

150 - THE PERCEPTUAL CAREGIVERS OF TBI PATIENTS ON THEIR QUALITY OF LIFE.

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INTRODUCTION

The Traumatic Brain Injury (TBI) is defined by Oliveira-Abreu and Almeida (2008), as an injury to the brain caused by an external physical force, that can be produce a diminished or altered state of consciousness, that result in commitments of cognitive skills or physical functioning.

The TBI is the major cause of deaths and sequelae in patients multitraumatizados. Among the main causes are: motor vehicle accidents (50%), falls (21%), assaults and aggressions (12%), sports and recreation (10%). In Brazil, annually, half a million of people require hospitalization due a head injuries, of these, 75 to 100 thousand people die in the course of hours while another 70 to 90 thousand developed some irreversible loss of neurological functional. (OLIVEIRA, 2005).

The victims who survive the TBI can have deficiencies and disabilities that interfere directly on the performance of their functions. Hence, the individual stricken by this condition will by significant conflicts and changes in style and quality of life, and this time the need arises from the presence of a caregiver.

In the literature, most studies assume the role of caregiver burden and stress, according to the evaluation of family members who have this role. In general, this condition is associated with direct care, continuous, intense, and the need for constant vigilance, the workload for a single caregiver, reducing the professional and social activities, and the abandonment of leisure activities (DIOGO, CEOLIM and CINTRA, 2005).

Before addition, aimed to preparation of this research seeking identify the caregivers perceptions about their quality of life and before the new assignments assumed under the condition of caregiver of a patient with TBI.

MATERIALS AND METHODS

This is a quantitative and qualitative study applied with four caregivers, of both genders and aged between 50 to 60 years, with average of age of 54.2 years. Having a requirement: to be caregivers of patients victims of TBI for a period of 1 to 10 years, doesn't necessary to be following this individual since the begining, where was applied a semi-structured questionnaire compound with 12 open questions (table 1).

Table 1 – Semi-structure interview.

1	What do you know about TBI?
2	Have you had any training and / or orientation about the disease and care?
03(a)	How long it takes care of the patient?
03(b)	What is your kinship with the patiente?
4	Why do you think that the care of the patient was for you?
5	There were changes in family structure after TBI?
6	How much time per day spent, on average, with the patient care?
07(a)	Is there any activity you did before and failed to achieve after becoming a caregiver?
07(b)	What?
8	What is the main difficulty for you, on the care for the patient?
9	How do you feel about being the caregiver of patient?
10	How do you believe that physiotherapy can help the patient?
11	Do you understand the instructions for exercise that the physiotherapist says?
12(a)	Carry out the exercise of the patient at home?
12(b)	Has difficulty? What?

Source: Jimenez, 2006.

The survey was held in clinical rehabilitation FAG and the collection instrument was based on questionnaire Jimenez (2006) - which us related to the objective of the research, which was criterion of the interviewee to used the time that thought necessary to answer them. The period of data collection happened between August and September 2010. Were provided to the research subjects the confidentiality and anonymity, as well as the right to withdraw at any time from the study and free access to the data collected.

After the application of questionnaires, was held the tabulate the results using the program Excel 2003, establishing the percentage of the sample referent for each item researched.

RESULTS

Given the survey it was possible to verify the knowledge of caregivers about the patient's illness, as well as the guidelines, the time that the patients were receiving care from their caregivers, the justification of ourselves in relation to the care and feelings towards the patient, the degree of kinship, family and personal changes, difficulties and expectations in relation of physiotherapy treatment in the patient, as presented in table 2.

Table 2 - Qualifying of the answers in the questionnaire

Question	Alternatives	(%)
1	Knowledge does not exist	0%
	Little knowledge	0%
	Partial knowledge	100%
2	Yes	50%
	No	50%
03(a)	0 to 2 years	50%
	2 to 4 years	50%
	Over 4 years	0%
03(b)	Husband	0%
	Children	50%
	Other	50%
4	Willingly	50%
	For convenience	25%
	For lack of choice	25%
5	No	25%
	Yes, to better	25%
	Yes, to the worse	50%
6	0 to 12 hours/Day	25%
	12 to 24 hotrs/day	75%
07(a)	Yes	100%
	No	0%
07(b)	Leisure	25%
	Work/Study	25%
	Both alternatives	50%
8	Activity of daily living	75%
	Personal hygiene	0%
	Other	25%
9	Responsability	100%
	Obligation	0%
	Other	0%
10	Higher independence	100%
	Postural control	0%
	Other	0%
11	Yes	100%
	No	0%
12(a)	Yes	100%
	No	0%
12(b)	With difficulty	75%
	Without difficulty	25%

Source: Author, 2010

Through the tabulation of results, it was possible to find that 100% of caregivers had partial knowledge about TBI and assumed the function in less than four years. 50% of sample opted for this assignment, but there is a linearity between convenience and lack of choice. Indeed, 50% of them felt that there negative changes in family rotine. 75% of these caregivers occupy between 12 and 24 hours of your day and 100% of them felt changes in any sphere of their daily lives

Another note is that 100% of these caregivers have difficulties in activities of daily life of patient, which shall ensure a greater degree of independence, however, despite understand and perform the activities directed by physiotherapist, 75% of them perform this function with difficulty.

DISCUSSION

In general the informal caregiver (or family caregiver) is an individual without training for it and assume totaly or the marjority part of responsibility for care of individual with dependence. This caregiver, being informal, isn't entitled to wages, vacation, rest, clearance as the formal caregivers, who are hired to assume the function of the caregivers. (PAVARINI e NERI, 2000). So, much of he caregivers obtain partial knowledge and did not receive guidelines / training in relation to the disease. Given this condition, it is important that professionals involved in care of this patient used language/information simple and easy to understand, or according to the family's knowledge.

According to Neri and Sommerhalder (2002), the function of caregiver is, usually, assumed by unique person. In most western countries who performs the task of caring in family is usually a woman - confirmed by the research data - because provide care (to children, the house, the spouse and the patients) is a secular female attribute. Some individuals assume this function by instinct, desire, availability, capacity or even moved by a sense of obligation and/ or duty which it owes to the family. This can be understood as a natural feeling and subjective connected to a compromise that was built along the family life.

In general, the negative perspective in relation the new family structure, is justified by the literature through Perlini and Gonçalves (2002), through financial difficulties due a need to buy medicine, food, wheelchair, damaging the family structure. Already the overload of care is directly linked to the level of physical dependence of the patient, often resulting in physical and emocional stress.

This fact occurs because in general, the caregivers spending more than 12 hours of your day with patient care, often causing the detachment from friends and family, changes in personal life and weight of the tasks, becoming apparent abandonment of its activities (leisure, work and study), taking the caregiver to the physical and emocional exhaustion.

The interviewed report that they feel responsible and with duty of care, changes in lifestyle, however, remain devoting himself to the care of the victim to TBI, trying to encourage greater independence, consequently, this condition will decrease your overload.

The knowledge becomes important for the functional evolution of the patient, therefore, it is necessary to perform the exercise by the physiotherapist. When the exercise isn't performed, or doesn't happen correctly, there is delay in the development and progress of the patient.

CONCLUSION

The TBI stands out in terms of magnitude, both in relation to the dead and the wounded. Therefore, research on this condition should continue to be performed in order to create opportunities a wider range of possibilities to the individual who was affected with this condition, as well as, awareness the population about the seriousness.

However, research on the changes entailed to the individual in relation to condition and a work and responsibility placed on care of that individual hasn't received the due importance.

But with this research, it was possible to identify the conditions faced by caregivers in carrying out their function as well as to reaffirm the literature that presents the yearnings and difficulties of these individuals.

Also, it is extremely important that the gaze of professionals isn't only for the patient affected by TBI, but also for what happens to their families so it will make difference in care and the treatment of the patient. The physiotherapy treatment also be done along with the caregivers in order to optimize the results, making them more independent and improved the quality of life for both.

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THE PERCEPTUAL CAREGIVERS OF TBI PATIENTS ON THEIR QUALITY OF LIFE.

ABSTRACT

Introduction: Traumatic brain injury (TBI) can be defined as an injury to the brain as a result of external trauma, resulting in momentary or permanent brain changes, cognitive in nature and / or functional. An individual with this condition, will undergo significant changes and conflicts in style and quality of life, and this time the need arises from the presence of a caregiver. Objective: To identify the perceptions of caregivers about their quality of life, given the new responsibilities assumed under the condition of caregiver of a patient with TBI. Methodology: The survey was conducted in clinical rehabilitation FAG, through a semi-structured questionnaire, based on questionnaire Jimenez (2006), with four caregivers of TBI patients. Results: The results showed that 100% of caregivers had partial knowledge about TCE and assumed the role less than 4 years. 50% have opted for this assignment and 50% of them felt that there were negative changes in family routine. 75% of these caregivers occupy between 12 and 24 hours of your day and 100% of them felt changes in any sphere of their daily lives. 100% of caretakers to perform physiotherapy exercises at home, seeking greater independence of this patient, however, 75% of them perform this function with difficulty. Conclusion: Regardless of the factors that contributed to the condition of caregiver, it is evident that there is interference in daily life and quality of life of caregivers due to the act of caring, where leisure, work and study just overlooked by this new assignment.

KEYWORDS: Traumatic brain injury, physical therapy, caregiver.

LA PERSPICACITÉ DE SOIGNANTES DE PATIENTS AVEC TCC SUR SA QUALITÉ DE VIE.

RÉSUMÉ

Introduction : Le Traumatisme Crânio-Cérébral (TCC) peut être défini comme une agression au cerveau en conséquence d'un traumatisme externe, résultant de modifications cérébraux momentanément ou permanents, de nature cognitive et/ou fonctionnelle. L'individu frappé par cette condition, passera par de conflits et changements significatifs dans le style et qualité de vie, et à ce moment apparaît la nécessité de la présence d'un soignant. Objectif : Identifier les perceptions de soignantes concernant sa qualité de vie, en avant les nouvelles attributions assumés dans de condition de soignante d'un patient avec TCC. Méthodologie : La recherche a été réalisé dans la clinique de réhabilitation FAG, par le moyen d'un questionnaire semi-structuré, basé sur le questionnaire de Jimenez (2006), avec quatre soignantes de patients avec TCC. Résultats : Les résultats ont démontré que 100% de soignantes présentent connaissance partiel concernant le TCC et ils ont assumé la fonction moins de 4 ans. 50% de l'échantillon ont opté par cette attribution et 50% d'eux ont senti qu'il a eu des changements négatifs dans la routine familiale. 75% de ceux soignantes occupent entre 12 et 24 heures de son jour et 100% d'eux ont senti des modifications dans quelques sphère de son quotidien. 100% de ceux soignantes ont réalisé les exercices physiothérapeutiques à

la maison, en visant plus grande indépendance de ce patient, cependant, 75% d'eux ont réalisé cette fonction avec difficulté. Conclusion : Indépendamment des facteurs qui ont contribué pour la condition de soignant, il est évident qu'il a interférence dans le quotidien et dans la qualité de vie de ceux soignants en fonction de l'acte de soigner, où, loisir, travail et étude finissent négligés en fonction de cette nouvelle attribution.

MOTS-CLÉS : Traumatisme Crânio-Cérébral, Physiothérapie, Soignant.

LA PERCEPCIÓN DE LOS CUIDADORES DE PACIENTES CON TCE SOBRE SU CALIDAD DE VIDA.

RESUMEN

Introducción: El traumatismo craneoencefálico (TCE) se puede definir como una lesión en el cerebro como resultado de un trauma externo, resultando en alteraciones en el cerebro momentáneas o permanentes, de naturaleza cognitiva y / o funcional. Una persona con esta condición, pasará por conflictos y cambios significativos en el estilo y la calidad de vida, y en este momento surge la necesidad de la presencia de un cuidador. Objetivo: Identificar las percepciones de los cuidadores acerca de su calidad de vida, dadas las nuevas atribuciones asumidas en virtud de la condición de cuidador de un paciente con TCE. Metodología: La investigación se realizó en la clínica de rehabilitación FAG, a través de un cuestionario semi-estructurado, basado en el cuestionario Jimenez (2006), con cuatro cuidadores de pacientes con TCE. Resultados: Los resultados mostraron que el 100% de los cuidadores presentan un conocimiento parcial acerca del TCE y asumieron la función a menos de 4 años. El 50% optaron por esta asignación y el 50% de ellos sintieron que hubo cambios negativos en la rutina familiar. El 75% de estos cuidadores ocupan entre 12 y 24 horas de su día y el 100% de ellos sintieron cambios en alguna esfera de su cotidiano. El 100% de los cuidadores realizan los ejercicios fisioterapéuticos en el hogar, buscando una mayor independencia de este paciente, sin embargo, el 75% de ellos realizan esta función con dificultad. Conclusión: Independientemente de los factores que contribuyeron para la condición de cuidador, es evidente que hay interferencia en el cotidiano y en la calidad de vida de estos cuidadores debido a la acción de cuidar, donde el ocio, trabajo y estudio acaban en descuido por esta nueva atribución.

PALABRAS-CLAVE: Traumatismo Cranioencefálico, fisioterapia, cuidador.

A PERCEPTIVIDADE DOS CUIDADORES DE PACIENTES COM TCE SOBRE SUA QUALIDADE DE VIDA.

RESUMO

Introdução: O Traumatismo Cranioencefálico (TCE) pode ser definido como uma agressão ao cérebro em consequência de um trauma externo, resultando em alterações cerebrais momentâneas ou permanentes, de natureza cognitiva e/ou funcional. O indivíduo acometido por essa condição, passará por conflitos e mudanças significativas no estilo e qualidade de vida, e nesse momento surge a necessidade da presença de um cuidador. Objetivo: Identificar as percepções dos cuidadores acerca de sua qualidade de vida, diante das novas atribuições assumidas na condição de cuidador de um paciente com TCE. Metodologia: A pesquisa foi realizada na clínica de reabilitação FAG, por meio de um questionário semi-estruturado, baseado no questionário de Jimenez (2006), com quatro cuidadores de pacientes com TCE. Resultados: Os resultados demonstraram que 100% dos cuidadores apresentam conhecimento parcial acerca do TCE e assumiram a função a menos de 4 anos. 50% da amostra optaram por essa atribuição e 50% deles sentiram que houve mudanças negativas na rotina familiar. 75% destes cuidadores ocupam entre 12 e 24 horas do seu dia e 100% deles sentiram alterações em alguma esfera de seu cotidiano. 100% destes cuidadores realizam os exercícios fisioterapêuticos em casa, visando maior independência deste paciente, entretanto, 75% deles realizam esta função com dificuldade. Conclusão: Independientemente dos fatores que contribuíram para a condição de cuidador, fica evidente que há interferência no cotidiano e na qualidade de vida destes cuidadores em função do ato de cuidar, onde, lazer, trabalho e estudo acabam negligenciados em função desta nova atribuição.

PALAVRAS-CHAVE: Traumatismo Cranioencefálico, fisioterapia, cuidador.