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Original Article

Psychological state and needs of family member caregivers for victims of traumatic brain injury: A cross-sectional descriptive study

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ABSTRACT

Objective: Here we evaluated the impact of varying severity of traumatic brain injury on the psychological state and demands of family caregivers. Further, we determined the most significant and least significant daily needs among family caregivers.

Methods: We performed a cross-sectional descriptive study in three public hospitals in Tai'an, China. Three hundred caregivers related to traumatic brain injury victims were randomly selected. Patients had varying degrees of injuries (mild to severe). The Symptom Checklist-90 (SCL-90) was used to assess family caregivers' psychological statuses. The Critical Care Family Needs Inventory (CCFNI) was used to determine family caregivers' needs. Finally, the Glasgow Coma Scale (GCS) was employed to define patients' level of traumatic brain injury.

Results: SCL-90 scores for each psychological dimension were significantly higher with increasing TBI severity ($p < 0.05$). Similarly, CCFNI scores were significantly higher with increasing TBI severity ($p < 0.05$) for information, reassurance, and accessibility. These same dimensions were found to be the most important needs for family members of TBI injury victims, while support and comfort were the least important dimensions.

Conclusions: The more severe pathogenic condition of the patient, the heavier the psychological pressure is on their family member caregivers. Medical staff should therefore pay close attention to the psychological health of family caregivers of TBI patients, especially family caregivers of critical cases. Interventions should be accordingly designed and conducted to meet the needs of family caregivers.

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1. Introduction

Traumatic brain injury (TBI) is a common disease that causes death and disability around the world [1]. In the United States, TBI is the leading cause of disabilities in people under 40 years of age, disabling ~150–200 people per million each year [2]. In China, TBI accounts for ~60% of all injuries. The World Health Organization (WHO) predicts that TBI will be a leading cause of death by the year 2020 [3].

TBI results in cognitive, psychosocial, emotional, economic, and physical changes. These changes lead to a substantial impact on the lives TBI victims as well as their families [4]. TBI victims are often unable to live independent lives. Family members often take on the role of caregiver, resulting in disrupted social, vocational, recreational activities, and dramatic changes in daily routines [5]. As a result, caregiving is associated with psychological distress, anxiety and depression, financial problems, and decreased quality of life [6–8]. However, the daily needs of caregivers to ameliorate these burdens have not been thoroughly investigated. This is even more apparent in developing nations, where the burden of caregiving is greater due to additional barriers that increase their needs (e.g. lack of TBI rehabilitation, community resources, and social support networks).

Here we investigated the psychological states and daily needs of people providing care for a TBI family member. We determined the most significant and least significant needs among family caregivers, while also considering the degree of TBI injury. Such analyses may lead targeted approaches to help family caregivers maintain a healthy state of mind and meet their daily needs, while still sustaining caregiving.

2. Methods

2.1. Participants

Three hundred caregivers related to TBI victims were randomly selected. Patients had varying degrees of injuries (mild to severe). All participants were 18 years of age or older, were the main caregiver of a family member diagnosed with TBI, were able to understand and respond to research questions, and agreed to participate in the study. The Glasgow Coma Scale/Score (GCS) was used to define patients' degree of TBI. Patients with scores of 3–8 were considered severe, 9–12 were considered moderate, and scores of 13–15 were considered to be mild TBI. The Medical Ethical Committee at the Taishan Medical University Affiliated Hospital approved this study.

Our research team obtained consent from the College of Nursing and the management department of three nearby public hospitals. Family members who meet the inclusion criteria were invited to participate in the study and received information about its objectives. If they agreed, an interview appointment was scheduled. At the appointment, after learning about the study, caregivers were asked to sign informed consent forms in accordance with regulations approved by the Free and Informed Consent Terms. Interviews were held in a private location, and lasted 20–30 min.

2.2. Assessments

Three sets of data were collected from family caregivers, namely demographic characteristics of patients and their family caregiver, the Symptom Checklist-90 (SCL-90), and the Critical Care Family Needs Inventory (CCFNI). Each of these is described below.

2.2.1. Demographic characteristics of patients and their family caregiver

The family caregivers' gender, age, education level, occupation, economic income, and relationship to the patient were recorded. Patients' gender, age, duration of hospitalization, insurance, and severity of injury were also recorded.

2.2.2. Symptom Checklist-90 (SCL-90)

The Chinese version of the SCL-90 is a tool derived from Derogatis' SCL-90 from 1973. The scale assesses the psychological symptoms of subjects and has had high reliability and validity in Chinese studies [9]. Here we assessed the psychological states of family caregivers. The SCL-90 consists of 90 questions, each of which is answered on a 5-point scale of degree of distress. It includes nine primary symptom dimensions, namely somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The SCL-90 has been proven to be particularly useful in discriminating symptoms related to depression and anxiety [10]. We investigated whether there was a relationship between the three traumatic brain groups (mild, moderate, severe) and the results of the SCL-90.

2.2.3. Critical Care Family Needs Inventory (CCFNI)

We assessed the needs of family caregivers of TBI victims using the Critical Care Family Needs Inventory (CCFNI), which was revised by Leske in 1991 [11]. The CCFNI consists of 45 needs items, and scoring is based on their importance. The items were classified into five dimensions: support, comfort, information, accessibility, and reassurance [12,13]. The CCFNI has been adapted and validated for Chinese culture. It was translated into Chinese and its Cronbach's alpha coefficient is 0.89 [14]. The scoring scale ranges from 1 to 4, and was also adopted in the present study. The higher the score attributed to the item, the higher the level of need.

2.3. Data analysis

All statistics were performed in SPSS 13.0 for Windows. Basic characteristics of patients and their respective relatives were described by descriptive statistics. All comparisons were performed with variance analysis and Kruskal–Wallish tests. Statistical significance was defined as $p < 0.05$.

3. Results

3.1. Demographic characteristics of patients and their family caregiver

66% of TBI patients were male, while 34% patients were female. 13.7% of patients had mild TBI, 36.3% patients had

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