

**Sociodemographic profile and post-traumatic feelings of family caregivers of individuals who are victims of traumatic brain injury**

*Perfil sociodemográfico y sentimientos postraumáticos de los cuidadores familiares de personas víctimas de traumatismo craneoencefálico*

*Perfil sociodemográfico e sentimentos pós-traumáticos de familiares cuidadores de indivíduos vítimas de trauma cranioencefálico*

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**Submission:** 09-10-2020**Approval:** 09-17-2020**Abstract**

Cranioencephalic Trauma (CET), as a pathological change in brain function, has consequences for the individual, changes his social role and the context in which he is inserted. Thus, the events resulting from a CET include victim and family, requiring a comprehensive approach by health services. Therefore, the objective of this study was to characterize the sociodemographic profile of family caregivers of individuals victims of CET treated at a hospital in Sergipe. For this, a descriptive and analytical research was carried out with family caregivers of individuals due to CET. Data were collected through telephone contact with a collection instrument containing objective questions regarding the characterization of the family caregiver. Thus, after the construction of the caregivers' profiles and the identification of feelings related to post-trauma, it was possible to realize how important these findings are for health services, serving as a subsidy for proposing interventions and programs that suit the public- target. In the context of family caregivers, this tool becomes essential to guarantee comprehensive health care for these individuals.

**Descriptors:** Family Caregiver; Cranioencephalic Trauma; Public Health Nursing; Public Health.

**Resumen**

El Trauma Craneoencefálico (TCE), como cambio patológico en la función cerebral, tiene consecuencias para el individuo, cambia su rol social y el contexto en el que se inserta. Así, los hechos resultantes de un TCE incluyen víctima y familia, requiriendo un abordaje integral por parte de los servicios de salud. Por tanto, el objetivo de este estudio fue caracterizar el perfil sociodemográfico de los cuidadores familiares de personas víctimas de TCE atendidas en un hospital de Sergipe. Para ello, se realizó una investigación descriptiva y analítica con cuidadores familiares de personas con TCE. Los datos fueron recolectados a través del contacto telefónico con un instrumento de recolección que contenía preguntas objetivas sobre la caracterización del cuidador familiar. Así, luego de la construcción de los perfiles de los cuidadores y de la identificación de sentimientos relacionados con el postraumático, se pudo dar cuenta de la importancia de estos hallazgos para los servicios de salud, sirviendo como un subsidio para proponer intervenciones y programas que se adapten al público objetivo. En el contexto de los cuidadores familiares, esta herramienta se vuelve imprescindible para garantizar una atención integral de salud a estas personas.

**Descriptoros:** Cuidador Familiar; Traumatismo Craneoencefálico; Enfermería de Salud Pública; Salud Pública.

**Resumo**

O Trauma Cranioencefálico (TCE), como alteração patológica na função cerebral, apresenta consequências ao indivíduo, altera seu papel social e o contexto em que se insere. Dessa forma, os eventos decorrentes de um TCE englobam vítima e família, sendo necessária uma abordagem integral por parte dos serviços de saúde. Diante disso, o objetivo desse estudo foi caracterizar o perfil sociodemográfico de familiares cuidadores de indivíduos vítimas de TCE atendidos em um hospital de Sergipe. Para tanto, foi realizada uma pesquisa descritiva e analítica com familiares cuidadores de indivíduos devido ao TCE. Os dados foram coletados através do contato telefônico com instrumento de coleta contendo questões objetivas a respeito da caracterização do familiar cuidador. Assim, após a construção dos perfis dos cuidadores e a identificação de sentimentos relacionados ao pós-trauma, foi possível perceber o quanto esses achados são importantes para os serviços de saúde, servindo de subsídio para proposição de intervenções e programas que se adequem ao público-alvo. No contexto dos familiares cuidadores, essa ferramenta se torna imprescindível a fim de garantir atenção integral à saúde desses indivíduos.

**Descriptoros:** Familiar Cuidador; Traumatismo Cranioencefálico; Enfermagem em Saúde Pública; Saúde Coletiva.



## Introduction

Cranioencephalic Trauma (CET) is a pathological alteration in brain function, due to external factors. Thus, episodes of instability of consciousness, memory loss, modification of the individual's mental state and neurological impairment are some of the common clinical signs of this injury<sup>1</sup>.

The CET can be considered mild, moderate, or severe, depending on the assessment of the level of consciousness that can be performed with the Glasgow Coma Scale (GCS). Subsequently, the health professional can add to this assessment the data related to neuropsychomotor changes, which allows identifying sequelae and determining the general condition of this individual. The survivor of a CET, therefore, may have physical, cognitive, or behavioral limitations and disabilities<sup>2</sup>.

In this context, it is important to highlight that the changes resulting from a CET do not affect only the individual, but his family and, mainly, his closest caregiver. In a study<sup>3</sup>, it was perceived that caregivers of individuals victims of CET had physical and mental overload related to increased responsibilities, lack of time for themselves and self-care, the perception that life had been interrupted and the feeling of loss in relation to the individual receiving care.

Thus, considering trauma as a broad process that encompasses victim and family member / caregiver, it is necessary for health services to act in an integral manner, addressing the whole family when establishing goals and therapeutic interventions for this. To achieve this objective, in Brazil, the Unified Health System (SUS) has a Family Health Program (PSF) instituted as a Primary Care strategy (AB) through Ordinance No. 2,436/2017. In this scenario, according to the ordinance, primary care services oversee the performance of multiprofessional teams with families since it considers it a relevant and conditioning element in people's way of life and in care<sup>4</sup>.

Thus, by knowing the family environment and its components, the professional can identify health determinants to be worked on and act on them. In the context of a family nucleus with a victim of CET, this strategy becomes essential since the trauma experienced by a family member will modify the dynamics of the house and reconfigure the roles of family members. Therefore, the objective of this research is to describe the sociodemographic profile of family members of victims of CET treated at a referral hospital in Sergipe, Brazil.

## Methodology

This is a descriptive and analytical cross-sectional research with a quantitative approach, developed through the Scientific Initiation Program (PIC) of the Federal University of Sergipe (UFS).

Thus, family members who live with or care for individuals victims of CET participated in the research, identified during the stage of clinical validation held in 2018 that, through the extraction of data from hospital records, sought to observe the response of patients to nursing care. Thus, the non-probabilistic sample was made up of 30

The inclusion criteria adopted were providing care to individuals with CET, living in the same household as the individual receiving care and signing the Informed Consent Form (ICF) sent by email, accepting participation and collaboration in the research. Exclusion criteria are family members who did not accept to participate in the study.

During the development of this study, the ethical precepts of research involving human beings were respected and approved with an opinion number 3,550,349 by the Ethics and Research Committee of UFS, as governed by Resolution No. 466/12 of the Ministry of Health.

The collection was carried out by telephone contact, between October 2019 and February 2020. The data collection instrument included objective questions aimed at the subjects' sociodemographic characterization, clinical evidence, diagnoses, and nursing interventions aimed at family members / caregivers. However, for the construction of this article, data relating to sociodemographic.

The results were tabulated in Microsoft Office Excel (2010) and then imported into the IBM® SPSS- Statistical Package for the Social Sciences 20.0 Mac software (SPSS 20.0, SPSS Inc., Chicago, Illinois, USA). The statistical analysis of the results related to the sociodemographic profile was presented in percentage data and in the degree of relevance obtained through the chi-square statistical test, presented in tables.

## Results and Discussion

Thirty relatives of victims of CET participated in the research, the vast majority (93.3%) being female and 6.7% male. The prevalence of female caregivers was pointed out in other studies previously<sup>5-6</sup> and it is related to a historical process that imposes the role of caring on women, as a tendency inherent to their nature<sup>7</sup>.

Among the post-traumatic feelings, 63.3% of the sample experienced sadness and 50% said they felt depressed. When associating sex with reports of depression and sadness (Table 1), no statistical relevance was observed ( $p = 1$  and  $p = 0.265$ , respectively). In contrast, while no statistical association was found between the respondent's sex and reports of sadness and depression within the current research sample, a North American study found that women, when playing the role of caregivers, tended to have higher levels of burden<sup>8</sup>. In addition, it was observed that female caregivers were more subject to sleep disorders, physical stress and feeling unmotivated compared to male caregivers<sup>9</sup>, this being a data to be evaluated by the health team when characterizing the profile of the caregiver.

In addition, there was a predominance of the age group of 40 to 49 years old (40%), the other groups include those over 50 years old (23.3%), those under 25 years old (20%) and those between 25 and 39 years (16.7%). In this context, it is understood that age is directly related to the individual's way of life and well-being, and it was observed from a Brazilian study that the caregiver's age was inversely



Santos TS, Silva IA, Freitas CKAC, Rodrigues IDC, Santos ACFS, Barreiro MSC found that the lack of time for social relationships, associated with increased workload and misinformation, was the main trigger for symptoms of depression and anxiety among caregivers of women with ovarian cancer<sup>15</sup>.

proportional to the feeling of hope. Thus, caregivers over 69 years of age were the ones who least reported willingness to feel<sup>10</sup>. Such a relationship with feelings could be observed when analyzing the reports of family members interviewed in this research, with 85.7% of the participants over 50 years old saying they felt sad and depressed.

In terms of skin color, 86.7% of the interviewees declared themselves to be brown, while 6.7% were white and 6.7% black, reflecting the Brazilian ethnic reality. When observing the association with feelings of depression and sadness, no statistical significance was observed for skin color ( $p = 0.341$  and  $p = 0.838$ , respectively). However, one study observed differences within the experience of being a caregiver when considering the ethnicity of the interviewees. Thus, compared to white caregivers, black caregivers found it more difficult to report emotional difficulties, despite being more willing to seek training and less likely to experience restrictions related to the role of caregiver<sup>11</sup>, exposing an aspect to be analyzed when working with individuals providing care.

As for marital status, the sample consisted of 60% single, 20% married, 13.3% separated and 6.7% in a stable relationship, unlike other surveys regarding caregivers, in which they report that most of them are married, often being the husband or wife of the care receiver<sup>12-13</sup>, the sample of the present study was mostly composed of single individuals. Regarding the association of marital status with reports of sadness and depression, it was observed that singles had statistical significance ( $p = 0.046$ ) when feeling depressed. Thus, similar data was found in a survey conducted at an organ transplant center in Nepal, in which it was observed that the burden levels of caregivers of hemodialysis patients were affected by their marital status<sup>14</sup>. Within this perspective, a study conducted in Singapore

When asked about education and level of education, 53.3% of respondents said they had between 10 and 20 years of study, 20% under 5 years, 13.3% between 5 and 10 years and 13.3% with over 20 years of study. In view of this, there is a representation of the heterogeneity of Brazilian education, reflecting the 2010 demographic census in which it was observed that 23% of Brazilian adults completed their studies at the end of high school, with average schooling equivalent to 8.5 years in 2007<sup>16</sup>. Years of study are important strands within the individual's perception of their quality of life, since it was pointed out that caregivers with low levels of education are more likely to have low quality of life<sup>17</sup>.

Regarding spiritual support, 76.7% of the sample reported being Catholic, 13.3% Protestant, 3.3% Spiritists and 6.7% declared belonging to other religions. The predominance of the Catholic faith reflects what was perceived in another Brazilian study that assessed the needs of family members of victims of traumatic brain injury, in which 81.8% of the 22 family members interviewed declared themselves to be Catholic<sup>5</sup>. The positive relationship between caregiver and spiritual support is linked to a better impact on mental health. In this way, interactions and perceptions linked to a non-punitive view of a religion assist the individual in improving performance in his role in caring and provide benefits to the emotional state of that person<sup>18</sup>.

There was no association between sex, age, skin color, education, and religion with reports of depression and sadness. Table 1 shows the results presented above.

**Table 1.** Distribution of sociodemographic characteristics of family members of individuals suffering from CET according to reports of depression and sadness. São Cristóvão, SE, Brazil, 2019-2020

	N (%)	Feeling depressed			Feel sad		
		No	Yes	p-value*	No	Yes	p-value
<b>Sex</b>							
Feminine	28 (93,3%)	14	14	1	11	17	0,265
Male	2 (6,7%)	1	1		0	2	
<b>Age</b>							
Less than 25 years	6 (20%)	3	3	0,164	3	3	0,547
Between 25 and 39 years	5 (16,7%)	3	2		2	3	
Between 40 and 49 years	12 (40%)	8	4		5	7	
More than 50 years	7 (23,3%)	1	6		1	6	
<b>Skin color</b>							
White	2 (6,7%)	2	0	0,341	1	1	0,838
Black	2 (6,7%)	1	1		1	1	
Brown	26 (86,7%)	12	14		9	17	
<b>Marital Status</b>							
Married	6 (20%)	3	3	0,046	2	4	0,221
Separate	4 (13,3%)	4	0		2	2	
Single	18 (60%)	6	12		5	13	



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Stable union	2 (6,7%)	2	0		2	0	
<b>Education</b>							
Less than 5 years	6 (20%)	4	2	0,446	3	3	0,570
Between 5 and 10 years	4 (13,3%)	2	2		2	2	
Between 10 and 20 years	16 (53,3%)	6	10		4	12	
More than 20 years	4 (13,3%)	3	1		2	2	
<b>Spiritual support</b>							
Catholic	23 (76,7%)	13	10	0,183	9	14	0,349
Protestant	4 (13,3%)	2	2		2	2	
Others	3 (10%)	0	3		0	3	

Note: \* Chi-square significance values (p <0.05).

Regarding the family nucleus (Table 2), it was found that the majority had three and four members, each representing 26.7% of the sample. Following this, the other families were composed of two (20%), five (16.7%) and six members (10%). Furthermore, it was observed that the number of members was statistically significant in relation to reports of sadness (p = 0.018). In this perspective, a study conducted in Campina Grande, Brazil, showed that the number of people who live with the caregiver interferes with their perception of life, and those who lived with six or more people reported the best quality of life in the social domain<sup>19</sup>.

In terms of income, 73.3% of families received between two and three salaries, while 16.7% received less than one salary and 10% received between one and two

salaries. Regarding housing, 56.7% of respondents said they had their own home, in contrast to 43.3% who lived in a rented home. In addition, 70% lived in urban areas, while 30% were rural residents. No association was established between these variables and feelings of depression and sadness. In view of this, it is essential that the researcher concomitantly assess the interviewee's perception of his / her socioeconomic situation, since the perception of financial difficulties is linked to negative impacts on the caregiver's mental health and higher rates of depression and anxiety<sup>20</sup>. In addition, the social context in which this individual is inserted also has an impact on his emotional state, and those who live in places with little dynamics between neighbors and with constant occurrences of violence are more likely to report low levels of mental health<sup>21</sup>.

**Table 2.** Distribution of number of members, family income, housing, and origin of family members of individuals victims of CET according to reports of depression and sadness. São Cristóvão, SE, Brazil, 2019-2020

	N (%)	Feeling depressed			Feel sad		
		No	Yes	p-value*	No	Yes	p-value
<b>Number of family members</b>							
Two	6 (20%)	2	4	0,070	1	5	<b>0,018</b>
Three	8 (26,7%)	4	4		2	6	
Four	8 (26,7%)	4	4		3	5	
Five	5 (16,7%)	5	0		5	0	
Six	3 (10%)	0	3		0	3	
<b>Family income</b>							
Less than 1 wage	5 (16,7%)	2	3	0,699	1	4	0,414
Between 1 and 2 wages	3 (10%)	1	2		2	1	
Between 2 and 3 wages	22 (73,3%)	12	10		8	14	
<b>Residence</b>							
Owned	17 (56,7%)	9	8	0,713	5	12	0,346
Rented	13 (43,3%)	6	7		6	7	
<b>Origin</b>							
Rural	9 (30%)	6	3	0,232	3	6	0,804
Urban	21 (70%)	9	12		8	19	

Note: \* Chi-square significance values (p <0.05).

About to the degree of dependency of the victim, 53.3% of family members declared that the dependency was

partial, in 26.7% of the cases the dependency was none and in 10% they stated that it depended entirely on care. When



associating the degrees of dependence with reports of depression and sadness, no statistical significance was observed (Table 3). The degree of dependence on the care recipient is also classified as a determining factor in the

**Table 3.** Distribution of the degree of dependence of the individual victim of CET according to reports of depression and sadness of the family caregiver. São Cristóvão, SE, Brazil, 2019-2020

	N (%)	Feeling depressed			Feel sad		
		No	Yes	p-value*	No	Yes	p-value
<b>Dependence degree</b>							
Total	6 (10%)	2	4	0,338	2	4	0,982
Partial	16 (53,3%)	10	6		6	10	
None	8 (26,7%)	3	5		3	5	

Note: \* Chi-square significance values (p <0.05)

By associating the degree of dependence of the individual suffering from CET with significant changes in the caregivers' lifestyle and mood, it was observed that the participants who reported no changes in lifestyle were

caregivers of individuals without dependence, but it was not a significant relationship was established between the data (Table 4).

**Table 4.** Distribution of changes in lifestyle and mood experienced by the family caregiver according to the degree of dependence of the individual victim of CET. São Cristóvão, SE, Brazil, 2019-2020

	N (%)	Total	Dependence degree		p-value*
			Partial	None	
<b>Lifestyle change</b>					
Yes	28 (93,3%)	6	16	6	0,053
No	2 (6,7%)	0	0	2	
<b>Mood swing</b>					
Yes	7 (23,3%)	1	4	2	0,877
No	20 (66,7%)	5	10	5	
Never	3 (10%)	0	2	1	

Note: \* Chi-square significance values (p <0.05).

In this sense, considering the characteristics related to the impact experienced by the family members of the individual victim of CET (Table 5), 93.3% of the interviewees stated changes in lifestyle after the accident. Of these, 60% reported sadness and 46% depression. Still, regarding fluctuations in mood, 66.7% of the sample said they did not have any, while 23.3% said they did and 10% never did, with the feeling of depression and sadness predominating in 50% and 63.3% , respectively, since the accident. Mood changes showed statistical significance for the feeling of depression (p = 0.005).

In this sense, in a study carried out in Iran with 150 caregivers of women with breast cancer, it was observed that 49.4% of them had abandoned their jobs due to the activities of caring<sup>23</sup>. Thus, changes such as the reduction of tasks performed by the individual receiving care, changes in work, the workload dedicated to care together with their multiple tasks and the need for the caregiver to maintain parallel working hours are some of the stressors for overloading this individual<sup>24</sup>.





**Table 5.** Distribution of changes in lifestyle and mood of family members of individuals suffering from CET according to reports of depression and sadness. São Cristóvão, SE, Brazil, 2019-2020

	N (%)	Feeling depressed			Feel sad		
		No	Yes	p-value*	No	Yes	p-value
<b>Lifestyle change after accident</b>							
Yes	28 (93,3%)	15	13	0,143	11	17	0,265
No	2 (6,7%)	0	2		0	2	
<b>Change of mood</b>							
Yes	7 (23,3%)	0	7	0,005	0	7	0,061
No	20 (66,7%)	12	8		10	10	
Never	3 (10%)	3	0		1	2	

Note: \* Chi-square significance values ( $p < 0.05$ ).

Thus, the sociodemographic characterization of family caregivers becomes an essential tool for health services, especially in the context of Primary Care, in which social determinants are considered when dealing with issues. Articulated as a way to subsidize support actions by health units, the construction of these profiles helps in the detection and tracking of factors influencing physical and emotional problems in these individuals, considering that the characteristics of the caregiver have a relationship and impact on burden on the health of that individual<sup>25</sup>.

Thus, understanding the family as a fundamental unit for human development, it is important that health services develop strategies aimed at it, since all components are affected in the event of a member's illness. In this perspective, it is worth highlighting the influence that the family context has on the process, from the perspective of the individual victim of CET and from the perspective of the caregiver<sup>26</sup>. Thus, when working with strategies focused on the family, it becomes possible to improve the levels of quality of life, efficiency and self-esteem of these individual caregivers and their care recipients, significantly reducing the levels of burden<sup>27</sup>, since a positive family dynamic, with cohesion, satisfaction and communication between members, is related to lower levels of burden on the individual providing care<sup>28</sup>.

### Final Considerations

In view of the data collected regarding the sociodemographic profile of family caregivers of individuals victims of CET, it was noticed that the sample was composed mainly of female individuals, brown in color, belonging to the age group of 40 to 49 years, Catholics and singles. As for housing, there was a predominance of individuals of urban origin and living in their own home. Still, the family members

interviewed mostly belonged to groups with three to four members, living on an income between two and three minimum wages.

Regarding aspects related to trauma, there was a predominance of individuals partially dependent on care. Faced with this, most family members said they had undergone a significant change in lifestyle. Most participants did not experience changes in mood. However, more than half of family members have been depressed and sad since the accident.

Still in this scenario, there was an association between reports about feeling depressed and the caregiver's marital status, as well as changes in mood. In addition, there was statistical significance between the reports of sadness and the number of family members who lived with the caregiver.

Finally, it is evident the importance of the role played by Primary Care since it is inserted in the territory of the population. Thus, this level of care becomes closer to the context in which users of health services experience, making it possible to articulate approaches with caregivers and family nuclei.

Thus, from this research, together with data that the basic health units themselves have from these families, it is expected to contribute to the development of interventions that address the characteristics of these individuals and that suit their profile and need.

Therefore, it is worth noting that the present study had limitations during its execution that may have interfered with the results identified, such as the number of participants who composed the sample and the lack of a questionnaire about the quality of life of these individuals. Thus, during data analysis, the need to investigate and assess the overload levels of these family members was perceived in future research.

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