



Clinical Research

Brain injury knowledge in family members of neurosurgical patients[☆]

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ARTICLE INFO

Article history:

Received 29 March 2017

Accepted 19 September 2017

Available online xxx

Keywords:

Brain injury

Knowledge

Misconceptions

Neurosurgery

Family members

ABSTRACT

Background and objectives: Several studies have shown misconceptions about brain injury in different populations. The aim of this study was to assess the knowledge and perceptions about brain injury of family members of neurosurgical patients in our hospital.

Material and methods: The participants ($n=81$) were relatives of patients admitted to the neurosurgery department between February and August 2016. They voluntarily completed a 19-item true-false format survey about brain injury based on a translation of other questionnaires used in previous studies from other countries (USA, Canada, UK, Ireland and New Zealand). Also, some sociodemographic data were collected (age, sex, education level and the patient's pathology). Data analysis was developed through graphical modelling with a regularisation parameter plotted on a network representing the association of the items of the questionnaire from the response pattern of participants.

Results: Data analysis showed two conceptual areas with a high rate of wrong answers: behaviour and management of patients, and expectations about acquired brain injury recovery.

Conclusions: The results obtained in this study would enable us to objectify misconceptions about acquired brain injury in patients' relatives attended in the neurosurgery department. This lack of knowledge could be a great obstacle in patients' recovery process. Therefore, we suggest placing the emphasis on the provision of information on brain injury to patients' families, especially with regard to its symptoms and course of development.

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DOI of original article: <http://dx.doi.org/10.1016/j.neucir.2017.09.007>.

* Please cite this article as: Navarro-Main B, Castaño-León AM, Munarriz PM, Gómez PA, Ríos-Lago M, Lagares A. Conocimiento sobre daño cerebral adquirido en familiares de pacientes neuroquirúrgicos. Neurocirugía. 2017. <https://doi.org/10.1016/j.neucir.2017.09.007>

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Conocimiento sobre daño cerebral adquirido en familiares de pacientes neuroquirúrgicos

RESUMEN

Palabras clave:

Daño cerebral
Conocimiento
Conceptos erróneos
Neurocirugía
Familiares

Antecedentes y objetivos: Diversos estudios han puesto de manifiesto las creencias erróneas sobre el daño cerebral en diferentes poblaciones. Nuestro objetivo consiste en valorar el conocimiento que poseen los familiares de los pacientes neuroquirúrgicos sobre el daño cerebral adquirido.

Material y métodos: Participaron 81 familiares de pacientes ingresados durante el periodo comprendido entre febrero y agosto de 2016. Se utilizó la traducción de un cuestionario aplicado en estudios anteriores en múltiples países (EE. UU., Canadá, Reino Unido, Irlanda y Nueva Zelanda). Se registraron algunos datos sociodemográficos (edad, sexo, nivel educativo y patología del paciente) así como las respuestas a los 19 ítems verdadero/falso que constituyen el cuestionario sobre daño cerebral adquirido. El análisis de datos se ha desarrollado mediante una modelización gráfica con parámetro de regularización configurando así una red que muestra el nivel de asociación de los ítems del cuestionario a partir del patrón de respuestas de los participantes.

Resultados: El análisis de los datos muestra dos áreas conceptuales con una elevada tasa de error en los ítems asociados: el comportamiento y el manejo de los pacientes, y las expectativas sobre la recuperación en daño cerebral adquirido.

Conclusiones: Con este estudio podemos objetivar las áreas de falsas creencias sobre el daño cerebral que poseen los familiares de los pacientes atendidos en el servicio de neurocirugía. Este desconocimiento puede suponer un obstáculo en el proceso de recuperación de los pacientes. Por lo tanto, proponemos hacer hincapié en la información sobre el daño cerebral a los familiares de estos pacientes, sobre todo sus síntomas y su evolución.

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Introduction

Acquired brain injury (ABI) is defined as sudden physical damage to the brain that is not related to a congenital or a degenerative disease. Brain tumours, strokes, traumatic brain injuries (TBI), infections and anoxia are the most common causes. ABI causes physical, cognitive and emotional deficits,¹⁻³ and is currently one of the leading causes of disability in adults and young people. In Spain, according to the latest data from the *Encuesta de Discapacidad, Autonomía personal y Situaciones de Dependencia* [Disability, personal autonomy and dependency situations survey],⁴ 420,064 people live with ABI, and the annual incidence is 104,071 people. The vast majority of patients who request a medical disability evaluation are diagnosed with a degree of disability of over 65%⁵ (*Base de datos Estatal de personas con discapacidad 2012* [Spanish Database of People with Disabilities 2012]). Therefore, ABI is a major health problem with a high incidence and prevalence in Spain.

ABI cannot be defined as a particular syndrome associated with a single pathology, since it is a set of symptoms with very heterogeneous manifestations. Because of this, the family and close friends of ABI sufferers find it difficult to understand their situation, and this lack of comprehension is often one of the major obstacles to progress in these patients. It is essential for family members to understand the patient's pathological process, since family members and immediate social circle play an important role in the patient's evolution from the initial moments to the most advanced phases of the process.⁶

Therefore, providing information on ABI fulfils a social need, and may directly affect the recovery of these patients by giving reliable, comprehensive insight into the reality faced day in and day out by both the patients and their immediate family and friends.

In this study, we determined the extent to which the family members of patients treated in the Neurosurgery department of our hospital understand ABI. For this purpose, we translated the questionnaire formulated by Guilmette and Paglia⁷ (2004) and applied it to family members of patients admitted to our department. We analysed the pattern of responses to the different items in the questionnaire in order to identify the most widely held misconceptions and the influence of education on knowledge of ABI. Our ultimate aim is to improve the support and treatment that relatives need to improve their approach to ABI patients.

Materials and method

Participants

Ninety-one relatives of patients admitted to the Neurosurgery department of our hospital between February and August 2016 were included in the study. The only inclusion criterion was to be a family member of a patient admitted to the Neurosurgery department. Subjects were invited to take part in the study and asked to complete a questionnaire on ABI. Ten subjects who did not fully complete the

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