

# Predictors of family burden in families caring for children with special needs

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**Abstract:** Having a child with special needs has a significant impact on family life. While adapting to this new situation, parents often face difficulties related to the care of their children, family relations, and financial situation. The present study examined differences between family burden and spousal support perceived by mothers and fathers of children with special needs and investigated predictors of perceived family burden and spousal support. A total of 394 parents of children with disabilities (197 couples) from a large urban city in Northern Turkey participated in this survey study. Results showed the perceived family burden and spousal support differed significantly between couples. Mothers of children with special needs had significantly higher perceived family burden and significantly lower perceived spousal support in comparison to fathers. Moreover, perceived spousal support significantly predicted family burden perceived by mothers and fathers. Implications in relation to services offered to families of children with disabilities along with the recommendations for future research in this area are discussed.

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## Keywords

Family burden; Spousal support; Children with special needs; Parent

## Introduction

Having a child with special needs has a significant impact on family life. While adapting to this new situation, parents often face difficulties related to the care of their children, family relations, and financial situation. This process, in which parents often need to quickly adapt to new responsibilities and roles of taking care of their children with special needs, can be very challenging for parents and can negatively affect their marital relationships (Bhatia, 2018). Some parents isolate themselves and their children from the society to cope with this new way of life (De Caroli & Sagone, 2013). The fact that many children with special needs need lifelong care imposes burdens on parents (Sahu et al., 2019). Family burden is described as “the difficulties and challenges experienced by families as a consequence of someone’s illness” (or disability in this case; Sales, 2003, p. 34). The concept of burden includes objective burdens (e.g., loss of income, restriction of social activities, disruption of family routines), and subjective burdens (e.g., emotional distress about the child). Family burden is usually evaluated based on four categories including psychological, physical, social, and economic burden (Chou, 2000). Family burden is impacted by the necessity of changing expectations and plans for future (Yildirim-Dogru & Arslan, 2008) and increased physical burden due to the need for care (Kaner, 2004). Moreover, it is impacted by withdrawal from social environments due to the presence of problem behaviors in children (Bildirici, 2014), and the economic difficulties related to the education, daily care and treatment of children (Ozsenol et al., 2003).

## Family Burden

Compared to parents of children with neurotypical development, parents of children with autism spectrum disorder (ASD) (Smith et al., 2010) and intellectual disability (Manor-Binyamini, 2011) experience

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increased levels of family burden. Research has reported that among the most obvious reasons for increased family burden are the increase in the need for care of the child, the decrease in leisure time activities (Smith et al., 2010), and increased health expenditures or economic difficulties due to reasons such as leaving the job (Cidav et al., 2012). The burden placed on the family after diagnosis appears to be related to age and gender of the child (Aysan & Ozben, 2007), the type or severity of disability the child has (Langley et al., 2017; Plant & Sanders, 2007), behavior problems demonstrated by the child (Unwin & Deb, 2011), the presence of comorbidities (Irazábal et al., 2012), and social support (Picardi et al., 2018). Among the disability types, ASD draws attention as an area of disability that affects parents more than other disability types (Hayes & Watson, 2013). Compared to other types of disabilities, parents spend more time helping their children with ASD in their daily living activities and managing the emotional-behavioral problems accompanying ASD (Smith et al., 2010). Further, when children with disabilities display intense behavior difficulties, their families may isolate themselves from the social environments, thus limiting their access to services and increasing the burden of parents as caregivers (Unwin & Deb, 2011). Therefore, the type of disability alone is not a factor that determines the family burden; the severity of disability and the presence of emotional-behavioral problems are more important factors affecting the family burden.

Research has shown that mothers are more affected by the burden of having a child with special needs in the family for several reasons (Irazábal et al., 2012). First, a large portion of working mothers often have to quit their jobs to meet the needs of their children with special needs (Di Giulio et al., 2014). Second, they take more responsibilities for the care of their children (Ström et al., 2012). It seems inevitable that the burden of mothers will increase as fathers take less responsibilities than mothers in supporting development and learning of the family member with disability (Harper et al., 2013). Research has shown that mothers who shoulder the burden of childcare alone limit their social relationships and interactions with others (Atila-Demir & Keskin, 2018), are exposed to more stress (Ilhan et al., 2019), and experience increased burnout due to psychological strain (Langley et al., 2017). Accordingly, mothers question their marriage more frequently (Hartley et al., 2017) and express more concerns about marital relationships (Harper et al., 2013). As a result of the increased family burden, parents of children with special needs spend less time with their spouses (Woodgate et al., 2008), and have fewer resources to provide spousal support and create time for spousal intimacy (Hartley et al., 2017). To reduce the mothers' responsibilities, burden, and stress, fathers can share responsibilities in relation to the care of children with special needs in the family; thus, providing spousal support.

### **Spousal Support**

Spousal support can be defined as the provision of emotional, financial, informational, appreciation, and self-esteem support (Huber et al., 2010). Thus, the concept of spousal support is not limited to care support that includes help with housework and childcare. Spousal support also includes emotional support that spouses provide (e.g., spouses provide information to and value each other, and appreciate and understand each other). The existence of all these dimensions of spousal support makes it easier for couples to cope with the negative events they encounter in daily life (Aydoğan & Kizildag, 2017). Due to the fact that families that have children with special needs often isolate themselves from the social environment to address their children's unique needs (De Caroli & Sagone, 2013), the social support resources of the couples decrease and they have to cope with the challenges alone (Woodgate et al., 2008). Thus, it is of particular importance that the spouses provide support to each other when raising a child with special needs. Spousal support plays a critical role in reducing the negative emotions that may arise because parents of children with special needs cannot spare enough time for each other (Woodgate et al., 2008). Couples who support each other are likely to perceive changes in their families as less stressful and can be more successful in coping with the challenges.

Men and women differ in both their needs for support and their ability to provide support to their spouses (Reevy & Maslach, 2001). Women expect more support from their husbands than men expect from their spouses (Xu & Burleson, 2001). Thus, it is possible that women do not see the support they receive from their husbands as sufficient. In addition to perceived spousal support, the types of support provided

may also differ between spouses. Traditionally, men provide financial and instrumental support, while women provide more emotional support (Lawrence et al., 2008). As a result, the emotional support women show to their spouses can make it easier for men to cope with stressful life events. However, men's focus on providing instrumental support rather than emotional support may not adequately respond to women's emotional needs. Karakus and Kirlioglu (2019) stated that women do not consider the support they receive from their spouses sufficient during stressful days and times. The perceptions of parents of children with special needs regarding the support they receive from their spouses may also change depending on the family burden brought on by the amount of extra services and needs that the child with a disability might need. Therefore, it is expected that the perceived spousal support will differ according to the type and severity of the child's disability.

Spousal support has a positive effect on parenting behaviors because it reduces parental stress (Kanter & Proulx, 2019). Couples with children with special needs need more support from each other in order to meet the needs of their children (Busillo-Aguayo, 2010). Spousal support and communication between couples are seen as a key factor affecting conflict between spouses (Busillo-Aguayo, 2010). Poor marital adjustment leads to child-rearing conflicts and overreactive parenting, which increases problem behaviors demonstrated by the child (O'Leary & Vidair, 2005). Moreover, low marriage quality increases behavior problems in children (Papp et al., 2004; Wieland & Baker, 2010). For example, Kanter and Proulx (2019) found that children's aggression levels were negatively affected by the level of spousal support provided from their fathers to mothers. On the contrary, spousal support and high marital quality can positively affect the quality of parent-child relationships (Wieland & Baker, 2010). Recent literature in child development reaffirms the strong link between the quality of the parent-child relationship and child outcomes. Support and opportunities provided by the family act as a protective factor by improving children's ability to cope and adapt to life's challenges (Frost et al., 2020; Spiteri, 2021). From this point of view, it can be asserted that marital relationships where family burden is shared among spouses by providing spousal support to each other are more likely to result in positive parent-child relationships and therefore, enhance child development.

Studies on the marital relations of parents of children with special needs have shown parents of children with ASD have lower satisfaction in their marriage and a higher risk of divorce (Sim et al., 2016). Research has shown that mothers of children with ASD experience more stress than mothers of children with other disabilities (Hayes & Watson, 2013). Although the literature emphasizes the importance of spousal support for couples with children with special needs, there is limited research investigating how spousal support varies based on severity and types of disability the child has. In addition, most studies including parents of children with special needs are based on the opinion of one of the spouses (usually wife's). In the present study, the participation of both spouses was ensured, so that the differences between the couples could be examined.

### **Support Services for Children with Special Needs and Their Families**

Family and Divorce Counseling Services are provided by psychologists in Provincial Directorates of Family and Social Policies and Social Service Centers in Turkey. Psychological support services offered in these centers are not specific to families of children with special needs, but all families. There are Care, Rehabilitation and Family Counseling Centers in every province affiliated to the General Directorate of Services for the Disabled and Elderly in the Turkish Ministry of Family and Social Services (TMOFaSS). Psychologists in the Family Support Units across these centers provide information and counseling services to the families of individuals with special needs. This includes psychological support for the family, information on the care and rehabilitation services offered to individuals with special needs, ensuring family participation, and informing about the continuation of rehabilitation services at home.

Activities to support individuals with special needs and their families in Turkey are also included in the 2022-2026 Strategic Plan of the TMOFaSS (TMOFaSS, 2022a). This plan aims to expand family-oriented care services and to increase the effectiveness of education-counseling services for families. In addition to the strategic plan, the TMOFaSS has developed a 2030 Barrier-Free Vision Document (TMOFaSS, 2022b).

The National Action Plan for the Rights of Persons with Disabilities (2023-2025) has been prepared within the scope of the Barrier-Free Vision Document (TMoFaSS, 2022c). In this plan, there are various objectives related to increasing the well-being of individuals with special needs and their families. Information, consultancy, guidance, and support services for individuals with special needs and their families will be strengthened. Studies will be carried out to increase the care competence of the family members who undertake the care responsibility of the individuals with special needs in the family. In line with these purposes, it is planned to expand the home-based social service model, to increase the effectiveness of family support units regarding disability, and to increase the effectiveness of free family counseling service.

### **Purpose of the Study**

The purpose of the present study was to examine the differences between family burden and spousal support perceived by mothers and fathers of children with special needs and investigate the predictors of perceived family burden and spousal support. Two main questions were addressed in this study: (1) Do couples who have children with special needs differ significantly in perceived family burden and perceived spousal support? (2) Does the gender of the child, and the type and severity of disability the child has significantly predict perceived family burden and perceived spousal support of couples who have children with special needs?

### **Theoretical Framework**

Research on child development has shown that presence of high-level parental stress (Woodman et al., 2015) and marital problems among couples including lack of spousal support (Hosokawa & Katsura, 2017), adversely impact children's development. While having children with special needs in the family impacts the level of stress and burden experienced by parents, increased burden and stress experienced by parents and problems in their marital relationship affect parents' relationship with their children and in turn, children's development (Hsiao, 2018; Peer & Hillman, 2014). Bronfenbrenner's ecological systems theory offers a useful theoretical framework for this reciprocal relationship (Bronfenbrenner, 1979; 1986; 1995). According to this theory, children develop within the context of interconnected layers of systems and interactions among structures within and between these systems impact the childhood development and family well-being. The child with his/her innate characteristics (e.g., genetics, intelligence, pre-existing conditions, or disabilities) is at the center of the Bronfenbrenner's model and encompassed by five intertwined systems from most immediate to most distal. The first system in which the child lives in is the *Microsystem* and includes the structures (e.g., the family, school, childcare, friends, teachers) the child directly interacts on a regular basis (Swick & Williams, 2006). Bi-directional relationships are strongest in this level, and they have the greatest influence on the child and vice versa. For example, when a child with special need joins the family, parents may need to interact with special education schools and services or when parents have high levels of stress, the child behavior may be influenced adversely. The second system, *Mesosystem*, encompasses connections between two or more systems. For example, a service provider in the microsystem can connect the child and family with a parent organization in the same system for support, or the service provider can connect parents to a health care provider (in the next system) to receive therapeutic support. The third system, *Exosystem*, includes informal and formal social structures (e.g., employers, health services) that indirectly influence the child through their impact on the microsystem (Chachar et al., 2021). For example, due to increased care responsibilities, many mothers of children with disabilities quit their jobs which may result in financial difficulties and impact services the child receives. Psychological supports provided by the governmental agencies may also help parents to cope with stress and burden, and as a result will help improve the relationships between parents and children. The fourth system, *Macrosystem*, includes cultural factors (e.g., values, political views, ethnicity, socioeconomic status) that influence development of children. Finally, *Chronosystem*, adds the dimension of time into the theory as it relates to the child and their environments. This system considers changes within the child and their environments over time to examine how these changes impact a child's development (Eriksson et al., 2018).

## Method

### Research Design

The survey design, a correlation research method, was used in this study to investigate the relationships between perceived family burden and perceived spousal support of couples who have children with special needs. Correlational research allowed investigators to examine the existing relationships among two or more variables without the researcher controlling or manipulating any of the investigated variables (Karasar, 2015).

### Participants

Participants of the present study were the parents of 197 children with special needs (197 couples, a total of 394 parents) who lived in a large urban city in Northern Turkey. They were identified using a simple random sampling method among the parents of children with ASD or intellectual disability (ID) who were enrolled in special education schools or rehabilitation centers during 2019-2020 school year. Questionnaire packages were sent to the families of 450 children with ASD or ID. Parents of 231 children consented to participate in this study and completed the questionnaires. A total of 31 questionnaires were completed by either mothers or fathers alone (not by both in the couple) and so they were excluded from the study. Three additional cases were also removed from the data set due to extreme values. Therefore, the final study sample included 197 questionnaires filled out by both the mother and father in each family, individually. As results, data analysis was conducted using data obtained from a total of 394 parents, 197 mothers and 197 fathers. Demographic characteristics of participants are provided in Table 1.

**Table 1.** Demographic characteristics of parents and children

Parent attributes	Mother ( <i>n</i> = 197)	Father ( <i>n</i> = 197)	Total ( <i>n</i> = 394)
Age (M, SD)	37.26 (6.16)	40.78 (5.60)	39.0 (6.13)
Education (%)			
Primary school	39.1	34.0	36.5
Middle school	20.3	16.2	18.3
High school	22.3	26.9	24.6
College	18.3	22.9	20.6
Employment (%)			
Public employee	7.6	24.9	16.2
Private/Freelance	7.6	61.4	34.5
Not working	84.8	13.7	49.3
Change in employment status (part- time, lay-off) (%)	18.8	10.2	14.5
Child attributes	Intellectual Disability ( <i>n</i> = 111)	Autism ( <i>n</i> = 86)	Total ( <i>n</i> = 197)
Gender (%)			
Male	40.5	16.3	29.9
Female	59.5	83.7	70.1
Severity of disability (%)			
Mild	38.7	33.7	36.5
Moderate	37.8	37.2	37.6
Severe	23.6	29.1	25.9
Number of siblings (%)			
0	7.3	24.4	14.7
1	48.6	43.0	46.2
2	36.0	25.5	31.5
3+	8.1	7.1	7.6
Age			
Diagnostic	1.95 (2.15)	2.92 (1.31)	2.37 (1.89)
When received initial services	3.35 (2.35)	3.38 (1.55)	3.37 (2.04)

## Instruments

Data were collected through a survey package that included a demographic information form, the Family Burden Rating Scale (Yildirim-Sari & Basbakkal, 2008), and the Spousal Support Scale (Yildirim, 2004).

### *Demographic Information Form*

Prepared by the researchers, this form was used to collect data about demographic backgrounds of participants. The form included questions regarding demographic characteristics, such as age, occupation, educational status, and duration of marriage. In addition, the participants were asked to report the number of children and their demographic attributes, including gender, chronological age, age of diagnosis, type, and degree of disability noted on the diagnostic evaluation report.

### *Family Burden Scale*

Yildirim-Sari and Basbakkal (2008) developed the Family Burden Scale to evaluate the burden perceived by the families with children with special needs. The scale includes 43 items under 6 sub-dimensions. Items on the scale were scored using a five-point Likert-type scale, ranging from never (1) to always (5). Scores on the scale range between 43 and 215. Higher scores on the scale indicated increased family burden. Reported Cronbach's alpha and test-retest correlation coefficient were .92 and .98, respectively (Yildirim-Sari & Basbakkal, 2008). In the present study, the Cronbach alpha coefficient was found to be .95. Sample items from the scale include "I spend most of my time taking care of my child" (item 37; time requirement subscale) and "I miss being alone with my wife/husband" (item 35; emotional burden).

### *Spousal Support Scale*

Yildirim (2004) developed the Spousal Support Scale to measure the perceptions of spouses about the support they receive from each other. The scale includes 27 items under 4 sub-dimensions. Items on the scale were scored using a five-point Likert-type scale, ranging from not suitable for me (1) to suitable for me (5). Scores on the scale range between 27 and 81. Higher scores on the scale indicated increased spousal support. Reported Cronbach's alpha and test-retest correlation coefficient were .95 and .89, respectively (Yildirim, 2004). In the present study, the Cronbach alpha coefficient was found to be .95. Sample items from the scale include "My spouse tries to make time to be with me" (item 3) and "My spouse helps me cope with problems" (item 25).

## Data Collection Procedures

After obtaining ethical approval and permission from the local education agency, researchers contacted the administrators of all special education schools and rehabilitation centers in the city to obtain list of all students who had either ASD or intellectual disability ( $n = 1590$ ). Next, 450 randomly selected students with a diagnosis of ASD or an intellectual disability were sent the survey packages in closed envelopes. Along with the survey package, information about the purpose and content of the study, and informed consent forms were sent to the families. Parents who volunteered to participate in the present study were asked to complete the consent form and survey package anonymously and return it back to the school administrators in a closed envelope. Survey packages included forms for the mother and father separately. Mothers and fathers were asked to fill out the surveys independently and not to share their answers with each other. Each couple was given three weeks to return the survey package. Forms completed by only one of the parents were not included in the data analysis. Once the data collection packages were returned to the researchers, consent forms and survey were separated from each other to protect confidentiality and anonymity of the participants.

## Data Analysis

A paired samples  $t$ -test was used to determine whether perceived family burden and perceived spousal support differed significantly between couples (research question 1). This was done by comparing

the aggregate scores of the fathers on the Family Burden and then Spousal Support Scales to the scores of the mothers. Next, the scores of the families who had children with ASD were compared to the scores of the families with children with intellectual disabilities. Finally, the aggregate scores of the parents with male or female children were compared. To address the second research question, a multiple regression analysis was performed to determine the variables that predict perceived family burden of couples who have children with special needs. Prior to the multiple regression analysis, the Pearson product-moment correlation coefficient was computed to determine the relationship between perceived family burden and perceived spousal support. The SPSS 22 was used to conduct the data analysis. The significance of the obtained statistics was tested at the .05 level.

Prior to the data analysis extreme values in the data set were identified by calculating the Mahalanobis distance. Six data points with extreme values (3 couples) were noted and removed from the data set. The remaining analyses were conducted using the data from 197 couples (394 parents). Following the removal of cases with extreme values, univariate normality assumptions were examined by calculating kurtosis and skewness coefficients using the One Sample Kolmogorov-Smirnov (K-S) test. Results of K-S revealed a  $p$  value .20 ( $p > .05$ ) for the Family Burden Scale and Spousal Support Scale scores. In addition, kurtosis and skewness values were found to be -.801 and -.097 for mothers' perceived family burden scores; .089 and -.941 for mothers' perceived spousal support; -.606 and .102 for fathers' perceived family burden; and 1.125 and -1.240 for fathers' perceived spousal support. These results indicated that the data met the univariate normality assumptions. Next, normality, linearity and homogeneity assumptions to perform multivariate analyzes were tested (Cokluk et al., 2018). Scatter plots of all binary variable combinations were examined. The examination of scatter plots showed an ellipse or close to ellipse pattern, indicating that the normality assumption was met. When the residual graphs were examined, it was determined that the values were gathered around a linear axis. As a result of the Box's M test, the variances were homogeneous (Box's  $M = 163.16$ ,  $p = .39$ ). These results indicated that the data met the assumptions for multivariate analysis.

## Results

### Perceived Family Burden and Spousal Support by Couples and Child-Related Variables

A paired samples  $t$ -test was performed to determine whether perceived family burden and perceived spousal support differed significantly between couples. As seen in Table 2, perceived family burden,  $t(196) = 3.82$ ,  $p < .001$ , and perceived spousal support,  $t(196) = -3.62$ ,  $p < .001$ , differed significantly between couples. The mean perceived family burden score for mothers ( $M = 115.09$ ) was significantly higher than that of fathers ( $M = 109.48$ ) while the mean perceived spousal support score for fathers ( $M = 68.40$ ) was significantly higher for than mothers ( $M = 65.98$ ).

While both perceived family burden ( $p < .01$ ) and perceived spousal support ( $p < .01$ ) mean scores differed significantly between couples who have children with intellectual disabilities, parents of children with ASD differed significantly in perceived spousal support scores ( $p < .01$ ). The mean perceived family burden score of mothers of children with intellectual disabilities ( $M = 112.36$ ) was significantly higher than that of fathers ( $M = 105.88$ ) while the mean perceived spousal support scores for these mothers ( $M = 67.74$ ) was significantly lower than their spouses ( $M = 69.33$ ). While the mean perceived family burden scores of the parents of children with ASD did not differ significantly between the couples ( $p > .05$ ), the mean perceived spousal support of these mothers ( $M = 63.70$ ) was significantly lower than that of the fathers ( $M = 67.19$ ).

**Table 2.** Comparison of perceived family burden and spousal support across couples and demographic variables

			N	Mother		Father		Df	t	p
				M	SD	M	SD			
<b>Perceived Family Burden</b>										
Type of disability		Intellectual disability	111	112.36	32.73	105.88	31.09	110	3.53	.001
		Autism	86	118.60	33.09	114.13	33.43	85	1.86	.06
Severity of disability		Mild	72	100.56	31.39	91.22	27.77	71	3.63	.001
		Moderate	74	120.60	33.83	116.11	31.54	73	2.20	.03
		Severe	51	127.58	26.05	125.64	27.10	50	.61	.54
Gender of child		Female	59	107.07	34.16	105.97	32.25	58	.45	.65
		Male	138	118.51	31.93	110.98	32.34	137	4.17	.000
<b>Total</b>			197	115.09	32.95	109.48	32.31	196	3.82	.000
<b>Perceived Spousal Support</b>										
Type of disability		Intellectual disability	111	67.74	10.75	69.33	10.84	110	-1.74	.001
		Autism	86	63.70	12.88	67.19	11.79	85	-3.57	.001
Severity of disability		Mild	72	65.73	11.57	67.76	12.65	71	-1.72	.08
		Moderate	74	66.64	11.94	69.97	9.49	73	-3.17	.002
		Severe	51	65.37	12.35	67.00	11.59	50	-1.29	.20
Gender of child		Female	59	66.08	12.31	67.97	11.26	58	-1.48	.14
		Male	138	65.93	11.72	68.58	11.33	137	-1.09	.001
<b>Total</b>			197	65.98	11.87	68.40	11.29	196	-3.62	.000

Perceived family burden of parents of children with mild ( $p < .01$ ) and moderate disabilities ( $p < .05$ ), and perceived spousal support of parents of children with moderate disabilities ( $p < .05$ ) differed significantly between couples. The mean perceived family burden scores of mothers of children with mild and moderate disabilities ( $M_{\text{mild}} = 100.56$ ,  $M_{\text{moderate}} = 120.60$ ) were significantly higher than those of fathers ( $M_{\text{mild}} = 91.22$ ,  $M_{\text{moderate}} = 116.11$ ). The mean perceived spousal support of mothers of children with moderate disabilities ( $M_{\text{moderate}} = 66.64$ ) was significantly lower than that of father ( $M_{\text{moderate}} = 69.97$ ). Perceived family burden of parents of children with severe disabilities and perceived spousal support of parents of children with mild and severe disabilities did not differ between the couples (all values of  $p > .05$ ).

Perceived family burden ( $p < .001$ ) and perceived spousal support ( $p < .01$ ) of couples with a son with special needs differed significantly between couples while neither perceived family burden nor perceived spousal support differed significantly between couples who have daughters with disabilities (both values of  $p > .05$ ). The mean family burden score of mothers of boys with disabilities ( $M = 118.51$ ) was significantly higher than that of fathers ( $M = 110.98$ ) while the mean perceived spousal support for mothers ( $M = 65.93$ ) was significantly lower than fathers ( $M = 68.58$ ).

### Predictors of Perceived Family Burden

A multiple regression analysis was performed to determine the variables that predict the family burden of the parents of children with special needs. A prerequisite for conducting multiple regression analysis is statistically significant correlations among the variables (Buyukozturk, 2018). Therefore, a Pearson product-moment correlation analysis was conducted, and results showed that there was a statistically significant negative correlation between family burden and spousal support perceived by mothers ( $r = -.24$ ,  $p < .01$ ) and fathers ( $r = -.19$ ,  $p < .01$ ). Predictors of perceived family burden in mothers and fathers were analyzed separately by multiple regression analysis (see Table 3 & Table 4).

As shown in Table 3, perceived family burden in mothers had a positive and moderate relationship with the severity of child's disability ( $r = .33$ ), a negative and weak relationship with perceived spousal support ( $r = -.24$ ), and a weak and positive correlation with the gender of the child ( $r = .15$ ). When the other variables were controlled, the correlation between perceived family burden in mothers and the severity of child's disability was  $r = .36$ , perceived family burden and perceived spousal support was  $r = -.26$ , perceived family burden and gender of the child was  $r = .15$ . Results showed that the perceived family burden in mothers increased as the perceived spousal support decreased, or the severity of child's disability increased. Moreover, perceived family burden was higher in mothers of boys with special needs. Finally,



paired and partial correlations between the type of child's disability and perceived family burden by mothers were negligible.

**Table 3.** Predictors of family burden in mothers of children with special needs

Predictive Variable	Reg. Coeff.	St. Error	$\beta$	$t$	$p$	Paired $r$	Partial $r$
Constant	101.93	17.16	-	5.94	.000	-	-
Severity of disability	23.62	4.41	.34	5.35	.000	.33	.36
Perceived spousal support	-.69	.18	-.25	-3.80	.000	-.24	-.26
Gender of the child	12.45	4.80	.17	2.60	.010	.15	.18
Type of disability	-.76	4.50	-.01	-.17	.865	.09	-.01

$R = .45, R^2 = .20, F(4, 192) = 12.21, p = .000$

The  $t$ -test results regarding the significance of the regression coefficients indicated that the severity of child's disability ( $t = 5.35, p < .001$ ), the perceived spousal support ( $t = -3.80, p < .001$ ) and the gender of the child ( $t = 2.60, p < .05$ ) variables significantly predicted the perceived family burden in mothers. The type of child's disability did not significantly predict the perceived family burden ( $t = -.17, p > .05$ ). Based on the  $\beta$  values of the predictive variables, the severity of child's disability was the best predictor of family burden, while perceived spousal support was the second, and child's gender was the third. These three variables predict 20% of the perceived family burden in mothers ( $R^2 = .20, F(4, 192) = 12.21, p = .000$ ).

As shown in Table 4, perceived family burden in fathers had a positive and moderate relationship with the severity of child's disability ( $r = .45$ ) and a negative and weak relationship with perceived spousal support ( $r = -.19$ ). When the other variables were controlled, the correlation between perceived family burden in fathers and the severity of child's disability was  $r = .45$  and perceived family burden and perceived spousal support was  $r = -.23$ . Results showed that the perceived family burden in fathers increased as the perceived spousal support decreased, or the severity of child's disability increased. Paired and partial correlations between child's gender or disability and perceived family burden in fathers were negligible.

**Table 4.** Predictors of family burden in fathers of children with special needs

Predictive Variable	Reg. Coeff.	St. Error	$\beta$	$t$	$p$	Paired $r$	Partial $r$
Constant	87.02	16.59	-	5.24	.000	-	-
Severity of disability	29.32	4.22	.43	6.94	.000	.43	.45
Perceived spousal support	-.59	.18	-.20	-3.27	.001	-.19	-.23
Gender of the child	5.27	4.60	.07	1.14	.252	.07	.08
Type of disability	4.23	4.26	.06	.99	.322	.12	.07

$R = .49, R^2 = .24, F(4, 192) = 15.31, p = .000$

The  $t$ -test results regarding the significance of the regression coefficients indicated that the severity of child's disability ( $t = 6.94, p < .001$ ) and the perceived spousal support ( $t = -3.27, p < .01$ ) variables significantly predicted the perceived family burden in fathers. Child's gender ( $t = 1.14, p > .05$ ) and disability ( $t = .99, p > .05$ ) did not significantly predict the perceived family burden. Based on the  $\beta$  values of the predictive variables, the severity of child's disability was the best predictor of family burden, while perceived spousal support was the second. These two variables predict 24% of the perceived family burden in fathers ( $R^2 = .24, F(4, 192) = 15.31, p = .000$ ).

## Discussion

The present study was designed to examine the differences between family burden and spousal support perceived by mothers and fathers of children with special needs and investigate the predictors of perceived family burden and spousal support. Findings showed that perceived family burden and spousal support differed significantly between couples. More specifically, we found that the mothers of children with special needs have significantly higher perceived family burden and significantly lower perceived

spousal support in comparison to the fathers of children with special needs. This finding is consistent with the findings of previous studies reporting higher family burden perceived by mothers of children with special needs (Karayagiz-Muslu & Coskun-Cenk, 2018; Picardi et al., 2018; Ström et al., 2012). The main reason for why mothers of children with special needs have higher family burden may be explained by the fact that mothers are considered as primary caregivers and undertake more parenting responsibilities when compared to fathers (Bornstein & Putnick, 2016; Papadopoulos, 2021). In many societies, mothers leave their jobs and take care of their children when a child with special needs joins to the family (Turan-Gurhopur & Isler-Dalgic, 2017). Frequently, this results in social isolation of mothers (Karayagiz-Muslu & Coskun-Cenk, 2018), and could potentially bring economic, physical, social, and emotional burdens. Despite the changes in the contemporary family structures, the difference between male and female roles especially in families with low socioeconomic status still persists (Luz & Berni, 2010). In families where the traditional family structure is dominant, such as in Turkish society, the male does not directly take the responsibility of caring for children; they often provide support to the family indirectly by doing out-of-home duties (Marks et al., 2009; Rana et al., 2021). In the current study, most fathers (86%) were working outside of home and most mothers were not working outside the home; thus, they had more care responsibilities. This may have resulted in increased family burden perceived by mothers. Different levels of family burden reported by the mothers and fathers in the same family can be explained by the Family Systems Theory (Turnbull et al., 2011) which emphasizes that a family member's experience of having special needs has the potential to affect everyone else in the family system and its subsystems (Seligman & Darling, 2007). The way each family responds to having a family member with special needs is different, as each family's dynamics and inputs (family characteristics, family interactions, and family life cycle) are different. Moreover, each individual within the family (e.g., father or mothers) may also respond to this situation differently.

Research has shown that perceived spousal support plays a more critical role than the actual amount of support provided. Further, spousal support is extremely important for parents' well-being since many mothers of children with special needs limit their social relationships (Atila-Demir & Keskin, 2018; Ilhan et al., 2019; Karayagiz-Muslu & Coskun-Cenk, 2018) and cope with challenges they are facing alone (Woodgate et al., 2008). In the present study, we found that the perceived spousal support of mothers was lower than the spousal support perceived by fathers. The same pattern in perceived spousal support was observed when the types of child's disability was considered. It should be noted that the low spousal support perceived by mothers may not be a direct result of the amount of spousal support provided by fathers. The difference in perceived spousal support between mothers and fathers of children with special needs may be due to the different support needs of the spouses. Moreover, the types of support mothers expect from their spouses may be different than the types of support they receive from their spouses. Reevy and Maslach (2001) reported that men and women generally differ both in their support needs and in their ability to respond to their partner's support needs. For example, women are more likely to offer support spontaneously and when requested (Samter, 2002). Studies also showed that women provide more support to their spouses during stressful times but receive less support from their spouses in similar situations (Karakus & Kirlioglu, 2019). The high level of support women provide to their spouses may result in an expectation of a similar level of support from spouses. This difference between the level of expected and received spousal support may affect the marital relations negatively (Lawrence et al., 2008).

Findings of the present study also showed that the severity of the child's disability predicted the family burden of both mothers and fathers; as the severity of the child's disability increased, the burden perceived by mothers and fathers also increased. This finding may be related to the research showing that as children's disability severity increases, the time and expenses spent on childcare increase (Nam & Park, 2017), the level of exposure to social isolation increases (Karayagiz-Muslu & Coskun-Cenk, 2018); thus, the family burden increases (Langley et al., 2017). Moreover, the family burden perceived by mothers and fathers differs based on the level of the severity of child's disability. While the family burden of mothers of children with mild and moderate disabilities was significantly higher than that of fathers, the family burden of mothers and fathers of children with severe disability was found to be similar. In line with traditional

gender roles, the mothers in this study bear most of the burden in the families of children with mild and moderate disabilities, and therefore family burden perceived by those mothers was higher than the fathers. Whereas when children had more severe disabilities, childcare responsibilities were potentially shared more equally among the spouses which in turn resulted in a similar burden as perceived by the mothers and fathers.

Picardi et al. (2018) found that the family burden perceived by the mothers of children with ASD was higher than those perceived by the mothers of children with Down Syndrome and asserted that the difference was due to the severity of ASD and children with ASD having comorbid intellectual disability. Similarly, in the current study, we found that the family burden perceived by mothers and fathers of children with ASD was higher than the burden perceived by the parents of children with intellectual disabilities. When the perceived family burden of the parents was compared, we found that family burden perceived by mothers and fathers of children with intellectual disabilities was significantly different, while the family burden perceived by the parents of the children with ASD did not differ. This suggests that the burden is shared more between spouses in families of children with ASD. Due to the difficulties associated with the nature of ASD, it is thought that spouses shared the burden and therefore perceived family burden at a similar level. In addition, mothers bear most of the burden in the families of children with mild and moderate disabilities, in line with traditional gender roles, and therefore the burden perceived by mothers is higher. As the severity of disability increases, the increase in the family burden may ensure that the burden of care for children with severe disabilities is shared more among the spouses. For this reason, it is thought that the family burden does not differ between spouses within the families of children with severe disabilities.

In the present study, we also found that family burden and spousal support perceived by mothers and fathers differed based on the child's gender. The family burden perceived by the mothers of boys with disabilities was significantly higher than that of fathers and the spousal support perceived by mothers was found to be significantly lower. This finding may be explained by father involvement in the care of children. The low levels of father involvement in child care is explained by traditional gender roles in the literature. The decrease in father involvement in the care of boys may be related to the values attributed to the "male" children. Having a "male" child is considered to be important for the continuation of the lineage in Turkish society, and it may be more difficult for fathers to accept that a male child has special needs (Mese, 2013). Thus, having a male child with special needs may cause a greater social and emotional burden on the family.

Finally, the findings of this study showed that perceived spousal support significantly predicted family burden perceived by mothers and fathers of children with special needs. As the perceived spousal support increased, the family burden of the mothers and fathers decreased. Research has shown that spouses who have children with special needs are often not able to allocate enough time to each other; thus, they do not receive necessary support and intimacy from one another (Woodgate et al., 2008). Further, their marital relations deteriorate while rearranging their daily lives to support the child with disability (Sim et al., 2016). Spousal support is an important protective factor for relational resilience and marital harmony when parents face these challenges. Couples need more support from their spouses when they face difficult life or health issues and can cope with negative situations easier when they receive spousal support (Aydoğan & Kizıldag, 2017). They can therefore perceive stressors as more manageable and controllable, and cope with the family burden more easily when appropriated levels of spousal support are present. It is expected that the quality of marriage will be high in couples where the family burden is shared by providing spousal support. Marriage quality can also positively affect the quality of parent-child relationships (Wieland & Baker, 2010). Recent literature on child development indicates that there is a strong link between the quality of the parent-child relationship and child outcomes (Hintsanen et al., 2019). Children develop better skills to cope with and adapt to the difficulties of life when a strong and caring relationship exists between parents and children (Frost et al., 2020).

### **Limitations and Recommendations**

There are at least three limitations of this study the reader should consider when interpreting the findings from this study. First, the study focused on a cross-sectional analysis of family burden and spousal support perceived by parents of children with special needs using a survey design. Studies investigating these variables longitudinally and using different research approaches (e.g., mixed method approach) may reveal a deeper understating of factors that impact perceived family burden and spousal support. Second, this study only included parents of children with ASD and intellectual disabilities. Therefore, results may not be generalizable to other populations. Future research should examine perceived family burden and spousal support among parents of children who have other disabilities. Third, this study focused on the negative impact of having a child with special needs on the family. Recent studies have emphasized that children with special needs make positive contributions to the family over time (e.g., Gokgoz & Kabukcuoglu, 2022). Families of children with special needs also develop various skills because of different experiences and improve their functioning. Thus, future research should examine families of children with special needs in the context of positive and protective psychological characteristics such as forgiveness, post-traumatic growth, tolerance, self-compassion, and resilience.

### **Implications for Practice and Policy**

Findings from the present study have a number of implications for services and practices offered to parents of children with disabilities. First, parents of children with special needs should be provided with therapies focused on developing coping strategies and resources when their children are identified with disabilities. Moreover, the therapy and intervention efforts should focus on improving protective psychological characteristics identified in this study. These services should be readily available for parents to participate in following the diagnosis of their children with a disability. Second, parents of children with special needs should be offered psychoeducational therapies and participate in the intervention sessions together for maximum benefit. These therapies can be used to support couples to learn different types of spousal support, to develop an understanding of spousal expectations, to provide spousal support to the other spouse, and to recognize the support offered by the spouse. Although these supports may add additional burden to families of children with disabilities initially, parents who benefit from these services will be able to cope with the stress and burden associated with having a family member with disability and in turn, will be able to support development of their children more effectively. In fact, most parents focus on their children when they have identified disabilities and put themselves second, which often contribute to the increased parental stress and family burden. Moreover, parents of young children with disabilities may have difficulty in navigating systems to identify services they need (Brown et al., 2020). When parents experience high levels of stress and family burden, they may be less responsive to the needs of their children with special needs. The suggested support services will help parents to develop a supportive microsystem where strong, caring, and nurturing parent-child relationships exist. Parents who develop coping strategies to address stress and family burden will become more empowered within their exosystems and will be able to employ their mesosystems to respond to the difficulties they encounter while taking care of their family members with special needs.

The priority in the therapy services should be given to the parents of children with severe disabilities as the higher family burden and lower spousal support is more often associated with this group. These support services can be integrated into the currently existing Family Counseling Program offered by the Turkish Ministry of Family and Social Services. The current Family Counseling Program focuses on providing counseling services to families who have come to the point of divorce due to communication problems between spouses and within families. As the Ministry develops psychoeducational therapies for the parents and families of children with disabilities, they can be incorporated into the system and be offered by the professional working in the Community Mental Health Centers across the nation. In addition, parents of children with disabilities can receive temporary psychological support during urgent situation from the Social Support Line offered by the Ministry if the staff is trained to provide such support. Moreover, family counseling services or units can be established within the hospitals that provide medical diagnosis of disabilities for young children. These efforts require policy changes in macrosystem and

collaboration among the Ministry of Family and Social Services and Ministry of Health.

## Declarations

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## References

- Atila-Demir, S., & Keskin, G. (2018). The challenges that mothers of mentally handicapped children are facing with -a qualitative research. *The Journal of Academic Social Science Studies*, 66(2), 357-372. <http://dx.doi.org/10.9761/JASSS7528>
- Aydogan, D., & Kizildag, S. (2017). Examination of relational resilience with couple burnout and spousal support in families with a disabled child. *The Family Journal*, 25(4), 407-413. <https://doi.org/10.1177/1066480717731215>
- Aysan, F., & Ozben, Ş. (2007). An investigation of the variables related to the quality of life of parents of disabled children. *Journal of Buca Faculty of Education*, 22, 1-6.
- Bhatia, S. (2018). Promoting resiliency in families of individuals with disabilities: Role of coping resources, family support, social participation and perceived burden. *Indian Journal of Health & Wellbeing*, 9(4), 599-608.
- Bildirici, F. (2014). *Relationship between family burden and resilience of families of children with special education needs*. Unpublished Master Thesis. Halic University, İstanbul.
- Bornstein, M. H., & Putnick, D. L. (2016). Mothers' and fathers' parenting practices with their daughters and sons in lowand middle-income countries. *Monograph of the Society for Research in Child Development*, 81(1), 60-77. <https://doi.org/10.1111/mono.12226>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723-742.
- Bronfenbrenner, U. (1995). Developmental ecology through space and time: A future perspective. In P. Moen, G. H. Elder Jr., & K. Lüscher, *Examining lives in context: Perspectives on the ecology of human development* (pp. 619-647). American Psychological Association.
- Brown, A., McIsaac, J. L. D., Reddington, S., Hill, T., Brigham, S., Spencer, R., & Mandrona, A. (2020). Newcomer families' experiences with programs and services to support early childhood development in Canada: A scoping review. *Journal of Childhood, Education & Society*, 1(2), 182-215. <https://doi.org/10.37291/2717638X.20201249>
- Busillo-Aguayo, J. (2010). *Family experiences with accessing information, social and resource supports as participants in services for their special needs child over three years of age* (Publication No. 3412332) [Doctoral dissertation, Pepperdine University]. Proquest.
- Buyukozturk, S. (2018). *Sosyal bilimler için veri analizi el kitabı*. (24<sup>th</sup> ed). Pegem.
- Chachar, A. S., Younus, S., & Ali, W. (2021). Developmental understanding of death and grief among children during COVID-19 pandemic: application of Bronfenbrenner's bioecological model. *Frontiers in Psychiatry*, 12, 654584. <https://doi.org/10.3389/fpsy.2021.654584>
- Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing*, 15(6), 398-407. <https://doi.org/10.1053/jpdn.2000.16709>
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129(4), 617-623. <https://doi.org/10.1542/peds.2011-2700>
- Cokluk, Ö., Sekercioglu, G., & Buyukozturk, S. (2018). *Sosyal bilimler için çok değişkenli istatistik: SPSS ve LISREL uygulamaları*. (5<sup>th</sup> ed.).

Pegem Akademi.

- De Caroli, M. E., & Sagone, E. (2013). Siblings and disability: A study on social attitudes toward disabled brothers and sisters. *Procedia-Social and Behavioral Sciences*, 93, 1217-23. <https://doi.org/10.1016/j.sbspro.2013.10.018>
- Di Giulio, P., Philipov, D., & Jaschinski, I. (2014). Families with disabled children in different European countries. *Families and Societies, Working Paper*, 23, 1-44. <http://www.familiesandsocieties.eu/wp-content/uploads/2014/12/WP23GiulioEtAl.pdf>
- Eriksson, M., Ghazinour, M., & Hammarström, A. (2018). Different uses of Bronfenbrenner's ecological theory in public mental health research: what is their value for guiding public mental health policy and practice?. *Social Theory & Health*, 16(4), 414-433. <https://doi.org/10.1057/s41285-018-0065-6>
- Frost, N., Devaney, C., & Herrera-Pastor, D. (2020). Understanding contemporary family support: Reflections on theoretical and conceptual frameworks. *Social Work and Social Sciences Review: An Internal Journal of Applied Research*, 21(2), 27-45. <https://doi.org/10.1921/swssr.v21i2.1420>
- Gokgoz, C., & Kabukcuoglu, K. (2022). "Thanks to my child, I discovered that I am strong and I grew up with my child": Personal growth in mothers of children with Down syndrome in Turkey. *Research in Developmental Disabilities*, 124. <https://doi.org/10.1016/j.ridd.2022.104217>
- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43, 2604-2616. <https://doi.org/10.1007/s10803-013-1812-0>
- Hartley, S. L., DaWalt, L. S., & Schultz, H. M. (2017). Daily couple experiences and parent affect in families of children with versus without autism. *Journal of Autism and Developmental Disorders*, 47, 1645-1658. <https://doi.org/10.1007/s10803-017-3088-2>
- Hayes, S.A., & Watson, S. L. (2013). The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629-642. <https://doi.org/10.1007/s10803-012-1604-y>
- Hintsanen, M., Gluschkoff, K., Dobewall, H., Cloninger, C. R., Keltner, D., Saarinen, A., Wesolowska, K., Volanen, S.-M., Raitakari, O. T., & Pulkki-Råback, L. (2019). Parent-child-relationship quality predicts offspring dispositional compassion in adulthood: A prospective follow-up study over three decades. *Developmental Psychology*, 55(1), 216-225. <https://doi.org/10.1037/dev0000633>
- Hosokawa, R., & Katsura, T. (2017). Marital relationship, parenting practices, and social skills development in preschool children. *Child and Adolescent Psychiatry and Mental Health*, 11(2), 1-8. <https://doi.org/10.1186/s13034-016-0139-y>
- Hsiao, Y. J. (2018). Parental stress in families of children with disabilities. *Intervention in School and Clinic*, 53(4), 201-205. <https://doi.org/10.1177/105345121771295>
- Huber, C. H., Navarro, R. L., Womble, M. W., & Mumme, F. (2010). Family resilience and midlife marital satisfaction. *The Family Journal: Counseling and Therapy for Couples and Families*, 18(2), 136-145. <https://doi.org/10.1177/1066480710364477>
- Ilhan, N., Utaş-Akhan, L., Baygut, Ş., Dalli, G.N., & Yildirim, C. (2019). The factors affecting the family burden and depression status of families of children with down syndrome in Turkey. *Journal of Mental Health Research in Intellectual Disabilities*, 12(3-4), 176-195. <http://dx.doi.org/10.1080/19315864.2019.1654573>
- Irazábal, M., Marsà, F., García, M., Gutiérrez-Recacha, P., Martorell, A., Salvador-Carulla, L., & Ochoa, S. (2012). Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder. *Research in Developmental Disabilities*, 33(3), 796-803. <https://doi.org/10.1016/j.ridd.2011.12.002>
- Kaner, S. (2004). *Perceived stress, social support and life satisfaction in parents with disabled children*. Unpublished Research Report. Ankara University. <https://dspace.ankara.edu.tr/xmlui/handle/20.500.12575/68118>
- Kanter, J. B., & Proulx, C. M. (2019). The longitudinal association between maternal parenting stress and spousal supportiveness. *Journal of Family Psychology*, 33(1), 121-131. <https://doi.org/10.1037/fam0000478>
- Karakus, O., & Kirlioglu, M. (2019). Life experiences of having a disabled child: A qualitative research on mothers. *Selçuk University Social Sciences Institute Journal*, 41, 96-112.
- Karasar, N. (2015). *Bilimsel araştırma yöntemi*. Nobel Yayınevi.
- Karayagiz-Muslu, G., & Coskun-Cenk, S. (2018). The family burdens and hopelessness of Turkish parents of adolescents with intellectual disabilities. *Rehabilitation Nursing*, 43(6), 351-362. <http://dx.doi.org/10.1097/rnj.0000000000000081>
- Langley, E., Totsika, V., & Hastings, R. P. (2017). Parental relationship satisfaction in families of children with autism spectrum disorder (ASD): A multilevel analysis. *Autism Research*, 10(7), 1259-1268. <https://doi.org/10.1002/aur.1773>
- Lawrence, E., Bunde, M., Barry, R., Brock, R. L., Sullivan, K. T., Pasch, L. A., White, G. A., Dowd, C. E., & Adams, E. E. (2008). Partner support and marital satisfaction: Support amount, adequacy, provision and solicitation. *Personal Relationships*, 15(4), 445-463. <https://doi.org/10.1111/j.1475-6811.2008.00209.x>
- Luz, A., & Berni, N. (2010). Paternity process in the adolescence. *Brazilian Journal of Nursing*, 63(1), 43-50. <https://doi.org/10.1590/S0034->

[71672010000100008](#)

- Manor-Binyamini, I. (2011). Mothers of children with developmental disorders in the Bedouin community in Israel: Family functioning, caregiver burden, and coping abilities. *Journal of Autism and Developmental Disorders*, 41, 610–17. <https://doi.org/10.1007/s10803-010-1080-1>
- Marks, J. L., Lam, C. B. & McHale, S. M. (2009). Family patterns of gender role attitudes. *Sex Roles*, 61, 221–234. <https://doi.org/10.1007/s11199-009-9619-3>
- Mese, İ. (2013). Disabled motherhood: Mothers of children with intellectual disability. *Turkish Studies*, 8(12), 841-858. <http://dx.doi.org/10.7827/TurkishStudies.5974>
- Nam, S. J., & Park, E. Y. (2017). Relationship between caregiving burden and depression in caregivers of individuals with intellectual disabilities in Korea. *Journal of Mental Health*, 26(1), 50-56. <https://doi.org/10.1080/09638237.2016.1276538>
- O'Leary, S. G., & Vidair, H. B. (2005). Marital adjustment, child-rearing disagreements, and overreactive parenting: Predicting child behavior problems. *Journal of Family Psychology*, 19(2), 208-216. <https://doi.org/10.1037/0893-3200.19.2.208>
- Ozsenol, F., Isikhan, V., Unay B., Aydin, H. İ., Akin, R., & Gokcay, E. (2003). The evaluation of family functions of families with handicapped children. *Gülhane Medical Journal*, 45(2), 156-164.
- Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences*, 11(309), 1-16. <https://doi.org/10.3390/brainsci11030309>
- Papp, L. M., Goeke-Morey, M. C., & Cummings, E. M. (2004). Mothers' and fathers' psychological symptoms and marital functioning: Examination of direct and interactive links with child adjustment. *Journal of Child and Family Studies*, 13(4), 469-482. <https://doi.org/10.1023/B:JCFS.0000044728.34058.c0>
- Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 92-98. <https://doi.org/10.1111/jppi.12072>
- Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental burden and its correlates in families of children with autism spectrum disorder: A multicentre study with two comparison groups. *Clinical Practice & Epidemiology in Mental Health*, 14, 143–176. <http://dx.doi.org/10.2174/1745017901814010143>
- Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2) 109-124. <https://doi.org/10.1111/j.1365-2788.2006.00829.x>
- Rana, R., Sood, R., & Bhardwaj, S. (2021). Women and children's well-being in Indian nuclear families during the COVID-19 pandemic. *Journal of Childhood, Education & Society*, 2(2), 178-193. <https://doi.org/10.37291/2717638X.202122108>
- Reevy, G. M., & Maslach, C. (2001). Use of social support: Gender and personality differences. *Sex Roles*, 44, 437–59. <https://doi.org/10.1023/A:1011930128829>
- Sahu, S., Sahu, K.K., & Tanwar, S. (2019). Perceived stress, social support, family burden and stigma among caregivers of persons with intellectual disability. *Journal of Disability Studies*, 5(1), 31-36.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12(1), 33–41. <http://dx.doi.org/10.1023/A:1023513218433>
- Samter, W. (2002). How gender and cognitive complexity influence the provision of emotional support: A study of indirect effects. *Communication Reports*, 15(1), 5-16. <https://doi.org/10.1080/08934210209367748>
- Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children: A systems approach to childhood disability*. The Guilford Press.
- Sim, A., Cordier, R., Vaz, S., & Falkmer, T. (2016). Relationship satisfaction in couples raising a child with autism spectrum disorder: A systematic review of the literature. *Research in Autism Spectrum Disorder*, 31, 30–52. <https://doi.org/10.1016/j.rasd.2016.07.004>
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167–178. <http://dx.doi.org/10.1007/s10803-009-0844-y>
- Spiteri, J. (2021). The impact of the COVID-19 pandemic on children's mental health and wellbeing, and beyond: A scoping review. *Journal of Childhood, Education & Society*, 2(2), 126–138. <https://doi.org/10.37291/2717638X.20212294>
- Ström, H., Kreuter, M., & Rosberg, S. (2012). Quality of life in parents/caretakers of children with cerebral palsy in Kampong Cham, Cambodia. *Journal of Tropical Pediatrics*, 58(4), 303–306. <http://dx.doi.org/10.1093/tropej/fmr077>
- Swick, K. J., & Williams, R. D. (2006). An analysis of Bronfenbrenner's bio-ecological perspective for early childhood educators: Implications for working with families experiencing stress. *Early Childhood Education Journal*, 33(5), 371-378. <https://doi.org/10.1007/s10643-006-0078-y>
- Turan-Gurhopur, F. D., & Isler-Dalgic, A. (2017). Family burden among parents of children with intellectual disability. *Journal of Psychiatric Nursing*, 8(1), 9-16

- Turkish Ministry of Family and Social Services. (2022a). 2022- 2026 *Strategic Plan*. <https://www.aile.gov.tr/media/101050/2022-2026-stratejik-plani.pdf>
- Turkish Ministry of Family and Social Services. (2022b). 2030 *Barrier-Free Vision Document*. [https://www.aile.gov.tr/media/94718/2030\\_engelsiz\\_vizyon\\_belgesi.pdf](https://www.aile.gov.tr/media/94718/2030_engelsiz_vizyon_belgesi.pdf)
- Turkish Ministry of Family and Social Services. (2022c). 2023-2025 *The National Action Plan for the Rights of Persons with Disabilities*. [https://www.aile.gov.tr/media/122989/engell\\_haklari\\_ulusal\\_eylem\\_plani\\_2023-2025.pdf](https://www.aile.gov.tr/media/122989/engell_haklari_ulusal_eylem_plani_2023-2025.pdf)
- Turnbull, A., Turnbull, R., Erwin, E., Soodak, L., & Shogren, K. (2011). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (6<sup>th</sup> Ed.). Merrill/Prentice Hall.
- Unwin, G., & Deb, S. (2011). Family caregiver uplift and burden: Associations with aggressive behaviour in adults with intellectual disability. *Journal of Mental Health Research in Intellectual Disability*, 4(3), 186–205. <https://doi.org/10.1080/19315864.2011.600511>
- Wieland, N., & Baker, B. L. (2010). The role of marital quality and spousal support in behaviour problems of children with and without intellectual disability. *Journal of Intellectual Disability Research*, 54(7), 620-633. <https://doi.org/10.1111/j.1365-2788.2010.01293.x>
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075–1083. <https://doi.org/10.1177/1049732308320112>
- Woodman, A. C., Mawdsley, H. P., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. *Research in Developmental Disabilities*, 36, 264-276. <https://doi.org/10.1016/j.ridd.2014.10.011>
- Xu, Y., & Burleson, B. R. (2001). Effects of sex, culture, and support type on perceptions of spousal social support: An assessment of the "support gap" hypothesis in early marriage. *Human Communication Research*, 27(4), 535-566. <https://doi.org/10.1111/j.1468-2958.2001.tb00792.x>
- Yildirim, I. (2004). Development of spousal support scale. *Turkey Psychological Counseling and Guidance Journal*, 3(22), 19-25.
- Yildirim-Dogru, S., & Arslan, E. (2008). Engelli çocuęu olan annelerin süreklı kayęı düzeyi ile durumluk kayęı düzeylerinin karşılařtırılması. *Selçuk University Social Sciences Institute Journal*, 19, 543–553.
- Yildirim-Sari, H., & Basbakkal, Z. (2008). Developing "A Family Burden Assessment Scale" for the families of children with intellectual disability. *Journal of Anatolia Nursing and Health Sciences*, 11(3), 86-95.