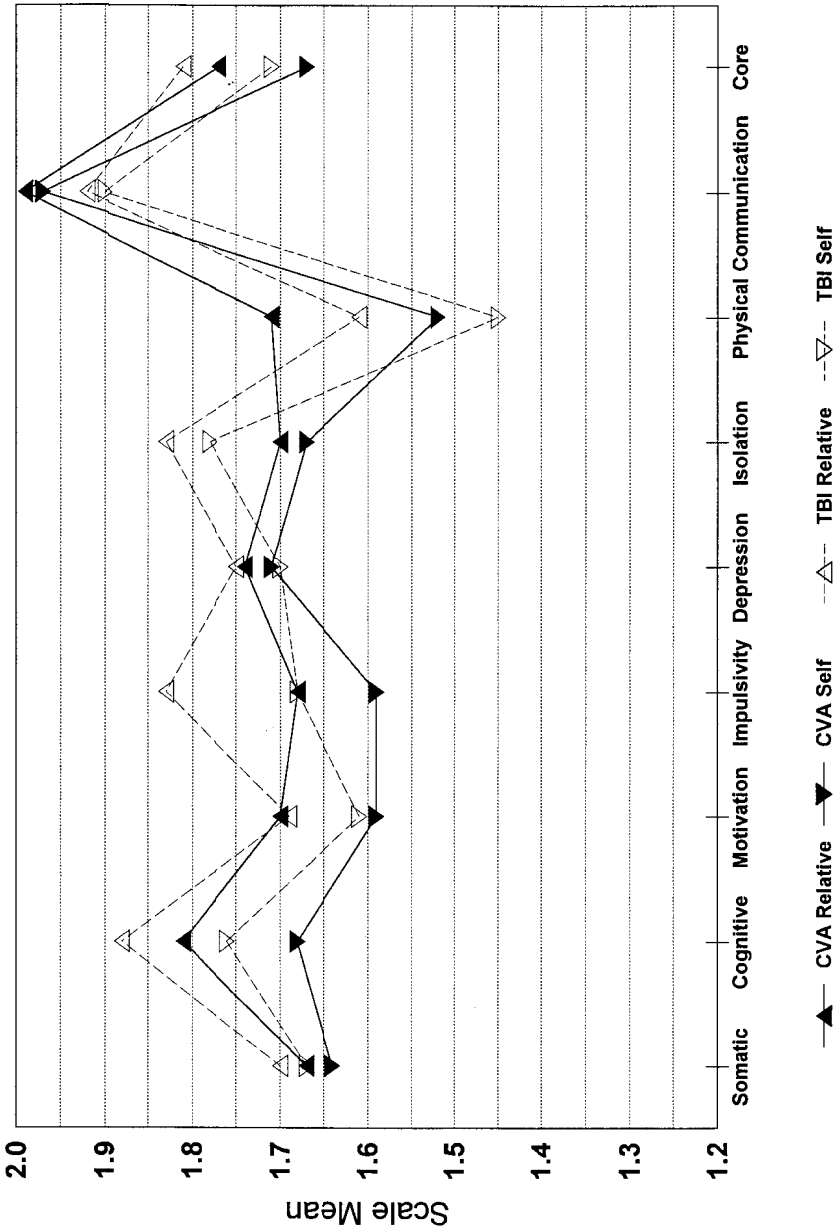


Figure 3. Mean scale scores in relation to type of injury.

Table 7. Mean scale scores in relation to time since injury

	Self				Relative				Significance of Comparisons [†]		
	≤ 18 months		≥ 19 months		≤ 18 months		≥ 19 months		SvR‡	18 v 19§	Interaction
	Mean	SD	Mean	SD	Mean	SD	Mean	SD			
Somatic	1.64	0.36	1.66	0.39	1.65	0.40	1.69	0.38	< 0.05	ns	ns
Cognitive	1.65	0.39	1.76	0.45	1.75	0.43	1.89	0.47	< 0.002	< 0.002	ns
Motivation	1.57	0.43	1.61	0.47	1.67	0.47	1.72	0.51	< 0.002	ns	ns
Impulsivity	1.57	0.38	1.68	0.41	1.65	0.44	1.79	0.47	< 0.002	< 0.002	ns
Depression	1.67	0.46	1.73	0.48	1.68	0.46	1.78	0.49	< 0.05	< 0.01	ns
Isolation	1.63	0.45	1.76	0.46	1.66	0.47	1.80	0.47	< 0.05	< 0.002	ns
Physical	1.51	0.39	1.49	0.38	1.67	0.40	1.68	0.41	< 0.002	ns	ns
Communication	1.86	0.47	2.01	0.50	1.87	0.50	2.04	0.54	ns	< 0.002	ns
Core	1.63	0.34	1.73	0.37	1.71	0.37	1.83	0.38	< 0.002	< 0.002	ns

[†] Derived from 2-way analysis of variance (Bonferroni correction $\alpha = 0.05/27 = 0.002$).

[‡] S v R = overall comparison of Self versus Relative.

[§] 18 v 19 = overall comparison of ≤ 18 months versus ≥ 19 months.

^{||} Interaction-intraction term.

Bonferroni) overall difference between the group who were a relatively shorter time since injury and the group who were relatively longer post-injury. In all significant cases problems are reported as being greater for the group who were longer post-injury. The absence of any significant interactions shows that this clear trend is equally true for both the brain-injured patients and for their relatives.

These results need, however, to be interpreted with caution, since they appear to vary between countries. The pattern described above holds true for the French data considered in isolation with virtually all scales showing significant differences among both the brain-injured patients and their relatives. By contrast, for the Brazilian data, in which the brain-injured patients are predominantly sampled at post-injury times of 18 months or less, the differences tend, albeit rarely significantly, in the opposite direction, i.e., that problems are reported as lesser among those who are 19 months or more post-injury.

Comparison of French and Brazilian control groups: It is worth noting that differences between the countries represented in this study could not have contributed importantly to the above findings with regard to overall brain-injured versus control comparisons. This is because the two countries most represented in the brain-injured group, France and Brazil, which together comprise 80% of all cases, have control groups whose sizes are in very close proportion to their respective brain-injured groups. Thus, for both countries there are about 3.6 brain-injured individuals to one control. Nor could national differences account for any substantial part of the comparisons between the CVA and TBI groups, since the distribution of injury types is not very disparate between the two countries. Thus 61% of the French sample had a CVA injury and 29% had a TBI, the corresponding figures for the Brazilian sample are 70% and 22%.

This is not, however, to say that there can be no important national differences in responses to the questionnaires. The point is best illustrated by examining the French and Brazilian control groups since the brain-injured groups from the two

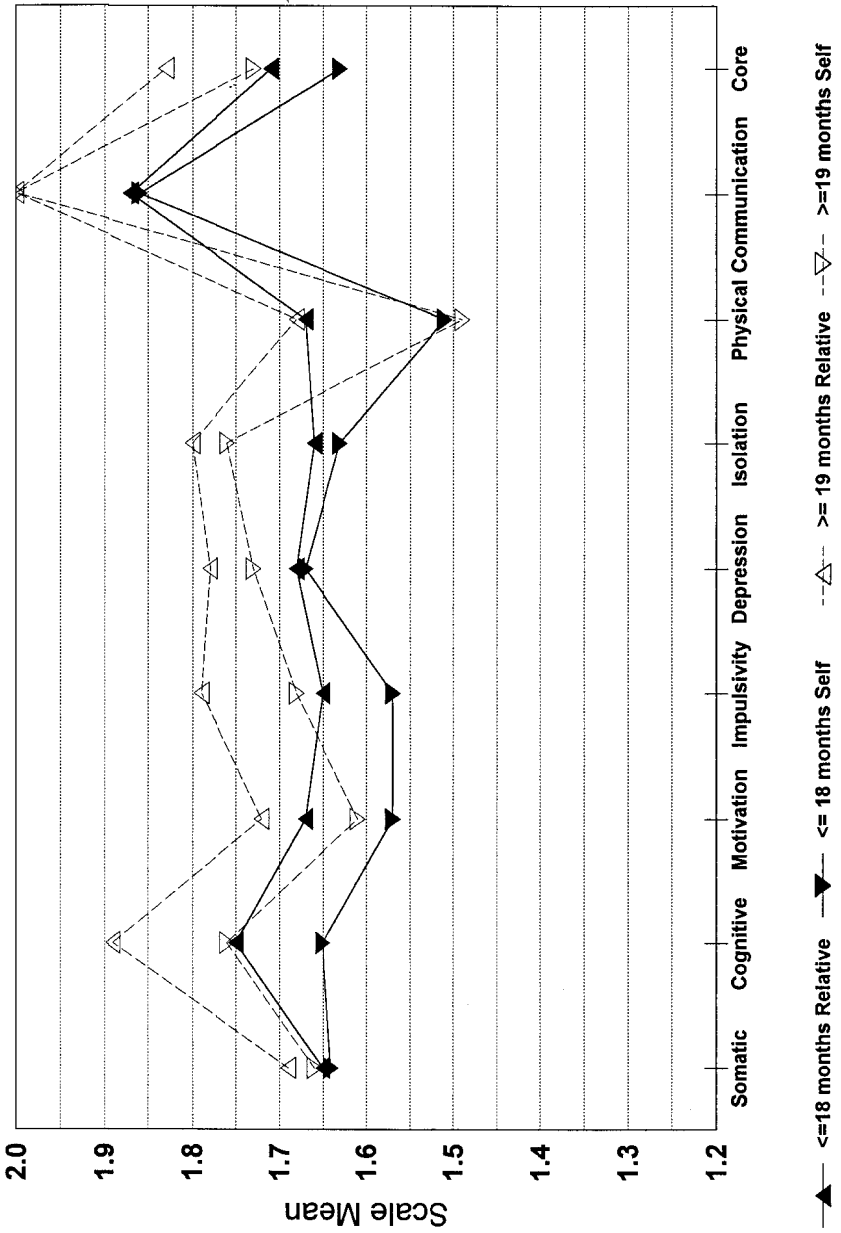


Figure 4. Mean scale scores in relation to time since injury.

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countries differ in time since injury (medians 20 months and 8 months respectively) and may also differ with regard to the severity of injury. Table 8 shows the means for the nine scales as a function of country and self-report versus relative-report. These means are also shown graphically in Figure 5. The French and Brazilian control groups differ in age (means 44.4 and 34.0 years respectively) and educational level (means 5.2 and 6.1 respectively) but after covarying for these variables (see Table 8) there remain significant differences on most of the nine scales for self-rating and all of them for relative-rating. Where the differences are significant they are invariably in the direction of a greater level of reported problems among the Brazilian control group.

Discussion

The findings presented here are broadly encouraging with regard to the validity of the European Brain Injury Questionnaire (EBIQ) and the scales derived from it, for use with brain-injured patients and their relatives. The large majority of the individual items in the EBIQ were found to be significantly elevated in the brain-injured group compared to the control group with regard to self-report. It is interesting to note that the ten items which most strongly discriminate between the two groups cover a diverse range of cognitive and emotional dysfunctions, whereas the sole items for which the brain-injured group showed a significantly lower level when compared with the control group are predominantly concerned with negative feelings towards others (see Table 3). This pattern of greater levels of problems for the brain-injured group was wholly replicated in the relative-report, where the effect was even stronger. There were almost no items in which the relatives in the brain-injured group reported lower levels of problems than the control groups. There was also a very high level of agreement between the brain-injured patients and their relatives with regard to which specific items in the EBIQ were most elevated.

The direct contrast of self-report with relative-report showed very different patterns within the brain-injured and control groups respectively. Among the control group we found only small and alternating differences between the self-rating

Table 8. Mean scale scores for French versus Brazilian control groups

	Self				Relative				Significance of Comparisons†	
	France		Brazil		France		Brazil		Self	Relative
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Somatic	1.49	0.38	1.68	0.36	1.44	0.30	1.59	0.32	< 0.05	> 0.003
Cognitive	1.37	0.31	1.53	0.29	1.36	0.29	1.52	0.28	< 0.0003	< 0.003
Motivation	1.33	0.33	1.38	0.27	1.36	0.36	1.44	0.33	< 0.05	ns
Impulsivity	1.60	0.39	1.65	0.30	1.62	0.43	1.66	0.38	ns	ns
Depression	1.42	0.39	1.46	0.33	1.33	0.34	1.45	0.28	ns	< 0.05
Isolation	1.63	0.42	1.70	0.35	1.57	0.42	1.71	0.33	ns	< 0.01
Physical	1.27	0.25	1.36	0.26	1.28	0.27	1.41	0.31	ns	< 0.003
Communication	1.53	0.45	1.86	0.34	1.40	0.41	1.75	0.28	< 0.003	< 0.003
Core	1.42	0.31	1.55	0.23	1.39	0.30	1.54	0.25	< 0.01	< 0.003

† Derived from one-way analysis of variance covarying for age, sex, and educational level (Bonferroni correction $\alpha = 0.05/18 = 0.003$).

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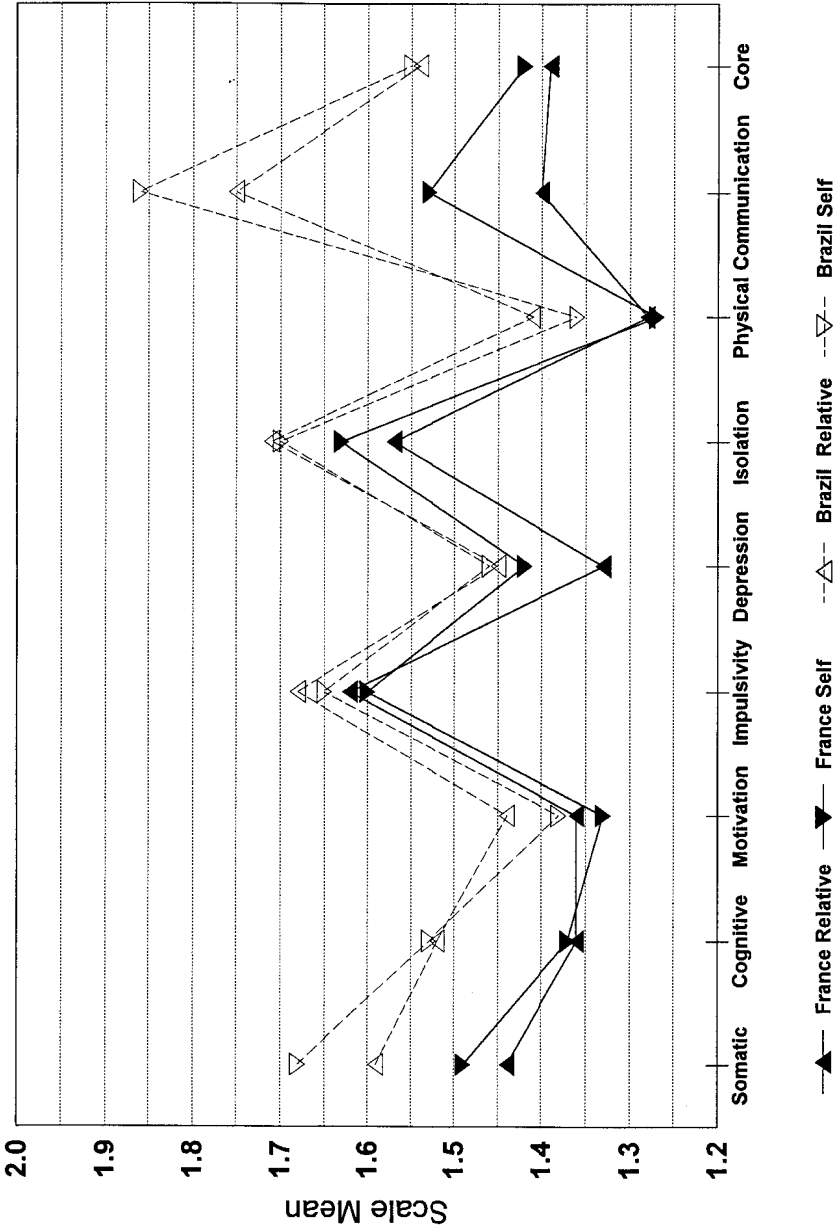


Figure 5. Mean scale scores for French and Brazilian Control groups.

and relative-rating. Within the brain-injured group, however, there were very persistent differences in the direction of greater levels of problems being reported by the relatives than by the brain-injured patients themselves. This finding is consistent with earlier reports [5], and also our own earlier report [19]. The fact that we here found no similar magnitude of differences within the control groups is, however, important, since it enables us to discount the possibility that, independently of brain-injury, relative-report might tend to be more generally negative than self-report.

It is rather striking that the items on which the brain-injured patients and their relatives differ most among themselves are quite different from those on which the two groups differed from their respective controls. In the case of the self versus relative comparison, the items showing the greatest degree of discrimination might perhaps be seen to be predominantly those in which the brain-injured patient's attitude and behaviour most negatively impinge upon a close, usually cohabiting, relative. The two items concerning reactions in dangerous situations could typify this. That the next strongest single item should concern sexuality draws attention to the fact that whereas hyposexuality is a not infrequent consequence of stroke [24] and traumatic brain injury [25] the topic continues to receive inadequate attention, particularly with regard to rehabilitation [26].

With regard to the supplementary questions concerning the relatives themselves, both the patients and the relatives consistently noted life changes since the injury and present problems and changed mood because of it. The reduced awareness and insight noted for the patients concerning their own condition manifests itself also, however, in their responses concerning the relatives, which are consistently lower than are the responses of the relatives themselves.

Using Cronbach's Alpha we have also established that there are largely satisfactory reliability levels (values about or well above 0.5) for the nine scales derived from the questionnaire. Of the nine scales four, namely cognitive, motivation, physical and core, showed a similar pattern of elevated levels for the brain-injured as compared to the controls, and even greater levels among the relatives to the brain-injured patients. Thus although a degree of insight is evidently present for the patients, they are perhaps still underestimating the extent of the problems. This could again be because these scales measure qualities which are manifest in the everyday behaviour of the brain-injured patient and will thus tend to be intrusively evident to the relatives. By contrast the somatic, depression, isolation and communication scales show much smaller differences between the brain-injured patients and their relatives and these differences are in the opposite direction to those seen in the controls. The qualities relating to these scales are rather more internal (somatic) and emotional (depression and isolation) and the communication scale can be interpreted as containing not simply language disorder but also an element of subjectively experienced social reserve. It is not surprising therefore that among 'normal' control levels of self-reporting are rather higher than are noted by relatives. That this pattern nonetheless reverses for the brain-injured patients and their relatives could be seen as further confirmation that the former are underestimating the level of their own problems here also.

It should be noted that the impulsivity and isolation scales both contain items concerning negative feelings towards others as discussed above. The fact that this is evidently not a specific characteristic of brain-injured patients explains the finding

that the differences between the brain-injured and control groups are smallest on these two scales.

Whatever the more subtle differences between the individual scales it is nevertheless striking that for all nine scales the level of reporting problems is highest for the relatives to brain-injured patients followed, with one minor exception (impulsivity), by the reporting of the brain-injured patients themselves. Similar findings have been reported by Cavallo *et al.* [27] and Hendryx [28].

Although the communication scale is not purely concerned with dysphasic symptoms, the finding that dysphasics have significantly higher levels of problems on the scale must be considered as a form of construct validation of it. It is possible that the wider social aspects of communication included in the scale may make it a sensitive measure of improvement following language therapy and rehabilitation.

The validity of the communication scale as relating to dysphasia accounts for the significant difference on this scale within the brain-injured group between CVA patients and TBI since the former, who score higher on the scale, are also more commonly dysphasic. The higher-level of the CVA group on the physical scale probably reflect this scale's loading with items sensitive to hemiplegias, e.g., needing help with personal hygiene. As would be expected, TBI patients report greater levels of cognitive problems—these being primarily attentional and memory dysfunctions. They also manifest greater impulsivity, in particular as reported by the relatives. This is consistent with the particular vulnerability of the frontal lobes to traumatic brain injury.

As stated above our finding of greater problems, as reported by both the brain-injured patients and by relatives, with the passage of time since injury needs to be interpreted with caution. First, this result did not hold true for the Brazilian cases. Secondly, and perhaps related to the preceding point, it should be remembered that all of the patients included in the present study were recruited from hospitals or other rehabilitation facilities. As such those who were a long time post-injury are perhaps not representative of all such patients, in that they are those who continue to need treatment. Patients with a better course of recovery are necessarily not represented in our data.

Nonetheless the finding of generally increasing rather than decreasing problems is consistent with longitudinal studies which have shown at best stagnation across years of follow-up [5,7,29], in particular with respect to psychological rather than physical difficulties. Thus it is particularly noteworthy that two of the three scales *not* to show significantly greater problems for those who were longer post-injury (see Table 7) were the somatic and physical scales. By contrast thus, it is predominantly the psychological scales in which the deterioration is occurring.

The issue of the comparability of the control groups is important. There are consistently higher levels of reporting of problems among the Brazilian controls as compared to the French controls and these differences remain present even after statistical adjustment for differences in age and educational level. It is beyond the scope of this study to speculate about what linguistic or cultural differences might underlie the differences, and as has been argued they do not contaminate any of the above comparisons of brain-injured against controls taken as a whole. The finding is however salutary in serving to underline the potential risk in applying control data or norms derived in one country to another country with a different language and culture.

In summarizing one may conclude that the questionnaire has proved to be generally reliable and valid for brain-injured groups and can thus serve as a useful adjunct to objective neuropsychological assessment and the gathering of psychosocial data. Following the present study, and on the basis of its findings, the questionnaire has been modified in some small respects. Translations in most western European languages may be obtained on application to the second author.

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