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# Original article

# Is there a correlation between family functioning and functional recovery in patients with acquired brain injury? An exploratory study



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#### ABSTRACT

Background: Acquired Brain injury (ABI) is a very critical event in a family, as it is a highly distressing and traumatic experience, imposing a very deep reorganization of the whole family.

Objective: This study aims to evaluate the possible correlation between the family aspects and the patients' functional outcomes after rehabilitation.

*Methods:* Fifteen patient-caregiver pairs were enrolled in the study. All the patients were assessed by using specific neuropsychological and functional scales, including the Family Adaptability and Cohesion Evaluation Scales, before and after treatment.

Results: The results reveal that when the caregiver is the son or the spouse (p = 0.71), the perception of the emotional and physical burden is stronger, while the scores related to the burden were lower in the presence of other kinds of relationship. The family functioning seems to be connected to the burden level for the caregivers. Furthermore, there is a significant correlation between the improvements observed in the patients during their rehabilitative training and the family dynamics.

*Conclusions*: in our opinion, the family plays a key role in allowing a suitable compliance of the patient to the treatments, and supports the processes of adaptive reorganization.

# 1. Introduction

Acquired Brain Injury (ABI) is a brain damage, that occurs from a traumatic or non-traumatic event, and it is a leading cause of death and disability (De Luca, Calabrò, & Bramanti, 2016). According to Ownsworth, McFarland, and Young (2000) symptoms of brain injury can be grouped in four categories: perceptual, physical, cognitive and behavioural. Moreover, ABI is also a very critical, unexpected event in a family, and a highly distressing and traumatic experience, with a high psychological impact and adverse effects on patients and their caregivers, (Douglas & Spellacy, 1996; Perlesz, Kinsella, & Crowe, 1999; Walsh, 2003) imposing a very deep reorganization of the whole family. This situation can condition in many different ways the patient and all the members of their family. In fact, when the family is facing a traumatic event, all the members go through different phases, allowing a reorganization after the event: (Leibach et al., 2014; Onnis, 2002;

Scabini, 1985) at the beginning they feel "shock" (desperation, distress) and denial (refusal and the search for some kind of magic solutions); then there is the reorganization and, at the end, they could reach the acceptance, and a reinforcement of the new equilibrium may appear. If the family does not overcome each of these steps, there may be an "arrest". Consequently, family is a fundamental resource and an ally in the treatment of neurological patients, (Patterson & Garwick, 1994; Rolland, 1994; Rolland, 2002; Rolland, 2011; Rolland & Walsh, 2005) and it could be very important to consider the family as an essential element in the rehabilitative training. Indeed, the role of the family allows a suitable *compliance* of the patient to the treatments, and supports the processes of adaptive reorganization. Rolland (1994) asserts that adopting a systematic approach to the illness is fundamental.

Aim of the present study is to evaluate if it is possible to find a correlation between the family dynamics and the and the patients' functional outcomes after rehabilitation.

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 Table 1

 Descriptive analysis of patients and caregivers characteristics.

	Males	Females	All
Patients	9 (60.0%)	6 (40.0%)	15 (100%)
Age (years)	47.2 ± 17.5	56.0 ± 9.0	50.7 ± 14.9
Education			
Elementary	0 (0.0%)	0 (0.0%)	0 (0.0%)
Middle	3 (33.3%)	4 (66.6%)	7 (46.7%)
High	5 (55.6%)	1 (16.7%)	6 (40.0%)
University	1 (11.1%)	1 (16.7%)	2 (13.3%)
Etiology			
Hemorrhagic stroke	4 (44.5%)	5 (83.3%)	9 (60.0%)
Ischemic stroke	2 (22.2%)	0 (0.0%)	2 (13.3%)
Traumatic brain injury	2 (22.2%)	0 (0.0%)	2 (13.3%)
Aneurism	0 (0.0%)	1 (16.7%)	1 (6.7%)
Polytrauma	1 (11.1%)	0 (0.0%)	1 (6.7%)
Caregivers	6 (40.0%)	9 (60.0%)	15 (100%)
Relation to patient			
Son/daughter	2 (33.3%)	3 (33.3%)	5 (33.3%)
Spouse/partner	3 (50.0%)	5 (55.6%)	8 (53.4%)
Other	1 (16.7%)	1 (11.1%)	2 (13.3%)

Mean  $\pm$  standard deviation we used to describe continuous variables; proportions (numbers and percentages) were used to describe categorical variables.

# 2. Materials and methods

# 2.1. Subjects and design

15 patient-caregiver pairs were enrolled in the study. All the patients (6 females and 9 males), affected by ABI (with a traumatic or vascular etiology), were hospitalized at Neurorehabilitation Unit of the IRCCS Centro Neurolesi "Bonino-Pulejo", Messina, Italy. The mean age of the patients was 50.7 ± 14.9 years; all the study subjects were enrolled in the post-acute phase (i.e. 3-6 months from the acute neurological event). The paired caregivers (9 females and 6 males) were all patients' relatives. A more detailed description of both groups is reported in Table 1. All the participants were adequately informed about the study, and offered their collaboration and written consent. All the patients completed a specific and intensive rehabilitative training, consisting in daily sessions of standard physiotherapy, robotic training, cognitive rehabilitation, for 5 days a week for 6 weeks. Each subject was evaluated by a skilled neuropsychologist and a physiotherapist, through the administration of a specific neuropsychological battery (see Table 2). The patient's battery included: FACES IV for family aspect assessment (only to T1), MOCA to evaluate general cognitive status,

Hamilton Rating Scale Anxiety/Depression (HRS-D/HRS-A) to notice the emotional condition; and a functional scale (FIM), to assess the autonomy and physical independence. Caregiver's assessment included: FACES IV, HRS-A/HRS-D and Caregiver Burden Inventory. The patient's evaluation was carried out both before (T0) and after the treatment (T1). The caregiver's evaluation was carried out only before the treatment of the patient.

# 2.2. Statistical analysis

Continuous variables were expressed as mean  $\pm$  standard deviation or median  $\pm$  first–third quartile, as appropriate. Categorical variables were expressed as frequencies and percentages.

Because of the reduced sample's dimension, and since the Shapiro—Wilk test showed irregular distributions for many variables, a non-parametric analysis was performed. Correlations between variables were computed by Spearman's coefficient. Fisher's exact test was used to assess the associations in contingence tables, and the Mann–Whitney U test was used for comparison when appropriate. We used the Wilcoxon signed-rank test for comparing the patients' psychometric test scores between T0 and T1. Finally, we performed linear regression models to investigate the effects of the rehabilitative outcomes changes (i.e., for each clinical test we computed the difference between the two times as score at T1 - score at T0) on the family functioning of the patients.

# 3. Results

The analysis of all the data concerning the perception of the family dimensions, by using the FACES IV in the group of ABI patients, shows high levels of "Cohesion" (67.53), a high level of "Flexibility" (63.66), a medium trend to the "Disengagement" (48.93), a medium-high trend to the "Enmeshment" (56.2) and to the "Rigidity" (55.6), a low trend to the "Disorganization" (41.2). Moreover, patients declare to be in possess of a discrete perception of the quality of family communication (39.8), and to be generally satisfied (38.4) of their own family functioning. The analysis of the FACES IV data in the group of the caregivers shows high levels of "Cohesion" (75.46), and of "Flexibility" (69.93), a low trend to the "Disengagement" (39), of the medium levels of "Enmeshment" (50.4), very low levels of "Rigidity" (31), a low trend to the "Disorganization" (39). Moreover, caregivers show a good perception of the quality of family communication (40.8) and a good level of general satisfaction (39.6). No significant differences in caregiver's burden were observed between son/daughter and spouse/partner (p = 0.71), whereas the scores of the other family members were

Table 2
Tools of neuropsychological and functional measure.

Test/scale	Domain	Description
FACES IV	Family Functioning	The Family Adaptability And Cohesion Evaluation Scale IV is a family self-report used to assess the six dimensions of the Circumflex Model of Marital and Family Systems: cohesion (i.e. the emotional bonding that family members have toward one another), flexibility (i.e. the quality and expression of leadership and organization, role relationship), disengagement (i.e. lower levels of cohesion), enmeshment (i.e. very high levels of cohesion), rigidity (i.e. lower levels of flexibility) and disorganization (i.e. chaotic system) (Olson, Sprenkle, & Russel, 1979).
MoCA	Cognitive domains	The Montreal Cognitive Assessment is a brief cognitive screening assessing: The short-term memory, Visual-spatial abilities, executive functions, Attention, concentration and working memory, Language and orientation to time and place.
HAM-A	Anxiety	The Hamilton Anxiety Rating Scale is a rating scale developed to measure the severity of anxiety symptoms; the scale consists of 14 items, each defined by a series of symptoms, and measures both psychic anxiety and somatic anxiety.
HRS-D	Depression	The Hamilton Depression Rating Scale is a multiple item questionnaire used to provide an indication of depression, it is designed for adults and is used to rate the severity of their depression by feelings of guilt, suicidal ideation, insomnia, apprehension or retardation, anxiety, weight loss and somatic symptoms.
CBI	Caregiver burden	Caregiver Burden Inventory is a multi-dimensional questionnaire measuring caregiver burden with 5 subscales: Time Dependence (i.e. Burden associated with the time restriction for the caregiver); Developmental (i.e. perception to feeling excluded, compared to expectations and opportunities of their peers); Physical Burden (i. e. feelings of chronic fatigue and problems of somatic health); Social Burden (i. e. perception of a role conflict); Emotional Burden (i. e. feelings toward the patient). Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive).
FIM	Disability	The Functional Independence Measure is a questionnaire that allows measuring the disability, and it also inspects 18 activities of everyday life.

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