ORIGINAL ARTICLE



Quality of life in persons after traumatic brain injury as self-perceived and as perceived by the caregivers

Rita Formisano¹ · Eloise Longo² · Eva Azicnuda¹ · Daniela Silvestro^{1,3} · Mariagrazia D'Ippolito^{1,3} · Jean-Luc Truelle⁴ · Nicole von Steinbüchel⁵ · Klaus von Wild⁶ · Lindsay Wilson⁷ · Jessica Rigon⁸ · Carmen Barba⁹ · Antonio Forcina¹⁰ · Marco Giustini²

Received: 25 July 2016/Accepted: 27 October 2016/Published online: 8 November 2016 © Springer-Verlag Italia 2016

Abstract The primary aim of the study was to adopt QOLIBRI (quality of life after brain injury) questionnaire in a proxy version (Q-Pro), i.e., to use caregivers for comparison and to evaluate whether TBI patients' judgment corresponds to that of their caregivers since the possible self-awareness deficit of the persons with TBI. A preliminary sample of 19 outpatients with TBI and their proxies was first evaluated with the Patient Competency Rating Scale to assess patients' self-awareness; then they were evaluated with the QOLIBRI Patient version (Q-Pt) and a patient-centered version of the Q-Pro. Subsequently, 55 patients and their caregivers were evaluated using the patient-centered and the caregiver-centered Q-Pro versions. Q-Pt for assessing Quality of Life (QoL) after TBI, as patients' subjective perspective and Q-Pro to assess the QoL of patients as perceived by the caregivers. The majority of patients (62.2%) showed better self-perception of QoL than their proxies; however, patients with low self-

Electronic supplementary material The online version of this article (doi:10.1007/s10072-016-2755-y) contains supplementary material, which is available to authorized users.

Marco Giustini marco.giustini@iss.it

- ¹ IRCCS, Rehabilitation Hospital Santa Lucia Foundation, Rome, Italy
- ² National Institute of Health, Viale Regina Elena 299, 00161 Rome, Italy
- ³ Department of Psychology, Sapienza University of Rome, Rome, Italy
- ⁴ Service de Medicine Physique et Réadaption, C.H.U. Raymonde-Poincaré, Garches, France
- ⁵ Department of Medical Psychology and Medical Sociology, Georg-August-University, Goettingen, Germany

awareness were less satisfied than patients with adequate self-awareness. Low self-awareness does not impair the ability of patients with TBI to report on satisfaction with QoL as self-perceived.

Keywords Caregiver · Health-related quality of life · Selfawareness · Traumatic brain injury

Introduction

Most studies on traumatic brain injury (TBI) report outcome data in terms of dependence in the activities of daily living and underestimate social isolation and health-related quality of life (HRQoL), whereas in the last decade, outcome studies on TBI have been particularly concerned with the quality of social reintegration and participation.

QOLIBRI (quality of life after brain injury) is a recognized international instrument that was developed to assess HRQoL after TBI. HRQoL in the field of TBI is a construct, which encompasses patients' subjective perspective of health and well-being. In the area of HRQoL, the

- ⁶ Psychology, Department of Neurosurgery and Early Neurotraumatological Rehabilitation, Clemens Hospital, Westfalian Wilhelms University of Münster, Münster, Germany
- ⁷ Department of Psychology, University of Stirling, Stirling, UK
- ⁸ IRCCS San Camillo Hospital Foundation, Venezia-Lido, Italy
- ⁹ Pediatric Neurology Unit, A. Meyer Children's Hospital, University of Florence, Florence, Italy
- ¹⁰ Department of Engineering, University of Naples, Parthenope, Naples, Italy

individual is seen as the best expert on his/her own health status; indeed, the QOLIBRI shows "a person's perspective on his or her subjective health condition, functioning, and well-being in the physical, psychological (emotional and cognitive), social and daily life domains" [1-3].

The general aim of the multi-center international development of the QOLIBRI was to validate the instrument in seven languages, including Italian, as a specific tool for the self-assessment of individuals' extent of satisfaction with life areas and degree of botheredness after TBI (see Appendix I). Indeed, this tool has demonstrated satisfactory correlations with physical, neuropsychological and social disability also in the recently published Italian validation of the QOLIBRI [4–7].

First, we were interested in assessing the ability of individuals to report their self-perceived HRQoL after TBI, because they could have introspection and self-awareness deficits.

Self-awareness (SA) deficits, which are commonly present after severe TBI, are usually measured by comparing patients' perception of their own abilities and caregivers' perception of the patients' abilities [8]. Self-unawareness (SU) refers to partially or totally reduced ability to recognize problems caused by brain damage [8–10] and it was recently correlated with executive dys-function, empathy and theory of mind impairment after severe TBI and caregivers quality of life [11–13].

The specific aim of the study was to use the caregiver for comparison and to evaluate whether the judgment of the patient corresponded with that of the caregiver and to correlate possible discrepancies with the main disability indicators and self-awareness of the persons with TBI.

This study consisted of two parts: the first concerns the start-up of the QOLIBRI tool; the second regards the further development that subsequently will lead to the validated version of the QOLIBRI tool ([1–7, 14].

The primary aims of part 1 were:

- To assess how persons with TBI perceive their quality of life (QoL) compared to how their caregivers perceive it by means of a QOLIBRI Proxy version (Q-Pro) [15];
- To correlate patients' self-awareness after TBI with caregivers' perception of the patients' quality of life;
- To correlate quality of life discrepancies between patients and caregivers with clinical and neuropsychological features.

As in the part 1, the primary aim of part 2 of the study was to compare the self-perceived quality of life of the patients with that as perceived by the caregivers but in a larger sample and with ad hoc custom-made tools for the caregiver. The secondary aim was to verify whether the presence of self-awareness deficit of the patients might impair their ability to report on their quality of life as selfperceived.

Materials and methods

A preliminary population of 19 patients with TBI, who had been discharged from the Santa Lucia Foundation rehabilitation hospital, was enrolled in a multi-center Italian study (see Appendix II). All patients met the following inclusion criteria, according to the multi-center international validation study of QOLIBRI: diagnosis of TBI according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) criteria [16]; time interval from TBI between 3 months and 15 years, age 15 years or more at the time of TBI; age range 17-68 years at the time of the interview; outpatient status. Exclusion criteria were: Glasgow Outcome Scale (GOS) score <3 [17]; spinal cord injury; significant current or pre-injury psychiatric history or ongoing severe addiction; diagnosis of terminal illness. Furthermore, only patients who were able to understand and cooperate during the interview were enrolled in the study; no cut-off values were adopted for cognitive performance.

The characteristics of the population of patients recruited in the outpatient neurorehabilitation unit of Santa Lucia Foundation in Rome are reported in Table 1.

According to Glasgow Coma Scale (GCS) [18], severity of patients' TBI was distributed as follows: severe (GCS ≤ 8): 76.0%; moderate (GCS 9–12): 11.3%; mild (GCS 13–15): 12.7%.

The proxies of the enrolled population included ten mothers, four partners, two fathers, two sisters and one brother.

The 19 individuals with TBI and their proxies were evaluated using the following instruments:

- Patient Competency Rating Scale (PCRS) which is a self-report scale that aims to assess self-awareness following brain injury. It consists of 30 items that specify different tasks and functions in four domains (emotional, interpersonal, daily life and cognitive functioning); participants indicate how much difficulty they have with each task/function on a 5-point Likert scale. An informant rating is obtained from a relative or a therapist. Awareness scores are obtained from the discrepancy between "self" and "other" ratings, which can be based on the whole scale or on specific items;
- QOLIBRI (quality of life after brain injury) Patient version (Q-Pt) [1–4]: the QOLIBRI version used in part 1 of study was the first instrument specifically

Table 1 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 lenght	Mean PTA (days)	SD PTA (days)	Mean chron. (days)	SD chron. (days)
Male	16	34.7	8.3	10.7	2.7	34.3	35.4	166.9	110.6	1825.0	110.6
Female	3	33.3	2.8	13.0	0.0	71.7	93.8	274.3	109.9	851.7	210.7
Total	19	34.5	7.5	11.0	2.6	40.3	47.1	183.8	114.7	1671.3	1224.6

Ed. Lev. educational level, PTA post-traumatic amnesia, Chron. chronicity, SD standard deviations

developed to assess HRQoL of individuals after TBI. It was a comprehensive questionnaire which consisted of 56 items, 42 in section A and 14 in section B, that covered different dimensions of HRQoL after TBI, structured in subscales: six in section A (Satisfaction) and four in the section B (Bother/Discomfort). Section A concerned level of satisfaction and was structured in six subscales: physical condition, thinking skills, feelings and emotions, activities of daily living, social activities, current situation and future perspectives. Section B concerned the discomfort or bothered domain and consisted of four subscales: physical condition, feelings and emotions, activities of daily living, current and future perspectives. The QOLIBRI items were rated on a five-step Likert scale: 1 (not at all), 2 (slightly), 3 (moderately), 4 (quite) and 5 (very). Section B also provided an additional response (does not apply), which was considered as "Not at all" in this analysis, in agreement with the international and Italian validation of the QOLIBRI [1-4]. For the purposes of this study we also calculated two overall QOLIBRI scores by summarizing all items in both sections: Overall Satisfaction Score (OSS) and Overall Botheredness Score (OBS), missing data were imputed using horizontal mean imputation. To give the QOLIBRI scores the same direction, the scores of Section B (discomfort/bother) were reversed, that is, the best situation was associated with higher scores, as for the satisfaction score;

• QOLIBRI Proxy version (Q-Pro): the Proxy QOLIBRI of part 1 of the study was patient-centered for both the "satisfaction" and "bothered" items and examples of the questions were as follows:

In your opinion, how is your...satisfied with his/her physical condition.

In your opinion, how bothered is your ...by his/her balance problems?

The following neuropsychological tests were used to evaluate executive functions:

- Wisconsin card sorting test (WCST) [19].
- Tower of London test (ToL) [20].

We then recruited 55 patients (41 males and 13 females) in the same outpatient neurorehabilitation unit; they had a mean age of 30.7 years (range 16–59 years), a GCS with a median of 7 (range 3–15 years), a mean coma duration defined as Time to Follow Commands (TFC) of 31.9 days (range 2–150), with a median PTA duration of 57.5 days (range 0–3650). The median interval in years from injury to date of assessment (chronicity) was 414 days (range 86–6416). We also recruited 55 caregivers (43 females, i.e., 78.2%, and 12 males, i.e., 21.8%), including 31 mothers (56.4%), 9 fathers (16.4%), 9 partners (16.4%) and 6 other (10.9%). A neuropsychologist administered the following neuropsychological test battery to the patients in one or more sessions depending on their fatigability.

Memory functions were measured with the Italian validated versions of the digit span test (forward and backward) [21] and of the prose memory test [22]. Executive functioning was assessed with the WCST, Tower of London test (ToL) and verbal fluency (VF) Test [22]. Attention was assessed with the go-no go test of the Test for Attentional Performance [23]. Self-awareness was measured with the Patient Competency Rating Scale (PCRS) as a self-report scale and a proxy version with the PCRS Discrepancies Scores (DS) [8], which were computed by subtracting the relatives' ratings from the patients' selfratings.

The QOLIBRI Patient Version (Q-Pt) and QOLIBRI Proxy version (Q-Pro) were also administered, as described above.

Q-Pro included two different versions of the questions, patient-centered and caregiver-centered quality of life perception.

Examples of "satisfaction" items were as follows:

"In your opinion, how is your ... satisfied with his/ her physical condition?" (patient-centered).

"How satisfied are you with the physical condition of your...." (caregiver-centered).

Examples of "bothered" items were as follows:

"In your opinion how bothered is your by his/her balance problems?" (patient-centered).

"How bothered are you by his/her balance problems?" (caregiver-centered).

Pearson's correlation coefficients were calculated to study the associations between the PCRS-DS and the single variables. According to the cut-off chosen, the PCRS-DS were categorized as follows: PCRS-DS ≥ 5 (index of poor SA) and PCRS-DS < 5 [index of good or (<-5) height-ened SA] [8]. Differences between groups on the categorical parameters (based on the categorized PCRS-DS) were tested using the Fisher's exact test.

The QOLIBRI Patient version (Q-Pt) and QOLIBRI Proxy version (Q-Pro) were also administered. For the purposes of the study we calculated two overall QOLIBRI scores by summarizing all items of both sections (Satisfaction and Bothered); missing data were imputed using horizontal mean imputation.

Data are presented as proportions, medians or mean \pm SD, as appropriate. Differences in categorical variables between respective comparison groups were analyzed using the Chi-Square test or Fisher's exact test. The continuous variables were analyzed using Student's t-test, when applicable.

Correlations between QOLIBRI and PCRS differences (patients' self-reports/proxies) and clinical and neuropsychological variables were obtained using Fisher's exact test. The following variables were correlated: coma length defined as Time To Follow Commands (TFC) [24–26], Glasgow Outcome Scale (GOS) [17], Glasgow Outcome Scale-Extended (GOS-E) [27], post-traumatic amnesia (PTA) duration [28], Wisconsin card sorting test (WCST) [19] and Tower of London (ToL) [20]. Patients were classified according to the number of problems (impaired yes/no) on the ToL and WCST (executive functioning) as follows: 0 = not impaired; 1 = impaired on ToL or WCST; 2 = impaired on ToL and WCST.

Cohen's k was performed to measure the agreement between patients and caregivers. We assumed that the strength of agreement was: (1) poor if k < 0.20; (2) fair if k = 0.21-0.40; (3) moderate if k = 0.41-0.60; (4) good if k = 0.61-0.80; and (5) very good if k = 0.81-1.00 [29].

Data analysis was carried out using Stata/SE 13.1 (StataCorp, College Station, Texas, USA).

Results

Twelve out of 19 TBI patients (62.2%) expressed better QoL self-perception than that reported by their proxies. The average OSS on the QOLIBRI was higher for patients than for caregivers (58.1 vs 46.3%, p < 0.05), whereas the
 Table 2
 ToL and WCST pooled test by QOLIBRI differences (patients vs caregivers)

Thinking skills

ToL and WCST	Differe	Total	
	No	Yes	
0 = not impaired	10	0	10
1 = impaired at ToL or WCST	5	0	5
2 = impaired at ToL and WCST	2	2	4
Total	17	2	19

Pearson $chi^2 = 8.3824 Pr = 0.015$

Fisher's exact = 0.035

mean score of OBS, which was also higher for the patients, showed no statistically significant difference (77.6 vs 71.4%, p = ns). As expected the OSS and OBS scores were positively correlated ($r^2 = 0.21$, p < 0.05).

PCRS findings showed a tendency of patients to underestimate their own problems compared with proxies' perception of patients' quality of life (items 1, 4 and 9 = short-term memory, crying and temper outbursts, respectively).

Conversely, there were no statistically significant correlations between patient/proxy differences and clinical/ neuropsychological features in relation to PCRS scores.

Some QOLIBRI subscales showed differences in ratings in the responses of patients and their caregivers.

The QOLIBRI investigation, instead, showed a statistically significant difference between the impairment of executive functions of the patient (Tower of London more than Wisconsin card sorting test) and the patient/caregiver differences on the thinking skill subscale of section A (see Table 2).

For each subscale of the QOLIBRI questionnaire the strength of the agreement (according to Cohen's Kappa) between patient and caregiver is shown in Table 3, with an agreement generally very poor, and fair only for thinking skills, activities of daily living in Section A and feelings and emotions in section B (see Table 3).

In all ten subscales of the QOLIBRI the mean score of the patients is higher than that of the caregivers, with a statistically significant difference for thinking skills, feelings and emotions and social activities subscales in section A (see Table 3).

According to the OSS and OBS, caregivers (proxies) perceived a worse quality of life than that self-perceived by the patients (Fig. 1).

According to the GOS most of the larger sample of patients (55 pts) showed a low disability level (GOS 5 = 56%), followed by patients with moderate (GOS

	Kappa	IC95%	Ζ	р	Qolibri patient (mean score) (%)	Qolibri caregiver (mean score) (%)	р
Satisfaction							
Physical condition	0.164	-0.047 to 0.214	1.26	ns	62.9	55.5	ns
Thinking skills	0.288	0.156 to 0.413	2.34	< 0.01	59.0	41.9	< 0.05
Feelings and emotions	0.068	-0.052 to 0.168	0.58	ns	62.4	48.3	< 0.05
Activities of daily life	0.302	0.217 to 0.427	2.22	< 0.05	52.1	45.2	ns
Social activities	0.152	0.036 to 0.392	1.25	ns	56,0	41.3	< 0.05
Actual situation and future perspectives	-0.015	-0.143 to 0.139	-0.12	ns	58.3	49.1	ns
Bother							
Physical condition	0.167	0.092 to 0.376	1.07	ns	81.9	75.3	ns
Feelings and emotions	0.360	0.238 to 0.651	2.48	< 0.01	75.3	68.9	ns
Activities of daily life	0.155	0.200 to 0.380	1.01	ns	81.1	75.9	ns
Actual situation and future perspectives	-0.031	-0.109 to 0.061	-0.26	ns	69.7	63.2	ns

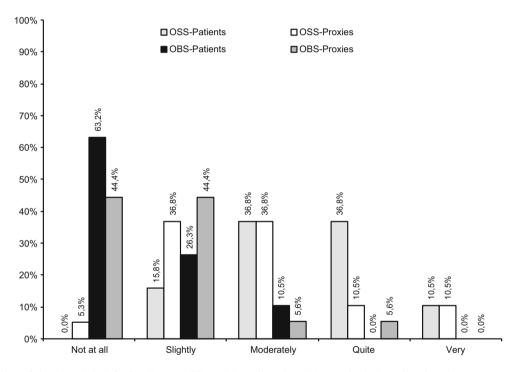


Fig. 1 Distribution of the Overall Satisfaction Score (OSS) and Overall Bothered Score (OBS) in patients/proxies

4 = 36%) and severe disability (GOS 3 = 8%). A similar distribution was observed on the GOS-E, where 44.0% of the patients showed good recovery (upper good recovery ery = 17.3%; lower good recovery = 26.7%) and 38.0% moderate disability (upper moderate disability = 24.0%; lower moderate disability = 14.0%); only 12.0% of the patients showed upper severity disability.

As in the small sample, in the larger sample of 55 patients the main results of the study was that all patients perceived their quality of life better than their caregivers perceived it. Moreover, according to the OSS and OBS, patients with adequate self-awareness (PCRS-DS < 5) were more satisfied than patients with high self-awareness or low selfawareness, whereas patients with low self-awareness were less satisfied than aware patients. However, also patients with adequate self-awareness perceived their quality of life better than their proxies perceived it (see Fig. 2).

Similarly, the caregivers of low self-aware patients were significantly more bothered than the patients by the latters' physical, cognitive and behavioral disorders (see Fig. 3).

No statistically significant differences were found between relatives' patient-centered reports and caregivers'

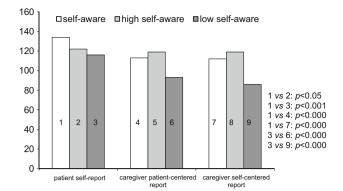


Fig. 2 Distribution of the Overall Satisfaction Score by level of selfawareness

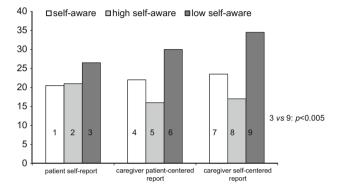


Fig. 3 Distribution of the Overall Bothered Score by level of self-awareness

self-centered reports: furthermore, there were no statistically significant differences between relatives' relationship (parents vs partners) and quality of life of the patients as perceived by the proxies.

Discussion

The main finding of our study was that, all the patients perceived their quality of life better than their proxies. Nevertheless, low self-aware patients were less satisfied with their HRQoL than patients with adequate selfawareness. A possible interpretation of this result could be that proxies perceived the HRQoL of the low self-aware patients as worse than that self-perceived by these patients.

In previous studies we reported that low self-awareness was correlated with empathy and theory of mind impairment, as well as with the caregivers quality of life [10-12].

Indeed, in this study we found higher self-perceived HRQoL satisfaction together with lower botheredness self-perception of the persons with TBI, that compared with the proxies perception, might actually be interpreted as an empathy deficit rather than low self-awareness.

The main current views consider empathy, i.e., the ability to infer and share the experiences of others, as a multidimensional construct that includes both emotional and cognitive aspects [30-35].

Wells and coll. [36] found that lack of empathy in a general sample of individuals with TBI (regardless of their levels of SA and severity of TBI) was the most detrimental factor in their caregivers' HRQoL.

In a previous study [11], a causal relationship was demonstrated between low self-awareness and perspectivetaking difficulties in a population of persons after TBI; furthermore, theory of mind (ToM) and perspective-taking was impaired in persons after TBI who had adequate levels of SA, with a statistically significant correlation between the ToM deficit and caregivers' HRQoL [12].

Indeed, it is well-known that severe TBI may disrupt critical connections in circuits underpinning social cognition, which is often impaired in persons with TBI [37].

People with TBI can impinge on another person's wellbeing, because of their empathy and perspective-taking deficits. Consequently, without understanding the social feedback about the unacceptability of their behavior, they can end up socially withdrawn and isolated, whereas their self-unawareness may persist in a vicious circle [12, 38].

Previous studies [39] also reported that persons with severe TBI felt indifferent to satisfaction of life items or that they were neither satisfied nor dissatisfied, similar to what we found in previous studies on empathy disorders and perspective-taking deficits [12].

Conclusions

In summary, all patients with TBI perceived their quality of life better than their proxies. However, it is possible to assess HRQoL with the QOLIBRI even in patients with self-awareness deficits. Indeed, self-rated HRQoL may result as impaired also in patients with low self-awareness after TBI. This finding partially contradicts the findings reported in a recent paper by [40], which showed that, in a much milder TBI group, lower SA was associated with higher estimates of HRQoL, particularly in the cognitive domain. However, in the same study HRQoL as perceived by the caregivers was overall worse than patients' self-perceived quality of life, as in our population, in which most patients were diagnosed with severe TBI.

Our preliminary results seem to show that low selfawareness does not impair the ability of patients to report on their well-being and quality of life as self-perceived.

It must, however, be underlined that the emotional distress of caregivers may also influence their judgment on the HRQoL of patients with TBI [41]. Since the self-awareness deficit may limit the reliability of the patients with TBI, whereas the differences between patients' self-related HRQoL and caregivers' perception might be influenced by the reliability of the caregivers' judgment, future studies should focus on the high burden of family members of persons with TBI [42]. Finally, the impact of our results on rehabilitation should also be studied.

Compliance with ethical standards

Conflict of interest The authors declare no conflicts of interest.

Funding This research was partially supported by the Italian Ministry of Health (Grant RF2008, No. 31) and a Grant from the G.B. Baroni Foundation.

References

- von Steinbüchel N, Wilson L, Gibbons H et al (2010) Quality of life after brain injury (QOLIBRI): scale development and metric properties. J Neurotrauma 27:1167–1185
- 2. von Steinbüchel N, Wilson L, Gibbons H et al (2010) QOLIBRI task force. Quality of life after brain injury (QOLIBRI): scale validity and correlates of quality of life. J Neurotrauma 27:1157–1165
- Truelle JL, Koskinen S, Hawthorne G et al (2010) Qolibri Task Force. Quality of life after traumatic brain injury: the clinical use of the QOLIBRI, a novel disease-specific instrument. Brain Inj 24:1272–1291
- Giustini M, Longo E, Azicnuda E et al (2014) Health-related quality of life after traumatic brain injury: Italian validation of the QOLIBRI. Function Neurol 29:167–176
- von Steinbuechel N, Wilson L, Gibbons H et al (2012) QOLIBRI overall scale: a brief index of health-related quality of life after traumatic brain injury. J Neurol Neurosurg Psychiatry 83:1041–1047
- Wilson L, Marsden-Loftus I, Koskinen S et al (2016) Interpreting Quality of Life after Brain Injury Scores: cross-walk with the short form-36. J Neurotrauma. Jul 8 (Epub ahead of print)
- Muehlan H, Wilson L, von Steinbüchel N (2016) A rasch analysis of the QOLIBRI six-item overall scale. Assessment. 23(1):124–130
- 8. Ben-Yishay Y, Rattok J, Lakin P et al (1985) Neuropsychological rehabilitation: quest for a holistic approach. Semin Neurol 5:252–259
- Prigatano GP, Fordyce DJ, Zeiner HK et al (1986) Neuropsychological rehabilitation after brain injury. Johns Hopkins University Press, Baltimore
- Sherer M, Hart T, Nick TG (2003) Measurement of impaired selfawareness after traumatic brain injury: a comparison of the patient competency rating scale and the awareness questionnaire. Brain Inj 17:25–37
- Bivona U, Ciurli P, Barba C et al (2008) Executive function and metacognitive self-awareness after severe traumatic brain injury. J Int Neuropsychol Soc 14(5):862–868
- Bivona U, Riccio A, Ciurli P et al (2014) Low self-awareness of individuals with severe traumatic brain injury can lead to reduced ability to take another person's perspective. J Head Trauma Rehabil 29:157–171
- Bivona U, Formisano R, De Laurentiis S et al (2015) Theory of mind impairment after severe traumatic brain injury and its

relationship with caregivers' quality of life. Restor Neurol Neurosci 33(3):335-345

- 14. von Steinbuechel N, Covic A, Polinder S, et al (2016). Assessment of health-related quality of life after TBI: comparition of a disease-specific (QOLIBRI) with a generic (SF-36) instrument. Behav Neurol 2016:14. doi:10.1155/2016/7928014
- Formisano R, Silvestro D, Azicnuda E et al (2016) Quality of life after brain injury (QOLIBRI): Italian validation of the proxy version. Int Emerg, Med (Epub ahead of print)
- World Health Organization (2011) International statistical classification of diseases and related health problems. -10th revision, 2010 edn, vol 1. World Health Organization, Geneva
- Jennett B, Bond M (1975) Assessment of outcome after severe brain damage. Lancet 1:480–484
- Teasdale G, Jennett B (1974) Assessment of coma and impaired consciousness. A practical scale. Lancet 13:81–84
- Heaton RK, Chelune GJ, Talley JL et al (2000) WCST: Wisconsin card sorting test. In: Adattamento italiano a cura di Hardoy MC, Carta MG, Hardoy MJ, Cabras PL. (eds). Forma Completa Revisionata, Firenze, Italy, O.S. Organizzazioni Speciali, 1–100
- Krikorian R, Bartok J, Gay N (1994) Tower of London procedure: a standard method and developmental data. J Clin Exp Neuropsychol 16:840–850
- Orsini A (2003) La memoria diretta e la memoria inversa di cifre in soggetti dai 16 ai 64 anni. Boll di Psicol Appl 239:73–77
- Novelli G, Papagno C, Capitani E et al (1986) Tre test clinici di ricerca e produzione lessicale. Taratura su soggetti normali. Archivio di Psicologia Neurologia e Psichiatria 47:477–506
- Zimmerman P, Fimm B (1992) Test Batterie zur Aufmerksamkeitsprüfung (TAP). Psytest, Würselen
- Dikmen S, McLean A Jr, Temkin NR et al (1986) Neuropsychologic outcome at one-month post-injury. Arch Phys Med Rehabil 67:507–513
- 25. Dikmen SA, Temkin N, Machamer J et al (1994) Employment following traumatic head injuries. Arch Neurol 51:177–186
- Katz DI, Alexander MP (1994) Predicting outcome and course of recovery in patients. Arch Neurol 51:661–670
- Wilson JTL, Pettigrew LEL, Teasdale GM (1997) Structured interviews for the Glasgow Outcome Scale and the Extended Glasgow Outcome Scale: guidelines for their use. J Neurotrauma 15:573–585
- Artiola L, Fortuny I, Briggs M et al (1980) Measuring the duration of post traumatic amnesia. J Neurol Neurosurg Psychiatry 43:377–379
- 29. Altman DG (1991) Practical statistics for medical research. Chapman and Hall, London, p 610
- Hogan R (1969) Development of an empathy scale. J Consult Clin Psychol 33:307–316
- Brothers L, Ring B (1992) A neuroethological framework for the representation of minds. J Cogn Neurosci 4(2):107–118
- Mehrabian A (2000) Manual for the Balanced Emotional Empathy Scale (BEES). 2000:93040. Available from: Albert Mehrabian, 1130 Alta Mesa Road, Monterey, CA
- Gallese V (2003) The roots of empathy: the shared manifold hypothesis and the neural basis of intersubjectivity. Psychopathology 36:171–180
- Frith U, Frith C (2003) The biological basis of social interaction. Curr Dir Psychol Sci 10:151–155
- Baron-Cohen S, Wheelwright S (2004) The empathy quotient: an investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. J Autism Dev Disord 34:163–175
- Wells R, Dywan J, Dumas J (2005) Life satisfaction and distress in family caregivers as related to specific behavioral changes after traumatic brain injury. Brain Inj 19:1105–1115

- 37. McDonald S, Gowland A, Randall R et al (2014) Cognitive factors underpinning poor expressive communication skills after traumatic brain injury: theory of mind or executive function? Neuropsychology 28(5):801–811
- Santoro J, Spiers M (1994) Social cognitive factors in brain injury-associated personality change. Brain Inj 8(3):265–276
- Mailhan L, Azouvi P, Dazord A (2005) Life satisfaction and disability after severe traumatic brain injury. Brain Inj 19:227–238
- Sasse N, Gibbons H, Wilson L et al (2013) Self-awareness and health-related quality of life after traumatic brain injury. J Head Trauma Rehabil 28:464–472
- 41. Tramonti F, Bonfiglio L, Di Bernardo C et al (2015) Family functioning in severe brain injuries: correlations with caregivers' burden, perceived social support and quality of life. Psychol Health Med 10:1–7
- 42. Struchen MA, Pappadis MR, Sander AM et al (2011) Examining the contribution of social communication abilities and affective/ behavioral functioning to social integration outcomes for adults with traumatic brain injury. J Head Trauma Rehabil 26:30–42