

Examination of the Relationship Between the Social Participation of Children with Autism and the Quality of Life and Caregiver Burden of the Parents: Cross-Sectional Study

Otizimli Çocukların Sosyal Katılımı ile Ebeveynlerin Yaşam Kalitesi ve Bakım Veren Yükü Arasındaki İlişkinin İncelenmesi: Kesitsel Çalışma

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ABSTRACT Objective: Children with autism (CwA) often face challenges in social participation, which can impact their ability to form relationships, engage in daily living activities, and develop important life skills. The impact of these challenges is not limited to the CwA alone but also extends to their parents or caregivers who assume the primary responsibility for their care. Our study aims to examine the relationship between the social participation of CwA and the quality of life (QoL) of parents and caregiver burden. **Material and Methods:** 32 caregivers with children aged 5-12 years with autism spectrum disorder were included in the study. Children's social participation was evaluated with the Child and Adolescent Participation Scale (CASP). Parents' QoL was assessed with the WHOQOL-BREF and caregiver burden with the Zarit Caregiver Burden Scale (ZCBS). **Results:** A moderate negative significant correlation was found between CASP and ZCBS ($r=-0.593^{**}$, $p<0.01$), a low moderate positive significant correlation between CASP and WHOQOL-BREF ($r=0.374^{*}$, $p<0.05$). **Conclusion:** The findings of our study highlight the importance of promoting social participation in CwA, not only for the benefit of the child but also for the well-being of the parents and the family as a whole. In this context, occupational therapy interventions to be applied to increase the social participation of CwA are very important in reducing the burden of care and increasing the QoL of parents.

Keywords: Autism spectrum disorder; social participation; quality of life; caregiver burden

ÖZET Amaç: Otizimli çocuklar, sosyal katılımında genellikle ilişki kurma, günlük yaşam aktivitelerine katılma ve önemli yaşam becerileri geliştirme becerilerini etkileyebilecek zorluklarla karşılaşabilirler. Bu zorlukların etkisi yalnızca otizimli çocuklarla sınırlı kalmayıp, onların bakımı için birincil sorumluluğu üstlenen ebeveynleri veya bakım verenlerini de etkilemektedir. Çalışmamızın amacı, otizimli çocukların sosyal katılımları ile ebeveynlerin yaşam kaliteleri ve bakım veren yükü arasındaki ilişkiyi incelemektir. **Gereç ve Yöntemler:** Çalışmaya otizm spektrum bozukluğu tanımlı 5-12 yaş arası çocuğa sahip 32 bakım veren dâhil edildi. Çocukların sosyal katılımı Çocuk ve Ergen Katılım Ölçeği [Child and Adolescent Participation Scale (CASP)] ile değerlendirildi. Ebeveynlerin yaşam kalitesi WHOQOL-BREF ile bakım veren yükü Zarit Bakım Veren Yükü Ölçeği ile değerlendirildi. **Bulgular:** CASP ile Zarit Bakım Veren Yükü Ölçeği arasında orta derecede negatif anlamlı korelasyon ($r=-0.593^{**}$, $p<0.01$), CASP ile WHOQOL-BREF arasında düşük orta pozitif anlamlı korelasyon ($r=0.374^{*}$, $p<0.05$) bulundu. **Sonuç:** Çalışmamızın bulguları, yalnızca çocuğun yararı için değil, aynı zamanda ebeveynlerin ve bir bütün olarak ailenin iyiliği için de otizimli çocukların sosyal katılımını teşvik etmenin önemini vurgulamaktadır. Bu bağlamda otizimli çocukların sosyal katılımlarının artırılması amacıyla uygulanacak ergoterapi müdahaleleri ebeveynlerin bakım yükünün azaltılmasında ve yaşam kalitesini artırmada oldukça önem arz etmektedir.

Anahtar Kelimeler: Otizm spektrum bozukluğu; sosyal katılım; yaşam kalitesi; bakım veren yükü

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Autism spectrum disorder (ASD) is defined as “a neurodevelopmental condition characterized by social and communication difficulties, restricted and repetitive behaviours, and differences in sensory sensitivity”. Individuals with ASD display restricted, repetitive, and stereotyped behaviors, interests, or activities that can significantly impact their daily life. These symptoms typically emerge during early childhood and can persist throughout the individual’s lifespan.¹ Poor eye contact and the inability to understand social cues from the environment in children with autism (CwA) may impair their communication skills. This may increase anxiety and lead to more obvious consequences of social participation such as social isolation and peer bullying.²

Participation is the individual’s involvement in life situations and is one of the important components of health. A specific type of life situation, especially behavior and experience involving interpersonal interaction, is referred to as social participation.³ Participation in social activities can have a positive impact on children’s communicative, intellectual, emotional, and physical development.² However, the participation of CwA in social activities with their peers is often limited, especially when it comes to group activities, and when they do, they are often restricted either with their caregivers or within groups of people with disabilities.⁴

CwA requires assistance with activities of daily living (ADLs) throughout their lives. Providing continual assistance for ASD children who struggle to execute ADLs can impact the caregiver burden on their parents. Marsack-Topolewski et al., reported that the caregiver burden increased when CwA needed more help to complete their ADLs.⁵ In a study conducted by Lin with mothers of individuals with ASD, the relationship between the ability of individuals with ASD to complete ADLs and caregiving burden was investigated. The results of the study showed that there is a negative relationship between the ability to complete ADLs and caregiver burden.⁶ The caregiver burden experienced while raising a CwA can affect parents and the family as a whole, potentially leading to a decline in the parent’s quality of life (QoL).

QoL is defined as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns”.⁷ Several studies have shown that parents of CwA have a lower QoL than parents of typically developing children.^{8,9} Although there is a large literature on the QoL of parents of mentally retarded children, studies on ASD are limited.^{10,11} Existing studies suggest that parents of children with ASD perceive the impact of their child’s disability on their QoL higher than those of children with typical developmental or other neurodevelopmental disorders.^{12,13} In a study, it was emphasized that as the severity of ASD increases, the burden of caregivers increases and the QoL decreases.¹⁴

Considering the positive impact of social participation of CwA on parents, it is important to help CwA perform their daily tasks and increase their social participation.¹⁵ According to the literature, limited research has been done on the association between the social participation of CwA and their parents’ QoL and caregiver burden. Therefore, current research aims to investigate the association between the social participation of CwA and parental QoL and caregiver burden. The hypothesis of the study:

H1: There is relationship between CwA’s social participation and parents’ QoL and caregiver burden.

MATERIAL AND METHODS

ETHICS COMMITTEE

This study was designed as a descriptive, cross-sectional study to investigate the relationship between CwA’s social participation parents’ QoL and caregiver burden. The study was authorized by the Ethics Committee of the University of Health Sciences Türkiye (date: February 14, 2023; permission number: 2023/61). A signed informed consent form containing the research protocol was obtained from the individuals. The study was conducted in accordance with the principles of the Declaration of Helsinki. The sample calculation was made with the G*Power (Version 3.1.9.7, University of Düsseldorf, Düsseldorf, Germany) program. Taking Type 1 error as 0.05

and Power as 0.80, 30 sample numbers were obtained.

The study was conducted with 32 mothers of CwA. Inclusion criteria for the study are: 1) Being over 18 years old; 2) Having a child diagnosed with autism between the ages of 5-12; 3) Having a Mini-Mental State Test score of 24 or higher; 4) Volunteering to participate in the study. The exclusion criterion was having any additional chronic disease that could affect the study.

The convenience sampling method was used in this study. Demographic information form, Child and Adolescent Participation Scale (CASP) to evaluate children's social participation, Quality of Life Scale (WHOQOL-BREF) to evaluate parents' quality of life, and Zarit Caregiver Burden Scale (ZCBS) to evaluate caregiver burden were used in the study. Scales were collected face to face.

ASSESSMENTS

Demographic Question Form

This form includes demographic data of the caregiver (e.g., age, education level, marital status) and children (e.g., age, gender, age at diagnosis).

Child and Adolescent Participation Scale (CASP)

The scale, developed by McDougall et al., evaluates children's participation in various activities based on information provided by families.¹⁶ The scale includes 20 items and uses a 5-point scale to grade participation levels, with "Age appropriate" indicating full participation and "Not applicable" indicating the child is not expected to participate. The scale is suitable for children aged 5 and above, and a Turkish version was evaluated for reliability and validity by Atasavun Uysal et al. in 2018.¹⁷

Quality of Life Scale (WHOQOL-BREF)

WHOQOL-BREF-TR was developed by the World Health Organization and consists of 26 questions and a total of 4 sub-areas: physical health, psychological health, environment and social relations.¹⁸ Since each sub-domain indicates the QoL in its own field independently of each other, domain scores are calculated between 4-20. The total QoL score can vary between a minimum of 27 and a maximum of 135. As the

score increases, the QoL increases. Eser et al. investigated the scale's validity and reliability in Türkiye.¹⁹

Zarit Caregiver Burden Scale (ZCBS)

It was developed by Zarit et al. to evaluate the impact of caregiving on an individual's life.²⁰ It is comprised of 22 questions with Likert-type ratings ranging from 0 to 4 for never, seldom, sometimes, very frequently, or virtually constantly. The scale has a score range of 0 to 88. A high grade on the scale indicates extreme distress. Özer et al. carried out validity and reliability research for Türkiye.²¹

ANALYSIS OF THE DATA

The data analyses were carried out using SPSS software version 26 (IBM SPSS Statistics 26 software, Armonk, NY: IBM Corp.). To summarize the characteristics of the data, descriptive statistics such as frequency, percentage, median, minimum/maximum values, mean, and standard deviation were utilized. The normality of the data was assessed using the Kolmogorov-Smirnov test, which indicated that the data was non-normally distributed. To investigate the correlation between variables, Spearman correlation analysis was used, with a significance level of $p < 0.05$. Spearman's correlation coefficient (r) values were classified as indicating very weak (0.00-0.19), weak (0.20-0.39), moderate (0.40-0.59), moderately strong (0.60-0.79), and strong (0.80-1.0) relations between variables.²²

RESULTS

Thirty-two mothers with autistic children with a mean age of 36.25 ± 5.32 years were included in the study. The mean age of the CwA in the study was 7.53 ± 1.84 years. All mothers were married. In terms of educational background, 18.8% had completed primary school, 21.9% had completed secondary school, 31.3% had completed high school, and 28.1% had completed university. Table 1 provided further details on the demographic characteristics of the participating mothers (Table 1).

When the participation levels of CwA are examined according to CASP; It was determined that the highest participation was in home participation (10.81 ± 3.55), and the lowest participation was in

TABLE 1: Demographic information of parents and children with autism.

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Parents		n	%
Gender	Female	32	100
	Male	-	-
Education status	Primary school	6	18.8
	Secondary school	7	21.9
	High school	10	31.3
	University	9	28.1
Income status	Low	12	37.5
	Medium	13	40.6
	High	7	21.9
		Minimum-maximum	$\bar{X}\pm SD$
Age (year)		29-45	36.25±5.32
Number of children		1-4	2.06±0.91
Children with autism		n	%
Gender	Female	10	31.3
	Male	22	68.8
		Minimum-maximum	$\bar{X}\pm SD$
Age (year)		5-12	7.53±1.84

SD: Standard deviation.

TABLE 2: The CASP, ZCBS, and WHOQOL-BREF scores.

Variables	Minimum-maximum	$\bar{X}\pm SD$
CASP-total score	21-44	27.41±6.79
CASP-home participation	7-18	10.81±3.55
CASP-neighborhood and community participation	4-11	5.06±1.81
CASP-school participation	5-11	6.06±1.66
CASP-home and community activities	5-7	5.47±0.67
Zarit-total score	30-70	53.44±11.09
WHOQOL-BREF-total	60-105	84.34±11.63
WHOQOL-BREF-physical health	12-28	22.06±3.74
WHOQOL-BREF-psychological health	12-25	18±3.85
WHOQOL-BREF-social relationships	5-15	9.81±2.58
WHOQOL-BREF-environment	15-36	26.44±5.13

CASP: Child and Adolescent Participation Scale; ZCBS: Zarit Caregiver Burden Scale; WHOQOL-BREF: Quality of Life Scale; SD: Standard deviation.

neighbor and community participation (5.06±1.81). CASP's total mean score was found to be 27.41±6.79. ZCBS mean score was found to be 53.44±11.09. The mean score from the WHOQOL-BREF scale was 84.34±11.63. The participants' CASP, Zarit, and WHOQOL-BREF scores are shown in Table 2 (Table 2).

In this study, the relationship between social participation of CwA, caregiver burden of parents, and

QoL was examined. A moderate negative significant correlation between CASP-total score and ZCBS-total score ($r=-0.593^{**}$, $p=0.000$), and a weak positive significant relationship between CASP-total score and WHOQOL-BREF- total score correlation was found ($r=0.374^{*}$, $p=0.035$). When the relationship between CASP sub-dimensions and WHOQOL-BREF sub-dimensions is examined; positive, moderate ($r=0.472$, $p=0.006$) between CASP total subscale and WHOQOL BREF-psychological health; A positive, weak ($r=0.365$, $p=0.040$) significant relationship was found between WHOQOL-BREF social relationships. A positive, moderate ($r=0.440^{*}$, $p=0.012$) significant correlation was found between CASP home participation and WHOQOL-BREF psychological health. There was a positive, poor level ($r=0.368^{*}$, $p=0.038$) between CASP neighbor and community participation and WHOQOL-BREF physical health; There were positive, moderate ($r=0.520^{**}$, $p=0.002$) correlations between WHOQOL-BREF psychological health and positive, moderate ($r=0.495^{**}$, $p=0.004$) relationships between WHOQOL-BREF social relationships. There was no significant relationship between CASP school participation and WHOQOL-BREF sub-dimensions ($p>0.05$). A positive, weak correlation ($r=0.366$, $p=0.039$) was found

TABLE 3: The relationship between CASP, ZCBS, and WHOQOL-BREF.

	ZCBS- total score		WHOQOL-BREF- total score		WHOQOL-BREF- physical health		WHOQOL-BREF- psychological health		WHOQOL-BREF- social relationships		WHOQOL-BREF- environment	
	r value	p value	r value	p value	r value	p value	r value	p value	r value	p value	r value	p value
CASP-total	-0.593**	0.000	0.374*	0.035	0.240	0.185	0.472**	0.006	0.365*	0.040	0.025	0.894
CASP-home participation	-0.588**	0.000	0.345	0.053	0.259	0.152	0.440*	0.012	0.345	0.053	-0.010	0.955
CASP-neighborhood and community participation	-0.578**	0.001	0.462**	0.008	0.368*	0.038	0.520**	0.002	0.495**	0.004	0.070	0.703
CASP-school participation	-0.321	0.073	0.272	0.133	0.063	0.734	0.288	0.110	0.206	0.258	0.098	0.592
CASP-home and community activities	-0.388*	0.028	0.285	0.114	0.298	0.097	0.266	0.140	0.366*	0.039	-0.035	0.851

*p<0.05; **p<0.01; CASP: Child and Adolescent Participation Scale; ZCBS: Zarit Caregiver Burden Scale; WHOQOL-BREF: Quality of Life Scale.

between CASP home and community activities and WHOQOL-BREF social relations (Table 3).

DISCUSSION

In this study, the relationship between the social participation of CwA and the caregiver burden of parents and QoL was examined. Results indicate that social participation among CwA is associated with a beneficial effect on the QoL of parents, while conversely to a negative effect caregiver burden.

CwA are highly dependent on their parents for social activities. Therefore, parental influence is an important factor in participation in social activities. Germani et al. stated that the social participation of preschool-aged CwA occurs most frequently between parents and their children, not with their peers.²³ In the current study, it was stated that the burden of caregivers could decrease with the increase in the participation of CwA in social activities. We think that with the increase in the participation of CwA in social activities, their dependence on their parents will decrease, and the burden of caregivers will decrease.

Participation in household chores is very important as it supports many skills necessary for the development and independent living.²⁴ The literature has limited information about CwA and their home participation. Participating in household chores necessitates physical and cognitive abilities such as muscle strength, attention, imitation, and instruction following. These are abilities that CwA typically struggles with. In the current study, we found that the caregiver burden on parents decreased with the increase in home activities participation of CwA. We think that the continuous parental support required for CwA to initiate, maintain and complete the desired activities limits the participation of CwA and increases the caregiver burden. In this context, occupational therapy interventions aiming to increase the participation of CwA have an important place. In addition, a significant relationship was found between the CASP-home participation dimension of CwA and WHOQOL-BREF psychological health of their mothers. It is frequently stated in studies that the stress, depression and guilt experienced by parents of CwA may negatively affect the psychological health of the parents.^{25,26} In this context, we think that when the child's home participation increases, this will positively affect the psychological health of the parents.

According to the researchers, parents tend to avoid activities outside of the home due to their constant attention on their CwA, and the perception that others do not comprehend the child's behavior issues.²⁷ Research studies have consistently shown that CwA tend to participate in fewer social and enjoyable activities compared to their typically developing peers. Often, the activities they engage in involve parents or caregivers instead of same-aged peers.²⁸ Parental QoL is adversely af-

ected by the behavior of CwA and the judgmental attitudes of others. However, the current study revealed that an increase in neighborhood and community participation among CwA correlates with an increase in parents' QoL and a decrease in caregiver burden. Increased neighborhood and community involvement of the CwA can provide informal support from friends, family, and acquaintances, which can significantly mitigate feelings of isolation and loneliness in caregivers. Therefore, increasing neighborhood and community involvement may be an impressive strategy to improve the QoL of parents and reduce caregiver burden. In addition, in our study, relationships were found between neighborhood and community participation of CwA and the physical health, psychological health and social relations sub-dimensions of the mother's WHOQOL-BREF. In the study by Rizk et al., it was stated that the parents of CwA had significantly poorer psychological and physical health compared to the parents of normally developing children.²⁹ CwA need constant care and this can be physically and psychologically exhausting for parents. At the same time, the social relations of the parents decrease. In this context, as the neighborhood and social participation of CwA increase, the responsibilities of parents will decrease; it has been deduced that the psychological, physical health and social relations of the parents can be positively affected.

Several studies examining CwA's participation in school have found that these students experience higher rates of absenteeism, are often excluded from school activities, have limited interaction with their peers, and need more support. It has been stated that this situation may interrupt the educational progress of CwA.³⁰⁻³² These factors can negatively affect parents' QoL and caregiver burden. The analysis conducted in our study did not show a significant association between school participation of CwA and parents' QoL, QoL sub-dimensions, and caregiver burden. This could be attributed to the fact that none of the children included in our sample attended school.

Attendance in activities at home and in the community, such as meal preparation and visiting neighbors, provides structure for children's daily lives and

fosters their development and learning.³³ Research stated that CwA participates in fewer personal care, mobility, and leisure activities than their typically developing peers.³⁴ Additionally, Rizk et al. reported that families of CwA experience a higher caregiver burden and less frequent participation in religious ceremonies and social activities. Our study found that increasing the participation of CwA in home and community activities can reduce caregiver burden. The reduced participation in social activities reported by families of CwA may be attributed to the challenges of taking the CwA out of the home environment. The WHOQOL-BREF social relationship area includes parents' personal relationships and social support. Parents of CwA try to avoid social situations, such as meeting friends and relatives, to avoid embarrassment. The family support system of parents is also disrupted, as relatives and friends are often unaware of the child's condition and avoid contact with the family.²⁹ In our study, it was found that WHOQOL-BREF social relations of mothers increase in participation of their children in CASP- home and community activities. In this context, we think that it is important to increase the social support of the parents by increasing the community participation of CwA.

Under the WHOQOL-BREF environment subtitle, economic resources, physical security, access to health and social services, home environment and physical condition of the environment (pollution, traffic, climate, noise) and transportation opportunities are evaluated. In our study, no significant relationship was found between the WHOQOL-BREF environment and CASP subtitles. We think that this may be due to the fact that our sample group consisted of CwA who did not experience physical difficulties.

The current study's first limitation was the small sample size, which necessitated careful data interpretation. The second limitation is that all caregivers are female. Fathers who work during the day may have limited availability to participate in their children's services and interventions, as child therapies, appointments and meetings often take place during daylight hours. We could not reach the fathers because the data were collected in the special education

and rehabilitation center during the daytime. There is a need for studies in which male caregivers are also examined. We think that it is also important to investigate the roles and effects of the father in caregiving in different studies.

CONCLUSION

To summarize, our study highlighted the positive impact of social participation of their CwA on parents' QoL and caregiver burden. Therefore, intervention efforts should prioritize promoting social inclusion among the CwA when identifying and addressing the challenges faced by caregivers. In this context, we think that occupational therapy interventions to be applied to increase the social participation of CwA are very important. The findings could inform the development of interventions aimed at reducing the burden of caregiving and improving parents' q.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: Serkan Pekçetin, Kübra Ersoy; **Design:** Serkan Pekçetin, Berkan Torpil, Barkın Köse, Kübra Ersoy; **Control/Supervision:** Serkan Pekçetin; **Data Collection and/or Processing:** Kübra Ersoy; **Analysis and/or Interpretation:** Serkan Pekçetin, Kübra Ersoy; **Literature Review:** Kübra Ersoy; **Writing the Article:** Serkan Pekçetin, Berkan Torpil, Barkın Köse, Kübra Ersoy; **Critical Review:** Serkan Pekçetin, Berkan Torpil, Barkın Köse; **References and Fundings:** Serkan Pekçetin; **Materials:** Kübra Ersoy.

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