Original Article

DOI: 10.7860/JCDR/2026/85899.24190

Physiotherapy Section

Psychological Distress, Quality of Life and Burden among Caregivers of Patients with Traumatic Central Nervous System Injuries: A Cross-sectional Study

SANJANA MANOJ MOHATA[1], RAGHAVENDRASINGH DHARWADKAR[2]

ABSTRACT

Introduction: Caregivers of individuals with traumatic Central Nervous System (CNS) conditions face significant physical, emotional, and psychological challenges. These demands often compromise their well-being and disrupt the caregiving process, leading to adverse outcomes.

Aim: To assess the levels of burden, Quality of Life (QoL), anxiety, depression, and stress among primary caregivers of patients with traumatic CNS conditions.

Materials and Methods: The present cross-sectional study was conducted at KLE's Dr. Prabhakar Kore Hospital and Medical Research Centre, Belagavi, Karnataka, India, from October 2024 to March 2025. A total of 42 primary caregivers were recruited using a convenience sampling method based on a pre-calculated sample size. Eligible participants were required to be aged ≥18 years and caring for patients with acute traumatic CNS conditions without financial compensation. Anxiety, depression, and stress were measured using the Depression, Anxiety, and Stress Scale (DASS-21); caregiver burden with Zarit Burden Interview (ZBI); and QoL with Family Caregiver Specific Quality of Life Scale (FAMQOL). Demographic data (age, gender, caregiver-patient relationship) were collected. Statistical analysis was performed in Statistical Package for Social Sciences (SPSS) v 29.0.10 using descriptive statistics and Pearson's correlation, with $p<0.05$ considered significant.

Results: The sample included more male than female caregivers. The majority exhibited extremely severe levels of depression and anxiety, while 7 (16.7%) reported extremely severe stress. Higher DASS-21 scores were significantly associated with lower FAMQOL scores and higher ZBI scores ($p<0.001$), indicating that increased psychological distress was correlated with a decrease in QoL and increased burden.

Conclusion: Caregivers of patients with traumatic CNS conditions experience substantial psychological distress, diminished QoL, and heightened burdens. These findings emphasise the importance of recognising and responding to the psychological challenges and unmet needs of this vulnerable population.

Keywords: Brain injuries, Depression, Mental health, Trauma

INTRODUCTION

Traumatic CNS conditions are unprecedented events and a significant global factor in long-term impairment with a consistently rising prevalence [1]. Millions of patients worldwide suffer from Traumatic Brain Injury (TBI), a serious public health concern that is the primary reason causing death and long-term health problems [2]. In a similar vein, between 250,000 and 500,000 individuals globally experience spinal cord trauma, which results in persistent neurological problems. Falls, auto accidents, and interpersonal violence are some of the causes of Spinal Cord Injury (SCI) [3].

These patients often experience short-term or long-lasting motor and cognitive impairments, necessitating continuous, round-the-clock nursing care [4]. In most cases, spouses, parents, siblings, and close friends often assume the role of primary caregivers [5]. These caregivers are often untrained and unprepared for the complex demands of care, especially during the transition from hospital to home settings.

Studies reveal that those who look after individuals with long-term health issues often experience higher levels of depression, fatigue, burden, burnout, and anxiety [6,7]. They also tend to report reduced overall health and personal satisfaction compared to non caregivers. They frequently work for nothing in return, and with time, especially when caring for people with severe disabilities, their level of fulfilment in life tends to decrease. Therefore, it is crucial to address the psychological health of both patients and caregivers to support their well-being [8].

Existing studies have predominantly focused on the needs of patients and their increased risk of developing mental health issues, including depressive symptoms and anxiety [9,10]. They are given the highest priority with empathy directed toward them; however, the needs of the caregiver, who has an essential role in the patient's care, are often overlooked and neglected, which leads to increased psychosocial stress and burden for the caregiver. While previous research has explored aspects of caregiver burden in specific conditions, a comprehensive assessment of psychological distress, QoL, and burden for those who care for people with a broader range of traumatic CNS conditions remains less explored. This is particularly evident in the regional context during the acute phase of injury, where the immediate psychological crisis for the family is most intense. Therefore, the aim of the present research was to evaluate the burden, QoL, anxiety, depression, and stress faced by caregivers of patients with traumatic conditions of the CNS. The objective was to study the relationship between psychological distress with QoL and caregiving burden within this population.

MATERIALS AND METHODS

The present cross-sectional study took place at KLE's Dr. Prabhakar Kore Hospital and Medical Research Centre, Belagavi, Karnataka, India, over a period of six months, between October 2024 and March 2025. The ethical clearance was taken from the Institutional Ethical Committee (REF/SL no. 645), and everyone who participated provided written informed consent ahead of their enrollment.

Sample size calculation: The sample size was determined using the following formula:

$$n = \frac{\left(Z_{1-\alpha/2}\right)^2 p(1-p)}{d^2}$$

where,

p=Anticipated prevalence (54%)

α=Significance level (5%)

d=Precision (15%)

$$n = \frac{(1.96)^2 * 0.54(1-0.54)}{(0.15)^2} = 42$$

Thus, the sample size for this study was determined to be 42 [11].

With an anticipated prevalence-54% of caregiver burden reported in a similar population [11], significance level-5%, and precision-15%. For this investigation, a convenience sampling strategy was applied.

Inclusion and Exclusion criteria: The inclusion criteria were primary caregivers of age 18 or above, irrespective of sex, who have been taking care of patients with traumatic conditions of the CNS during the acute phase of illness, that is, within the first four weeks post-injury [12,13], and informal caregivers who assist with daily activities without any financial compensation. The exclusion criteria included participants who were unable or unwilling to participate in the study procedures and caregivers with chronic medical illnesses.

Study Procedure

The present study was conducted in accordance with the principles outlined in the Helsinki Declaration of 1975, as revised in 2013. All procedures adhered to the guidelines of the Indian Council of Medical Research (ICMR), and all appropriate safety measures were implemented. Participants received an extensive description of the study before their involvement, including its objectives, potential benefits, confidentiality measures, and informed consent process. Information about the participant's name, age, gender, and relationship with the patient was noted, and assessments of psychological distress were conducted using the DASS-21 [14]. The ZBI [15] was used to measure burden, and the FAMQOL [16] was used to measure QoL through an interview process.

Measures:

Depression, Anxiety, and Stress Scale (DASS-21): It is a psychological evaluation tool that measures three negative emotional states: depression, anxiety, and stress. It contains seven items, divided into subscales with similar content. Every item was scored on a 4-point Likert scale (0-3). Scores are summed and multiplied by two to obtain final values for each domain and then divided into five categories for severity: normal, mild, moderate, severe, and extremely severe. Based on established cut-offs [17,18].

Family Caregiver-Specific Quality of Life Scale (FAMQOL): The 16 items of the scale are divided into four sections: physical, psychological, religious, and social well-being. Each item was scored on a 5-point Likert scale ranging from 1 (poor) to 5 (excellent). Items 1-7 are reverse-scored so that 1=5, 2=4, 3=3, 4=2, and 5=1, as per the scoring instructions, before calculating the total score. The final score ranges from 16 to 80. Better caregiver QoL was indicated by higher ratings, which range from 16 to 80 [19]. This instrument is copyright-protected (© 2007 Julie A. Nauser) and is freely available for academic and clinical use [16].

Burden by Zarit Burden Interview (ZBI): Burden was assessed using the short 12-item ZBI-12. It is utilised in several areas, including relationships with the care receiver and physical, emotional, social, and financial load [15]. Each item is rated on a 5-point Likert scale from 0 (never) to 4 (nearly always). The total score ranges from 0 to 48, where scores of 0-10 indicate no to mild burden, 10-20 indicate mild to moderate burden and >20 indicate high burden. Enough proof of its validity and reliability has been documented in several nations and languages, and it is widely employed in the care of people with impairments or medical conditions requiring continuous support. The ZBI is copyright-protected and distributed by Mapi Research Trust, and permission for its use in this study was obtained [20,21].

STATISTICAL ANALYSIS

The data were analysed using SPSS software (SPSS Inc., Chicago, IL), version 29.0.10. Descriptive statistics were used to summarise the information collected, such as frequency, percentage, mean, and Standard Deviation (SD). The distribution of gender, the caregiver-patient relationship, and the evaluation of stress, anxiety, and depression were determined. Before conducting the inferential analysis, the assumptions of Pearson's correlation were verified. The normality of the data distribution was assessed using the Shapiro-Wilk test, and the linearity of the relationships between variables was confirmed by inspection of scatterplots. To find the relation of anxiety, depression, and stress scores with FAMQOL score and ZBI score, the Pearson's correlation coefficient (r) was used, and a p-value <0.05 was considered statistically significant.

RESULTS

A total of 42 participants completed the questionnaires. The ages of the participants varied greatly from 19 to 68 years, with an average age of 42.60 years and a SD of 15.40 years. The mean (SD) of the ZBI score was 27.14±12.63 and ranged from 10 to 47, indicating that while the mean burden was moderate, some caregivers experienced moderate to severe levels of burden [19]. Their mean (SD) of the FAMQOL score was 39.50±11.57, with a range of 22 to 60, reflecting that caregivers in this sample generally reported lower perceived QoL [16]. Their depression scores varied from 0 to 42, with a mean (SD) of 22.10±15.57; their anxiety and stress scores ranged from 0 to 36, with a mean (SD) of 17.48±12.00 and 22.43±11.16, respectively. This implies that moderate to severe depressive symptoms were experienced by a significant percentage of participants [Table/Fig-1] [17].

Among the participants, 24 (57.1%) were male, and 18 (42.9%) were female. The caregiver-patient relationships were diverse, including spousal 9 (21.4%), intergenerational (e.g., son-father, daughter-mother), and extended family roles (e.g., uncle-niece). This sample reflected a broad range of familial caregiving relationships, with a slight predominance of male caregivers and a significant representation of both spousal and intergenerational caregiving. The diversity in caregiver-patient relationships underscores the complexity of caregiving roles and the need for support systems that are adaptable to different family structures [Table/Fig-2].

The majority of caregivers exhibited high levels of psychological distress. As shown in [Table/Fig-3] 20 (47.6%) of the participants had extremely severe depression, 19 (45.2%) had extremely severe anxiety, and 7 (16.7%) reported extremely severe stress. These findings highlight the emotional toll of caregiving in CNS trauma cases.

The relationship between the FAMQOL and ZBI scores and the stress, anxiety, and depression scores was determined using the Pearson's correlation coefficient (r). There was a strong negative correlation between FAMQOL and depression (r=-0.877, p<0.001), anxiety (r=-0.806, p<0.001), and stress (r=-0.816, p<0.001). Conversely, ZBI scores showed a strong positive correlation with depression (r=0.898, p<0.001), anxiety (r=0.872, p<0.001), and stress (r=0.843, p<0.001), [Table/Fig-4]. These correlations suggest a clear link between family dynamics, caregiver burden and mental health. Specifically, better family QoL appears to buffer against emotional distress, and greater caregiver burden is associated with increased psychological symptoms.

Parameters	Range	Mean	SD	Interpretation of scores
Age (years)	19 to 68	42.60	15.40	-
Depression score	0 to 42	22.10	15.57	Severe
Anxiety score	0 to 36	17.48	12.00	Severe
Stress score	0 to 36	22.43	11.16	Moderate
FAMQOL score	22 to 60	39.50	11.57	-
ZBI score	10 to 47	27.14	12.63	High burden

[Table/Fig-1]: Descriptive statistics of the study variables (N=42).
DASS-21: Depression, anxiety, and stress scale; FAMQOL: Family caregiver-specific quality of life scale; ZBI: Zarit burden interview; SD: Standard deviation.

Parameters		n (%)
Gender	Male	24 (57.1)
	Female	18 (42.9)
Caregiver-patient relationship	Brother-brother	2 (4.8)
	Brother-sister	2 (4.8)
	Daughter-father	2 (4.8)
	Daughter-mother	3 (7.1)
	Father-daughter	1 (2.4)
	Father-son	4 (9.5)
	Husband-wife	3 (7.1)
	Mother-son	4 (9.5)
	Sister-brother	3 (7.1)
	Son-in-law-father-in-law	5 (11.9)
	Son-father	5 (11.9)
	Uncle-nephew	1 (2.4)
	Uncle-niece	1 (2.4)
	Wife-husband	6 (14.3)

[Table/Fig-2]: Distribution of gender and caregiver-patient relationship.

Parameters		n (%)
Depression score	Extremely severe	20 (47.6)
	Severe	1 (2.4)
	Mild	4 (9.5)
	Moderate	3 (7.1)
	Normal	14 (33.3)
Anxiety score	Extremely severe	19 (45.2)
	Severe	2 (4.8)
	Mild	4 (9.5)
	Moderate	6 (14.3)
	Normal	11 (26.2)
Stress score	Extremely severe	7 (16.7)
	Severe	14 (33.3)
	Mild	4 (9.5)
	Moderate	4 (9.5)
	Normal	13 (31)

[Table/Fig-3]: Severity levels of psychological distress among caregivers.

Parameters		FAMQOL score	ZBI score
Depression score	r-value	-0.877	0.898
	p-value	<0.001*	<0.001*
Anxiety score	r-value	-0.806	0.872
	p-value	<0.001*	<0.001*
Stress score	r-value	-0.816	0.843
	p-value	<0.001*	<0.001*

[Table/Fig-4]: Correlation between psychological distress, Quality of Life (QoL) and burden.
*Significant (p<0.001); r-value Pearson's correlation coefficient; FAMQOL: Family caregiver-specific quality of life scale; ZBI: Zarit burden interview

DISCUSSION

The present study aimed to assess the burden, QoL, anxiety, depression, and stress faced by caregivers of patients with traumatic conditions of the CNS. The findings revealed that a substantial proportion of caregivers exhibited extremely severe depression and anxiety, with the majority reporting severe stress. These results are consistent with a high incidence of psychological distress reported in existing literature. For instance, Keramati M et al., observed that severe to very severe stress and anxiety affected over 70% of caregivers of patients with head injuries in Iran, underscoring the global relevance of these challenges [22].

The QoL was significantly compromised among caregivers in the present study, with FAMQOL scores ranging from 22 to 60, indicating a low to moderate perceived QoL. This is comparable to earlier findings among family caregivers of individuals with SCI, who experience a significant reduction in QoL [23]. Similarly, caregivers of patients with TBI have also been shown to experience marked impairments in QoL [24].

In terms of caregiver burden, the present study found that it was notably high, with the majority reporting moderate to severe levels. Previous studies have reported varying degrees of burden, with most caregivers experiencing mild to moderate hardships [25]. The discrepancy between the findings is likely attributed to the caregivers of patients at a less acute stage of illness, or geographic and cultural differences between the two study populations, which can significantly influence caregiver experiences. Unlike the existing study, which was limited to SCI, the present study encompassed a broader range of CNS trauma.

Research consistently highlights that mental health challenges in caregivers of individuals with chronic conditions negatively affect their QoL and heighten their sense of burden [26,27]. While existing research has explored aspects of caregiver burden in specific CNS conditions, a comprehensive assessment of psychological distress, QoL, and burden among caregivers of patients with a broader range of traumatic CNS conditions, particularly in this regional context during the acute phase, remains less explored.

Limitation(s)

The limitations of the study include, firstly, the socioeconomic status of the participants was not assessed, which may have influenced psychological outcomes and caregiving experiences. Additionally, the cross-sectional design limits causal inference between caregiver burden, psychological distress, and QoL. Although the sample size was statistically sufficient for this population, the use of convenience sampling may have introduced selection bias. The high prevalence of psychological distress among caregivers of traumatic CNS condition patients underscores the need for routine mental health screening and targeted interventions. Structured support programs, counselling services, and caregiver training can mitigate the burden and improve the QoL. Future research should incorporate socioeconomic variables, explore longitudinal designs, and track how these psychological parameters evolve as patients move into the chronic phase of recovery, which will help in forming policies and practices that support the well-being of caregivers.

CONCLUSION(S)

In addition to a significant drop in the general QoL and an increased caring load, caregivers of people with traumatic conditions of the CNS also report elevated levels of stress, anxiety, and depression. These caregiver challenges are closely linked to patient outcomes, including recovery and QoL. While the direction of this relationship requires further longitudinal studies, the observed correlations suggest that caregivers require greater support than what is presently provided. Tracking these factors and their effects can help doctors, healthcare professionals, researchers, educators, and decision makers provide better support to patients and their caregivers.

REFERENCES

[1] Hofer AS, Schwab ME. Enhancing rehabilitation and functional recovery after brain and spinal cord trauma with electrical neuromodulation. Curr Opin Neurol. 2019;32(6):828-35.
[2] Muehlschlegel S, Rajajee V, Wartenberg KE, Alexander SA, Busl KM, Creutzfeldt CJ, et al. Guidelines for neuroprognostication in critically ill adults with moderate–severe traumatic brain injury. Neurocrit Care. 2024;40(2):448-76.
[3] Sandrow-Feinberg HR, Houlé JD. Exercise after spinal cord injury as an agent for neuroprotection, regeneration and rehabilitation. Brain Res. 2015;1619:12-21.
[4] Qadeer A, Khalid U, Amin M, Murtaza S, Khaliq MF, Shoaib M, et al. Caregiver's burden of the patients with traumatic brain injury. Cureus. 2017;9(8):e1590.
[5] Ryerson Espino SL, O'Rourke K, Kelly EH, January AM, Vogel LC. Coping, social support, and caregiver well-being with families living with SCI: A mixed methods study. Top Spinal Cord Inj Rehabil. 2022;28(1):78-98.
[6] Massouh A, Deek H, Avedissian T. Living with chronic illness: Exploring informal caregiver burnout. Eur J Cardiovasc Nurs. 2025;24(Suppl 1):zvaf122-119.
[7] Cejalvo E, Martí-Vilar M, Gisbert-Pérez J, Badenes-Ribera L. Stress as a risk factor for informal caregiver burden. Healthcare. 2025;13(7):731.
[8] Kreitzer N, Kurowski BG, Bakas T. Systematic review of caregiver and dyad interventions after adult traumatic brain injury. Arch Phys Med Rehabil. 2018;99(11):2342-54.
[9] Dehbozorgi M, Maghsoudi MR, Mohammadi I, Firouzabadi SR, Mohammaditabar M, Oraee S, et al. Incidence of anxiety after traumatic brain injury: A systematic review and meta-analysis. BMC Neurol. 2024;24(1):293.
[10] Molina-Gallego B, Ugarte-Gurrutxaga MI, Molina-Gallego L, Plaza del Pino FJ, Carmona-Torres JM, Santacruz-Salas E. Anxiety and depression after spinal cord injury: A cross-sectional study. Healthcare. 2024;12(17):1759.
[11] Backx AP, Spooren AI, Bongers-Janssen HM, Bouwsema H. Quality of life, burden and satisfaction with care in caregivers of patients with a spinal cord injury during and after rehabilitation. Spinal Cord. 2018;56(9):890-99.
[12] Hellenbrand DJ, Quinn CM, Piper ZJ, Elder RT, Mishra RR, Marti TL, et al. The secondary injury cascade after spinal cord injury: An analysis of local cytokine/chemokine regulation. Neural Regen Res. 2024;19(6):1308-17.
[13] Maas AI, Menon DK, Adelson PD, Andelic N, Bell MJ, Belli A, et al. Traumatic brain injury: Integrated approaches to improve prevention, clinical care, and research. Lancet Neurol. 2017;16(12):987-1048.
[14] Jacobsen G, Casanova MP, Dluzniewski A, Reeves AJ, Baker RT. Examining the factor structure and validity of the Depression Anxiety Stress Scale-21. Eur J Investig Health Psychol Educ. 2024;14(11):2932-43.
[15] Wisconsin Alzheimer's Institute. Zarit Caregiver Burden Assessment Instruments. Madison (WI): University of Wisconsin–Madison; 2021. Available from: https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf.
[16] Nauser JA, Bakas T, Welch JL. A new instrument to measure quality of life of heart failure family caregivers. J Cardiovasc Nurs. 2011;26(1):53-64.
[17] Lovibond SH, Lovibond PF. Manual for the Depression Anxiety Stress Scales. 2nd ed. Sydney: Psychology Foundation; 1995.
[18] Psychology Foundation of Australia. Depression Anxiety Stress Scales (DASS-21): Scoring Instructions. Sydney: Psychology Foundation; 2016. Available from: https://maic.qld.gov.au/wp-content/uploads/2016/07/DASS-21.pdf
[19] Nauser JA. Family Caregiver-Specific Quality of Life Scale (FAMQOL): Psychometrics and Scale. Storrs (CT): University of Connecticut; 2024. Available from: https://m3ewb-research.media.uconn.edu/wp-content/uploads/sites/3234/2024/01/FAMQOL-Psychometrics-and-Scale.pdf.
[20] Cejalvo E, Gisbert-Pérez J, Martí-Vilar M, Badenes-Ribera L. Systematic review following COSMIN guidelines: Short forms of Zarit Burden Interview. Geriatr Nurs. 2024;59:278-95.
[21] Domínguez-Vergara J, Santa-Cruz-Espinoza H, Chávez-Ventura G. Zarit Caregiver Burden Interview: Psychometric properties in family caregivers of people with intellectual disabilities. Eur J Investig Health Psychol Educ. 2023;13(2):391-402.
[22] Keramati M, Ebrahimi H, Basirinezhad MH, Shamsizadeh M, Mohammadpourhodki R. The prevalence of anxiety, stress, and depression with respect to coping strategies in caregivers of patients with head injuries. Arch Trauma Res. 2019;8(3):165-69.
[23] Graça Á, Nascimento MA, Lavado EL, Garanhani MR. Quality of life of primary caregivers of spinal cord injury survivors. Rev Bras Enferm. 2013;66:79-84.
[24] Ilaghi M, Gharib F, Pirani A, Vahabie AH, Grafman J, Shariat SV, et al. The burden of traumatic brain injury on caregivers: Exploring the predictive factors in a multi-centric study. BMC Psychol. 2024;12(1):150.
[25] Castellano-Tejedor C, Lusilla-Palacios P. A study of burden of care and its correlates among family members supporting relatives and loved ones with traumatic spinal cord injuries. Clin Rehabil. 2017;31(7):948-56.
[26] Pucciarelli G, Ausili D, Galbussera AA, Rebora P, Savini S, Simeone S, et al. Quality of life, anxiety, depression and burden among stroke caregivers: A longitudinal, observational multicentre study. J Adv Nurs. 2018;74(8):1875-87.
[27] Shukri M, Mustofai MA, Md Yasin MA, Tuan Hadi TS. Burden, quality of life, anxiety, and depressive symptoms among caregivers of hemodialysis patients: The role of social support. Int J Psychiatry Med. 2020;55(6):397-407.

PARTICULARS OF CONTRIBUTORS:
1. Postgraduate Student, Department of Neurology Physiotherapy, KLE Academy of Higher Education and Research (Deemed to be University), Institute of Physiotherapy, Belagavi, Karnataka, India.
2. Assistant Professor, Department of Neurology Physiotherapy, KLE Academy of Higher Education and Research (Deemed to be University), Institute of Physiotherapy, Belagavi, Karnataka, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:
Raghavendrasingh Dharwadkar,
Assistant Professor, Department of Neurology Physiotherapy, KLE Academy of Higher Education and Research (Deemed to be University), Institute of Physiotherapy, Belagavi-590010, Karnataka, India.
E-mail: raghavendrasingh@klekipt.edu.in; sanjanamohata2908@gmail.com

PLAGIARISM CHECKING METHODS: [Jain H et al.]
- Plagiarism X-checker: Jan 03, 2026
- Manual Googling: Apr 20, 2026
- iThenticate Software: Apr 22, 2026 (3%)

ETYMOLOGY: Author Origin

EMENDATIONS: 6

AUTHOR DECLARATION:
- Financial or Other Competing Interests: None
- Was Ethics Committee Approval obtained for this study? Yes
- Was informed consent obtained from the subjects involved in the study? Yes
- For any images presented appropriate consent has been obtained from the subjects. NA

Date of Submission: **Dec 16, 2025**
Date of Peer Review: **Feb 19, 2026**
Date of Acceptance: **Apr 24, 2026**
Date of Publishing: **Aug 01, 2026**