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Investigation of Stress Levels of Parents of Children with Special Needs, According to the Type of Special Needs

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Abstract

This study aims to determine the stress levels of parents of children with special needs according to the type of special needs. The study group of the research consisted of 289 parents with children diagnosed with various disability groups between the ages of 6-18. The study is a descriptive research conducted with the relational survey model. In the study, demographic information form and the Perceived Stress Scale were used as data collection tools. The Perceived Stress Scale consists of 14 items. Participants evaluate each item on a 5-point Likert-type scale ranging from 'never (0)' to 'very often (4)'. In the analysis of the study, parametric analyses such as independent sample t-test and one-way analysis of variance ANOVA were selected since the data showed normal distribution. As a result of the study, it was determined that the level of stress perceived by parents differed according to the type of special need. It was determined that parents of children with intellectual disability felt more stress than parents with autism spectrum disorder, Down syndrome and other types of disabilities.

Keywords: Stress, Children with special needs, Parental stress

1. Introduction

Individuals with special needs are defined as 'children who cannot benefit sufficiently from regular education services due to physical, mental, emotional and social disabilities' (Kılıçkaya & Zelyurt, 2015). The birth of a child with special needs causes a traumatic effect in the family. Learning at birth that a child has special needs has a devastating effect on families. When the literature is reviewed, there are some models that try to explain the reactions of families with children with special needs. These are stage model, constant sadness model, personal structuring model and powerlessness and meaninglessness model (Alkan, 2010).

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The Stage Model consists of three stages. The Stage Model consists of three stages. In the first stage, family members who learn that they have a child with disability first experience a sense of shock. Then, the family members, who try to reject the situation because they cannot adapt to this situation, try to confirm that their child is normal by consulting to different specialists. Afterwards, they realise that their child's inadequacy problems have not disappeared and fall into despair. In the second stage, there is a stage of confusion. In this process, family members who have negative feelings about their children also realise that they love them and feel complex emotions. In the guilt stage, family members who are thinking about whether this situation has anything to do with them or whether they have been punished morally may feel intense anger that this has happened to them and may blame their relatives. In the third phase, there is an effort to eliminate the child's disabilities, for which the family has to enter into agreements with everyone and negotiate, and finally, a process in which the child's disability is accepted as it is as a whole (Cavkaytar, 2010).

Having a child with special needs brings along a number of special difficulties regardless of the problem (Yaşaran, 2009). Lack of adequate information about the condition of the child, difficulties in explaining the condition of the child to the family or others in the community, coping with the negative attitudes of the people around, efforts to find a suitable educational institution for their children, economic difficulties due to increased costs of care and education, inadequate fulfilment of other family needs and many processes such as shame, sadness and disappointment can cause family members to experience stress (Çiftçi Tekinarslan, 2010; Dyson, 1997; Havens, 2005; Kavak, 2007; Küçüker, 2001; Metin, 2012).

Stress is 'a situation that occurs when the physical and mental limits of the organism are threatened and forced' (Baltaş & Baltaş, 2013). According to Avşaroğlu and Üre (2007), stress is the reactions to environmental factors that threaten the individual and the difficulties encountered in meeting expectations. With the inclusion of a child with special needs into the family, the disruption of the balance of the family system, crises that cannot be corrected, changed and that show continuity can turn into a source of stress that parents have to deal with constantly (Şengül &Baykan, 2013). In addition, depending on the degree of disability of the child, problems in social relations in the family and having to change the lifestyle are important reasons for increased stress in the family. At the same time, the fact that the uncertainties that the child will experience now and in the future seem to be unsolvable is one of the reasons why families are stressed (Özkan, 2002; Kumcağız, Bozkurt & Kurtoğlu, 2018; Smith, 2002).

When the literature is reviewed, there are studies showing that the stress levels of parents with children with special needs are high (Bahar, Bahar, Savaş & Parlar, 2009; Johnston, Hessl, Blasey vd., 2003; Küçüker, 2001). In this direction, in this study, it was aimed to examine the stress levels of mothers and fathers of children with special needs according to the type of special needs.

2. Method

The type of this study is a descriptive research. Relational research model was employed in this study.

2.1. *Participants*

The study group of the research consisted of 289 parents with children diagnosed with various disability groups between the ages of 6-18. It is seen that 22.5% of the participants were fathers and 77.5% were mothers. When the type of special needs of the children of the parents with children with special needs included in the study is examined, it is seen that 36.7% (n=106) have ASD, 32.9% have Mild-Moderate-Severe Intellectual Disability (95), 18.3% have Cerebral Palsy (n=53), 12.1% have Down Syndrome (n=35).

Of the participants included in the study, 14.5% defined their monthly income as minimum wage, 28% as below minimum wage and 42.9% as above minimum wage. The educational status of the participants is 28% primary school graduates, 19% secondary school graduates, 31.5% high school graduates, 21.1% university graduates. The gender of the children of the participants in the study is 60.2% male and 39.1% female. The number of children of the participants in the study was 34.9% with 1 child, 46.4% with 2 children, 14.5% with 3 children, and 4.2% with 4 or more children. When the number of children with special needs of the participants is indicated, it is seen that 61.6% of the participants had a first child with special needs, 29.1% had a second child, 7.3% had a third child, and 2.1% had a last child with special needs. It is seen that 12,5% of the participants are in extended family, 8% in fragmented family and 79,6% in nuclear family type.

2.2. Data Collection Tools

Demographic information form and the Perceived Stress scale were used to collect research data.

2.3. Demographic Information Form

In the Demographic Information Form developed by the researchers, the variables of the respondent's gender, age, child's disability status, monthly income, educational status, child's gender, child's educational status, number of children, number of children with special needs, family type and what having a child with disability has changed in his/her life were included.

2.4. Perceived Stress Scale

In this study, the scale developed by Cohen, Kamarck and Mermelstein (Cohen, Kamarck& Mermelstein, 1983) was used to determine the stress level of parents. The 5-point Likert-type scale consisting of fourteen items measures the extent to which a person subjectively perceives certain situations as stressful. 7 of the scale items are reverse-scored. The total score obtained from the scale indicates the stress level of the person. The original scale is considered as a valid and reliable scale (0.84 - 0.86) by many studies.

Turkish adaptation of the scale was conducted by Eskin et al. (20). The internal consistency coefficient of the Turkish scale was found to be 0.84 and the test-retest reliability was 0.87 (Eskin, Harlak, Demirkıran & Dereboy, 2013). For the approval of the use of the 'Perceived Stress Scale', Mehmet Eskin, who adapted the Turkish version, was contacted and an approval letter was received. The internal consistency coefficient of the Perceived Stress Scale was recalculated and found to be .81. This shows that the measurement tool is at an acceptable level for this study.

2.5. Data Collection Process

In order to conduct this study, the necessary official permissions were obtained from Edirne Provincial Directorate of National Education. In the 2023-2024 academic year, parents of children with special needs between the ages of 6-18 studying in public and private special education institutions affiliated to the Directorate of National Education were reached.

The researcher went to the public and private special education schools affiliated to the Ministry of National Education and informed the administration about the purpose of the study and learned the days and hours of the parents' presence at the school. According to the appointment received, the schools were visited again and necessary explanations were made to the parents of children with special needs about the purpose of the study and the questionnaire, and the participation of the parents who volunteered to participate in the study was ensured. The 'Demographic Information Form' and 'Perceived Stress Scale' used in the study were administered to the parents one-on-one by the researcher. The researcher conducted these applications in a classroom allocated to her in the schools. The data were collected by the researchers between February 5, 2024 and April 22, 2024. The data were transferred to excel. Those with errors due to anomalies and omissions were removed from the data, leaving 289 data.

2.6. Data Analysis

In this study, which was conducted to examine the stress levels of parents of children with special needs according to the type of special needs, the data collected with 'Demographic Information Form' and the "Perceived Stress Scale' were analysed with SPSS-26.0 package program. The mean, standard deviation, skewness and kurtosis values of the Perceived Stress Scale scores of the parents of children with special needs included in the study were examined and it was found that the skewness and kurtosis values were in the range of -1.96 to + 1.96, which is accepted as normal distribution (Hair, Black, Babın & Anderson, 2010). Therefore, parametric methods were selected for data analysis. One-way Analysis of Variance (ANOVA) was also performed to determine the difference between the variables in the study. When a significant difference was found in these analyses, Post Hoc LSD test was used to determine the source of the difference. For more than two variables with a significant difference, the eta-squared (η^2) effect size was taken into consideration (Tabachnick & Fidell, 2013). When evaluating the effect size, the range of .000 and .003 indicates that there is no effect size, .010 and .039 indicates a small effect size, .060 and .110 indicates a medium effect size, and .140 and .200 indicates a large effect size (Cohen, 1992).

3. FINDINGS

In this part of the study, which was conducted to examine the stress levels of mothers and fathers of children with special needs according to the type of special needs, research findings are given in this section.

Table 1

*The mean and standard deviation value of the **Perceived Stress Scale** score of the parents participating in the study **according to the type of special needs** of the child with special needs*

		N	Mean	Std. deviation	Min	Max
Perceived Stress Scale Total	Autism Spectrum Disorder	106	2,7763	,69559	1,00	4,29
	Intellectual Disability	95	2,9797	,51696	1,71	4,64
	Cerebral Palsy	53	2,7470	,53522	1,29	3,86
	Down Syndrome	35	2,7172	,70229	1,00	4,36
	Total	289	2,8306	,62036	1,00	4,64
Perceived Stress Inadequacy Self-Efficacy Perception Sub	Autism Spectrum Disorder	106	2,7155	,82880	1,00	4,57
	Intellectual Disability	95	2,9556	,68667	1,57	5,00
	Cerebral Palsy	53	2,6721	,79184	1,00	4,14
	Down Syndrome	35	2,6061	,80639	1,00	4,43
	Total	289	2,7732	,78217	1,00	5,00
Perceived Stress Discomfort Sub	Autism Spectrum Disorder	106	2,8302	,69431	1,00	4,43
	Intellectual Disability	94	3,0142	,51828	1,57	4,71
	Cerebral Palsy	53	2,8181	,48009	1,50	3,71
	Down Syndrome	35	2,8272	,78689	1,00	4,29
	Total	288	2,8877	,62155	1,00	4,71

Table 1 shows the Perceived Stress Scale score of the parents participating in the study according to the type of special needs of the child with special needs. It is seen that the mean scores of the parents who participated in the study according to the type of need of the child with special needs were ASD ($\bar{x}$=2.77, sd=,695), Intellectual Disability ($\bar{x}$=2.97, sd=,516), CP ($\bar{x}$=2.74, sd=,535), Down Syndrome ($\bar{x}$=2.71, sd =,702), and total ($\bar{x}$=2.83, sd=,620). The show that Perceived Stress Inadequacy Self-Efficacy Perception Sub-ASD ($\bar{x}$=2,71, sd=,828), Intellectual Disability ($\bar{x}$=2.95, sd=,686), CP ($\bar{x}$=2,672, sd=,791), Down Syndrome ($\bar{x}$=2,606, sd=,806). Perceived Stress Discomfort Sub-ASD ($\bar{x}$=2,830, sd=,694), Intellectual Disability ($\bar{x}$=3,01, sd=,518), CP ($\bar{x}$=2,818, sd=,480), Down Syndrome ($\bar{x}$=2,827, sd=,786).

Table 2

One-way analysis of variance (ANOVA) on the Perceived Stress Scale score of the parents participating in the study according to the type of special needs of the child with special needs

		Sum of Squares	Df	Mean Square	F	Sig.	Significant Difference
Perceived Stress Scale	Between Groups	3,246	3	1,082	2,866	**,037***	ID > ASD ID > DS ID > CP
	Within Groups	107,590	285	,378			
	Total	110,836	288				
Perceived Stress Inadequacy Self-Efficacy Perception Sub	Between Groups	5,033	3	1,678	2,794	**,041***	ID > ASD ID > DS ID > CP
	Within Groups	171,163	285	,601			
	Total	176,196	288				
Perceived Stress Discomfort Sub	Between Groups	2,241	3	,747	1,953	,121	-
	Within Groups	108,636	284	,383			
	Total	110,877	287				

1=ASD 2=ID 3=CP 4=DS

1= Autism Spectrum Disorder, 2= Intellectual Disability, 3= Cerebral Palsy, 4= Down Syndrome

Table 2 shows the Perceived Stress Scale score of the parents participating in the study according to the type of special needs of the child with special needs. A statistically significant difference (F(3-285)=2,866 p=,037) was determined in the total scores of the Perceived Stress Scale of the parents of children with special needs according to the type of special needs. In addition, a statistically significant difference was found in the Perceived Stress Inadequacy Self-Efficacy Perception sub-dimension scores of the scale (F(3-285)=2,794 p=,041), but the Perceived Stress Discomfort sub-dimension scores of the scale (F(3-284)=1,953 p=,121) were not statistically significant. When the table was examined, it was determined that the problems related to self-efficacy of the parents with children with intellectual disability were higher than those of the parents with children with ASD, the problems related to self-efficacy of the parents with children with intellectual disability were higher than those of the parents with children with Down Syndrome, and the problems related to self-efficacy of the parents with children with intellectual disability were higher than those of the parents with children with CP.

Table 3

LSD Test Results

Dependent Variable	The Type Of Special Needs	The Type Of Special Needs	Mean Difference (I-J)	Sig.
Perceived Stress Total	Intellectual Disability	ASD	**,20345***	**,020**
		CP	**,23273***	**,028**
		Down Syndrome	**,26252***	**,032**
Perceived Stress Inadequacy Self-Efficacy Perception Sub	Intellectual Disability	ASD	,24014*	,029
		CP	,28349*	,034
		Down Syndrome	,34952*	,023

Table 3 shows the LSD test results. According to the LSD test results, it was found that parents with children with intellectual disabilities experienced more intense stress than parents with children with ASD, parents with children with intellectual disabilities experienced more intense stress than parents with children with Down Syndrome, and parents with children with intellectual disabilities experienced more intense stress than parents with children with CP.

4. Discussion and Conclusion

As a result of this study, which aimed to examine the stress levels of parents of children with special needs according to the type of disability of the child, it was determined that parents with children with intellectual disabilities experienced more stress than parents with children with ASD, Down Syndrome and CP. In the literature, it is frequently investigated whether parental stress varies according to the type of disability of the child with special needs. Sanders and Morgan (1997) examined stress and family adjustment in parents with typically developing children, Down syndrome and ASD and determined that parents with children with ASD experienced more stress and adjustment problems than parents with children with Down syndrome, while parents with children with Down syndrome experienced more stress and adjustment problems than parents with typically developing children. In contrast to this study, in the study conducted by Hou, Stewart, Iao, and Wu (2018), mothers with children with ASD and mothers with children with developmental disabilities in other areas were compared and according to the findings of the study, mothers with children with ASD experienced more stress and showed symptoms of depression than other mothers. In the study conducted by Felizardo, Ribeiro, and Amante (2016), parents with children with intellectual disability, physical disability and ASD were compared and according to the findings of the study, it was found that the stress and social support levels of parents differed according to the type of disability in parallel with this study. Shyam et al. (2014) examined the level of family burden and stress in mothers of children with intellectual disability and children with physical disabilities. According to the results obtained, mothers of children with intellectual disability had higher stress and family burden than mothers of children with physical disabilities and mothers in the control group. Alpan (2013) compared the depression and stress coping skills of mothers of children with attention deficit hyperactivity disorder and mothers with

typically developing children and found that the depression levels of mothers of children with ADHD were higher than those of mothers with typically developing children.

Chalım (2022) examined the family stress level and family resilience levels of parents of children with special needs in terms of various variables and found that the stress level of the mother and father did not differ according to the type of disability of the child, unlike this study. İlhan (2017) determined that the stress levels of parents of children with special needs did not differ according to the type of disability. Çandır (2015) studied the relationship between depression, anxiety, stress and coping attitudes in mothers of children diagnosed with ASD and Down syndrome between the ages of 4-24 and indicated that the levels of depression, anxiety and stress in mothers of children with ASD were higher than in mothers of children with Down syndrome and typically developing children. Yavuz et al. (2024) examined the stress and depression coping levels of parents with disabled individuals and found that the depression and stress levels of parents with children with ASD were higher than those of parents with children with other types of special needs. Eren et al. (2020) examined the stress levels and coping methods of fathers of children with intellectual disabilities and found a significant difference between father stress scores and disability level. In the literature, when parents of children with ASD were compared with parents of children with physical disabilities, it was found that parents with children diagnosed with ASD had higher levels of stress and depression (Yavuz & Armağan, 2024).

Another result of this study is that parents with children with intellectual disability have more problems related to stress self-efficacy than parents with children with ASD and CP. The findings of the study showed that as stress self-efficacy perception problems increase, family stress also increases. Therefore, it is important to support families with psychoeducational programs.

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