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EVALUATION OF THE QUALITY OF LIFE OF CHILDREN WITH SPECIAL NEEDS FROM THE PERSPECTIVE OF MOTHERS: A DESCRIPTIVE CROSS-SECTIONAL ANALYSIS STUDY

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Abstract

This study aimed to examine quality of life in children with special needs and affecting factors from the perspective of mothers. A descriptive cross-sectional study was conducted with mothers (n=99) of children with special needs between the ages of 5-18 living in a province in the Eastern Black Sea Region of Türkiye. Personal Information Form and QI-Disability-Parent Form were used to collect data. A significant difference was found between children's QI-Disability-Parent Form total scores and their diagnosis and verbal communication ability ($p<0.05$). Multiple linear regression analysis showed that verbal communication ability was a statistically significant negative predictor of QI-Disability-Parent Form scores, meeting personal needs of positive emotions, verbal communication ability of social interaction, and verbal communication ability and ability to use one's hands of independence ($p<0.01$, $p<0.05$). Verbal communication ability was a particularly important factor affecting quality of life.

Keywords: *Child, special needs, quality of life*

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ÖZEL GEREKSİNİMLİ ÇOCUKLARIN YAŞAM KALİTESİNİN ANNE PERSPEKTİFİNDEN DEĞERLENDİRİLMESİ: TANIMLAYICI BİR KESİTSEL ANALİZ ÇALIŞMASI

Öz

Bu çalışma annelerin bakış açısından özel gereksinimi olan çocukların yaşam kaliteleri ve etkileyen faktörleri incelemeyi amaçlamıştır. Tanımlayıcı kesitsel tipteki çalışma, Türkiye'nin Doğu Karadeniz Bölgesi'nde bulunan bir ilde yaşayan 5-18 yaş arasındaki özel gereksinimli çocukların anneleri (n=99) ile yürütüldü. Veriler, Kişisel Bilgi Formu ve QI-Disability-Parent Form ile toplandı. QI-Disability-Parent Form toplam puanları ile çocuğun tanısı, sözlü iletişim durumu arasında anlamlı bir fark bulundu (p<0,05). Çoklu doğrusal regresyon analizi ile çocuğun sözlü iletişim durumunun QI-Disability-Parent Form, çocuğun kişisel ihtiyaçlarının karşılanması durumunun Pozitif duygular, çocuğun sözlü iletişim durumunun Sosyal etkileşim, çocuğun sözlü iletişim ve ellerini kullanabilme durumunun Bağımsızlık alt boyutlarını negatif yönde istatiksel olarak anlamlı yordadığı belirlendi (p<0,01, p<0,05). Özellikle çocuğun sözlü iletişim durumu yaşam kalitesini etkileyen önemli faktörlerden biriydi.

Anahtar Kelimeler: *Çocuk, özel gereksinim, yaşam kalitesi*

INTRODUCTION

Special needs affecting the social, cultural and educational life of individuals can negatively influence emotions, thoughts and behaviors in all areas of life, suggesting that individuals with special needs may face a higher risk of lower quality of life than others (Acarlar, 2013). Quality of life may further decrease due to comorbidities and other problems frequently seen in individuals with special needs (Blick et al., 2015). Quality of life covers an individual's health, independence level and social relations (Çivi et al., 2011) and extends over a wide range including living conditions, function, economic conditions, perceptions, behaviors, happiness and lifestyle (Wallander and Koot, 2016). Studies have shown that individuals with special needs had significantly decreased quality of life (van Heijst and Geurts, 2015; Sakız, 2016).

Children, especially those with special needs, are often unable to recognize and address their own needs and they depend on adults to act on their rights, including the right to a quality life (Downs et al., 2019). Considering that children with special needs are at risk cognitively, behaviorally, emotionally and socially (Top and Akıl, 2017), aspects affecting quality of life in children with special needs should be determined and solutions should be generated to help them overcome the educational, psychological and social problems they face (Top and Akıl, 2017; Sarıçam et al., 2023). Services for children with special needs should aim to increase their life satisfaction and quality of life. To meet the needs of these children to the furthest extent and as fast as possible, their quality of life needs to be accurately evaluated. Hence, there is a need for studies evaluating quality of life in children with special needs (Sarıçam et al., 2023). In this context, this research aimed to examine the quality of life of children with special needs and the factors affecting it from the perspective of mothers.

MATERIAL AND METHODS

Settings and Participants

The study was conducted as descriptive cross-sectional type. The study was conducted in May-June 2023 with the mothers (n=99) of 5 to 18 years old children with special needs living in a province in the Eastern Black Sea Region of Türkiye. 76% of mothers with children with special needs were reached. Before data collection, permission from the Provincial Directorate of National Education and consent from the participants were obtained.

Measures

Data were collected one-on-one in an average of 15 minutes.

Personal Information Form: Included questions about the mother's sociodemographic characteristics and information about the child such as age, gender, comorbidities, and dependence/independence in daily activities.

QI-Disability-Parent Form: The validity and reliability study of the measure's Turkish version was conducted by Sarıçam et al. (2023). It comprises 32 items each rated on a 5-point Likert scale (1=Never – 5=Mostly) with six domains: leisure and outdoors, independence (daily life), physical health (health and wellbeing), negative emotions, positive emotions, and social interaction. The higher the score indicates the higher the quality of life. Cronbach's α coefficient of the measure is .92. In our study, Cronbach's α coefficient was .88.

Statistical Analysis

Data were evaluated using the Statistical Package for Social Sciences (SPSS) 26.0 for Windows. Normal data distribution was measured by skewness and kurtosis in the range of ±1.5 (Hair et al., 2013). Independent Samples t-Test, One-Way ANOVA and Multiple Linear Regression were used for data analysis. Statistical significance value was set at $p<0.01$ and $p<0.05$.

Ethical Considerations

Ethics committee approval (25.04.2023/ Decision no: 177/8) and institutional permission were obtained before the study. The participants were informed about the study in accordance with the Declaration of Helsinki and their consent was obtained for the Informed Consent Form. Volunteer participants were included in the study.

RESULTS

Table 1 shows the mean total scores and a comparison of the sociodemographic and some characteristics of the mothers and children.

Mean total scores obtained from the QI-Disability-Parent Form were 119.45±18.11. A significant difference was found between children's QI-Disability-Parent Form total scores and their diagnosis and verbal communication ability ($p<0.05$). Post hoc analysis showed that the difference in diagnosis was between Down syndrome (DS) and autism spectrum disorder (ASD), while the difference in verbal communication ability was between those speaking well and speaking with clarity and non-verbal children or those unable to speak. A significant difference was found between children's QI-Disability-Parent Form total scores and their ability to use hands ($p<0.05$). The study revealed a significant difference between QI-Disability-Parent Form physical health scores and verbal communication ability ($p<0.05$). Post hoc analysis showed that the difference in verbal communication ability was between children speaking with difficulty and non-verbal children or those unable to speak. A significant difference was found between QI-Disability-Parent Form positive emotions scores and number of children and meeting personal needs ($p<0.05$). Post hoc analysis showed that the difference in number of children was between having 2 children and having 3 children, while the difference in meeting personal needs was between being able to meet or control personal needs and being dependent on other people to meet personal needs. A significant difference was found between QI-Disability-Parent Form positive emotions scores and ability to use hands and ability to eat ($p<0.05$). A significant difference was found between QI-Disability-Parent Form social interaction scores and diagnosis and verbal communication ability ($p<0.05$). Post hoc analysis showed that the difference in diagnosis was between DS and ASD, while the difference in verbal communication ability was between speaking well and speaking with clarity and non-verbal children or those unable to speak. A significant difference was found between QI-Disability-Parent Form leisure and outdoors scores and diagnosis ($p<0.05$). Post hoc analysis showed that the difference in diagnosis was between DS and intellectual disability (ID) and between DS and ASD. A significant difference was found between QI-Disability-Parent Form independence scores and diagnosis, verbal communication ability and meeting personal needs ($p<0.05$). Post hoc analysis showed that the difference in diagnosis was between DS and ID and between DS and ASD; the difference in verbal communication ability was between speaking well and speaking with clarity and non-verbal children or those unable to speak; and the difference in meeting personal needs was between being able to meet or control personal needs and being dependent on other people to meet personal needs. A significant difference was found between QI-Disability-Parent Form independence scores and ability to eat and ability to use hands ($p<0.05$, Table 1).

Table 1. Comparison of Mother and Child Characteristics with Scale Total Score Averages (n= 9

Variables	n (%)	QI-Disability-Parent Form	Sub-dimension-1 Physical health	Sub-dimension-2 Positive emotions
			Average age of mothers: 40.07±7.39	
Number of children				
1^{1}	14(14.1)	117.57±15.42	13.71±3.51	15.50±2.53
2^{2}	22(22.2)	123.36±16.33	13.77±4.13	16.63±2.88
3^{3}	31(31.3)	116.61±17.07	12.29±3.80	14.09±3.89
4 and above^{4}	32(32.4)	120.34±21.29	12.28±3.86	15.68±2.97
		F=.665	F=1.098	**F=2.852^{a}**
		p=.576	p=.354	**p=.041****
Diagnosis of the child				
Down syndrome^{1}	13(13.1)	130.76±14.55	13.23±4.69	17.07±2.87
Learning disability^{2}	10(10.1)	128.40±11.42	13.10±3.51	16.20±3.22
Intellectual disability^{3}	37(37.4)	116.32±16.43	12.54±4.18	14.62±3.18
Autism spectrum disorder^{4}	27(27.3)	111.96±20.20	12.88±3.34	15.33±2.89
Other (Cerebral palsy, Rett syndrome, etc.)^{5}	12(12.1)	126.25±17.07	12.83±3.85	15.25±4.63
		F=4.220^{b}	F=.096	F=1.526
		p=.003**	p=.983	p=.201

9)

Sub-dimension-3 Negative emotions	Sub-dimension-4 Social interaction	Sub-dimension-5 Activities and outdoor activities	Sub-dimension-6 Independence
verage age of children: 10.32±4.41			
23.14±6.23	25.85±6.28	18.92±5.71	20.42±3.15
25.18±5.81	27.59±5.96	19.22±4.92	20.95±3.51
25.64±4.88	25.51±6.44	18.96±4.67	20.09±4.68
23.87±6.39	26.62±6.92	20.34±5.14	21.53±3.99
F=.869	F=.485	F=.494	F=.716
p=.460	p=.694	p=.687	p=.545
24.76±6.09	30.00±4.69	22.23±3.24	23.46±1.94
27.60±5.58	28.20±4.28	20.70±5.12	22.60±2.71
24.40±4.96	25.97±5.95	18.54±4.59	20.24±4.30
22.77±7.01	23.37±7.56	17.96±6.02	19.62±3.63
26.75±3.79	29.00±5.46	21.66±3.25	20.75±5.06
F=1.824	**F=3.583[c]**	**F=2.857[d]**	**F=2.893[e]**
p=.131	**p=.009****	**p=.012****	**p=.001****

Table 1. More

Variables	**n (%)**	**QI-Disability-Parent Form**	**Sub-dimension-1 Physical health**	**Sub-dimension-2 Positive emotions**
Verbal communication status of the child				
Speaks well and is understandable[1]	39(39.4)	123.94±18.71	12.46±369	15.92±3.26
Has difficulty speaking[2]	45(45.4)	121.00±14.08	13.75±3.87	15.31±3.21
Does not speak or cannot speak[3]	15(15.2)	103.13±19.32	10.93±3.67	14.13±3.60
		F=8.608[f]	**F=3.429[g]**	F=1.613
		p=.000**	**p=.036****	p=.205
Nutritional status of the child				
Self-fed	73(73.7)	121.23±16.64	13.06±3.89	15.78±3.14
Need help with feeding	26(26.3)	114.46±21.29	12.11±3.77	14.23±3.58
		t=1.469	t=1.080	**t=2.082**
		p=.150	p=.283	**p=.040***
Meeting the child's personal needs				
Can meet or control personal need[s]1	35(35.4)	123.31±16.68	12.08±3.96	16.25±3.10
Help is provided, but it also helps[2]	50(50.5)	119.08±18.46	13.36±3.61	15.30±3.07
Depends on others to meet personal needs[3]	14(14.1)	111.14±18.60	12.71±4.44	13.42±3.95
		F=2.341	F=1.126	**F=3.880[k]**
		p=.102	p=.329	**p=.024****
The child's ability to use hands				
Manages daily activities using hands	79(79.8)	121.35±18.35	12.93±3.79	15.73±3.21
Can pick up objects or pieces of food	20(20.2)	111.95±15.35	12.35±4.23	13.95±3.39
		t=2.110	t=.604	**t=2.191**
		p=.037*	p=.547	**p=.031***

*Independent t-Test **One-Way ANOVA

[a]Bonferroni 2>3 [b]Bonferroni= 1>4 [c]Bonferroni= 1>4 [d]Games-Howell= 1>3, 1>4 [e]Games-Howell= 1>3,
[m]Games-Howell= 1>3

Sub-dimension-3 Negative emotions	**Sub-dimension-4 Social interaction**	**Sub-dimension-5 Activities and outdoor activities**	**Sub-dimension-6 Independence**
25.56±5.77	27.97±6.16	19.97±5.11	22.05±3.58
24.86±5.32	26.40±5.94	19.75±4.69	20.91±3.44
21.40±6.44	22.20±7.04	17.26±5.33	17.20±4.70
F=2.992 p=.055	**F=4.694[h]** **p=.011****	F=1.756 p=.178	**F=9.296[j]** **p=.000****
24.49±5.94	26.76±6.35	19.52±4.79	21.60±3.46
24.96±5.45	25.30±6.64	19.30±5.63	18.53±4.61
t=-.352 p=.725	t=.993 p=.323	t=.186 p=.853	**t=3.089** **p=.004***
25.88±5.70	26.68±6.62	20.20±4.58	22.20±3.52
24.10±5.89	26.70±6.57	18.94±5.30	20.68±3.53
23.28±5.45	24.50±5.47	19.50±4.97	17.71±5.12
F=1.420 p=.247	F=.695 p=.502	F=.650 p=.524	**F=7.07[m]** **p=.009****
24.32±6.12	26.98±6.64	19.83±5.04	21.53±3.51
25.75±4.20	24.00±4.96	18.00±4.62	17.90±4.62
t=-.980 p=.330	t=1.879 p=.063	t=1.476 p=.143	**t=3.864** **p=.000***

1>4 [f]Bonferroni= 1>3 [g]Bonferroni= 2>3 [h]Bonferroni= 1>3 [j]Bonferroni= 1>3 [k]Bonferroni= 1>3

In line with the literature, the relationship between some variables of the mothers and children and the QI-Disability-Parent Form and its domains was analyzed with a multiple linear regression model (Table 2).

In the analysis of some variables of the mothers and children, it was seen that the model was significant in evaluating the model goodness of fit (F/p) regression coefficients (R/R^2) ($p<0.05$). It was found that the variance in the dependent variable of the QI-Disability-Parent Form was explained by independent variables to 13.5% (R^2 adjusted= .135) and that verbal communication ability was a statistically significant negative predictor ($p<0.01$). It was found that the variance in the dependent variable of the QI-Disability-Parent Form Positive emotions domain was explained by independent variables to 7.2% (R^2 adjusted= .072) and that meeting personal needs was a statistically significant negative predictor ($p<0.05$). It was found that the variance in the dependent variable of the QI-Disability-Parent Form Social interactions domain was explained by independent variables to 10.3% (R^2 adjusted= .103) and that verbal communication ability was a statistically significant negative predictor ($p<0.01$). It was found that the variance in the dependent variable of the QI-Disability-Parent Form Independence domain was explained by independent variables to 25.1% (R^2 adjusted= .251) and that verbal communication ability and ability to use hands were statistically significant negative predictors ($p<0.05$, Table 2).

DISCUSSION

This study aimed to examine quality of life in children with special needs and affecting factors from the perspective of mothers. The researchers found that the children's diagnosis affected their quality of life. Children diagnosed with DS had a better quality of life than those diagnosed with ASD. This finding supports the findings of previous studies (Jacoby et al., 2022;

Leonard et al., 2022; Williams et al., 2021). Further, children speaking well and speaking with clarity were found to have a better quality of life than non-verbal children or those unable to speak. In a study by Downs et al. (2019), it was found that verbal children had higher social interaction scores.

Likewise, children able to manage daily activities requiring the use of hands had a better quality of life than those not. Williams et al. (2021) reported in their study that more frequent participation and functionality were associated with higher quality of life.

Table 2. Multiple Linear Regression Analysis Model of QI-Disability-Parent Form and Sub-Dimensions Predictive Factors According to Some Characteristics of Children

							95,0 CI		Model fit
Scale	**Variables**	**B**	**SE**	**β**	**t**	**p**	**Lower**	**Upper**	
QI-Disability-Parent Form Positive emotions	**(Constant)**	18.777	1.171	-	16.032	.000	16.452	21.102	
	The child's ability to use hands	-1.227	.841	-.149	-1.460	.148	-2.896	.442	**Adj. R^2 = .072**
	Meeting the child's personal needs	-1.078	.503	-.219	-2.143	**.035**	-2.077	-.079	**F = 4.785**
QI-Disability-Parent Form Socia interaction l interaction	**(Constant)**	33.485	2.152	-	15.563	.000	29.213	37.756	**Adj. R^2 = .103**
	Verbal communication status of the child	-2.760	.861	-.311	-3.207	**.002**	-4.468	-1.052	**F = 6.588**
	Diagnosis of the child	-.653	.513	-.123	-1.273	.206	-1.671	.365	

QI-Disability-Parent Form	**Independence**	**(Constant)**	29.993	1.565	-	19.166	.000	26.885	33.101	
		Diagnosis of the child	-.509	.312	-.149	-1.633	.106	-1.128	.110	**Adj. R^2 = .251**
		Verbal communication status of the child	-1.474	.563	-.258	-2.619	**.010**	-2.592	-.356	**F = 7.557**
		The child's ability to use hands	-2.466	.949	-.248	-2.597	**.011**	-4.351	-.581	
		Meeting the child's personal needs	-.615	.659	-.103	-.933	.353	-1.925	.694	
		Nutritional status of the child	-.741	.980	-.082	-.757	.451	-2.686	1.204	
,QI-Disability-Parent Form		**(Constant)**	147.947	7.280	-	20.321	.000	133.494	162.401	
		The child's ability to use hands	-6.695	4.331	-.149	-1.546	.125	-15.294	1.903	**Adj. R^2 = .135**
		Verbal communication status of the child	-7.908	2.452	-.306	-3.225	**.001**	-12.776	-3.040	**F = 6.114**
		Diagnosis of the child	-2.077	1.494	-.134	-1.391	.168	-5.042	.888	

Predictive Factors According to Some Characteristics of Children

Adj.R^2: Adjusted R square; B: Partial regression coefficient; β: Standard partial regression coefficient; 95% CI: 95% confidence interval.

Children speaking with difficulty had higher physical health scores than non-verbal children or those unable to speak. Physical health and physical activity are a prerequisite for a child's physical development, coordination, growth, motivation, socialization and body health (Top and Akıl, 2017).

Positive emotions scores were higher in the children of mothers with 2 children than in those with 3, and in children able to meet or control personal needs than those dependent on other people to meet personal needs. Similarly, children able to manage daily activities requiring the use of hands and those able to eat by themselves had higher scores, suggesting that function and good motor skills have a positive impact on quality of life.

The study found that social interaction scores were higher in children diagnosed with DS than in those diagnosed with ASD, which is in line with previous studies, which found that children with DS had higher scores than in others (Downs et al., 2019; Jacoby et al., 2022; Leonard et al., 2022). This may be because children diagnosed with DS have fewer problems in communication than children diagnosed with ASD. In addition, the fact that children diagnosed with ASD do not pay much attention to the people around them may have caused this situation. The study found that children speaking well and speaking with clarity had higher scores in this domain than non-verbal children or those unable to speak. In a study by Downs et al. (2019), it was found that verbal children had higher social interaction scores. A study examining the relationship between function, participation, and quality of life in children and adolescents with special needs showed that a higher degree of dysfunction was associated with worse quality of life. The same study reported that more frequent participation was associated with a higher overall quality of life and that it partially mediated the association between function and quality of life (Williams et al., 2021).

The study found that leisure and outdoors scores were higher in children with DS than in those with ID or ASD. Similarly, Jacoby et al. (2022) and Leonard et al. (2022) found that children with DS had higher scores than others. Physical disorders and dysfunction are less common in DS than in others, meaning social communication, activity and leisure levels are better in children with DS than in others.

The study found that independence scores were higher in children with DS than in those with ID or ASD, which supports the finding of previous studies reporting higher scores for children with DS (Downs et al., 2019; Jacoby et al., 2022; Leonard et al., 2022). The study revealed that children speaking well and speaking with clarity had higher independence scores than non-verbal children or those unable to speak, and children able to meet or control personal needs than those dependent on other people to meet personal needs. QI-Disability-Parent Form independence scores were higher also in children able to eat by themselves than those needing assistance to eat, and in children able to manage daily activities requiring the use of hands than those not. The study by Jacoby et al. (2022) showed that children fully dependent on other people to meet personal needs with no communication, either verbal or non-verbal, had the lowest independence scores. In the study by Downs et al. (2019), children able to walk unassisted and speak had slightly higher independence scores than those not able to walk or speak.

Finally, the independent variables that predicted quality of life in children with special needs in the study were meeting personal needs, verbal communication ability and ability to use hands. In a study by Williams et al. (2021), poorer function in all domains was associated with poorer quality of life in univariate analyses, and while in multivariate models negative correlations were reported between dependence on others in managing personal needs, poor eye contact when speaking and quality of life, mobility and communication disorders were found to be less effective. Dependence on others in managing personal needs was associated with lower quality of life scores. In this context, education and training programs in the field of knowledge, attitudes, behaviors and skills are recommended to encourage and motivate affected families to actively participate in the care of their children with special needs (Caldwell et al., 2018).

The study had some limitations. First, the study used self-report measures that may cause a response bias to a certain extent. Second, the study results cannot be generalized. Third, since the study was of cross-sectional type, causality could not be determined. Therefore, caution is advised when interpreting the study results. Despite these limitations, the study also had its strengths. The study is valuable as it researches quality of life in children with special needs.

Declarations

Funding

This study did not receive any external funding.

Competing Interests

The author declares no competing interests.

Ethical Approval

Ethics committee approval (25.04.2023/ Decision no: 177/8) and institutional permission were obtained before the study. The participants were informed about the study in accordance with the Declaration of Helsinki and their consent was obtained for the Informed Consent Form. Volunteer participants were included in the study.

CONCLUSION

The study shows the variability, affecting factors and common points in quality of life of children with special needs. Given that improving quality of life is a valuable goal, the current findings highlight the importance of quality of life in determining access to intervention and support services, rather than the presence or absence of a diagnostic label, to identify areas where interventions can best be targeted.

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