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Psychological status and role of caregivers in the neuro-rehabilitation of patients with severe Acquired Brain Injury (ABI)

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ABSTRACT

Objective: To investigate the relationships between (a) the *psychological status* of the caregiver, (b) the specific *features of caregiving* as perceived by the cognitive therapist in neuro-rehabilitation, (c) the caregivers' *subjective approach* to neuro-rehabilitation, and (d) the *functional outcome* of the patient.

Methods: Twenty-four patients with severe acquired brain injury and their 24 caregivers participated in this observational study. Caregivers underwent a psychological assessment examining emotional distress, burden and family strain; their subjective approach to neuro-rehabilitation has been evaluated by two specific answers. The patients' cognitive therapists responded to an ad-hoc questionnaire, namely the "Caregiving Impact on Neuro-Rehabilitation Scale" (CINRS), evaluating the features (i.e., amount and quality) of caregiving. Finally, the functional outcome of the patient was assessed through standardized scales of disability and cognitive functioning.

Results: The caregivers' *psychological well-being* was associated to the features of caregiving, to the subjective *approach* to neuro-rehabilitation, and to the *functional recovery* of their loved ones. A better caregivers' *approach* to neuro-rehabilitation was also associated to an overall positive impact of caregiving in neuro-rehabilitation and to a better *functional outcome* of the patients.

Conclusions: We posited a virtuous circle involving caregivers within the neuro-rehabilitation process, according to which the caregivers' psychological well-being could be strictly associated to a better level of caregiving and to a better functional outcome of the patients that, in turn, could positively influence the caregivers' psychological well-being. Although preliminary, these results suggest a specific psycho-educational intervention, aimed at improving the caregivers' psychological well-being and at facilitating their caring of the loved one.

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Introduction

Severe Acquired Brain Injury (ABI) can cause a wide range of neuromotor, neuropsychological and psycho-behavioural sequelae (1–6) requiring a complex, multi-professional and long-lasting rehabilitative process, as well as a constant assistance by at least one informal caregiver. Indeed, since the '80s of the past century, brain damage has been considered "a family affair" (7), since it involves not only the patient, but also the whole family system at different levels. Within the kinship network, a single person (the informal caregiver) is designated as the primary person that will take care of the patient. The informal caregiver ("caregiver" from now on) is defined as a person who, voluntarily and without receiving any payment, provides care and support to a loved one who is not self-sufficient in his/her family or social network (8).

Caregivers can have an active role in the rehabilitation process (9), and it is commonly observed in clinical practice the negative influence of inappropriate caregiving approaches to the patient, that in many cases hamper the neuro-rehabilitation team. Many factors may potentially influence caregiving. For example, it has been demonstrated that when

the patient is a man, the balance of functions in the family may upset since the mediator (i.e. the husband) loses his/her role because of brain injury; this change leads to conflict or alienation between the family of origin and the nuclear family of the patient, with predictable consequences on caregiving (10). Moreover, it is common to observe in the clinical practice that patients' mothers, differently than their spouses, often tend to do, *in place of* the patients, many daily-life activities, that is, they tend to substitute the patient even if he/she could be still able to perform such activities without any (or at least with a minimum) aid.

Since caregivers are deeply involved in the management of the patient and actively participate to the neuro-rehabilitation process, the wide range of physical, cognitive and psychological changes suffered by the person with severe ABI can cause in them a high burden (11,12) in terms of emotional or physical diseases (13,14), and social life and financial status negative changes (15,16), as a result of caring for their loved one (17–19). Caregivers are also often forced to many changes in their lifestyle and habits (20), so that their quality of life can be substantially affected

in many functional domains and needs (20–25), including sexual life (26) and quality of the relationship with the patients due to impairment in social cognition competences (27). All these factors may negatively impact on caregiving and, in turn, on the patient's outcome.

On the other side, the facilitating role of the caregiver has been demonstrated in several studies on patients with ABI. For example, the effective use of problem-solving and behavioural coping strategies by the caregivers was significantly related to lower levels of depression in patients with traumatic brain injury (TBI) (28). In patients with stroke, a caregiver empowerment program positively influenced functional capacity and quality of life of the patients (29). Also, as reported in some studies (30,31), a better emotional functioning (measured by Brief Symptom Inventory–Global Severity Index) in the caregivers contributed to greater productivity and social integration outcomes in patients with TBI after neuro-rehabilitation.

However, as stated in a recent review (32), there is still a gap in the knowledge of the impact of interventions on caregivers over the outcome of patients with TBI, as well as over the caregivers' psychological status and the patients' overall functional outcomes. Indeed, the literature has taken into account psycho-emotional variables mainly with respect to the overall *status of being* a caregiver, and with respect to the patient's outcome, but the relationship between these variables and specific features of caregiving has not been still examined.

Given this background, the present study aimed at investigating the relationships between (a) *the psychological status* of the caregiver (in terms of emotional distress, burden and strain), (b) *specific features of caregiving* as perceived by the cognitive therapist in neuro-rehabilitation (in terms of amount of time spent by caregivers in participating in the neuro-rehabilitation sessions, and quality of the caregiver assistance to the patient, mainly in terms of their availability, compliance and perceived trust with respect to the neuro-rehabilitation), (c) *the caregivers' subjective approach* to neuro-rehabilitation (in terms of difficulties in following therapist's suggestion and subjective trust in the neuro-rehabilitation project), and (d) *the functional outcome* of the patient.

In particular, the amount and quality of caregiving has been evaluated by cognitive neuro-rehabilitation therapists, through an ad-hoc developed questionnaire, namely the "Caregiving Impact on Neuro-Rehabilitation Scale" (CINRS).

We hypothesized the existence of a virtuous circle involving caregivers within the neuro-rehabilitation process, positing that caregivers' psychological well-being could be strictly associated to a better level of caregiving and to a better functional outcome of the patients that, in turn, could positively influence the caregivers' psychological well-being.

Methods

Participants

Twenty-five caregivers and their corresponding patients with severe ABI, consecutively admitted to the Post-Coma Unit of Santa Lucia Foundation in Rome (Italy) from May to

November 2019, have been included. The study was approved by the local Ethics Committee; all caregivers were included in the study after providing their written informed consent to be examined.

Patients were selected according to the following *inclusion* criteria: (1) age ≥ 16 years; (2) diagnosis of severe ABI [Glasgow Coma Scale (GCS) score ≤ 8 in the acute phase]; (3) presence of a primary caregiver who was actively involved by the cognitive therapist in the neuro-rehabilitation project of their loved one.

Caregivers *inclusion* criteria were: (1) willingness to undergo formal psychological evaluation; and (2) absence of any current or previous severe neurological or psychiatric disorders.

After enrolment, one caregiver was excluded because he refused to complete the assessment. Thus, the final sample consisted of 24 caregivers with the following socio-demographic features: 18 females (9 wives, 6 mothers, 2 partners and 1 daughter) and 6 males (3 fathers, 2 husbands and 1 partner), with a mean age of 51.8 years (SD = 12.6), and a mean educational level of 12.4 years (DS = 4.6).

The related 24 patients involved in the study were 16 males and 8 females, with a mean age of 45.0 years (SD = 15.9), and a mean educational level of 12.9 years (SD = 3.5); their time since injury ranged from 78 to 1793 days, with a mean of 372.8 days (DS = 365.2); 15 of them were inpatients and 9 were outpatients in day hospital regimen of neuro-rehabilitation. Among the 24 patients with a diagnosis of severe ABI, 12 suffered from TBI, 10 from vascular brain injury, one from sequela of neurosurgical tumour excision and one from anoxic brain damage due to cardiac arrest, because of Brugada Syndrome.

Measures

Caregiver psychological evaluation

The caregiver assessment provided information regarding their *emotional distress, burden* and *strain*, as well as their *approach to neuro-rehabilitation*.

Emotional distress.

Beck depression inventory (BDI-II). The BDI-II (33) is a self-report checklist for depressive symptoms (i.e., cognitive, somatic and behavioural symptoms of depression), composed of 21 items based on a Likert scale from 0 to 3; higher scores reflect higher depression levels. The internal consistency (Cronbach's alpha) has been described as around 0.9 and the test-retest reliability ranged from 0.73 to 0.96 (34). The BDI-II has been already used to assess caregiver's level of depression in different patients populations (35,36). In the present study we used the Italian version of the inventory (37).

State-trait anxiety inventory (STAI). The STAI (38) is composed by two sub-scales: STAI-X1, which assesses the *state* anxiety (i.e., the emotional state of an individual in a particular situation), and STAI-X2, which assesses the *trait* anxiety (i.e., a relatively stable characteristic of personality for predisposition to anxiousness). In the present study, we used only the STAI-X2. This part of the scale is comprised of 20 self-report questions based on a 4-point Likert scale. Higher scores

reflect higher anxiety levels. Internal consistency coefficients for the scale have ranged from .86 to .95; test-retest reliability coefficients have ranged from 0.65 to 0.75 (38). In the present study we used the Italian version of the inventory (39).

Prolonged grief disorder (PG-12). The PG-12 (40) is a 12-item questionnaire designed to help clinicians to diagnose the so called “Prolonged Grief Disorder” by measuring the persistently elevated set of specific symptoms of grief identified in people with problematic adjustment to a loss. It is divided into three sections: the first one (4 items) evaluates thoughts about the relative’s health condition, the second one (7 items) investigates the consequences of changes in free time and the third one (1 item) focuses on significant reduction in social activity or working because of the patient’s health condition. Higher scores reflect higher grief levels. PG-12 showed a good internal consistency of 0.88, and a mono-factorial structure (40); it has been used to assess the risk of prolonged grief in caregivers of different patients population (41,42). In the present study we used the Italian version of the PG-12 (43).

Burden and strain.

Caregiver burden inventory (CBI). The CBI (44) is a self-report questionnaire comprised of 24 items on burden on a 5-point Likert scale. CBI provides sub classification in five different domains: time dependency, development, physical health, emotional health, and social relationship. Higher scores reflect higher burden levels. Internal consistency reliability of the scale’s factors ranged from 0.73 to 0.85 (44). This inventory is commonly used for assessing level of burden in caregivers of different patients population (45,46) also in ABI (47). In the present study we used the Italian version of the inventory (48).

Family strain questionnaire (FSQ). The FSQ (49) has been used to evaluate family strain in caregiver of different patients population (50,51). It is a brief semi-structured interview consisting of 44 dichotomous items that investigate five areas: emotional burden (14 items), problems of social involvement (7 items), need for knowledge (4 items), quality of family relationships (4 items) and thoughts of death (6 items). For the purpose of the present study, we used the FSQ total score (higher total score reflects the presence of more family strain problems). The internal consistency value for the instrument as a whole was 0.87 (49).

Caregivers’ subjective approach to neuro-rehabilitation

To investigate possible caregivers’ difficulties in following the therapists’ suggestions about interacting with and managing the patient (i.e., caregivers’ *compliance*), as well as their *trust* in the neuro-rehabilitation process, the following two questions have been asked to the caregivers:

- CQ1: “Are you in trouble in following the therapist suggestions?” [scored as 0 (“Yes”) or 1 (“Not at all”)];
- CQ2: “Do you generally feel trust in the neuro-rehabilitation process involving your loved one?” [scored as 1 (“Not at all”), 2 (“A little”), 3 (“Enough”), 4 (“Much”), or 5 (“Very much”)].

Caregiving evaluation by the cognitive therapist

Caregiving impact on neuro-rehabilitation scale (CINRS). The CINRS is a new Italian questionnaire, developed to collect information on the neuro-rehabilitation process in adult

patients with severe ABI, with specific reference to the role played by the caregivers in the neuro-rehabilitation of their loved one. In particular, the CINRS was aimed at investigating the caregivers’ participation to the neuro-rehabilitation sessions, as well as their tendency to follow the suggestions by the therapist, potentially useful to help the patients in generalizing to the activities of daily life what they learned in neuro-rehabilitation. It has been administered to the cognitive therapist of the patient, who responded to questions included into two sections: CINRS-A, which specifically investigated the *amount of time* spent by the caregiver in participating to the neuro-rehabilitation sessions, as well as the quality of the caregiver assistance to the patient (in terms of *trust, compliance, and cooperation* to the neuro-rehabilitation team and project); CINRS-B, by which the therapist judged the *general improvement of the patient* at the end of the neuro-rehabilitation project.

The CINRS-A consists of eight items (A1-A8), with three or five response options [(from low (1) to high (5) level of *amount* or *quality* of caregiving)]. They assess: A1: *time spent* by the caregiver for caring the care recipient (from “Never/Less than once a week” = 1 point, to “Every day, all day” = 5 points); A2: *frequency of caregiver participation to the therapy sessions* (from “Never/Less than once a week” = 1 point, to “Every day” = 5 points); A3: *caregiver presence in the neuro-rehabilitation process in terms of participation/collaboration* (from “Not at all” = 1 point, to “Very much” = 5 points); A4: *substituting attitude* (from “Not at all” = 5 points, to “Very much” = 1 point); A5: *patient’s cooperation in presence of caregiver* (from “Much less” = 1 point, to “Much more” = 3 points); A6: *caregivers’ trust in the neuro-rehabilitation process* as perceived by the therapist (from “Not at all” = 1 point, to “Very much” = 5 points); A7: *availability* of the caregiver (e.g., in terms of whether it was possible to interact with them when necessary) (from “Not at all” = 1 point, to “Very much” = 5 points); A8: *global influence* of the caregiver (facilitating or hindering) in the whole neuro-rehabilitation process of the patient (from “He/she has clearly hampered it” = 1 point, to “He/she has clearly facilitated it” = 5 points). The SECTION-A total score can range from 8 to 38: higher scores indicate a better caregiving (in terms of *amount* and *quality*).

The CINRS-B consists of a 10-point Likert-type scale by which the therapist judged the improvement of the patient at the end of the neuro-rehabilitation project, ranging from 0 (“no improvement”) to 10 (“as much improved as possible”). For details on the CINRS please see the Annex).

Functional outcome of the patients

Disability rating scale (DRS). The DRS (52) is a 30 point scale that assesses 8 areas of functioning: eye opening, verbalization, motor response, levels of cognitive ability for feeding, toileting, and grooming, level of independence, and employability. Scores on the 8 items are summed to obtain an overall score that can range from 0 to 29, with 0 representing intact functioning and 29 representing a vegetative state.

Level of cognitive functioning scale (“Rancho Los Amigos Scale”) (LCF). The LCF scale (53) examines the *cognitive* and *behavioral* functioning levels of the patients, ranging from 1 to 8. Higher scores reflect better functioning.

For our purpose, we considered the LFC and DRS at the entrance of the patient into the hospital and at the discharge (i.e., at the end of the neuro-rehabilitation process).

Procedure

Within 10 days before the patients neuro-rehabilitation hospital discharge, a caregiver (identified as *primary* caregiver by one of the cognitive therapists who took part to this study and cared for the patients) has been contacted by a psychologist to request his/her availability to participate to this study and, accordingly, to obtain the informed consent.

After enrolment, within one week, a psychologist carried out the psychological assessment of each caregiver, as well as the data collection on the caregiver's subjective approach to neuro-rehabilitation. The psychologist separately administered also the CINRS to the cognitive therapist involved in the neuropsychological rehabilitation of the related patient. Finally, a neurologist completed the patient's final functional assessment (i.e., DRS and LFC), as already done at the beginning of the neuro-rehabilitation project.

Statistical analysis

Data analysis was carried out using SPSS software (version 22). Descriptive statistics were used to illustrate the demographic characteristics of the patients and caregivers sample (see the Participants paragraph).

The total scores of each test of the caregiver psychological evaluation, the CINRS-A total score, the variables related to caregivers' subjective approach to neuro-rehabilitation, and the neuro-rehabilitation outcome total scores, were submitted to bivariate correlation analysis. Spearman's rho coefficients were computed.

Moreover, given their specific relevance, the CINRS-A4 (i.e., "How much does the caregiver replace the patient") and

CINRS-A8 sub-scores ("In your opinion, which influence the caregiver globally had on patient neuro-rehabilitation?"), as well as the CINRS-B score ("According to your opinion, on a scale of 1 to 10, from the beginning of the treatment, how much has the patient improved?") have also been included in the analysis, separately.

Results

Descriptive data for caregiving assessment (CINRS-A total score and CINRS-A4 and CINRS-A8 sub-scores) and complete caregiver psychological evaluation are reported in Tables 1 and 2, respectively.

Correlation between therapist's and objective assessment of patients' functional level

The clinical judgment of the cognitive therapists about the general patient's improvement (CINRS-B sub-score) was related to the *objective* cognitive and functional improvement measure by the above mentioned standardized Scales (LFC and DRS) scores.

A partial correlation analysis between LFC score at the end of the neuro-rehabilitation and CINRS-B score was preliminarily run, controlling for the effect of the LFC score at the patient's admission. Results from this analysis showed a significant positive correlation between the therapist judgment of the patient improvement and LCF score at the discharge time ($\rho = 0.579, p = .04$), after controlling its effect at the admission time.

A similar analysis was performed taking into account the two DRS scores (admission vs. discharge times), that is controlling the effect of the DRS at the entrance. Even in this case, results showed a significant negative correlation between the therapist judgment of the patient improvement and level of disability ($\rho = -0.641, p = .001$), when the effect of disability at

Table 1. Descriptive data of CINRS total score and CINRS sub-scores specifically analyzed.

Variable	Possible range	Mean	SD
CINRS-A total score	5–48	26.8	4.3
CINRS-A4: Caregiver substitutive attitude toward the patient	1–5	4.0	0.9
CINRS-A8: Influence of the caregiver in patient's rehabilitation	1–5	4.1	1.0
CINRS-B: Patient's improvement from the beginning of the treatment	1–10	6.4	2.1

Legend

CINRS: Caregiving Impact on Neuro-Rehabilitation Scale

Table 2. Descriptive data of psychological scales scores.

Variable	Range	Mean	SD
BDI-II	0–63	8.9	7.6
STAI-X2	20–80	34.6	8.5
PG-12	11–55	24.9	13.7
CBI	0–96	23.5	14.2
FSQ	0–44	19.2	6.5

Legend

BDI-II: Beck Depression Inventory

STAI-X2: State-Trait Anxiety Inventory: *trait* anxiety

PG-12: Prolonged Grief Disorder

CBI: Caregiver Burden Inventory

FSQ: Family Strain Questionnaire

the entrance was controlled (notice that the lower is the DRS score, the lower the patients' disability).

Correlation between CINRS scores and caregivers' psychological variables

Table 3 shows the correlation matrix between the *quality* and *amount* of caregiving through the cognitive therapists' judgment (i.e., CINRS-A and CINRS-A4 and CINRS-A8 sub-scores) and the patients' outcome [as perceived by the same therapists (CINRS-B scores) and by an objective functional disability scale (DRS score)], and the caregivers' *psychological status* (in terms of emotional distress, burden and strain).

To assess mood and other psychological variables, we included in the analysis the BDI-II (depression), STAI-X2 (trait anxiety), and PG-12 (prolonged grief disorder) total scores.

As shown in Table 3, the analysis revealed significant negative correlations between CINRS-A8 sub-score (*influence of the caregiver on neuro-rehabilitation* according to the therapist) and all the variables of interest (BDI-II, STAI-X2, and PG-12), that is, the better the influence of caregivers on neuro-rehabilitation outcome, the lower the presence of depression ($\rho = -0.477, p = .009$), trait anxiety ($\rho = -0.617, p = .001$) and prolonged grief disorder ($r = -0.420, p = .021$); a significant negative correlation emerged also between CINRS-A total score (i.e., the *overall quality of caregiving* according to the cognitive therapist) and STAI-X2 score ($\rho = -0.572, p = .002$).

Also the DRS score (i.e., an objective measure of the patients' functional disability) correlated with STAI-X2 score (i.e., trait anxiety; $\rho = 0.349, p = .047$), PG-12 score (i.e., prolonged grief disorder; $\rho = 0.498, p = .007$), as well as the CINRS-B score (i.e., the therapist judgment about patients' improvement) correlated with the PG-12 score ($\rho = -0.463, p = .011$). In both cases, as expected, the higher the index of functional recovery of the patients, the lower the psychological distress in their caregivers.

As for the results related to burden and family strain of the caregivers, we considered the CBI and FSQ scores. As expected, analysis revealed all significant correlations (in the expected directions) between both these variables with all the CINRS scores taken into account, as well as with both the (subjective and objective) measures of the patients' outcome (see Table 3).

Correlation between caregivers' subjective approach to neuro-rehabilitation, caregivers' psychological status and features, and patients' functional outcome

Table 4 shows the correlation between caregivers' subjective approach to neuro-rehabilitation process (in terms of *trust* and *difficulties*) and the same *psychological* variables, the *quality* and *amount* of caregiving, and the *functional outcome* of the patient.

As shown in Table 4, CQ1 score (*caregivers difficulties* following the therapists recommendations, that can be considered an index of the caregivers' compliance to the neuro-rehabilitation team) showed significant negative correlations in the expected direction with the FSQ score (*family strain*; $\rho = -0.481, p = .018$), that is the higher the compliance (i.e., higher CQ1 scores), the lower the family strain. Also the CQ2 score (i.e., the *trust* in the neuro-rehabilitation process) showed significant negative correlation with PG-12 score (*prolonged grief disorder*; $\rho = -0.600, p = .001$) and with FSQ score ($\rho = -0.426, p = .019$), as expected.

Finally, another interesting finding is the relationship between caregivers' perspective in the neuro-rehabilitation process, and both the typology of caregiving according to the therapists and the functional outcome of the patient. Indeed, the CQ2 score (caregivers' feeling of *trust* in neuro-rehabilitation) correlated positively with the CINRS-A8 sub-score (i.e., the caregivers' facilitating role in the patient's neuro-rehabilitation; $\rho = 0.418, p = .021$), as well as with the CINRS-B score (i.e., the patients' functional improvement as perceived by the therapists; $\rho = 0.445, p = .015$).

Table 3. Rho Spearman bivariate correlation between CINRS scores and caregiver's psychological variables.

	Psychological variables				
	BDI	Emotional Distress STAI-X2	PG-12	Burden and Strain CBI	FSQ
CINRS-A total score	-.326	.572**	-.203	-.397*	-.486**
CINRS-A4	-.197	-.073	-.131	-.506**	-.498**
CINRS-A8	-.477**	-.617**	-.420*	-.494**	-.644**
CINRS-B	-.229	-.070	-.463*	-.457*	-.428*
DRS	.292	.349*	.498**	.616**	.508**

Legend

* $p < 0.05$

** $p < 0.01$

CINRS: Caregiving Impact on Neuro-Rehabilitation Scale

CINRS-A4 sub-score: Caregiver substitutive attitude toward the patient

CINRS-A8 sub-score: Influence of the caregiver in patient's rehabilitation

CINRS-B score: Patient's improvement from the beginning of the treatment

DRS: Disability Rating Scale

BDI-II: Beck Depression Inventory

STAI-X2: State-Trait Anxiety Inventory: *trait* anxiety

PG-12: Prolonged Grief Disorder

CBI: Caregiver Burden Inventory

FSQ: Family Strain Questionnaire

Table 4. Rho Spearman bivariate correlation between caregivers questions about their own perception of the rehabilitation process, and scores on psychological, caregiving and functional outcome variables.

	Psychological variables					Features of caregiving			Patients functional outcome (therapist's judgment)
	Emotional Distress			Burden and Strain		CINRS-A4	CINRS-A8	CINRS-A total score	CINRS-B
	BDI	STAI-X2	PG-12	CBI	FSQ				
CQ1	-.329	-.372	-.328	-.328	-.481*	0.357	0.198	0.121	-0.022
CQ2	-.307	-.29	-.600**	-.282	-.426*	0.22	0.418*	0.297	0.445*

Legend

*p < 0.05

**p < 0.01

CQ1): Question 1 to the caregiver: "Are you in trouble in following the therapist suggestions?"

CQ2): Question 2 to the caregiver: "Do you generally feel trust in the rehabilitation process involving your loved one?"

BDI-II: Beck Depression Inventory

STAI-X2: State-Trait Anxiety Inventory: *trait* anxiety

PG-12: Prolonged Grief Disorder

CBI: Caregiver Burden Inventory

FSQ: Family Strain Questionnaire

CINRS: Caregiving Impact on Neuro-Rehabilitation Scale

CINRS-A4 sub-score: Caregiver substitutive attitude toward the patient

CINRS-A8 sub-score: Influence of the caregiver in patient's rehabilitation

CINRS-B: Patient's improvement from the beginning of the treatment

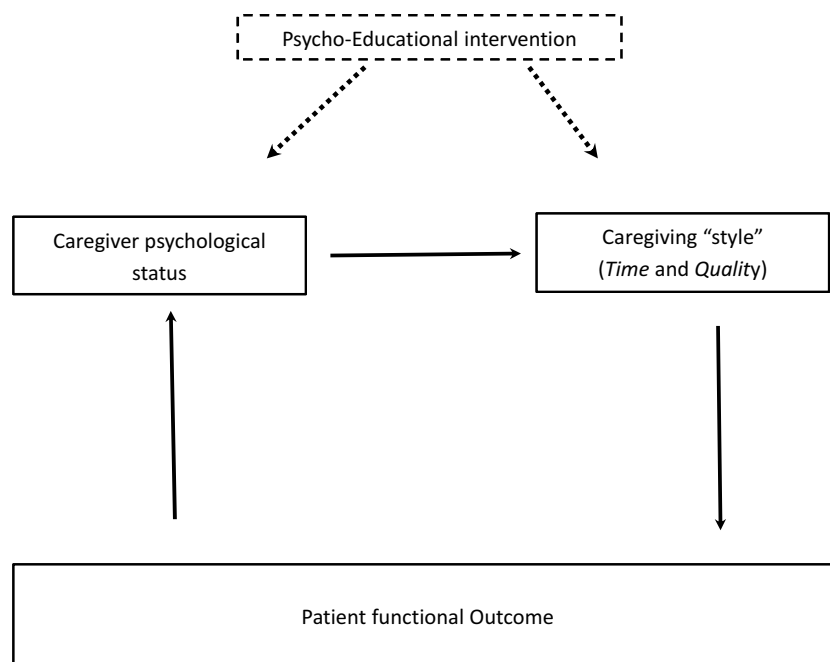
Discussion

The present study aimed at investigating the possible relationships between the *psychological status* of the caregivers, specific *features of caregiving*, the caregivers' *subjective approach* to neuro-rehabilitation, and the *functional outcome* of the patient. In particular, we hypothesized a virtuous circle, according to which the caregivers' psychological well-being can be strictly associated to a better caregiving and to a better functional outcome of the patients that, in turn, could positively influence the caregivers' psychological well-being (see [Figure 1](#)).

The study tried to overcome limits of the existing literature, by deeply investigating the features of caregiving in relation to the other variables of interest, that is, the psychological status

of caregivers and the functional outcome of the related patients. With this in mind, we created the CINRS, a newly developed questionnaire that, through the judgment of an expert cognitive therapist, allowed obtaining information on eight specific domains of caregiving.

Since the scoring of the CINRS is based on the cognitive therapist judgment, we performed a preliminary statistical analysis between both the *objective* validated measures of the patients' residual disability (i.e., LFC and DRS scores) at the end of the neuro-rehabilitation project, and the therapist judgment on *whether* and *how much* the patients functionally improved at the discharge from the neuro-rehabilitation hospital (i.e., CINRS-B score), controlling for their effect at the

**Figure 1.** Virtuous-Circle Model on the impact of *Psycho-Educational intervention* on both caregivers *psychological well-being* and type of *caregiving style*, which in turn can be strictly associated to *patient rehabilitation outcome*. Circularly, it is also expected that a better patients' rehabilitation outcome could increase caregivers' psychological well-being.

patients' admission. Such analysis showed significant correlations between the therapist judgment and both LFC and DRS scores at the discharge time, when their effect at the admission time were controlled, thus suggesting that all the therapists who participated to the study were sufficiently reliable regarding their clinical judgment.

Our data showed that a better psychological status of caregivers, in terms of lower levels of *trait anxiety*, *burden* and *strain*, was significantly associated to better features of caregiving (in terms of *amount* and *quality* of assistance to the loved one), according to the cognitive therapist judgment (i.e., the CINRS total score). In particular, being caregivers who positively influenced the neuro-rehabilitation of their loved ones (i.e., CINRS-A8 scores) was strictly associated to lower levels of *depression*, *trait anxiety*, *prolonged grief*, *burden* and *strain*, as well as lower levels of *burden* and *strain* were also associated to lower caregivers' attitude to be substitutive of the patient (i.e., CINRS-A4 scores). These results join with those of previous studies, which demonstrated that an adequate approach in caring of the loved one was significantly related to lower levels of depression in the patients with TBI (28), as well as that navigating the system is one of the main caregivers' needs (54). Conversely, previous results have shown that caregivers who actively participating to the neuro-rehabilitation process, were also exposed to emotional distress, mood disorders, burden (11–14,17–19), and reduced personal independence (55–61). However, it is worth noting that the cited studies did not deeply investigate the quality of caregiving as we did in the present study. Indeed, our results seem to suggest that the emotional distress, burden and strain of caregiver could be mainly related to the *quality* of assistance to the loved one, rather than to the caregiving itself. In fact, we found that the better the quality of caregiving (for instance, in terms of availability, compliance, trust in neuro-rehabilitation project, as demonstrated by the CINRS), the lower the level of emotional distress. Furthermore, even exploring the caregivers subjective *approach toward neuro-rehabilitation*, our data revealed that feeling of *trust* in neuro-rehabilitation (CQ2 score) was strictly related to lower levels of prolonged grief disorder and of family strain; this latter variable, coherently, was also related to lower difficulties in following the therapists suggestions within the neuro-rehabilitation setting (CQ1 score). Taken together, these results can be considered among the innovative aspects of the present work, since to our knowledge no studies to date have specifically investigated and linked the constructs above in terms of a possible virtuous circle. The close relationship between the *specific features* of caregiving and the psychological well-being of caregivers we found, underlines the importance for a caregiver to facilitate the patients' autonomy, avoiding substitutive behaviours, not only to allow the loved on to reach earlier the rehabilitative aims, but also to reduce the burden that caregiving itself may cause.

Another innovative aspect of the present work is the close significant relationship emerged between the index of *trust* in the neuro-rehabilitation reported by the caregivers, and the overall positive influence of caregiving in neuro-rehabilitation and the patient's functional outcome, according to the therapist's clinical judgment. This result suggests that the better the subjective approach to neuro-rehabilitation, the better the

feature of caregiving and the better the outcome of the patient at the end of the neuro-rehabilitation process.

Finally, the final functional recovery of the patients was also significantly associated to *emotional distress* of caregivers, that is, the better the patient's functional outcome (as objectively measured by DRS score), the lower the caregivers' levels of *trait anxiety* and *prolonged grief disorder*. We found this relationship also after using, as a measure of functional outcome of the patients, the therapist clinical judgment (i.e., the CINRS-B score). Furthermore, both measures of patients' functional outcome were also congruently associated to caregivers' *burden* and *strain*. Taken together, our data are in line with those of previous studies, which demonstrated that the functional outcome of the patients was related to the psychological well-being of their caregivers (30,31).

Although preliminary, these results suggest the usefulness of a specific psycho-educational intervention, aimed at improving the caregivers' psychological well-being and at facilitating their caring of the loved one, in a context of trust, with the final aim of a better functional recovery of the patients after severe ABI. In fact, our results sustain the hypothesis of a virtuous circle, fully in line to what we usually observe in our clinical practice.

The present study presents some limits. First, the relatively small sample size of caregivers could have affected the power of statistical analyses, particularly as for negative results, being more difficult to identify smaller potential contributions from other variables included in the analysis (62). Thus, further studies on larger samples of caregivers with severe ABI are needed to increase the validity and generalizability of our results. Moreover, we included only patients whose primary caregivers were available, at least partially, in the neuro-rehabilitation process. This latter limit requires caution in interpreting data on the relationship between caregiving and the outcome of the patient, since a comparison with a subgroup of patients without the (or with a minimum) support of a primary caregiver is recommended to obtain more reliable data. Finally, we must underline that the CINRS is an unpublished questionnaire. In fact, even if it was developed by the authors, according to their long-term clinical experience in treating the patients and their caregivers during post-acute neuro-rehabilitation phase, the questionnaire likely does not incorporate all the possible caregiving domains. However, CINRS could be considered a useful measure to assess at least some important aspects of the caregiving features (in terms of quality and quantity) after severe ABI.

Conclusion

The present study may offer some relevant and innovative contributes to the existing literature on caregiving in the field of severe ABI. Indeed, to our knowledge this is the first study that deeply considered the relationship between some specific features of caregiving (by the observations of expert cognitive therapists in neuro-rehabilitation, as well as by caregivers' reports themselves), in relation to the caregivers' psychological status and to the functional outcome of the related patients.

First, our data revealed that the emotional distress of caregivers, besides its close relationship with the functional recovery of the patient, might be strictly related also to the specific feature of caregiving. Indeed, the *amount* and *quality* of caregiving, as well as participating with ease to the neuro-rehabilitation project, together with feeling trust in the neuro-rehabilitation of the patient, were found to be relevant factors significantly associated to the psychological well-being of caregivers. In particular, it is worth noting that – as revealed by the CINRS – the psychological well-being of caregivers is mostly associated to their positive impact on the neuro-rehabilitation project. Another relevant data emerged from our study is that the functional outcome of the patients has been significantly associated to the trust in the neuro-rehabilitation experienced by caregivers.

Accordingly, our results underline once again the importance of adequately integrating at least one primary caregiver within the neuro-rehabilitation process of persons with severe ABI. With this in mind, in our neuro-rehabilitation hospital each cognitive therapist, in team with a clinical psychologist specially dedicated to caregivers, usually involve a primary caregiver at least once a week within the cognitive neuro-rehabilitation setting, in order to guide him/her in congruently approaching and managing the patient as best as possible, thus avoiding dysfunctional practices.

Accordingly, we recommend a specific psycho-educational intervention on caregivers, aimed at contributing both to the functional improvement of the patient, and – last but not least – to the psychological well-being of caregivers themselves, in this very dramatic phase of their life.

Conflicts of interest

The authors declare that they have no conflicts of interest regarding the publication of this paper.

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