

# Long-term services for the care and rehabilitation of people with severe acquired brain injury: a multicentre, cross-sectional study of 536 Italian families

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## ABSTRACT

**Background.** People with severe acquired brain injuries (ABIs) require complex, long-term multidisciplinary healthcare, and social welfare programmes, and their families experience social and emotional consequences that profoundly condition their quality of life.

**Objective.** To investigate whether the possibility of gaining access to local rehabilitation and other services positively influences not only the quality of life of the patients but also the quality of life of their families.

**Methods.** The sample consisted of 536 families of patients with severe ABIs. They were administered a specific 50-item questionnaire with a mix of multiple choice answers, dichotomous (yes/no) answers, or answers based on a Likert-type scale.

**Results.** The results suggest that the long-term services provided to patients are substantially satisfactory but the data concerning the patients' social and working reintegration are disconcerting. Furthermore, the families experience profound social discomfort related to their economic, emotional and caregiving burden regardless of the number and quality of the rehabilitation services activated, or the amount of welfare support received.

**Conclusions.** Post-severe ABI services provided at a local level should include not only long-term rehabilitative and social support for the patients, but also long-term social and psychological support for their families.

## Key words

- severe acquired brain injury
- family
- caregiver
- healthcare
- quality of life
- services

## INTRODUCTION

The motor, cognitive, behavioral and emotional disorders that occur as a result of a severe acquired brain injury (ABI) tend to persist and become chronic in the majority of cases [1]. It has long been recognized that the family plays an essential role in the rehabilitation of patients with severe ABIs [2-7] but it has also been pointed out that severe ABIs have a devastating effect on the family [5, 8], the members of which frequently manifest anxiety, mood and adaptation disorders [9-12]. Various factors interact in defining the disease experience of a family, which may involve changes in its social and economic situation [7, 11, 12-15], a need to provide for multiple healthcare, rehabilitation and so-

cial welfare needs, a need to reorganize the roles of the patient and other members of the family [16-18], and to deal with pervasive cognitive and behavioral disorders [12, 19]. Other important factors are the planning of the discharge and the caregiver's training provided by rehabilitation centers, and the connection with local health and welfare services [20-23].

Many of these factors are influenced by the possibility of gaining access to local services; this leads to questioning how a country's welfare policies can support long-term needs of severe ABI patients and assist their families in their care tasks.

Although the Italian GISCAR and GRACER studies [24-26] have defined the entity of the long-term needs

of patients and created a national registry, there is still a lack of detailed knowledge of the real healthcare, social and economic burden that has to be borne by the families of patients suffering from the outcomes a severe ABI. An Italian study carried out in 2011 [27] found that only 34 (15%) of the 234 interviewed caregivers declared that they were supported by local services in the everyday management of discharged patients with a severe ABI, whereas 122 (52%) said they were only helped by relatives; furthermore, 104 (44%) said that they had not been able to arrange follow-up examinations at their patients' rehabilitation centre.

Another question is whether the presence or absence of the support of local welfare services in the long-term management of patients with an ABI has an effect on the caregivers' mood, because it is still not known whether there is a relationship between the availability and accessibility of welfare services and the psychological burden of the members of a patient's family. A study by Kolakowsky-Hayner and colleagues [28], designed to validate the Services Obstacles Scale, does not suggest a significant relationship between the quality of life perceived by members of the families of patients with traumatic brain injury and their perception of being obstructed from receiving services: 80 of the 136 caregivers (58.5%) declared that they were satisfied with their quality of life even though only 29 (21%) considered the number of healthcare services received adequate, and only 20 (15%) were satisfied with local resources. On the contrary, the findings of a study by Leonardi and colleagues [29] in which 487 caregivers of patients with severe disorders of consciousness were interviewed, showed that the number of hours dedicated to caregiving was the only factor associated with their perceived level of burden.

Given this uncertainty, the aims of this study were to investigate which rehabilitation and social welfare services offered by the Italian national health system are actually available and accessible to patients with severe ABIs and their families, and to verify whether there is a relationship between the amount and quality of the services provided and the social and psychological discomfort felt by family members.

## MATERIALS AND METHODS

This multicentre study involved ten rehabilitation centers and eight family associations that offer various local services for patients with severe ABI. The caregivers of patients who had been discharged from rehabilitation centers were contacted and given an explanation of the aims of the study; those who gave their informed consent to participate were administered a questionnaire by a psychologist. The questionnaires were completed autonomously, but the respondents were able to seek the help of the centers' medical staff in case they needed any assistance in answering the clinical questions concerning the characteristics of the severe ABIs at the time of discharge (e.g. its degree of severity on the Extended Glasgow Outcomes Scale [GOSE]) [30].

The questionnaire consisted of 50 items with a mix of multiple choice answers, dichotomous (yes/no) answers, or Likert-type scale answers. The items were selected on the basis of an analysis of the literature [7,

9-12, 19, 28, 31-33] and of critical factors regarding the care of patients with a severe ABI stated by the Italian national consensus conferences [2, 3]. A first draft of the questionnaire was administered to a sample of 15 caregivers and, on the basis of the results, corrections were made in order to make the questions clearer and to broaden the range of responses. The 50 items of the final version of the questionnaire were divided into three conceptual categories investigating: 1) the profile of the ABI patient and of their family environment (questions 4-14); 2) the quality and quantity of the local services provided (questions 15-40); 3) the effect of the caregiving burden on the caregiver, and its social and emotional impact (questions 41-50).

## Statistical analysis

Data analysis was performed with SPSS for Windows version 21. The responses were analyzed using descriptive statistics (frequencies, mean values, and standard deviations) and inferential statistics. In order to verify possible correlations between the categorical variables, contingency tables were drawn up and analyzed using Pearson's  $\chi^2$  test and, in the case of repeated measures, the Mantel-Haenszel test of marginal homogeneity (MH). Continuous variables were analyzed using Student's *t*-test and Fisher's one-way analysis of variance (ANOVA) with Newman-Keuls *post hoc* test.

## RESULTS

### ABI patients and family environment

#### Characteristics of ABI patients

The sample consisted of 536 families of severe ABI patients. Table 1 shows the demographic and clinical characteristics of the patients. The majority of patients (62.4%) have had cerebral lesion within the previous 5 years (the median corresponds to 2-5 years). Gender was significantly associated with the etiology of the lesion ( $\chi^2 = 11.13$ , *df* = 3; *P* < 0.05), with a prevalence of males among the patients with traumatic lesions (251, 68% vs 89, 53.6%) and, in line with the published GIS-CAR data [26], a prevalence of females among those with lesions of vascular origin (54, 32.5% vs 78, 21.1%). Dividing the lesions into only two categories (traumatic and non-traumatic), the patients with traumatic lesions were significantly younger at the time of the study ( $38.89 \pm 13.92$  vs  $50.46 \pm 13.66$  years; *t*-test -9.237, *df* = 527; *P* < 0.001) and at the time of the event ( $32.07 \pm 14.32$  vs  $46.42 \pm 14.62$  years; *t*-test -10.984, *df* = 527; *P* < 0.001).

At the time of discharge, the majority of patients (45.8%, *n* = 242) required assistance in carrying out some or all activities of daily living (GOSE scores 3-4), and only a small percentage of them (12.9%, *n* = 68) showed functional recovery close to pre-injury levels (GOSE scores 7-8). Remaining patients showed moderate disability (19.3%, *n* = 102 have GOSE scores 5-6) or severe disability (21.2%, *n* = 112 have GOSE scores 2). A very small percentage of patients (0.8%, *n* = 4) died after discharge (GOSE scores 1). The last group of patients was excluded from the family survey.

GOSE scores at the time of discharge were significantly associated with age at the time of the occurrence

of the brain lesion ( $F = 10.24$ ,  $df_{3,518}$ ;  $P < 0.001$ ). Newman-Keuls' *post hoc* test ( $\alpha < 0.05$ ) showed that the mean age of the patients experiencing a good recovery ( $28.9 \pm 12.41$  years; GOSE scores 7-8) was significantly different from that of the patients who were moderately disabled ( $35.26 \pm 13.37$  years; GOSE scores 5-6), severely disabled ( $38.3$  years  $\pm 16.41$ ; GOSE scores 3-4), or in a vegetative state ( $41.4 \pm 16.42$  years; GOSE score 2). Severity was also associated with the etiology of the brain damage ( $\chi^2 = 36.55$ ;  $df = 12$ ;  $P < 0.001$ ): 20 (51.3%) patients with post-anoxic lesions had consciousness disorders (GOSE scores 2), whereas 154 (45.7%) with traumatic injuries and 66 (50.4%) with stroke required assistance with all or nearly all activities (GOSE scores 3-4).

Information concerning the typology of pre-lesion working or educational activities was available for 433 patients: 241 (55.7%) were employees, 102 (23.6%) were self-employed, 57 (13.2%) attended school, and 29 (6.7%) were university students. Information concerning current occupation was available for 500 patients: only 45 (9%) and 40 (8%) had respectively fully or partially resumed their previous activities, whereas 415 (83%) had not been able to do so.

#### Characteristics of family environment

Table 2 shows information concerning the patients' living environments: 254 (47.6%) were living with their family of origin, 219 in their acquired family (41%), 17 (3.2%) were living alone, 10 (1.9%) were living with a professional caregiver, and 34 (6.4%) were living in an extra-family environment. The association between age class and the living environment was significant ( $\chi^2 = 231.90$ ;  $df = 12$ ;  $P < 0.001$ ). Most of the patients in the youngest age classes were living with their family of origin: 30 (96.8%) of those aged 14-21 years, and 124 (83.8%) of those aged 22-35 years. Most of the patients in the oldest age classes were living with their acquired families: 122 (77.7%) of those aged 51-70 years, and eight (61.5%) of those aged  $> 70$  years. The patients aged 36-50 years were almost equally divided between those living with their family of origin (83, 47.2%) and those living with their acquired family (74, 42%).

The associations between the patients' GOSE scores and their living environments were also significant ( $\chi^2 = 54.528$ ;  $df = 12$ ;  $P < 0.001$ ). The patients living in an extra-family environment were mainly those with consciousness disorders.

#### Characteristics of the principal caregiver

One hundred and ninety (35.8%) of the 531 patients for whom the information was available had a parent as their principal caregiver, particularly mothers (30.9%), and 166 (31.3%) their spouses, particularly wives (23.92%). Only 40 (7.5%) had another family member (sibling, child or another relative) as their principal caregiver, and only 32 (6%) were assisted by more than one member of their family in turn.

The mean age of the parental caregivers was  $58.78 \pm 9.77$  years (mothers  $58.20 \pm 9.54$  years), and that of the spouses was  $51.27 \pm 10.95$  years (wives  $50.15 \pm 11.02$  years).

**Table 1**

Demographic and clinical characteristics of the ABI patients. Absolute frequencies (F) and percentages

		N	F (%)
Total sample		536	100
<b>DEMOGRAPHIC CHARACTERISTICS</b>			
Gender (N = 536)	Male	370	69
	Female	166	31
Residence area (N = 514, Missing = 22)	Northern Italy	342	66.5
	Central Italy	77	15
	Southern Italy	95	18.5
Age (N = 534, Missing = 2)	14-21	31	5.8
	22-35	148	27.7
	36-50	180	33.7
	51-70	160	30
	71-90	15	2.8
Education (N = 533, Missing = 1)	Primary school	41	7.7
	Middle school	193	36.2
	High school	222	41.7
	University	77	14.4
<b>CLINICAL CHARACTERISTICS</b>			
Etiology (N = 535, Missing = 1)	Trauma	340	63.5
	Road accident	262	77
	Working accident	31	9.1
	Domestic accident	14	4.1
	Sport accident	13	3.8
	Other	16	4.7
	Missing type of trauma	4	1.2
	Stroke	132	24.7
	Anoxia	39	7.3
	Other	24	4.5
Disease duration (N = 535, Missing = 1)	6-12 months	141	26.4
	2-5 years	192	35.9
	6-10 years	117	21.9
	11-20 years	56	10.5
	21-30 years	26	4.9
	>30 years	3	0.6
GOSE level (N = 528, Missing = 8)	GOSE 1	4	0.8
	GOSE 2	112	21.2
	GOSE 3-4	242	45.8
	GOSE 5-6	102	19.3
	GOSE 7-8	68	12.9

#### Marital stability

The pre- and post-lesion situations of the 527 patients for whom the information was available were analysed in order to verify whether the injury and its outcomes had led to any changes in the marital status of the patients. The findings were statistically significant (standard MH = -4.824,  $P < 0.001$ ). The contingency table shows that 17 (7.7%) out of 221 couples divorced after the ABI and that 16 (6%) patients out of 266 previously single got married after the ABI. Four (14.3%) patient out of 28 previously divorced got married after the ABI.

**Table 2**  
Living environments of the ABI patients. Absolute frequencies (F) and percentages

	N	F (%)
Total sample	536	100
Living environment (N = 534, Missing = 2)		
Alone	17	3.2
Professional caregiver	10	1.9
Family of origin	254	47.6
1 parent	55	21.7
2 parent	81	31.9
1 parent and siblings	22	8.7
2 parent and siblings	76	29.9
Siblings	7	2.8
Parent and grandparents	1	0.4
Aunts/uncles and grandparents	3	1.2
Parents and caregiver	2	0.8
Parents and spouse	7	2.8
Acquired family	219	41
Spouse and children	129	58.9
Spouse alone	76	34.7
Children alone	10	4.6
Spouse and in law	3	1.4
Spouse and caregiver	1	0.5
Extra-family environment	34	6.4
Nursing home	26	76.5
Residential community	3	8.8
Other	5	14.7

### Rehabilitative and social services given to ABI patients after discharge from rehabilitation centres

Table 3 shows information concerning the rehabilitative and social services given to the patients after their discharge from rehabilitation centres. Among the rehabilitative services provided, 401 patients (80.7%) had access to physiotherapy, while only 221 (44.5%)

received cognitive rehabilitation and only 109 (21.9%) received psychotherapy.

The association between GOSE scores and the type of rehabilitative support received was not significant.

Table 4 shows the frequencies of the other variables, such as the supply of aids (lifting devices, wheelchairs, communicators, etc.) and their use, the availability of means of transport, current activities, and opportunities of leading a social life.

Of the 510 patients for whom information was available, as many as 360 (70.6%) did not engage in any occupational activities. As expected, being engaged in any type of activity or not was significantly associated with GOSE scores at the time of discharge ( $\chi^2 = 82.30$ ;  $df = 3$ ;  $P < 0.01$ ) and with patient's age at the time of this study ( $\chi^2 = 34.56$ ;  $df = 4$ ;  $P < 0.01$ ): the majority of patients with GOSE scores of 7-8 (49, 73.1%) and a fair number of those with GOSE scores of 5-6 (22, 32.4%) were active, as against 57 (23.7%) with GOSE scores of 3-4. Similarly, it was the youngest patients who engaged in some form of activity: 14 (46.7%) of those aged 14-21 years, 57 (39%) of those aged 22-35 years, 58 (33.7%) of those aged 36-50 years, and only 20 (12.5%) of those aged > 70 years.

With regard to patients' social activities, 306 respondents (61.3%) declared that they had a social life. As expected, severity at the time of discharge influenced the opportunities to lead a social life ( $\chi^2 = 25.509$ ;  $df = 3$ ;  $P < 0.001$ ), which were taken up by the majority of patients with GOSE scores of 7-8 (54, 81.8%), 5-6 (66, 66.7%) and 3-4 (143, 60.6%). The age of the patients was also associated with social activities ( $\chi^2 = 14.046$ ;  $df = 4$ ;  $P < 0.01$ ), which were engaged in by 22 patients aged 14-21 (73.3%), 92 (64.8%) of those aged 22-35 years, 113 (65.7%) of those aged 36-50 years, 75

**Table 3**  
Respondents' evaluation of the amount and type of local specialist support received after discharge

	N	F (%)		N	F (%)	
Total sample	536	100				
Number of local support services activated (N = 517, Missing = 19)	None	108	20.9			
	1	335	64.8	Type of local support services activated (N = 409)		
	2	55	10.6	House assistance	122	29.8
	3	16	3.1	House nursing	75	18.4
	4	3	0.6	Periodic controls	196	47.9
				Other services	143	35
Number of specialist support services activated (N = 513, Missing = 23)	None	16	3.1	Type of specialist s support services activated (N = 497)*		
	1	70	13.6	Pharmacological	282	56.7
	2	134	26.1	Medical specialist	247	47.7
	3	127	24.8	Motor rehabilitation	401	80.7
	4	85	16.6	Language rehabilitation	223	44.9
	5	57	11.1	Cognitive rehabilitation	221	44.5
	6	24	4.7	Psychotherapy	109	21.9
				Other	5	1

\*= more than one answer was accepted for this item.

**Table 4**  
Aids, means of transport, current activities, social life

		N	F (%)
Total sample		536	100
<b>AIDS</b>			
Aids provision (N = 514, Missing = 22)	Provided upon discharge	324	63
	Not provided upon discharge	190	37
Aids use (N = 452, Missing = 84)	Fully used habitually	240	53.1
	Partially used habitually	43	9.5
	Not habitually used	169	37.4
Aids chagement (N = 428, Missing = 106)	Fully charged	129	30.1
	Partially charged	40	9.3
	Not charged	259	60.5
Aids payment (N = 433, Missing = 103)	Fully paid	53	12.2
	Partially paid	54	12.5
	Not paid	326	75.3
<b>MEANS OF TRANSPORT</b>			
Adapted car (N = 500, Missing = 36)	Possession of an adapted car	71	14.2
	No possession of an adapted car	429	85.8
Other means of transport (N = 394, Missing = 140)	None	157	39.8
	Volunteers	73	18.5
	Own car	57	14.5
	Ambulance	48	12.2
	Public transport	20	5.1
	Municipal	13	3.3
	Reimbursed taxi	7	1.8
	Unreimbursed taxi	17	4.3
	Other	2	0.5
<b>CURRENT ACTIVITIES</b>			
Type of current occupational activity (N = 510, Missing = 26)	None	360	70.06
	Study	25	4.9
	Work	70	13.7
	Sheltered employment	41	8.1
	Other	14	2.7
Current activity with respect to the previous one (N = 486, Missing = 52)	Not resumed previous occupation	408	82.9
	Fully resumed previous occupation	45	9.1
	Partially resumed previous occupation	39	7.9
<b>SOCIAL LIFE</b>			
Present/absent (N = 499, Missing = 37)	No social life	193	38.7
	Social life	306	61.3
Number of place for social life (N = 305, Missing = 1)			
		At least one place for social life	209 68.1
		Two or more places for social life	96 31.9
Social life context (N = 306)*		Friends	227 74.2
		Associations	96 31.4
		Parish church	45 14.7
		Local day care centres	48 15.7
		Other type of centres	5 1.6

\*= more than one answer was accepted for this item.

**Table 5**  
Evaluation of training, information and services received, and causal effect on the course of post-discharge outcomes

		N	F (%)
Total sample		536	100
Evaluation of healthcare training (N = 512, Missing = 24)	Negative	104	20.3
	Positive but with doubts	79	15.4
	Positive	282	55.1
	Don't know	47	9.2
Evaluation of information received during rehab. (N = 508, Missing = 28)	False	0	0
	Inexact	11	2.2
	Insufficient	83	34.7
	Difficult to understand	26	5.1
	Late	12	2.4
	Clear	47	9.3
	Specific	37	7.3
	Adequate	292	57.5
Evaluation of information received after discharge (N = 475, Missing = 61)	False	3	0.6
	Inexact	18	3.8
	Insufficient	165	34.7
	Difficult to understand	32	6.7
	Late	27	5.7
	Clear	31	6.5
	Specific	38	8
	Adequate	161	33.9
Evaluation of the response of local services (N = 494, Missing = 40)	Inadequate	168	34
	Fair	192	38.9
	Adequate	134	27.1
Causal attribution of post-discharge course (N = 497, Missing = 39)*	Caregiver's commitment	338	68
	Patient's commitment	175	35.2
	Time	56	11.3
	Rehabilitation	194	39
	Medical therapy	48	9.7
	Psychotherapy	31	6.2
	Solidarity	47	9.5
	Other	9	1.8

\*= more than one answer was accepted for this item.

(52.4%) of those aged 51-70 years, and three (27.3%) of those aged 71-90 years.

It is also worth noting that 96 (31.5%) of those who declared that they take part in social activities do so at two or more places, whereas the remaining 209 (68.1%) at only one. Furthermore, the main place for the 227 (74.2%) socially active patients was a "group of friends", although voluntary associations also play a role (96, 31.4%). Religious meeting places seemed to be less frequently attended (45, 14.7%), and the same was true of local daycare centres (48, 15.7%).

Table 5 shows information about the caregiver's judgments of the training they received from the rehabilitation centres concerning the autonomous post-discharge management of the patients, and the information received from the local services. It also shows the caregivers' assessments of the response given by local services to the need for assistance, and the factors that they considered to have had a causal effect on the course of the patients' outcomes after discharge from rehabilitation. The GOSE score at the time of patient discharge was associated with the evaluation of the training received ( $\chi^2 = 25.68$ ;  $df = 9$ ;  $P < 0.01$ ): the number of caregivers' who gave positive judgement increased from 42 (42.9%) in the case of patients with a GOSE score of 2 to 47 (69.1%) in the case of patients with GOSE scores of 7-8; the opposite was true of the negative judgements, which decreased from 36 (36.7%) to seven (10.3%).

Two hundred and ninety-one caregivers (56.9%) felt the need to receive further information, and 220 (43.1%) did not; 290 (55.1%) consulted sources of information about their patients' disabilities, and 236 (44.9%) did not. It is also interesting to note that other sources were consulted by 88 (39.1%) of those who had previously declared that they did not need further information. The most frequently consulted sources were Internet sites (122, 44.5%) and associations (96, 35%); only 17 caregivers (6.2%) consulted books or magazines, and the same number consulted other sources such as doctors and relatives. The GOSE score correlated with both the need to receive further information ( $\chi^2 = 19.05$ ;  $df = 3$ ;  $P < 0.01$ ) and the consultation of other sources ( $\chi^2 = 27.60$ ;  $df = 3$ ;  $P < 0.01$ ): in both cases the percentage of consultant grows with the increase of the severity of ABI.

Only "internal" factors were significantly associated with the attribution of post-discharge course of the ABI outcomes: i.e. the commitment of caregivers ( $\chi^2 = 16.398$ ,  $df = 3$ ,  $P < 0.01$ ) and that of the patients themselves ( $\chi^2 = 33.268$ ,  $df = 3$ ,  $P < 0.01$ ). The percentage of respondents who considered the commitment of caregivers important increased with the severity of the patients' condition (GOSE 2: 70, 79.5% and GOSE 3-4: 167, 71.1%); the percentage of respondents who consider the commitment of the patients important decreased with the severity of the patients' condition (GOSE; 5-6: 49, 49.5% and GOSE 7-8: 34, 50.7%).

#### **Social and emotional impact of the ABI on the family**

Table 6 shows information about the economic impact, discomforts, worries, and qualitative and quantitative changes in interpersonal relations experienced by the families.

Most of the caregivers were sometimes (204, 39.8%) or often (111, 21.7%) worried about the caregiving commitment, and this was related to the severity of patients' condition ( $\chi^2 = 60.17$ ;  $df = 12$ ;  $P < 0.001$ ). Among caregivers of patients with good functional recovery (GOSE scores 7-8), the most frequent responses were "never" (26, 38.8%) or "rarely" (15, 22.4%), whereas the caregivers of patients with lower GOSE scores more frequently responded "sometimes" (GOSE scores 5-6: 67, 48.5%; GOSE scores 3-4: 92, 39%; GOSE score 2: 45, 43.3%)

**Table 6**  
Costs, discomforts, worries, interpersonal relations, state of mind

		N	F (%)
Total sample		536	100
Costs borne (N = 476, Missing = 60)*	Specialist medical expenses	151	31.7
	Rehabilitation expenses	136	28.6
	Lost patient earnings	112	23.5
	Lost caregiver earnings	53	11.1
	Transport expenses	81	17
	Change of home	57	12
	Adaptation of home	54	11
	Costs of care	57	12
	Legal expenses	42	8.8
	Prostheses and aids	11	2.3
	Other costs	23	4.8
Major discomfort felt (N = 491, Missing = 45)*	Uncertainty about fate of patient	257	52.3
	Economic costs	140	28.5
	Sense of abandonment	130	26.5
	Distance of services	87	17.7
	Distance of family members	63	13.8
	Indifference of family members	66	13.4
	Other	34	6.9
Worries about caregiving burden (N = 404, Missing = 132)	Feeling insecure about caregiving	39	9.7
	Difficulties in handling new situations	90	22.3
	Bad organization of caregiving services	58	14.4
	Architectonic barriers	39	9.7
	Isolation	63	15.6
	Economic problems	31	7.7
	More than one	18	4.5
	Other	66	13.3
Frequency of worries about caregiving burden (N = 512, Missing = 24)	Never	81	15.8
	Rarely	55	10.7
	Sometimes	204	39.8
	Often	111	21.7
	Almost always	61	11.9
Interpersonal relations, quantity (N = 512, Missing = 24)	More frequent than before	49	9.6
	As frequent as before	143	27.9
	Less frequent than before	174	34
	Greatly reduced	146	28.5
Interpersonal relations, quality (N = 475, Missing = 61)	More positive than before	81	17.1
	Unchanged	187	39.4
	Less positive than before	174	36.6
	Conflictual	33	6.9
Current state of mind (N = 521, Missing = 15)*	Tired	232	44.5
	Worried	229	44
	Angry	97	18.4
	Abandoned	56	10.7
	Serene	133	25.5
	Other	30	5.8

\* = more than one answer was accepted for this item.

or “often” (GOSE scores 5-6: 24, 24.7%; GOSE scores 3-4: 55, 23.3%; GOSE score 2: 28, 26.9%). The most frequent worries were about difficulties in knowing how to handle new situations (90, 22.3%), the perception of the sense of isolation (63, 15.6%), and the inadequacy of caregiving services (58, 14.4%).

The frequency of interpersonal relations was associated with GOSE scores ( $\chi^2 = 21.549$ ;  $df = 9$ ;  $P < 0.1$ ), but not with disease duration, the age of the patient or caregiver, the family environment. There was a prevalence of the responses “as before” or “more frequent” among the caregivers of patients with good functional recovery (37, 56% GOSE 7-8), but a prevalence of the responses “less frequent” or “greatly reduced” among the caregivers of patients with lower GOSE scores: GOSE score 2 (155, 66.5%); GOSE scores 3-4 (70, 64.8%); GOSE scores 5-6 (60, 61.2%). The quality of interpersonal relations was not associated with the severity of the ABI, the age of the patient or caregiver, the family environment, but there was a significant association with disease duration ( $\chi^2 = 23.73$ ;  $df = 12$ ;  $P < 0.05$ ). The best relations (those prevalently described as “as before” or “more positive”) were among the caregivers of the patients with a more recent brain damage (one year or less: 87, 69%) or patients who suffered the brain damage 21 to 43 years before (14, 63%).

The adjectives that were most frequently chosen to describe the state of mind of the caregivers were “tired” (232, 44.5%) and “worried” (229, 44%); 97 (18.4%) chose “angry”, 56 (10.7%) “abandoned”. There were also 133 (25.5%) caregivers who chose the adjective “serene”. Some caregivers (30, 5.8%) have chosen “other”: 26 of them describe their state of mind with negative connotations adjective such as “demoralised”, “distressed” or “depressed” and 4 with positive connotations adjective, such as “trustful”. The severity of ABI at the time of discharge was only associated with the adjectives “tired” ( $\chi^2 = 17.27$ ;  $df = 3$ ;  $P < 0.01$ ) and “serene” ( $\chi^2 = 22.11$ ;  $df = 3$ ;  $P < 0.01$ ): the percentage of caregivers who chose “tired” increased with the severity of their patient’s condition (e.g. GOSE scores 7-8: 21, 30.9% and GOSE score 2: 60, 55.6%), whereas the percentage of caregivers who chose “serene” decreased (e.g. GOSE scores 7-8: 31, 45.6% and GOSE score 2: 15, 13.9%). The other  $\chi^2$  tests carried out in order to verify the associations between each state of mind and other variables as patient’s or caregiver’s age or disease duration were as expected: for example, the adjective “serene” was significantly associated with disease duration ( $\chi^2 = 11.08$ ;  $df = 4$ ;  $P < 0.05$ ), and the age of the caregiver ( $\chi^2 = 17.81$ ;  $df = 3$ ;  $P < 0.01$ ), and was more frequently chosen by caregivers of patient’s with disease duration of 21-43 years (12, 46.2%), and the younger caregivers aged 25-35 years (16, 50%).

#### *Relationship between the number of services received and the adaptation of the families*

A large number of contingency tables were drawn up in order to verify whether there were any relationships between the number of services received (0, 1, and > 1) and the emotional and social impact of the ABI on the family. Caregiver’s state of mind and declared worries,

as well as the quality of the family’s interpersonal relationships, were used as indicators of the quality of the adaptation of the caregiver. However, despite the large number of  $\chi^2$  tests, no significant associations emerged except for the relationship between the number of local services received and the caregiver’s declared worries ( $\chi^2 = 6.327$ ;  $df = 2$ ;  $P < 0.05$ ): there were more worries among the caregivers of patients who had not received any service (44/106, 41.5%) or had received only one (156/327, 47.7%) than among the caregivers of the patients who had received more than one service (23/72, 31.9%).

#### *Relationship between the social relations of the caregivers and patients, and the caregivers’ state of mind and worries*

There were significant relationships between the quantity/quality of interpersonal relations perceived by the caregivers and their state of mind. Those who declared a quantitative reduction in their interpersonal relations after the ABI were more likely to consider themselves to be tired (159/320, 49.7%) than those who declared that their interpersonal relations were as frequent as, or more frequent than before (67/187, 35.8%) ( $\chi^2 = 18.776$ ,  $df = 3$ ;  $P < 0.01$ ), and same was true of feelings of abandonment (46, 14% vs 9, 4.8%) ( $\chi^2 = 16.364$ ,  $df = 3$ ;  $P < 0.01$ ).

Caregivers who had experienced a decrease in their opportunities of social contact were those who were less likely to declare a state of serenity (53, 16.5%) than those who declared no change (77, 41%) ( $\chi^2 = 42.150$ ,  $df = 3$ ;  $P < 0.01$ ).

The quality of interpersonal relations was also associated with fatigue ( $\chi^2 = 9.270$ ,  $df = 3$ ;  $P < 0.05$ ), worry ( $\chi^2 = 9.144$ ,  $df = 3$ ;  $P < 0.05$ ), anger ( $\chi^2 = 14.111$ ,  $df = 3$ ;  $P < 0.05$ ) and abandonment ( $\chi^2 = 28.698$ ,  $df = 3$ ;  $P < 0.001$ ). In comparison to the 264 caregivers who considered the quality of relations the same as, or more positive than before the ABI, the 207 who declared that their relations were conflictual or less positive than before the ABI were more likely to describe themselves as tired (106, 52% vs 101, 38%), worried (102, 49% vs 101, 38%), angry (52, 25% vs 32, 12%), or abandoned (37, 18% vs 12, 9%).

There were also significant relationships between the quantity ( $\chi^2 = 58.179$ ,  $df = 12$ ;  $P < 0.001$ ) and quality ( $\chi^2 = 49.856$ ,  $df = 2$ ;  $P < 0.001$ ) of the caregivers’ interpersonal relations and the frequency with which they expressed concerns about their caregiving commitment. Those who declared a reduction in social relations (131, 41%) or who said that their relations were less positive or conflictual (101, 49%) were more frequently “often or almost always” worried than those who did not declare a reduction in relations (37, 20%) or who said the quality of their relations was unchanged (59, 22%).

The statistical analysis showed some significant relationships between caregiver’s state of mind and patients’ opportunities of experiencing a social life. In particular, the sense of abandonment was less frequent ( $\chi^2 = 3.88$ ;  $df = 1$ ;  $P < 0.05$ ) among the families of patients who have such opportunities (68/287, 23.69%) than among those of patients who do not (57/178, 32.02%). Similarly, the caregivers of patients without a social life were



more likely to feel anger (53/191, 27.75% vs 38/301, 12.62%) ( $\chi^2 = 17.73$ ;  $df = 1$ ;  $P < 0.001$ ). As the other states of mind, serenity was also positively associated with the patients' opportunities of having a social life ( $\chi^2 = 16.10$ ;  $df = 1$ ;  $P < 0.001$ ).

## DISCUSSION

The aims of this study were to analyse which services are provided by the Italian national health system and regional social welfare services to severe ABI patients and to investigate whether access to these services has a positive impact on the families' emotional burden.

Data were collected using an *ad hoc* questionnaire given to the patients' caregivers.

### **ABI patients and family environment**

The demographic and clinical characteristics of the 536 patients are consistent with Italian and international epidemiological data [26, 34]. However, the percentage of patients returning home after discharge (93.6%) is higher than that recorded by the Italian GISCAR registry [26], which evidence a decrease from 67% in the 2001-2003 to 54% in 2008-2011; the percentage of couples separating after the acute event (7%) is lower than the 15-25% recorded in other studies [35, 36]. These different trends may be explained by two main biases in caregiver and patients recruitment. The first one concerns the time from injury: in our study 81 patients (15.4%) experienced the acute event more than 10 years before the study. Furthermore, many caregivers have been recruited among associations of families of people with ABI: this led us to contact a larger number of families living together with the patients. However, these biases allowed us to obtain a more detailed picture of the local and rehabilitation services the families obtained after discharge.

The GISCAR study involved a large sample of severe acquired brain injured patients in Italy. However, GISCAR study is not comparable to our research. The GISCAR study, in fact, is a prospective multicentre study with the aim to collect data about clinical features of severe ABI. The study involved about fifty rehabilitation centers and collected data on about ninety different variables related to demographic factors, clinical history, rehabilitation treatments, and outcomes. Our study does not allow us to build such a specific picture of ABI's patients but rather focuses more on the long-term territorial services available and on the family emotional condition.

### **Rehabilitative and social services given to ABI patients after discharge from rehabilitation centres**

Data referring to the local rehabilitation and social services for patients who have been discharged from hospital indicate the overall adequacy of the Italian healthcare system, which offers multiple long-term services: most of the patients (63%) were provided with the necessary aids upon discharge, a large majority (81%) had the opportunity of joining physiotherapy rehabilitation programmes, and only 21% have not activated any domiciliary or outpatient control service.

Cognitive rehabilitation was provided in less than a

half of the cases. It is however well known that severe acquired brain injury, due to the widespread nature of lesions, results not only in motor but also in cognitive and behavioural consequences [37]. Cognitive and behavioural deficits not only affect the vocational and social integration of patients but are also factors that influence the mood and stress of caregivers [11, 17, 19]. For this reason, complex and multidisciplinary intervention is required in an integrated and holistic treatment context [4, 19, 37, 38], providing cognitive rehabilitation, behavioural interventions, and psychotherapy. Although physiotherapy and health and social care are generally well-organized and widely provided in Italy, cognitive and behavioural rehabilitation should be still incremented.

This discrepancy between physiotherapy and neuropsychological rehabilitation does not affect only Italy. For example, Munce and colleagues [39] interviewed 42 health professionals of Ontario (Canada) working in services for patients with acquired brain injury. The authors highlighted the presence of service gaps for people with cognitive and behavioural disorders, as lack of counseling and neuropsychological/psychiatric services. When present, these services are poorly integrated with others. Heinemann and colleagues (2002) assessed 895 TBI patients about services needs and utilisation of services in Illinois. The authors highlighted that the most prevalent unmet needs reported were increasing memory or problem-solving skills (52%). Similarly, in a study involving 105 women with TBI in Canada [40], emerges that emotional and mental difficulties treatment is one of the areas declared to be poor.

In addition to this gap, our data also indicate a lack of services in terms of employment and occupational integration of ABI patients. Only 22% of ABI patients are regularly employed (14%) or sheltered employed (8%) which is significantly lower than the 53% of patients reported by Avesani and colleagues [41] in a study involving 353 Italian patients. The high percentage of non-reintegration in our sample is probably due to the severity of the outcome: 87% of patients in our sample need assistance in undertaking at least some activities whereas, in the study of Avesani and colleagues [41], only 38% of patients need assistance. However, the most worrying finding of our study is that 78% of the patients with GOSE levels of 5-6 and 71% of those with GOSE levels of 3-4 are not engaged in any activity. There are many factors predicting the lack of occupational reintegration after a brain injury, including advanced age [42], the presence of major motor disabilities [43], a low level of global cognitive functioning [44], long-lasting post-traumatic amnesia [45], and the presence of major personality changes [46]. These factors are often simultaneously present after a severe ABI which, by definition, causes motor, cognitive and behavioural alterations. It is, therefore, necessary to provide regional services to support the patients that cannot return to work. Two Italian Consensus Conferences [2, 3] have stressed the need to structure working and occupational alternatives not only to improve the patients' quality of life but also to encourage them to join in social activities and favour their reintegration within the community.

Our data show that 39% of the patients do not have any opportunity to participate in social activities, thus confirming published data indicating that social isolation is one of the factors underlying the most significant changes in the patients' and their families' lives [11, 33, 47]. In 2005, Lefebvre and colleagues [48] interviewed patients affected by traumatic brain injury, their relatives and physicians, and other healthcare professionals in Canada, and found a discrepancy between the substantial adequacy of the services during the acute phase and an overall lack of resources relating to the long term. Moreover, health professionals interviewed by Munce and colleagues [39] stressed the lack of dedicated work-return services for patients with acquired brain injury in Ontario, Canada.

Concerning caregiver's evaluation of the information received during hospitalization in the rehabilitation centers, 74% of the caregivers consider the information as adequate (58%), specific (7%) and clear (9%). Consistently with the discrepancy between rehabilitation and social services, the information received by the territorial services are considered by 53% of the caregivers as inadequate (35%), unclear (7%), late (6%) inaccurate (4%) and false (1%).

Rehabilitation services seem to offer not only adequate rehabilitation treatments but also to pay special attention to severe ABI's family. In two Italian Consensus Conferences on severe ABI [2, 3] the fundamental role of the family as a resource for the rehabilitation project is emphasized: the family and, whenever possible, the patient must be informed, trained and involved. The need to receive regular information is, in fact, the most prevalent need expressed by family members and it is one of the needs that literature emphasizes in a prevailing way [5, 9, 20, 31].

It is clear that the communication between hospitals and territorial services, which should facilitate the continuity of care of individuals with severe ABI [4] is still complex and difficult.

### ***Social and emotional impact of the ABI on the family***

The caregivers declared that they often (22%) or almost always (12%) feel worried about the caregiving commitment. They feel fatigued (44%), angry (19%) and abandoned (11%), and have fewer opportunities for social encounters (64%), which in any case seem to be less positive (34%) or more conflictual (7%) than before the event. We did not use specific questionnaire to investigate the emotional condition of caregiver. The literature has adequately demonstrated the impact of a severe acquired brain injury on family [10-15, 18]. For example, one of the first studies, conducted by the European Federation of Road Traffic Victims [49], refers to relatives of 1364 patients with TBI. The study found that 85% of the families of the victims with disabilities declared a significant decline in the quality of life. Such decline was defined as dramatic in half of the cases: a large proportion of the relatives of the victims suffer permanent psychological disorders, including anxiety attacks (46%) and suicidal feelings (37%). A review by Verhaeghe and colleagues [11] highlighted that level of stress requiring professional support in families of TBI

patients was present even after 10 to 15 years after the injury.

We wanted instead to verify whether there is a relationship between the amount of rehabilitation and assistance services provided and the social and psychological discomfort felt by family members. Caregiver's state of mind and declared worries, as well as the quality of the family's interpersonal relationships, were used as indicators of the quality of the adaptation of the caregiver. We did not find any significant association except for, as expected, that between the number of services and the caregiver's declared worries related to caregiving commitment: there were more worries among caregivers of patients who had not received any service (41.5%) or had received only one (47.7%) than among caregivers of the patients who had received more than one service (31.9%).

The results are in line with those obtained in a study designed to validate the Services Obstacles Scale by Kolakowsky-Hayner [28], which highlighted the substantial independence of the quality of life perceived by the members of 136 families of patients with a traumatic brain injury and the perception of not being supported with receiving services.

The lack of significant associations between the amount of rehabilitative and assistance services and the variables related to caregiver's adaptation to ABI can be explained by our analysis about the patient's occupational and social integration. As previously described, despite the adequacy of rehabilitative and assistance services, the majority of ABI patients are not engaged in any activity, neither leisure nor work activities. We, therefore, can presume that the care and assistance load experienced by the caregiver is very high, despite the rehabilitation services provided. Recent studies, in fact, highlighted how the number of daily hours dedicated to caregiving is one of the main factors associated with the level of burden perceived by caregivers [29, 50]. When the rehabilitative and social welfare services offered to patients do not lead to their subsequent social and occupational reintegration, the emotional adaptation of families becomes even more difficult. This is confirmed by Geurtsen and colleagues [51] who demonstrate a significant increase in psychological health and a significant decrease in perceived burden in a sample of 41 caregivers of ABI patients joining a community reintegration programme.

According to this, our findings related to the significant association between caregiver's state of mind and patients' opportunities of experiencing a social life, support our hypothesis. In particular, the sense of abandonment is less frequent among caregivers of patients who have such opportunities (24%) than among those of patients who do not experience any social life opportunities (32%). Similarly, the caregivers of patients without a social life are more likely to feel anger as well as serenity is positively associated with the patients' opportunities of having a social life.

Finally, according to the literature, caregivers who have the possibility to enjoy an extra-family social life reduces their perceived emotional burden. The relatives declaring a quantitative reduction in interpersonal

relations, and those who think that their relationships are more conflictual or less positive considered themselves to be the most fatigued and abandoned, and were more frequently “often” or “almost always” worried than those whose relations remained unchanged.

A number of published studies [33, 47, 52] have identified the perception of inadequate social support as one of the major determinants of a poor quality of life and a greater perceived caregiving burden. For example, Marsh and colleagues [10] found that social isolation and the presence of behavioural disorders were the most reliable predictors of the level of burden in 63 caregivers of patients with a traumatic brain injury.

### Study limitations

Firstly, a limitation of the study is that ABI patient's caregivers had not been assessed by means of specific questionnaires in order to better investigate their emotional condition. Secondly, most of the participants were recruited among hospitals and associations in the north Italy. This factor highlights a non-homogeneous national situation in the distribution of rehabilitation hospital and voluntary associations in Italy. However, we could not specifically analyze the variables “area of residence” because data are not balanced among the three main Italian areas. Furthermore, it would be interesting to analyze the variable “disease duration” in relation to caregiver's emotional condition in a future research. We could not address this variables in the present study because of an unbalanced sample distribution.

### CONCLUSIONS

Motor, cognitive, behavioural and emotional disorders affecting people after a severe acquired brain injury (ABI) can last for a long time and become chronic. Italian health system provides adequate rehabilitation services (e.g. aids, motor rehabilitation programs, follow-up), while data relating to the social and vocational rehabilitation are discouraging. The quantity and

quality of caregivers' social relationships seem to play a fundamental role on the emotional load perceived. A complex and multidisciplinary approach is necessary for patient and caregivers' quality of life, more focusing on participation and environmental aspects.

### Acknowledgements

The authors wish to thank everyone who has contributed to this study, all of the patients' families, the directors and staff operators of the rehabilitation centres, and the associations:

Istituto Sant'Anna (Crotone); Associazione Traumi Cranici Toscani; Presidio Sanitario Ausiliatrice (Fondazione Don Gnocchi Onlus, Turin); Associazione Traumi Onlus Casa Azzurra (Parma); Ospedale San Bartolomeo (Fondazione Don Gnocchi Onlus, Sarzana, La Spezia); Istituto Palazzolo (Fondazione Don Gnocchi Onlus, Milan); Ospedale Criscuoli (Fondazione Don Gnocchi Onlus, Sant'Angelo dei Lombardi, Avellino); Associazione gli Amici di Luca (Bologna); Ospedale SS. Trinità (Fossano, Cuneo); Eliasneuro-risabilitazione (Parma); Associazione Brain Onlus (Vicenza); Presidio Riabilitativo di Ceglie (Messapico, Brindisi); IRCCS Santa Maria Nascente (Fondazione Don Gnocchi Onlus, Milan); Ospedale E. Spalenza (Fondazione Don Gnocchi Onlus, Rovato, Brescia); Arco 92 (Casa Dago, Rome); Associazione Risveglio Onlus (Rome); Associazione Rinascita e Vita (Genoa); Associazione Genesis (San Pellegrino, Bergamo).

### Conflict of interest statement

The authors declare that they have no conflict of interest directly relating to the content of this paper. The authors disclose any financial and personal relationships with other people or organizations that could inappropriately influence their work.

Received on 7 December 2016.

Accepted on 13 July 2017.

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