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Research Article / Araştırma Makalesi

Mealtime Behaviors of Children with Autism Spectrum Disorder and Parental Burnout: Cross-Sectional and Relationship Exploring Study

Otizm Spektrum Bozukluğu Olan Çocukların Yemek Zamanı Davranışları ve Ebeveyn Tükenmişliği: Kesitsel ve İlişki Arayıcı Çalışma

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Abstract

Aim: The aim of this study was to investigate the effect of mealtime behavior in children with autism spectrum disorder on parental burnout.

Methods: The population of the study, in which a cross-sectional and relationship exploring design was used, consisted of parents of children with autism spectrum disorder studying in special education schools and special education subclasses in other educational institutions in two central districts of a province in Turkey. Parents of 151 children with autism who met the inclusion criteria were included in the sample. Research data were collected face to face using a Parental Descriptive Information Form, the Brief Autism Mealtime Behavior Inventory (BAMBI), and the Parental Burnout Assessment (PBA) scale between April 2021 and December 2022. Statistical significance level was accepted as $p<0.05$.

Results: The number of children in the family, age, gender and breastfeeding problems affected the child's mealtime behaviours. In the study, it was found that fathers with children with autism spectrum disorder experienced more burnout than mothers, and non-working fathers experienced more burnout than working fathers. In addition, parents with children with severe autism spectrum disorder experienced more burnout.

Conclusion: It was determined that as the problematic mealtime behavior of children with autism spectrum disorder increased, parental burnout also increased.

Keywords: Autism spectrum disorder, burnout, mealtime behavior, parent

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Özet

Amaç: Otistik bozukluğu olan çocukların yemek zamanı davranışlarının ebeveyn tükenmişliği üzerine etkisinin incelenmesidir.

Yöntem: Kesitsel ve ilişki arayıcı tipte planlanan çalışmanın evrenini Türkiye'de bir ilin 2 merkez ilçesinde, özel eğitim okullarında ve diğer eğitim kurumları içinde bulunan özel eğitim alt sınıflarında eğitim alan otizm spektrum bozukluğu tanısına sahip çocuğu olan ebeveynler oluşturmaktadır. Örneklem grubunu ise dahil edilme kriterlerine uyan 151 çocuğun ebeveyni oluşturmuştur. Araştırma verileri Nisan 2021-Aralık 2022 tarihleri arasında, Ebeveynleri Tanımlayıcı Bilgi Formu, Otizm Öğün Davranış Kısa Ölçeği (BAMBI) ve Ebeveyn Tükenmişliği Değerlendirmesi (PBA) aracılığıyla yüz yüze toplanmıştır. İstatiksel anlamlılık düzeyi $p<0,05$ olarak kabul edilmiştir.

Bulgular: Ailedeki çocuk sayısı, yaşı, cinsiyeti, anne sütü ile beslenme problemleri çocuğun yemek zamanı beslenme davranışlarını etkilemektedir. Çalışmada otistik bozukluğa sahip çocuğu olan babaların annelere göre daha fazla tükenmişlik yaşadığı, çalışmayan babaların çalışanlara göre daha tükenmiş oldukları ve ağır derecede otistik bozukluğu olan çocuğa sahip ebeveynlerin daha tükenmiş oldukları belirlenmiştir.

Sonuç: Otistik bozukluğu olan çocukların problemli yemek zamanı davranışı arttıkça ebeveyn tükenmişliğinin arttığı saptanmıştır.

Anahtar Kelimeler: Beslenme davranışı, otistik bozukluk, tükenmişlik, ebeveyn

Introduction

Autism spectrum disorder (ASD), diagnosed according to DSM-V ((Diagnostic and Statistical Manual of Mental Disorder) criteria, is defined as ‘a disorder characterised by limited, repetitive patterns of behaviour, interests or activities manifested by persistent deficits in social communication and social interaction in various forms’.[1]

In addition to many clinical symptoms of ASD, such as restrictive and repetitive behavior patterns, inadequacies in communication and social interaction[1], problematic mealtime behavior, as stated in the literature, draws attention. Problematic mealtime behavior includes food refusal and limited variety[2], behavior problems such as pushing the spoon or feeder's arm at mealtime, throwing the food, making negative noises during meals, crying, screaming, swearing, or shouting[3], intolerance to a new food on the plate, not trying the food that they disliked previously, and tendency to have one type of food, choosing the food according to its texture, heat, and shape.[4] Organic factors such as sensory sensitivity and difficulty in sucking and chewing in children with ASD may affect their food choices.[5]

The examination of the effects of mealtime behavior problems of children with ASD on themselves has shown that children may harm themselves during meals and exhibit problematic behavior, such as gagging, vomiting, coughing, and choking.[4] Bandini et al. (2017) examined whether the food selectivity of children with ASD continued during adolescence and concluded that they refused food less with age but that half of these children were still picky eaters even as they got older.[6]

The investigation of the effects of mealtime behavior problems of children with ASD on parents and siblings has indicated that these problems and food selectivity negatively affect parents and the family. The child's refusal to eat is associated with mealtime behavior problems, and the families of children with ASD are thought to be under higher parental stress at mealtimes.[7] Parents are concerned about their children’s feeding due to selective food intake and the stress caused by their nutrition and eating habits[8], and mealtime difficulties are one of their most important concerns.[9] Mothers, despite the difficulties they experience, initially devote their lives to ensuring that their children get adequate food and then begin to look for creative ways for their children to receive more varied food.[10] Parents usually use methods to solve the nutritional problems of their children with ASD, such as trying to make differences in the shape and presentation of the food, often allowing the child to consume foods that they prefer, letting them play with their favorite toy during the meal, scolding or tricking the child into eating the food with a sweet voice, stopping the meal when the child exhibits destructive

behavior [11], and persuasion, begging, scolding, and praising.[3] The examination of the effects of mealtime problematic behavior of children with ASD on their parents has shown that parents are under higher stress at mealtimes[7,8] and that families are worried about their children's nutrition.[9]

In addition, it was found that factors such as caring for a child with neurological disease and behavioral problems, fatigue, difficulties in accessing services, inadequate information about the diagnosis, difficulty in providing education and rehabilitation of their children, difficulties in participating in social life[12], parents' income status, low educational status, living an isolated life and distancing themselves from society[13] can cause burnout. However, no study directly investigating the effect of problematic mealtime behaviors on parental burnout was found. Accordingly, the objectives of our study were (1) to determine the child-related factors affecting problematic mealtime behaviors and (2) to investigate the effect of mealtime behaviors of children with autism spectrum disorder on parental burnout.

Methods

Study design, setting and sample

A cross-sectional and relationship exploring design was used. The study was carried out between April 2021 and December 2022. The population of the study consisted of parents of children diagnosed with ASD attending special education schools in two central districts of a province in Turkey and special education subclasses in other educational institutions. The study included 151 parents of children with ASD between the ages of 3 and 11 who were not diagnosed with atypical ASD and whose parents gave voluntary and written consent.

Compliance with ethical standards

Research ethics clearance for the research was obtained from the X University Non-Interventional Clinical Research Ethics Committee (number: E.83869) and the permission to apply the questionnaires was obtained from the Provincial Governorship and the Provincial Directorate of National Education (number: E-16605029-44-34927017), where the children to be included in the study were educated, in accordance with the principles specified in the " İnformed Consent" circular. Written informed consent was obtained from all parents who participated in the study and all study processes were conducted in accordance with the ethical standards of the national research committee and the Declaration of Helsinki.

Data collection tools

The research data were collected with the help of the Parent Descriptive Information Form, Autism Meal Behavior Brief Scale (BAMBI), and Parental Burnout Assessment (PBA)

data collection tools. The data were collected via face-to-face interviews in educational establishments where children who met the inclusion criteria were enrolled.

Parental Descriptive Information Form

This form consisted of 12 questions prepared by researchers following a review of the literature. The questions on the form were about the sociodemographic characteristics of parents with children with ASD and the factors that were likely to affect parental burnout. [2, 5, 14]

Brief Autism Mealtime Behavior Inventory (BAMBI)

This inventory was developed by Lukens to measure mealtime behavior problems in children with autism between the ages of 3 and 11 years. [15] The Turkish validity and reliability study of the scale was carried out by Meral and Fidan in 2014. The scale consisted of 18 items and three sub-dimensions to evaluate the nutritional problems observed in individuals with autism and mental disability. These sub-dimensions were classified as limited variety, food refusal, and features of autism. The items on the scale are scored according to a five-point Likert-type system, and items 3, 9, 10, and 15 are reverse-scored. Cronbach's alpha internal consistency coefficient of the scale was calculated as .88. High total scores on the scale indicate high severity levels of nutritional problems. [2] In our study, Cronbach's α internal consistency coefficients of the mean scores on the BAMBI inventory were found as (0.737), (0.701), (0.721), and (0.789) for the limited variety, food refusal, and features of autism sub-dimensions and the total scale, respectively.

Parental Burnout Assessment (PBA)

This scale consisted of 23 items and four sub-dimensions. Its Turkish validity and reliability study was carried out by Arıkan, Budak, and Akgün in 2020. The sub-dimensions of the scale are emotional exhaustion, emotional distancing, feelings of being fed up, and contrast with previous parental self. A seven-point Likert-type scale is used to score the scale items, and high total scores indicate high levels of parental burnout severity. Cronbach's alpha internal consistency coefficient of the total scale score was calculated as .90.[16] In our study, Cronbach's α internal consistency coefficients of the mean scores on the PBA scale were calculated as (0.771), (0.757), (0.768), (0.791), and (0.726) for the emotional exhaustion, contrast with previous parental self, feelings of being fed up, and emotional distancing sub-dimensions and the total scale, respectively.

Data analysis

Data were analysed using SPSS 24.0 (Statistical Package for the Social Sciences). Mann-Whitney U test, Kruskal-Wallis H test, and Spearman correlation coefficient were used

according to the normality of the data. Bonferroni correction was applied for paired comparisons of variables with significant differences for three or more groups. Significance was accepted as $p<0.05$.

Limitations

Children who were aged 3-11 years and typically developing children ASD were included in the study. Research results cannot be generalized to all age groups and children with ASD in all ASD types. For this reason, it is recommended to carry out future studies in which the age range is taken wider and other types of ASD are included.

Results

Of the parents who participated in the study, 78.1% were mothers and 21.9% were fathers. It was found that 37.1% of the mothers were in the 35-39 age group, 36.4% had completed primary school and 74.2% were not working. On the other hand, 32.5% of the fathers were in the age group 40-44, 39.7% had completed primary education and the majority of them were employed. When the family type was analyzed, nuclear family type was determined with the highest rate (72.8%). It was determined that almost half of the families had an income equal to their expenses and 53.6% had two children. 39.1% of the children were in the 8-9 age group, 86.1% were boy, 53.6% had severe ASD.

Mealtime behaviors of children with ASD according to some characteristics are shown in Table 1. A significant difference was found between the number of children and the mean score of the limited diversity sub-dimension, and between the age group and the mean scores of total BAMBI and all sub-dimensions ($p<0.05$). Post hoc bonferroni test was used to determine from which group the difference originated. There is a significant difference between those with 2 children and those with ≥3 children. The limited food variety scores of those with two children are significantly higher than those with ≥3 children. In addition, the mean total scores of the children in the ≤7 and 8-9 age groups were significantly higher than those in the 10-11 age group in all sub-dimensions, while the mean total score of BAMBI was significantly lower in the 10-11 age group compared to the other groups. A statistically significant difference was found between the status of discovering negative mealtime behaviours and mean BAMBI total score and between the child's gender and mean score on the limited variety subscore ($p<0.05$). Post hoc bonferroni test was used to determine from which group the difference originated. A significant difference was found between the status of refusing breast milk in infancy and the status of refusing food with increasing age. The mean total score of BAMBI in

the group who refused breast milk was found to be significantly higher than the mean total score of the group who refused food as they grew older.

Table 1. Examination of mealtime behaviors of children with ASD according to some characteristics

Variable (N=151)	n	Brief Autism Mealtime Behavior Inventory			
		Limited variety	Food refusal	Features of autism	BAMBI – Total
		$\bar{X}$ ± S.D.	$\bar{X}$ ± S.D.	$\bar{X}$ ± S.D.	$\bar{X}$ ± S.D.
Number of children					
1 (1)	26	29.23±3.13	16.85±3.53	14.69±3.08	60.77±7.75
2 (2)	81	30.02±3.44	17.90±2.89	16.01±3.56	63.93±8.05
≥3 (3)	44	28.32±3.00	17.03±3.55	15.73±3.67	61.07±7.84
Statistical analysis		χ^2=7.469	χ^2=2.084	χ^2=2.989	χ^2=4.486
Probability		**p=0.024**	p=0.353	p=0.224	p=0.106
Difference		**[2-3]**			
Age of the child with ASD					
≤7 (1)	49	30.02±3.68	19.02±2.82	17.49±3.28	66.53±7.59
8-9 (2)	59	29.89±3.01	17.86±2.24	16.20±2.57	63.97±5.49
10-11 (3)	43	27.98±2.96	15.14±3.52	12.98±3.37	56.09±7.67
Statistical analysis		χ^2=12.159	χ^2=30.658	χ^2=35.807	χ^2=35.484
Probability		**p=0.002**	**p=0.000**	**p=0.000**	**p=0.000**
Difference		**[1,2-3]**	**[1,2-3]**	**[1,2-3]**	**[1,2-3]**
Discovery of negative mealtime behavior					
Breastfeeding difficulties (1)	35	30.14±2.68	18.40±3.16	16.74±3.41	65.29±7.11
Difficulty giving complementary food(2)	42	29.21±3.68	17.30±3.16	15.26±3.56	63.78±8.37
Food refusal with age(3)	74	29.14±3.39	17.10±3.25	15.46±3.52	61.70±8.06
Statistical analysis		χ^2=3.127	χ^2=5.094	χ^2=3.823	χ^2=6.873
Probability		p=0.209	p=0.078	p=0.148	**p=0.032**
					[1-3]
Gender of the child					
Boy	130	29.12±3,17	17.60±3.24	15.80±3.51	62.52±7.97
Girl	21	31.10±3.82	16.62±3.01	15.09±3.66	62.81±8.55
Statistical analysis		Z=-2.596	Z=-1.299	Z=-0.816	Z=-0.266
Probability		**p=0.009**	p=0.194	p=0.414	p=0.790

The Mann-Whitney U test (Z-table value) was used to compare the measurement values of two independent groups for data that did not have a normal distribution, and the Kruskal-Wallis H test (χ2-table value) statistics were employed for the comparison of three or more independent groups.

The comparison of the mean PBA scores according to the sociodemographic characteristics of the parents is given in Table 2. Parental burnout differed according to being a mother or father. A statistically significant difference was found between the parent participating in the study and mean scores on the total PBA and contrast with previous parental self and emotional exhaustion sub-dimensions ($p<0.05$). While no significant relationship was found between the employment status of the mother and the PBA ($p>0.05$), a statistically significant difference was found between the employment status of the father and the mean score of the contrast with previous parental self sub-dimension ($p<0.05$). Another statistically significant relationship was found between the child's ASD level and the mean score of the feelings of being fed up sub-dimension ($p<0.05$)

Table 2. Comparison of parents' mean scores on the PBA according to their sociodemographic characteristics

Variable (N=151)	n	Parental Burnout Assessment (PBA)				
		Emotional exhaustion	Contrast with previous parental self	Feelings of being fed up	Emotional distancing	**PBA – Total**
		$\bar{X}$ ±S.D.	**$\bar{X}$ ± S.D.**	**$\bar{X}$ ± S.D.**	**$\bar{X}$ ±S.D.**	**$\bar{X}$ ± S.D.**
Parents participating in the study						
Mother	118	35.44±5.10	22.56±4.29	18.61±3.42	12.11±1.87	88.72±11.99
Father	33	38.67±3.99	24.39±4.10	18.69±3.81	12.67±2.05	94.42±9.24
Statistical analysis*		Z=-3.332	Z=-2.692	Z=-0.252	Z=-1.345	Z=-2.391
Probability		**p=0.001**	**p=0.007**	p=0.801	p=0.179	**p=0.017**
Mother's employment status						
Yes	39	37.36±5.72	22.63±4.99	18.95±4.02	12.54±1.95	91.44±14.06
No	112	35.76±4.77	23.05±4.06	18.51±3.31	12.12±1.89	89.46±10.72
Statistical analysis		Z=-1.932	Z=-0.223	Z=-0.682	Z=-0.911	Z=-1.577
Probability		p=0.053	p=0.823	p=0.495	p=0.363	p=0.115
Father's employment status						
Yes	135	36.07±5.16	22.67±4.33	18.41±3.52	12.13±1.94	89.27±11.82
No	16	36.82±4.13	25.44±3.18	20.50±2.71	13.06±1.53	95.81±8.46
Statistical analysis		Z=-0.015	Z=-2.013	Z=-1.724	Z=-1.787	Z=-1.598
Probability		p=0.988	**p=0.044**	p=0.085	p=0.074	p=0.110
Child's ASD level						
Mid-range	70	36.37±5.98	22.17±5.10	17.73±3.84	12.11±1.90	88.39±13.57
Severe	81	35.95±4.12	23.64±3.35	19.41±2.98	12.33±1.94	91.33±9.60
Statistical analysis*		Z=-1.050	Z=-1.514	Z=-2.955	Z=-0.951	Z=-0.839
Probability		p=0.294	p=0.130	**p=0.003**	p=0.342	p=0.402

Mann-Whitney U test (Z-table value) statistics were used to compare the measurement values of two independent groups for non-normally distributed data.

The relationship between the mean scores on the total BAMBI and total PBA is given in Table 3. A positive, very weak/weak, and statistically significant relationship was found between scores ($p<0.05$).

Table 3. The relationship between the mean scores on the total BAMBI and the total PBA

Correlation* (N=151)	**Brief Autism Mealtime Behavior Inventory (BAMBI)** BAMBI – Total
Parental Burnout Assessment (PBA) PBA-Total	r= 0.334 **p= 0.000**

* In cases where at least one of the two quantitative variables did not fit the normal distribution, the "Spearman" correlation coefficient was used.

Discussion

According to the research findings, children with ASD who had fewer siblings had problematic mealtime behavior (Table 1). According to the literature, children with ASD have higher levels of food selectivity than other children with typically developing in the family. [17, 3] Children with ASD have more problematic mealtime behavior than their typically developing siblings. No study indicated that the number of children in a family affected the problematic mealtime behavior of the child with ASD. In our study, it was detected that the negative mealtime behavior of the child with ASD was higher in families with a low number of children. However, there are some studies that show that when the number of children increases, parents do not spend enough time with their children and have difficulty seeing their children's problems.[18, 19] In this direction, it is thought to be related to the fact that crowded families with a large number of children have limited time to identify problematic mealtime behaviors.

Younger children with ASD have more problematic mealtime behaviors (Table 1). According to the literature, the mealtime behavior problems of children with ASD begin at a young age [20, 4, 21], these children start to choose food at a young age, and they are resistant to trying new foods. [22] In addition, children with ASD have more chewing problems than typically developing children [20], It has been observed that children with ASD experience more frequent coughing, vomiting, choking and gagging problems at mealtimes.[4] Our study results are consistent with the literature.

Children with ASD who have breastfeeding difficulties in infancy have problematic mealtime behaviors later in life (Table 1). Children with ASD begin to have feeding problems when they are still infants, and these problems gradually increase at later ages.[4, 10] These children even have difficulty sucking or accepting different foods during infancy, they have difficulty switching to different food textures as they get older, and they do not want to try new foods.[23] In addition, in a study on the comparison of children with ASD and children with

typical development, a significant difference was found in terms of not receiving breastmilk at all. It was determined that not taking breastmilk at all was higher in the group involving children with ASD.[24] Also, exclusive breastfeeding for these children was shorter than for children with typical development.[25, 24] Our study results were consistent with the literature.

Limited food variety in girl children emerged as problematic mealtime behavior (Table 1). According to the literature, girl children with ASD exhibit more negatives mealtime behaviors. [26] It was found that eating problems of girls with ASD were affected by their emotional states, and they exhibited inadequate or excessive eating behaviors when they were happy, angry or anxious.[27, 28, 29]

In our study, it was found that fathers who had children with ASD and were not working experienced more burnout than mothers (Table 2). It is seen that mothers generally assume the caregiver role of the ASD.[30] With the addition of the child with ASD to the family, it causes some of the parents' work life to be affected, family income to decrease and financial difficulties to be experienced[31], while fathers are seen to assume the economic responsibilities of the family with the influence of culture. Among the difficulties experienced by fathers, social difficulties, health and care difficulties, and financial difficulties were found to increase the stress experienced by fathers.[32] It has been revealed that the burnout levels of unemployed fathers increase due to the further decrease in the family's income level.[31] In our study, it is thought that the reasons why non-working fathers were more burned out are related to the structure of the Turkish family system. In general, while mothers take care of the child with ASD, fathers provide the family's livelihood. With the addition of the child with ASD to the family, the increased health and educational needs bring an additional financial burden to the family, and since mothers generally do not work, the burden is tried to be lifted by fathers.

It was determined that the burnout levels of parents who had children with severe ASD were high (Table 2). According to studies in the literature, the parents of children with severe autism behavior give more commands to the child and need more help[33] As the child's ASD and disability level increases, the burnout level of the parents also increases.[34, 35] It is thought that the intense care needs and other needs of children with severe disability increase parents' burnout levels.

As the negatives mealtime behavior of the child with ASD increased, the burnout level of the parents also increased (Table 3). Children with ASD exhibit many behavior problems, such as talking, crying, or playing during mealtime[33], refusing to switch to pureed foods[36], refusing or choosing food[2], throwing food[3], and selecting food according to food texture,

heat, color, and smell. In the face of these behavioral problems, parents state that they are worried about their child's nutrition[8] and that they experience higher stress at mealtimes.[7] Accordingly, it has been determined that almost half of the children with disabilities and their families experience stress at mealtimes[37] and that families with children with ASD find life less meaningful.[14]

In line with studies, it was concluded that children with ASD had negatives mealtime behaviors and that the burnout levels of parents with children with ASD were high. However, there was no study in the literature on the effect of problematic mealtime behaviors of children with ASD on parental burnout. In our study, it was concluded that as the child's negatives mealtime behavior increases, parental burnout levels also increased.

Conclusion and Recommendations

When the results of the study were examined, it was determined that as the negatives mealtime behavior of children with ASD increased, parental burnout also increased, the children of parents with fewer children had more negatives mealtime behaviors, the younger the children were, the more problematic mealtime behavior they had, girl children with ASD had more problematic mealtime behavior, and that children with ASD who did not want to take breastmilk during infancy had problematic mealtime behaviors at later ages. It was also found that fathers with children with ASD experienced more burnout, fathers who were not working experienced more burnout in the contrast with previous parental self sub-dimension than those who were working, and parents with children with severe ASD experienced more burnout. Today, although medical and technological developments can significantly reduce the clinical signs and symptoms of children, the problematic mealtime behaviors of children have remained in the background. Therefore, it is recommended that pediatric nurses should be aware of the negative mealtime behaviours of children with ASD and the problems of their parents from birth, breastfeeding counselling should be given to all parents, and in addition to the scope of the national action plan for individuals with autism spectrum disorders implemented in our country, regular training programmes should be organised and given on different presentation methods and coping with stress in 18-36-month-old infants [38] in the transition to complementary foods.

Conflict of interest

The authors declare no potential conflicts of interest regarding the research, authorship and/or publication of this study.

Authors' contributions

Concept: R.N.T.K. and B.Ç.; Design: R.N.T.K. and B.Ç.; Data collection and processing: R.N.T.K. and B.Ç.; Analysis and interpretation: R.N.T.K. and B.Ç.; Literature review: R.N.T.K. and B.Ç.; Drafting: R.N.T.K. and B.Ç.

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