EVALUATION OF THE NEEDS OF FAMILY MEMBERS OF TRAUMATIC BRAIN INJURY PATIENTS

AVALIAÇÃO DAS NECESSIDADES DOS FAMILIARES DE VÍTIMAS DE TRAUMA CRANIOENCEFÁLICO

EVALUACIÓN DE NECESIDADES DE FAMILIARES DE VÍCTIMAS DE TRAUMATISMO CRANEOENCEFÁLICO

Lorranny Santana Rodrigues¹
Ana Carla Ferreira Silva dos Santos²
Edilene Curvelo Hora Mota³
Leda Rodrigues dos Santos⁴
Bruno Melo da Silva⁵
Karoline Cravo de Melo⁶

Objective: identify the needs of family members of traumatic brain injury patients treated in an outpatient setting and the extent of fulfillment of such needs. Method: quantitative descriptive study. Two data collection instruments were used, one for characterization of the family member and patient, and the Family Needs Questionnaire, in its adapted Portuguese version, applied to 22 family members. Results: most of the needs (93.1%) listed were considered "important or very important" and relate to the subthemes "health information" and "professional support." Conclusion: the rates of fulfillment of needs presented by the family members show the service quality offered by the health professionals during the treatment and rehabilitation of traumatic brain injury patients.

Descriptors: Traumatic brain injuries. Family. Family relations.

Objetivo: identificar as necessidades dos familiares de vítimas de Trauma Cranioencefálico atendidas ambulatorialmente e o quantitativo do atendimento dessas necessidades. Método: estudo descritivo de abordagem quantitativa. Foram utilizados dois instrumentos de coleta, um para caracterização do familiar e da vítima e outro, o Family Needs Questionnaire, em sua versão adaptada para o português, aplicados com 22 familiares. Resultados: a grande maioria (93,1%) das necessidades elencadas foi considerada "importante ou muito importante" e estão relacionadas aos subtemas "informações sobre saúde" e "suporte profissional". Conclusão: as taxas de atendimentos das necessidades apontadas pelos familiares demonstram a qualidade do serviço oferecido pelos profissionais de saúde durante o tratamento e a reabilitação das vítimas de Trauma Cranioencefálico.

Descritores: Traumatismos encefálicos. Família. Relações familiares.

Master's degree in Health Sciences. Doctoral student in Health Sciences, Universidade Federal de Sergipe. Assistant Professor B, Nursing Department, Universidade Federal de Sergipe. Member of the Academic League of Trauma, Universidade Federal de Sergipe, and of the Trauma Study and Research: Prevention, Treatment and Rehabilitation Care. Lagarto, Sergipe, Brazil. carlafss@yahoo.com.br

Nurse. Master's and doctor's degree in Adult Health Nursing. Specialization in Hospital Department Management, High School Methodology and Workplace Nursing. Associate Professor, Department of Nursing and Graduate Program in Health Sciences, Universidade Federal de Sergipe. Coordinator, Academic League of Trauma the Universidade Federal de Sergipe and Trauma Research Group: Prevention, Treatment and Rehabilitation Care. São Cristovão, Sergipe, Brazil. edilenechs@yahoo.com.br

⁴ Nurse, Teaching Hospital of the Universidade Federal de Sergipe. Specialization in Workplace Nursing. Aracaju, Sergipe, Brazil. ledrod6@hotmail.com

Nurse. São Cristovão, Sergipe, Brazil. colossobm@gmail.com

Nurse. Lagarto, Sergipe, Brazil. lorrannysr@outlook.com

⁶ Undergraduate student in Nursing and scholarship holder of Scientific Initiation, Universidade Federal de Sergipe. São Cristovão, Sergipe, Brazil. karolzinhacravo@hotmail.com

Objetivo: identificar las necesidades de familiares de víctimas de Traumatismo Craneoencefálico atendidas en forma ambulatoria y el número de atenciones de dicha índole. Método: estudio descriptivo, de abordaje cuantitativo. Fueron utilizados dos instrumentos de recolección, uno para caracterización del familiar y la víctima, y otro, el Family Needs Questionnaire, en su versión adaptada al portugués, aplicados sobre 22 familiares. Resultados: la gran mayoría (93,1%) de las necesidades listadas fue considerada "importante o muy importante", y están relacionadas a los subtemas "información sobre salud" y "soporte profesional". Conclusión: las cantidades de atenciones de las necesidades expresadas por los familiares demuestran la calidad del servicio ofrecido por los profesionales de salud durante el tratamiento y la rebabilitación de víctimas de Traumatismo Craneoencefálico.

Descriptores: Traumatismo encefálico; Familia; Relaciones familiares.

Introduction

Traumatic brain injury (TBI) is one of the main types of trauma that helps increase morbidity and mortality rates and deficits in the quality of life of patients ⁽¹⁾. It is defined as any traumatic injury, such as fracture or laceration, involving the scalp, skull and brain, resulting in functional alterations to the central nervous system (CNS) ⁽²⁾. This injury is one of the most frequent caused by external causes ⁽³⁾, mainly affecting the young male population aged 21 to 49 years. These data may be linked with several factors, such as fast population growth, motorization and cultural aspects. For women, when compared to men, TBI is more frequent in the age group of 41 years and older ⁽⁴⁾.

The changes caused by TBI can have consequences that require post-hospital care. Around 15% of patients with mild TBI present symptoms and physical dysfunctions that persist for up to three months and become chronic conditions, which may lead to other conditions, such as fatigue, insomnia, dizziness, headache, and other disorders, such as cognitive and emotional problems⁽²⁾. Another study in the literature highlights that 65% of patients with moderate to severe TBI present disabilities requiring long-term care.

Rehabilitation is one method to treat these patients in the post-hospital context. It is, therefore, a process for patient reinsertion in society so that they can reach their maximum potential in terms of physical, sensorial, intellectual and psychological abilities⁽⁶⁾. It should be noted that the adaptive capacity of both patients and

their family members during rehabilitation is individual and depends on personal, social and cultural factors (7-9).

Although the patient is the central part of a rehabilitation program, caregivers are also relevant, as they end up forgetting to take care of themselves in an attempt to meet the patient's needs. The way TBI patients and their family members address the trauma has a direct impact on their recovery, interpersonal relationships and future 100. Therefore, the families may have different needs, such as increased expenses, health information, emotional support, professional and community support, and involvement with care. In addition, the failure to meet these needs may cause problems that can lead to health disorders (11-12).

The interest in this theme came after the experience in the outpatient setting of a university hospital, in which TBI patients were sent to rehabilitation. Their family members reported challenges in care provision to patients and that the attention provided to them was not well targeted. Thus, the interest in enhancing the knowledge related to this theme was raised, to understand and produce information to show the actions conducted by the health team toward these families.

In this context, the objective of this study was to identify the needs of the family members of patients with traumatic brain injuries treated in an outpatient clinic and the extent of fulfillment of these needs.

Method

A quantitative descriptive study was conducted at the outpatient clinic of a university hospital located in the state of Sergipe, which is specialized in TBI. This outpatient clinic has a multidisciplinary team comprised of professionals, professors and students from nursing, psychiatry, neurosurgery, psychology, speech therapy and nutrition programs, through the university extension project called REVIVA-LITRAUMA, which is focused on rehabilitation.

In one year, there were 86 visits of TBI patients. Among these, 22 family members of the patients were selected for intentional nonprobability sampling, following these inclusion criteria: the participants should provide verbal and written consent to participate in this study; be 18 years old or older; have studied at least until the 6th year of elementary education or have an understanding, according to the guidelines described in the application manual of the Family Needs Questionnaire (FNQ); participate in the care to the patient over 12 years of age. Only one family member per patient was invited to participate.

Two data collection instruments were used in this study, one was the Family Needs Questionnaire (FNQ)⁽¹³⁾ in its validated version for the Portuguese language called *Questionário* de Necessidades da Família. This questionnaire has 40 items of needs listed in the following subscales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care. The instrument was designed to determine the needs of families of TBI patients classified as psychosocial and educational needs. The second instrument was a form developed by the author, containing two sections: one for characterization of the family member and the other for characterization of the TBI patient.

Data collection was conducted once a week (every Friday), from September to December 2015, in the afternoon, during the REVIVA-LITRAUMA service, after an authorization from the service coordinator and approval

by the Human Research Ethics Committee of the Universidade Federal de Sergipe, under protocol no. 50411015.3.0000.5546. The development of the study met all requirements of Resolution no. 466/2012 of the Brazilian National Health Council, and used an informed consent form (ICF).

Data were tabulated and analyzed using the computerized database of SPSS 23.0. A descriptive analysis of the quantitative variables was conducted, with data expressed as mean and standard deviation (mean ± sd), and the qualitative variables, as the percentage of their distribution, were presented in tables. The results of family needs were presented in percentages according to their frequency, calculated with the needs evaluated by the family members as "important or very important." Needs classified as "unimportant," "unmet," and "met" were calculated separately.

The proportional index of needs (PIN) was also calculated, according to a study 1, to measure the degree of importance and fulfillment of needs. The percentage of importance for each family member was calculated by dividing the total number of needs classified as "important or very important" by the total number of items. Using the same procedure, another percentage was calculated by dividing the total number of needs assessed as "unimportant" by the total number of items.

Regarding the needs that have been met, only those evaluated as "important or very important" were considered. The number of needs assessed as "unmet" or "met" was divided by the number of items evaluated as "important or very important." The average of these indexes was presented in tables.

Results

According to the data analysis, most family members were female (90.9%) and married (45.4%). The prevalent age groups were between 26 and 40 years old (45.4%) and 41 and 60 years old (45.4%), with a mean age of 39.8 years. The family income of the interviewees was mostly

between R\$ 1,001.00 and R\$ 2,000.00 (45.4%) and they lived with 3 to 5 people, including themselves. Regarding their educational level, 40.9% had completed higher education; and for the religion variable, 81.8% reported being Catholics.

Patients with TBI were mostly men (77.3%), aged 26 to 40 years (36.4%). Among those who had information about the type of TBI, most of them had mild trauma, although this evaluation is overshadowed by the fact that most patients do

not have information about the trauma severity in their medical records. In addition, 68.2% of the patients reported cognitive-behavioral changes after the TBI.

In the analysis of the FNQ, the PIN presented a high value (97.5%) for the needs listed as "important and very important." Among these, the needs that have been met reached 55.6% and unmet needs, 17.5%. Needs considered as "unimportant" reached a low value (2.5%). Table 1 presents these data.

Table 1 – Mean and standard deviation of the proportional index of needs of family members. Aracaju, Sergipe, Brazil, 2015. (N=22)

Proportional index of needs highlighted by the family members	Result (%) = X ± Standard deviation
Important or very important	97.5 ± 3.54
Unimportant	2.5 ± 0.12
Met	55.68 ± 23.2
Unmet	17.5 ± 11.75

Source: Created by the authors.

Table 2 shows the needs classified as "important or very important." Most of these needs are related to health information, such as the first two reported by all participants (100%)

as "very important," while the third and fourth needs, also 100% classified as "very important," are linked with instrumental, i.e. financial and material, resources.

Table 2 – Most frequent needs, evaluated as "important or very important." Aracaju, Sergipe, Brazil, 2015. (N=22)

I need to		Important (3)		Very important (4)	
	N	%	N	%	
11. have complete information about the treatment of traumatic brain injury (e.g.: medication, injections, surgery).	0	0,0	22	100,0	
18. have information about the patient's progress in the rehabilitation or training program.	0	0,0	22	100,0	
20. have sufficient resources for the patient (e.g.: rehabilitation programs, physical therapy, counseling, job guidance).	0	0,0	22	100,0	
21. have sufficient resources to me or my family (ex.: financial or legal support, day off from care, counseling, nursing service).	0	0,0	22	100,0	
2. always know what is conducted with or to the patient.	1	4,5	21	95,5	
4. be informed of all changes in the patient's health condition.	1	4,5	21	95,5	
6. receive explanations from the health professionals in a way that I can understand.	1	4,5	21	95,5	
9. have a health professional that I can contact for guidance or services whenever the patient requires it.	1	4,5	21	95,5	

Source: Created by the authors

Table 3 shows the needs classified as "unimportant" and "less important." The most frequent items are 38, 39 and 40, related to emotional support.

Table 3 - Most frequent needs, evaluated as "unimportant" and "less important." Aracaju, Sergipe, Brazil, 2015. (N=22)

I need to		Unimportant (1)		Less important (2)	
	N	%	N	%	
38. receive help to remain hopeful about the patient's future.	1	4.5	0	0.0	
39. receive support to prepare myself for the worst.	1	4.5	O	0.0	
40. be encouraged to ask others for help.	1	4.5	0	0.0	
32. have the understanding of the patient's friends regarding his/her problems.	0	0.0	3	13.6	
26. spend some time with my friends.	0	0.0	3	13.6	
8. see that my opinions are used to plan the patient's treatment, rehabilitation or training.	0	0.0	3	13.6	
3. always give my opinions to the other people involved in the patient's care, rehabilitation or training.	0	0.0	2	9.1	
35. discuss my feelings towards the patient with other people (friends or family members).	0	0.0	2	9.1	
34. discuss my feelings about the patient with someone who has had the same experience.	0	0.0	2	9.1	

Source: Created by the authors.

Table 4 presents the frequency of the needs considered as "met." It is noteworthy that "be informed of all changes in the patient's health condition" was the most frequent need, with 100% fulfillment.

Table 4 - Most frequent needs evaluated as "met." Aracaju, Sergipe, Brazil, 2015. (N=22)

I need to		(%)
4. be informed of all changes in the patient's health condition.	22	100.0
10. see that all different professionals agree on the best method to help the patient.	20	90.9
18. have information about the patient's progress in the patient's rehabilitation or	19	86.4
training program.		
1. see that the medical team, training team or rehabilitation team respect the	18	81.8
patient's needs or desires.		
40. be encouraged to ask others for help.	17	77.3

Source: Created by the authors.

Table 5 shows the most frequent needs evaluated as "unmet." The items with the highest percentage were "spend some time with my friends" (54.5%) and "have some time away from my problems and responsibilities" (50.0%).

Table 5 - Most frequent needs evaluated as "unmet." Aracaju, Sergipe, Brazil, 2015. (N=22)

(to be continued)

I need to		(%)
26. spend some time with my friends.	12	54.5
25. have some time away from my problems and responsibilities.	11	50.0
16. know how long each problem of the patient may last.	10	45.5

Table 5 – Most frequent needs evaluated as "unmet." Aracaju, Sergipe, Brazil, 2015. (N=22) (conclusion)

I need to		(%)
19. have support to decide to what extent I should let the patient do something	9	40.9
alone.		
39. receive support to prepare myself for the worst.	8	36.4
17. receive guidance about what to do when the patient is nervous or acting	8	36.4
strangely.		

Source: Created by the authors.

The needs identified as "important or very important" ranged from 54.5% to 100% and only three needs were considered "unimportant." In addition, half of the family members (50.0%) provided the answer "not applicable" to the item "have the understanding of the boss, co-workers or teachers regarding the patient's problems."

Discussion

Regarding the items evaluated as "important or very important," a high mean proportional index (97.5%) was observed, as most interviewees evaluated the importance of family needs as favorable. Some authors (14-15), who participated in the production of the original scale and the translation and validation of the Portuguese version, also obtained high mean PIN values of 93.1% and 84%, respectively.

The most frequent needs evaluated as "important and very important" were those containing the "health information" subtheme, related to the physical and cognitive-behavioral changes caused by the TBI, and the "professional support" subtheme, related to the fulfillment of needs by the professionals from the various areas that support the patient and the family member. These data validate the fact that the support provided by the health professionals is critical to reduce the number of unmet needs. Many families require professional intervention to help them cope with emotional distress and accept long-standing changes because they expect the patient will soon recover his/her health condition (16-18).

The needs listed as "important and very important" are "have complete information

about the treatment of traumatic brain injury (ex.: medication, injections, surgery)" (100%), "have information about the patient's progress in the rehabilitation or training program" (100%), "have sufficient resources for the patient (ex.: rehabilitation programs, physical therapy, counseling, job guidance)" (100%), which all had a positive evaluation of the participants.

It should be mentioned that some studies (3,19) report a positive impact on patient care from a family member with knowledge about the disease, but many caregivers do not have the necessary knowledge of the issue, which is a relevant theme. In this context, authors emphasize that nurses play a crucial role in promoting healthy family functioning and adjustment to TBI patients and their families, and promoting family support and the insertion of health education in rehabilitation programs.

The most frequent needs listed as "unimportant" are in the subscale of "emotional support" and correspond to the support received by other family members and friends, the understanding of feelings and creation of an emotional foundation for the caregiver. Of these, the three needs considered less important were "receive help to remain hopeful about the patient's future," "receive support to prepare myself for the worst," and "be encouraged to ask for help to others," with 4.5% each.

In this case, the literature (14,22) highlights that the most plausible explanation would be that many family members, when providing care to a TBI patient, forget their own problems and extra-family relationships and do not receive the necessary support to address these issues. In addition, at the time of the interview, many

of them considered these issues as something negative that would make them lose hope of a speedy recovery of the patient.

Among the needs classified as "unmet," the ones with the highest percentage were "spend some time with my friends" (54.5%), "have some time away from my problems and responsibilities" (50.0%), and "know how long each problem of the patient may last" (45.5%).

When comparing this study to an investigation conducted with 161 family members, a disagreement was observed, as the unmet needs were "have sufficient resources to me or my family (ex.: financial or legal support, day off from care, counseling, nursing service)" (93.2%), "have sufficient resources for the patient (ex.: rehabilitation programs, physical therapy, counseling, job guidance)" (88.6%), and "know how long each problem of the patient may last" (87.9%).

Many family members reported that providing care to a patient leaves "no time" to take care of themselves and the results below reflect this fact. Thus, the classification of these needs as unmet is justified by the authors (22-23), as indications that the family member has relationship and social life issues, especially in the recent post-trauma period. This is an issue of concern, as it can lead to caregiver's disorders.

In this study, the fulfillment rates of the needs highlighted by the family members show the quality of the service provided by the health professionals during the treatment and rehabilitation of TBI patients, so that the most frequent items were "have information about the patient's progress in the rehabilitation or training program" (100%), "see that all different professionals agree on the best method to help the patient" (90.9%), and "be informed of all changes in the patient's health condition" (86.4%).

Regarding the questions that received a "not applicable" answer, item 33 "have the understanding of the boss, co-workers or teachers regarding the patient's problems" had a high rate (50.0%). It may be related to the fact that many family caregivers stop working to take care of the patient or that the primary caregiver

is someone who does not have a job, so that this person can dedicate more time to providing care to the patient ²³.

Conclusion

Most of the interviewees consider that all the needs listed in the FNQ are important. This fact confirms the importance of understanding the family context of a TBI patient to allow prevention of caregiver disorders.

More than half of the items considered as "very important and important" were identified as met, which indicates that the support provided to the family members, although not targeted, produces positive results. In addition, this study also concludes that when the number of met needs increases, the rate of illness may be lower, which is encouraging.

This study concludes that the fulfillment rates of the needs highlighted by the family members indicate the quality of service provided by the health professionals during the treatment and rehabilitation of traumatic brain injury patients.

The opportunity to apply this instrument was a valid experience, since the theme addressed by the FNQ is extremely important, given the dimension that TBI has in the public health context. With so many challenges the family caregiver may have to face, an evaluation of their needs is important to guide the actions of a nurse in the provision of care to the family during the nursing process and, thus, improve the quality of life of those who are impacted by the consequences of having a traumatic brain injury.

Collaborations

- conception, project, analysis and interpretation of data: Lorranny Santana Rodrigues, Ana Carla Ferreira Silva dos Santos and Edilene Curvelo Hora Mota;
- 2. article writing, relevant critical review of its intellectual content: Lorranny Santana Rodrigues, Ana Carla Ferreira Silva dos Santos,

Edilene Curvelo Hora Mota and Leda Rodrigues dos Santos;

3. final version approval for publication: Lorranny Santana Rodrigues, Ana Carla Ferreira Silva dos Santos, Edilene Curvelo Hora Mota, Leda Rodrigues dos Santos, Karoline Cravo de Melo and Bruno Melo da Silva.

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