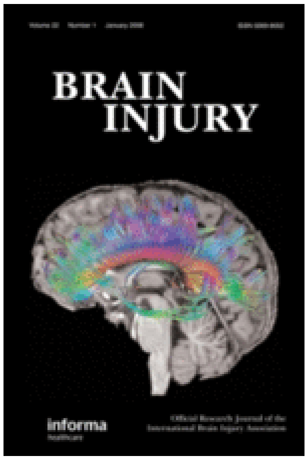

Quality of Life, Psychological Well-being, and Resilience in Caregivers of People with Acquired Brain Injury (ABI)

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Quality of Life, Psychological Well-being, and Resilience in Caregivers of People with Acquired Brain Injury (ABI)

Abstract:

Aim: The study aims to examine whether characteristics of patients with Acquired Brain Injury–ABI (time elapsed since injury, level of dependence and behavioural problems) and resilience factors of the caregiver predicted caregiver well-being (quality of life, anxiety,depression and positive aspects of caregiving).

Methods*:* 78 voluntary family caregivers (75.6% female) of patients with ABI completed the Barthel Index, Head Behaviour Injury Scale, Questionnaire of Resilience in Caregivers of Acquired Brain Injury, WHOQOL-BREF, Hospital Anxiety and Depression Scale,and Positive Aspects of Caregiving Scale. Correlation analysis and stepwise regression were carried out.

Results: Time elapsed since injury showed a negative relationship with positive aspects of caregiving. On the other hand, care-recipients' behavioural problems showed significant associations with all caregiver variables: negatively with quality of life and positive aspects of caregiving, and positively with anxiety and depression. Regarding resilience, we found a positive relationship with quality of life and positive aspects of caregiving, and a negative association with anxiety and depression, showing better predictive power with depression.

Conclusions:We confirm the relevance of developing multidisciplinary caregiver intervention programmes focused on positive ways to handle care-recipients' behavioural problems and developing positive coping skills, such as positive reinterpretation, acceptance and seeking social support, that may optimize caregiver resilience.

Keywords: caregivers, ABI patients, quality of life, resilience, positive aspects of care, anxiety, depression

Introduction

Acquired Brain Damage (ABI) is a health problem with a significant presence in our society. Stroke (or Cerebrovascular Accident, CVA) is the second most frequent cause of death in developed countries and the primary cause of disability among adults [1]. According to the World Stroke Organization [2], stroke affects 15 million people every year, of which six million die. It is the main cause of prolonged disability among different ages, genders, ethnicities and countries. In Spain, according to a report produced by FEDACE (the Spanish Brain Damage Federation) in partnership with Real Patronato sobre Discapacidad (the Royal Spanish Disability Board), 420,000 people were living with Acquired Brain Injury in 2015 [3]. Stroke was the originator in 78% of cases, and the remaining 22% resulted from traumatic brain injury and other causes. Every year, 104,701 new cases of Acquired Brain Injury are recorded in Spain.

ABI is a health problem which also has sequelae affecting different functional areas (cognitive, motor, sensory and behavioural) [4-5-6-7] and, frequently, a prolonged progression time, which involves increasing severity levels and turns it into a chronic health problem [4]. Thus, people with ABI frequently have special needs requiring the support of caregivers, who may be relatives or professionals. Indeed, after the acute phase and hospitalisation, much of the burden of care for the patient falls on people within their family environment [8-9].

A family-member caregiver, also called informal caregiver, is defined as an untrained individual who provides assistance and unpaid care to a relative or friend over the age of 18 with the aim of helping them take care of themselves [10]. The importance of actively including relatives in the process of rehabilitating the person affected by ABI, has recently received increased attention due to the stress and suffering that the prolonged role of caregiver can have on them and because of their important role in the patient's care and progress [11-12]. Changing their lifestyle to meet the needs of the patient, family-member caregivers of people with a chronic illness have the capacity to develop in the care they provide and in the process of learning development skills [13, 14]. Nevertheless, this learning process can cause physical and mental discomfort which is closely related to the care activities required by the patient.

Several studies have examined the burden of the family-member caregiver [15-17]. In Doser and Norup's study [16], 45% and 16% of caregivers experienced medium or high levels of burden, respectively. The highest levels of burden were found among caregivers of patients with the most severe injuries and who spent the most time providing care. With stress and family burden often becoming chronic [17], caregiver quality of life is also negatively affected [18], and there is an increase in the prevalence of depression [10].

Despite the high levels of stress and burden often placed on family-member caregivers, their emotional and professional support needs frequently receive insufficient attention [11]. Indeed, untrained caregivers display higher levels of anxiety, depression, burden, and lower self-esteem than those receiving training [10]. It is therefore relevant to investigate the different variables that can be associated with family caregiver distress (stress, anxiety, depression, etc.), as well as with their well-being (positive aspects of care, quality of life, etc.).

In this respect, the existing literature reports positive associations between family carers distress (burden, anxiety and depression) and patient variables such as care-recipient functioning [19,20,21], cognitive disability [19], impairment severity [22, 23];

and behavioural problems, such as aggressiveness and irritability ([24, 25, 26, 27], sudden or rapid mood changes and argumentativeness [28], and disinhibited behaviour [29].

Research also indicates associations between caregiver variables and psychological adjustment in caregivers. The caregiver variables found to be most predictive of caregiver stress and burden include age, gender, coping resources used, social support and family financial burden [30, 22, 31, 32, 23]. Furthermore, the literature also indicates that the pernicious effects of the caregiver role do not lessen with time [33, 34].

Of interest here are the variables which may be related to the characteristics and progression of the illness and the patient so that intervention programmes can be adjusted; for example, to the different stages of the illness or the patient's level of dependency, and also in terms of the caregiver's personal variables which can be changed through specific treatments.

On the other hand, recent studies have begun to focus not only on the negative aspects of providing care (burden, stress, anxiety, depression, etc.) but also on the positive aspects of being a caregiver (self-affirmation, positive outlook on life, positive post-traumatic growth, and resilience). In a recent study, Las Hayas, López de Arroyabe and Calvete [35] reported that caregivers who scored higher on the variable "Positive aspects of care" had a better psychological and social quality of life and also exhibited fewer burden indicators. Similarly, in a systematic review of studies conducted between 1999 and 2009 carried out with the aim of identifying positive experiences of people caring for stroke survivors, Mackenzie and Greenwood [36] confirmed the existence of positive experiences with the disease in the long term. These positive experiences were fundamentally related to an increase in the caregiver's self-esteem and the sense of appreciation, which led not only to a strengthening of the caregiver's relationship with the patient but also to the patient's progress.

Along similar lines, some early work with a positive psychology approach has also been carried out on the qualities of caregiver resilience. Resilience is defined as the process of adapting positively in the face of adversity, trauma, tragedy, threats and significant sources of stress [37]. Resilience is a dynamic construct made up of a variety of personal qualities [38], such as optimism, spirituality, personal and social competence. Resilience is not a trait that you have or do not have, but rather a set of skills [37, 39, 38]; it involves thoughts (e.g. maintaining a positive outlook), feelings (e.g. paying attention to their own needs and feelings, hopefulness, sense of humour) and actions, (e.g., setting goals, taking decisive actions, accepting support from others) [40] that anyone can develop [41] at any time during their life [37], and research has shown that people with higher resilience are more likely to adapt positively when exposed to potentially traumatic events [37, 40, 42, 43].

Since this study is seeking to examine whether resilience affects caregivers′ quality of life and well-being, let us examine briefly the association between resilience and both concepts, well-being and quality of life.

Resilience and well-being and quality of life

A considerable amount of research about resilience has suggested that people with higher resilience avoid the potentially adverse effects of stress ([eg. 44, 45]), are more protected from the experience of depression [46], and report healthier levels of psychological adaptation and functioning when facing either acute or chronic traumatic events [42, 47].

Furthermore, research on resilience emphasizes its potential to help family caregivers when facing a loss of physical or emotional health [48,49,50]. Specifically, when focusing on caregivers of patients with ABI, resilience shows a strong association with caregiver quality of life, positive aspects of care and posttraumatic growth [51] and a negative association with burden perception and decreased levels of carer burden [40]. In this line, Simpson and Jones [40] in their study of 61 family caregivers found that self-rated resilience correlated positively with positive affect, and negatively with negative affect and caregiver burden.

Resilience thus acts as a protective factor against stress and increases the positive consequences resulting from caring [52, 55], even among caregivers of people with ABI [54]. However, we have found little research concerning the positive aspects of caring and resilience in caregiver of patients with ABI.

In summary, the main objective of this study is centred around the analysis of the relationship between variables connected to the patient and those involved in the caregiver's psychological well-being. More specifically, the aim is to study the extent to which the variables relating to a person with ABI (progression time, level of independence during everyday life activities and the existence of behavioural problems) and those relating to the caregiver (resilience) explain caregiver well-being (quality of life, anxiety and depression and the perceived positive aspects of caring). Firstly, we expected to find the following relationships between the variables of ABI patients and caregiver well-being.

H1. We hypothesized that a negative relation would be found between caregiver quality of life and the perception of positive aspects of care with time elapsed since injury and presence of behavioural problems in patients with ABI.

H2. In contrast, caregiver quality of life and the perception of positive aspects of care will show a positive relationship with the patient level of autonomy (less functional dependency).

H3. We also hypothesized that we would find a positive relationship between caregiver anxiety and depression with time elapsed since injury and patients with ABI behavioural problems.

H4. In contrast, caregiver anxiety and depression will have a negative relationship with the patient's level of autonomy.

Secondly, we expected to find the following relationship between caregiver resilience and caregiver well-being.

H5. We hypothesized that resilience would have a negative relationship with caregiver anxiety and depression.

H6. In contrast, we predicted that resilience would have a positive relationship with caregiver quality of life and the perception of positive aspects of care.

Methods

Procedure

Participants were recruited through different day care centres and hospitals in several Spanish cities (Madrid, Barcelona, Valencia and Palma de Mallorca) as well as from the Spanish Federation for Brain Damage (FEDACE) to which 3 regional federations and 41 associations or foundations (representing 10,100 members), belong. The researchers contacted the person responsible at each institution, inviting them to take part in the research, sending them a summary of the research and a template of a presentation letter to inform caregivers about the project. If participation was agreed, the person responsible at each institution informed all caregivers attending their centre about the present project. Caregivers who decided to take part in the research signed an informed consent form and provided their contact details for a subsequent interview with a member of the research team. Data were collected in three different ways: most by telephone (interview conducted by a trained psychologist) (N=53), others by online questionnaire (N=22) and by responding to questionnaires in writing and then sending them by email or post (N=3).

Ethical considerations

This study was approved by the Ethics Committee of the Universidad Pontificia Comillas. All caregivers who participated gave their written informed consent to participate and were also informed about the possibility of dropping out of the study with no negative consequences at any time. Data were analysed anonymously.

Participants

Characteristics of caregivers

The sample consisted of 78 caregivers meeting the following inclusion criteria: a) is the relative who "looks after" and makes decisions about the care of the person with ABI regardless of whether or not they live with the person and/or 2) is the relative who spends most hours per day or week with/caring for the affected person.

The characteristics of the family caregivers are described in Table 1. Participant age ranged from 22 to 80 years, with a mean age of 57.42 (SD = 12.20). Women made up 75.6% of the sample and 24.4% were men. The majority were spouses (66.7%) or parents (19.3%).

-----Insert table 1 about here----

Characteristics of persons affected by Acquired Brain Injury.

As shown in Table 2, the mean age of those affected by ABI was 55.86 (*SD* = 16.38). The predominant type of brain damage was stroke (82%). Time elapsed since the injury ranged from 2 months to 14 years, with a mean of 25.3 months (*SD* = 34.51). The majority of subjects were in the post-acute phase, as 65.7% had an elapsed time of between 2 and 12 months.

-----Insert table 2 about here----

Variables and instruments

Demographic characteristics

Participants indicated their age, gender, marital status, kinship with the dependent adult (mother/father, son/daughter, brother/sister, husband/wife), employment status, and time as a caregiver.

Patient functional independence

Participants completed the Barthel Index [55], adapted to the Spanish population [56]. This instrument is a tool for assessing an adult's baseline ability in terms of eating, using the toilet, bathing, dressing, continence, transfers, and ambulation. Caregivers rate the person's dependence level from 15 (maximum independence) to 0 (maximum dependence) in each of the abilities. The functional independence total score is rated from 0 to 100, and the higher the score, the higher the patient's autonomy. Specific reliability has been reported by Loewen and Anderson [57], who obtained a Cronbach's alpha of between 0.86 and 0.92. Cronbach's alpha was .92.

Patient behavioural problems

The Head Injury Behaviour Scale (HIBS) [58] (Spanish version by López de Arroyabe, Calvete, Las Hayas & Zubizarreta [59]) is a 28-item set of psychological problems which occur owing to brain injury. For each item, caregivers answer "Is the behaviour a problem?" (yes/no) and "'How much distress does this problem cause?" on a 4-point Likert-type scale ranging from 1= *no distress* to 4=*severe distress*. The HIBS contains items relating to emotional management, behavioural management and the patient's psychological problems. Cronbach's alpha was .82.

Caregiver resilience

We used the Questionnaire on Resilience in Caregivers of Acquired Brain Injury (QRC-ABI) [54], consisting of 17 items measuring four factors: (a) optimism, (b) acceptance, (c) social support and (d) spirituality. All items were rated on a 4-point Likert-type scale ranging from 1 (never) to 4 (always). A total resilience score (ranged from 24 to 68 points) is obtained by adding the five subscales scores. The QRC-ABI showed a good Cronbach's alpha (0.88) [54]. Cronbach's alpha was .80.

Quality of life

Participants were asked to complete the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire [60] in its Spanish version [61]. This questionnaire has 26 items assessing physical health, psychological health, social relationships and environment; it is measured on a 1-5 scale, with higher scores indicating better quality of life. Cronbach's alpha was .89.

Anxiety and depression

We used the Hospital Anxiety and Depression Scale (HADS) [62] adapted to the Spanish population [63]. This instrument consists of 14 items on two subscales (7 for anxiety and 7 for depression) using a 0 to 3 scale, so possible total scores ranged from 0 to 21 for anxiety and 0 to 21 for depression. The instructions were: "Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate response is best". Despite the term "hospital", the use of this scale is widespread in community settings and primary medical care. Cronbach's alpha was .86.

Positive aspects of caregiving

The Positive Aspects of the Caregiving Scale [64] (PACS) was used, adapted to the Spanish population [35]. It measures positive aspects which could result from caregiving and is made up of 9 items with two factors, Self-Affirmation (e.g. `*Providing help to (name) has made me feel good about myself; made me feel strong and confident'*) and Outlook on life (e.g. *'Providing help to (name) has enabled me to appreciate life more and to develop a more positive attitude towards life*). It is measured on a 0-4 scale with 0 "never" at the negative end of the scale and 4 "always" at the positive. The high correlation between the two factors justified combining the items to generate a total score. This scale has been already used with primary caregivers of persons with ABI [54, 59], with good reliability α= .82 [59]. Cronbach's alpha was .816.

Data analyses

First, descriptive statistical analyses were conducted for patient and caregiver variables, along with Pearson correlation analysis between the patient variables (time elapsed since the ABI (months), dependency and behavioural problems) and caregiver variables (resilience, quality of life, positive aspects of care, anxiety, depression). Pearson correlations examine bivariate relationships (not adjusted by third variables) and we used them to study the strength and significance of linear relationship between independent and dependent variables previous to the regression analysis (see regression analysis later).

Regression analysis was subsequently performed to explore the predictive value of the characteristics of the person with ABI and the resilience factors of their caregivers. Four separate stepwise regression analyses were conducted to test the role of the variables “patient dependency”, “time elapsed since ABI”, “patient behavioural problems” and “caregiver resilience” to explain four dependent variables: anxiety, depression, quality of life, and positive aspects of caregiving. Due to the exploratory nature of the study, the stepwise method was used, and variables with an associated probability value of $F < 0.1$ were retained. The assumptions of homoscedasticity, independence, no multicollinearity, residual normality distribution and linearity were checked and met.

Measures of effect size were included in all tests performed [37] and Cohen’s recommendations [67] were followed to assess the magnitude of these measures.

All statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS 19.0, year 2012). In all cases, a confidence interval of 95% was used, with values of $p < .05$ considered statistically significant.

Results

Descriptions of ABI patients.

In terms of the degree of patient autonomy for carrying out everyday activities, as evaluated by their caregivers using the Barthel scale [56], the average score was 64.55 (*n*= 78; SD = 29.73), and mean time elapsed since the ABI was 25.25 months (*SD* = 34.51).

With regard to the Head Injury Behavioural Scale (HIBS) [59], caregivers reported an average of 10.33 behavioural problems present among relatives with ABI (out of 28 such problems assessed using this scale) (*n*= 78; SD = 5.04). As can be seen in Table 3, the most frequently reported behavioural problem was "Due to their difficulties (the person with ABI) is unable to hold down a job" (71.8%), followed by problems of "impulsiveness" (60.3%). The least frequent behavioural problems were wishing they were dead (9%), drug abuse (9%) and problematic sexual behaviour (5.1%).

-----Insert table 3 about here----

Descriptive statistics of caregiver variables

Caregiver age ranged from 22 to 80, with a mean age of 57.42 and a standard deviation of 12.20. Women comprised 75.6% and men 24.4% of the sample. The majority were spouses (66.7%) or parents (19.3%). The highest percentage of caregivers were either retired (32.1%) or housewives (24.4%). Table 4 shows the descriptive statistics for caregiver variables.

-----Insert table 4 about here----

Relationship between ABI patient variables and caregiver psychological variables

With regard to the Pearson correlations between the patient and caregiver variables analysed as shown in Table 5, the elapsed time of illness had a significant and negative correlation with the positive aspects of care. On the other hand, elapsed time did not correlate significantly with other caregiver variables such as quality of life or anxiety-depression. However, the patient's level of autonomy had a positive and significant correlation with the caregiver's quality of life. Meanwhile, behavioural problems on the part of the patient correlated with all caregiver variables relating to his or her well-being. The resilience score was positively associated with quality of life and positive aspects of care and negatively associated with depression. It did not, however, correlate significantly with caregiver anxiety.

-----Insert table 5 about here----

Regression analysis

We conducted several regression analyses to identify those variables which explain quality of life and psychological well-being of caregivers. Table 6 displays the main results from these analyses. As shown, patient behavioural problems were significantly associated with greater anxiety and depression as well as lower levels of quality of life and a less positive outlook on life among caregivers. Patient autonomy was associated with higher levels of quality of life and lower anxiety. Resilience was negatively associated with depression. Finally, time spent caring was negatively associated with positive aspects of caregiving.

-----Insert table 6 about here----

Discussion

The aim of this study was to examine whether certain patient variables and caregiver resilience predicted caregiver well-being. The main assumptions are that the characteristics of patients with Acquired Brain Injury (time elapsed since injury, level of dependency and behavioural problems) would show an association with lower levels of caregiver quality of life and perception of positive aspects of care, and higher levels of caregiver anxiety and depression. Secondly, caregiver resilience would show a positive association with caregiver quality of life and positive aspects of caregiving, as well as a negative association with anxiety and depression.

As expected, the results showed that patient variables are indeed closely related to caregiver well-being/distress (perception of positive aspects, quality of life as well as anxiety and depression), with behavioural problems highlighted as the most significant, as opposed to variables such as the elapsed time of illness or the patient's level of dependence. Previous studies have reported on the pivotal role of behavioural problems in determining the consequences of care of a person with ABI. In this line, Connolly and O'Dowd [24] examined the association between categories of disability following head injury (motor, cognition, behaviour, perception or speech and language) with caregiver strain and perceived stress and found that behavioural disabilities showed the strongest association with perceived stress. Similarly, Marsh et al. [28] found that behavioural problems have the most severe and pervasive impact on all aspects of caregiver functioning. Therefore, it is possible that caregivers are more likely to experience depression and anxiety if they feel unprepared for the task of assuming the care for their family with ABI and behavioural problems or if they perceive the impact of the behavioural problems as being beyond their control. Hence it appears that behavioural problems are those that have the greatest impact on caregiver quality of life and well-being, above the caregiver variables of this study, including resilience. Therefore, professionals may wish to emphasize behavioural problems in their psychoeducational plans.

With regard to the elapsed time of illness, it was noted that time was negatively and significantly related to the perception of positive aspects of care, but not significantly linked to quality of life or anxiety and depression. This was shown by both correlational analysis and regression analysis. The patient's levels of autonomy or independence were associated positively with quality of life and inversely with anxiety.

The results also showed that patient variables may be relevant to caregiver well-being or distress, but that these are not the only ones to be taken into consideration, as some personal caregiver variables, such as resilience, are related to caregiver depression. With regard to resilience, correlational and multiple regression analyses were used in an attempt to understand the relationship between resilience and caregiver well-being and quality of life. The results from the correlational analysis demonstrated a significant relationship with anxiety, depression quality of life and perception of positive aspects of care. However, the results from the regression analysis indicated a significant relationship only with depression. Therefore, there are indications of the relationship between resilience and caregiver well-being and quality of life, since the correlational analysis is significant; the lack of statistical significance in the multiple regression analyses may be due to the small sample size.

These results are in line with those found by López de Arroyabe y Calvete [65], in which patient sequelae perceived by the caregiver had a significant impact on the psychological distress of the family member, but this was not as high as might have been expected. However, previous studies have reported a significant relationship between caregiver resilience and their quality of life and positive aspects of care [e.g. 54, 68].

As already mentioned, resilience is a multidimensional construct, a "dynamic process encompassing positive adaptation within the context of significant adversity" [69, p.1], which comprises a set of skills that allow the caregiver to experiment healthier levels of psychological adaptation and functioning.

On the other hand, as a multidimensional construct, it can be influenced by different aspects, as previous researchers have noted. In this line, previous studies have noted the relationship between resilience and other variables such as personality [30, 42, 70], coping styles [30, 42] or social support [30, 34, 71, 72]. Therefore, future research should take into account these other constructs that might be influencing caregiver resilience.

In summary, from this study we can highlight two important aspects. Firstly, behavioural problems seem to have a pivotal role in caregiver well-being and quality of life; these results therefore suggest the importance of training the caregiver in skills to cope with them. Secondly, resilience, along with other caregiver variables, also seem to have an important role, although it needs more research.

Limitations

Certain methodological considerations of this study should be noted. The main limitation was the small sample size, which necessarily implies a certain caution when extrapolating results since participants may not be representative of the population of families supporting relatives with traumatic brain injury.

Another limitation of this study has been not including other caregiver variables that have proven to be important in explaining the pathway to caregiving consequences (e.g. social support, coping strategies, self-efficacy, personality). One of our first main concerns was to develop a short questionnaire, since one of the key issues in caregivers of patients with ABI is the short time available; this study has therefore focused on resilience and positive consequences, which have received less attention and are thus in need of more research.

A further limitation was the use of self-reporting tests and the lack of objective measures of both caregiver and patient variables for extracting data. However, this does not have such an impact on many of the variables studied, given that they are psychological variables such as quality of life, resilience and mood in which the person's subjective perception is the most salient aspect. Nevertheless, further research could include objective measures for both caregiver (e.g. physiological record of stress responses) and patient (an external observer reporting behavioural problems).

Finally, this is a cross-sectional study, which means conclusions regarding relationships between variables can only be drawn at that particular moment and prevents us from establishing causal relationships, even over the long term. In this respect, it would be of interest to implement longitudinal research with broader samples which enable analysis of the caregivers' process of adapting throughout the different stages of the disease.

Implications and future areas of research

Regarding the model which might explain the consequences of the caregiving role of persons with ABI, future research should integrate the various combinations of variables outlined above. Regarding caregiver variables, it would be desirable to include variables such as social support, personality and coping strategies, and include positive and negative outcomes, providing a larger model.

The results of this study highlight the relevance of designing interventions which involve family-member caregivers in the rehabilitation process and which seek to help caregivers handle patients' behavioural problems through the different phases of the disease, as well as provide greater support to enable the patient's everyday needs to be met.

Various studies **[73**, 14] have also begun to note that intervention involving families should aim to improve emotional, instrumental and professional support, and also help caregivers develop adaptive coping strategies, such as acceptance and positive thinking, in such situations. It is necessary to help caregivers to develop critical skills associated with resilience (e.g., positive thinking, social skills, self-competence, self-efficacy), so that they become more able to deal with the process of caring for a person with ABI. In this line, several studies have shown that educational and skill-building interventions improve caregivers´ positive adaptation to the process [71, 74, 75]. As Kreutzer et al. [32. highlight, interventions which include education, skill building, and psychological support seem to be effective, and positively perceived by both caregivers and patients. This increase in social and community support for families could lead to an improvement in their quality of life.

We must therefore highlight the need to implement multidisciplinary rehabilitation programmes which respond not only to the medical needs of patients but also their emotional and social needs as well as those of their families. This will provide broader support to the person affected by ABI and thus support the family system as a whole. In this vein, recent work by Godwin, Lukow and Lichiello **[76]** with good results has involved an experimental intervention with patients and families of people with ABI, based around the theory of resilience and using an interdisciplinary approach to neuropsychology along with family and marital therapy. We stress the need to continue empirical research of this type, where the principles of resilience are integrated into rehabilitation techniques, and interdisciplinary approaches encompassing medical, psychological and social elements are employed.

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Declaration of interest statement

The authors have no conflicts of interest.

REFERENCES

1. Velasco F. Prevención Primaria del ictus. Gaceta Médica de Bilbao, 2003;100, 3: 99-104.

2. Organización Mundial de la Salud. Preventing chronic diseases: a vital investment: global WHO report (2005) Available at: http://www.who.int/chp/chronic_disease_report/full_report.pdf

3. FEDACE (2015): Las personas con Daño Cerebral Adquirido en España. Informe: Madrid: INTERSOCIAL. Available from https://fedace.org/

4. Chan J, Parmenter T and Stancliffe R. The impact of traumatic brain injury on the mental health outcomes of individuals and their family carers. Australian e-Journal for the Advancement of Mental Health. 2009; 8: 1–10. http://dx.doi.org/10.5172/jamh.8.2.155

5. Cunningham JM, Chan F, Jones J, Kramnetz B, Stoll J and Calabresa J. Brain injury rehabilitation: A primer for case managers. In: F. Chan, M. J. Leahy editors. Health care and disability case management. Lake Zurich, IL: Vocational Consultants Press; 1999. p. 475–526.

6. Perry DC, Sturm VE, Peterson MJ, et al. Association of traumatic brain injury with subsequent neurological and psychiatric disease: a meta-analysis. Journal of Neurosurgery. 2016; 124(2): 511–526. https://doi.org/10.3171/2015.2.JNS14503

7. Ricker JH. Traumatic brain injury in adults. In: Frank RG, Rosenthal M, Caplan B, editors. Handbook of rehabilitation Psychology. 2nd ed. Washington, DC: American Psychological Association; 2010. p. 43–62. http://dx.doi.org/10.1037/15972-003

8. Hosack KR and Rocchio CA. Serving families of persons with severe brain injury in an era of managed care. Journal of Head Trauma Rehabilitation. 1995; 10(2): 57–65.

9. Knight RG, Devereux R and Godfrey HP. (1998). Caring for a family member with a traumatic brain injury. Brain Injury. 1998; 12(6):467-81.

10. Malec, JF. Courtney Harold Van Houtven, Terri Tanielian, Adrian Atizado & Michael C. Dorn. Impact of TBI on caregivers of veterans with TBI: Burden and interventions, Brain Injury, 2017; 31:9, 1235-1245, Doi: 10.1080/02699052.2016.1274778

11. López de Arroyabe-Castillo E, Calvete E. Evaluación de las necesidades de los familiares de personas afectadas de daño cerebral adquirido mediante el cuestionario de necesidades familiares. Anales de Psicología, 2012; 28,3: 728-735. doi: http: // dx.doi.org/10.6018/analesps.28.3.156021

12. Elbaum J. Acquired Brain Injury and the Family: Challenges and Interventions. In: Elbaum J. (editor) Acquired Brain Injury; 2019. Springer, Cham.

13. Barrera L, Pinto N, Sánchez B. Cuidando a los cuidadores. Un programa de apoyo a familiares de personas con enfermedad crónica. Index de Enfermería, 2006;15:52-53.

14. Zambrano R, Ceballos P. Síndrome de carga del cuidador. Revista Colombiana de Psiquiatría, 2007; 36,1: 26-39.

15. Chronister J, Eboneé T. Johnson PhD, Fong Chan PhD, Wei-Mo Tu MS, Yi-Chieh Chung PhD, Gloria K. Lee PhD. Positive Person–Environment Factors as Mediators of the Relationship Between Perceived Burden and Quality of Life of Caregivers for Individuals with Traumatic Brain Injuries. Rehabilitation Counseling Bulletin 2015; 59,4: 235 – 246.

16. Doser K, Norup, A. Caregiver burden in Danish family members of patients with severe brain injury: The chronic phase. Brain Injury, 2016;30:3,334-342, DOI: 10.3109/02699052.2015.1114143

17. Masel B, Dewitt D. Traumatic Brain Injury: A Disease Process, Not an Event. Journal of Neurotrauma, 2010; 27,8:1529-1540.

18. Florez IE, Montalvo A, Herrera A. Calidad de vida de cuidadores de adultos con accidente cerebrovascular. Avances en enfermería, 2010; 28:52-60.

19. Allen K, Linn RT, Gutierrez H and Willer BS. Family burden following traumatic brain injury. Rehabilitation Psychology. 1994; 39(1): 29-48 http://dx.doi.org/10.1037/h0080313

20. Kreutzer, JS, Serio, CD and Bergquist S. Family needs after brain injury: A quantitative analysis. The Journal of Head Trauma Rehabilitation. 1994; 9: 104–115.

21. Oddy M, Humphrey M and Uttley D. Subjective impairment and social recovery after closed head injury. Journal of Neurology, Neurosurgery & Psychiatry. 1978; 41: 611–616.

22. Chwalisz K. Perceived stress and caregiver burden after brain injury: A theoretical integration. Rehabilitation Psychology. 1992; 37: 189–203.

23. Sander AM, High WM, Hannay HJ and Sherer M. Predictors of psychological health in caregivers of patients with closed head injury. Brain Injury. 1997; 11: 235–249.

24. Connolly, D., and O'Dowd, T. (2001). The impact of the different disabilities arising from head injury on the primary caregiver. British Journal of Occupational Therapy, 64(1), 41Y46.

25. Godfrey HPD, Harnett MA, Knight RG, Marsh NV, Kesel, D. A., Partridge FM, et al. Assessing distress in caregivers of people with a traumatic brain injury (TBI): A

psychometric study of the Head Injured Behavior Scale. Brain Injury. 2003; 17(5): 427-435. https://doi.org/10.1080/0269905031000066201

26. Kitter B and Sharman R. Caregivers' support needs and factors promoting resiliency after brain injury. Brain Injury. 2015; 29(9): 1082–1093. doi:10.3109/02699052.2015.1018323

27. McPherson KM, Pentland B and McNaughton HK. Brain injury Perceived health of carers. Disability and Rehabilitation. 2000; 22(15): 683-689.

28. Marsh NV, Kersel DA, Havill JH and Sleigh JW. (1998). Caregiver burden at 6 months following severe traumatic brain injury. Brain Injury. 1998; 12(3): 225-238.

29. Gillen R, Tennen H, Affleck G and Steinpreis R. Distress, depression symptom and depressive disorder among caregiver of patients with brain injury. Journal of Head Trauma Rehabilitation. 1998; 13(3): 31-43.

30. Anderson MI, Simpson GK, Daher M and Matheson L. The relationship between coping and psychological adjustment in family caregivers of individuals with traumatic brain injury: A systematic review. Annual Review of Nursing Research. 2015; 33(1): 219-247. doi: 10.1891/0739-6686.33.219

31. Douglas JM and FJ Spellacy. Indicators of long-term family functioning following severe traumatic brain injury in adults, Brain Injury. 1996; 10(11): 819-840. 10.1080/026990596123936

32. Kreutzer JS, Stejskal TM, Godwin EE, Powell VD and Arango-Lasprilla JC. A mixed methods evaluation of the Brain Injury Family Intervention. NeuroRehabilitation. 2010;27(1):19–29.

33. Degeneffe CE. Family caregiving and traumatic brain injury. Health and Social Work. 2001;26(4): 257-268.

34. Verhaeghe S, Defloor T and Grypdonck M. Stress and coping among families of patients with traumatic brain injury: A review of the literature. Journal of Clinical Nursing. 2005; 14(8): 1004-1012.

35. Las Hayas C, López de Arroyabe E, Calvete E. Positive aspects of caregiving in Spanish caregivers of individuals with acquired brain injury. Rehabilitation Psychology, 2014;59,2:193-202. DOI: 10.1037/a0035622

36. Mackenzie A, Greenwood N. Positive experiences of caregiving in stroke: A systematic review. Disability and Rehabilitation, 2012;34:1413-1422. doi: 10.3109/09638288.2011.650307.

37. American Psicological Association (2010). The road to resilience. Retrieved from https://www.apa.org/centrodeapoyo/guia.aspx

38. White B, Driver S and Warren A-M. Considering resilience in the rehabilitation of people with traumatic disabilities. Rehabil Psychol. 2008; 53: 9–17

39. Earvolino-Ramirez M. Resilience: a concept analysis. Nursing Forum 2007; 42: 73–82.

40. Simpson G and Jones K. How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury? Clinical Rehabilitation. 2013; 27(4): 367–377. doi:10.1177/0269215512457961

41. Connor KM, Davison JR. Development of a new resilience scale: The Coonor-Davidson Risilience Sacale (CD-RISC). Depression and Anxisty, 2003;18:76-82

42. Campbell-Sills L, Cohan SL and Stein MB. Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. Behaviour Ressearch and Therapy. 2006; 44: 585–599

43. Mancini AD and Bonanno GA. Resilience in the face of potential trauma: clinical practices and illustrations. Journal of Clinical Psychology. 2006; 62: 971–975.

44. Beardslee WR. The role of self understandig in resilient individuals. American Journal of Orthopsychiatry. 1989; 59: 266-278. doi:10.1111/j.1939-0025.1989.tb01659.x

45. Masten, A. S., & O'Connor, M. J. Vulnerability, stress, and resilience in the early development of a high risk child. Journal of the American Academy of Child & Adolescent Psychiatry 1989; 28(2): 274-278. http://dx.doi.org/10.1097/00004583-198903000-00021

46. Edward KL. Resilience: A protector from depression. Journal of the American Psychiatric Nurses Association. 2005; 11(4): 241-243. http://dx.doi.org/10.1177/1078390305281177

47. Bonanno GA. Loss, trauma, and human resilience. American Psychologist. 2004; 59: 20–28

48. Chow SM, Hamagani F, Nesselroade JR. Age differences in dynamical emotion–cognition linkages. Psychology and Aging, 2007;22,4:765-780

49. Felten B, Hall J. Conceptualizing resilience in women older than 85: Overcoming adversity from illness of los. Journal of Gerontological Nursing, 2001;27,1:46-54

50. Rossi NE, Bisconti TL, Bergeman CS. The role of dispositional resilience in regaining life satisfaction after the loss of a spouse. Death Studies, 2007;31,10:863-883

51. Las Hayas C, López de Arroyabe E and Calvete, E. Resilience in family caregivers of persons with acquired brain injury. Rehabilitation Psychology. 2015; 60(3): 295-302. http://dx.doi.org/10.1037/rep0000040

52. Crespo M, Fernández-Lansac V. Resilience in caregivers of elderly dependent relatives. **Anal. Psicol.**, 2015;31,1. Retrieved from http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S0212-97282015000100003

53. O'Rourke, N. Psychological resilience and the well-being of widowed women. Ageing International, 2004;29: 267–280

54. Las Hayas C, López de Arroyabe E, Calvete E. Resilience in family caregivers of persons with acquired brain injury. Rehabilitation Psychology, 2015;60,3: 295-302. DOI: 10.1037/rep0000040

55. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. Maryland State Medical Journal,1965: 1461-65.

56. Barrero Solís CL, García Arrioja S, Ojeda Manzano, A. Índice de Barthel (IB): Un instrumento esencial para la evaluación funcional y la rehabilitación. Plasticidad y Restauración Neurológica, 2005;4:81-85.

57. Loewen SC, Anderson BA. Reliability of the modified motor assessment scale and the Barthel Index. Physical Therapy, 1988;68:1077-1081

58. Godfrey HP, Harnett MA, Knight RG, Marsh NV, Kesel DA, Partridge FM, Robertson RH. Assessing distress in caregivers of people with a traumatic brain injury (TBI): a psychometric study of Head Behaviour Injury Scale. Brain Injury, 2003; 17,5:427-435.

59. López de Arroyabe E, Calvete E, Las Hayas C, Zubizarreta A. Distress of the Caregiver in Acquired Brain Injury: Positive aspects of care to moderate the effects of psychological problems. Australian Journal of Rehabilitation Counselling, 2013;19,2:84-99. Doi 10.1017/jrc.2013.13

60. Skevington SM, Lofty M, O'Connell KA, & the WHOQOL Group. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL Group. Quality of Life Research, 2004;13:299-310. http://dx.doi.org/10.1023/B:QURE.0000018486.91360.00

61. Espinoza I, Osorio P, Torrejón MJ, Lucas-Carrasco R, Bunout D. Validación del cuestionario de calidad de vida (WHOQOL-BREF) en adultos mayores chilenos. Revista

Médica de Chile, 2011;139:579-586. http://dx.doi.org/10.4067/S0034-98872011000500003

62. Zigmond AS, Snaith RP. The Hospital Anxiety And Depression Scale, Acta Psychiatrica Scandinavica,1983; 67:361-370.

63. Quintana JM, Padierna A, Esteban C, Arostegui I, Bilbao A. Ruiz I. Evaluation of the psychometric characteristics of the Spanish version of the Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 2003;107,3:216-21

64. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive aspects of caregiving: Contributions of REACH project to the development of new measures for Alzheimer's caregiving. Research on Aging, 2004;26:429-453. Doi:10.1177/0164027504264493

65. López de Arroyabe-Castillo E, Calvete E. Daño cerebral adquirido: percepción del familiar de las secuelas y su malestar psicológico. Clínica y Salud, 2013;24,1:27-35. http://dx.doi.org/10.5093/cl2013a4

67. Cohen J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Lawrence Earlbaum Associates.

68. Simpson G, Jones K. How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury? Clinical Rehabilitation, 2013;27,4: 367-377.

69. Luthar SS, Cicchetti D and Becker B. The construct of resilience: a critical evaluation and guidelines for future work. Child Development. 2000; 71: 543–562.

70. Friborg O, Barlaug D, Martinussen M, Rosenvinge JH and Hjemdal O. Resilience in relation to personality and intelligence. International Journal of Methods in Psychiatric Research. 2005; 14: 29–42.

71. Glass TA, Dym B, Greenberg S, Rintell D, Roesch C and Berkman LF. Psychosocial intervention in stroke: Families in recovery from stroke trial (FIRST). American Journal of Orthopsychiatry. 2000;70(2):169-181. http://dx.doi.org/10.1037/h0087746

72. López de Arroyabe E and Calvete E. (2012). Evaluación de las necesidades de los familiares de personas afectadas de Daño Cerebral Adquirido mediante el Cuestionario de Necesidades Familiares. Anales de psicología. 2012; 28(3): 728-735

73. Calvete E, López de Arroyabe E. Depression and grief in Spanish family caregivers of people with traumatic brain injury: The roles of social support and coping. Brain Injury, 2012;26,6: 834-843. doi:10.3109/02699052.2012.655363

74. Backhaus SL, Ibarra SL, Klyce D, Trexler LE and Malec JF. Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. Archives of physical medicine and rehabilitation. 2010; 91(6): 840-848

75. Simpson G, Pfeiffer D, Keogh S and Lane B. Describing an Early Social Work Intervention Program for Families after Severe Traumatic Brain Injury. Journal of Social Work in Disability & Rehabilitation. 2016; 15(3-4): 213–233. doi:10.1080/1536710x.2016.1220888

76. Godwin EE, Lukow HR, Lichiello S. Promoting resilience following traumatic brain injury: Application of an interdisciplinary, evidence-based model for intervention. Family Relations,2015;64,3:347-362. Retrieved from https://search.proquest.com/docview/1687620064?accountid=14478

Table 1. *Caregiver characteristics (N=78)*

Characteristics	Mean	SD
Age	57.42	**± 12.199**
Time elapsed since ABI (months)	25.25	± 34.511
Gender		
Women	59	75.6%
Men	19	24.4%
ABI Type		
StrokeTraumatic brain injury	64	82.1%
TCE	4	5.1%
Other	10	12,8%
Family relationship to the person with ABI		
Mother	13	16.7%
Father	2	2.6%
Son/daughter	7	9%
Brother/sister	4	5.1%
Spouse/partner	52	66.7%
Employment situation		
Works full-time	11	14.1%
Works part-time	13	16.7%
Housewife	19	24.4%
Seeking work	3	3.8%
Retired	25	32.1%
Student	1	1.3%
Other	6	7.7%
Have you ever needed to reduce your working hours in order to care for the person?		
Yes	21	26.9%
No	51	65.4%
Missing data	6	7.7%

Table 2. *Patient characteristics (N=78)*

Age	55.86	**± 16.376**
Gender		
Women	29	37.2%
Men	49	62.8%
ABI Type		
Stroke Traumatic brain injury	64	82.1%
Other	4	5.1%
	10	12.8%
Degree of dependence		
Slightly dependent	33	42.3%
Moderately dependent	29	37.2%
Severely dependent	9	11.5%
Fully dependent	7	9%
Time elapsed since injury (N= 67)		
0-6 months	28	41.8%
7-12 months	16	23.9%
13-24 months	4	5.9%
2 years +	19	28.4%

Table 3. Frequency of behavioural problems in the patient

Problematic behaviour	**N**	**Yes (%)**	**No (%)**
Cannot work	77	71.8	26.9
Impulsiveness	78	60.3	39.7
Too sensitive	78	53.8	46.2
Anxious	77	48.7	50
Dependent	78	46.2	53.8
Lack of initiative	78	46.2	53.8
Childlike	76	44.9	52.6
Lack of interest in things	78	44.9	55.1
Poor decision-making	77	43.6	55.1
Lack of motivation	77	42.3	56.4
Not very aware	74	41	53.8
Mood swings	78	41	59
Shuts him/herself off	75	39.7	56.4
Irritable	77	39.7	59
Depressive	77	39.7	59
Lack of control	78	37.2	62.8
Leisure	77	26.9	71.8
Argumentative	76	25.6	71.8
Has no friends	76	25.6	71.8
Irresponsible	77	25.6	73.1
Aggressive	76	14.1	83.3
Insults others	77	11.5	87.2
Wishes they were dead	77	9	89.7
Abuses drugs	77	9	89.7
Sexual behaviour	77	5.1	93.6

Table 4. *Descriptive statistics for caregiver variables (N=78)*

	Mean	*SD*	Minimum	Maximum
Resilience Total (QRC-ABI) (score range 0-68)	46.83	10.08	24	68
Resilience Optimism (score range 0-20)	13.85	3.95	5.00	20.00
Resilience Acceptance (score range 0-16)	11.74	3.09	4.00	16.00
Resilience Social Support (score range 0-16)	11.65	3.35	4.00	16.00
Resilience Spirituality (score range 0-16)	9.590	5.20	.00	16.00
Quality of life (WHOQOL-BREF) (score range 26-130)	91.26	14.37	56	124
HADS Total (score range 0-42)	14.40	7.36	1	31
HADS Anxiety (score range 0-21)	7.77	4.29	.00	17.00
HADS depression (score range 0-21)	6.63	3.87	.00	15.00
Positive aspects of care (PACS) (score range 0-36)	23.17	7.29	5	36
Positive Aspects of Care (Self-affirmation) (score range 0-24)	15.22	5.35	.00	24.00
Positive Aspects (outlook on life) (score range 0-12)	7.95	3.29	.00	12.00

Table 5. *Pearson correlations between patient and caregiver variables*

		Total Quality of Life	Positive Aspects of Care	Anxiety	Depression
Patient Variables	Time elapsed since the ABI (months)	-.129	-.285*	-.092	.137
	Autonomy- ADLs - Barthel Total	.247*	.023	-.187	-.105
	Behavioural problems	-.304**	-.263*	.402**	.406**
Caregiver Variables	Resilience Total	.257*	.348**	-.161	-.381**
	Resilience Optimism	.229*	.532**	.014	-.370**
	Resilience Acceptance	.207	.222	-.290**	-.377**
	Resilience Social Support	.324**	-.020	-.275*	-.318**
	Resilience Spirituality	-.009	.151	.026	.028

Table 6. Regression models for seven dependent variables

Predictors	*B* est.	*S.E.*	*Β*	*p-value*	*Lower*	*Upper*
Outcome = Anxiety $F(2,66) = 8.885$, $p < 0.001$, $r^2 = .217$						
Constant	7.057	1.507		<.001	4.047	10.066
Patient behavioural problems	0.334	0.096	.383	.001	0.141	0.526
Patient autonomy	-0.042	0.017	-.275	.015	-0.076	-0.008
Outcome= Depression $F(2,66) = 10.269$; $p< .001$; $r^2 = 0.243$						
Constant	10.236	2.350		<.001	2.142	13.316
Patient behavioural problems	.290	0.085	.373	.001	0.372	1.957
Resilience	-0.138	0.045	-.331	.003	-0.220	-0.035
Outcome = Quality of life $F(2,66) = 6.746$; $p = 0.002$; $r^2 = 0.174$						
Constant	88.532	5.057		<.001	78.078	103.876
Patient autonomy	0.169	0.057	.340	.004	-0.076	-0.008
Patient behavioural problems	-.714	0.323	-.251	.031	0.372	1.957
Outcome = positive aspect of caregiving $F(1, 65) = 5.762$; $p = 0.019$; $r^2 = 0.081$						
Constant	25.386	1.023		<.001	23.343	27.430
Time taking care	-0.058	0.24	-.285	.019	-0.106	-0.010
Outcome = Positive view of life $F(1, 65) = 7.824$; $p = 0.007$; $r^2 = 0.107$						
Constant	10.331	0.879		<.001	5.522	10.113
Patient behavioural problems	-0.219	0.078	-3.28	.007	-1.761	-0.339