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STS Reference ID:

Vasipalli S, Andi Sadayandi R, Rajasegaran R, Nagaraju N, Ravi S, Sudarsan K. Stress and quality of life in caregivers of patients with traumatic brain injury: A cross-sectional study. J Neurosci Rural Pract. 2025;16:76-83. doi: 10.25259/JNRP_398_2024

TITLE:**Assessment of Stress and Quality of Life among Caregivers of Patients with Traumatic Brain Injury****INTRODUCTION:**

Traumatic Brain Injury (TBI) is a form of acquired brain injury due to sudden trauma that may be a result of a bump, blow, or jolt to the head or a penetrating head injury [1,2]. Consistent with trends in low- and middle-income countries, India's TBI burden, most commonly due to road traffic accidents, followed by falls, is severe and underreported [3]. In recent years, advancements in acute trauma care have reduced the mortality rate, corresponding to a rise in morbidity and survivors of TBI [4].

Patients with moderate-to-severe TBI often require prolonged intensive and high-dependency care unit treatment and have persistent motor, cognitive, emotional, and social deficits. The major long-term responsibility of care is placed on the primary caregiver. However, the psychological burden on and the caregiver's needs are often overlooked [4,5,6].

Increased stress levels and impaired quality of life are expected in caregivers, but data from TBI and caregiver-specific scales and individual measures are scarce. Hence, this study aims to use sensitive, specific measures to quantify stress levels and quality of life in TBI caregivers and their association with socio-demographic and clinical factors.

OBJECTIVES:

- a. To assess the stress level in caregivers of patients with Traumatic Brain Injury using Kingston Caregiver Stress Scale (KCSS)
- b. To assess the Quality of Life in caregivers of patients with Traumatic Brain Injury using the Traumatic Brain Injury-Caregiver Quality of Life (TBI-CareQOL) scale
- d. To assess the association between demographic factors, stress levels, and quality of life in the aforementioned caregivers.

METHODOLOGY:

Study design: Cross-sectional study

Study participants: Humans

a. Inclusion criteria: Individuals more than 18 years of age who are primary caregivers of patients diagnosed with TBI, undergoing treatment or discharged from the Department of Neurosurgery following intensive care or high dependency unit care, and now undergoing supportive care in the hospital or at their residence since 2 - 4 weeks. The primary caregiver will be the person who, among the relatives, would help the patient the most, accompany him/her for the treatment at the Institution, and is generally perceived to perform essential caregiving tasks [7].

b. Exclusion criteria: Caregivers with a history of medical disorders, psychiatric disorders, cognitive deficits, and pregnant women will be excluded from the study.

c. Classification of groups in the study: One (primary caregivers of patients diagnosed with and have undergone treatment for TBI)

Sampling

a. Sampling population: Individuals over 18 years of age who are primary caregivers of TBI patients and providing supportive care in the hospital or at their residence.

b. Sample size calculation: The sample size was estimated with an anticipated proportion of caregivers with moderate and above levels of stress and impaired quality of life as 0.90 at a 5% level of significance and 8% absolute precision.

Estimated sample size: 55 participants

Sampling technique: Consecutive sampling

Study Procedure

The study will be carried out in the Department of Neurosurgery after obtaining approval from the Institute Research and Ethics Committee. The study participants will be recruited from the outpatient section of the Department of Neurosurgery during the follow-up visits of TBI patients. The study details will be explained, and informed consent will be obtained from all the participants via an informed consent form [**Annexure I and Annexure II**] before enrolling them in the study. The socio-demographic and clinical details of study participants will be collected and entered in a data sheet [**Proforma - Annexure III**]. Caregivers stress levels and Quality of life will be assessed by using KCSS and TBI-CareQOL questionnaires. The raw scores entered in the proforma sheet will be converted into standardized T-scores (TBI QoL) and used for statistical analysis.

Assessment of Caregiver Stress: [Annexure IV]

The Kingston Caregiver Stress Scale (KCSS) is a 10-item straightforward, easy-to-implement, self-reported questionnaire with high test-retest reliability [8]. It assesses the caregiver's stress in three domains - Caregiving issues, Family issues, and Financial issues. For each item, a score of 1 indicates no stress, and a score of 5 indicates extreme stress. The maximum achievable score is 50. The total score indicates the subjective level of stress. The higher the score, the higher the level of caregiver stress.

Assessment of Quality of Life (QOL) of Caregivers: [Annexure V]

The TBI-CareQOL is a self-reported, psychometrically sound questionnaire that is brief, specific, and sensitive to caregivers of individuals with TBI [9,10]. The following relevant caregiver-specific measures - Caregiver Strain, Caregiver Vigilance, Caregiver-Specific Anxiety, Emotional Suppression, Feeling Trapped, Feelings of Loss – Person with TBI, and Feelings of Loss – Self will be assessed using Short Form 6a - questionnaires.

Caregivers respond to each item on a 5-point summation scale (Likert scale), with '1' representing that the caregiver 'never' experienced a feeling as described by the individual item and '5' representing that the caregiver 'always' experiences a feeling as described by the individual item. Total raw scores will be converted into standardized T-scores for each measure, with a mean of 50 and a standard deviation (SD) of 10. For the considered measures, a higher T-score indicates worse QoL.

According to guidelines, the KCSS and TBI-CareQOL questionnaires will be translated into the local language (Tamil). [11]

List of variables:

Independent variables:

Socio-demographic: Age, Sex, Relationship with patient

Clinical: Mode of injury, GCS score, Time from injury

Dependent variables:

Level of stress

Quality of Life (T-score for each measure)

Statistical Analysis:

The distribution of categorical data, such as clinical characteristics, socio-demographic characteristics, mode of injury, etc., will be expressed as frequency and percentages. The quantitative data, such as age, level of stress, QoL, duration of injury, etc., will be expressed as mean with 5.0 or median with range. The comparison of the level of stress and QoL between different categories of the categorical variables will be carried out by using an independent Student's t-test or Mann-Whitney U test.

The linear relationship between the level of stress and QoL with different quantitative variables will be carried out using correlation analyses. The level of stress and QoL will be further classified as mild, moderate, and severe based on the scores.

The association of these categories with the categorical variables mentioned above will be carried out by using the Chi-square test or Fisher's exact test. All statistical analyses will be carried out at a 5% level of significance, and a p-value < 0.05 will be considered significant.

IMPLICATIONS

Caregiving groups tend to predominantly be women and spouses of persons with TBI [12]. The results of this study will provide greater cognizance of nuanced differences in stress levels and change in the quality of life in these groups. It can be used as the framework for developing interventions to reduce stress levels and improve the quality of life for TBI caregivers in the future.

Novelty

To our knowledge, this is the first study of its kind that associates socio-demographic factors, stress, and quality of life among caregivers of patients with TBI using advanced quality-of-life measures specific to TBI caregivers.

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