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Quality of life after brain injury (QOLIBRI): Italian validation of the proxy version

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Abstract To validate the proxy version of the Quality of Life after Brain Injury (QOLIBRI) questionnaire to utilize caregivers for comparison and to evaluate the correspondence between patients' self-perceived and caregivers' perception of patients' Health-Related Quality of Life (HRQoL). Ninety-two patients with severe TBI and their main caregivers were enrolled. Patients' and caregivers' HRQoL was assessed by the Patient-QOLIBRI (Pt-QOLIBRI) and the Proxy-QOLIBRI (Pro-QOLIBRI), respectively. The Pro-QOLIBRI is a modified version of the QOLIBRI to investigate caregivers' perception of patients' HRQoL (Pro-QOLIBRIpatient-centered), and their degree of satisfaction and botheredness (Pro-QOLIBRIcaregiver centered). The patients' disability and their social reintegration was investigated by means of Glasgow Outcome Scale Extended and Community Integration Questionnaire. Pro-QOLIBRI has good internal consistency and homogeneity. There was also positive correlation between the level of satisfaction measured by Pro-QOLIBRI but not by Pt-QOLIBRI, and the disability severity and social integration of the patients. The comparison between the Pt-QOLIBRI and Pro-QOLIBRI confirmed the usefulness of the Pro-QOLIBRI, especially the caregiver-centered version, to predict the social reintegration of survivors. To our knowledge this is the first study that correlates the HRQoL of survivors, as self-perceived and as perceived by the caregivers with social reintegration.

Keywords Caregiver · Health-related quality of life · Social reintegration · Disability severity · Traumatic brain injury

Introduction

Health-related quality of life (HRQoL) following traumatic brain injury (TBI) has been defined as "a person's perspective on his or her subjective health condition, functioning and well-being in the domains of physical, psychological (emotional and cognitive), social and daily life" [1–3]. To assess HRQoL in terms of both satisfaction and botheredness as self-perceived by survivors of TBI, the Quality of Life after Brain Injury (QOLIBRI) questionnaire, i.e., both the extended and the short forms, was validated in persons with TBI [1–5]; results of the Italian validation of the QOLIBRI [6] shows statistically significant correlations with physical, neuropsychological, and social disability.

A relevant factor, which should be considered in the field of severe TBI, is impaired self-awareness [7–11], namely, the ability to be aware of one's own thoughts, feelings, and mental states [12], which implies that one actively identifies, processes, and stores information about the self [13]. Impaired self-awareness consists of a partial or total reduction of the ability in recognizing problems due to the brain damage. Since low self-awareness can impair a patient's capacity to estimate and self-report the

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individual's post-TBI abilities, the reliability of tools that evaluate self-perceived quality of life by means of self-report scales in persons with TBI may be accordingly questionable [14].

Indeed, Sasse and coll [15] studied a population with prevalent mild TBI, and reported that a lower SA is associated with higher estimates of HRQoL, particularly in the cognitive domain. Conversely, in our recent study on more severe TBI, persons with low SA after TBI are less satisfied than patients with adequate SA (Formisano et al., submitted).

The primary aim of this study was to validate the proxy version of the QOLIBRI (i.e., the Pro-QOLIBRI). The secondary aim was to utilize caregivers for comparison, and to evaluate the correspondence between patients' self-perceived Quality of Life (QoL) and caregivers' perception of patients' QoL.

Finally, we wish to verify the hypothesis that both patients' and proxies' HRQoL could be related to some TBI severity and disability indicators as well as to their social reintegration.

Materials and methods

Participants

We enrolled 92 patients with severe TBI (75.0 % males and 25.0 % females) who had a Glasgow Coma Scale (GCS) [16] score equal to, or less than 8 in the first 24 h after coma onset. They were selected from a larger population of patients who had undergone TBI, and were enrolled in a multicenter national and international study (Appendices 1 and 2). All the patients had been discharged from the Santa Lucia Foundation Rehabilitation Hospital in Rome.

Each patient's main proxy/caregiver was also enrolled. The population of caregivers included 69 females and 23 males (75 and 25 % respectively); 51 (55.4 %) were mothers, 16 (17.4 %) fathers, 14 (15.2 %) partners, and 11 (12.0 %) other relatives.

As in the international validation of the QOLIBRI, we administered the Pro-QOLIBRI with face-to-face interviews, self-reports, or telephone interviews [1].

The study was approved by the local ethics committee.

Inclusion criteria were: (a) diagnosis of TBI according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) criteria (WHO 1992) [17]; (b) outpatient status; (c) time interval from TBI between 3 months and 15 years, in accordance with the inclusion criteria used in the multicenter international validation study of the QOLIBRI [1–4]; (d) score on the Levels of Cognitive Functioning Scale (LCF) >6; (e) being a relative of a patient with TBI; and (f) informed consent of patients and their caregivers.

The exclusion criteria were: (a) a Glasgow Outcome Scale Extended (GOS-E) [18] score <3; (b) spinal cord injury; (c) significant current or previous psychiatric disease or ongoing severe addiction; and (d) diagnosis of terminal illness.

Patients with vegetative state, minimally conscious state plus and minus, and patients with severe cognitive disability were excluded, since as inclusion criterion, the enrolled patients should be able to understand and answer the questions of the QOLIBRI questionnaire.

Quality-of-life evaluation

Patients' and caregivers' HRQoL were assessed with the Patient-QOLIBRI (Pt-QOLIBRI) [1–3] and the Pro-QOLIBRI, respectively.

The Pt-QOLIBRI was administered to all patients with the support of a trained psychologist when needed. Similarly, the Pro-QOLIBRI was administered to the main caregivers of the enrolled patients.

The Pt-QOLIBRI consists of 47 items and divided into two sections (A and B). Section A concerns the level of satisfaction, and consists of four subscales: cognition (seven items), self (seven items), daily life and autonomy (DLA) (seven items), social relationships (six items), and an overall section (six items), which provide a summary of the HRQoL issues investigated by each QOLIBRI subscale.

Section B concerns the discomfort/bother domain and consists of three subscales: emotions (five items), physical problems (four items), and physical conditions (four items). In Section B, there is also one item that provides a summary of discomfort conditions investigated in this section.

The Pro-QOLIBRI is a modified patients' version of the QOLIBRI, which was developed to investigate caregivers' perception of patients' HRQoL (Pro-QOLIBRI$_{\text{patient-centered}}$) and their level of satisfaction and degree of botheredness (Pro-QOLIBRI$_{\text{caregiver-centered}}$).

As Pt-QOLIBRI, the Pro-QOLIBRI consists of 47 items and divided into two sections (A and B). Section A concerns the level of satisfaction, and consists of four subscales: cognition (seven items), self (seven items), daily life and autonomy (DLA) (seven items), social relationships (six items), and an overall Section (six items), which provide a summary of the HRQoL issues investigated by each QOLIBRI subscale.

Section B concerns the discomfort/bother domain, and consists of three subscales: emotions (five items), physical problems (four items), and physical conditions (four items). In Section B, there is also one item that provides a summary of discomfort conditions investigated in this section.

Unlike the Pt-QOLIBRI, each item of Pro-QOLIBRI was administered in two versions: the first "Patient-centered" (i.e., "In your opinion how much is your son/daughter/father…. satisfied with the ability to express themselves?") and the second "Caregiver-centered" (i.e., "how much are you satisfied with the ability of your son/daughter/father…. to express themselves?").

The Pro-QOLIBRI and Pt-QOLIBRI items are rated on a five-point Likert scale: 1 (Not at all), 2 (Slightly), 3 (Moderately), 4 (Quite), and 5 (Very). Section B also provides an additional response ("Not applicable") considered as "Not at all" in the statistical analysis, in agreement with the international validation of the QOLIBRI [1–4]. According to the International and Italian validation of the QOLIBRI [1–4, 6], the scores in Section B (discomfort/bother) were reversed to give the QOLIBRI subscales the same direction, that is, the best situation was associated with higher scores, as in Section A (level of satisfaction). For each QOLIBRI subscale, a score was calculated by summing each item and was presented as a percentage (0–100 %) of the maximum possible score; missing data were imputed using horizontal mean imputation.

Patients' social reintegration evaluation

The CIQ (Community Integration Questionnaire) [19] is focused on the social reintegration of the person over the past month. It is composed of three parts: familiar integration, social integration, and work integration. A different score is computed for each of the three areas, with a maximum total score of 29, obtained by summing the three areas.

Data analysis

The Kruskall–Wallis χ^2 for equality-of-medians rank test and the Cuzick non-parametric test for trend between ordered groups were performed. Spearman rho correlation (with Bonferroni correction) was performed to correlate QOLIBRI subscales with severity indicators, such as GOS-E and coma length. We assumed that the two QOLIBRI scales were: (a) functionally unitary if $\rho > 0.80$; (b) shared a common construct if $\rho = 0.60$–0.79; and (c) were mostly unique, but had something in common, if $\rho = 0.40$–0.59. Internal consistency was assessed using Cronbach'α. The following values are widely accepted in the social sciences: a cutoff of $\alpha = 0.70$ for a set of items to be considered as acceptable for a scale and $\alpha > 0.90$ for clinical application. The most important measure that a set of items must meet to constitute an acceptable survey construct is Loevinger's homogeneity coefficient (H). Indeed, to evaluate the homogeneity of the Pro-QOLIBRI scales, Loevinger's H coefficient was used and a cutoff of 0.5 was chosen to indicate strong homogeneity [20]. Data analysis was carried out using Stata/SE 13.1 (StataCorp, College Station, Texas, USA).

Results

The socio-demographic and clinical characteristics of the patients are reported in Table 1.

For each subscale of Pro-QOLIBRI, no statistically significant difference is found between male's and female's scores.

Internal consistency was assessed for each version of the Pro-QOLIBRI (patient-centered and caregiver-centered) (see Table 2). In Section A of the questionnaire (level of satisfaction), the only low value of Cronbach's α regards the Patient-centered Cognition subscale ($\alpha = 0.32$). The other individual subscale scores exceed $\alpha = 0.80$, ranging from 0.85 for social relationship (patient-centered scale) to 0.91 of DLA (caregiver-centered scale). In Section B, both Emotions individual scores exceed Cronbach's $\alpha = 0.70$ as well as the Physical Problems score (caregiver-centered).

Results indicate that the Pro-QOLIBRI scores generally have good internal consistency as well as good internal homogeneity. Indeed, all individual scale scores in Section A (level of satisfaction) exceed Loevinger's $H = 0.50$ (Table 2). No individual item score in Section B (level of discomfort) shows strong homogeneity, but both Emotions individual items and Physical Problems item scores (caregiver-centered) exceed Loevinger's $H = 0.40$, showing medium-strong homogeneity according to Mokken [20].

Finally, the Physical Condition score (patient-centered) shows Loevinger's $H = 0.37$, which indicates a clinically useful scale. The Loevinger's H_s are supportive of strong scale homogeneity.

Results indicate that the Pro-QOLIBRI scale has good internal homogeneity.

Consistent with the results of internal consistency and homogeneity, all Pro-QOLIBRI individual items in Section A positively correlate with each other with a statistically significant Spearman rho coefficient (Table 3) ranging from $\rho = 0.5235$ for cognition$_{\text{patient-centered}}$ vs social relationship$_{\text{caregiver-centered}}$ to $\rho = 0.8859$ (social relationship$_{\text{patient-centered}}$ vs social relationship$_{\text{caregiver-centered}}$).

As expected, all Pt-QOLIBRI sub-scores correlate with each other within each scale ($p < 0.01$ in all the cases) as do the Pro-QOLIBRI sub-scores of both patient-centered and caregiver-centered versions ($p < 0.01$ in all cases). Instead, regarding the correlation between Pt-QOLIBRI and Pro-QOLIBRI sub-scores, only a few correlations are found. In particular, in the Satisfaction domain, significant differences are found between the Pt-QOLIBRI and Pro-QOLIBRI$_{\text{patient-centered}}$ vs Pro-QOLIBRI$_{\text{caregiver-centered}}$ sub-

Table 1 Socio-demographic and clinical characteristics of the patients

	n	Mean age (years)	SD age (years)	Mean Ed. Lev. (years)	SD Ed. Lev. (years)	Mean coma length (days)	SD coma length	Mean Chron. (days)	SD Chron. (days)
Male	69	30.6	11.0	12.2	3.5	23.7	24.8	1166	1174
Female	23	29.4	8.7	13.3	2.9	45.5	40.3	1274	1323
Total	92	30.3	10.5	12.5	3.3	28.6	30.1	1194	1208

SD standard deviation, *Ed* educational, *Lev* level, *Chron* chronicity

Table 2 QOLIBRI scales reliability and homogeneity analyses

	Pro-QOLIBRI $_{\text{patient-centered}}$		Pro-QOLIBRI $_{\text{caregiver-centered}}$	
	Cronbach's α	Loevinger's H	Cronbach's α	Loevinger's H
Level of satisfaction				
Overall	0.8988	0.6541	0.9137	0.6957
Cognition	0.3169	0.7946	0.9078	0.6762
Self	0.9074	0.6056	0.9088	0.6206
Daily life and autonomy (DLA)	0.9139	0.6378	0.9141	0.6354
Social relationships	0.8484	0.5357	0.8532	0.5420
Level of bother				
Emotions	0.7835	0.4505	0.7651	0.4172
Physical problems	0.6795	0.3706	0.7181	0.4133
Physical condition	0.4195	0.1758	0.3698	0.1420

scores. Indeed, among the 50 possible correlations between the five Pt-QOLIBRI subscales and both Pro-QOLIBRI versions sub-scores, 27 are statistically significant (54 %), 19 are between the Pt-QOLIBRI and the Pro-QOLIBRI$_{\text{patient-centered}}$ version, and only 8 are between the Pt-QOLIBRI and the Pro-QOLIBRI$_{\text{caregiver-centered}}$ version (Fisher's Exact Test: $p = 0.004$) (see Table 3). In this domain, the highest statistically significantly correlated subscales are the social relationship$_{\text{patient-centered}}$, Overall and Self$_{\text{caregiver-centered}}$ version.

There is also a statistically significant positive relationship between the level of satisfaction measured by all the Pro-QOLIBRI subscales and the social integration of the patients assessed by CIQ, which ranges from $\rho = 0.4323$ for cognition$_{\text{patient-centered}}$ to $\rho = 0.6845$ for DLA$_{\text{caregiver-centered}}$; that is, the higher the patients' score on the CIQ scale (indicating they were more integrated), the higher their caregivers' QOLIBRI score (i.e., they were more satisfied).

All individual Pro-QOLIBRI item scores correlate with GOS-E, although the correlation is weaker than with the CIQ. Moreover, the GOS-E weakly correlates with Cognition$_{\text{patient-centered}}$ ($\rho = 0.3384$). As expected, the correlation between the caregiver's level of satisfaction, measured by the Pro-QOLIBRI, and coma length is negative: (the longer the duration of coma, the less satisfied the caregiver), but this negative correlation is not statistically significant (Table 4).

According to the non-parametric analysis performed with the Kruskall–Wallis test, the median scores in Section A of the Pro-QOLIBRI (level of satisfaction of the caregiver) for the five subscales increase with the outcome level of the patients evaluated by the GOS-E (Table 5); that is, the more favorable the patient's outcome and the higher the median level of the caregiver's satisfaction. Performing the non-parametric test for trend across ordered groups [21], we observe a significant increasing trend for the median scores of each QOLIBRI subscale.

According to the Spearman correlation, all Pro-QOLIBRI individual item scores in Section B (level of discomfort) are significantly correlated with each other (Table 6), ranging from $\rho = 0.4090$ for Physical Problems$_{\text{patient-centered}}$ vs Emotions$_{\text{caregiver-centered}}$ to $\rho = 0.9350$ for Physical Condition (patient vs caregiver). In the bother domain (which includes four subscales), only 8 of the 32 possible correlations (25 %) are significantly correlated among the Pt-QOLIBRI and both versions of the Pro-QOLIBRI; 6 of them regarded the Physical Problems items, which correlate for both the patient-centered and the caregiver-centered versions with the following subscales: limitations, physical problems, and overall of the Pt-QOLIBRI items. In Section B, higher correlations are also found among the subscales of the same version of the Pro-QOLIBRI (patient-centered and caregiver-centered).

According to Table 7, statistically significant positive correlations between the level of discomfort measured by

Table 3 Satisfaction domain correlation between Pt-QOLIBRI, Pro-QOLIBRI$_{\text{patient-centered}}$ and Pro-QOLIBRI$_{\text{caregiver centered}}$

	Pt-QOL: Overall	Pt-QOL: Cognition	Pt-QOL: Self	Pt-QOL: DLA	Pt-QOL: Social relationship	Pro-QOL: Overall (patient centered)	Pro-QOL: Overall (caregiver centered)
Pt-QOL: Overall	1.0000						
Pt-QOL: Cognition	0.6884	1.0000					
	0.0000						
Pt-QOL: Self	0.8058	0.7090	1.0000				
	0.0000	*0.0000*					
Pt-QOL: DLA	0.7073	0.7033	0.6904	1.0000			
	0.0000	*0.0000*	*0.0000*				
Pt-QOL: Social relationship	0.6252	0.5325	0.5374	0.6129	1.0000		
	0.0000	*0.0000*	*0.0000*	*0.0000*			
Pro-QOL: Overall *(patient-centered)*	0.4800	0.5227	0.4549	0.4909	0.5032	1.0000	
	0.0002	*0.0000*	*0.0009*	*0.0001*	*0.0001*		
Pro-QOL: Overall *(caregiver-centered)*	0.2719	0.3742	0.2614	0.3516	0.4164	0.7844	1.0000
	1.0000	*0.0346*	*1.0000*	*0.0820*	*0.0057*	*0.0000*	
Pro-QOL: Cognition *(patient-centered)*	0.3650	0.5912	0.3563	0.4417	0.4392	0.7353	0.6048
	0.0495	*0.0000*	*0.0689*	*0.0017*	*0.0020*	*0.0000*	*0.0000*
Pro-QOL: Cognition (*caregiver-centered)*	0.2815	0.4840	0.2212	0.3575	0.3348	0.6445	0.7413
	0.8282	*0.0002*	*1.0000*	*0.0659*	*0.1505*	*0.0000*	*0.0000*
Pro-QOL: Self *(patient-centered)*	0.4898	0.5063	0.5236	0.5002	0.4505	0.8488	0.6614
	0.0001	*0.0001*	*0.0000*	*0.0001*	*0.0011*	*0.0000*	*0.0000*
Pro-QOL: Self (*caregiver-centered)*	0.3219	0.3732	0.3388	0.3517	0.3737	0.7478	0.8380
	0.2334	*0.0359*	*0.1307*	*0.0819*	*0.0352*	*0.0000*	*0.0000*
Pro-QOL: DLA *(patient-centered)*	0.3874	0.4142	0.3273	0.4996	0.3804	0.8030	0.6640
	0.0202	*0.0063*	*0.1946*	*0.0001*	*0.0269*	*0.0000*	*0.0000*
Pro-QOL: DLA (*caregiver-centered)*	0.2900	0.3339	0.2448	0.4083	0.3648	0.7071	0.7651
	0.6446	*0.1552*	*1.0000*	*0.0083*	*0.0499*	*0.0000*	*0.0000*
Pro-QOL: Social Rel. *(patient-centered)*	0.3356	0.3409	0.3306	0.3358	0.4841	0.7527	0.6886
	0.1459	*0.1211*	*0.1740*	*0.1453*	*0.0002*	*0.0000*	*0.0000*
Pro-QOL: Social Rel. (*caregiver-centered)*	0.2666	0.2579	0.2640	0.2436	0.4213	0.6510	0.7737
	1.0000	*1.0000*	*1.0000*	*1.0000*	*0.0046*	*0.0000*	*0.0000*

	Pro-QOL: Cognition (patient-centered)	Pro-QOL: Cognition (caregiver-centered)	Pro-QOL: Self (patient-centered)	Pro-QOL: Self (caregiver-centered)	Pro-QOL: DLA (patient-centered)	Pro-QOL: DLA (caregiver-centered)	Pro-QOL: Social relationship (patient-centered)	Pro-QOL: Social relationship (caregiver-centered)
Pt-QOL: Overall								
Pt-QOL: Cognition								
Pt-QOL: Self								
Pt-QOL: DLA								
Pt-QOL: Social relationship								
Pro-QOL: Overall *(patient centered)*								
Pro-QOL: Overall *(caregiver-centered)*								

Table 3 continued

	Pro-QOL: Cognition (patient-centered)	Pro-QOL: Cognition (caregiver-centered)	Pro-QOL: Self (patient-centered)	Pro-QOL: Self (caregiver-centered)	Pro-QOL: DLA (patient-centered)	Pro-QOL: DLA (caregiver-centered)	Pro-QOL: Social relationship (patient-centered)	Pro-QOL: Social relationship (caregiver-centered)
Pro-QOL: Cognition (*patient-centered*)	1.0000							
Pro-QOL: Cognition (*caregiver-centered*)	0.8362	1.0000						
	0.0000							
Pro-QOL: Self (*patient-centered*)	0.7108	0.6220	1.0000					
	0.0000	*0.0000*						
Pro-QOL: Self (*caregiver-centered*)	0.6162	0.7582	0.8096	1.0000				
	0.0000	*0.0000*	*0.0000*					
Pro-QOL: DLA (*patient-centered*)	0.6821	0.6327	0.7217	0.6936	1.0000			
	0.0000	*0.0000*	*0.0000*	*0.0000*				
Pro-QOL: DLA (*caregiver-centered*)	0.5966	0.6975	0.6482	0.7856	0.8843	1.0000		
	0.0000	*0.0000*	*0.0000*	*0.0000*	*0.0000*			
Pro-QOL: Social Rel. (*patient-centered*)	0.6589	0.5593	0.7313	0.6772	0.7405	0.6789	1.0000	
	0.0000	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Pro-QOL: Social Rel. (*caregiver-centered*)	0.5235	0.6172	0.6393	0.7457	0.6187	0.6986	0.8859	1.0000
	0.0000	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	

the three Pro-QOLIBRI items scores (emotions, limitations, and physical problems) and the social integration of the patients assessed by CIQ are demonstrated, except for the physical problems items score, which ranges from $\rho = 0.4919$ for physical problems (patient-centered) to $\rho = 0.6275$ for the overall Condition (caregiver-centered). Only the Pro-QOLIBRI Physical Problems item and the Summary Discomfort Condition (caregiver-centered) correlate with GOS-E, but more weakly than with CIQ. As in Section A, the correlation between the caregiver's level of bother and the patient's coma length is negative but not statistically significant.

As for Section A, the median scores in Section B of the Pro-QOLIBRI (level of bother/discomfort of the caregiver) for the individual items scores increase slightly with the improved outcome of the patients evaluated with the GOS-E (see Table 5), except for the scores on the physical conditions items.

According to the Spearman correlation analysis, the only statistically significant correlations between the Pt-QOLIBRI and the GOS-E are found with Daily Life and Autonomy (DLA) in the Satisfaction domain and with the overall subscales in the satisfaction and bother domain. Instead, the Pro-QOLIBRI$_{\text{patient-centered}}$ correlates with the GOS-E for all subscales except cognition in the satisfaction domain, and correlates only with the limitations subscale in the bother domain. In addition, the Pro-QOLIBRI$_{\text{caregiver-centered}}$ is significantly correlated with the GOS-E for all subscales except Emotion and Physical Problems in the bother domain (see Table 8). With regard to social reintegration, none of the Pt-QOLIBRI subscales correlate with the Community Integration Questionnaire (CIQ); conversely, all the Pro-QOLIBRI subscales correlated with the level of social reintegration except for physical problems in the bother domain, which again seems to be the subscale least correlated with the level of social reintegration and with disability outcome severity (GOS-E) (Table 8).

Discussion

The comparison between the Pt-QOLIBRI and Pro-QOLIBRI confirms the utility of the Proxy-QOLIBRI, especially the caregiver-centered version, at least for predicting the social reintegration of persons with TBI.

This emphasizes that a similar relationship between patients' and caregivers' viewpoints has been reported in other neurological disorders [22–24].

In the present study, we first aim to validate the proxy version of the QOLIBRI in an Italian sample of caregivers of persons with TBI. The statistical analysis demonstrates the internal consistency of the Proxy-QOLIBRI as well as

Table 4 Correlation among Pro-QOLIBRI individual scores (Section A—level of satisfaction), outcome, coma length, and social integration level (CIQ)

	GOS-E	Coma length	CIQ	Overall *(patient-centered)*	Overall *(caregiver-centered)*	Cognition *(patient-centered)*	Cognition *(caregiver-centered)*	Self *(patient-centered)*	Self *(caregiver-centered)*	DLA *(patient-centered)*	DLA *(caregiver-centered)*	Social relationship *(patient-centered)*	Social relationship *(caregiver-centered)*
GOS-E	1.0000												
Coma lengh	−0.3776	1.0000											
	0.1273												
CIQ	0.3580	−0.2357	1.0000										
	0.2291	*1.0000*											
Overall *(patient-centered)*	0.4763	−0.3044	0.5926	1.0000									
	0.0002	*0.9570*	*0.0000*										
Overall *(caregiver-centered)*	0.4323	−0.2749	0.6230	0.7844	1.0000								
	0.0018	*1.0000*	*0.0000*	*0.0000*									
Cognition *(patient-centered)*	0.3384	−0.3373	0.4323	0.7353	0.6048	1.0000							
	0.0920	*0.4097*	*0.0181*	*0.0000*	*0.0000*								
Cognition *(caregiver-centered)*	0.4093	−0.2996	0.4971	0.6445	0.7413	0.8362	1.0000						
	0.0053	*1.0000*	*0.0013*	*0.0000*	*0.0000*	*0.0000*							
Self *(patient-centered)*	0.4216	−0.1906	0.5119	0.8488	0.6614	0.7108	0.6220	1.0000					
	0.0030	*1.0000*	*0.0006*	*0.0000*	*0.0000*	*0.0000*	*0.0000*						
Self *(caregiver-centered)*	0.5014	−0.1811	0.5739	0.7478	0.8380	0.6162	0.7582	0.8096	1.0000				
	0.0000	*1.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*					
DLA *(patient-centered)*	0.4839	−0.3604	0.6589	0.8030	0.6640	0.6821	0.6327	0.7217	0.6936	1.0000			
	0.0001	*0.2134*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*				
DLA *(caregiver-centered)*	0.5067	−0.2876	0.6845	0.7071	0.7651	0.5966	0.6975	0.6482	0.7856	0.8843	1.0000		
	0.0000	*1.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*			
Social relationship *(patient-centered)*	0.3715	−0.2616	0.5745	0.7527	0.6886	0.6589	0.5593	0.7313	0.6772	0.7405	0.6789	1.0000	
	0.0263	*1.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Social relationship *(caregiver-centered)*	0.3755	−0.1702	0.5800	0.6510	0.7737	0.5235	0.6172	0.6393	0.7457	0.6187	0.6986	0.8859	1.0000
	0.0224	*1.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	

CIQ community integration questionnaire

Table 5 Median scores of Pro-QOLIBRI individual scales by GOS-E level

	GOS-E						Kruskall-Wallis test		Cuzick test	
	Lower severe disability	Upper severe disability	Lower moderate disability	Upper moderate disability	Lower good recovery	Upper good recovery	χ^2	*P* value	*Z* value	*P* value
Satisfaction										
Overall 1	25.0	31.2	41.7	50.0	58.3	62.5	23.23	<0.01	4.71	<0.01
Overall 2	20.8	29.2	29.2	50.0	58.3	62.5	21.96	<0.01	4.33	<0.01
Cognition 1	37.5	43.7	62.5	50.0	66.6	70.8	14.32	<0.05	3.35	<0.01
Cognition 2	16.7	43.7	50.0	50.0	70.8	66.7	17.89	<0.01	3.97	<0.01
Self 1	40.6	39.1	43.7	53.1	62.5	65.6	19.06	<0.01	4.24	<0.01
Self 2	25.0	39.1	37.5	56.2	65.6	65.6	25.39	<0.01	4.86	<0.01
DLA 1	10.7	35.7	46.4	50.0	64.3	71.4	22.13	<0.01	4.68	<0.01
DLA 2	0.0	33.9	35.7	50.0	64.3	71.4	25.26	<0.01	4.96	<0.01
Social relationship. 1	29.2	39.6	41.6	50.0	62.5	70.8	16.10	<0.01	3.83	<0.01
Social relationship. 2	33.3	39.6	37.5	50.0	58.3	66.7	16.19	<0.01	3.77	<0.01
Bother										
Emotion 1	85.0	67.5	60.0	80.0	85.0	85.0	12.414	<0.05	2.42	<0.05
Emotion 2	30.0	50.0	55.0	80.0	80.0	85.0	17.758	<0.01	3.46	<0.01
Physical problems 1	50.0	50.0	56.2	68.7	87.5	78.1	14.641	<0.05	3.50	<0.01
Physical problems 2	31.2	43.7	56.2	68.7	81.2	75.0	16.703	<0.01	3.73	<0.01
Physical condition 1	81.2	75.0	68.7	87.5	87.5	93.7	5.844	ns	2.04	<0.05
Physical condition 2	81.2	75.0	71.9	87.5	87.5	87.5	7.929	ns	1.79	n.s.
Overall 1	50.0	25.0	50.0	50.0	75.0	62.5	8.797	ns	2.32	<0.05
Overall 2	25.0	0.0	25.0	50.0	50.0	50.0	15.358	<0.01	3.73	<0.01

1 patient-oriented, *2* caregiver-oriented

its high relationship with patients' outcome in terms of both severity of disability and social reintegration.

As expected, higher disability as outcome in patients corresponds with worse quality of life of the persons with TBI as perceived by their caregivers, as emerged from the correlation between most Pro-QOLIBRI$_{\text{caregiver-centered}}$ scores and patients' GOS-E and CIQ scores. These data suggest that, coherently with the QOLIBRI already largely used to assess HRQoL in patients with TBI, the Proxy-QOLIBRI can also be used in the field of TBI to assess the same variables perceived by caregivers.

Another aim of the study is to verify the hypothesis that both patients' and proxies' HRQoL could be related to some severity indicators and functional outcome of patients and their social integration, or restricted social participation, according to the bio-psychosocial model (ICF). Indeed, since the HRQoL reflects patients' perspectives about their subjective health condition, functioning and well-being [1], the high number of statistically significant correlations between the Pt-QOLIBRI and the Pro-QOLIBRI$_{\text{patient-centered}}$ version scores might demonstrate the reliability of the self-perceived quality of life of patients and the great ability of caregivers to empathize with patients, as previously reported [25]. However, given that the Pt-QOLIBRI and Pro-QOLIBRI$_{\text{patient-centered}}$ overlap, utilizing the Pro-QOLIBRI$_{\text{patient-centered}}$ to assess patients' HRQoL might be redundant; therefore, we suggest using both the Pt-QOLIBRI and the Pro-QOLIBRI$_{\text{caregiver-centered}}$ to evaluate not only the quality of life of patients, but also the quality of social reintegration of the whole family system.

The present study also demonstrates how different caregivers' HRQOL can be from patients' HRQoL based on the lower scores on both the satisfaction and bother sections of the Pro-QOLIBRI$_{\text{caregiver-centered}}$ version with respect to the Pt-QOLIBRI. Indeed, in line with a previous study [15], it is also likely that in our sample of patients, self-awareness issues may have compromised their ability to congruently estimate their quality of life, especially regarding social post-TBI consequences. This hypothesis is supported by the low number of correlations between the Pt-QOLIBRI and the GOS-E scores (except for Daily Life and Autonomy in the Satisfaction section and overall bother), as well as with respect to the CIQ scores (no correlations between Pt-QOLIBRI and CIQ). However, partially divergent data emerged in another study by our group, which also demonstrates that patients with low self-awareness are able to self-report on their HRQoL (Formisano et al., submitted) and thus, as in previous studies [25], the proxy report need could be challenged.

Conversely, the high number of statistically significantly correlations found between Pro-QOLIBRI$_{\text{caregiver-centered}}$

Table 6 BOTHER DOMAIN Correlation between Pt-QOLIBRI, Pro-QOLIBRI$_{\text{patient-centered}}$, and Pro-QOLIBRI$_{\text{caregiver-centered}}$

	Pt-QOL: Emotions	Pt-QOL: Limitations	Pt-QOL: Physical Problems	Pt-QOL: Overall	Pro-QOL: Emotions (*patient-centered*)	Pro-QOL: Emotions (*caregiver-centered*)	Pro-QOL: Limitations (*patient-centered*)	Pro-QOL: Limitations (*caregiver-centered*)	Pro-QOL: Physical Problems (*patient-centered*)	Pro-QOL: Physical Problems (*caregiver-centered*)	Pro-QOL: Overall (*patient-centered*)	Pro-QOL: Overall (*caregiver-centered*)
Pt-QOL: Emotions	1.0000											
Pt-QOL: Limitations	0.6408	1.0000										
	0.0000											
Pt-QOL: Physical Problems	0.4400	0.4711	1.0000									
	0.0012	*0.0002*										
Pt-QOL: Overall	0.5223	0.5743	0.5851	1.0000								
	0.0000	*0.0000*	*0.0000*									
Pro-QOL: Emotions *(patient-centered)*	0.2775	0.2574	0.2244	0.1834	1.0000							
	0.5845	*1.0000*	*1.0000*	*1.0000*								
Pro-QOL: Emotions *(caregiver-centered)*	0.2559	0.1941	0.1464	0.1077	0.8728	1.0000						
	1.0000	*1.0000*	*1.0000*	*1.0000*	*0.0000*							
Pro-QOL: Limitations *(patient-centered)*	0.2515	0.4684	0.2619	0.3075	0.6117	0.6045	1.0000					
	1.0000	*0.0003*	*0.9413*	*0.2488*	*0.0000*	*0.0000*						
Pro-QOL: Limitations *(caregiver-centered)*	0.2168	0.4592	0.2792	0.2984	0.5776	0.6271	0.8772	1.0000				
	1.0000	*0.0006*	*0.6090*	*0.3476*	*0.0000*	*0.0000*	*0.0000*					
Pro-QOL: Physical Problems *(patient-centered)*	0.3162	0.3953	0.6133	0.4542	0.4869	0.4090	0.5680	0.5539	1.0000			
	0.1989	*0.0109*	*0.0000*	*0.0007*	*0.0001*	*0.0046*	*0.0000*	*0.0000*				
Pro-QOL: Physical Problems *(caregiver-centered)*	0.3197	0.3846	0.5894	0.4107	0.5048	0.4558	0.5600	0.5756	0.9350	1.0000		
	0.2120	*0.0219*	*0.0000*	*0.0076*	*0.0000*	*0.0006*	*0.0000*	*0.0000*	*0.0000*			
Pro-QOL: Overall *(patient-centered)*	0.2046	0.2177	0.2262	0.3313	0.6316	0.6199	0.5578	0.5373	0.5653	0.5100	1.0000	
	1.0000	*1.0000*	*1.0000*	*0.1289*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Pro-QOL: Overall *(caregiver-centered)*	0.2123	0.2358	0.2115	0.3313	0.5629	0.6434	0.5251	0.6217	0.5138	0.5453	0.8371	1.0000
	1.0000	*1.0000*	*1.0000*	*0.1287*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	

Table 7 Correlation among Pro-QOLIBRI individual scores (Section B—level of bother), outcome, coma length, and social integration level (CIQ)

	GOS-E	Coma length	CIQ	Pt-QOL: Emotions (*patient-centered*)	Pt-QOL: Emotions (*caregiver-centered*)	Pt-QOL: Limitations (*patient-centered*)	Pt-QOL: Limitations (*caregiver-centered*)	Pt-QOL: Physical Problems (*patient-centered*)	Pt-QOL: Physical Problems (*caregiver-centered*)	Pt-QOL: Overall (*patient-centered*)	Pt-QOL: Overall (*cargiver-centered*)
GOS-E	1.0000										
Coma length	−0.3776	1.0000									
	0.0898										
CIQ	0.3580	−0.2357	1.0000								
	0.1615	*1.0000*									
Pt-QOL: Emotions *(patient-centered)*	0.2597	−0.1158	0.5143	1.0000							
	0.7701	*1.0000*	*0.0004*								
Pt-QOL: Emotions *(caregiver-centered)*	0.3171	−0.0898	0.5428	0.8728	1.0000						
	0.1437	*1.0000*	*0.0001*	*0.0000*							
Pt-QOL: Limitations *(patient-centered)*	0.3694	−0.2508	0.4919	0.6117	0.6045	1.0000					
	0.0219	*1.0000*	*0.0013*	*0.0000*	*0.0000*						
Pt-QOL: Limitations *(caregiver-centered)*	0.3629	−0.2429	0.5834	0.5776	0.6271	0.8772	1.0000				
	0.0303	*1.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*					
Pt-QOL: Physical Problems *(patient-centered)*	0.2039	−0.2580	0.3865	0.4869	0.4090	0.5680	0.5539	1.0000			
	1.0000	*1.0000*	*0.0742*	*0.0001*	*0.0038*	*0.0000*	*0.0000*				
Pt-QOL: Physical Problems *(caregiver-centered)*	0.1691	−0.2573	0.3984	0.5048	0.4558	0.5600	0.5756	0.9350	1.0000		
	1.0000	*1.0000*	*0.0671*	*0.0000*	*0.0005*	*0.0000*	*0.0000*	*0.0000*			
Pt-QOL: Overall *(patient-centered)*	0.2601	−0.3456	0.5185	0.6316	0.6199	0.5578	0.5373	0.5653	0.5100	1.0000	
	0.8563	*0.2643*	*0.0005*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*		
Pt-QOL: Overall *(caregiver-centered)*	0.3817	−0.4219	0.6275	0.5629	0.6434	0.5251	0.6217	0.5138	0.5453	0.8371	1.0000
	0.0158	*0.0255*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	*0.0000*	

Table 8 Spearman's rho correlation coefficients between Pt-QOLIBRI, Pro-QOLIBRI$_{\text{patient-centered}}$, and Pro-QOLIBRI$_{\text{caregiver-centered}}$ vs GOS-E and CIQ

	Pt-QOLIBRI		Pro-QOLIBRI$_{\text{patient-centered}}$		Pro-QOLIBRI$_{\text{caregiver-centered}}$	
	GOS-E	CIQ	GOS-E	CIQ	GOS-E	CIQ
Satisfaction						
Overall	0.3223	0.2209	0.4763**	0.5926**	0.4323**	0.6230**
Cognition	0.2866	0.1995	0.3384	0.4323*	0.4093**	0.4971**
Self	0.2924	0.1339	0.4216**	0.5119**	0.5014**	0.5739**
DLA	0.4357**	0.2621	0.4839**	0.6589**	0.5067**	0.6845**
social relationship	0.3080	0.1919	0.3715*	0.5745**	0.3755*	0.5800**
Bother						
Emotions	0.2618	0.1510	0.2597	0.5143**	0.3171	0.5428**
Limitations	0.2863	0.2812	0.3694*	0.4919**	0.3629*	0.5834**
Physical problems	0.1670	0.1753	0.2039	0.3865	0.1691	0.3984
Overall	0.3894*	0.3264	0.2601	0.5185**	0.3817*	0.6275**

* $p < 0.05$

** $p < 0.01$

and both GOS-E and CIQ, demonstrates that the caregivers' perception is different from that of the patients, that is, the worse the patients' outcome severity, the worse the HRQoL of their caregivers, suggesting the usefulness of the Pro-QOLIBRI$_{\text{caregiver-centered}}$ to evaluate the social impact of TBI on the whole family system.

This study also demonstrates that HRQoL, as assessed by the Proxy-QOLIBRI, is not only related to the disability severity of patients, but also to their social reintegration. Indeed, to our knowledge, this is the first study that correlates the quality of life of persons with TBI as self-perceived and as perceived by the caregiver, with social reintegration measured by a specific tool such as the CIQ.

The validation of the Proxy QOLIBRI sheds new light on the reduced ability of persons with TBI to perceive their social disability more than they perceive their subjective quality of life [1–3], as reported in the previous studies (Formisano et al., submitted).

In a recent study [26], a causal relationship is demonstrated between low self-awareness and perspective-taking difficulties in a population of persons who had suffered a TBI; Theory of Mind (ToM), and perspective-taking are also impaired in persons after TBI, even those with adequate levels of SA, with a statistically significant correlation between the ToM deficit and caregivers' HRQoL [27].

As a self-awareness deficit may limit the reliability of persons with TBI, whereas differences between patients' self-related HRQoL and caregivers' perception may be influenced by the reliability of the caregivers' judgment, it should be emphasized that the emotional distress of caregivers may also influence their judgment about the HRQoL of individuals with TBI [28–30]. Therefore, future studies should focus on the high burden of the family members of persons with TBI and the reliability of their perceived quality of life [31]. Further studies are also needed to confirm the usefulness of associating the Pro-QOLIBRI with the Pt-QOLIBRI in investigating the social disability, adjustment and reintegration of persons with TBI and their caregivers.

The usefulness of the Pro-QOLIBRI in clinical practice and in the development of more effective health and social networks for people with severe brain injury has to be emphasized.

Indeed, as it is well known, TBI is a family affair [32]; consistently, the present study suggests the usefulness of evaluating the caregivers' quality of life in the clinical practice, by means of a specific tool such as Pro-QOLIBRI, to monitor their emotional distress related to the injury of the person they care of. Thus, Pro-QOLIBRI could allow the development of a structured psychologic support of the caregivers, as well as effective health and social networks for people with severe brain injury and their significant others [31].

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Statement of human and animal rights All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent of patients and their caregivers.

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