

ORIGINAL ARTICLE

Anxious attachment style and hopelessness as predictors of burden in caregivers of patients with disorders of consciousness: A pilot study

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Abstract

Objective: Previous studies on caregivers of patients with disorders of consciousness (DOCs) have highlighted that their overall burden is not related to disease duration or diagnosis, but mainly to their personal characteristics. The aim of this study was to investigate the impact of attachment style and hopelessness on overall burden in caregivers of patients in both vegetative state and minimally conscious state.

Methods and procedure: Nineteen caregivers of patients with DOCs, hosted in a long-term care facility, were assessed using the Caregiver Burden Inventory, the Attachment Style Questionnaire, and the Beck Hopelessness Scale. Socio-demographic information was also collected. Data were analysed through descriptive statistics, correlations, one sample *t*-test and a multiple regression analysis using SPSS.

Outcomes and results: Burden was not associated with duration of caregiving and gender had no effect on overall burden. Multiple regression analysis indicated that preoccupied attachment style and hopelessness together predicted 49% of the total variability of burden ($R^2 = 0.489$; adjusted $R = 0.43$).

Conclusions: These data suggest that caregivers need psychological assessment and support in order to keep under control the level of burden and to help themselves be a better resource for their relatives.

Keywords

Attachment, burden, caregivers, hopelessness, minimally conscious state, vegetative state

History

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Introduction

Vegetative state (VS) and minimally conscious state (MCS) are considered clinical conditions that may occur after an acquired severe brain injury. The prevalence and the incidence of VS and MCS are ever-increasing, as is life expectancy of these patients, which has risen up to ~15 years [1], due to progress in medical science [2]. These data raise the question about the strains informal caregivers are exposed to due to chronicity of DOCs.

Informal caregivers are defined as people who have an emotional bond with the patient and take care of him or her. The impact of a chronic illness on caregivers has often been conceptualized as caregiver burden [3]. As Luchetti et al. [4] pointed out, several interpretations of burden are present in the literature [5–7]. However, there is a consensus among defining burden, a multi-dimensional construct [8], as the overall strain resulting from physical, psychological, social and financial demands of caregiving [9] that results in psychological distress, anxiety, depression and complaint [4]. Such reports

have focused on caregivers managing long-term illnesses like Alzheimer's [10], dementia [11] and cancer [12]. Further studies underlined that burden is not related to either the duration of illness [13] or the degree of physical disability of patients [14].

Furthermore, it is widely known that chronic stress of caregiving has significant consequences on physical well-being of informal caregivers as well [15, 16], for instance increasing vulnerability to the development of cardiovascular diseases [17], type II diabetes [18], disorders of musculo-skeletal system [19] and immunologic dysregulation [20].

Unfortunately, few studies are focused on caregivers of patients in vegetative state or minimally conscious state [21–24]. Caregivers of patients with DOCs complain of a decrease of leisure time [8], poor social life and unsatisfactory family relationships [25]. Furthermore, they show lower levels of physical and mental health in comparison with normative sample [8]. Specifically they reported severe levels of anxiety, depression and emotional distress that remained unvaried at 5 year follow-up [26].

Interestingly, diagnosis, disease duration and place where the patient was hosted has been found to not show any relationship with overall burden of caregivers. Burden may be mostly associated with the personal characteristics of

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caregivers [27], their coping strategies [25, 28–30] and possibly their relational style. Unfortunately, the relational aspect of burden in caregivers of VS and MCS patients remains unclear.

In accordance with attachment theory [31, 32] and with clinical experience with caregivers of patients in VS and MCS, burden can be impacted by the attachment style that can determine a peculiar and stable style of caregiving [33–35]. While this was confirmed in some studies on caregivers of patients with cancer [36] and dementia [37], it remains unexplored in caregivers of patients in VS and MCS.

According to Bowlby [31], attachment is a psychobiological system that motivates humans to build emotional bonds with significant others (attachment figures) to protect themselves from threats and alleviate distress through emotional regulation.

Bowlby [31] and successive researchers [32] pointed out that caregiving and attachment are deeply inter-related [38]. Caregiving, understood as a basic emotion, has been associated with specific neural circuitries [39] as well as the attachment system, which has been linked to neuronal processes [40].

To preserve the attachment bond in case the attachment figure is threatened [41], for instance by an illness or separation, the individual will attempt to engage in caregiving behaviours [42].

Avoidant and anxious attachment styles in general are associated with different modalities of caregiving [43]. Empirical findings have suggested that insecure attachment correlates with depression and anxiety and is predictive of personal distress in the context of caregiving [44, 45]. In particular, the anxious style of attachment, which is typical of hyper-vigilant and self-oriented people [46], interferes with sensitive and efficient care [47, 48]. It is associated with enduring emotional distress in response to threat [49] and with compulsive care [50].

In accordance with the contributions from the literature and clinical observations, hopelessness also plays an important role on overall burden [51]. Hopelessness [52] is a psychological construct characterized by a negative view of the future. According to Stotland [52], hopelessness and hope stand on a continuum, however in the literature there are different interpretations regarding this relationship [53, 54]. Stotland's concept of hopelessness refers to the following cognitive schemes: (a) nothing will prove in own favour, (b) own attempts will never succeed, (c) own goals will never be reached, and (d) own problems will never be solved. Empirical findings suggest that hopelessness is one of the most frequent conditions described in patients with mental [55] and medical illness [56]. Hopelessness is associated with poor-related quality-of-life [57], may represent a pathway of distress in medically ill populations [56, 58, 59] and may be key to understanding adaptations to stress and illness [60].

Unfortunately, the impact of attachment style and hopelessness on overall burden in caregivers of patients in VS and MCS has not been explored yet. Therefore, the aim of this study is to investigate the relationship between attachment style, hopelessness and overall burden of caregivers of patients in VS and MCS. Specifically, it is hypothesized that caregivers' burden can be predicted by the presence of anxious attachment style and hopelessness.

Methods

Participants

This study involved 19 caregivers of patients in vegetative and minimally conscious states treated at the Santa Viola Hospital in Bologna (Italy). It is a long-term care facility with a section exclusively dedicated to patients with DOCs. The diagnosis of VS was based on the definition issued by the Multi-Society Task Force [61]. The diagnosis of MCS was made in accordance with Aspen Consensus Group's criteria [62, 63].

After the approval by the local ethical committee, participants were enrolled between January and May 2013. A clinical psychologist, trained in supporting and evaluating caregivers of patients with DOCs and supervised by a medical doctor specialist in Clinical Psychology and Psychosomatic Medicine, collected written informed consent and introduced participants to the protocol. It was composed of a battery of self-reported questionnaires which took 30 minutes to complete.

Measures

Caregiver Burden Inventory (CBI [64, 65])

This is a 24-item questionnaire that measures burden. The five dimensions that are assessed are: time-dependent burden evaluating stress caused by restriction of personal time (five items); developmental burden referring to failure of hopes and expectations (five items); physical burden that is physical stress and somatic disorders (four items); social burden caused by conflict of roles concerning work or family burden (five items); and emotional burden referring to embarrassment and shame caused by the patient (five items). Each item ranges on a Likert scale from 0 (minimum stress) to 4 (maximum stress). The sum of scores in each sub-scale results in a total score of CBI (CBI-TOT). It ranges from 0–100 and was used in this study as a measure of overall burden.

Attachment Style Questionnaire (ASQ [66, 67])

This is a 40-item self-report instrument assessing attachment style through five dimensions: confidence, discomfort with closeness, need for approval, preoccupation with relationships and relationships as secondary. Confidence (in self and others) reflects a secure attachment orientation [66]. Discomfort with closeness is a central theme of the conceptualization of avoidant attachment proposed by Hazan and Shaver [68]. Need for approval reflects the need for confirmation and acceptance from others and is the nuclear theme of fearful and preoccupied attachment style as theorized by Bartholomew [69]. Preoccupation with relationships, which involves an anxious and dependent attitude towards relationships, characterizes the original conceptualization of anxious/ambivalent attachment of Hazan and Shaver [68]. The relationships as secondary scale is consistent with the concept of dismissing attachment theorized by Bartholomew [69]. The attachment dimensions examined by the ASQ questionnaire can be associated with the three dimensions of attachment, as theorized by Hazan and Shaver [68] and the four dimensions identified by Bartholomew [69] and Bartholomew and Horowitz [70]. This study utilized the dimension 'preoccupation with

relationships' (ASQ-P), which is indicative of an anxious attachment style, according to Hazan and Shaver [68].

Beck Hopelessness Scale (BHS [55, 71])

This is a 20-item true/false scale which measures hopelessness and quantifies the gravity of negative expectations about the future. Hopelessness is the third element of the depressive triad according to Beck [72] and is consistent with Stotland's [52] conceptualization. Total score ranges from 0–20.

Statistical analysis

Frequencies, means and percentages were used to describe socio-demographic characteristics of caregivers.

Due to the small sample size, Shapiro-Wilk tests were used to verify that each variable was normally distributed. A Pearson correlation was employed to evaluate the correlation between CBI-TOT and the duration of the caregiving condition expressed in days. Furthermore, the sample's means were compared to the means of the available Italian normative sample using a one sample *t*-test. To assess the predictive role of anxious attachment style and hopelessness on overall burden, a multiple linear regression was tentatively performed. The model considered CBI-TOT as the variable explained. The BHS and ASQ-P scores were included as regressors. It was verified that all the assumptions for multiple linear regression analysis were respected. Despite the fact that the number of regressors used in this model complies with the minimum ratio between number of observations and number of regressors suggested elsewhere [73–77], the authors are well aware of the merely explorative character of this analysis whose results must be considered cautiously. A univariate ANOVA was performed to evaluate the effect of gender on CBI-TOT. The data were analysed using SPSS v.19 (SPSS, Inc; Chicago, IL) and statistical significance was set at $p < 0.05$.

Results

A total of 22 caregivers were invited to take part in this study, 19 of which accepted and gave their written consent. The characteristics of caregivers are shown in Table I. On average, the age of caregivers was 55.85 years (SD = 10.91 years) and the duration of caregiving was 1662.15 days (SD = 1087.96 days).

Shapiro-Wilk tests revealed that the variables considered were normally distributed. The one sample *t*-test showed that BHS was higher and CBI-TOT was lower in the sample compared to the normative Italian sample. Regarding ASQ-P, no differences were detected compared to the Italian normative sample (see Table II).

Pearson correlations pointed out that there was no significant correlation between CBI-TOT and duration of the caregiving condition ($p = 0.185$). The results of the univariate ANOVA showed that gender had no effect on overall burden as measured by CBI-TOT ($F = 0.459$, $p = 0.507$). The multiple regression model was statistically significant ($p \leq 0.05$), with BHS ($\beta = 0.542$; $p = 0.008$) and ASQ-P ($\beta = 0.397$; $p = 0.042$) as regressors and CBI-TOT as the explained variable (see Figure 1). The model explained 49% of the variability of CBI-TOT ($R^2 = 0.489$; adjusted

Table I. Socio-demographic characteristics of caregivers. The number of subjects and percentages were reported for each category.

| | Frequency | % |
|-------------------------------|-----------|-------|
| Gender | | |
| Male | 4 | 21.05 |
| Female | 15 | 78.95 |
| Relationship with the patient | | |
| Parent | 1 | 5.26 |
| Son/Daughter | 3 | 15.79 |
| Partner/Spouse | 15 | 78.95 |
| Education level | | |
| Primary school | 2 | 10.53 |
| Secondary school | 7 | 36.84 |
| High school | 7 | 36.84 |
| University | 3 | 15.79 |
| Work status | | |
| Employed | 11 | 57.90 |
| Sick Leave | 1 | 5.26 |
| Retired | 7 | 36.84 |

Table II. Comparison with Italian normative data.

| | Mean (SD) | Italian normative data | <i>p</i> Value |
|---------|---------------|------------------------|----------------|
| CBI-TOT | 22.89 (14.22) | 32.50 | 0.009* |
| ASQ-P | 26.37 (5.67) | 28.91 | 0.067 |
| BHS | 7.84 (5.05) | 5.35 | 0.043* |

Total score of Caregiver Burden Inventory (CBI-TOT), 'preoccupation with relationships' sub-scale of Attachment style Questionnaire (ASQ-P) and total score of Beck Hopelessness Scale (BHS) compared with corresponding Italian normative data. SD, standard deviation. The asterisks indicate the presence of a statistical difference (p value < 0.05).

$R^2 = 0.425$; SE = 10.78; $F(2) = 7.66$; $p = 0.005$). The effect size indicated that BHS was the most important predictor ($f^2 = 0.57$) of CBI-TOT, whereas ASQ-P had a less strong effect size ($f^2 = 0.34$).

Discussion

In this study an Italian sample of caregivers of patients in VS and MCS was enrolled. Most caregivers were middle-aged women and spouses of the patients. The majority of the sample was female and over 50 years old, similar to the Italian sample investigated by Leonardi et al. [8]. This is consistent with the international literature which reports a high prevalence of women in the caregiver population [78]. In this sample a lower overall burden compared to the Italian normative sample was found. This data can be explained considering differences between this sample and the Italian normative sample which instead was composed of caregivers of patients with dementia. Caring for patients with dementia may involve different emotions and responsibilities compared to caring for patients with DOCs. While caregivers of patients with dementia primarily lived with their ill relatives [64], the patients of this study were treated in a specialized facility which may offer greater support and, consequently, reduce overall burden of caregiving.

Additionally, hopelessness was found to be greater in the caregivers compared to the Italian normative sample. In this

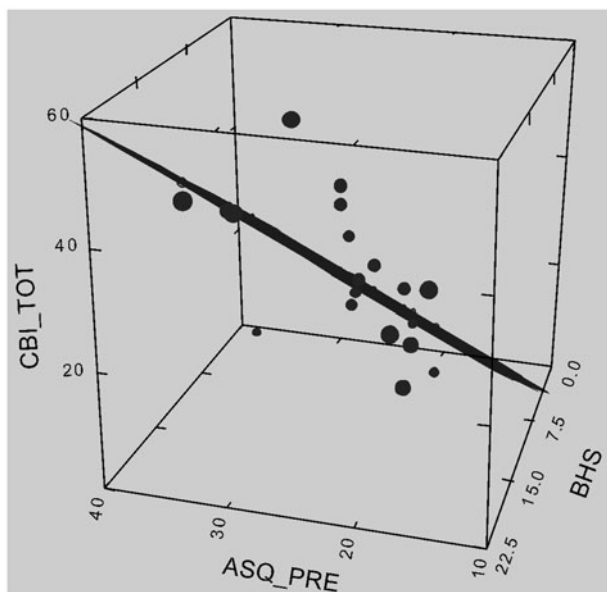


Figure 1. Linear regression model explaining the variability of overall burden as measured by Caregiver Burden Inventory. Results of least-squares linear regression analysis considering total score of Caregiver Burden Inventory (CBI-TOT) as dependent variable (ordinate) and total score of Beck Hopelessness Scale (BHS) and 'preoccupation with relationships' sub-scale of Attachment Style Questionnaire (ASQ-P) as independent variables (abscissae). In-plane view of the regression plane (black line). Black spots represent data considered in the regression analysis: dimensions are proportional to the distance from the observer.

sample high levels of hopelessness may be linked to the chronic nature of VS and MCS conditions. Regarding the attachment style, the scores of 'preoccupation with relationships' sub-scale which reflects an anxious attachment style, did not differ from the scores reported in the Italian normative sample.

To the authors' knowledge, this study is the first to investigate the relationship between burden, anxious attachment and hopelessness in a sample of caregivers of patients with DOCs. It was found that overall burden was not related to the duration of the caregiving condition. On the other hand, overall burden is predicted by anxious attachment style and hopelessness. The results are consistent with previous studies on caregivers of patients in VS, patients with dementia and patients with cancer: first of all, burden seems mainly associated with personal characteristics [27]. Second, anxious attachment style and hopelessness are associated with personal distress [58, 79].

Gender has also been reported to be a critical factor to describe physical and mental health of caregivers [80]. However, this variable was not included in this regression because the univariate ANOVA showed that there was no difference between males and females in perceived overall burden.

In accordance with other authors [36], it was hypothesized that attachment style can shape the pattern of caregiving which in turn may contribute to constructing perceived burden.

Indeed previous studies [46–50] found that the pattern of care typical of caregivers with anxious attachment is characterized by need of closeness, compulsiveness in care, intense but passive care and hyper-vigilance. This pattern of

care is reported to be more self-focused than sensitive and to overwhelm the caregivers, physically and emotionally [34]; furthermore, these caregiving features may contribute to the time-dependent burden due to the lack of leisure time. One may think that anxious attachment style is even more stressful for caregivers of DOCs patients in respect to caregivers of patients who are responsive. Since in the case of DOCs the patient is still alive, the attachment behaviours are continuously activated, but are doomed to fail because of their low responsiveness. Since caregivers spend a lot of time in the hospital, they also interface substantially with professional operators. Caregivers with anxious attachment have a heightened perception of partner pain [48] and they could over solicit professional operators about several aspects, for instance posture, drugs or daily hygiene. Furthermore, persons with anxious attachment may have difficulties in interacting with strangers; one may hypothesize that the collaboration between this kind of caregiver and professional operators may be particularly strenuous. Taken together, the features of caregivers with anxious attachment style may contribute to several aspects of total burden perceived.

Since DOCs are enduring conditions, hopelessness is almost to be expected and, therefore, under-valued in their caregivers. Conversely, this study confirms the importance of not under-estimating the presence of hopelessness and the need to assess its presence. As pointed out by the results, hopelessness may be an important determinant of overall burden in caregivers of patients with DOCs. According to Utne et al. [51], hope is considered an important factor in adjustment and adaptation during suffering. High levels of hope are reported to appraise a caregiving experience more positively and to serve as a buffer to stress: thus it could be considered an effective coping strategy.

Hopelessness could implicate the absence of these positive effects in caregivers, contributing to perceived overall burden. Moreover, since hopelessness is associated with physical illness [81–84], one may think that it could contribute to some aspects of burden, especially to the physical and emotional ones.

Hopelessness, as an important component of demoralization [85], has been studied extensively as playing a role in the outcomes of medically ill patients. Engel [86] in 1967 described the role of hopelessness in the medically ill in the 'Giving Up–Given Up Complex' which is more recently integrated in the definition of Demoralization in the Diagnostic Criteria for Psychosomatic Research (DCPR) [87]. Both the 'Giving Up–Given Up Complex' and the Demoralization Syndrome are considered psychological states which create a biological vulnerability to the development of medical diseases [81] or represent a prodromal manifestation of illness [88].

In light of these considerations, the results underlined the importance of assessing overall burden regardless of the duration of caregiving condition. Moreover, the assessment of hopelessness and attachment style may also be useful to prevent burden, which contributes to vulnerability to the development of physical illnesses, as well as mental disorders [15]. Caregivers' psychophysical health plays an important role *per se*, but also for the care of patients. Since the disability of patients with DOCs is severe and their chronicity

is enduring, caregivers represent an important resource in the care-network of patients [27]. Consistent with a bio-psycho-social framework, caregivers can be considered to constitute the environment of patients. Taking care of caregivers implies providing better care and improving patients' quality-of-life, as pointed out by Etchegary [89].

In line with further studies [27, 30, 90], the results support the importance of providing therapeutic interventions when necessary. It may be useful to:

- (1) identify early prognostic factors, specifically anxious attachment style and hopelessness, to prevent high levels of burden and vulnerability to physical diseases; and
- (2) evaluate how clinical characteristics of caregivers are expressed in the relationships with their ill relatives and with professional operators.

This study has a number of limitations. (i) The single-centre design of this study yields a small sample size with specific socio-demographic features, which limits the power of statistical analysis and requests caution in generalizing the results. (ii) In line with other studies [91–94], a single measurement (ASQ) has been used to characterize attachment style in caregivers of patients with DOCs. Further studies should be done in order to carry out an individual clinical assessment with different instruments (e.g. Adult Attachment Interview [95]). (iii) Further studies would be needed to consider the role of other variables impacting the burden of caregivers of patients in VS and MCS.

Future multi-centre studies may be useful to replicate the findings of this pilot study in a larger sample and in other care settings; for instance, home settings or post-acute facilities. Moreover, future studies are considered to be advantageous with specific instruments [96, 97] to clarify if the psychological characteristics above described (attachment styles and hopelessness) are contextually derived or reflect a trait, since this issue is still largely debated in the literature and no unequivocal indication has been stated [97–105].

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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