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Latent Profile Analysis of the Uncertainty Experienced among Parents of Children with Central Nervous System Tumors: A Cross-Sectional Study

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Abstract

Objective: The study aims to identify and characterize the latent categories of illness uncertainty among parents of children diagnosed with central nervous system tumors, examine the influencing factors, and propose targeted nursing strategies. **Methods:** Conducted as a cross-sectional study, this research utilized convenience sampling to recruit parents of children undergoing treatment for central nervous system tumors at a tertiary hospital in Guangzhou between October 2023 and July 2024. Data collection involved a general information questionnaire, the Illness Uncertainty Scale, the Self-Rating Anxiety Scale, and the Self-Rating Depression Scale. Latent profile analysis was employed to determine the potential categories of illness uncertainty, while binary logistic regression analysis was used to assess the influencing factors. **Results:** The study included 108 parents, whose illness uncertainty was categorized into two distinct groups: "Information Acceptance Group" (n = 66, 61.1%) and "Cognitive Deficiency Group" (n = 42, 38.9%). The binary logistic regression analysis identified the gender and anxiety level of the parents as significant influencing factors in the categorization of illness uncertainty. **Conclusion:** The study reveals distinct categorical characteristics of illness uncertainty among parents of children with central nervous system tumors. It is recommended that nursing professionals implement gender-specific psychological interventions, provide informational support, and employ positive reinforcement strategies to mitigate parental anxiety, reduce illness uncertainty, and enhance the overall quality of pediatric care.

Keywords

Central Nervous System Tumors, Pediatric, Parental, Illness Uncertainty, Latent Profile Analysis, Influencing Factors Analysis, Psychological Nursing, Oncology Nursing

1. Introduction

Central nervous system (CNS) tumors represent the most prevalent form of solid tumors in children, originating from tissues or structures within the CNS [1]. In China, the incidence of CNS tumors in children ranges from 21 to 25.9 per million, constituting about 25% of all pediatric solid tumors [2], and they are the principal cause of death among children with malignant tumors [3]. Parents, as the primary caregivers of these children, endure tremendous pressure due to the severe trauma CNS tumors inflict, which can result in cognitive and emotional disorders and a decline in physical function in affected children [4]. Insufficient understanding of the disease, unpredictability of treatment outcomes, and concerns about recurrence contribute to a heightened sense of illness uncertainty among parents. Illness uncertainty [5] is a cognitive state that occurs when individuals lack sufficient information to appropriately manage disease-related issues. The Transactional Model of Stress and Coping is a theoretical framework proposed by psychologists Richard Lazarus and Susan Folkman in 1984 [6]. The core of this model lies in emphasizing the dynamic interaction between individuals and the environment. When parents are burdened by illness uncertainty, It holds that stress is not simply triggered by external events, but stems from the interactive process between individuals' Cognitive Appraisal of events and Coping Strategies. Illness uncertainty can increase their psychological stress and impede their ability to provide adequate support to their children, thereby affecting the quality of care [7]. While significant research has been conducted internationally and domestically on illness uncertainty [8] [9], most studies focus on cancer patients themselves, with limited attention given to caregivers, especially parents of children with CNS tumors. Current research often relies on overall scores of illness uncertainty to determine its level, overlooking the heterogeneity among different characteristic groups. Latent profile analysis is a widely employed method for examining qualitative differences in individual psychology [10]. This study applies latent profile analysis to assess illness uncertainty levels among parents of children with CNS tumors, estimating the likelihood of parents belonging to various group types. This approach aims to enhance clinical interventions tailored to each parent type, providing a reference for reducing illness uncertainty and improving care quality within this population.

2. Subjects and Methods

2.1. Study Participants

This cross-sectional study employed a convenience sampling approach to recruit parents of children diagnosed with central nervous system (CNS) tumors, who met the inclusion criteria, from a tertiary hospital in Guangzhou, Guangdong Province, between October 2023 and July 2024. The inclusion criteria for patients were: ① Age of 14 years or younger; ② Diagnosis of CNS tumor confirmed by histopathological examination [2]. Exclusion criteria included: ① Being in a critical condition; ② Currently undergoing emergency medical treatment. The inclusion criteria for the parents were: ① The father or mother primarily responsible for the child's care; ② Willingness to participate in the survey study. Exclusion criteria for parents were: ① Inability to complete the questionnaire; ② A history of mental illness.

The sample size was calculated based on the principle that in regression analysis, the sample size should be at least 5 to 10 times the number of independent variables [11]. To account for potential invalid samples, the sample size was increased by 10%. With 14 independent variables included in this study, the required sample size was between 70 and 140 parents. To ensure the accuracy and statistical power of the model, a minimum of 100 participants was necessary. Ultimately, 108 participants were included in the study. The study received approval from the hospital's ethics committee (B2024-133-01). All study participants were recruited from tertiary grade-A hospitals in Guang Zhou. The researchers explained the purpose, significance, and contents of the research to parents, selected participants in accordance with the selection criteria, and administered an anonymous paper questionnaire to the participants. Researchers collected questionnaires face-to-face on the spot, and participants needed to complete them within 15 minutes. The questionnaire was prepared in accordance with standard guidelines and promised confidentiality of all research data. After collecting the questionnaires, invalid questionnaires were discarded. The elimination criteria were as follows: a) incomplete questionnaires, b) questionnaires showing apparent patterns in the responses, or c) questionnaires in which all answers were the same. Among the 108 questionnaires collected, all 108 were valid, yielding an effective response rate of 100%.

2.2. Survey Instruments

2.2.1. General Demographic Information Questionnaire

In this study, a general demographic information questionnaire was designed following a review of pertinent literature. The data to be gathered primarily include: the gender, age, occupation, and marital status of the parents of children diagnosed with central nervous system tumors; whether the child is an only child; the family's place of residence; educational attainment; monthly household income; method of payment for medical expenses; and religious beliefs.

2.2.2. Parents' Perception of Uncertainty in Illness Scale

The original English version was developed by Mishel [12] in 1983, encompassing four dimensions: disease status uncertainty, information ambiguity, information deficiency, and unpredictability, comprising a total of 31 items. A higher score indicates a greater level of perceived illness uncertainty among the parents. The original 31 items may cause respondent fatigue and increase the risk of invalid responses. The Chinese version of the PPUS, revised by Ye Zengjie [13], retains 14 items. The 14 versions are more in line with clinical feasibility requirements and the Chinese population. Exploratory Factor Analysis (EFA) identified two factors, termed "ambiguity" and "lack of communication," with Cronbach's α coefficients for these dimensions being 0.830 and 0.877, respectively.

2.2.3. Self-Assessment Tools for Anxiety and Depression

The Self-Rating Anxiety Scale (SAS) and Self-Rating Depression Scale (SDS) each consist of 20 items [14], evaluated using a 4-point Likert scale. Each item is scored from 1 to 4: 1. for rarely, 2. for sometimes, 3. for most of the time, and 4. for almost always. The sum of scores across all 20 items constitutes the raw score, which is then converted to a standard score (Y) by multiplying by 1.25 and rounding to the nearest whole number. A score of 50 or above suggests a tendency towards anxiety or depression, with higher scores indicating a more pronounced tendency. Scores ranging from 50 to 59 suggest mild anxiety or depression, 60 to 69 indicate moderate levels, and scores above 70 signify severe anxiety or depression.

2.3. Data Collection and Quality Assurance

With approval from the hospital's ethics committee, department heads, and head nurses, and following the study's inclusion and exclusion criteria, parental consent was obtained for conducting a questionnaire survey using a convenience sampling method. Researchers communicated the study's purpose and significance to the parents of the children, securing their informed consent. In instances involving privacy concerns, confidentiality assurances were reiterated to ensure respondents of the protection of their information. Researchers employed clear and straightforward language to elucidate the questionnaire's content and completion method to the parents. The completed questionnaires were thoroughly checked for completeness, and researchers assessed the quality of each response. In cases of incomplete or inconsistent answers, participants were asked to provide additional information or to complete the questionnaire again. Disease-related data were gathered by investigators through a review of medical records.

2.4. Statistical Methods

Data entry was performed by two individuals to ensure accuracy, followed by database creation and data entry using Epidata 3.1 software. Statistical analyses were conducted using SPSS 26.0. Descriptive statistics such as frequency, percentage, mean, and standard deviation were employed to summarize general demographic data. For univariate analysis of the potential profiles of parents of affected children, chi-square tests or Fisher's exact tests were used for unordered categorical data; the Kruskal-Wallis H test was applied for ordered categorical data; and analysis of variance was used for continuous data. Binary logistic regression analysis was employed to investigate the factors influencing the potential categories of illness uncertainty among parents of children with central nervous system tumors. A P-value of less than 0.05 was considered indicative of statistical significance.

Latent profile analysis was conducted using Mplus 8.3 software. Starting with a single latent category, the number of categories was incrementally increased, developing models with one to five latent categories until optimal model fit indices were achieved. The model fit indices included [15]: ① Log-likelihood ratio, Akaike information criterion (AIC), Bayesian information criterion (BIC), and sample-size adjusted BIC (aBIC), where smaller AIC and BIC values indicate better model fit; ② Information entropy, ranging from 0 to 1, with values closer to 1 indicating more precise classification, <0.6 indicating more than 20% misclassification, and >0.8 suggesting classification accuracy of 90%; ③ Lo-Mendell-Rubin adjusted likelihood ratio test (LMR) and Bootstrapped likelihood ratio test (BLRT), with a P-value of less than 0.05 suggesting that the k model is superior to the $k - 1$ model.

3. Results

3.1. General Demographic Information of Survey Participants

Table 1. General demographic information of parents of children with central nervous system tumors (n = 108).

Item	n (%)	Item	n (%)
Gender		Education Level	
Male	43 (39.8)	Primary School	7 (6.5)
Female	65 (60.3)	Junior High School	46 (42.6)
Marital Status		High School/Technical Secondary School	29 (26.9)
Married	105 (97.2)	Junior College	12 (11.1)
Divorced	2 (1.9)	Bachelor's Degree or Above	14 (13.0)
Widowed	1 (0.9)		
Religious Belief		Monthly Household Income (RMB)	
Yes	11 (10.2)	<3000	18 (16.7)
No	97 (89.8)	3000 - 5000	32 (29.6)
Only Child		5000 – 10,000	36 (33.3)
Yes	20 (18.5)	>10,000	22 (20.4)
No	88 (81.5)	Payment for Medical Expenses	
Place of Residence		Self-pay	6 (5.6)
Provincial Capital	13 (12.0)	New Rural Cooperative Medical Scheme	63 (58.3)
Other Urban Areas	57 (52.8)	Urban Medical Insurance	37 (34.3)
Rural Areas	38 (35.2)	Commercial Medical Insurance	2 (1.9)

A total of 108 questionnaires were distributed and collected, achieving a 100% effective response rate. The average age of parents of children with central nervous system tumors was 36.5 years (±6.165). Among them, 43 were male (39.8%) and

65 were female (60.3%). There were 20 only children (18.5%) and 88 non-only children (81.5%). In terms of residence, 13 participants (12%) lived in provincial capital cities, 57 (52.8%) in towns, and 38 (35.2%) in rural areas. Regarding educational level, 53 participants (49.1%) had education below junior high school, 29 (26.9%) had a high school education, 12 (11.1%) had a college education, and 14 (13%) had a bachelor's degree or higher. See Table 1.

3.2. Illness Uncertainty among Parents of Pediatric Patients with Central Nervous System Tumors

The total score on the Parent Perception of Uncertainty Scale (PPUS) for parents of children diagnosed with neural tumors is 45.28 ± 8.428, exceeding the established threshold of 42.5. Specifically, the score for the ambiguity dimension is 17.69 ± 3.274, while the score for the lack of communication dimension is 27.68 ± 5.925. Refer to Table 2 for details.

Table 2. Scores and aggregate scores for dimensions of disease uncertainty among parents of children with central nervous system tumors (n = 108).

Item	Possible Score Range	Actual Score Range	Mean Score ($\overline{x} \pm s$)
Ambiguity Dimension	0 - 25	10 - 24	17.69 ± 3.274
Lack of Communication Dimension	0 - 45	11 - 42	27.68 ± 5.925
Total Disease Uncertainty Score	0 - 70	23 - 65	45.28 ± 8.428

3.3. Latent Profile Analysis Results of Illness Uncertainty among Parents of Children with Central Nervous System Tumors

In this study, we conducted a latent profile analysis to assess the illness uncertainty among parents of children diagnosed with central nervous system tumors. We fitted five different latent profile models, with their respective fit indices summarized in Table 3. The analysis revealed that when the model comprised two categories, the LMR and BLRT tests were statistically significant ($P < 0.05$), and the entropy value reached a relatively high level of 0.898. Moreover, both AIC and BIC values showed a significant reduction compared to models with fewer categories. After thoroughly evaluating the fit indices, Model 2 was determined to be the optimal model. This model demonstrated a high probability of correctly classifying parents into each category, ranging from 96.1% to 99.2%.

In Model 2, the average scores for each category on the 14 items of the revised Illness Uncertainty Scale for parents are illustrated in Figure 1. Categories were named based on their average scores. Parents in the first category scored low across both dimensions, suggesting they are more open to receiving information about the illness, which helps them build a better understanding and reduce uncertainty. Thus, this category is termed the "Information Acceptance Group," comprising 66 parents (61.1%). Conversely, parents in the second category scored high on both ambiguity and lack of communication dimensions, indicating insufficient basic knowledge of the disease, vague illness concepts, and inadequate communication with healthcare providers, which hinders effective disease understanding. This category is labeled the "Cognitive Deficiency Group," including 42 parents (38.9%).

Table 3. Fitting indices for the latent profile model of disease uncertainty in parents of pediatric central nervous system tumor patients (n = 108).

Model	AIC	BIC	aBIC	Entropy	LMRT	BLRT	Class Probability
1	4296.817	4344.916	4256.445				1
2	3987.331	4102.669	3966.801	0.898	0.0041	0.0000	0.611/0.389
3	3925.506	4081.070	3897.807	0.880	0.2366	0.0000	0.250/0.333/0.417
4	3880.775	4076.570	3845.912	0.911	0.3020	0.0000	0.204/0.250/0.241/0.305
5	3868.300	4104.327	3826.273	0.929	0.6213	0.0200	0.040/0.166/0.254/0.231/0.309

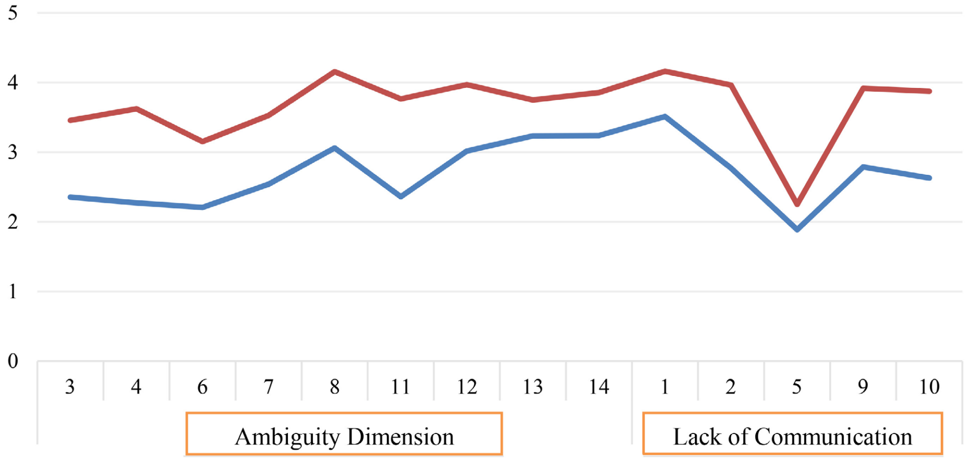

Figure 1. Characteristic distribution of two latent categories of illness uncertainty in parents of children with central nervous system tumors.

3.4. Univariate Analysis of Latent Categories of Illness Uncertainty in Parents of Children with Central Nervous System Tumors

The analysis reveals statistically significant differences ($P < 0.05$) between the two latent categories of illness uncertainty among parents of children with central nervous system tumors, particularly concerning parental gender and anxiety scores. Refer to Table 4.

Table 4. Univariate analysis of latent categories of illness uncertainty in parents of children with central nervous system tumors (n = 108).

Item	Information Reception Group	Cognitive Deficiency Group	Test Statistic	P Value
Age	36.59 ± 5.689	36.38 ± 6.917	0.029$^{1)}$	0.864
Gender				
Male	21 (31.8)	22 (52.4)	4.529$^{2)}$	0.033*
Female	45 (68.2)	20 (47.6)		

Continued

Occupation			8.051 4)	0.210
Worker	14 (21.2)	9 (21.4)		
Farmer	11 (16.7)	3 (7.1)		
Teacher	0 (0)	1 (2.4)		
Businessperson	5 (7.6)	9 (21.4)		
Self-employed	18 (27.3)	12 (28.6)		
None	5 (7.6)	1 (2.4)		
Homemaker	13 (19.7)	7 (16.7)		
Marital Status			0.98 4)	1.000
Married	64 (97.0)	41 (97.6)		
Divorced or Widowed	2 (3.0)	1 (2.4)		
Is Only Child			0.013 2)	1.000
Yes	12 (18.2)	8 (19)		
No	54 (81.8)	34 (81)		
Place of Residence			3.665 2)	0.160
Provincial Capital City	9 (13.6)	4 (9.5)		
Other Urban Areas	30 (45.5)	27 (64.3)		
Rural Areas	27 (40.9)	11 (26.2)		
Education Attainment			4.951 3)	0.407
Primary Education	5 (7.6)	2 (4.8)		
Secondary Education	32 (48.5)	14 (33.3)		
High School/Technical	13 (19.7)	16 (38.1)		
Associate Degree	7 (10.6)	5 (11.9)		
Bachelor's Degree	9 (13.6)	5 (11.9)		
Monthly Income (RMB)			6.751 3)	0.080
<3000	15 (22.7)	3 (7.1)		
3000 - 5000	21 (31.8)	11 (26.2)		
5000 - 10,000	20 (30.30)	16 (38.1)		
>10,000	10 (15.2)	12 (28.6)		
Payment for Medical Expenses			2.994 4)	0.320
Self Financed	2 (3.00)	4 (9.50)		
New Rural Cooperative Medical Scheme	40 (60.60)	23 (54.80)		
Urban Resident Medical Insurance	22 (33.30)	15 (35.70)		
Other	2 (3.00)	0 (0.00)		
Religious Affiliation			1.086 4)	0.297
Yes	9 (13.6)	3 (7.1)		

Continued

No	57 (86.4)	39 (92.9)		
Depression Scale Score	40.9 ± 7.119	41.98 ± 6.851	0.619$^{1)}$	0.433
Anxiety Scale Score	33.5 ± 6.221	37.2 ± 7.124	7.612$^{1)}$	0.007*

1) F value; 2) Chi-square (x≤) value; 3) H value; 4) Fisher's exact probability method. *P < 0.05.

3.5. Multivariate Analysis of Factors Influencing Latent Categories of Illness Uncertainty among Parents of Children with Central Nervous System Tumors

A binary Logistic regression analysis was performed, assigning values of 1 and 2 to the "Information Acceptance Group" and "Cognitive Deficiency Group," respectively. For the independent variables, actual scores from the Self-Rating Anxiety Scale were used, and gender was coded as male = 0 and female = 1. The results of the binary Logistic regression analysis are presented in Table 5.

Table 5. Binary logistic regression analysis of factors influencing latent categories of illness uncertainty among parents of children with central nervous system tumors (n = 108).

	B	SE Value	Wald	OR	95% CI	P Value
Gender (=Reference Category)	0.189	0.223	3.940	1.103	0.787 - 1.731	0.044
Anxiety Scale Score	0.078	0.033	5.531	1.081	1.013 - 1.154	0.019

Note: Beta Coefficient (B); Standard Error (SE); $R^2 = 0.217$.

4. Discussion

4.1. Latent Profile Characteristics of Illness Uncertainty among Parents of Children with Central Nervous System Tumors

This study identifies two categories of illness uncertainty among parents of children with central nervous system tumors: the "Cognitive Deficit Group" and the "Information Reception Group." This indicates individual differences in illness uncertainty among these parents. The analysis is as follows:

The "Cognitive Deficit Group" comprises 42 cases (38.9%), suggesting that nearly half of the parents experience a high level of illness uncertainty, particularly in the ambiguity dimension. This reflects a certain deficiency in the parents' understanding and awareness of the disease and their child's condition. Previous studies have pointed out [16] [17] that the treatment methods for children with central nervous system tumors are complex and varied, and their course and prognosis are influenced by many uncertain factors. Additionally, there is a general lack of relevant disease information among the parents.

Regardless of whether they belong to the "Cognitive Deficit Group" or the "Information Reception Group," both groups scored the lowest on the item "the explanation of the condition by medical staff is easy to understand." This indicates a high level of acceptance among parents regarding medical education, as they can clearly comprehend the knowledge and information conveyed by medical staff.

Therefore, medical staff should communicate promptly with the parents of children with tumors, explain relevant information about disease treatment, and address their queries to reduce their illness uncertainty.

4.2. Analysis of Factors Influencing Potential Categories of Disease Uncertainty among Parents of Children with Central Nervous System Tumors

The study's findings reveal that parental gender significantly influences disease uncertainty. Mothers of affected children are more likely to be categorized into the "information acceptance group," indicating a greater propensity than fathers to assimilate disease-related information. In many domestic contexts, caregiving responsibilities are disproportionately distributed, with mothers shouldering a larger share of family duties and childcare, thereby skewing the caregiving burden towards them [18]. As mothers engage more in caregiving, they tend to have a deeper understanding of their child's condition compared to fathers. Consequently, mothers are often better equipped to accept and comprehend the realities of their child's illness and to facilitate effective communication with healthcare providers. Conversely, the diminished involvement of fathers in the daily life of the ill child exacerbates their sense of disease uncertainty. Therefore, clinical practice should encourage fathers to engage more actively in the treatment and routine care of their children, which can enhance the overall quality of family care and mitigate disease uncertainty.

The findings from this study demonstrate that anxiety acts as a hindrance in alleviating the uncertainty surrounding the illness of parents whose children have central nervous system tumors ($OR = 1.081$, $P < 0.05$). Parents experiencing anxiety are more likely to fall into the "cognitive deficiency group." Previous research [19] has shown that higher anxiety levels in parents of children with tumors correlate with increased levels of disease uncertainty, aligning with our study's findings ($P < 0.01$). Following a tumor diagnosis in their child, parents may encounter negative emotions such as sleep disturbances, anger, compulsions, anxiety, and depression [20] [21]. The anxiety experienced by these parents can impair their caregiving abilities during their child's routine care, which directly impacts their sense of disease uncertainty [22]. Moreover, the anxiety and other negative emotions in parents can intensify the psychological distress and mental stress experienced by the child, potentially affecting the child's prognosis and recovery [23]. A review of the literature [24] [25] indicates that parents of children with neurological tumors generally experience higher levels of uncertainty than those of children with leukemia or lymphoma, with their anxiety and depression reaching moderate to severe levels, meriting attention from healthcare providers.

In light of this, it is suggested that healthcare providers offer informational support, engage parents in discussions to understand their knowledge needs, assist them in acquiring relevant disease knowledge and caregiving skills, and promote interaction among parents from different families. This includes especially enhancing the involvement of fathers in the child's illness to bolster their sense of engagement and progressively improve their caregiving competencies. Medical staff should provide more specific information support related to the condition of the "cognitive impairment group", use positive psychology intervention methods such as mindfulness therapy to reduce parents' anxiety about the disease, conduct more regular communication activities between parents of children, conduct regular follow-ups and distribute home care knowledge. Thereby improving the quality of life of the entire family.

5. Conclusion

Parents of children diagnosed with central nervous system tumors demonstrate clear classification traits related to illness uncertainty. Evaluating the anxiety levels and severity in advance, considering the varying degrees of parental involvement in caregiving, aids healthcare professionals in early identification of the "cognitive deficiency group." It is advisable for healthcare providers to implement tailored psychological interventions, provide informational support, and employ positive reinforcement strategies to effectively alleviate the anxiety experienced by these parents. This approach aims to reduce their uncertainty about the illness and enhance the quality of care they provide.

6. Limitations and Future Directions

This study has certain limitations. Firstly, it is a cross-sectional survey that only examined the characteristics of illness uncertainty among parents of children with central nervous system tumors. Future research could adopt a longitudinal design to dynamically observe changes in parents' illness uncertainty throughout the entire course of the child's illness—from onset to later stages—in order to identify targeted strategies to reduce their uncertainty. In addition, the relatively small sample size may limit the statistical power and the reliability of the identified latent classes. It is hoped that future research can be conducted across multiple regions and centers with a larger sample size.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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