Online First

The European Research Journal 2026 Research Article

DOI: https://doi.org/10.18621/eurj.1251 *Physiotherapy and Rehabilitation*

Mapping Participation in Children with Severe Cerebral Palsy through Structural Equation Modeling

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Abstract:

Objective: Activity and participation restrictions in children with severe cerebral palsy (CP) at Gross Motor Function Classification System (GMFCS) levels IV–V are poorly described, and the influence of parental mental health remains unquantified. This study aims to identify determinants of participation in this group and quantify the contribution of parental depression, anxiety and stress using structural equation modelling (SEM).

Methods: Sixty-nine children with CP (2–18 years; mean 8.81±3.43 years) at GMFCS IV–V and their primary caregivers were recruited from three rehabilitation centres. Child activity measures included gross motor capacity (Gross Motor Function Measure-66), while child participation outcomes were assessed across self-care, mobility, and social function domains using the Pediatric Evaluation of Disability Inventory (PEDI). Body structures/functions were evaluated using the ICF (International Classification of Functioning, Disability and Health) Core Set. Caregivers completed the Depression Anxiety Stress Scale-21. A theoretically driven SEM was evaluated.

Results: The final model (χ^2/df = 1.83, CFI [Comparative Fit Index] = 0.95, RMSEA [Root Mean Square Error of Approximation] = 0.06) explained 71 % of the variance in participation. Participation was predicted by self care ($\beta = 1.41$, $P < 0.001$), mobility ($\beta = 1.55$, $P < 0.001$) and social function ($\beta = 0.82$, $P < 0.01$) and was inversely related to body impairments ($\beta = –0.69$, $P < 0.01$). Parental distress showed a modest but significant direct effect ($\beta = 0.25$, $P = 0.03$) independent of motor capacity.

Conclusion: This is the first study to integrate child function and caregiver psychosocial status within one analytic model for GMFCS IV–V, illuminating an evidence gap. Rehabilitation should couple intensive self care and mobility training with screening and, when necessary, treatment of parental depression, anxiety and stress to maximise participation.

Keywords: Cerebral Palsy, Participation, Gross Motor Function Classification System, Activity, Environmental Factors.

Cerebral Palsy (CP) is a condition characterized by movement and postural disorders resulting from non-progressive damage in the developing brain, leading to activity limitations.[1] Non-progressive brain damage occurs during early childhood, between the ages of 0-2 years.[2,3] According to the Gross Motor Function Classification System (GMFCS), 47.6% of individuals with CP are classified as severely affected.

Submitted: March 13, 2026 **Accepted:** June 23, 2026 **Published Online:** July 18, 2026

How to cite this article: Sel SA, Gürüzmaden G, Balta KM, Cebeci Ş, Eroğlu Ü. Mapping Participation in Children with Severe Cerebral Palsy through Structural Equation Modeling. *Eur Res J.* 2026. doi: 10.18621/eurj.1251

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Available Online at https://www.eurj.org.tr

Secondary problems, such as sensory, cognitive, communication, perceptual, and behavioral disorders, as well as epilepsy, are also highly prevalent in individuals with severe CP.[4] Due to low ambulation levels, hip dislocation and scoliosis occur at high rates in these individuals.[5,6] All the aforementioned problems lead to activity and participation limitations.

Activity is defined as a "task or action" undertaken by an individual, while participation is defined as "involvement in a life situation".[7] Participation in activities enhances children's academic performance, shapes their social relationships, and fosters the development of their personal identity.[8] However, children with CP experience more significant limitations in daily living activities and participation compared to typically developing children.[9] As motor, sensory, and cognitive impairments increase in CP, activity and participation limitations also rise.[10]

Children with severe CP experience greater activity and participation restrictions in daily living activities than children with moderate or mild CP.[11] Additionally, the presence of accompanying problems, such as visual, auditory, and speech impairments, as well as epilepsy, further decreases participation levels.[12] Moreover, higher levels of parental education and family organization are associated with the activity and participation levels of children with severe CP.[13] Although many factors that affect the activity and participation levels of children with severe CP have been identified, current literature has not clearly established the factors that directly or indirectly affect the participation of children with severe CP. It is believed that ultimately identifying the factors restricting activity and participation could guide clinicians in implementing new intervention programs aimed at eliminating these restrictive factors in children with severe CP. Furthermore, this would assist academics in adopting different approaches to develop new intervention programs. In this context, the aim of this study is to examine the determinants of activity and participation limitations in children with severe CP.

METHODS

Prior to starting the study, the necessary permissions and approval were obtained from the Clinical Research Ethics Committee of Akdeniz University (KAEK-962). All research procedures involving human participants were performed in compliance with the ethical guidelines. The study was conducted in Special Education and Rehabilitation Centers located in Antalya.

The study included individuals with CP aged 2-18 years who were classified as levels IV and V according to the GMFCS, along with their parents. Children with CP who were not classified as levels IV and V according to the GMFCS and those who declined to participate were not included in the study.

After thoroughly explaining the study procedures and the assessments to be administered, written informed consent was secured from participants aged 7 years and above, as well as from their primary caregivers. For those younger than 7 years, written informed consent was obtained from their primary caregivers only. The assessments were completed either before or after the children's therapy sessions in a way that would not interfere with their physiotherapy and rehabilitation practices. Completing the questionnaires took an average of 30 minutes.

Assessments

Classification Tool

GMFCS was applied to describe gross motor function levels of participants.[14] The GMFCS is a 5-level tool that categorizes motor function in cerebral palsy; levels IV and V represent children with severe motor impairments who require extensive assistive technology and physical assistance for mobility.[14]

1. Gross Motor Function Measurement (GMFM)

The GMFM-66 is a standardized, valid, and reliable measurement method used to assess motor functions in children with CP and to demonstrate changes in these functions. The test consists of five subsections and 66 items, which are based on criteria referenced in assessing motor functions. These subsections include lying and rolling, sitting, crawling and kneeling, standing, and walking, running, and jumping. Each item is scored between 0-3 points. Higher scores indicate better gross motor function. The Turkish version demonstrates excellent test-retest and inter-rater reliability with Intraclass Correlation Coefficients (ICC) ranging between 0.92 and 0.97.[15,16]

2. Depression Anxiety Stress Scale-21 (DASS-21)

The DASS-21 is a scale developed to determine depression, anxiety, and stress levels in individuals.[17] The instrument contains 21 self-administered items rated on a 4-point Likert scale to capture the degree and frequency of symptoms reported during the preceding week. The scale is divided into three subscales, each containing seven items: Depression (DASS-Depression), Anxiety (DASS-Anxiety), and Stress (DASS-Stress). The Turkish adaptation of the scale has undergone validity and reliability testing.[18] The scale was filled out by the parent or primary caregiver. The Turkish validation study reported high internal consistency, with Cronbach's alpha values of 0.86 for Depression, 0.79 for Anxiety, and 0.81 for Stress.[18]

3. International Classification of Functioning, Disability and Health (ICF)-Core Set

ICF Core Sets were created to enhance generalizability and to support easier implementation in practice. A specific core set consists of selected ICF codes considered most relevant for describing an individual's functions within a defined clinical situation or care environment.[19] In the current study, the framework developed for evaluating children with CP between 0 and 6 years of age was selected for implementation.[19] Scoring was performed using only age-specific codes selected from the activity and participation sections of the 2-18 age ICF-Core Set.[19]

4. Pediatric Evaluation of Disability Inventory (PEDI)

PEDI is an assessment tool scored by parents to evaluate the functional ability and performance of children with disabilities.[20] PEDI has two main subsections: "Functional Skills" and "Caregiver Assistance." The Functional Skills section consists of three parts: self-care, mobility, and social functions. Children are scored as "0=unable to perform" or "1=able to perform" for items in this section. The scale has been validated and tested for reliability in Turkish.[21] The scale was filled out by the parent or primary caregiver. The Turkish adaptation demonstrated excellent internal consistency, with Cronbach's alpha values ranging from 0.87 to 0.97 across the Functional Skills and Caregiver Assistance scales.[21]

Statistical Analysis

Statistical analyses were carried out using IBM SPSS 26.0 software (IBM Corp., Armonk, NY, USA). Descriptive statistics for the children with CP and their caregivers' demographic and clinical characteristics, as well as the ICF-Core Set items, were presented as mean (standard deviation) or median (minimum–maximum) for continuous variables, and as frequency (%) for categorical variables. For the modelling process, IBM SPSS Statistics 26 and Amos 23 (Amos Development Corporation, 3000 Village Run Road Unit 103, #315, Wexford, PA 15090, USA) were employed. First, an exploratory factor analysis was performed to determine the factor structure and loadings of the items. After this step, a structural equation model (SEM) was developed based on the identified factor structure. The relationships among activity and participation, environmental factors, and body functions were then examined using SEM. An exploratory factor analysis (EFA) was performed using principal component analysis with rotation to determine the factor structure and loadings of the items. The number of factors was determined based on eigenvalues greater than 1.0 and visual inspection of the scree plot. Items with factor loadings less than [0.40] or high cross-loadings were excluded. After this

TABLE 1. Descriptive Statistics of Participants (n=69)

		Data
Gender, n (%)	Boy	34(49.3)
	Girl	35(50.7)
Age (years)		8.81 ± 3.43 (n=69)/%
CP type, n (%)	Diplegic	2(2.99
	Quadriplegic	39(56.5)
	Dyskinetic	13(18.8)
	Hypotonic	12(17.4)
	Mixt	3(4.3)
GMFCS, n (%)	IV	32(46.4)
	V	37(53.6)

Data are shown as mean±standard deviation or n (%) where appropriate. CP, cerebral palsy; GMFCS, gross motor function classification system.

step, a SEM was developed based on the identified factor structure. The relationships among activity and participation, environmental factors, and body functions were then examined using SEM.

RESULTS

Descriptive statistics of participants given in Table 1. The model given in Figures 1 and 2. The standardized regression weights of the predictors of the self care, mobility, social function, body functions and participation construct/latent variables are given in Table 2. The determinants related to participation were found to be significant based on the regression weights ($P < 0.001$). The results indicated that self-care, mobility, social function, body structures and functions, and the total ICF core set score are determinants of participation in children with severe CP. As self-care (β=1.79), mobility (β=1.55), and social function (β=0.82) levels increase, the level of participation also increases. Additionally, as barriers in body structures and functions (β=-0.66) increase, the level of participation decreases. According to the total ICF core set results (β=-0.96), as the level of barriers experienced by children increases, participation decreases. It was determined that the greatest determinants of participation in children with severe CP are self-care and mobility.

Standardized direct, indirect, and total effects of the variables given in Table 3. The high positive unstandardized estimates for PEDI Self Care (β = 1.79, P<0.001), PEDI Mobility (β = 1.55, P<0.001), and PEDI Social Function (β = 0.82, $P < 0.001$) indicate that higher functional independence and performance in these daily domains are strong, positive reflections of the latent Participation construct. Conversely, the negative estimates for the ICF Total Score (β = -0.96, $P < 0.001$) and ICF Body Functions (β = -0.66, $P < 0.001$) clearly demonstrate that greater physiological and structural impairments significantly co-occur with lower latent Participation levels. According to the path analysis results, direct paths revealed that self-care (β = 1.41), mobility (β = 1.55), social function (β = 0.82), and body structures and functions (β = -0.69) are related to gross motor function ($P < 0.001$). Increased levels of self-care, mobility, and social function are associated with increased gross motor function. According to the ICF, there is an inverse relationship between increased barriers in body structures and functions and gross motor function (β = -0.69). For the total ICF Core set score, the same pattern applies, where an increase in the barriers experienced by the children is associated with a decrease in gross motor function level (β = -0.96). As an environmental factor, it was found that

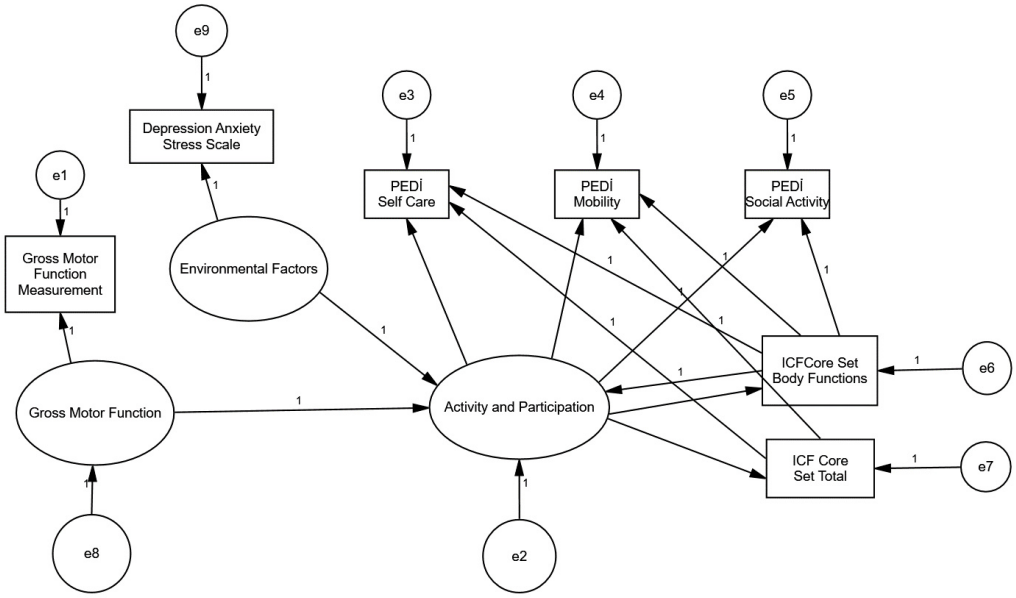

FIGURE 1. Structural model of determinants of participation of children with cerebral palsy classified at Gross Motor Function Classification System Levels IV and V.

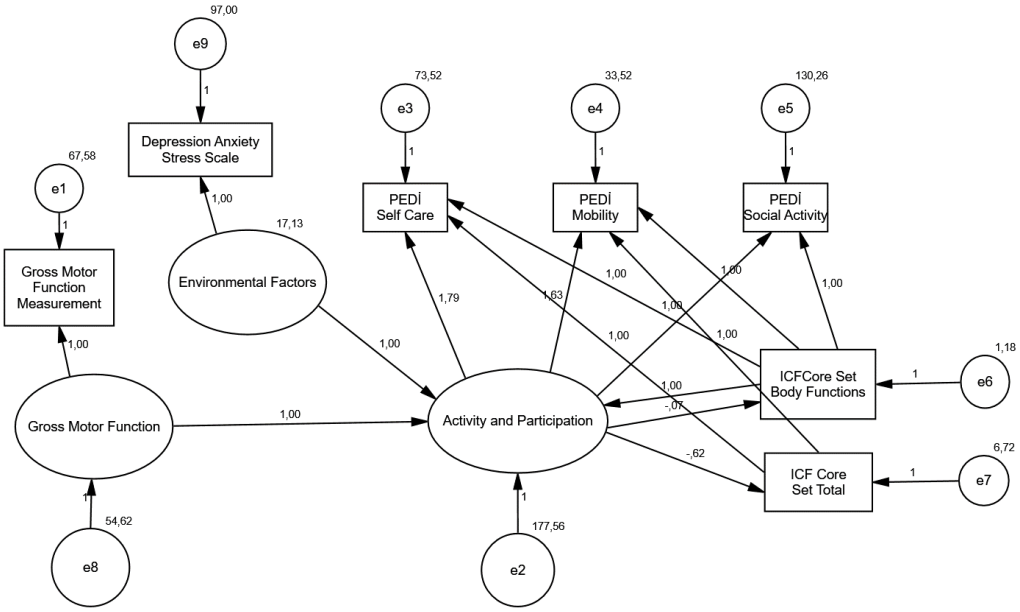

FIGURE 2. Path model of variables.

parents' levels of depression, anxiety, and stress have a low-level impact on parameters such as gross motor function, participation, self-care, mobility, social function, and body structures and functions. The model created to identify the determinants of participation in children with severe CP was found statistically significant. Goodness of fit indices of the structural equation modeling is given in Table 4.

DISCUSSION

The aim of this study was to identify the factors that may influence participation in children with severe CP. A model was developed to determine factors affecting participation. It was found that self-care, mobility, social function, body structures and functions, and ICF core set data are key factors shaping participation in children with severe CP. The structural equation model showed that as self-care, mobility, and social function levels increase, participation levels also increase. Additionally, it was found that as barriers in body structures and functions increase, participation level decrease, and according to the total ICF core set results, as the barriers experienced by the children increase, their participation decreases. Path analysis revealed that the strongest predictors of participation in children with severe CP are self-care and mobility. It was determined that a decrease in motor function level negatively impacts participation parameters.

TABLE 2. Goodness of Fit Indices of the Structural Equation Modelling

Goodness of fit indices	Good fit	Acceptable value	Model fit
X2/df	<3	3<X2/df<5	1.23
RMSEA	<0.05	<0.08	0.059
SRMR	<0.05	<0.08	0.01
CFI	>0.95	>0.90	0.98
GFI	>0.95	>0.90	0.93
AGFI	>0.95	>0.90	0.87

AGFI, adjusted goodness-of-fit index; CFI, comparative fit index; GFI, goodness-of-fit index; RMSEA, root mean square error of approximation; SRMR, standardized root mean square residual.

TABLE 3. Unstandardized Regression Weights of the Predictors of the Self Care, Mobility, Social Function, Body Functions and Participation Construct/Latent Variables

			Estimate(β)	S.E.	C.R.	P-value
PEDI self care	<---	Participation	1.79	0.18	9.73	**<0.001**
PEDI mobility	<---	Participation	1.55	0.061	14.003	**<0.001**
PEDI social function	<---	Participation	0.82	0.101	7.773	**<0.001**
ICF total score	<---	Participation	-0.96	0.042	-12.822	**<0.001**
ICF body functions	<---	Participation	-0.66	0.011	-7.885	**<0.001**

C.R, critical ratio; ICF, international classification of functioning, disability and health; PEDI, pediatric evaluation of disability inventory; S.E, standard error; <--- represents the direction of the predictive relationship.

Statistically significant P-values are shown in bold.

Furthermore, the decrease in gross motor function level was found to increase the barriers experienced by children, according to the ICF core set. As an environmental factor, parental levels of depression, anxiety, and stress were found to have a low impact on participation.

Previous research indicates that participation in CP is affected by various factors such as motor skills, cognitive functioning, gender, pain, psychological problems, age, CP subtype, epilepsy, visual impairments, and speech difficulties.[23] There are studies that identify motor function as a significant predictor of participation. According to the studies by McManus *et al*.[24] and Alghamdi *et al*.,[25] which investigated the determinants of participation in children with CP, motor function is the primary predictor of participation. The study's findings correspond to those of earlier studies on this topic. In the current study, it was determined that the participation parameters most affected by motor function level are self-care, mobility, and social function. In the study conducted by Dang *et al*.,[26] which included children with GMFCS levels I-V, it was concluded that motor skills are a determinant of participation. Additionally, it was found that motor function negatively impacts self-care and social

TABLE 4. Unstandardized Direct, Indirect, and Total Effects of the Variables

Predictor variable	Endogenous/dependent variable	Direct effect (β)	Indirect effect (β)	Total effect (β)
Participation	Gross motor function	0.48	-0.30	0.45
PEDI self care	Gross motor function	1.41	-0.59	1.44
PEDI mobillity	Gross motor function	1.55	-0.70	0.89
PEDİ social function	Gross motor function	0.82	-0.10	0.98
ICF total score	Gross motor function	-0.96	0.06	-0.57
ICF body functions	Gross motor function	-0.69	0.04	-0.62
Gross motor function	Environmental factors	0.12	0.10	0.22
Participation	Environmental factors	0.25	-	0.25
PEDI self care	Environmental factors	-	0.19	0.19
PEDI mobility	Environmental factors	-	0.20	0.20
PEDI social function	Environmental factors	-	0.17	0.17
ICF total score	Environmental factors	-	-0.21	-0.21
ICF body functions	Environmental factors	-	-0.15	-0.15

ICF, international classification of functioning, disability and health; PEDI, pediatric evaluation of disability inventory.

function.[27] Our findings correspond to what has been reported in the literature. The unique aspect of this study is that it specifically examined the participation determinants in children with GMFCS levels IV and V. As a result, social function, mobility, and self-care, are of great importance for participation in children with GMFCS levels IV and V. In the current study, it was believed that children with severe CP need various modifications in the areas of self-care, mobility, and social function to increase their participation level. It was suggested that reducing the barriers these children experience, particularly in social function, mobility, and self-care would enhance their participation.

According to Van der Kemp *et al*.,[27] family ecology, school type, and parental stress are among the most common environmental factors affecting participation in children with CP. Dang *et al*.,[26] stated that the level of parental stress may be a factor influencing participation in adolescents with CP. The present study suggested that parental depression, stress, and anxiety, as environmental factors, may influence the participation of children with severe CP. In this context, it was concluded that while parental depression, stress, and anxiety do not directly affect participation, they have a total impact on it. According to the results of the current study, participation in children with severe CP was more influenced by gross motor function than by parental depression, stress, and anxiety. It can be concluded that the priority should be to improve gross motor function to increase participation in children with severe CP. Additionally, strategies should be developed to reduce stress, parental depression, and anxiety.

According to the results of this study, it was considered that the gross motor function level is directly related to the ICF Core Set. Based on this conclusion, the level of gross motor function negatively affects body structures and functions, activity, and participation levels according to the ICF. The results obtained from the model indicate that body structures and functions are particularly influenced by the level of gross motor function. Furthermore, it was concluded that as perceived barriers in body structures and functions increase, the participation of children with severe CP is negatively affected. There are studies that have evaluated the parameters affecting the activity and participation levels of children with CP based on the parameters defined by the ICF, and the results of the study are consistent with these findings.[28,29] In Lee's study,[29] which included children diagnosed with spastic CP, the ICF-CY components for activity, participation, and body functions were used for evaluation. Consequently, a strong association was identified between the functional level of individuals with spastic CP and their activity and participation.[29] The results of the this study are consistent with the literature in this regard; however, it is the first study to specifically use the ICF Core Set to evaluate the determinants of participation in children with severe CP. In this study, the ICF core set was added to the model as a whole, and the relationship of each code with gross motor function and environmental factors was not examined. In future studies, the relationship of each code within the ICF Core Set with gross motor function, activity, and participation could be investigated.

Strengths and Limitations

The key strength of this study lies in its specific focus on children with severe CP (GMFCS levels IV and V), addressing a significant gap in the literature. By employing Structural Equation Modeling, the study goes beyond simple correlations to establish clear, hierarchical relationships proving that self-care and mobility are the strongest predictors of participation. Furthermore, by evaluating both clinical factors and parental psychological distress in a single model, it provides a clear roadmap for intervention, demonstrating that prioritizing gross motor function is the most effective strategy for enhancing participation.

This study has some limitations. It can be observed that the sample size of the study is relatively small compared to other studies where structural equation models have been established. However, it should be considered that the inclusion of only children with severe CP in the study led to a limitation in the sample size. Another limitation of the study can be considered the lack of a valid and reliable scale that includes environmental factors in the assessment parameters.

CONCLUSION

In conclusion, the primary determinants of participation in children with severe CP were

identified as self-care and mobility, according to the model developed. It was also concluded that gross motor function negatively affects the mobility and self-care parameters. Strategies should be implemented to increase participation in the rehabilitation process of children with severe CP and to enhance their self-care and mobility skills. Improving the level of gross motor function should be of great importance in the rehabilitation process of these children. It should be considered that parental depression, stress, and anxiety levels may also impact the rehabilitation process of children with severe CP, and solutions should be developed to address the depression, anxiety, and stress levels experienced by parents. We believe that a family-centered approach should be integrated into the rehabilitation process of children with severe CP.

Ethics Approval and Consent to Participate

This study was approved by the Antalya University Faculty of Medicine Clinical Research Ethics Committee (Decision No: 2012-KAEK-20/962; Date: December 13, 2023). All procedures were conducted in accordance with the ethical standards of the institutional and national research committees and with the 1964 Helsinki Declaration and its later amendments. Informed consent was obtained from all subjects involved in the study.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' Contribution

Study Conception: SAS; Study Design: SAS, GG, KMB; Supervision: SAS; Funding: TUBITAK; Materials: SAS, GG, KMB; Data Collection and/or Processing: ŞC, ÜE, GG, KMB; Statistical Analysis and/or Data Interpretation: SAS, GG, KMB, ŞC, ÜE; Literature Review: SAS, GG, KMB, ŞC, ÜE; Manuscript Preparation: SAS; Critical Review: SAS.

Conflict of Interest Statement

All authors have completed the ICMJE uniform disclosure form and declare that no potential conflicts of interest, financial or otherwise, exist regarding the research, authorship, or publication of this manuscript.

Funding

This study was supported by the Scientific and Technological Research Council of Türkiye (TUBITAK) [Project No. B.14.2.TBT.0.06.01.00-221-249164].

Acknowledgments

The authors have no acknowledgments to declare.

Generative Artificial Intelligence Statement

The authors declare that no artificial intelligence-based tools or applications were used during the preparation process of this manuscript. All content of the study was produced by the authors in accordance with scientific research methods and academic ethical principles.

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