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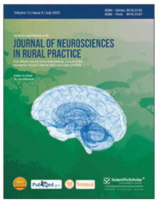

Original Article

Stress and quality of life in caregivers of patients with traumatic brain injury: A cross-sectional study

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ABSTRACT

Objectives: Improvements in acute trauma management have contributed to an increase in morbidity and survival rates among traumatic brain injury (TBI) patients. Caregivers report high levels of physical strain and emotional stress. Yet, research on stress and quality of life (QoL) in caregivers of patients with TBI remains limited, especially in low- and middle-income countries (LMICs). The objectives of this study are to assess the stress and QoL in caregivers of patients with TBI and their association with socio-demographic (age, sex, relationship with patient) and clinical factors (mode of injury, type of TBI, time since injury).

Materials and Methods: We conducted a cross-sectional observational study involving 55 adult primary caregivers of patients diagnosed with moderate-to-severe TBI at a tertiary care hospital. Caregivers were recruited from the Department of Neurosurgery outpatient section. Data on sociodemographic and clinical characteristics were collected, and stress levels and QoL were assessed through the Kingston Caregiver Stress Scale (KCSS) and relevant components of the TBI-Caregiver QoL (TBI-CareQOL) scale, respectively. Statistical analyses were performed to evaluate the relationships between variables.

Results: Caregivers recruited ranged from 19-64 years in age (Mean ± standard deviation [SD] = 37.51 ± 10.01 years) and were predominantly women (63.6%). TBI patients ranged from 15 to 70 years of age (Median [Q1, Q3] = 31 [24, 44]) and were predominantly male (36.4%). Moderate TBI occurred in 63.6% of patients, and the most common etiology was road traffic accidents (RTAs) (87.3%). Caregivers experienced severe stress (KCSS Total Score Mean ± SD = 30.18 ± 9.3) and worse QoL than the standard population mean. Caregivers of patients with TBI due to RTAs had significantly worse stress levels in terms of financial issues and worse QoL in terms of feelings of loss of self compared to TBI due to falls. Caregivers of patients with severe TBI had a significantly worse QoL in terms of feelings of loss of self compared to those with moderate TBI. Stress levels were highly correlated with all measured components of QoL. Increasing caregiver age was significantly correlated with a worse emotional suppression component of QoL ($r = -0.289$, $P < 0.05$).

Conclusion: The study highlights the substantial burden of stress and impaired QoL among caregivers of TBI patients, necessitating targeted interventions. Stress and QoL are closely linked, and some sociodemographic and clinical factors were associated with increased stress and impaired QoL, while other factors, such as the severity of TBI and time since injury, did not appear to have a significant effect. Further research should explore longitudinal changes in caregiver well-being and the development of tailored support services to mitigate these challenges.

Keywords: Caregiver burden, Psychological stress, Quality of life, Rehabilitation, 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] India's TBI burden, primarily due to road traffic accidents (RTAs), reflects the severe and underreported rates seen across low-and-middle-income countries (LMICs),[3] where the incidence is nearly triple that in high-income countries.[4] In recent years, advancements in acute trauma care have reduced the mortality rate, corresponding to a rise in morbidity and survivors of TBI.[5]

Patients with moderate-to-severe TBI, defined as a Glasgow Coma Scale (GCS) score <13 at presentation, often require prolonged intensive and high-dependency care unit treatment and have persistent motor, cognitive, emotional, and social deficits.[6,7] Caregivers are individuals who provide care that is typically uncompensated, usually at home, involves significant amounts of time and energy, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding.[8] However, the psychological burden on and the caregiver's needs are often overlooked. Understanding the factors that influence

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caregiver stress and quality of life (QoL) allows for tailoring support services and resources to meet the unique needs of caregivers and TBI patients.

Studies on associations between the severity of TBI, demographic factors, outcomes, and QoL of patients with TBI have been undertaken,[9-11] but there is a relative paucity of research on stress and QoL in caregivers of patients with TBI using TBI and caregiver-specific scales.

Hence, sensitive, specific measures were used to quantify stress levels and QoL in TBI caregivers and their association with sociodemographic and clinical factors. A cross-sectional study was conducted to assess the stress and QoL in caregivers of patients with TBI and their association with sociodemographic (age, sex, relationship with patient) and clinical factors (mode of injury, type of TBI, time since injury).

MATERIALS AND METHODS

Study setting

A prospective observational cross-sectional study on human participants was conducted between December 2023 and February 2024 at a tertiary care center in Puducherry, India. Approval was obtained from the Institute Research and Ethics Committee (JIP/IEC-OS/207/2023) and the study was conducted in agreement with the ethical guidelines of the Declaration of Helsinki. Written informed consent was obtained from all participants, including the patient and caregiver. The informed consent process was conducted in the presence of a witness after explaining the study objectives and procedure in simple, non-technical terms. Caregivers were interviewed separately in a private setting to ensure privacy and minimize bias.

Operational case definition

The primary caregiver is the person who, among the relatives, would help the patient the most, accompany him/her for the treatment or follow-up at the department, and is generally perceived to perform essential caregiving tasks.[12]

The following variables were assessed:

- Demographic variables: Age, sex, relationship to patient
- Clinical variables
    - Patient characteristics: Severity of TBI (moderate: GCS 9–12, severe: GCS <9), mode of injury (RTA or fall), and duration since injury.
    - Caregiving characteristics: Duration of caregiving

Outcome measures

- Stress levels: Assessed using the Kingston Caregiver Stress Scale (KCSS), across three domains – caregiving issues, family issues, and financial issues
- QoL: Assessed using the TBI-CareQOL scale

Study participants

Inclusion criteria

Adult primary caregivers of patients diagnosed with moderate (GCS 9–12) to severe (GCS <9) TBI, undergoing treatment at 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 at least 4 weeks, were recruited.

Exclusion criteria

Caregivers with a known history of psychiatric disorders, cognitive deficits, and pregnant women were excluded from the study.

Sampling

Fifty-five caregivers were recruited through consecutive sampling. The sample size was estimated with an anticipated proportion of caregivers with moderate and above levels of stress and impaired QoL as 0.90 at a 5% level of significance and 8% absolute precision.

Data collection

Study participants' sociodemographic and clinical details were collected and entered in a pro forma. Caregivers' stress levels and QoL were assessed using the KCSS and TBI-CareQOL questionnaires, respectively. Data were collected by the authors in the presence of a medical social worker using structured printed questionnaires in a quiet, private room to ensure confidentiality and comfort. After obtaining consent, caregivers were given KCSS and TBI-CareQOL tools to complete. The principal investigator monitored the process for completeness and accuracy and adherence to ethical and procedural guidelines. Completed forms were reviewed immediately, and missing information was clarified on the spot. The raw scores entered in the proforma were converted into standardized T-scores (TBI-CareQOL) and used for statistical analysis, as recommended in the tool's official scoring manual.[13]

Assessment of caregiver stress

The KCSS is a 10-item self-reported questionnaire with high internal consistency, test-retest reliability, and a strong factor structure.[14] It assesses caregiver stress in three domains – Caregiving issues, Family issues, and Financial issues. Each item is scored on a 5-point Likert scale, where 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 QOL of caregivers

The TBI-CareQOL is a self-reported questionnaire with high internal consistency and excellent psychometric properties, developed and calibrated in TBI caregivers.[15,16] The following relevant caregiver-specific measures – Feelings of Loss - Person with TBI,[17] Feelings of Loss - Self,[17] Caregiver Strain,[18] Caregiver Vigilance,[19] Caregiver-Specific Anxiety,[20] Emotional Suppression, Feeling Trapped,[21] were assessed using Short Form 6a questionnaires.

Caregivers responded 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 were 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 were translated into the local language (Tamil).[22]

Statistical analysis

The distribution of categorical data is expressed as frequency and percentages. Quantitative data are expressed as mean with SD or median with range. Normality of data was assessed using the Kolmogorov–Smirnov (K-S) test.

The comparison of the level of stress and QoL between different categories of the categorical variables was carried out by using an independent Student's t-test or Mann–Whitney U test, based on the normality of data. Relation to the patient was compared using a one-way analysis of variance test or Kruskal–Wallis test. The linear relationship between the level of stress and QoL with different quantitative variables was carried out using correlation analyses. Karl Pearson Correlation or Spearman Rank correlation was performed based on the normality of data.

Statistical analysis was done using the Statistical Package for the Social Sciences (SPSS) (IBM SPSS Statistics 27.0.1.0) software. All analyses were carried out at a 5% level of significance, and a $P < 0.05$ was considered significant.

RESULTS

Caregiver and patient characteristics

A total of 55 adult caregivers of patients with moderate-to-severe TBI from the Department of Neurosurgery outpatient section were included in this study. The clinical and sociodemographic characteristics of the recruited caregivers and TBI patients are summarized in Table 1. Caregivers recruited had a mean age of 37.51 years. About two-thirds (63.6%) were women, with most being the wife (36.4%) or the mother (23.6%) of the patient. Caregiving duration ranged widely, with a median of 114 days (IQR: 21–556 days). TBI patients had a median age of 31 years and were predominantly male (87.3%). Most patients (63.6%) had moderate TBI, with RTAs being the primary cause (87.3%).

Stress levels in caregivers

The overall level of stress in caregivers was measured using the KCSS. No significant association was found between demographic factors (e.g. age, sex, relationship to the patient, caregiving duration) or clinical characteristics (e.g., TBI severity) and total stress levels, stress due to caregiving issues, and stress due to family issues. However, caregivers of patients with TBI due to RTAs reported significantly higher stress levels related to financial issues compared to those caring for patients with TBI due to falls.

QoL in caregivers

Caregiver QoL, assessed using TBI-CareQOL measures, showed no significant associations with demographic or clinical factors in terms of Caregiver Strain, Caregiver Vigilance, Caregiver-Specific Anxiety, Emotional Suppression, Feeling Trapped, or Feelings of Loss of the TBI patient.

However, caregivers of patients with severe TBI had significantly worse QoL in terms of feelings of loss of self compared to those caring for patients with moderate TBI. Similarly, caregivers of patients with TBI due to RTAs experienced worse QoL in terms of feelings of loss of self compared to TBI due to falls [Table 2].

Correlation analysis

Correlation analysis revealed that increasing caregiver age was significantly associated with worse QoL in terms of emotional suppression. All analyzed correlations are shown in the network graph, with significant correlations in red [Figure 1]. In addition, all measured components of stress and QoL were significantly correlated, illustrated in a heatmap with a color-coded matrix representing Pearson's r for the two measures at each of the tile intercepts [Figure 2].

DISCUSSION

Caregiver and patient characteristics

The findings underscore the significant burden placed on caregivers of individuals with TBI. Caregivers are predominantly female and often immediate family members such as wives and mothers, a recurrent trend seen across studies.[5,23] While some studies found that men reported

Table 1: Socio-demographic and clinical characteristics of patients and caregivers.

Patient characteristics	Patient sex	Variable *n* (%)
	Male	48 (87.3)
	Female	7 (12.7)
	Patient age	31 (24.44)†
	Mode of head injury	
	RTA	48 (87.3)
	Fall	7 (12.7)
	Type of TBI	
	Moderate	35 (63.6)
	Severe	20 (36.4)
	GCS score	10 (8.11)†
Caregiver characteristics	Caregiver sex	
	Male	20 (36.4)
	Female	35 (63.6)
	Caregiver age	37.51±10.01*
	Relation to patient	
	Mother	13 (23.6)
	Wife	20 (36.4)
	Son	7 (12.7)
	Others	15 (27.3)
	Number of days of care	114 (21,556)†
KCSS Scores	Total score	30.18±9.3*
	Caregiving issues	23.11±7.21*
	Family issues	2 (2.6)†
	Financial issues	4 (2.4)†
TBICareQOL T-scores	Caregiver strain	51.64±10.08*
	Caregiver-specific anxiety	57.6±8.49*
	Emotional suppression	47.15±10.73*
	Caregiver vigilance	56.2 (47.55, 61.75)†
	Feeling trapped	57.06±7.89*
	Feelings of loss - person with TBI	52.3±10.9*
	Feelings of loss - self	54 (49.44, 58.69)†

*Mean±SD, †Median (Q1, Q3). RTA: Road traffic accident, TBI: Traumatic brain injury, GCS: Glasgow coma scale, KCSS: Kingston caregiver stress scale, TBICareQOL: Traumatic brain injury caregiver quality of life scale

higher burdens than women,[23] others found that affliction tethers more toward females as compared to males.[5] However, we found no significant association between caregiver sex and stress or QoL. Considering women's socialization into nurturing roles,[24] this may also result from differences in the subjective experience of burden vis à vis a sense of responsibility and must be explored further.

Stress levels in caregivers

Interestingly, we did not find significant associations between the severity of TBI and the overall stress levels or stress related to caregiving issues. Qadeer *et al*.[5] reached similar conclusions, suggesting that caregivers of patients with moderate TBI, despite the differences in the extent of neurological impairment between moderate and severe TBI cases, may face similar challenges and stressors.

Notably, caregivers of patients with TBI resulting from RTAs experienced significantly higher stress levels related to financial issues compared to those of patients with TBI due to falls. RTAs likely pose additional financial burdens on caregivers due to associated healthcare costs and potential loss of income. This is further exacerbated by the peak of TBI

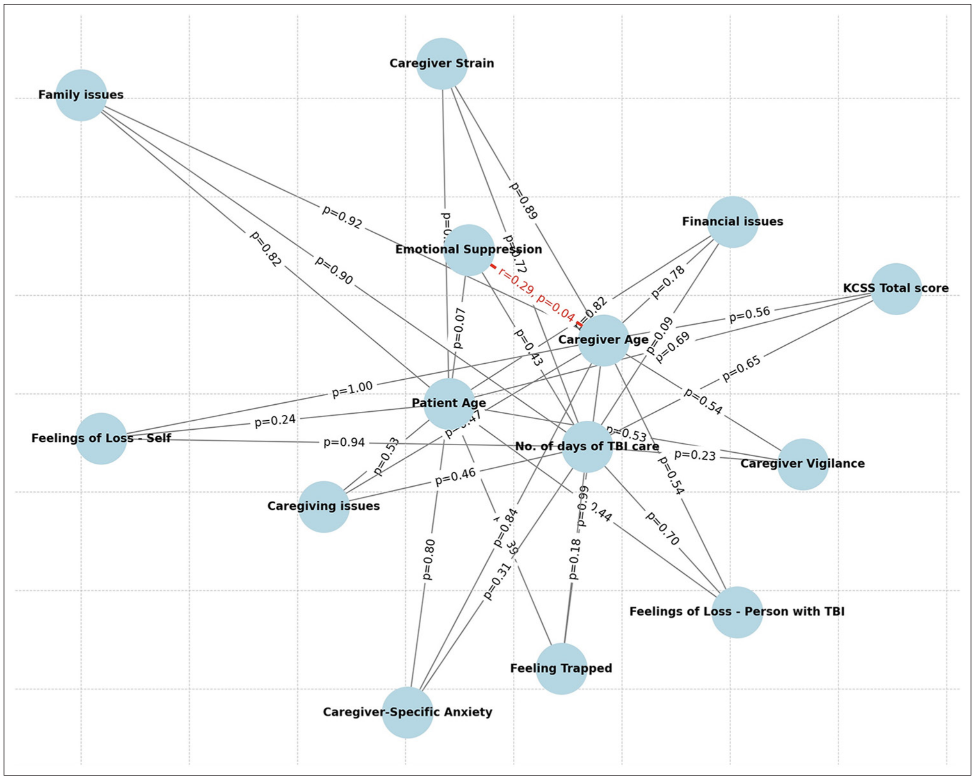

Figure 1: Network graph of correlations with significant correlations in red. TBI: Traumatic brain injury, KCSS: Kingston caregiver stress scale, p: *P*-value, r: Pearson's correlation coefficient.

Table 2: Comparison of demographic factors and clinical characteristics with TBICareQOL feelings of loss-self t-score.

	Category	*n*	Mean±SD	*P*-value
Patient sex	Male	48	52.5±11.17	0.916
	Female	7	51.2±9.47	
Caregiver sex	Male	20	53.4±12.31	0.563
	Female	35	51.7±10.13	
Mode of injury	RTA	48	53.5±10.58	*P*<0.05*
	Fall	7	44.2±10.22	
Type of TBI	Moderate	35	50.1±9.85	*P*<0.05*
	Severe	20	56.2±11.8	
Relation to patient	Mother	13	48.7±11.79	0.568
	Wife	20	54.2±8.28	
	Son	7	52.1±9.24	
	Others	15	52.9±13.85	

*Significant at *P*<0.05. SD: Standard deviation, RTA: Road traffic accident, TBI: Traumatic brain injury, TBICareQOL: Traumatic brain caregiver injury quality of life

incidence at a relatively younger age in LMICs,[25] when they are more likely to be the primary earner in the family.

QoL in caregivers

Increasing caregiver age was associated with worse emotional suppression in QoL, likely due to compounded caregiving stress and age-related declines in emotional resilience. Older caregivers often face their own health challenges, making emotional regulation more difficult, which aligns with prior findings that emotional suppression is a maladaptive strategy linked to poorer psychological outcomes in older adults.[26]

Duration of care

The median caregiving duration in our study was 114 days (IQR: 21–556), reflecting a wide range of caregiving experiences from acute to chronic phases. Despite this variability, the number of caregiving days was not found to be significantly associated with stress or QoL. Various studies have found a variable relief of stress with time.[5,27] However, burden trajectories are mediated by a complex interplay of factors such as caregiver resilience, availability of support systems, and patient recovery trajectory that may not have been accounted for by virtue of the cross-sectional study design.

Correlation analysis

All measured components of stress and QoL were found to be significantly correlated. Family caregivers are typically uncompensated, usually stay at home, and devote considerable effort and time to provide care or assistance for ill family members.[28] Caregivers under significant psychological distress may perceive elevated stress levels

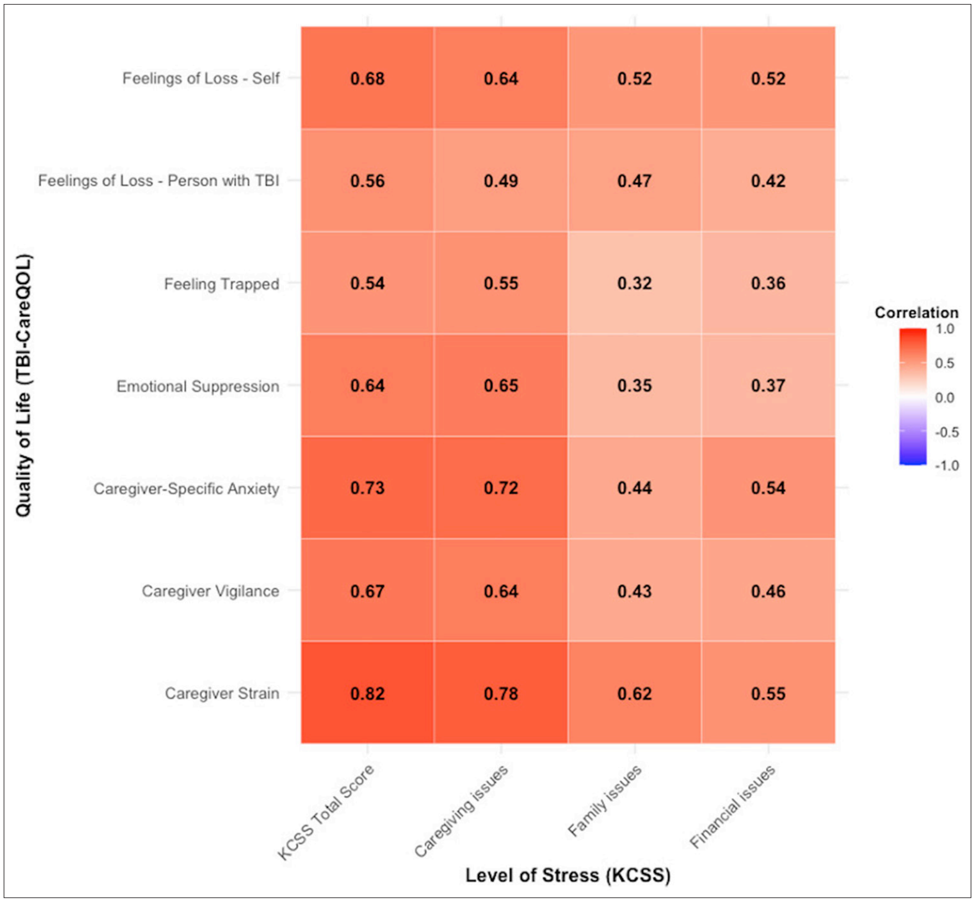

Figure 2: Correlation heatmap of quality of life and level of stress. TBI: Traumatic brain injury, KCSS: Kingston caregiver stress scale, TBI-CareQOL: Traumatic brain injury caregiver quality of life.

and a reduced sense of control, substantially impacting their QoL.[29]

Future directions

Caregivers of TBI patients in LMICs face unique challenges due to limited healthcare infrastructure, financial constraints, and a high prevalence of young patients with TBI from RTAs. Previous studies have shown caregiver stress and reduced QoL to be correlated with negative outcomes in individuals with TBI, including poorer functional outcomes, increased cognitive impairments, decreased psychosocial well-being, and less social integration and adjustment.[30-32]

To address these challenges, targeted interventions are essential. Evidence suggests that tailored psychoeducational interventions can significantly reduce caregiver burden and improve coping in LMIC settings.[5] Studies in LMICs have also demonstrated the feasibility and impact of Mobile Health (mHealth) tools for chronic care management. Developing affordable respite care services, such as short-term institutional care or trained in-home assistance, can help mitigate caregiver burnout. Policy-backed interventions are critical in alleviating the socioeconomic burden on caregivers.

Researchers and clinicians alike should be aware of and sensitive to the needs of their patients' informal caregivers.[33] Future research should consider additional patient-related variables, such as cognitive and functional impairment, behavioral symptoms, and social determinants such as level of education, and rehabilitation needs, to better understand their impact on caregiver well-being. Well-powered ambispective observational studies with a long follow-up period can bring to light nuanced differences in stress and QoL and enable the development of personalized interventions for TBI caregivers across the spectrum of severity.

Limitations

Generalizability of this study is limited by certain factors. We utilized a cross-sectional design, limiting the ability to establish temporal relationships between variables. Longitudinal studies are needed to elucidate the trajectory of caregiver outcomes.

Strengths

Research on TBI caregivers in LMICs is scarce, despite the disproportionately high burden of TBI in these regions and the limited availability of caregiver support systems. In addition, this study is among the first to utilize a TBI caregiver-specific QoL assessment tool, the TBI-CareQOL, ensuring that the unique challenges faced by TBI caregivers are captured with precision.

CONCLUSION

This study assessed the stress levels and QoL of caregivers of patients with TBI and explored their associations with sociodemographic and clinical factors. Caregivers were found to experience severe stress and significantly impaired QoL, with stress levels showing a strong correlation with all measured components of QoL. These findings underscore the critical need for interventions aimed at reducing caregiver stress and improving their QoL, such as psychoeducation programs, support groups, mobile health applications, respite care services, and policy interventions. By addressing factors such as age, sex, relationship with the patient, mode of injury, type of TBI, and time since injury, targeted support systems can be developed to enhance caregiver well-being, ultimately benefiting both caregivers and patients.

Ethical approval: The research/study was approved by the Institutional Review Board at Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry, number JIP/IEC-OS/307/2023, dated 13/10/2023.

Declaration of patient consent: The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest: There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation: The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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