



Beyond the Classical Psychotherapeutic Setting to Better Provide Support for Caregivers of Persons with Severe Acquired Brain Injury: Some Clinical Evidence

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Abstract

The psychological distress of caregivers of individuals with acquired brain injury (ABI) has been well documented. In fact, there are frequent reports of family strain, depression, emotional difficulties, burden, anxiety, social isolation, loss of income and problems adjusting to new roles.. Given the above background, the present paper aimed at better defining the role of the psychologist in a severe ABI rehabilitation setting through the identification of "new" practices to support caregivers. Our clinical experience with caregivers suggest the usefulness of "sewing" the psychological setting (where and how) on the basis of the specific context (in terms of chronicity and severity of injury) in which the therapeutic relationship occurs. The intervention is mainly educational in the early phase, as the psychologist can support the caregiver also outside the therapy room and essentially on the basis of his/her relationship with the survivor. It becomes purely psychological only later, because it is more classically structured and takes place inside the therapy room and is essentially based on the emotional needs of the caregivers. In conclusion, our study suggests to adapt psychological support according to caregivers needs specifically related to the rehabilitation process and phases, even informally outside the classic psychotherapeutic setting.

Keywords: Neuropsychoterapy; Psychological support; Caregiver; Acquired brain injury; Psychological setting; Neurorehabilitation setting

Introduction

Over the last three decades the psychological distress of caregivers of individuals with acquired brain injury (ABI) has been well documented in the literature. In fact, there are frequent reports of family strain, depression, emotional difficulties, burden, anxiety, social isolation, loss of income and problems adjusting to new roles [1-8]. Survivors of severe ABI may show many personality, cognitive and psychosocial changes that can impair the whole family system [9]. The unpredictable and dramatic nature of the event, uncertainty about the future, frustration related to length of recovery, difficulty understanding and accepting behavioral disorders, financial problems, role changes and social isolation can contribute to affecting the family system of survivors [10]. In particular the caregiver, defined as the person close to the survivor who, "without financial compensation, regularly assists a care recipient in carrying out one or more activities or instrumental activities of daily living" [11], may sacrifice a career, personal ambitions, relationships and leisure to care for an injured family member [8].

The occurrence of a family crisis can be due to the interaction between the stressor event (i.e., the ABI), family resources for dealing with this event and family members' perceptions of it [12-14]. Among survivors' injury-related consequences, severity of injury has been shown to bear little relationship to caregivers' levels of burden or psychological distress three months after the injury [1,15]. A moderate relationship has been found between cognitive difficulties and caregiver distress [1,15], whereas survivors' emotional and behavioural changes have been shown to be more related to relatives' burden and psychological distress [15-17] and caregivers' strategies to cope with stress [17].

The most useful coping strategies for the family are talking to friends, participating in psychological support groups, being actively involved in the patient's rehabilitation, living day by day and focusing on the here and now as well as on positive aspects, identifying and

using community resources, engaging in prayer, devoting time to themselves and taking care of their physical appearance [18]. Thus when studying caregiver adjustment following ABI it is important to consider the characteristics of caregivers such as coping style and satisfaction with social support. Indeed, according to Sander et al. [14], these characteristics are more predictive of caregiver outcome than the level of patient functioning regardless of time since injury [14].

Caregivers' involvement and management is very useful in the early stages of patients' hospitalization (i.e., in the Intensive Care Unit - ICU) to facilitate the rehabilitation process and promote better outcomes. In fact, Smith and Smith [19] suggested that during the course of patients' ICU stay the family should receive immediate and continuing support to enable it to bear the physical, social and financial costs of its caregiving responsibilities. Furthermore, the need for information is considered more important in the first phases [20], whereas emotional support is required later, when the caregiver is no longer exclusively focused on the patient's needs [21,22]. Thus, family support is crucial from the early phases of traumatic brain injury (TBI) to enhance the entire rehabilitation process. In fact, it is important that professionals pay more attention to the suffering of close relatives [23]. Indeed, the severe ABI patient's caregiver primarily needs information, trust, hope and understanding, support, talk in behalf of the patient and be part of the rehabilitation project [19].

Recently, various psychological interventions have been carried out

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in rehabilitation facilities to help caregivers deal with their emotional needs after the ABI of a close relative [24-26]. However, although there is clear evidence that all family members are profoundly affected after an ABI, few and controversial data exist about the psychological support they should receive [27,28]. Indeed, systematic reviews comparing several interventions for caregivers, such as education, case management, psychotherapy, individual and family counseling, support groups, respite, skills training, computer networking and multi-component interventions, found no single intervention that had a consistent significant impact on caregiver or family well-being [8,29-31]. In particular, Cooke et al. [30] found that two-thirds of interventions produced no desired outcomes, probably because of methodological issues [8]. However, what is still unknown is whether no intervention would result in poorer outcomes.

Given the above background, the present paper aimed at better defining the role of the psychologist in a severe ABI rehabilitation setting through the identification of “new” practices to support caregivers. In particular, we took into account individual differences between caregivers including the context they had to deal with.

A Preliminary Study to Better Target the Psycho-Educational Support in a Post-Acute Rehabilitation Setting

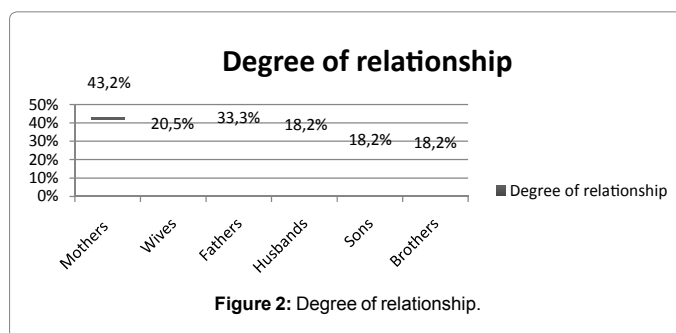
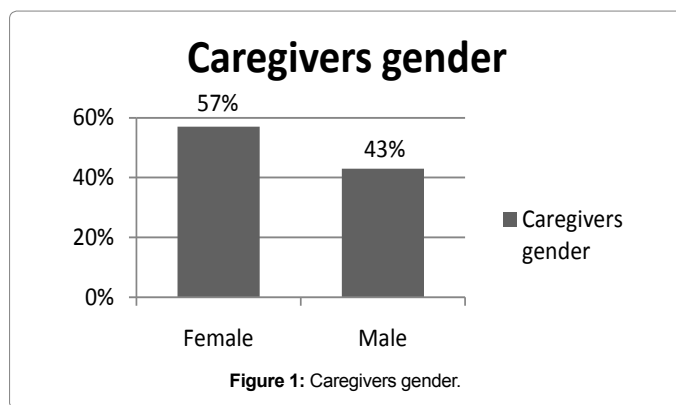
To better address the above mentioned clinical issues concerning the possible psychological intervention in this field and to investigate the emotional burden and psychological needs and difficulties of family members of persons with severe ABI, we previously designed an unpublished ad-hoc questionnaire, namely, “The Family Needs Questionnaire (FNQ)”, which was administered to all caregivers. The FNQ collects psychosocial data (i.e., age, gender, educational level, kind of work/study, cultural and/or social activities) of caregivers and information about the number of caregivers and the possible presence of an emotional or practical support: it also collects other basic information including the possibility of caregivers continuing to work or study full- or part-time. In particular, the FNQ aims to identify the main needs of caregivers and any other information they think is relevant during the rehabilitation process.

The FNQ was preliminarily administered to 77 caregivers (44F and 33M) of 39 persons with severe ABI (in half of the cases due to a severe TBI) consecutively admitted to our post-Coma Unit (PCU) from January 2009 to January 2010.

As shown in Figure 1, the female caregivers were mostly mothers (43.2 %), wives (20.5 %) or other (e.g., sisters, grandmothers or aunts in other cases – 36.3 %) (Figure 1), whereas most of the male caregivers were fathers (33.3%), husbands, sons or brothers (18.2 % in each case) or other (12.1%) (Figure 2).

The role of caregiver was defined on the basis of the total amount of time spent with the survivor, the closeness of the emotional relationship and the degree of the family relationship.

Based on these criteria, 39 primary and 38 secondary caregivers were identified. Analysis of the differences between these two groups of caregivers, who were matched for age, gender and level of education, revealed that an ABI has a similar effect on the social life activities of the two groups. However, there was a tendency for primary caregivers to reduce some activities to a greater extent, including the frequency of leisure activity (e.g., going to the cinema or theater or walking),



thus demonstrating a high level of unwillingness to leave the home. Consistently with their greater burden of care provided to survivors, primary caregivers complained of economic problems related to the event more than secondary caregivers (53.9% vs 39.5%).

Our data are in line with the literature [20] in which the main needs of caregivers are to receive medical and technical information about the survivor to better manage their anxiety, confusion and doubts regarding outcome, which are typical in the acute and post-acute phase. Our investigation also revealed the importance of considering the caregiver together with the survivor throughout the rehabilitation period in the PCU.

Interestingly, the data emerged from the FNQ suggest that besides clinical and technical information specific individual support from the psychologist in a standard setting is required only by a few caregivers (mainly women). Indeed, caregivers’ typical statements are: “Thanks for your proposal to support me, but at the moment I prefer that you care for my (the patient)! I don’t want to take time from my daily caregiving activities. He/she needs me!”.

Taken together, our data suggest the importance of adapting the psychological intervention by considering two main dimensions: caregivers’ specific characteristics and their coping styles strictly related to chronicity (i.e., the distance between ABI onset and the time and level of current rehabilitation).

Psycho-Educational Support in the Post-Coma Unit of Santa Lucia Foundation

In this section we will describe the procedure we carry out to psychologically assist caregivers in the Post-Coma Unit (PCU) of Santa Lucia Rehabilitation Hospital on the basis of the data that emerged from the FNQ and our clinical experience.

The first meeting between the family and the psychologist

When the patient is admitted to the PCU, the family is welcomed by a physician and a psychotherapist of the ward who is expert in the field of ABI. The family receives a “welcoming letter” and the “Guide for family members of comatose and post-comatose patients” [32], which is an Italian information booklet (pamphlet) that describes coma (after an ABI) and the possible short- and long-term neurological/neuropsychological consequences of coma. It also gives the family some suggestions about how to be close to their loved survivor from the acute phase until the end of the rehabilitation process.

The primary caregiver is then assigned to a psychotherapist and is invited to an initial talk (meeting) aimed at: a) giving information, b) creating a therapeutic alliance, c) identifying all possible caregivers, d) evaluating their possible role changes, e) investigating the quality of the relationship between the survivors and their family, f) offering them the chance for psychological support. The family members who attend this first meeting are interviewed using the Psychosocial Questionnaire, which gathers some information about the survivor (i.e., socio-demographic and clinical data, such as etiology and duration of consciousness disturbance, social network, school/work and hobbies) and family (i.e., socio-demographic and school/work activity data).

The second step: multi-dimensional psychological support

After the first meeting, if a caregiver accepts being supported by the psychologist, some further talks are scheduled to empower the caregivers' resources by focusing on: a) increasing self-awareness of needs and expectations and, consequently b) establishing some realistic aims; c) focusing on possible emotional distress related to the injury (e.g., depression, anger, feelings of guilt, anguish and anxiety about the future, etc.) d) facilitating their expression and e) increasing self-awareness about the survivor's possible outcome.

In order to mainly set the treatment educationally or psychologically, an analysis of the context and the specific characteristics of caregivers is made in terms of age, kind of relationship, rehabilitation phases of survivors and different needs to create a therapeutic alliance with the rehabilitation team and particularly with the psychologist.

In our clinical experience, psychological support can be differentiated according to three different post-acute phases. During the early post-acute phase, at the time of admission to the PCU, the intervention is mainly psycho-educational. In fact, caregivers need information regarding the survivor, because they are greatly involved in the caring process; psychologically they feel they are a part of the survivor and consequently lose a dimension of their self. In this phase, they usually forget to be a person and continuously talk only about “Him/Her”, i.e., the survivor. Their own needs, such as hobbies or activities related to social life, are exclusively oriented towards the current situation of the survivor and primarily to fear about future perspectives (“Will everything be as it was before the injury?”). Denial is the main defensive mechanism; in this phase it represents a strength, allowing the caregiver to paradoxically cope with the loss of some cognitive, behavioural, psychological and/or physical parts of the survivor that the brain injury has taken away.

In a later phase, about six months after rehabilitation begins, some of the survivors' needs, unrelated to their loved cared, partially arise, such as personal care, social life and attention to themselves; at this time, caregivers start to cut the emotional link with the survivors. The psychological status of the caregiver slowly changes from the dimension of “Him/Her”, to that of “We”, which demonstrates a growing separation

from the survivor, even if the couple caregiver-survivor is in fact a unique entity. During this phase, the psychological intervention aims to assist the caregiver to pass through this separation process. However, it is still very difficult for caregivers to deal with this partial loss.

The last phase regards the chronic phase and starts about one year after the injury. At this point the caregivers' self reappears because they are focused on themselves and on some long repressed needs. In this phase, caregivers are much more prone to feel emotion and the difficulties resulting from the injury. Denial is now an obstacle for caregivers, and the psychologist aims to break down this barrier to help them focus on the survivors' resources, e.g., the cognitive functions spared by the injury and their own personal coping strategies.

In light of these different steps, it is expected that the caregiver will not necessarily feel the need to explicitly ask for help from the psychologist. Therefore, we propose a new model of psychological support that goes beyond the classical approach. Indeed, during the first two steps it is likely that rather than feeling the need to meet with a psychologist, caregivers need to be practically assisted in many situations in which they are experiencing difficulty, and need to request specific information from the psychologist (and the rehabilitation team) regarding the survivor. This informal exchange takes place in the hospital corridor or in the patient's room, when caregivers need to be supported for only a few moments and do not require a formal meeting with the psychologist. In this view, the classical psychological setting is no longer needed in a rehabilitation setting, because the psychologist “comes out of his/her room” and goes wherever he can to meet the caregiver (in the hall, in the survivor's room or even in a phone conversation), as this intervention is therapeutic per se.

It is worth noting that even if the psychological intervention in the first two phases seems like a friendship, the psychologist's expertise allows empathically sustaining and assisting caregivers on the base of their specific needs. In fact, the psychologist can be a liaison between the family and the rehabilitation team, facilitating communication between them, improving efficacy in coping and helping caregivers to be active rather than passive in addressing rehabilitative issues.

Conclusion

Our clinical experience with caregivers in a PCU and the data that emerged from a preliminary analysis of their needs suggest the usefulness of “sewing” the psychological setting (where and how) on the basis of the specific context (in terms of chronicity and severity of injury) in which the therapeutic relationship occurs. The intervention is mainly educational in the early phase, as the psychologist can support the caregiver also outside the therapy room and essentially on the basis of his/her relationship with the survivor. It becomes purely psychological only later, because it is more classically structured and takes place inside the therapy room and is essentially based on the emotional needs of the caregivers.

It is important to underline that in this way caregivers are psychologically assisted in any case, both formally and informally, and regardless of their level of self-awareness, so that their wellbeing is also effectively improved.

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