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Knowledge, attitude, and practice towards neonatal palliative care of medical and nursing staff in an Indian context: A web-based survey

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ABSTRACT

Objectives: Neonatal palliative care (NPC) is a holistic and interdisciplinary approach towards newborns with life-limiting conditions and encompasses their physical, psychosocial, and spiritual care and the redressal of pain. This study was designed to determine the knowledge, attitude, and practices towards NPC by the medical and nursing staff involved in neonatal care.

Material and Methods: It was a questionnaire-based prospective cross-sectional study done at a tertiary care hospital in India by collecting data using the Neonatal Palliative Care Attitude Scale (NiPCAS) survey which has 26 attitudinal questions on a Likert scale.

Results: There were 87 participants including 58 doctors (66.7%) and 29 (33.3%) nurses. Almost all of the respondents agreed that palliative care was necessary in neonatal nursing and medical education; but less than half had received education for the same. There was an overall agreement in the organization, resources, and clinician subscale by both medical and nursing respondents.

Conclusion: There were similarities and differences in perceptions of NPC between medical and nursing staff. Several facilitators and barriers of NPC were identified. Efforts should be taken to strengthen facilitators while simultaneously mitigating barriers.

Keywords: Neonatal palliative care, NiPCAS survey, Pain management, Web-based survey, Life-limiting conditions

INTRODUCTION

European Association for Palliative Care (EAPC) defines palliative care as the care of a patient whose disease is not responsive to curative treatment.^[1] Catlin and Carter defined neonatal palliative care (NPC) as the holistic and extensive care of a neonate who is not going to recover.^[2] It is a comprehensive perspective incorporating physical, psychosocial, and spiritual care and pain alleviation by multidisciplinary care in hospitals, hospice, and communities.^[3] NPC involves prevention of pain, family support, and involvement of family in decision-making.^[4]

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and should be considered in cases where the benefits of active treatment are insignificant or negligible. Advances in the field of neonatology have led to an increasing survival of neonates with critical and incurable diseases of which some may warrant palliation. Despite the imperative role of palliative care in neonates, there is a paucity of guidelines for its implementation. Haug *et al.* found that nearly half of neonatal intensive care unit (NICUs) in the United States did not have NPC guidelines.^[5]

A family-centered integrative model of care promotes family bonding while actively supporting, educating and entitling the family to act as their child's proponent. This collaborative approach helps in the bereavement process, while minimizing futile invasive interventions and meeting the evolving biopsychosocial needs of the patient and their families. Palliation has not been consolidated into medical and nursing education and training and enhanced efforts should be taken to promote an interdisciplinary approach to end-of-life decision-making.^[6]

Neonatal deaths account for one-third of all childhood mortality with prematurity and congenital malformations being common causes.^[7] It is estimated that approximately 18% of all infants are admitted in the NICU due to a life-threatening condition.^[8] American Academy of Pediatrics upholds the initiation of palliative care and its incorporation over the course of disease to improve quality of life and to facilitate informed decision making.^[9]

Despite these recommendations, there are inconsistencies in the delivery of NPC.^[10-12] Cortezzo *et al.* found that end-of-life practice was variable among various NICUs,^[10] with low provision of palliative care services even in institutions with established NPC standards.^[11]

The Neonatal Palliative Care Attitude Scale (NiPCAS) survey was developed to assess institutional and individual barriers and facilitators of palliative care.^[12] Facilitators were as follows: support for NPC by medical professionals; the ability to express opinions and beliefs; counseling and support for newborn's family; and guidelines to support practice.^[12] Barriers identified were inadequate staff; a physical environment not conducive to palliative care; and technological imperatives and parental demands.^[12] The NiPCAS survey has also been done on neonatal nurses in the United States,^[13] Taiwan,^[14] and Iran^[15] with similar findings to the original study. Kyc *et al.* used NiPCAS survey to compare palliative care perceptions of both doctors and nurses and it has been found to be appropriate to use for a broader population of caregivers.^[16]

A survey of pediatric critical care professionals revealed that physicians were less comfortable with palliation, communication, and pain relief practices than nurses; although there was no difference in the psychosocial aspects of palliative care.^[17] In another study, both doctors and nurses felt an absence of societal support for palliative care; even though nurses reported greater impediments at the system level.^[18]

A multidisciplinary and combined effort is required to effectuate NPC. To the best of our knowledge, use of NiPCAS to compare palliative care perceptions of both medical providers and nurses in low- and middle-income countries (LMICs) has not been previously studied.

This study was conducted to determine the knowledge, attitude, and practices of NPC by the medical and nursing staff involved in neonatal care through a web based survey.

MATERIAL AND METHODS

We conducted a questionnaire-based prospective cross-sectional study over a duration of 1 month by collecting data from the NiPCAS survey. All medical personnel (attending physicians, Faculty, pediatric junior and senior residents, registered nurses and nursing students) working in the Department of Pediatrics and involved in Neonatal care were invited to complete the survey which was distributed electronically; with the online version being hosted and stored on Google forms. The survey was conducted over a 1-month period in January 2023.

The NiPCAS survey includes 26 statements on a Likert scale with the response coding being- strongly disagree = 1, somewhat disagree = 2, unsure (neutral) = 3, somewhat agree = 4, and strongly agree = 5. Kain *et al.* had used exploratory factor analysis to identify subscales of the instrument: organization, resources, and clinician, which we also calculated for our study.^[12] The content of the NiPCAS survey was assessed by our organization's NPC committee.

Ethics approval

Institutional Review Board approval was not obtained because the study was an audit conducted to understand the lacunae in knowledge, attitude, and practices of healthcare professionals so as to improve NPC delivery at our institution. Moreover, no personal information was collected from the participants in this survey. Participants took part in the survey at their discretion and anonymously after agreeing to the questionnaire-indicated consent.

Statistical analysis

The Statistical Package for the Social Sciences (SPSS) software was used for computing statistics. Continuous variables with normal distribution were analyzed by two sample *t*-test; whereas Fisher exact test was used for categorical data. P < 0.05 was considered statistically significant.

Various measures were taken to alleviate bias in the survey design and responses. To reduce non-response bias, we made the survey anonymous, sent reminder emails to those who had not responded and allowed the respondents have enough time to complete the survey. To mitigate acquiescence bias, no leading questions were used in the survey and we allowed the respondents enough time to answer the survey. To eliminate primacy bias, recency bias and end aversion, we randomized the order of options and scales presented in the answers. To reduce conformity bias, we made the survey anonymous. We avoided questionnaire flaws such as inappropriate wording, missing data, or improper formatting.

RESULTS

Of the 93 neonatal medical and nursing staff invited, 87 participants took part in the survey, amounting to a response rate of 93.5%. Fifty eight participants were doctors (66.7%) and 29 (33.3%) were nurses, among whom 49 doctors (56.3% of the study population) were undergoing training as junior and senior residents and 9 (10.3%) respondents were consultant pediatricians (faculty). Amongst the nursing staff, 24 (27.6%) were nursing graduates and 5 (5.75%) were nursing students. Around 42.28% had a work experience of less than 1 year, 26.02% had an experience of 1 to 4 years, 4.88% had an experience of 5 to 10 years, while 26.83% had worked for more than 10 years. Nearly a fourth of the respondents had an experience of more than 10 years in their current role. Table 1 demonstrates the demographic characteristics of respondents.

Most respondents agreed to have experience with NPC, with nursing staff having more experience as compared to medical staff taking care of dying neonates (P = 0.195). Almost all of the respondents agreed that palliative care was necessary in neonatal nursing and medical education; but less than half had received education for the same. Table 2 shows the survey questions and their responses.

Organization subscale

The organization subscale measured the effect of the institution on the delivery of palliative care. There was an overall agreement in this subscale by both medical and nursing respondents (medical mean score 3.74 [0.91], nursing mean score 3.35 [1.09], and P = 0.079). Individual questions in this subscale were associated with parental involvement in decision-making, support of palliative care by staff, and ability of team members to express opinions. Table 3 demonstrates the organizational subscale.

Resources subscale

The resources subscale measured resource related issues such as staffing, physical environment of the unit, policies and guidelines, counseling, and availability of time to spend with the families. The mean score for all questions in this subscale

Table 1: Demographic characteristics.	
Variable	Frequency % (n)
Current role	
Faculty	10.34 (9)
Senior resident	8.04 (7)
Junior resident	48.28 (42)
Staff nurse	27.59 (24)
Nursing student	5.75 (5)
Years in current role	
<1 year	42.28 (52)
1–4 years	26.02 (32)
5–10 years	4.88 (6)
>10 years	26.83 (33)
<i>n</i> : Number	

was similar in the medical and nursing groups (medical mean score 3.34 [0.91], nursing mean score 3.25 [1.03], and P < 0.676]), suggestive of agreement between medical and nursing personnel. Table 4 demonstrates the resources subscale.

Clinician subscale

The clinician subscale assessed ethics, aptitude and skill, including parental demands and technological imperatives. The majority of all respondents agreed that staff are asked by parents to continue life-extending care beyond what they feel is right and that staff go beyond their comfort zone in using technological life support (total mean score 2.72 [0.87]). Table 5 demonstrates the clinician subscale.

Four facilitators and six barriers to NPC were found.

Facilitators to NPC

The findings from this study highlight four facilitators to NPC: (1) medical and nursing team's support of palliative care, (2) availability of counseling, (3) integration of palliative care in medical and nursing education, and (4) parental informed consent and decision-making. Facilitators were designated as those survey elements that had an overwhelmingly positive responses by the participants (mean score > 3.75).

Both doctors and nurses agreed that the health care team supports NPC (total mean score 3.59 [1.02]) and that palliative care is supported by medical and nursing practice (total mean score 3.71 [0.75]). While both groups agreed that palliative care is as important as curative care, doctors' level of agreement (mean score 3.93 [0.78]) was significantly higher than nurses' level of agreement (mean score 3.43 [0.89]) (P = 0.0082).

Both medical and nursing staff agreed that parents are involved in decision-making, although, medical staff's level of agreement (mean score 3.46 [1.04]) was greater than those of nurses. (mean score 3.03 [1.25]) (P = 0.091). In a prior study, Wool had found that physicians felt more confident in their ability

NiPCAS item	n	A	Medical (n=57)		Z	Nursing (n=30)		P
		Strongly/ somewhat disagree, n (%)	Strongly/ somewhat agree, n (%)	Unsure, n (%)	Strongly/ somewhat disagree, n (%)	Strongly/ somewhat agree, n (%)	Unsure, n (%)	
1. Mean (SD)	In my unit, when a diagnosis with a likely poor outcome is made, parents are informed of	5 (8.77%)	40 (70.18%) 3.86 (0.89)	12 (21.05%)	5 (16.67%)	18 (60%) 3.5 (0.97)	7 (23.33%)	0.0858
	palliative care options The medical staff support palliative care for dying	8 (14.04%)	43 (75.44%)	6~(10.53%)	5 (16.67%)	18 (60%)	7 (23.33%)	0.2224
Mean (SU) 3.	babtes in my unit In my unit the team expresses its opinions, values,	4 (7.02%)	3.68 (1.03) 43 (75.44%)	10 (17.44%)	9 (30%)	3.4 (0.97) 18 (60%)	3(10%)	0.0047
lean (SD)	and beliefs about providing care to dying babies		3.89 (0.88)	10 (01 DE0/)	(7007) C1	3.23 (1.22)	(7001) 6	
4. Mean (SD)	in my unit, parents are involved in decisions about their dying baby	(0% CO.17) 71	3.46 (1.03)	(0% CN.17) 71	12 (40%)	(0705) C1 3.03 (1.25)	(0/01) C	CK0N.N
5. Mean (SD)	There is enough assistance from peers to provide the needs of dying babies requiring palliative care	12 (21.05%)	30 (52.63%) 3.35 (0.92)	15 (26.32%)	8 (26.67%)	20 (66.67%) 3.4 (1.00)	2 (6.67%)	0.816
	and their families							
6. Mean (SD)	All members of the health care team in my unit agree with and support palliative care when it is	2(3.51%)	44 (77.19%) 3.79 (0.59)	11 (19.3%)	5(16.67%)	20 (66.67%) 3.57 (0.97)	5 (16.67%)	0.1921
~	implemented for a dying baby		~			~		
	The physical environment of my unit is ideal for	8~(14.04%)	29 (50.88%)	20 (35.09%)	6 (20%)	16 (53.33%)	8 (26.67%)	0.4053
Mean (SD)	providing palliative care to dying babies		3.44(0.82)			3.27~(1.04)		
(U3) ===	There are policies/guidelines to assist in the	15 (26.32%)	23 (40.35%) 2 10 (0 82)	19(33.33%)	10(33.33%)	17 (56.67%)	3(10%)	0.962
9.	When a baby dies in my unit, counseling is	11 (19.3%)	38 (66.67%)	8 (14.04%)	2 (6.67%)	22 (73.33%)	6 (20%)	0.588
Mean (SD)	available if I need it		3.56 (0.96)			3.67 (0.76)		
.01	When a baby dies in my unit, I have sufficient	15 (26.32%)	24 (42.11%)	18 (31.58%)	5 (16.67%)	18~(60%)	7 (23.33%)	0.173
Mean (SD)	time to spend with the family		3.18 (0.96)			2.87 (1.07)		
11. Moon (CD)	I have had the experience of providing palliative	16 (28.07%)	26 (45.61%) 2 25 (1.01)	15(26.32%)	3 (10%)	19 (63.33%) 2 E2 (0 01)	8 (26.67%)	0.1946
мсан (че) про 12.	date to uping babies and men fammes My previous experiences of providing palliative	12 (21.05%)	23 (40.35%)	22 (38.6%)	5 (16.67%)	14 (46.67%)	11 (36.67%)	1.0000
Mean (SD)	care to dying babies have been rewarding		3.23 (0.89)			3.23 (0.89)		
	I am often exposed to death in the neonatal	8(14.04%)	33 (57.89%)	16 (28.07%)	5 (16.67%)	20 (66.67%)	5(16.67%)	0.5394
Mean (SD)	environment		3.67 (0.99)			3.53(1.04)		
	I have received in-service education that assists	18 (31.58%)	25 (43.86%)	14 (24.56%)	11 (36.67%)	13(43.33%)	6 (20%)	0.6547
Mean (SD)	me to support and communicate with parents of dving habies		3.21(1.10)			3.1(1.06)		
15.	Palliative care is against the values of neonatal	37 (64.91%)	3 (5.26%)	17 (29.82%)	20 (66.67%)	6 (20%)	4(13.33%)	0.5843
Mean (SD)	nursing and neonatology practice		3.79 (0.88)			3.67 (1.12)		
16.	My personal attitudes about death affects my	22 (38.6%)	17 (29.82%)	18 (31.58%)	12(40%)	12 (40%)	6 (20%)	0.9650
Mean (SD)	willingness to deliver palliative care		3.12(0.95)			3.13(1.11)		
17. Maan (CD)	I feel a sense of personal failure when a baby dies	8~(14.04%)	38 (66.67%) 2 30 (0 84)	11 (19.3%)	10 (33.33%)	15 (50%) 2 87 (0 97)	5 (16.67%)	0.0186

Table 2: (Continued).	itimued).							
NiPCAS item	U	M	Medical (<i>n</i> =57)		Ż	Nursing (n=30)		Ρ
		Strongly/ somewhat disagree, n (%)	Strongly/ somewhat agree, n (%)	Unsure, n (%)	Strongly/ somewhat disagree, n (%)	Strongly/ somewhat agree, n (%)	Unsure, n (%)	
18. Mean (SD)	Curative care is more important than palliative care in the neonatal unit	17 (29.82%)	31 (54.39%) 2 7 (1 07)	9 (15.79%)	10 (33.33%)	13 (43.33%) 2 77 (1 25)	7 (23.33%)	0.7851
19. Mean (SD)	In my unit, the staff go beyond what they feel comfortable with in using technological life	11 (19.3%)	31 (54.39%) 2.63 (0.82)	15 (26.32%)	5 (16.67%)	2.57 (0.89)	7 (23.33%)	0.7536
20.	support In my unit, staff are asked by parents to continue	18 (31.58%)	24 (42.11%)	15 (26.32%)	8 (26.67%)	15 (50%)	7 (23.33%)	0.6562
Mean (SD)	life-extending care beyond what they feel is right	~	2.86 (0.91)	~	~	2.77 (0.86)	~	
21.	Palliative care is necessary in neonatal nursing and	1(1.75%)	51 (89.47%)	5 (8.77%)	4(13.3%)	23 (76.67%)	3 (10%)	<0.0001
Mean (SD)	medical education		4.67(0.68)			3.8 (0.99)		
22.	When babies are dying in my unit, providing pain	8(14.04%)	39 (68.42%)	10(17.54%)	12(40%)	$14 \ (46.67\%)$	4(13.33%)	0.0191
Mean (SD)	relief is a priority for me		2.35 (0.86)			2.87 (1.14)		
23.	Palliative care is as important as curative care in	4 (7.02%)	46 (80.7%)	7 (12.28%)	6 (20%)	17 (56.67%)	7 (23.33%)	0.0082
Mean (SD)	the neonatal environment		3.93 (0.78)			3.43(0.89)		
24.	There is support for neonatal palliative care in	27 (47.37%)	22 (38.6%)	8(14.04%)	9 (30%)	14 (46.67%)	7 (23.33%)	0.2713
Mean (SD)	society		2.88 (0.98)			3.13(1.04)		
25.	Caring for dying babies is traumatic for me	18(31.58%)	23(40.35%)	16(28.07%)	7 (23.33%)	15(50%)	8 (26.67%)	0.2841
Mean (SD)			2.91 (1.02)			2.67 (0.92)		
26.	There is a belief in society that babies should not	11(19.3%)	38 (66.67%)	8(14.04%)	4(13.33%)	19 (63.33%)	7 (23.33%)	0.5197
Mean (SD)	die, under any circumstances		3.53(0.98)			3.67 (0.92)		
NiPCAS: Neor	NiPCAS: Neonatal palliative care attitude scale, SD: Standard deviation, the l	deviation, the bold values are statistically significant $(P<0.05)$	ically significant (P	<0.05)				

Table 3: Organization subscale comparison.				
NiPCAS item	Medical mean score (SD)	Nursing mean score (SD)	All respondents mean score (SD)	Р
In my unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options	3.86 (0.89)	3.5 (0.97)	3.74 (0.93)	0.086
The medical staff support palliative care for dying babies in my unit	3.68 (1.04)	3.4 (0.97)	3.59 (1.02)	0.226
In my unit the team expresses its opinions, values, and beliefs about providing care to dying babies	3.89 (0.88)	3.23 (1.22)	3.67 (1.05)	0.0047
In my unit, parents are involved in decisions about their dying baby	3.46 (1.04)	3.03 (1.25)	3.31 (1.12)	0.091
All members of the health care team in my unit agree with and support palliative care when it is implemented for a dying baby	3.79 (0.59)	3.57 (0.97)	3.71 (0.75)	0.192
Average organization subscale	3.74 (0.91)	3.35 (1.09)	3.60 (0.99)	0.079
NiPCAS: Neonatal palliative care attitude scale, SD: Standard deviation				

Table 4: Resources subscale comparison.				
NiPCAS item	Medical mean score (SD)	Nursing mean score (SD)	All respondents mean score (SD)	Р
There is enough assistance from peers to provide the needs of dying babies requiring palliative care and their families	3.35 (0.92)	3.4 (1.00)	3.37 (0.94)	0.816
The physical environment of my unit is ideal for providing palliative care to dying babies	3.44 (0.82)	3.27 (1.05)	3.38 (0.91)	0.407
There are policies/guidelines to assist in the delivery of palliative care in my unit	3.19 (0.83)	3.2 (1.10)	3.20 (0.93)	0.962
When a baby dies in my unit, counseling is available if I need it	3.56 (0.96)	3.67 (0.76)	3.60 (0.90)	0.588
When a baby dies in my unit, I have sufficient time to spend with the family	3.18 (0.97)	2.87 (1.07)	3.07 (1.01)	0.175
Average resources subscale	3.34 (0.91)	3.25 (1.03)	3.32 (0.95)	0.676
NiPCAS: Neonatal palliative care attitude scale, SD: Standard deviation				

Table 5: Clinician subscale comparison.				
NiPCAS item	Medical mean score (SD)	Nursing mean score (SD)	All respondents mean score (SD)	Р
In my unit, the staff go beyond what they feel comfortable with in using technological life support	2.63 (0.82)	2.57 (0.89)	2.61 (0.84)	0.754
In my unit, staff are asked by parents to continue life-extending care beyond what they feel is right	2.86 (0.91)	2.77 (0.86)	2.83 (0.89)	0.656
Average clinician subscale	2.75 (0.87)	2.67 (0.88)	2.72 (0.87)	0.686
NiPCAS: Neonatal palliative care attitude scale, SD: Standard d	eviation			

to counsel parents than nurses, perhaps leading to the medical staff having an increased perception of parental involvement.^[18]

DISCUSSION

A study from Ethiopia indicated that there was a low level of knowledge of palliative care among nurses, thereby necessitating education and training in this aspect.^[19] In our study, both groups strongly agreed about the necessity of NPC education, although the level of agreement of doctors (mean score 4.67 [0.68]) was significantly more than that of the nurses (3.8 [0.99]) P < 0.0001. Fischer *et al.* found that anxiety levels were higher in pediatric residents with

suboptimal knowledge about palliative care.^[20] More doctors (mean score 3.21 [1.1]) reported having received education on palliative care than nursing staff (mean score 3.1 [1.06]) (P = 0.655). Both medical and nursing staff agreed that the physical environment of the NICU was ideal for providing palliative care (total mean score 3.38 [0.91]).

Pain management is a part of comfort care for critical babies and should be addressed. In our study, both groups weakly agreed that pain relief is a priority for dying neonates, although doctors prioritized pain relief more than nurses (P = 0.019). This finding is similar to the study by Kyc *et al.*^[16] and may be due to the differences between nursing and medical working culture.

Barriers to NPC

The findings from this study highlight six barriers to NPC: (1) parental demands to continue life-extending care, (2) belief that curative care is more important than palliative care, (3) comfort level of staff in stopping technological life support, (4) provision of pain relief in dying babies, (5) traumatic experience in caring for dying babies, and (6) the societal belief that babies should not die. Survey components with a predominant negative response by the participants were pronounced as barriers (mean score <3).

Both groups agreed that there is parental pressure to continue life-extending care beyond what staff feel is right (total mean score 2.83 [0.89]) and that staff go beyond their comfort level in using technological life support (total mean score 2.61 [0.84]). Medical and nursing staff agreed that there is a social sentiment that babies should not die, thereby reflecting a lack of societal support for NPC.

Differences between medical and nursing staffs' attitudes

Around 80.7% of the medical staff considered palliative care to be as important as curative care, while only 56.7% of the nursing staff believed so (P = 0.0082). Medical staff had comparatively more negative perceptions regarding multiple resource-related items: assistance from peers (P = 0.816), availability of counseling (P = 0.588), and ability to spend time with families of dying neonates (P = 0.173). Both medical and nursing staff agreed regarding the existence of NPC policies or guidelines (P = 0.962).

Peng *et al.*, reported higher level of confidence amongst neonatologists working in a more supportive workplace.^[21] Psychosocial support is recommended for healthcare workers who provide palliative care; however, Haug *et al.* found that 39% of NICUs did not address physician compassion fatigue or burnout secondary to palliative care.^[5]

An integrative approach can help provide quality palliative care and support bereavement process of families, minimizing futile invasive interventions.^[22]

The strength of this study is that it is the first to utilize a validated survey to compare perceptions about NPC between medical and nursing staff in LMICs. In addition, the response rate was good. The limitations of this study are the small sample size and the limitation to a single center. The survey instrument in our study was closed-ended, which limited participants' opportunity to express their opinions that were different from the options we provided.

CONCLUSION

We identified potential facilitators and barriers for the provision of NPC. Efforts should be taken to strengthen facilitators, while simultaneously mitigating barriers. Health personnels and parents can collaborate on the goals of palliative care in each individual case. Perceptions of NPC between medical and nursing personnels are both identical and divergent.

Palliative care education is a necessity; education of staff could reinforce support of palliative care. Recommendations for future research would be to compare medical and nursing staff's perceptions about NPC from multiple institutions and to study the effects of an educational intervention on the delivery of NPC.

Ethical approval

Institutional Review Board approval is not required.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Nil.

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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