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Original Article

Palliative care needs of stroke patients at a tertiary care center in South India

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ABSTRACT

Objectives: Stroke survivors have palliative care needs in multiple domains, which are overlooked. Accurate estimation of these is pivotal in ensuring proper rehabilitation and planning interventions to improve quality of life (QoL). We aimed to assess the palliative care needs of stroke patients in various domains in a structured manner at the neurology service of a tertiary care center in South India.

Materials and Methods: Seventy-five consecutive stroke patients presenting to the neurology service were recruited over six months with assessment across various domains including symptom burden, physical domain, activities of daily living (ADL), psychiatric/psychological domain, and QoL at baseline and with follow-up at one month and three months.

Results: Despite improvement in the conventional stroke impairment measures among stroke survivors, there were significant unmet needs across various domains; 98% were severely or entirely dependent on ADL at three-month follow-up; and pain and insomnia were the most frequent (33% incidence) troubling symptoms encountered. There were substantial mental health related issues. The QoL measurement tools employed were the stroke impact assessment questionnaire (SIAQ), a novel tool and the World Health Organization Quality Of Life Brief Version (WHO-QOL-BREF). SIAQ scores at one month showed that 19 patients (42.22%) had their QoL severely affected, and 36 patients (80%) showed the same trend at the three-month follow-up. WHO-BREF scores showed that 27 (62%) did not report good QoL, and 32 (73%) were found not to be satisfied with their health at a one-month follow-up.

Conclusion: There is a significant burden of unmet palliative care needs among stroke survivors in India across various domains.

Keywords: Quality of life, Palliative care, Activities of daily living, Stroke, Developing countries

INTRODUCTION

In India and other low- and middle-income countries (LMICs), the stroke burden is exceptionally high, with temporal data showing an increasing prevalence of ischemic and hemorrhagic strokes.^[1,2] Stroke is the fourth leading cause of death and the fifth leading cause of DALY's in India.^[3] Although organized stroke unit care has improved stroke survival and outcomes,^[4] specialized services are concentrated in urban areas.^[5] There are enormous lacunae in the support and rehabilitation services available to stroke patients in India, especially in a rural setting.^[5] The problem is compounded by the escalating burden of non-communicable diseases, including stroke in India and other

LMIC, coupled with limited access to prevention, treatment, and rehabilitation services.^[6] The higher prevalence of poverty and the impact of poverty on stroke prevalence impact access to stroke care across the continuum.^[7] The burden on caregivers of stroke survivors is very high and is influenced by stroke characteristics (stroke severity and disability) and socioeconomic status.^[8]

Serious health suffering (SHS) associated with illness or injury can compromise the physical, social or emotional functioning of stroke patients and their families and needs to be addressed with medical and non-medical interventions.^[9] In LMICs, 44% of deaths in all age groups are associated with SHS.^[9] Stroke ranks as the second most

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common cause of non-decedent SHS worldwide and in LMICs.^[9] Palliative care provides an integrated approach that improves the quality of life (QoL) of patients and their families facing a life-threatening illness by utilizing early identification, assessment, and treatment of problems such as pain, psychosocial distress, and spiritual struggles.^[10] In the context of limited resources, the palliative care approach must adopt a safe, effective, and low-cost "Essential Package" to address SHS.^[9]

The literature on the palliative care needs of stroke patients is sparse, especially from LMICs. The palliative care needs of stroke patients are different from other illnesses. The natural history of stroke with abrupt onset disability leaves little time for the patient or caregiver to cope with the tragic situation.^[11] Higher palliative care needs in various domains (psychological, psychiatric, and functional dependence) are associated with low QoL in stroke survivors.^[12] Higher disability and socioeconomic and demographic profile (rural residence, education, and marital status) of the stroke patients are often associated with increased palliative care needs.^[13]

A qualitative study from South India identified multiple palliative care needs for stroke patients and their families.^[14] Expanding on this approach, we sought to describe the palliative care needs of stroke patients and families using multiple validated instruments across various domains.

MATERIALS AND METHODS

Study Design-This prospective observational study recruited consecutive acute stroke patients admitted to a Neurology unit at Thiruvananthapuram Medical College over six months (September 2019–June 2020) with follow-up at one month and three months after stroke onset.

The objective of the study was to measure the palliative care needs of imaging-confirmed stroke patients.

Our stroke unit has two stroke emergency admission days per week. We use four to six beds out of the 16 intensive care unit beds on admission days. Subsequently, depending on the recovery, we shift them to one of the two high-care step-down beds and then to the 13 general ward beds. The average admission during the week is around 10-12. Patients coming within the window period undergo an emergency computed tomography (CT) scan, and CT angiogram, and eligible patients are thrombolysed. We do not have an inhouse facility for thrombectomy.

Palliative care needs were measured across multiple domains: symptom burden, physical domain (stroke impairment [National Institutes of Health Stroke Scale-NIHSS, Canadian neurological scale], disability scales [modified Rankin scalemRS], activities of daily living [ADL] Barthel Index [BI]), psychiatric/psychological domain (depression [Patient Health Questionnaire-9 (PHQ-9) questionnaire] and anxiety [Generalized Anxiety Disorder-7 (GAD-7) questionnaire]), QoL domain (stroke impact assessment questionnaire [SIAQ] and the World Health Organization Quality Of Life Brief Version [WHO-QOL-BREF]).^[15-21] Symptom burden was addressed by looking into the presence of 12 strokerelated symptoms as part of the assessment at baseline using a questionnaire. The WHO-QOL (100 items) and WHO-QOL-BREF (26 items) are QoL scales developed to be culturally appropriate across different cultures in collaboration with multiple international centers.^[19] Local language (Malayalam) translated versions of the questionnaires (GAD-7, PHO-9, and WHO-QOL-BREF) were used. Patients with stroke confirmed on imaging (CT/magnetic resonance imaging) were eligible to be enrolled in the study. According to the protocol, data collection was done by a research nurse using a pre-designed case record form [Table 1]. The SIAQ was developed by investigators in our team in the context of South India's medical system and has undergone validation (Neurology India, in press). The SIAQ is a stroke-specific comprehensive patient-reported outcome measure (PROM) validated for assessment beyond one month of stroke. There are 30 items, with scores ranging from 0 to 60, covering eight principal domains: Sensory, motor, social, economic, emotional, behavioral, cognitive, and communication.

Statistical analysis

Mean and median measured the central tendency. Standard deviation and interquartile interval showed the variability. Paired *t*-test was used to measure the difference in means within a sample. The patient's identity has been anonymized.

Ethics approval was obtained from the Institutional Human Ethics Committee, and informed consent was obtained from patients.

RESULTS

Seventy-five patients were enrolled at baseline. At one month follow-up, three died and eight were lost to follow-up. There were three further deaths in three months.

Our study cohort had a higher proportion of males (65%), rural residents, married (76%), lower education attainment, and lower occupational strata. The complete sociodemographic profile is presented in Table 2.

The prevalence of comorbidities and health-related behavior (smoking and alcohol) is presented below in Table 3.

Most patients had an ischemic stroke (93%), with 50% receiving thrombolysis and 85% having a moderate-severe stroke. The details of stroke characteristics are presented in Table 4.

Table 1: Overview of timeline of data collection and scales used.					
	Baseline	1 m follow-up	3 m follow-up		
Demographic and socioeconomic data	Х				
Symptom burden	Х				
NIHSS	Х		Х		
Modified Rankin scale	Х		Х		
Barthel index	Х		Х		
Canadian neurological scale	Х		Х		
SIAQ	Х		Х		
WHO-QOL-BREF	Х		Х		
PHQ-9	Х	Х	Х		
GAD-7	Х	X	Х		
NIHSS: National Institutes of Health Stroke Scale. PHO-9: Patient Health Ouestionnaire 9. GAD-7: Generalized anxiety disorder 7. SIAO: Stroke impact					

NIHSS: National Institutes of Health Stroke Scale, PHQ-9: Patient Health Questionnaire 9, GAD-7: Generalized anxiety disorder 7, SIAQ: Stroke impact assessment questionnaire, WHO-QOL-BREF: World Health Organization Quality of life Brief Version

A considerable proportion of respondents (40%) were not interested in answering the mental health screening questionnaire over the phone. In the cohort that responded to the GAD-7 questionnaire, 48% had minimal anxiety and ~11% had mild anxiety symptoms, with none having moderate/severe anxiety. Among the respondents to PHQ-9, 8% did not have any signs of depression, 35% had minimal depression, 13% had mild depression, and none had evidence of moderately severe or severe depression.

The mRS score and BI at three months are presented in Table 5. Independent outcome/mild disability (mRS 0–2) was seen in 36% and a moderate disability (mRS 3–4) at three months in 48%. A considerable proportion of stroke survivors had severe to total dependency for ADLs at three months.

The symptom burden is presented in Table 6. The most frequent three encountered were pain (33.3%), insomnia (33.3%), and fatigue (17.30%).

The various stroke impairment scales, disability scales, anxiety, and depression questionnaires and the QoL scales are summarized in Table 7. There was a statistically significant improvement in stroke impairment and disability scales at three months compared to baseline and is in line with the expected natural history of stroke recovery. The QoL scales showed a significant burden in multiple domains at baseline, which significantly improved at three months in the physical, psychological, and environmental domains. The social relations domain scores narrowly missed the statistically significant improvement, possibly highlighting the lack of adequate social support for stroke survivors and their families.

DISCUSSION

Our results indicate that stroke patients have substantial palliative care needs within multiple domains. At three months, the stroke impairment scales (mRS, BI, NIHSS, and Canadian Neurological Scale [CNS]) showed improvement compared to baseline. Nevertheless, the social domain failed to show improvement at three months follow-up. We will discuss the findings from our study in the context of unmet palliative care needs.

The BI, which assesses independence for ADL, and the mRS, a subjective global disability scale, are two traditional stroke outcome measures used in stroke clinical trials.^[18,22-24] An independent functional status (mRS 0–2) was achieved in 36% of subjects at three months and is comparable to stroke outcomes from other studies.^[18,25] Despite a higher proportion of patients achieving a good outcome, as defined by mRS, a considerable proportion (98%) were severely or entirely dependent on BI. The mRS and BI scores differ in sensitivity and responsiveness to stroke recovery and explain our findings.^[26] Our data show high rates of dependency for ADLs among stroke survivors and highlighting the unmet palliative care needs of survivors.

Our data also suggest a mental health burden (anxiety and depression) among stroke survivors; however, data were missing for many survivors. The prevalence of post-stroke depression and anxiety is high in stroke survivors and can directly impact their QoL.^[27-29] This highlights the need to consider and address stroke survivors' mental health with adequate screening and early referral for professional intervention, hopefully translating to a better QoL. The possible reasons for missing data include a lack of interest in answering questionnaires and the stigma surrounding mental health in India.^[30,31]

There was a high symptom burden in stroke patients at baseline. This was not assessed at the follow-up given the high response burden from other questionnaires. In a cross-sectional study from China at a stroke rehabilitation center, which tried for a multi-dimensional assessment of symptom burden (including frequency, severity, and distress) within one year among stroke survivors, the mean number of symptoms in patients with stroke was found to

Table 2: Sociodemographic profile of the patients.	
Variable	n (%) n=75
Age categories Less than 51 years 51–70 years More than 70 years Age (median [IQR] years)	23 (31) 40 (53) 12 (16) 62 (48–68)
Sex Males Females	49 (65) 26 (35)
Marital status Never married Currently married Separated Widowed	2 (3) 57 (76) 4 (5) 12 (16)
Occupation categories Skilled worker (skilled/semi-skilled) Others (professional/semi-professional/clerk/ shop owner/farm Unplitled	15 (20) 8 (11)
Unemployed Educational categories	28 (31) 28 (38)
Above high school (prof/grad/post-secondary) High school Below high school (middle/prim/illiterate)	8 (11) 23 (31) 44 (59)
Location of residence Urban Rural Number of dependent adults	21 (28) 54 (72)
None One Two	40 (53.) 33 (44) 2 (2.67)
Number of dependent children None One Two Three	62 (82.67) 4 (5.33) 8 (10.67) 1 (1.33)
Age of the oldest child (median [IQR]) Age of the youngest child (median [IQR]) Type of house*	35 (21–42) 28 (15–38)
Pakka Kuppuswamy socioeconomic score 2019 Mean (SD)	23 (30.67) 51 (68) 11.18 (5.73)
Median (IQR) Kuppuswamy socioeconomic scale 2019 (3 categorie Upper and Upper middle	9 (7–13) es) 12 (16)
Lower middle Upper lower and lower	19 (25.33) 44 (58.67)

*Data missing for one patient. n: Number of patients.

Kutcha House: The walls and/or roof of which are made of material other than those mentioned above, such as unburnt bricks, bamboos, mud, grass, reeds, thatch, and loosely packed stones are treated as kutcha house. A pucca house is one, which has walls and roof made of the following material. Wall material: Burnt bricks, stones (packed with lime or cement), cement concrete, timber, ekra, etc., IQR: Interquartile range, SD: Standard deviation

Table 3: Health-related behaviors and comorbidities.				
Variable	n (%) (n=75)			
Smoking status				
Not a smoker	38 (50.67)			
Cigarette	21 (28.00)			
Hand rolled cigarettes	14 (18.67)			
Others - Chewing/snuff	2 (2.67)			
Alcohol use				
Never drunk	39 (52)			
Former/past drinker	23 (30.67)			
Current mild moderate drinker	8 (10.67)			
Current heavy drinker	3 (4.00)			
Unknown	2 (2.67)			
Hypertension	61 (81.33)			
Diabetes	43 (57.33)			
Dyslipidemia	15 (20)			
Hepatitis B positive status	1 (1.33)			
COPD	1 (1.33)			
Coronary artery disease	21 (28)			
COPD: Chronic obstructive pulmonary disease, <i>n</i> : Number of patients.				

Table 4: Stroke characteristics at baseline. n (%) Stroke type (n=75)Ischemic 70 (93.33) Hemorrhagic 5 (6.67) Thrombolysis 37 (49.3) Location of infarct on CT scan 01 (01.3) • No infarct seen • Cortical infarct 51 (68.0) 13 (17.3) • Subcortical infarct/Lacunar infarct • Cortical infarct and subcortical 05 (06.7) • ICH 05 (06.7) NIHSS 19 (25.33)

 • Severe (NIHSS >15)
 19 (25.33)

 • Moderate (NIHSS 5-14)
 45 (60.0)

 • Mild (NIHSS 1-4)
 11 (14.7)

CT: Computed tomography, ICH: Intracerebral hemorrhage, NIHSS: National Institutes of Health Stroke Scale, *n*: Number of patients.

be 11.7 \pm 3.5.^[32] Limb weakness was the most frequent and participation restriction was the most distressing among 19 different stroke-related symptoms contributing to the symptom burden. The number of stroke survivors' symptoms was more than other debilitating chronic diseases such as cancer.^[33,34] Dyspnea, pain, and respiratory secretions were identified as the three critical issues encountered by patients dying following a stroke diagnosis.^[35] Another study from Europe identified dyspnea and pain as the most prevalent symptoms in the last days of dying stroke patients referred for palliative care.^[36] Addressing these distressing symptoms
 Table 5: mRS and Barthel index at three months.

Distribution of individual scores	n (%)	
	(<i>n</i> =67)	
mRS 0 (no symptoms)	-	
mRS 1 (no significant disability despite symptoms)	10 (13.3)	
mRS 2 (slight disability)	17 (22.7)	
mRS 3 (moderate disability)	21 (28.0)	
mRS 4 (moderately severe disability)	12 (16.0)	
mRS 5 (severe disability)	01 (1.3)	
mRS 6 (expired)	06 (8)	
Overall mRS outcome		
Good outcome (mRS 0-2)	27 (36.00)	
Poor outcome (mRS 3-6)	40 (64.00)	
Barthel index score	3 month	
	(<i>n</i> =61)	
Total dependency (0–20)	24 (39.34)	
Severe dependency (21–60)	36 (59.02)	
Moderate dependency (61–90)	01 (1.64)	
Slight dependency (91–99)	00 (00.0)	
mRS: Modified Rankin scale		

Table 6: Symptom burden of stroke patients.

Symptoms	Frequency (%) <i>n</i> =75
Pain	25 (33.3)
Constipation	09 (12.0)
Dyspnea	04 (05.3)
Diarrhea	01 (01.3)
Nausea	12 (16.0)
Vomiting	05 (06.7)
Dizziness	07 (09.3)
Insomnia	25 (33.3)
Numbness	13 (17.3)
Fatigue	13 (17.3)
Dysphagia	12 (16.0)
Bedsore	01 (01.3)
<i>n</i> : Number of patients.	

is a significant challenge for the stroke palliative care team. Proper assessment of these is a crucial step in the planning of palliative intervention.

We attempted a QoL assessment using a stroke-specific tool (SIAQ) and a generic tool (WHO-QOL-BREF).^[19] Our data set's WHO-QOL-BREF scores are like other studies in the literature.^[37] Among 44 individuals, WHO-BREF scores showed that 27 (62%) did not report good QoL, and 32 (73%) were found not to be satisfied with their health at a one-month follow-up. The QoL scores in physical health, psychological, and environmental domains showed statistically significant improvement at three-month follow-up. The QoL score for the social relationship domain did not differ significantly compared to the baseline measurement. The trend for an improvement in QoL scores in stroke

survivors is expected.^[38] The previous data show a difference in the degree of improvement across the QoL domains, which is in line with our findings.^[38]

The novel tool, SIAQ, was developed by a team of researchers at our institution, keeping in mind the far-reaching consequences of stroke. SIAQ encompasses eight different domains and is culturally appropriate for the Indian context. The SIAQ scores at one-month and three-month follow-up reflect a poor QoL among stroke survivors in the present study. The QoL judged using SIAQ showed severe affection in 19 (42.22%) out of 45 patients assessed at one month, while 36 patients (80%) showed the same trend at the three-month follow-up. Higher dependency at three months, and low scores on QoL scales, reflect the unmet palliative care needs of stroke patients.

Palliative care is often confused with the end of life care.^[39] According to the WHO, palliative care can be defined as care to improve the QoL and relieve suffering for patients with life-threatening disease(s).[40] Palliative care can be initiated at any stage of the disease. It can address multiple domains such as physical, psychosocial, and spiritual health.^[40] A structured approach to integrating palliative care needs is recommended.^[11] Attempts at integration of palliative care services with oncology care in India and LMIC couniries have been ongoing for quite some time.^[10] As newer advances are being made in stroke imaging and definitive stroke treatment, including vascular interventions, minimal emphasis has been placed on the care and rehabilitation of stroke survivors who are left with a severe disability. Most patients from our study live in rural areas and often belong to lower socioeconomic strata. People from similar Indian and other LMIC settings have limited access to structured rehabilitation and palliative care services. There is accumulating evidence to suggest a growing unmet need of stroke survivors and caregivers.^[41,42] Patients' unmet needs in these various spheres need accurate estimation to facilitate patient-oriented care and optimal utilization of stroke care services. There is a growing recognition of the need to train neurologists in palliative care (Neuropalliative care); this includes integrating and expanding care services to patients with stroke, neuromuscular diseases, parkinsonism, and dementia.^[43-46] Stroke is a leading cause of disability globally, and stroke patients have complex palliative care needs. Integrating palliative care into conventional stroke care can improve QoL for the patients and their families.^[47,48] The data from developing countries show the disparities in the use of palliative care for stroke across different health systems influenced by patients' age, sex, race, religion, and hospital characteristics.^[49] Treating physicians in India and other LMICs, seldom find adequate time to address the suffering and symptom burden of stroke survivors and caregivers due to the higher caseload. There is a need to incorporate assessment of palliative care needs and palliative care service delivery models into routine stroke care in India and other LMICs.

Table 7: Summary of stroke outcomes and palliative care needs at baseline, one month and three months.								
	Baseline (n=75, enrolled)		1month (n=64; 3-died, 8-lost to follow-up)		3 months (n=61; 6-died, 8-lost to follow-up)		Paired 't' test for baseline vs 1 months (p value)	Paired 't' test for baseline vs 3 months (p value)
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	n=64	n=61
Canadian neurological scale ^ſ	8.14 (2.01)	8.5 (7-10)	-	-	5.21 (1.26)	5 (4.5-6)	< 0.001	< 0.001
SIAQ	37.02 (13.21)	38 (27-47.5)	19.87 (4.84)	19 (16-23)	23.8 (4.91)	23 (20-27)	< 0.001	< 0.001
NIHSS scale [∫]	10.89 (5.78)	10 (6-15)	-	-	5.69 (4.27)	5 (2-8)	< 0.001	< 0.001
Barthel index∫	38.12 (21.13)	35 (20-55)	-	-	27.13 (10.55)	25 (20-30)	0.09	< 0.001
Modified Rankin scale ⁽	4 (1)	4 (3-5)	-	-	3 (1.4)	3 (2-4)	< 0.001	<0.001 (n=67)
GAD-7 score*	4.06 (3.44)	3 (2-6)	3.46 (2.41)	3 (2-5)	2.8 (1.97)	3 (1-5)	NA	0.005 ^{\$}
PHQ-9 score**	3.06 (2.93)	2 (1-4)	5.58 (5.04)	5 (2-7)	2.87 (2.47)	2 (1-5)	NA	0.51 ^{\$}
WHO BREF								
Physical health Domain	48 (12.44)	50	59.84 (8.24)	63	74.54 (11.53)	75	< 0.001	< 0.001
Psychological Domain	49.66 (12.93)	50	63.23 (9.68)	63	77.89 (11.77)	81	< 0.001	< 0.001
Social relationships Domain	47.64 (19.60)	50	54.51 (12.74)	53	53.5 (15.44)	50	0.07	0.06
Environment Domain	59.06 (12.61)	63	63.89 (10.95)	63	65.20 (10.21)	63	0.06	0.01

*missing in 26 subjects at baseline, 30 subjects at 1m follow up, 30 subjects at 3m follow up, **missing in 25 subjects at baseline, 30 subjects at 1m follow up, 32 subjects at 3m follow up∫missing in 14 subjects at 3 months follow up, \$ n=41 subjects. SD: Standard deviation, IQR: Interquartile range, SIAQ: Stroke Impact Assessment Questionnnaire, NIHSS-National Institute Of Health Stroke Scale, GAD: Generalised Anxiety Disorder, PHQ-Physical Health Questionnaire, ∫: missing in 14 subjects at 3 months follow up, NA: Not assessed because of missing data

Reaching this goal will require some innovative strategies and partnerships. We hope that an emphasis on assessing various domains of QoL to assess palliative care needs will address the SHS of stroke survivors and their caregivers.

This study's strengths include the prospective nature of the study, assessing multiple domains of palliative care needs, and the use of validated and local language (Malayalam) translated versions of the scales (GAD-7, PHQ-9, and WHO-QOL-BREF). The limitation of the study includes the loss to follow up of patients for three months outcome, given their rural residence and the disabling nature of the stroke. The missing three-month outcome data were due to the patients' reluctance to provide the information over the phone. The COVID-19 pandemic also hampered the follow-up data collection. The lack of caregiver burden data prevents a holistic picture of the patient and the family. We also could not obtain the correct proportion of individuals who could resume their vocation. Finally, only patients receiving thrombolysis were admitted to the neurology unit, from where patients were recruited into the study. This makes our cohort unrepresentative of all stroke types. In addition, there is limited literature from India and other LMIC countries in this area.^[14] The specific region of South India where this study has been conducted has an average annual household income of just above rupees 2 lakhs per year as per official government data (which meets the middle income criteria of the World Health Organization). This is above the national average household income. Hence, other underdeveloped regions of the country are likely to have even more unmet needs among stroke survivors.

Future studies should further explore the palliative care needs of stroke patients in India and other LMICs. Future studies focusing on interventions aimed at addressing the palliative care needs of stroke survivors would be helpful. A holistic assessment of stroke survivors, using PROMs, can help identify QOL's impact beyond motor disability in various domains. The information obtained can be used to plan palliative care and stroke rehabilitation services in a structured manner and help plan further studies.

None of the authors report conflicts of interest.

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CONCLUSION

There is a significant burden of unmet palliative care needs in various domains among stroke survivors. It is pivotal that stroke care providers strive to address these needs to ensure better quality of life.

Ethical approval

The research/study approved by the Institutional Review Board at Government Medical College, Thiruvananthapuram, number HEC No.08/17/2019/MCT, dated September 03, 2019.

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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