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Authors: Aylin Kurt, Fatma Dinç, Emine Güneş Şan, İsmail Berat Uzun

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Predictors of family burden in parents of children with intellectual disabilities and their children's sexual development characteristics

Aylin Kurt, Fatma Dinç, Emine Güneş Şan, İsmail Berat Uzun

Pediatric Nursing, Department of Nursing, Faculty of Health Sciences, Bartin University, Bartin, Türkiye

Corresponding author: Aylin Kurt, e-mail: aylinkurt67@gmail.com

ORCID

AK: https://orcid.org/0000-0002-5521-0828

FC: https://orcid.org/0000-0003-1451-7441

EGS: https://orcid.org/0000-0002-5491-8621

IBU: https://orcid.org/0000-0003-0095-0738

ABSTRACT

Introduction and aim. Although the existing literature includes both quantitative and qualitative studies that examine the sexual characteristics of children with intellectual disabilities and the challenges they face, these studies have not addressed the impact of these characteristics on the burden of the family. Our objective was to examine the predictors of sexual development of family burden among parents of children with intellectual disability in this cross-sectional study.

Material and methods. We collected data from 815 parents with children aged 10–18 years with intellectual disabilities between May 2021 and March 2022. Data collection tools were 'Descriptive Characteristics Form", "Family Burden Rating Scale for families with Mentally Handicapped Children" and 'Sexual Development Characteristics scale of Adolescents with Intellectual Disability". A logistic regression analysis was performed.

Results. The predictive model for the burden of the family explained 60% of the variance in this sample of parents ($p < 0.001$). The sexual predictors with the strongest effect on the model were previous sexual development education ($\beta=0.74$; SE=0.16, $p \leq 0.001$), followed by sexual harassment ($\beta=-0.56$, SE=0.26, $p \leq 0.001$).

Conclusion. Education on sexual development in children with intellectual disability can facilitate management of challenges in adolescence.

Keywords. Child, family burden, intellectual disability, logistic models, sexual development.

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Introduction

Having a child with an intellectual disability influences family life, causes insufficiency and care burden to be at the center of a family's life, changes family roles, duties, private living spaces, social situations, desires, and plans. Some components such as family economy, parental instruction, calling, conjugal alteration, culture, diminished social skills, communication challenges, illness, child age, weakened family cycle, needs for therapeutic assistance, and monetary healthcare burden influence guardians of children with intellectual disability.[1] Challenges and uneasiness in families of children with intellectual disabilities cause adaptation issues and expand family burden. Families with children having intellectual disability by and large have lower vitality due to the increased reliance of their children on them.[2] They may have social confinement and depression, decreasing their quality of life.[3]

Children with intellectual disabilities are more likely than their peers to experience emotional and behavioral problems.[4] These problems can include anxiety disorders, oppositional defiant disorders, attention deficit/hyperactivity disorders, and peer troubles.[5] Among children with intellectual disabilities, aggressiveness, impatience, kicking, and socially inappropriate actions are troublesome.[6] Families of these children can view and treat their impaired children negatively as a result of the behavioral issues, high care demands, and stigma associated with them.[7] Particularly, children with intellectual disabilities exhibit some behaviors brought on by adolescence, increasing family burden and making it more difficult to cope with challenges.[8]

Impaired sexual development in adolescents is linked to behavioral issues.[9] For people with intellectual disabilities, regardless of age, sexuality and sexual development are challenging concerns.[10] Due to hormonal changes that accompany sexual development, children with intellectual disabilities may require assistance with cleanliness and behavior control.[11] Children who have intellectual disabilities may view their actions as typical and/or may be unable to comprehend and analyze the methods used by others. Children with intellectual disabilities are unable with communicate to their classmates, family, and friends regarding sexual development or why they find it difficult to control their sexual activity.[12]

During puberty, changes happen within the hormonal structure and bodies of children. These changes are related, for the most part, to sexuality and sexual improvement. Both sexuality and sexual desires of children with intellectual disabilities vary essentially in agreement with their insights remainder level.[13] Children with gentle intellectual disability have psychosocial and sexual behaviors comparable to their peers. They investigate and control sexual inclinations and driving forces and react to a verbal shape of sexual instruction.[14] The advancement of auxiliary sex characteristics may be deferred in children with direct intellectual disability. As they work generally by compensating and fortifying, operant conditioning and social learning-based behavior adjustment techniques may be required for sexual instruction to be successful in children with direct intellectual disability. Parents may be required to alter behaviors in children with extreme intellectual disability.[15] Families of children with intellectual disability attempt to clarify these circumstances to their children and to oversee them viably.[16] They may have trouble with respect to their children's social environment due to a few reasons such as expanded

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intrigued within the inverse sex, need of division between genders and outsiders, and running absent from domestic.[17,18]

Parents of children with intellectual disabilities may disregard their children's sexual improvement.[16] Besides parents who disregard the sexual advancement of their children, there may also be parents who make this issue a cause for concern.[17,18] The existing literature includes quantitative and qualitative studies on the sexual characteristics and problems experienced by children with intellectual disabilities.[17,18] However, these studies do not examine the effect of these characteristics and problems on families, particularly in terms of family burden. Given that children are more likely to engage in these sexual behaviors during adolescence, it is crucial to investigate the impact on family burden.

Aim

This current study aimed to examine the predictors of sexual development of family burden among parents of children with intellectual disabilities.

Research hypotheses:

H_0: The presence of sexual characteristics does not predict the family burden experienced by their parents.

H_1: The presence of sexual characteristics predicts the family burden experienced by their parents.

Material and methods

Study design and participants

This is a descriptive cross-sectional study. The study population constituted a total of 1131 parents of different socioeconomic backgrounds who were enrolled in six special education and rehabilitation centers affiliated with the National Directorate of Education. A convenience sample was used in the study.[19] The parents were informed about the purpose of the study. The study inclusion criteria were as follows: being the mother of a child with intellectual disability, having a child with intellectual disability aged between 10–18 years, agreeing to participate in the study. The study sample consisted of 815 parents (participation rate=72%) who were enrolled at these centers and agreed to participate in the study.

The mean age of the children with intellectual disability was 15.06±1.88 years, 56.07% of them were girls, 43.93% were boys, 24.29% had low intellectual disability, 45.16% moderate intellectual disability, 30.55% severe intellectual disability, and 46.63% had an additional disability. Of their mothers, 52.51% were primary school graduates and their mean age was 42.29±1.96 years. Of their fathers, 40.74% were primary school graduates and their mean age was 47.45±2.43 years. Of their families, 51.04% had an income lower than expenses, 65.64% had nuclear families, and 34.36% had large families. Furthermore, 81.97% of children with intellectual disabilities had not receive sexual health and development education prior to (Table 1).

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Table 1. Participant characteristics (n=815)

	Mean±SD	Low-high score
Age of child	15.06±1.88	10–18
Age of mother	42.29±1.96	34–49
Age of father	47.45±2.43	35–52
	n	**%**
Gender		
Girl	457	56.07
Boy	358	43.93
Intellectual disability level		
Mild	198	24.29
Moderate	368	45.16
Severe	249	30.55
Having another disability		
Yes	380	46.63
No	435	53.37
Education level of mother		
Primay school	428	52.51
High school	257	31.54
University	101	12.39
Postgraduate	29	3.56
Education level of father		
Primay school	332	40.74
High school	294	36.07
University	147	18.04
Postgraduate	42	5.15
Family income		
The income is less than the expenditures	416	51.04
Income is equal to the expenditures	261	32.02
The income is more than the expenditures	138	16.94
Family type		
Nuclear	535	65.64
Large	280	34.36
Having previous sexual education		
Yes	147	18.03
No	668	81.97

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Data collection

Data were collected between October 2021 and July 2022. The researcher went to six special education and rehabilitation centers and invited parents of children with intellectual disability to participate in the study. This time was used to ensure that the data collection tools were filled out as authentically and correctly as possible; The purpose of the study was explained to the participants in detail. It took the parents about 30 min to complete the questionnaires. Data collection tools were "Descriptive Characteristics Form", "Family Burden Assessment Scale for Families with Mentally Handicapped Children" and "Sexual Development Characteristics Scale of Adolescents with Intellectual Disability".

Sociodemographic Characteristics Form

The researcher prepared a form, including questions about the age of the parents, the level of education, the income of the family, the type of family and the child's age, gender, intellectual disability, the additional disability, and status of having sexual health education. The intelligence quotient of the children was obtained from the data they reported to the institution they received education after being evaluated by the clinicians.

Scale of Sexual Development Characteristics of Adolescents with Intellectual Disability

The Sexual Development Characteristics Scale of Adolescents with Intellectual Disability (SDCS) was developed by Gürbüz ve Eratay to determine the level of the understanding of sexual development characteristics of their children by parents of adolescents with intellectual disability during adolescence.[20] This is a five-point Likert-type scale. It consists of nine subscales. The Cronbach's alpha value of the scale was 0.85. It has no cutoff score. A median score on the total scale and subscales indicates the central level of understanding sexual development, whereas a scale score below the median value indicates a higher level of understanding sexual development. Therefore, parents with high scale scores do not understand the sexual development of their children.[20] In this study, the Cronbach alpha values was determined as 0.84 for the total scale, 0.865 for the subscale of sexual arousal, 0.84 for the subscale of information needs, 0.79 for the subscale of privacy and social trust, 0.77 for the subscale of information about bodily development, 0.87 for the subscale of sexual harassment, 0.74 for the subscale of urge for sexual satisfaction, 0.82 for the subscale of sharing sexual issues, 0.78 for the subscale of emotional change, and 0.73 for the subscale of sexual self-care.

Family Burden Assessment Scale

The Family Burden Assessment Scale for Families of Children with Intellectual Disability (FBAS), developed by Sarı and Basbakkal, was used to evaluate the burden of parents of children with intellectual disability.[21] The scale consists of 43 items and six subscales. This is a five-point Likert type scale with a cutoff score 97. A score of 97 and above indicates a high family burden, vice versa.[21] The Cronbach alpha coefficient of the scale was 0.92 and the test-retest correlation value was 0.93. In this study, the

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Cronbach alpha coefficient was found to be 0.88 for the total scale, 0.85 for the economic burden, 0.83 for the subscale of perceived inadequacy subscale, 0.86 for the subscale of physical burden subscale, 0.83 for the subscale of social burden subscale, 0.83 for the emotional burden, 0.75 for the subscale of need subscale.

Data analysis

Data were analyzed using the SPSS (Statistical Package for Social Sciences, IBM, Armonk, NY, USA) for Windows 25.0 program and evaluated using descriptive statistics (number, percentage, minimum and max values, median, mean, standard deviation). The suitability of the data for the normal distribution was checked using the skewness and kurtosis values, which should range from ±-1.5 to ±1.5.[22] To examine the associations between the SDCS and FBAS, a regression correlation was created using all variables. Parental family burden was determined according to the cutoff score of the Family Burden Assessment Scale. Those who scored 97 points or more on the Family Burden Assessment Scale were interpreted as experiencing a high family burden, while those who scored less than 97 points were interpreted as experiencing a low family burden. Two categorical variables (high family burden and low family burden) and predictors of family burden were subjected to analysis.

A logistic regression analysis was performed to determine the effect of sexual development characteristics (sexual arousal, information needs, privacy and social trust, information on bodily development, sexual harassment, desire for sexual satisfaction, sharing sexual issues, emotional change, and sexual self-care) of children with intellectual disabilities on family burden.

Ethical aspects

The study was approved by the Ethics Committee for Social and Human Sciences of the university in question (Protocol No. 2021-SBB-0241, dated 26 May 26, 2021). Furthermore, the research was approved by the provincial education directorate (No. 30644743, dated 02/09/2021). All study participants were required to sign an informed consent form, which was approved by the Institutional Review Board.

Results

Table 2 presents the SDCS and FBAS scores. Consequently, their SDCS total score was 127.84±9.41 and they obtained the highest score (23.43±4.8) on the subscale of information needs. Furthermore, their total FBAS score was 122.00±19.03 and they obtained the highest score (23.12±3.04) on the emotional burden. The study found that 75.70% of the families had a high family burden (Table 2).

Table 3 shows the interrelationships of the variables. The FBAS and all its subscales were positively but negatively associated with the SDCS. As the SDCS scores increased, their general family burden ($r=0.199$, $p=0.002$), economic burden ($r=0.240$, $p<0.001$), perceived inadequacy ($r=0.254$, $p<0.001$),

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social burden (r=0.265, p<0.001), physical burden (r=0.191, p<0.023), emotional burden (r=0.190, p<0.003), and the need for time (r=0.235, p<0.001) also increased.

Table 2. Distribution of the Sexual Development Characteristics Scale of Adolescents with Intellectual Disability and the Mean Scores of the Family Burden Assessment Scale of the participants (n=815)

	Mean±SD	**Min–max**
The Scale of Sexual Development Characteristics of Adolescents with Intellectual Disability	127.84±9.41	98–157
Sexual arousal	23.18±4.96	10–30
Information needs	23.43±4.80	10–30
Privacy and social trust	12.41±1.67	9–15
Information about bodily development	12.44±1.65	8–15
Sexual harassment	10.28±3.03	3–15
Urge for sexual satisfaction	12.48±3.03	5–15
Sharing sexual issues	12.48±3.05	5–15
Emotional change	12.61±3.10	5–16
Sexual self–care	12.56±3.08	5–15
The Family Burden Assessment Scale	122.00±19.03	85–162
Economic burden	17.38±8.66	6–30
Perceived inadequacy	20.08±3.93	12–24
Social burden	20.27±3.95	12–24
Physical burden	22.93±2.73	11–25
Emotional burden	23.12±3.04	11–32
Need for time	18.20±3.82	7–34
	n	**%**
Family burden*		
Low	198	24.3
High	617	75.7

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Table 4 presents the logistic regression analyses for risky sexual development factors related to family burden. The predictive model for the burden of the family explained 60% of the variance in this sample of parents (F (9.82)=16.24, p <0.001). The sexual predictors with the strongest effect on the model were previous sexual development education (β=0.74; SE=0.16, p≤0.001), followed by sexual harassmet (β=-0.56, SE=0.26, p≤0.001). Furthermore, the other sexual predictors with a significant effect on the model were sexual information needs (β=-0.46, SE=0.25, p≤0.001), sexual development characteristics (β=0.37, SE=0.17, p≤0.001), sexual self-care (β=-0.34, SE=0.14, p≤0.05) and the desire for sexual satisfaction (β=-0.16, SE=0.06, p≤0.001). In the case of the best model; sexual arousal (β=-0.01,

SE=0.20, $p>0.05$), privacy and social trust ($\beta=0.07$, SE=0.05, $p>0.05$), information on bodily development ($\beta=0.01$, SE=0.17, $p>0.05$), sharing of sexual issues ($\beta=-0.04$, SE=0.07, $p>0.05$), and emotional change were not predictive of family burden ($\beta=-0.07$; $t=0.07$; $p>0.05$).

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Table 3. Correlation matrix of variables (n=815)[a]

The Family Burden Assessment Scale and subdimensions	The Scale of Sexual Development Characteristics of Adolescents with Intellectual Disability and subdimensions									
	Total score	**Sexual arousal**	**Information needs**	**Privacy and social trust**	**Information about bodily development**	**Sexual harassment**	**Urge for sexual satisfaction**	**Sharing sexual issues**	**Emotional change**	**Sexual self-care**
Total score	0.199*	0.238**	0.245**	-0.190*	-0.176*	0.160*	0.173*	0.176*	0.181*	0.178*
Economic burden	0.240**	0.192*	0.194*	-0.177*	-0.158*	0.101	0.144	0.147	0.148	0.147
Perceived inadequacy	0.254**	0.110	0.096	-0.116	-0.105	0.089	0.014	0.015	0.023	0.019
Social burden	0.265**	0.234**	0.119	-0.128	-0.118	0.099	0.033	0.048	0.055	0.050
Physical burden	0.191*	0.074	0.108	-0.041	-0.041	0.052	0.153*	0.142	0.143	0.146
Emotional burden	0.190*	0.224**	0.224**	-0.129	-0.126	0.164*	0.150*	0.156*	0.158*	0.153*
Need for time	0.235**	0.057	0.103	-0.040	-0.042	0.055	0.138	0.125	0.125	0.130

[a] * p≤0.05, ** p≤0.01

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Table 4. Logistic regression model with the best fit of predictors for family burden

Effect	β	SE	OR	95% CI	
				LL	UL
Constant	0.27	0.22	1.27	0.85	1.98
Having previous sexual education[#]	0.74	0.16**	1.58	1.15	2.13
SDCS	0.37	0.17**	0.75	0.69	0.85
Sexual arousal	-0.01	0.20	0.96	0.67	1.46
Information needs	-0.46	0.25**	0.98	-0.96	0.02
Privacy and social trust	0.07	0.05	1.05	0.97	1.19
Information about bodily development	0.01	0.17	1.02	0.72	1.41
Sexual harassment	-0.56	0.26**	0.62	0.51	0.85
Urge for sexual satisfaction	-0.16	0.06**	0.86	0.76	0.97
Sharing sexual issues	-0.04	0.07	0.96	0.83	1.14
Emotional change	-0.07	0.07	0.93	0.92	1.03
Sexual self-care	-0.34	0.14*	1.40	1.07	1.84

[a] [#] yes = 0, no = 1, * – $p \leq 0.05$, ** – $p \leq 0.001$, SDCS The Sexual Development Characteristics Scale of Adolescents with Intellectual Disability, note: "Having previous sexual education, SDCS, sexual arousal, information needs, privacy and social trust, information about bodily development, sexual harassment, urge for sexual satisfaction, sharing sexual issues, emotional change, sexual self-care" is an independent variable, and family burden is a dependent variable

Discussion

Our objective was to examine the predictors of sexual development of family burden among parents of children with intellectual disability. A statistically significant relationship was found between the characteristics of sexual development of children with intellectual disability and the burden of the family. As their negative characteristics of sexual development increased, the parents' economic, physical, social and emotional burden of parents increased, causing them to feel inadequate. As the most significant risk that increases the family burden, children with intellectual disability did not receive sexual education about sexual development before. Other factors that increased the family burden were sexual harassment, sexual self-care, and the desire for sexual satisfaction.

In this study, the family burden of 75.70% was high. Perception of inadequacy and a higher level of family burden in social, physical, and emotional areas. In all studies that examine the family burden of families with children with intellectual disability, it is seen that the family burden is high.[2,23] It is stated that the rate of family burden in these families can reach up to 90%.[1] Parents experience perceived inadequacy and

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family burden more intensely in emotional areas. Determining the emotional factors that cause families to feel inadequate will be decisive in reducing the family burden.[24]

In this study, the total FBAS score of parents was 122±19.03 and they obtained the highest mean score (23.12±3.04) on the emotional burden. In a separate investigation conducted in Türkiye, the general FBAS score for parents of children with mild intellectual disabilities was found to be 121.91±33.50.[2] In the same study, the highest scores were observed for perception of inadequacy and emotional burden. In parents of children with intellectual disabilities, pessimism can emerge as economic, emotional, and temporal burdens increase with time. Parental problems may arise as social burdens increase, and dysfunction may emerge as physical burdens increase. This situation results in an increase in the family burden experienced by parents over time.[25] In this study, the characteristics of sexual development of children with intellectual disabilities were discussed as a factor that increases family burden.

The mean SDCS score of the parents in the study was 127.84±9.41 (98–157). According to this result, parents were inadequate in understanding their children's sexual development. Parents were more likely to feel inadequate in the areas of information needs and sexual arousal. In another study, the mean SDCS score of parents was reported as 111.33 (57 162) and information need and sexual arousal were the areas where parents felt more inadequate.[26] In their study, Krbaş and Odabaşı Aktaş reported the total SDCS score of parents as 117.73±16.78.[27] The highest scores were observed for sexual arousal, need for information, privacy, and social trust. These findings suggest that parents may experience challenges in managing their children's sexual arousal and privacy. Furthermore, the results indicate that parents have significant information needs, particularly regarding their children's sexual development.[27] Similar to the results of this current study, several studies have reported that parents with children with intellectual disability lacked information on sexuality.[12,28] Parents can feel competent about their children's sexual health and development through education. With these educations, parents were able to deal with their children's problems related to sexual development and effectively solve their children's problems.[16]

As another significant risk that increased family burden, most of parents of children with intellectual disability (81.97%) did not receive education about their children's sexual development before. In a parallel investigation, 45.7% of mothers indicated that they perceived themselves to be inadequately equipped to provide sexual education to their disabled adolescent children, and 97.6% stated that they had not received any information on this subject.[26] The findings of our study, as well as similar studies in the literature, indicate that a significant proportion of parents perceive themselves as lacking the necessary skills to effectively provide their children with sexual education.[26,27] This can result in an increase in parental stress and a greater family burden.[29] Parents of children with intellectual disability may have low awareness of their children's sexual development. They may not know what to discuss, when to talk, or how to direct conversations with their children.[8,14] Parents may be worried about not being able to provide education at a

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level that their child with intellectual disability can understand due to his intellectual disability. Parents may lack information on these issues and may feel helpless.[18,28]

Two important of the sexual predictors of family burden were sexual harassment and sexual satisfaction in this study. Similarly, in another study, it was reported that the average score of the scale was high in the subdimensions of sexual arousal (20.97±5.71), sexual harassment (12.22±3.13), sexual satisfaction (15.79±3.85), and sharing sexual topics (12.74±2.67).[26] These high rates indicate that some sexual behaviors are performed problematically in children with intellectual disabilities.[29] Children with intellectual disability may frequently engage in touching, hugging, and kissing behaviors that will not be accepted by their social environment and cause discomfort to individuals.[15] Exhibiting these behaviors in public places can cause stigma in families. Such behaviors may be perceived as sexual harassment and may cause embarrassment to their parents in the social environment.[12] The underlying reason why mothers of children with intellectual disability feel distressed about their children's social environment is that they worry about their children getting hurt.[18,28] Children with intellectual disability may be abused due to lack of attention, inability to react at the right time and place, insufficient understanding and comprehension skills and limited abilities, and fulfilling what they are requested without questioning.[30] Children with intellectual disability who receive sexual health and communication education exhibit less problematic behavior.[31] In a study examining the effectiveness of the sexual education program given to both adolescents with intellectual disabilities and their mothers, it is stated that the program is effective in children's gaining social skills, learning how to behave in dating, friendship, and family/parent relationship.[32] Children can organize their social relations more easily by exhibiting less problematic behavior with such educations.[9,33] Also, by providing privacy education to children, these behaviors will not cause stigma in families.[30] With the sexual health and abuse educations prepared for children with intellectual disability, children's level of privacy increases, they can learn to distinguish private and public areas, where to practice behaviors such as masturbation/walking around naked, and the concept of strangers.[34]

Study limitations and strengths

The study included all special education centers located in the city center. The diverse sociodemographic characteristics of the children attending these centers, who come from various districts and villages with transport services, reinforce the study's findings. While the study has several strengths, it also has some limitations. The research's limited scope, conducted solely in one city center in Türkiye, restricts the generalizability and representativeness of the results.

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Conclusion

This present study provided a need for information about the sexual development of children with intellectual disability and their sexual harassment behaviors, sexual self-care needs and urge for sexual satisfaction increase family burden. Providing education on sexual development in children with intellectual disability to both these children and their parents can facilitate their management of challenges in adolescence period. This education should be given by a multidisciplinary professional team, including nurses. Therefore, families of children with intellectual disability can cope more easily with situations that cause stress and anxiety about their children's sexual development process, and their family burdens can be reduced.

Declarations

Funding

No financial resources are associated with the work in this article.

Authors' contributions

Conceptualization, A.K, F.D., E.G.Ş., and İ.B.U. and A.K, F.D., E.G.Ş., and İ.B.U.; Methodology, A.K, F.D., E.G.Ş., and İ.B.U.; Software, A.K, F.D., E.G.Ş., and İ.B.U.; Validation, A.K, F.D., E.G.Ş., and İ.B.U.; Formal Analysis, A.K, F.D., E.G.Ş., and İ.B.U.; Investigation, A.K, F.D., E.G.Ş., and İ.B.U.; Resources, A.K, F.D., E.G.Ş., and İ.B.U.; Data Curation, A.K, F.D., E.G.Ş., and İ.B.U.; Writing – Original Draft Preparation, A.K, F.D., E.G.Ş., and İ.B.U.; Writing – Review & Editing, A.K, F.D., E.G.Ş., and İ.B.U.; Visualization, A.K, F.D., E.G.Ş., and İ.B.U.; Supervision, A.K, F.D., E.G.Ş., and İ.B.U.; Project Administration, A.K, F.D., E.G.Ş., and İ.B.U.; Funding Acquisition, A.K, F.D., E.G.Ş., and İ.B.U.

Conflicts of interest

No potential conflict of interest was reported.

Data availability

The data used in the study and the details of the method can be requested from the corresponding author.

Ethics approval

The study was approved by the Social and Human Sciences Ethics Committee of the university in question (Protocol No. 2021-SBB-0241, dated May 26, 2021).

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