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Evaluation of Family Burden and Quality of Life of Parents with Children with Disability

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ABSTRACT

This research was conducted to determine the family burden and quality of life of parents with children with disabilities. This descriptive study was carried out within special education and rehabilitation centers between the dates of October, 2017 and July, 2018. The sample of the study consisted of 518 parents. Data regarding the study were collected using the "Family Burden Assessment Scale" and "WHOQOL-BREF-TR Scale". A negative moderate and significant relationship has been detected between the physical domain and FBAS scores of the parents subjected while a negative strong and significant relationship was detected in the spiritual, social and environmental domains. It has been concluded that the quality of life has decreased as the family burden of the parents increased. In addition, family burden of parents had a negative effect on their quality of life.

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Family burden; children with disability; life quality; caregiver; parents

Introduction

Over 100 million children around the world have at least one type of disability (World Health Organization (WHO), 2018). Depending on the degree of disability, the life of a child with a disability and his or her family is affected in countless ways regarding the matter of children with any physical or mental disability such as not being able to perform specific activities along with self-care (Aykanat Girgin & Balcı, 2015; Bretherton & McLean, 2014). This situation may require these children to be under constant observation by eligible persons and cause such children to be in need of special care and rehabilitation (Araújo et al., 2016; Carlson & Miller, 2017; Dehghan et al., 2016; Kaçan Softa et al., 2016; Lu et al., 2015).

In recent years, studies on caregiving have shifted their focus to the concept of burden. The concept of family burden was first introduced by Grad and Sainsbury, which was defined as the negative costs that individuals with disabilities cause to their families (Gürhopur Turan & İşler Dalgıç, 2017). Family burden is a psychological burden that affects parents

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cognitively, physically, emotionally, socially, and economically. Such burden includes the difficulties and struggles experienced by all the family members as a result of an ill, suffering family member (Sivrikaya & Çiftçi Tekinarslan, 2013). Emotional burden; parents with such children experience sorrow since their children fall behind their peers, which becomes an emotional burden. (Timuçin, 2018). The economic burden is the burden that may be on the family due to private health and education costs of the child (Sarı Yıldırım, 2008). A child with a disability may not be able to perform self-care skills on their own and may need help from their parents. Parents can undertake self-care tasks such as bathing, toileting, eating, dressing, protection, and medication. All of which may create a serious physical burden on parents who are not able to rest sufficiently, especially on those also responsible for other household chores. The social burden occurs as a result of the family with a child with a disability not participating in a social environment for various reasons or the parents exposing themselves to isolation from society (Ahmadizadeh et al., 2015). Quality of life is a concept that reflects the well-being of people, which includes the sustainability of well-being, and positive and negative feelings, along with the experiences that create a sense of satisfaction in the person. All areas in the life of individuals, including physical, mental, environmental and social, affect the quality of life (Eser et al., 2008).

In the literature, family burden and quality of life among caregivers of schizophrenia and dementia patients (Swain et al., 2017) have been researched and mostly, care burden has been examined throughout such studies. When the literature is reviewed, it is seen that studies with parents of children with disabilities are mostly conducted with mothers. In addition, the absence of studies investigating the effect of family burdens on the quality of life of these parents reveals the importance of our study.

Materials and methods

The research was conducted in eight special education and rehabilitation centers between the October, 2017 and July, 2018. The mothers and fathers were informed about the study and written consent was obtained from the mothers who wanted to participate in the study. Ethical committee approval and permission from the related institution was obtained to conduct the research. The study was performed in accordance with the Declaration of Helsinki. Moreover, permission was obtained for the scales to be used in the study.

Participants

The population of the research was of 1800 parents of children between the ages of 0-15 who attended these institutions. The sample size was

calculated using the formula for a known population at a 95% confidence level and a 5% sampling error (Ural & Kılıç, 2018). According to the formula, the number of samples was determined as at least 317 people and the research was carried out with 518 parents. Besides this, by using a stratified random sampling method, the parents in the institutions were subject to stratified sampling.

Data collection

In the study, "Descriptive Information Form", "The Family Burden Assessment Scale (FBAS)", which was developed to evaluate the family burden of parents with a child with disabilities, and "The WHO Quality of Life Scale Short Form Turkish Version (WHOQOL)" were used to measure the quality of life of parents. -BREF-TR)" was used. These scales have been used in different studies before (Turan Gürhopur & İşler Dalgıç, 2017; Canarslan & Ahmetoğlu, 2015). In the special education and rehabilitation centers where the research was conducted there are waiting rooms where the parents can spend time while the children receive education. While the parents were waiting for their children, interviews were made by one of the researchers with these forms, and the data were collected. In this way, 518 people consisting of parents who agreed to participate in the study were included in the study.

Descriptive information form

Descriptive information form was prepared by the researchers in line with the literature (Gürhopur Turan & İşler Dalgıç, 2017; Kaytez et al., 2015; Yıldız, 2015), including type of parent, age of parent, education level of parent, family type, income status, number of children, age, gender and disability type of the child, adequacy status of findings received about the problems of the child with a disability and the duration of the special education that the child is receiving. The "Regulation of Special Education Services" in Turkey was taken into account (Diken, 2016) to classify the disability.

The family burden assessment scale (FBAS)

Developed by Yıldırım Sarı and Basbakkal (2008) the scale consists of economic burden (6 items), social burden (6 items), physical burden (5 items), emotional burden (11 items), perception of inadequacy (8 items), and time requirement (7 items) sub-dimensions. It is a 5-point Likert type and is scored as "Never (1), Rarely (2), Sometimes (3), Often (4), and Always (5)". The lowest score that can be obtained from the scale is 43, the highest score is 215. Those who get 97 points or more are considered

to have a family burden (Yıldırım Sarı & Basbakkal, 2008). In this study, Cronbach's Alpha reliability coefficient was found as 0.86. The parents stated the diagnoses of the children.

The WHO quality of life scale short form Turkish version (WHOQOL-BREF-TR)

In this study, the short form of the WHOQOL-BREF-TR, which was developed by WHO and whose validity and reliability was performed by Eser et al. (1999), was used. The scale consists of 4 sub-dimensions as physical, spiritual, social and environmental domains along with 27 items. A total score of the scale is not calculated and each sub-dimension is evaluated out of 20 or 100 points. In this study, the scores were evaluated out of 100. The increase in the score obtained from the sub-dimensions indicates that the quality-of-life increases (Eser et al., 1999; Skevington et al., 2004). In this study, Cronbach's alpha values were found as 0.91 in the physical domain, 0.92 in the spiritual, 0.85 in the social domain and 0.92 in the environmental domain.

Statistical analysis

The conformity of the data for normal distribution in the study was determined by the skewness and kurtosis normality test. Since the data conformed to the normal distribution, the "Independent sample t-test" was used in comparison of two independent groups, and "ANOVA" was used in comparisons of three independent groups. The Chi-square test was used in the analysis of the nonparametric variables (Ural & Kılıç, 2018).

To evaluate the effect of the significant differences, the phi coefficient was used for 2×2 tables in the Chi-square test, and the Cramer's V values were used for the tables larger than 2×2. For the independent samples of the t-test and Anova tests, the effect size was indicated by eta squared values. This value evaluates to 0.01 small effect, 0.06 medium effect, and 0.14 large effect (Pallant, 2017). In addition, correlation analysis was used to determine the strength and direction of the relationship between two variables; linear regression analysis was also used to determine the effects of the variables on each other.

Results

There was no participant with missing data in the study. Also, the number of people in each analysis was equal. The analyses were conducted with a total of 518 people. The results showed that 77.6% of the parents included in the study were mothers, 22.4% were fathers, 69.7% were 36 years and older, 57.5% had high school and above education level, 66.0% were unemployed, 58.3% had equal income and expenditure, 39.6% had less

income than expenditures, 87.5% had a nuclear family structure, 26.1% had a kinship marriage, 3.3% of couples lived apart, 75.5% had 2 or fewer children, and 2.5% had another child with a disability.

It was also seen that 59.5% of the children with disabilities were male, 62.7% were in the 7-15 age group, 37.3% were 6 years old and under, 20.5% had physical disabilities, 42.6% had mental disabilities, and 36.9% had other types of disabilities. 79.9% of these children had a special education period of 2 years or more, and 20.1% had a year or less special education. 41.1% of the parents received information about the problems of their children from teachers, 33.4% from doctors, 15.5% from psychologists, 5.0% from other families with children with disabilities, and 5.0% from no one. 79.9% of the mothers and 36.2% of the fathers were determined to have a family burden.

A statistically significant difference with a large effect size was found between the mothers and fathers in terms of their FBAS scores ($t = 11.190$; $p < 0.001$; $\eta 2 = 0.19$), and significant differences were observed in all the sub-dimensions of FBAS (Table 1). The FBAS scores of the mothers were higher than the fathers. The FBAS mean value of the parents who had high school or above education was found higher than the parents with below high school education. A statistically significant difference with a medium effect size was found between the FBAS scores of the parents in terms of their educational status ($t = 6.016$; $p < 0.001$; $\eta 2 = 0.06$). There was a statistically significant difference with a small effect size between the FBAS scores in terms of the family type of parents ($t = -2.308$; $p = 0.023$; $\eta 2 = 0.01$). The parents with extended families had a higher mean value of FBAS than those with nuclear families.

The mean values of the FBAS scores of the unemployed parents were found higher in all the sub-dimensions. A statistically significant difference was seen between the employed and unemployed parents with a large effect size in terms of FBAS scores ($t = -10.531$; $p < 0.001$; $\eta 2 = 0.17$,) and significant differences were found in all the sub-dimensions (Table 1). When we look at the income level of the parents involved; a statistically significant difference was seen between the income level and the FBAS score of the parents ($F = 35.042$; $p < 0.001$; $\eta 2 = 0.20$). The Bonferroni correction independent sample t-test was performed to identify of which groups the difference originated from and as a result and it was found that the FBAS scores of the parents whose income was higher than their expenditures (68.45 ± 34.39) were lower than the parents who had equal income and expenditures (111.16 ± 30.75) and whose income was less than the expenditures (132.80 ± 40.40) ($p < 0.001$).

When we look at the situation of the parents receiving sufficient information about their children; a statistically significant difference with a

Table 1. Comparison of FBAS and sub-dimension scores according to the characteristics of parents and their children.

		Economic burden		Inadequacy perception		Social burden		Physical burden		Emotional burden		Time requirement		FBAS	
Characteristics	N	Mean	Sd.	Mean	Sd.	Mean	Sd.	Mean	Sd.	Mean	Sd.	Mean	Sd.	Mean	Sd.
Parent															
Mother	402	17.69	6.58	27.08	7.79	14.61	6.51	14.67	5.85	31.12	10.33	22.40	7.34	127.64	34.30
Father	116	14.13	6.68	21.16	8.73	9.90	4.81	9.28	4.95	20.59	8.63	14.52	5.94	88.25	30.02
t; p			5.109; **p < 0.001**		6.581; **p < 0.001**		8.531; **p < 0.001**		9.889; **p < 0.001**		11.043; **p < 0.001**		11.902; **p < 0.001**		11.190; **p < 0.001**
η^2			**0.04**		**0.07**		**0.12**		**0.15**		**0.19**		**0.21**		**0.19**
Age groups of the parents															
20-35 age	157	17.29	6.73	25.20	8.16	14.15	6.13	13.68	5.89	10.14	29.49	20.91	7.49	120.34	33.97
36 age and over	361	16.72	6.77	25.99	8.46	13.30	6.60	13.36	6.17	11.20	28.44	20.52	7.90	118.16	38.54
t; p			0.879; p = 0.380		1.005; p = 0.316		1.422; p = 0.156		0.559; p = 0.577		1.040; p = 0.299		0.529; p = 0.590		0.645; 0.520
Education Level															
Under high school	220	18.12	6.11	28.97	7.16	14.42	6.25	14.27	5.96	30.83	10.77	23.57	6.98	129.89	33.18
High school and above	298	15.98	7.07	23.38	8.42	12.92	6.57	12.86	6.12	27.23	10.75	18.47	7.63	110.64	37.93
t; p			3.676; **p < 0.001**		8.143; **p < 0.001**		2.643; **p = 0.008**		2.633; **p = 0.009**		3.764; **p < 0.001**		7.897; **p < 0.001**		6.016; **p < 0.001**
η^2			**0.02**		**0.11**		**0.01**		**0.01**		**0.02**		**0.10**		**0.06**
Family type															
Nuclear	453	16.51	6.87	25.59	8.39	13.37	6.46	13.45	6.20	28.39	10.71	20.48	8.09	117.59	37.88
Extended	65	19.58	5.18	26.87	8.25	14.84	6.48	13.56	5.27	31.35	11.85	21.73	4.92	127.35	30.91
t; p			−4.271; **p < 0.001**		−1.153; p = 0.249		−1.710; p = 0.088		−0.166; p = 0.869		−2.054; **p = 0.040**		−1.741; p = 0.084		−2.308; **p = 0.023**
η^2			**0.03**		–		–		-		**0.01**		-		**0.01**
Employment Status															
Yes	176	15.15	6.70	23.77	8.71	9.88	4.14	10.44	4.79	22.43	8.58	16.59	6.39	97.03	28.72
No	342	17.79	6.62	26.77	8.01	15.45	6.648	15.02	6.10	32.02	10.53	22.72	7.61	130.03	36.10
t; p			−4.281; **p < 0.001**		−3.818; **p < 0.001**		−11.697; **p < 0.001**		−8.663; **p < 0.001**		−10.428; **p < 0.001**		−9.162; **p < 0.001**		−10.531; **p < 0.001**
η^2			**0.03**		**0.02**		**0.20**		**0.12**		**0.17**		**0.14**		**0.17**
Income Status															
Income more than expenditures [a]	11	8.54	5.20	16.27	8.29	12.86	5.44	8.36	7.10	13.27	3.34	14.72	5.51	68.45	34.39
Equal income and expenditures [b]	302	15.15	5.94	24.40	8.45	14.86	7.58	12.72	5.28	27.40	9.509	19.12	7.45	111.16	30.75
Income less than expenditures [c]	205	19.90	6.72	28.25	7.42	13.56	6.47	14.83	6.79	31.60	11.97	23.19	7.62	132.80	40.40
F; p			45.301; **p < 0.001**		21.752; **p < 0.001**		9.494; **p < 0.001**		11.758; **p < 0.001**		22.062; **p < 0.001**		21.468; **p < 0.001**		35.042; **p < 0.001**
η^2			**0.15;** c > b > a		**0.07;** c > b > a		**0.03;** c > b > a		**0.04;** c > b > a		**0.07;** c > b > a		**0.07;** c > b > a		**0.20;** c > b > a

(Continued)

Table 1. Continued

Status of finding the information received about the problems of the child with a disability adequate																
Yes	170	15.11	6.64	22.80	9.01	10.42	4.34	10.19	4.76	22,58	8,14	17,44	6,20	97,80	28,41
No	348	17.77	6.65	27.20	7.65	15.09	6.78	15.06	6.032	31,78	10,81	22,20	7,996	129,09	36,68
t; p		−4.270; **p < 0.001**		−5.475; **p < 0.001**		−9.468; **p < 0.001**		−9.976; **p < 0.001**		−10.791**; p < 0.001**		−7.444; **p < 0.001**		−10.659; **p < 0.001**	
η^2		**0.03**		**0.05**		**0.14**		**0.16**		**0.18**		**0.09**		**0.17**	
Age group of the child (year)															
6 and under	193	16.59	6.96	23.59	8.09	12.62	5.74	13.07	5.75	26,00	9,77	19,66	6,94	111,64	35,81
7-15	325	17.07	6.64	27.04	8.28	14.12	6.82	13.69	6.27	30,40	11,21	21,22	8,18	123,08	37,40
t; p		−0.783; p = 0.434		−4.624; **p < 0.001**		−2.679; **p = 0.008**		−1.116; p = 0.265		−4.692; **p < 0.001**		−2.217; **p = 0.027**		−3.418; **p = 0.001**	
η^2		-		**0.03**		**0.01**		-		**0.03**		**0.01**		**0.02**	
Gender of the child															
Girl	210	16.44	6.83	25.51	9.28	12.24	5.85	12.40	5.89	27,44	9,92	20,17	8,20	113,69	34,94
Boy	308	17.20	6.70	25.92	7.70	14.46	6.72	14.19	6.12	29,66	11,44	20,96	7,47	122,32	38,32
t; p		−1.251; **p = 0.211**		−0.525; **p = 0.600**		−3.885**; p < 0.001**		−3.319; **p = 0.001**		−2.350; **p = 0.019**		−1.119; **p = 0.264**		**-2.607; p = 0.009**	
η^2		-		-		**0.02**		**0.01**		**0.01**		-		**0.01**	
The duration of special education															
1 yıl year or less	104	15.33	7.17	20.90	10.17	12.39	6.26	11.18	5.54	25,45	11,29	17,03	6,72	100,74	36,82
2 yıl and over	414	17.59	6.12	25.35	7.41	16.11	7.07	15.93	5.68	32,33	11,38	21,86	7,83	129,80	36,52
t; p		−2.624; **p = 0.009**		−3.823; **p < 0.001**		−4.341; **p < 0.001**		−6.655; p < 0.001		−4.780; **p < 0.001**		−5.134; **p < 0.001**		−6.249; **p < 0.001**	
η^2		**0.01**		**0.02**		**0.03**		**0.07**		**0.03**		**0.04**		**0.07**	
Disability type															
Mental disability[a]	221	16.73	6.77	27.00	7.61	7.27	.48	14.22	5.91	29,64	11,60	7,71	,51	38,75	2,60
Physical disabilityb	106	16.59	6.56	24.92	9.77	5.49	.53	13.23	6.00	27,86	8,59	6,30	,61	29,94	2,90
Multiple disabilities[c]	58	21.13	5.08	30.68	5.51	4.74	.622	17.20	5.50	38,56	8,51	6,84	,89	19,75	2,59
Others[d]	133	15.55	6.88	22.18	7.88	5.52	.47	10.75	5.54	23,73	8,99	7,50	,65	34,86	3,02
F;p		9.948; **p < 0.001**		18.446; **p < 0.001**		13.352; **p < 0.001**		19.041; **p < 0.001**		30.164; **p < 0.001**		24.451; **p < 0.001**		30.483; **p < 0.001**	
η^2		**0.05** c > d > b, c > a > d		**0.09** c > d > b, c > a > d		**0.07** c > d > b, c > a > d		**0.10** c > d > b, c > a > d		**0.14** c > d > b, c > a > d		**0.12** c > d > b, c > a > d		**0.15** c > d > b, c > a > d	

large effect size was detected between the parents according to their status of acquiring adequate knowledge (t=-10.659; $p < 0.001$; $\eta 2 = 0.17$) in all the sub-dimensions. The parents who did not receive adequate information about the problems of their children with disabilities had higher mean values in the FBAS and subscale scores than the other parents (Table 1). When we examine the age of a child with a disability that the parents have; a statistically significant difference with a small effect size was found between the FBAS scores of the parents according to the age of the children (t=-3.418; $p = 0.001$; $\eta 2 = 0.02$). Besides, while there was a significant difference with a small effect size in the sub-dimensions of inadequacy perception, social burden, emotional burden and time requirement, no significant difference was found in other sub-dimensions. The FBAS mean values of the parents with children in the 7-15 age group were higher than the parents with children in the 1-6 age group (Table 1).

A statistically significant difference with a small effect size was found between the FBAS scores of the parents with disabilities according to the gender of children (t=-2.607; $p = 0.009$; $\eta 2 = 0.01$). There was a significant difference with a small effect size in the sub-dimensions of the perception of inadequacy, physical, and social burden. The FBAS mean values of the parents having boys had higher scores than the other parents (Table 1). Between the duration of the child's special education and the FBAS score, a statistically significant difference with a medium effect size was observed (t=-6.249; $p < 0.001$; $\eta 2 = 0.07$). The mean values of the FBAS score of the parents with children receiving 2-year and over special education were higher than the parents of the children with 1 year or less special education. When we examine the disability type of the disabled child; a statistically significant difference was found between the FBAS scores of the parents according to their children's disability type ($F = 30.483$; $p < 0.001$; $\eta 2 = 0.15$). Table 1 includes the Bonferroni correction t-test results. The family burden scores of the parents with children with multiple disabilities and severe mental disabilities were found to be significantly higher in all the sub-dimensions and total scale compared to the other groups. However, there was no significant difference between the parents of the children with multiple disabilities and the parents of the children with severe mental disabilities ($p > 0.05$).

According to the family burden assessment scale (FBAS) used in our study, it stated that parents who scored 97 and above, had a family burden. Accordingly, when Table 1 is examined, it can be seen that the parents of children with mild mental, hearing, learning difficulties and emotional and behavioral disorders do not have a family burden.

Between the mothers and fathers, a statistically significant difference with a medium effect size was found in terms of physical (t=-7.340;

$p < 0.001$; $\eta 2 = 0.09$), spiritual (t=-8.090; $p < 0.001$; $\eta 2 = 0.11$), social (t=-8.077; $p < 0.001$; $\eta 2 = 0.11$) and environmental (t=-7.771; $p < 0.001$; $\eta 2 = 0.10$) sub-dimension scores. The mean values of the fathers were higher than the mothers in all the sub-dimensions. According to the education levels of the patients, a statistically significant difference with a small effect size was detected between the scores of physical (t=-5.093; $p < 0.001$; $\eta 2 = 0.04$), spiritual (t=-3.162; $p < 0.001$; $\eta 2 = 0.01$), social (t=-4.113; $p < 0.001$; $\eta 2 = 0.03$), and environmental (t=-5. 365; $p < 0.001$; $\eta 2 = 0.05$) domains. In all sub-dimensions of WHOQOL-BREF-TR, the mean values of the parents with high school and above education levels were higher than those of high school and lower education levels.

According to the family type of the parents, there has been a statistically significant difference with a small effect size between the spiritual domain (t=-2.014; $p = 0.045$; $\eta 2 = 0.00$) (Table 2). When we evaluate according to the working status of the parents, there was a statistically significant difference with a large effect size between the physical ($t = 11.539$; $p < 0.001$; $\eta 2 = 0.20$), spiritual ($t = 8.402$; $p < 0.001$; $\eta 2 = 0.14$), social ($t = 9.712$; $p < 0.001$; $\eta 2 = 0.15$) and environmental ($t = 10.168$; $p < 0.001$; $\eta 2 = 0.16$) domains. It was found that the mean values of all the employed parents in the sub-dimensions of the WHOQOL-BREF-TR were higher than the unemployed parents (Table 2).

When we examine the income levels of the parents; there was a statistically significant difference between the scores of physical ($F = 7.309$; $p < 0.001$; $\eta 2 = 0.02$), spiritual ($F = 16.574$; $p < 0.001$; $\eta 2 = 0.06$), social ($F = 40.461$; $p < 0.001$; $\eta 2 = 0.13$) and environmental ($F = 32.632$; $p < 0.001$; $\eta 2 = 0.11$) domains. It was found that the parents whose income was more than expenditures, had higher mean values in all the sub-dimensions of the WHOQOL-BREF-TR than the other groups.

Between the parents receiving information about their children with disabilities, a statistically significant difference was observed between the scores of physical ($t = 8.311$; $p < 0.001$; $\eta 2 = 0.11$), spiritual ($t = 8.644$; $p < 0.001$; $\eta 2 = 0.12$), social ($t = 10.003$; $p < 0.001$; $\eta 2 = 0.16$) and environmental ($t = 10.199$; $p < 0.001$; $\eta 2 = 0.16$) domains. The mean values of the parents who had received adequate information about their children with disabilities in all the sub-dimensions of the WHOQOL-BREF-TR were higher than the parents who had not (Table 2).

Between age groups of the children with disabilities, a statistically significant difference with a small effect size was seen between the mean scores of physical ($t = 2.222$; $p = 0.027$; $\eta 2 = 0.00$), spiritual ($t = 4.448$; $p < 0.001$; $\eta 2 = 0.03$), social ($t = 5.367$; $p < 0.001$; $\eta 2 = 0.05$) and environmental ($t = 4.263$; $p < 0.001$; $\eta 2 = 0.03$) domains. In all the sub-dimensions of WHOQOL-BREF-TR, the parents of the children with disabilities aged 6

Table 2. Comparison of WHOQOL-BREF-TR scores according to the characteristics of the parents and their children.

		Physical domain		Spiritual domain		Social domain		Environmental domain	
Characteristics	n	Mean	Sd.	Mean	Sd.	Mean	Sd.	Mean	Sd.
Parent									
Mother	402	11.96	1.75	12.34	2.31	12.26	2.99	12.08	2.27
Father	116	13.28	1.53	14.30	2.19	14.81	3.01	13.93	2.22
t; p		−7.340; **<0.001**		−8.090; **<0.001**		−8.077; **<0.001**		−7.771; **<0.001**	
η^2		**0.09**		**0.11**		**0.11**		**0.10**	
Age groups of the parents									
20-35 age	157	12.03	1.67	12.75	2.51	12.89	3.30	12.38	2.50
36 age and over	361	12.35	1.83	12.80	2.39	12.80	3.13	12.54	2.33
t; p		−1.910; 0.057		−0.196; 0.845		0.272; 0.786		−0.726; 0.468	
Education Level									
Under high school	220	11.80	1.71	12.40	2.28	12.18	2.88	11.87	2.16
High school and above	298	12.59	1.77	13.07	2.49	13.31	3.30	12.96	2.44
t; p		−5.093; **<0.001**		−3.162; **<0.001**		−4.113; **<0.001**		−5.365; **<0.001**	
η^2		**0.04**		**0.01**		**0.03**		**0.05**	
Family type									
Nuclear	453	12.22	1.71	12.70	2.38	12.77	3.25	12.50	2.42
Extended	65	12.47	2.23	13.35	2.69	13.27	2.60	12.46	2.11
t; p		−0.866; 0.389		−2.014; **0.045**		−1.399; 0.165		0.118; 0.906	
η^2		-		**0.00**		-		-	
Employment Status									
Yes	176	13.38	1.75	13.96	2.02	14.57	2.85	13.85	2.00
No	342	11.67	1.51	12.18	2.40	11.93	2.96	11.79	2.26
t; p		11.539; **<0.001**		8.402; **<0.001**		9.712; **<0.001**		10.168; **<0.001**	
η^2		**0.20**		**0.14**		**0.15**		**0.16**	
Income Status									
Income more than expenditures [a]	11	14.02	1.12	14.66	.78	19.15	1.49	15.51	1.53
Equal income and expenditures [b]	302	12.33	1.65	13.18	2.02	13.28	2.68	12.98	2.08
Income less than expenditures [c]	205	12.04	1.95	12.09	2.82	11.82	3.38	11.61	2.50
F; p		7.309; **0.001**		16.574; **p < 0.001**		40.461; **p < 0.001**		32.632; **p < 0.001**	
η^2		**0.02**		**0.06**		**0.13**		**0.11**	
Status of finding the information received about the problems of the child with a disability adequate									
Yes	170	13.13	1.68	14.02	2.07	14.66	2.95	13.89	2.09
No	348	11.82	1.68	12.18	2.36	11.93	2.89	11.81	2.22
t; p		8.311; **<0.001**		8.644; **<0.001**		10.003; **<0.001**		10.199; **<0.001**	
η^2		**0.11**		**0.12**		**0.16**		**0.16**	
Age group of the child (year)									
6 and under	193	12.48	1.90	13.44	2.40	13.78	3.20	13.07	2.39
7-15 year	325	12.11	1.70	12.39	2.36	12.27	3.03	12.15	2.31
t; p		2.222; **0.027**		0.448; **<0.001**		5.367; **<0.001**		4.263; **<0.001**	
η^2		**0.00**		**0.03**		**0.05**		**0.03**	
Gender of the child									
Girl	210	12.28	1.88	12.97	2.25	13.04	2.80	12.67	2.33
Boy	308	12.23	1.72	12.65	2.54	12.68	3.40	12.37	2.42
t; p		0.341; 0.734		1.471; 0.142		1.309; 0.191		1.365; 0.173	
The duration of special education									
1 year and less	104	12.59	2.12	13.57	2.42	13.74	3.37	13.16	2.52
2 year and over	154	11.71	1.73	12.3030	2.23	12.22	3.10	11.95	2.37
t; p		3.507; **0.001**		4.254; **<0.001**		3.658; **<0.001**		3.853; **<0.001**	
η^2		**0.02**		**0.03**		**0.02**		**0.02**	
Disability type	221	11.98	1.87	12.52	2.45	12.53	3.30	12.17	2.52
Mental disability[a]	106	12.31	1.28	12.92	2.11	12.95	2.70	12.57	1.89
Physical disability[b]	58	11.54	1.52	11.20	1.76	10.71	2.13	11.04	1.45
Multiple disabilities[c]	133	12.96	1.88	13.80	2.44	14.16	3.12	13.60	2.37
Others[d]		12.515; **p < 0.001**		18.633; **p < 0.001**		18.851; **p < 0.001**		19.907; **p < 0.001**	
F;p		0.06		0.09		0.09		0.10	
η^2		d > a b > c d > b d > c		a > c d > a b > c d > b		a > c d > a b > c d > b		d > a b > c d > b d > c	

and under were found to have higher mean values than the parents of children with disabilities aged 7-15 (Table 2).

According to the duration of the special education of the children with disabilities, there was a statistically significant difference with a small effect size between the scores of physical ($t = 3.507$; $p = 0.001$; $\eta 2 = 0.02$), spiritual ($t = 4.254$; $p < 0.001$; $\eta 2 = 0.03$), social ($t = 3.658$; $p < 0.001$; $\eta 2 = 0.02$) and environmental ($t = 3.853$; $p < 0.001$; $r = 0.02$) domains. In all the sub-dimensions, the parents with a child attending a special education center for 1 year or less, were found to have higher mean values (Table 2).

When we examine the disabled child according to the type of disability; the statistically significant difference was found between the scores of physical ($F = 15.270$; $p < 0.001$; $\eta 2 = 0.23$), spiritual ($F = 20.017$; $p < 0.001$; $\eta 2 = 0.28$), social ($F = 27.119$; $p < 0.001$; $\eta 2 = 0.34$) and environmental ($F = 33.100$; $p < 0.001$; $\eta 2 = 0.39$) domains. The Bonferroni correction t-test results are given in Table 2. In all areas, the quality of life of the parents with children with multiple disabilities and severe mental disabilities was found to be lower (Table 2).

A negative moderate and significant relationship was detected between the physical domain (r=-0.597; $p < 0.001$) and parents' FBAS scores and a negative strong and significant relationship was seen in the spiritual (r=-0.737; $p < 0.001$), social (r=-0.758; $p < 0.001$) and environmental (r=-0.816; $p < 0.001$) domains (Table 3).

As a result of the regression analysis performed to evaluate the effect of the parents' FBAS and sub-dimension scores on the quality of life (the physical, mental, social, and environmental domain); FBAS and sub-dimension scores; quality of life explains 45% of the physical domain dimension, 56% of the spiritual domain dimension, 0.60 of the social domain dimension and 0.68 of the environmental domain dimension. The FBAS and emotional burden sub-dimension had a negative effect on the physical domain of the parents; social burden and emotional burden sub-dimensions had a negative effect on the spiritual domain of the parents; It was determined that the economic, social and emotional sub-dimensions had a negative effect on the social domain of the parents, while the economic, social, physical, and emotional burden sub-dimensions had a negative effect on the environmental domain of the parents (Table 4).

According to Table 5, the mean FBAS score of the parents of the children with disabilities was 118.82 ± 37.19 and the mean value of the economic, perception of inadequacy, social, physical, emotional burden, and time requirement scores were 16.98 ± 6.76, 25.75 ± 8.37, $13{,}56 \pm 6.47$, 13.46 ± 6.09, 28.76 ± 10.89, 20.64 ± 7.77 respectively. The quality-of-life mean scores of physical sub-dimension was 51.59 ± 11.20, the spiritual

Table 3. The relationship between parents' FBAS and WHOQOL-BREF-TR scores.

Quality of life	Family burden	Physical domain	Spiritual domain	Social domain	Environmental domain
Economic burden	r	−0.340	−0.500	−0.547	−0.593
	p	<0.001	<0.001	<0.001	<0.001
Inadequacy perception	r	−0.349	−0.492	−0.489	−0.523
	p	<0.001	<0.001	<0.001	<0.001
Social burden	r	−0.546	−0.639	−0.667	−0.681
	p	<0.001	<0.001	<0.001	<0.001
Physical burden	r	−0.421	−0.535	−0.543	−0.627
	p	0.001	<0.001	<0.001	<0.001
Emotional Burden	r	−0.593	−0.695	−0.721	−0.750
	p	<0.001	<0.001	<0.001	<0.001
Time Requirement	r	−0.574	−0.638	−0.629	−0.671
	p	<0.001	<0.001	<0.001	<0.001
FBAS Total	r	−0.597	−0.737	−0.758	−0.816
	p	<0.001	<0.001	<0.001	<0.001

Table 4. The effect of parents' FBAS and subscale scores on WHOQOL-BREF-TR scores.

	Physical domain			Spiritual domain			Social domain			Environmental domain		
	B	Beta	p	B	Beta	p	B	Beta	p	B	Beta	p
Economic Burden	0.147	0.089	0.157	−0.112	−0.050	0.345	−0.455	−0.155	0.002	−0.335	−0.152	0.001
Perception of Inadequacy	0.066	0.049	0.483	−0.205	−0.113	0.057	−0.242	−0.102	0.070	−0.150	−0.084	0.095
Social Burden	−0.173	−0.100	0.178	−0.417	−0.178	0.005	−0.705	−0.230	0.000	−0.338	−0.147	0.006
Physical Burden	−0.234	0.127	0.078	−0.043	−0.017	0.779	−0.085	−0.026	0.653	−0.273	−0.111	0.032
Emotional Burden	−0.194	−0.189	0.029	−0.309	−0.221	0.002	−0.527	−0.289	0.000	−0.319	−0.233	0.000
Time Requirement	−0.036	−0.025	0.756	0.152	0.078	0.249	0.093	0.036	0.569	0.066	0.034	0.551
FBAS	−0.158	−0.524	0.029	−0.143	−0.351	0.083	−0.088	−0.164	0.393	−0.113	−0.281	0.103
*Variance % (R2)		0.45			0.56			0.60			0.68	

*Adjusted R^2.

Table 5. FBAS and WHOQOL-BREF-TR score distributions.

Scales and Sub-dimensions	Mean	Sd.
FBAS	118.82	37.19
Emotional Burden	28.76	10.89
Perception of Inadequacy	25.75	8.37
Time Requirement	20.64	7.77
Economic Burden	16.98	6.76
Social Burden	13,56	6.47
Physical Burden	13.46	6.09
WHOQOL-BREF-TR Spiritual Domain	54.92	15.19
WHOQOL-BREF-TR Physical Domain	51.59	11.20
WHOQOL-BREF-TR Social Domain	55.21	19.88
WHOQOL-BREF-TR Environmental Domain	53.11	14.92

sub-dimension was 54.92 ± 15.19, the social domain sub-dimension was 55.21 ± 19.88 and the environmental domain sub-dimension was 53.11 ± 14.92 respectively (Table 5).

Discussion

In this study, the most commonly experienced burden type was the emotional burden for the mothers and the burden of the inadequacy perception for the fathers. Various studies suggest that mothers and fathers of children

with disabilities have social, physical, spiritual, material, emotional (Ausserhofer et al., 2009; Malhotra et al., 2012) and especially economic burdens (Oh & Lee, 2009). In this study, it was also determined that mothers had higher family burdens and a lower quality of life than fathers. These findings of our study are consistent with the literature (Çalışır et al., 2018; Kaçan Softa et al., 2016; Kazmi et al., 2014; Kumari and Joseph 2014; Maheswari, 2014; Malhotra et al., 2012; Misura & Memisevic, 2017; Muslu & Cenk, 2018; Shyam et al., 2014). We think that these results are the result of mothers taking care of the disabled child frequently. In addition, finding that the economic burden of these parents is quite high is a contribution of our study to the literature. Economic support must be provided to these families.

The parents with an education level lower than high school were found to have a higher family burden level and lower quality of life than the parents with high school or above education levels. The literature informs that as the education level of parents increases, the care burden decreases and thus, the family burden decreases (Al-Kuwari, 2007; Barros et al., 2017; Sethi et al., 2007) while the quality of life increases as the education level increases (Misura & Memisevic, 2017). Therefore, our finding is consistent with the literature. We conclude that the level of education affects the family burden and quality of life.

Unemployed parents and parents whose income was less than expenditures were found to have a higher family burden level and poorer quality of life. These findings are similar to the literature (Akandere et al., 2009; Avsaroğlu & Gilik, 2017; Chiu, 2013; Kaytez et al., 2015; Kumari & Joseph, 2014). The care of the disabled child requires special needs. Therefore, parents with a low income or who not working face more difficulties.

The study demonstrated that parents living in extended families had a higher family burden. The sub-dimensions that differed significantly were the sub-dimensions of time requirements and the economic burden. While more than half of the parents with nuclear families had a family burden, the majority of parents with extended families also had a family burden. There was no significant difference between the family type and quality of life scale scores, although, it is considered that parents living in an extended family have an increased family burden due to the fact that the parents are also responsible for an elderly person as well as the care of the child with a disability, and they have difficulty in making time for themselves and other additional difficulties of living as a crowded family. This finding of our research also contributes greatly to the literature because living with elders is a common situation in our country. Therefore, support should be provided by questioning the family types of parents who care for a child with disabilities.

It was determined that the parents who could not receive sufficient information about the problems of their children with disabilities had a high family burden and a lower quality of life since they obtained the information about their children mostly from the teachers and doctors, but did not find this information adequate. Similarly, Demir and Keskin (2018) conducted a study on the parents of children with autism and noted that parents received information about their child's situation mostly from doctors or psychologists and they found the information insufficient and felt helpless due to a lack of knowledge (Demir & Keskin, 2018). Parents who have children with disabilities must be informed about their children.

Similar to the literature, the parents of children with disabilities between the ages of 7-15 were found to have a higher family burden and a lower quality of life than parents with a child aged 6 and under in this study. Relevant studies report that as the age of the child with disabilities increases, the family burden also increases (Akarsu, 2014) and as the age of the child increases, the quality-of-life decreases (Bayat, 2005). With the increasing age of the child with a disability, his or her needs differ, which is thought to cause the family burden to increase and the quality of life to decrease.

Parents with boys had a higher family burden, but no significant difference was found between the quality of life of the child by means of gender. There are various studies with similar findings in the literature regarding this matter (Gürhopur Turan & İşler Dalgıç, 2017; Sevinç & Babahanoğlu, 2016).

In the study, the parents with a child who attended a special education and rehabilitation center for one year or less had a higher quality of life and a lower family burden. However, similar studies emphasize that the duration of the child's receiving special education (Ergin et al., 2007; Softa, 2013; Yıldırım et al., 2013) does not affect the parents. Parents are thought to be negatively affected because they have to spend most of their time in these institutions. After all, children with disabilities constantly need to go to special education and rehabilitation centers. Therefore, this finding of our research makes important contributions to the literature and shows that the time that parents devote to special education and rehabilitation takes a great deal of time for them.

The findings of this study are similar to the literature in that parents of children with severe mental disabilities and multiple disabilities have a higher family burden and a lower quality of life. The group with the lowest family burden and the highest quality of life are parents with children with learning difficulties. As the disability degree of the child increases, the family burden of parents also increases (Gürhopur Turan &

İşler Dalgıç, 2017; Shyam et al., 2014) and as the disability degree of the child increases, the quality of life of the parents also decreases (Yuen Shan Leung & Wai Ping Li-Tsang, 2003). Each type of disability has different specific care needs. Including all the disability groups in our research and comparing them all contributes to the literature because all the types of disability we deal with are the types of disability raised in special education and rehabilitation centers.

In the study, no significant difference was observed between the age groups of the parents and the family burden and quality of life; and the majority of both groups had a family burden and both groups had a moderate quality of life. Similar studies in the literature suggest that the age of the parents is not a significant predictor for the quality of life (Meral & Cavkaytar, 2015).

The study demonstrated that the quality of life decreased as the family burden increased. In addition, family burden was found to be an important predictor of quality of life. Family burden negatively affects the quality of life. Therefore, in order to improve the quality of life of parents who have children with disabilities, family burdens must also be evaluated. These findings are also of great importance in terms of contributing to the literature of our study. Kaçan Softa et al. (2016), stated that there is a low negative relationship between family burden and life satisfaction of parents who have children with disabilities. Marsack-Topolewski and Church (2019), stated that the care burden of parents with children with disabilities have a negative effect on the quality of life, and it was emphasized in the study that the care burden of parents with children with disabilities was a strong predictor of their quality of life.

The majority of the parents had a family burden; their economic, social, physical and emotional burdens, perception of inadequacy and time requirement sub-dimension scores and scale total score were found high and their quality-of-life scale scores was moderate in physical, mental, social and environmental domains. These findings overlap with similar studies as well (Ezzat et al., 2017; Kazmi et al., 2014; Macedo et al., 2015).

Implications for family therapy practice

In line with the findings of our study, it is seen that parents who have children with disabilities need family therapy practice. Parents are tired of their children's special care needs; family burden increases and their quality of life is negatively affected. Mothers in particular seem to be under more burden. In this regard, parents should be able to express themselves clearly with family therapy practices. Special time should be allocated to parents, and solutions should be developed by studying their

problems. With family therapy practices, support should be provided to parents, social support sources should be determined, and the father should be included in the care. It is observed that parents also have problems in caring for the child and there is a lack of knowledge. Accordingly, it is thought that pediatric nurses and family therapists should provide support to the family in cooperation. While parents who have problems in the care of the child with disability receive help from the pediatric nurse for care and education, family therapists are needed for psychological support, family functioning and information. Family therapy practices should be determined according to the needs and situations of the parents because the needs of the family change according to the type of disability the child has. This situation should be taken into consideration in family therapy practices. As a result, it is seen that parents with children with disabilities need family therapists.

Conclusions

In this study evaluating the quality of life and family burden of parents with children with disabilities, the family burden of the mothers was found to be higher than fathers and their quality of life was lower. The majority of the mothers and less than half of the fathers had a family burden and the most commonly experienced burden was emotional burden for the mothers and perception of inadequacy for the fathers. The quality of life of the parents was adversely affected by social, physical, spiritual and environmental domains. Besides, as the family burden of the parents has increased, the quality of life decreased. It was also found that parents' family burden has a negative effect on their quality of life. Family burden of parents is an important predictor of quality of life.

Family burden and quality of life of the parents were found to be affected by education, employment and income status, family type, number of children, acquiring enough information about the child, the age, gender and disability type of the child, and the duration of the special education. Parents who had an education lower than high school education, who were unemployed, who had a kinship marriage, who did not acquire enough information about the problems of their child, whose child had a special education for more than a year and who had children with a severe mental disability and multiple disabilities had a higher family burden and a lower quality of life.

In line with these results, the family burden and quality of life of parents with disabled children should be evaluated by nurses and family therapists, and appropriate interventions should then be made. In particular, factors that increase family burden and reduce the quality of life should be determined and families at risk should be supported. In this

direction, pediatric nurses and family therapists should support children with disabilities and their families with a holistic approach. Considering the findings of this study, family therapists should try to understand the psychology of parents with disabled children and be aware that their quality of life may be affected and act accordingly.

Direction for future research

In line with the results of our study, it is seen that parents who have children with disabilities experience many problems. In line with these, results it is seen that parents who have children with disabilities experience many problems. Many factors were identified that reduce the quality of life of these families and increase family burden. Accordingly, it is seen that disability significantly affects not only children, but also their families. Accordingly, it is important to have family therapists and especially pediatric nurses in institutions that provide education to children with disabilities. These parents should definitely get support from family therapists and they should get help from pediatric nurses in caring for the child. Many factors were identified that reduce the quality of life of these families and increase family burden. Interventional studies to reduce the family burden of parents and to increase their quality of life are recommended for further research. Multidisciplinary studies conducted by pediatric nurses and family therapists including therapeutic approaches for parents with children with disabilities could be increased.

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No known conflicts of interest associated with this study.

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Author contributions

BÇ designed the study, collected the data, analyzed the data, and prepared the manuscript.
İK guided article in the whole process from designing to writing.
BÇ reviewed articles and extracted data.
İK reviewed articles and extracted data.
All listed authors meet the authorship criteria and that all authors are in agreement with the content of the manuscript.

Compliance with ethical standards

To carry out the study, institutional permission was obtained from Directorate of National Education in Trabzon. Then, ethics committee approval dated 23.10.2017 and numbered 2017/184 was obtained from Karadeniz Technical University Scientific Research Ethics Committee. This study was conducted according to the guidelines laid down in the Declaration of Helsinki.

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