

Anxiety, depression, and hopelessness in family caregivers of patients with neuropsychological sequelae

Isadora Di Natale Nobre¹, Carolina dos Santos Lemos¹, Adriana Cristina Guimarães Pardini¹, Janaína de Carvalho¹, Isabel Chateaubriand Diniz Salles²

ABSTRACT

Objective: This article's aim is to determine the incidence of anxiety, depression, and hopelessness among 54 family caregivers of patients with neuropsychological sequelae after brain injury in adulthood. **Methods:** This is an observational cross-sectional study and quantitative analysis, developed in a rehabilitation center (Associação de Assistência à Criança Deficiente - AACD) located in the city of Sao Paulo. The following instruments were applied: Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), and Beck Hopelessness Scale (BHS), along with a questionnaire to characterize the sample. **Results:** Data was statistically analyzed and 55.6% of the family caregivers showed signs of anxiety, 20.4% depression, and 31.5% hopelessness. **Conclusion:** It was concluded that the family caregivers in this study were under significant psychological distress, indicating a need for actions aimed specifically at them in rehabilitation programs.

Keywords: Anxiety, Depression, Caregivers, Neuropsychology

¹ Psychologist, Association for the Assistance to Handicapped Children - AACD.

² Psychiatrist, Association for the Assistance to Handicapped Children - AACD.

Mailing address:

Associação de Assistência à Criança Deficiente - AACD
Isadora Di Natale Nobre
Av. Professor Ascendino Reis, 724
CEP 04027-000
São Paulo - SP
E-mail: isadora_nobre@hotmail.com

Received on June 21, 2015.

Accepted on September 14, 2015.

DOI: 10.5935/0104-7795.20150031

INTRODUCTION

Acquired Brain Injury (ABI) is an injury that occurs in the brain during the life of the individual.¹ It may be the result of cranial-encephalic trauma (CET), cerebrovascular accident (CVA), anoxia, infections, or brain tumors;² the first two etiologies are most predominant in rehabilitation centers.³ The sequelae and evolution are very specific,³ depending on factors such as age, pre-morbid conditions, etiology, time, and location of the injury.⁴ The changes can be physical and neuropsychological, involving cognitive, emotional, and behavioral factors,^{5,6} which can be diagnosed by the investigative method of neuropsychological assessment.

In a neuropsychological assessment, carried out exclusively by a psychologist, validated and standardized tests are used to qualitatively and quantitatively assess the skills of attention, reasoning, memory, executive functions, aspects of humor, and behavior, among other things.⁷ On the basis of this assessment, the psychologist structures the clinical diagnosis and assists in establishing the cognitive profile of the patient, delineating the prognosis, and defining cognitive rehabilitation programs.⁸

The patient, depending on their level of autonomy and independence in facing the demands of daily life, often needs a caregiver. The family caregiver is any member of the family who voluntarily or not, assumes the task of taking care of the patient,⁹ knowing about his or her current condition of life, and considering the clinical and social situation.¹⁰ This care may include tasks related to everyday activities, such as personal hygiene, feeding, medication routine, monitoring health services and other activities carried out regularly, such as going to banks or pharmacies.¹¹

The sequelae of the injury often cause sudden and dramatic changes in the life of individuals and their families. The motor impairments may hinder the capacity of the patient to move around or to perform activities of daily living, such as eating, bathing, and dressing. Neuropsychological changes, significantly impacting,^{12,13} also hamper the routine, since memory deficits, aggressiveness, and mood disorders may prevent the organization of daily life and the return to previous professional and social activities.^{13,14} The family caregiver experiences physical and emotional overload while facing the neuropsychological changes of the patient.¹³

There is a process of retraining necessary throughout the patient's environment,¹⁵ since the sphere of priorities is established around the most disabled family member and the needs of others are less evident, causing changes in roles assumed by each person.¹⁶ This new setting influences the stages of development expected for each stage of the life of the individual and his family, causing an interruption in their lives.¹⁷

The family experiences a deep feeling of loss when it realizes that the affected person is different from how they were before.¹⁸ The neuropsychological changes in patients make their relatives face mourning in life;¹⁹ the family is dedicated to the recovery of the patient at the same time that it deals with the symbolic death of previous aspects of his or her personality, having to live with it and adapt to this new reality.¹⁹

The physical changes are perceived soon after the injury, but the behavioral and cognitive disorders will be noticed some time later, while living with the patient.^{18,20} Treatments in Brazilian rehabilitation centers often begin long after the injury, with the patient already showing both physical and neuropsychological consequences.³ The aim of rehabilitation is, within a given period of time, through interventions from a multi-professional team, to provide support for the patient to reach or to maintain their maximum functional independence, allowing improvement in his quality of life.²¹

All these changes experienced by the family caregiver can negatively influence the patient's emotional state, leading to high levels of psychological suffering.^{12,22} Significant indices of depression, anxiety, and hopelessness were verified in people who have suffered major disruptions in their lives.²³⁻²⁶ Anxiety is characterized by the anticipation of a future threat, real or not, generating excessive concerns that are difficult to control.^{27,28} Depression is a mood disorder which is characterized mainly by feelings of sadness, hopelessness, tendency to passivity, and changes in appetite and sleep.^{28,29} Hopelessness relates to the dimension of pessimism and with negative expectations for the future.^{28,30}

OBJECTIVE

Corroborating the literature, this study seeks to identify the incidence of depression, anxiety, and hopelessness in family caregivers

of patients with neuropsychological changes caused by acquired brain injuries. Such rates will be related with data to characterize the patient, his or her family, and aspects related to the role of caregiver.

METHOD

This is a cross-sectional observational study, with a quantitative analysis. In the sample were included family members of both genders, with age above 18 years, who have become caregivers of patients who were diagnosed with impairments through a neuropsychological assessment carried out between 2010 and 2014 during treatment in the AACD - Ibirapuera rehabilitation center in São Paulo. Only one family member per patient was included in the sample. They were recruited by telephone contact, and presented themselves as being one of those responsible for care. The study excluded relatives of patients who were submitted to neuropsychological assessment who had not presented any changes, relatives of patients who had neuropsychological changes caused by progressive diseases, relatives under the age of 18, and caregivers who were not related.

In the present study, 78 subjects met the criteria; of those, 11 missed the scheduled interview on two occasions, 5 reported difficulties in transport, 4 did not reply to phone contact after four attempts, 2 reported health problems, 1 had no time available, and 1 whose patient had died. Therefore the sample for this research was composed of 54 family caregivers of patients who suffered brain injury.

The study was approved by the Ethics and Research Committee of the institution. The data were collected by only one individual interview, in a private setting, with the consent of the participants through their reading and signing the Free and Informed Consent Form. The questionnaire applied to characterize the sample was prepared specifically for the purposes of this research, based on the literature,^{13,22,31,32} with questions to identify the patient, the family, and aspects related to the role of caregiver.

In addition to that questionnaire, the following tools were applied: Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), and Beck Hopelessness Scale (BHS), all translated and validated for use in Brazil by Jurema Alcides Cunha.³⁰ The BAI is composed

of 21 items that cover the most frequent symptoms of anxiety, with each item scored from 0 to 3 and the higher the score, the more severe the symptoms. The classification of anxiety is performed through the following levels: minimum (scores from 0-10), mild (11-19), moderate (20-30), and severe (31-63). The BDI is composed of 21 items that assess symptoms related to depression, with each item scored from 0 to 3; the presence of depression is considered above the score of 18. The BHS is composed of 20 questions that can score 0 or 1, the higher the score, the higher the level of hopelessness, classifying the levels: minimum (0-3), mild (4-8), moderate (9-14), and severe (14-20). The three instruments are filled in via self-assessment.

The data were analyzed using the SPSS 17 and Minitab 16 programs. The Chi-square test was used to correlate the values of each scale with the questionnaire variables and the Chi-Square test was used again with the Yates correction to measure the degree of correlation between the three scales. Statistical significance was defined as $p < 0.05$.

RESULTS

The sample was composed of 54 family members with average age of 54.8 years (SD = 13.3). Of these, 79.6% were females; the largest portion (37%) was composed of the wives of the patients, followed by their mothers (35.2%) with the remainder being their children, brothers, fathers, cousins, or nephews. The majority (70.4%) lived with a partner. In relation to time as caregiver, 64.8% had performed this function between 1 and 5 years, 22.2% from 6 to 10 years, and 12.9% from 11 to 24 years. In relation to the distribution of schooling 38.9% completed elementary level, 26%, high school level, and 35.2%, college level. As for family income, 16.7% earned from 1 to 2 minimum wage salaries (MS); 20.4%, from 2 to 3 MS; 7.4%, from 3 to 4 MS; 14.8%, from 4 to 5 MS, and 40.7%, earned more than 5 MS. The great majority of the sample (92.6%) declared having a religion.

These family members were responsible for the care of 54 patients with neuropsychological sequelae. Of these patients, 51.9% had a stroke diagnosis, 44.4%, a CET diagnosis, and 3.7%, an anoxia diagnosis. The patients had a mean age of 48.6 years (SD = 19.1) and 70.4% were male. The mean time elapsed from the date of the injury until the

moment of the interview was 6.5 years (SD = 4.6). Of these patients, 38.9% were under treatment at the AACD at the time they were interviewed.

According to the results of the instruments applied, 20.4% of the sample presented signs of depression. In relation to anxiety, 44.4% of the family members presented a minimum level, 22.2%, mild, 20.4%, moderate level, and 13%, severe. In the distribution of the level of hopelessness 68.5% presented minimum level, 22.2%, mild level, 5.6%, moderate level, and 3.7%, severe level.

Analyzing the degree of relationship between the scales, only the relationship between anxiety and depression reached statistical significance (Table 1).

The indices of anxiety, depression, and hopelessness were related with the data obtained through the questionnaire to characterize the sample. Although the following categories were not statistically relevant, they constitute data to characterize the role of family caregivers. When questioned as to whether they had given up on personal plans after becoming caregivers, 87% of the sample answered yes; 61% said they felt the need for psychological help after assuming this role; and 70% mentioned receiving help from another person in the care of the patient. Of the family members, 59.3% changed their working situation, i.e., stopped working after the injury occurred and vice-versa. However, of these, only 31% related this change with the fact of having become a caregiver. The majority of the sample (57%) considers they dedicate less time to themselves than they like, 26% said that the time dedicated to themselves was ample or sufficient, and 17% said they never dedicated any time to themselves. Of the family members, 55% stated that there was a change in the relationship with the patient after the injury; of these, 35% classified it as negative. The categories with a *significant p-value*, or with a tendency toward significance are shown in Tables 2 and 3.

When asked which neuropsychological change of the patient most bothered them, each family member mentioned only one change. These were grouped in Figure 1.

DISCUSSION

The analysis of the indices of anxiety, depression, and hopelessness was significant. Studies with family caregivers of patients with

ABI indicate different emotional consequences to the family member such as indications of stress, anxiety, and depression.^{13,19,22,24,26,33}

Of the family caregivers interviewed in this study, considering the levels of mild to severe, 55.6% presented anxiety. This index was higher than the results of previous studies with family caregivers.^{24,34} Wallace & Bogner²⁴ discuss the fact that the family member has greater awareness of the sequelae and limitations of the patient than the patient himself, causing the family member to suffer greater emotional exhaustion. Often the family member does not recognize the cognitive, emotional, and behavioral changes as neuropsychological sequelae, believing that such changes are related to the will of the patient, that all his behaviors are intentional. This factor may cause anxiety in the caregiver, because when the patient does not recognize his own limitations, many times he devotes less than the family member to the recovery process.

The majority of family members (64.8%) had been performing the role of caregiver for a period between 1 to 5 years. Yikilkan et al.,³⁵ when comparing groups of family caregivers who perform such role for different periods of time, noticed that after the fifth year as a caregiver, the indices of anxiety in the family member decrease. In the present study, the fact that the majority of the sample had assumed the role of caregiver for less than 5 years may have contributed to the high indices of anxiety. This first phase after the injury is the period in which the family member invests in the improvement of the patient more intensely and searches for fast results; after the fifth year post injury the family caregiver faces greater frustrations of his or her expectations of total recovery for the patient.

The family caregiver who is available to invest in this recovery process is faced with his own restrictions and with others imposed by the sequelae of the injury, often presenting difficulties in acknowledging the limits of this recovery, which generates high expectations. When faced with the impossibility of the patient's full recovery of their previous condition, the family caregiver feels frustration, but still longs for the return of the personality characteristics that existed before the injury; possibly, in their fantasy, the patient's recovery also would allow the resumption of his life as it was before becoming a caregiver. All these situations can be experienced by the family caregiver as moments of loss, anguish, and

Table 1. Relationship between anxiety (BAI) and depression (BDI)

| BDI | | No | Yes |
|-----|----------|-----|-----|
| BAI | Minimum | 53% | 9% |
| | Light | 21% | 27% |
| | Moderate | 21% | 18% |
| | Serious | 5% | 45% |

p - value = 0.010 (Yates)

Table 2. Relationship of the indices of anxiety (BAI) with variables from the characterization questionnaire

| BAI | | Minimum | | Light | | Moderate | | Serious | | Total | | p-value |
|--|-----|---------|------|-------|------|----------|------|---------|------|-------|------|-----------|
| | | N | % | N | % | N | % | N | % | N | % | |
| Presents health problem after becoming a caregiver | No | 16 | 29.6 | 6 | 11.1 | 0 | 0.0 | 2 | 3.7 | 24 | 44.4 | 0.010 (Y) |
| | Yes | 8 | 14.8 | 6 | 11.1 | 11 | 20.4 | 5 | 9.3 | 30 | 55.6 | |
| Makes use of psychiatric medication | No | 19 | 35.2 | 8 | 11.1 | 6 | 11.1 | 2 | 3.7 | 35 | 64.8 | 0.081 |
| | Yes | 5 | 9.3 | 4 | 14.8 | 5 | 9.3 | 5 | 9.3 | 19 | 35.2 | |
| The neuropsychological change of the patient is bothersome | No | 10 | 18.5 | 0 | 7.4 | 1 | 1.9 | 1 | 1.9 | 12 | 22.2 | 0.074 (Y) |
| | Yes | 14 | 25.9 | 12 | 0.0 | 10 | 18.5 | 6 | 11.1 | 42 | 77.8 | |

Table 3. Relationship between the indices of depression (BDI) and variables of the characterization questionnaire

| BDI | | No | | Yes | | Total | | p-value |
|--|-----|----|------|-----|-----|-------|------|-----------|
| | | N | % | N | % | N | % | |
| Change in their work status after becoming a caregiver | No | 15 | 27.8 | 7 | 13 | 22 | 40.7 | 0.083 |
| | Yes | 28 | 51.9 | 4 | 7.4 | 32 | 59.3 | |
| Makes use of psychiatric medication | No | 31 | 57.4 | 4 | 7.4 | 35 | 64.8 | 0.063 (Y) |
| | Yes | 12 | 22.2 | 7 | 13 | 19 | 35.2 | |

impotence that also influence the onset of depressive symptoms, since the factors that generate anxiety can also affect the onset of depression. Most family caregivers of the sample with positive indices of depression also presented a severe index of anxiety, corroborating such a relationship.

In relation to the analyzed sample 20.4% presented positive indices of depression, which is lower than the rates found in the literature.^{19,23,24,35} However, it is clinically relevant, considering the mental suffering of this portion of the sample. The low index of hopelessness found (31.5%) may be related

to the low index of depression, since the hopelessness is seen as one of the symptoms of a depressed mood.³⁰ In the same way, the high percentage of relatives with religion (92.6%) may be considered a relevant data for these indexes, functioning as the coping mechanism and as a means of emotional and social support. Another factor that may be related with this result is the fact that part of the family caregivers of the research (20%) referred to a positive change in the relationship with the patient after the injury, confirming the literature findings that confirm positive repercussions on the family member to become a caregiver, as an opportunity to develop new skills and qualities, personal growth, satisfaction, closeness to the family, and the resolution of previously existing conflicts.²²

The health problems reported by the majority of the family caregivers (56%) such as fibromyalgia, hypertension, and gastritis, among others may, in addition to physical wear, indicate psychosomatic aspects as a consequence of the demands of the care provided to patients.^{22,36} The changes in the family caregiver's health may be related to the limited time for self-care; a great majority of the sample (74%) referred to never dedicating time to themselves or devoting less time than they like, and an even larger part of the sample (87%) said they had given up on their own plans in order to become a caregiver. In addition, the role of caregiver often makes the family member neglect their own needs, nullifying themselves and increasingly aggravating their health and quality of life.^{19,22,33} The results of the present study indicate that the number of family members who mentioned health problems after becoming caregivers is significantly higher than the rates of depression and anxiety. The answers of family caregivers to questions about their own health depend on their level of awareness of the relevance of their own suffering and in recognizing that they also need care. The family caregiver perceives health problems only when he or she becomes unfit to perform their daily activities;¹² the focus of their attention is on the patient, which makes it difficult to perceive themselves as someone who also suffers and requires attention and care.^{19,22}

Of the family caregivers who make use of psychiatric drugs (35.2%), the majority presents some degree of anxiety, considering the levels of mild to severe. With this result we can infer that the use of such medications does not necessarily prevent significant indices of

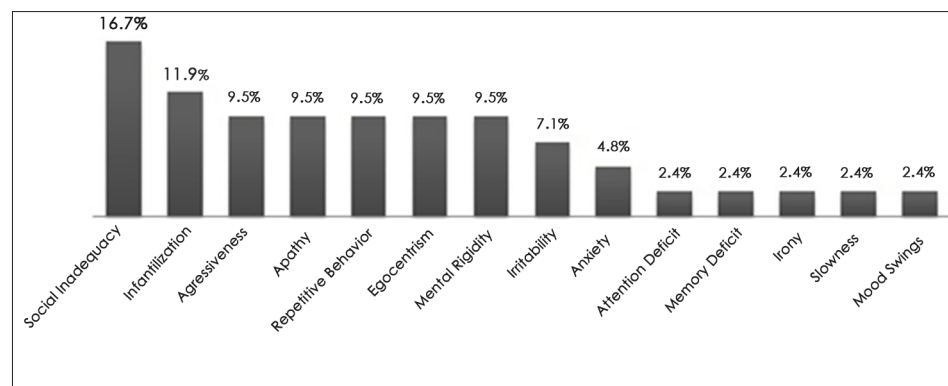


Figure 1. The distribution of the frequency of neuropsychological changes that annoy the family caregiver

anxiety, corroborating the hypothesis that the use of medication may be more effective if combined with other types of treatment, such as psychotherapy. Of the family members in this survey, 61% said they felt the need for such treatment after becoming caregivers.

The majority of the sample showed a change in their work status after having become a caregiver (59.3%). Of these, only a small part presented indices of depression. This shows that, in addition to the changes in family dynamics, there are changes in other aspects of the caregiver's life, such as the professional. These transformations may contribute to a process of illness.^{19,22} In the case of the family caregivers interviewed, it was possible to infer that such change has not contributed to the manifestation of depression.

Authors affirm that the neuropsychological changes of patients have a relevant influence on the general state of health of their family caregivers, leading them to experience significant physical and emotional overload.^{22,26} Most family caregivers (78%) said they were bothered by the neuropsychological changes of the patients. Of the changes that most often bothered them, the most mentioned were social inadequacy and infantilization, in agreement with the literature indicating that the major complaints of family caregivers are related to the behavioral and emotional changes of the patients.^{13,24,26,33} Such changes constitute relevant factors for the prognosis of the patients, since that assists in determining their degree of functional independence, as well as in the possibility of resuming previous activities such as returning to work and redeveloping family and social relationships.¹³ The neuropsychological sequelae contribute to a greater isolation of the patient, also impacting the life of the family, and even causing changes in their social roles and isolation from their previous social group.³⁶

CONCLUSION

This study led to confirming the relevant mental suffering of family caregivers of patients with neuropsychological changes caused by an adult-onset brain injury, observed through the indices of anxiety (55.6%), depression (20.4%), and hopelessness (31.5%). It was possible to conclude that data from the family caregiver such as the psychiatric medication used, discomfort caused by the neuropsychological

change of the patient, health problems, and the change in the work status after becoming a caregiver presented a statistically relevant relationship with the indices investigated.

There are very few Brazilian studies focusing on family caregivers of patients with neurological diseases. The present study has implications both for the involvement of family members in the rehabilitation process of patients as well as in relation to future research and interventions focused on improving the quality of life of these family caregivers.

REFERENCES

- Oliveira-Alonso GS, Silveira VC. Lesões encefálicas adquiridas. In: Fernandes AC, Ramos ACR, Casalis MEP, Hebert SK. Medicina e reabilitação: princípios e prática. São Paulo: Artes Médicas; 2007. p.161-9.
- Ferreira MS, Salles ICD, Branco DG, Gaspar AP. Reabilitações nas lesões encefálicas Adquiridas (LEA). In: Fernandes AC, Ramos ACR, Casalis MEP, Hebert SK. Medicina e reabilitação: princípios e prática. São Paulo: Artes Médicas; 2007. p.174-88.
- Riberto M, Miyazaki MH, Jucá SSH, Lourenço C, Battistella LR. Independência funcional em pessoas com lesões encefálicas adquiridas sob reabilitação ambulatorial. Acta Fisiatr. 2007;14(2):87-94.
- Muszkat M, Mello C. Neuropsicologia do desenvolvimento e suas interfaces. São Paulo: All Print; 2008.
- Rosenthal M, Whyte J. Reabilitação do paciente com traumatismo craniano. In: Delisa JA. Medicina de reabilitação: princípios e práticas. São Paulo: Manole; 1992. p. 677-708.
- Garrison SJ, Rolak LA, Dodaro RR, O'Callaghan AJ. Reabilitação do paciente com AVC. In: Delisa JA. Medicina de reabilitação: princípios e prática. São Paulo: Manole; 1992. p. 653-75.
- Tabaquir ML, Lima MP, Ciasca SM. Avaliação neuropsicológica de sujeitos com lesão cerebral: uma revisão bibliográfica. Rev Psicopedagogia. 2013;30(92):149-56.
- Hamdan AC, Pereira APA. Avaliação neuropsicológica das funções executivas: considerações metodológicas. Psicol Reflex Crit. 2009;22(3):386-93. DOI: <http://dx.doi.org/10.1590/S0102-79722009000300009>
- Cordova RAM, Cesariano CB, Tognola WA. Avaliação clínica evolutiva de pacientes pós - primeiro acidente vascular encefálico e seus cuidadores. Arq Ciênc Saúde 2007; 14(2):71-5.
- Arango-Lasprilla JC, Nicholls E, Villaseñor Cabrera T, Drew A, Jimenez-Maldonado M, Martinez-Cortes ML. Health-related quality of life in caregivers of individuals with traumatic brain injury from Guadalajara, Mexico. J Rehabil Med. 2011;43(11):983-6. DOI: <http://dx.doi.org/10.2340/16501977-0883>
- Floriani CA. Cuidador familiar: sobrecarga e proteção. Rev Bras Cancerol. 2004;50(4):341-5.
- Jennett B, Snoek J, Bond MR, Brooks N. Disability after severe head injury: observations on the use of the Glasgow Outcome Scale. J Neurol Neurosurg Psychiatry. 1981;44(4):285-93. DOI: <http://dx.doi.org/10.1136/jnnp.44.4.285>
- Hora EC, Sousa RMC. Os efeitos das alterações comportamentais das vítimas de trauma crânio-encefálico para o cuidador familiar. Rev Lat Am Enfermagem. 2005;13(1):93-8.
- Gouveia P, Bolognani S, Brucki S, Fabricio A, Bueno O. Metodologia em reabilitação neuropsicológica de pacientes com lesão cerebral adquirida. Rev Psiquiatr Clín. (São Paulo);2001;28(6):295-9.
- Bocchi SCM. Vivenciando a sobrecarga ao vir-a-ser um cuidador familiar de pessoa com acidente vascular cerebral (AVC): análise do conhecimento. Rev Lat Am Enfermagem. 2004;12(1):115-21. DOI: <http://dx.doi.org/10.1590/S0104-11692004000100016>
- Brito ES, Rabinovich EP. A família também adoecel!: mudanças secundárias à ocorrência de um acidente vascular encefálico na família. Interface (Botucatu). 2008;12(27):783-94.
- Carter B, Mcgoldrick M. As mudanças no ciclo de vida familiar: uma estrutura para terapia familiar. Porto Alegre: Artes Médicas; 1995.
- Junqué C, Bruna O, Mataró M. Traumatismos cranioencefálicos: uma abordagem da neuropsicologia e fonoaudiologia. São Paulo: Santos; 2001.
- Calvete E, Arroyabe EL. Depression and grief in Spanish family caregivers of people with traumatic brain injury: the roles of social support and coping. Brain Inj. 2012;26(6):834-43. DOI: <http://dx.doi.org/10.3109/02699052.2012.655363>
- Wilson BA. Reabilitação da memória: integrando teoria e prática. São Paulo: Artmed; 2011.
- Ackerman P, Asindua S, Blouin M, Cameron D, Clode K, Cockburn L, et al. Reabilitação. In: Relatório mundial sobre a deficiência. São Paulo: SEDPCD, 2012. p. 97-139.
- Fonseca NR, Penna AFG, Soares MPG. Ser cuidador familiar: um estudo sobre as consequências de assumir este papel. Physis. 2008;18(4):727-43. DOI: <http://dx.doi.org/10.1590/S0103-73312008000400007>
- Serna ECH, Sousa RMC. Depressão: uma possível consequência adversa do trauma cranioencefálico para o cuidador familiar. Acta Paul Enferm. 2005;18(2):131-5.
- Wallace CA, Bogner J. Awareness of deficits: emotional implications for persons with brain injury and their significant others. Brain Inj. 2000;14(6):549-62. DOI: <http://dx.doi.org/10.1080/026990500120457>
- Simpson GK, Tate RL, Whiting DL, Cotter RE. Suicide prevention after traumatic brain injury: a randomized controlled trial of a program for the psychological treatment of hopelessness. J Head Trauma Rehabil. 2011;26(4):290-300. DOI: <http://dx.doi.org/10.1097/HTR.0b013e3182225250>
- Carvalho J, Kaihami HN, Alves VLR. A relação do cuidador com o adulto jovem com sequelas de traumatismo cranioencefálico. Fam comunidade. 2005;2(1):83-102.
- American Psychiatric Association. Manual Diagnóstico e Estatístico de Transtornos Mentais (DSM-5). 5 ed. Porto Alegre: Artmed; 2014.
- Oliveira KL, Santos AAA, Cruvinel M, Neri AL. Relação entre ansiedade, depressão e desesperança entre grupos de idosos. Psicol Estud. 2006;11(2):351-9. DOI: <http://dx.doi.org/10.1590/S1413-73722006000200014>
- Aros MS, Yoshida EMP. Estudos da depressão: instrumentos de avaliação e gênero. Bol Psicol. 2009; 59(130):61-76.
- Cunha JA. Manual da versão em português das Escalas Beck. São Paulo: Casa do Psicólogo; 2001.

31. Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Inj.* 2003;17(6):453-68. DOI: <http://dx.doi.org/10.1080/0269905031000070143>
32. Hora EC, Sousa RMC, Chavez Alvarez RE. Caracterização de cuidadores de vítimas de trauma crânio-encefálico em seguimento ambulatorial. *Rev Esc Enferm USP.* 2005;39(3):343-9. DOI: <http://dx.doi.org/10.1590/S0080-62342005000300013>
33. Hassan ST, Khaw WF, Rosna AR, Husna J. Traumatic brain injury: caregivers' problems and needs. *JNMA J Nepal Med Assoc.* 2011;51(181):53-5.
34. Yengil E, Acipayam C, Kokacya MH, Kurhan F, Oktay G, Ozer C. Anxiety, depression and quality of life in patients with beta thalassemia major and their caregivers. *Int J Clin Exp Med.* 2014;7(8):2165-72.
35. Yıkılkan H, Aypak C, Görpelioğlu S. Depression, anxiety and quality of life in caregivers of long-term home care patients. *Arch Psychiatr Nurs.* 2014;28(3):193-6. DOI: <http://dx.doi.org/10.1016/j.apnu.2014.01.001>
36. Serna EC, Sousa RM. Changes in social roles: a consequence of traumatic brain injury for the family caregiver. *Rev Lat Am Enfermagem.* 2006;14(2):183-9.