

# Assessment of depression levels, quality of life and care burden of parents with disabled children.

Gulay Manav<sup>1</sup>, Busra Marash<sup>2</sup>, Pelin Uymaz<sup>3\*</sup>

<sup>1</sup>Department of Pediatric Nursing, Mugla Sitki Kocman University, Muğla, Turkey

<sup>2</sup>Department of Pediatric Nursing, Uskudar University, Health Science Instituted, Istanbul, Turkey

<sup>3</sup>Department of Pediatric Nursing, Alanya Alaaddin Keykubat University, Alanya, Turkey

## Abstract

**Aim:** This study was conducted to evaluate depression levels, quality of life and care burden of parents with disabled children.

**Methods:** This descriptive study was conducted with 198 parents in special education and rehabilitation centers of two provinces of Turkey. The data were collected using a parental identification form, the Beck Depression Inventory, the WHOQOL-BREF quality of life questionnaire, and the Zarit caregiver burden scale. Appropriate statistical analyses were done to evaluate the data.

**Findings:** Parents with disabled children had a mild depression and their mean scale score was  $15.19 \pm 9.35$ . Their scores were;  $53.54 \pm 19.39$  from the general health status,  $50.58 \pm 12.49$  from the physical health,  $61.30 \pm 16.99$  from the psychological,  $54.80 \pm 22.31$  from the social relations, and  $58.03 \pm 16.64$  from the environment subscales of the quality of life scale. Their mean score from the Zarit scale was  $46.30 \pm 14.34$ . A negative correlation was found between the parents' scores from the beck depression inventory and the quality of life scale, and a positive and statistically significant difference was found between the beck depression inventory and Zarit scale.

**Results:** Nurses, by using a family-centered approach, should develop care protocols, guidelines and institutional policies to support parental health in the care of disabled children and put these into practice.

**Keywords:** Family-centered care, Parental care, Disabled child, Nursing.

Accepted 26<sup>th</sup> December, 2021

## Introduction

It is crisis for all family members when a disabled child is born. Having a disabled child may affect the quality of life, roles, economy, physical and mental health, marriage and social support of the family members [1]. The World health organization made research on global burden of disease in 2014 reporting the number of moderately or severely disabled individuals to be 93 million (5.1%), of whom 13 million (0.7%) are severely disabled. According to the Turkish Statistical Institute (TUIK), the proportion of the population with at least one disability was 1.2% in the 0-4 age group, 2.1% in the 5-9 age group, 2.1% in the 10-14 age group, and 2.3% in the 15-19 age group.

Parents learn about disability of the child either at birth or at any period of life as the child grows older. As a result, the parents show similar psychological adaptation responses in every type of loss [2]. It is seen that parents focus on stage theory with regard to adapting to their disabled child [3]. In such cases, parents show such reactions as shock, denial, grief, anger, guilt, anxiety, unexpected crises, avoidance of confronting with others' attitudes, disappointment, decreased self-confidence and self-esteem [2].

There are several studies in the literature conducted with mothers and fathers with disabled children. The studies have discussed subjects such as parents' self-perception, depression levels, self-acceptance levels, way of coping with stress,

perceived social support and domestic adjustment, family burden of parents with disabled children, need for home care, unmet care needs, and difficulties experienced by parents [4]. A study conducted to determine depression levels of mothers with disabled children identified that most of those mothers had depression at moderate and severe levels [5]. Kurt et al. explained the needs of families with disabled children by use of such factors as the need for information, the need for support, the need for social services, the need that children can explain their condition to others, financial needs, and the functioning of the family [6]. Coşkun reported that severity of care burden of physically disabled children was at moderate level [7]. Another study stated that family burden of mentally disabled children was at high levels [8]. It is obvious from the literature that the interactions of mothers and fathers who have disabled children with each other, their families, their circle, life and society have taken on a new dimension, and based on the type and degree of disability, they are negatively affected physiologically, sociologically, emotionally and intellectually. This causes their course of life and care burden to be also negatively affected, which poses risk to the disabled children [9].

Both the disabled children and their parents need for nursing care in every part of life. This mentioned care can be described as physical and emotional support to parents by health care professionals and can be applied to all health institutions for all patients at any age [10]. Nurses, who have an active role in the care of disabled children, believe that the number of studies in

this area is not adequate. Families with disabled children need additional family support and experts because there is need for child's care, treatment, education, and to acquire various social skills, and such care requires special knowledge [11]. The health of disabled children affects parents' health and vice versa. For this reason, it is important to consider the depression, quality of life and family care burden that affect the parents' health as they provide care to disabled children, and to plan family-centered nursing care in consideration of family care, which has a great importance in children's life to develop, protect and improve the their health. This study can contribute to nursing care practices in disabled children within the scope of family centered nursing approach.

This descriptive study was conducted to evaluate depression levels, quality of life and care burden of parents with disabled children.

### **Hypotheses of the study are as follows**

- What are depression levels of parents with disabled children?
- How is the quality of life of parents with disabled children?
- How is the family burden of parents with disabled children?

Is there any interaction among depression levels, quality of life and family care burden of parents?

### **Materials and Methods**

The research was done with the parents of the children who received treatment and education between June 25 and August 25, 2018 in special education and rehabilitation centers in two provinces that provide individual therapy, group therapy, space therapy, physiotherapy, speech therapy, hydrotherapy, hearing therapy, sensory therapy, dark room sensory therapy, family counseling and PECS system.

The study, using purposeful sampling, was carried out with 198 parents who agreed to participate and signed the informed consent form.

To collect the data, a parental identification form, the Beck Depression Inventory (BDI), the WHOQOL-BREF quality of life questionnaire, and the Zarit caregiver burden scale were used. The parent identification form, developed by the researcher, consists of 14 questions and examines socio-demographic attributes of parents. The BDI was developed by Beck et al. in 1961 [12] and was adapted to Turkish by Hisli in 1989, with Cronbach's alpha of 0.80 obtained in the item analysis. The cut-off point was determined as 17 in the Turkish validity and reliability of the BDI. The obtainable total score from the scale ranged from 0 to 63 [13]. The parents' scores from the BDI ranged between 0 and 39, the mean was  $15.19 \pm 9.35$  and internal consistency of the scale was  $\alpha=0.885$ .

The WHOQOL BREF TR (World Health Organization Quality of Life Short Form) was used to determine patients' quality of life. The WHOQOL BREF TR consists of global and national 27 questions. This form adverts general health status and quality of life and physical, social, psychological and environmental well-being of individuals [14]. The questions include Likert

type closed-ended responses. The scale was translated into Turkish by Eser et al. and its validity and reliability was proved [15]. Internal coefficients of the scale were found to be very high. The highest internal consistency was 0.83 in physical area and the lowest was 0.53 in social area. The WHOQOL-Bref is scored over 20 points. A higher score from the scale shows higher quality of life [16].

The BDI scale was developed by Zarit et al. in 1980 and it was adapted to Turkish by İnci in 2006 [17,18]. This scale is used to evaluate the problems experienced by caregivers. A higher score from the scale indicates greater distress [19].

For the statistical analyses, Number Cruncher Statistical System) (NCSS) 2007 software (Kaysville, Utah, USA) was used. Descriptive statistical methods were used for evaluating the data. Correspondence of quantitative data to normal distribution was tested using the Shapiro-Wilk test. The student t-test was used in the comparisons of quantitative variables that showed normal distribution between two groups, and the Mann-Whitney U-test was used for quantitative variables that did not show normal distribution. One-way ANOVA and binary assessments with Bonferroni correction were used in comparisons of quantitative variables that showed normal distribution among more than two groups. In the comparisons of quantitative variables that did not show normal distribution, however, the Kruskal-Wallis test and Dunn-Bonferroni test were used. The Pearson correlation and spearman correlation analyses were used to evaluate correlations between quantitative variables. The risk factors that affected the BDI score were calculated using the linear regression analysis (backward). The statistical significance level was taken as  $p<0.05$ .

### **Research Ethics**

A written permission with number B.08.6.YÖK.2.ÜS.0.05.0.06/2018/598 was obtained from the Uskudar university institute of health sciences ethics committee on 25.04.2018 to conduct the study. The study included informed consent forms to ensure voluntary participation and took into consideration the principles of autonomy, confidentiality and protection of confidentiality, receiving adequate and correct care, not doing harm, and utility. The Helsinki declaration of human rights was adhered throughout the research.

### **Findings**

The study was conducted with 198 children between June 25 and August 25, 2018. Table 1 shows some characteristics of children and their parents.

Mv	Mv	Mv
Child's age		
0-3 years	30	15.2
4-6 years	51	25.8
7-12 years	85	42.9
13-18 years		16.2
Birth order of child		
First	57	28.8
Second	82	41.4
Third	35	17.7
Fourth or later	24	12.1

Having another child		
Yes, disabled	3	1.5
Yes, non-disabled	168	84.8
No other child	27	13.6
Child's having a health problem besides disability		
Yes	48	24.2
No	150	75.8
Diagnosis		
Mentally disabled	137	69.2
Orthopedically handicapped	33	16.7
Mentally and orthopedically handicapped	8	4
Mentally disabled and with chronic disease	3	1.5
Learning disorder	9	4.5
Physically handicapped	1	0.5
Hearing and speech handicapped	5	2.5
Speech and mentally disabled	1	0.5
Growth retardation	1	0.5
Parent responsible for the child's care		
Single parent	41	20.7
Parents together	157	79.3
Age of parents		
18-25 years	9	4.5
25-35 years	64	32.3
35-45 years	87	43.9
≥ 45 years	38	19.2
Parental education level		
Literate	5	2.5
Primary school	50	25.3
Secondary school	31	15.7
High school	79	39.9
University	30	15.2
Other	3	1.5
Social security		
Yes	166	83.8

No	32	16.2
Occupation		
Workmen	43	21.7
Office worker	31	15.7
Self-employed	15	7.6
Freelancer	8	4
Not working	94	47.5
Other	7	3.5
Income status		
Less income than expense	49	24.7
Equal income to expense	134	67.7
More income than expense	15	7.6
Chronic health problem		
Yes	35	17.7
No	163	82.3
Family Structure		
Nuclear family	166	83.8
Extended family	26	13.1
Other	6	3
Child's feelings about the disability		
Shock, denial, grief	18	9.1
Guilt, indecision, anger, embarrassment	27	13.6
Reconciliation, acceptance, adaptation	153	77.3

Table 1. Distribution of some characteristics of children and their parents (n=198).

Of the children who participated in the study, 85 were between the ages of 7 years and 12, 41.4% of whom were the second child of the family. Three of other children in the families were disabled, while 168 were non-disabled. Of the disabled children, 69.2% were mentally disabled. Of them, 157 lived together with their parents; 87 of the parents aged between 35 and 45 years and 39.9% were high school graduates. While 47.5% of the parents were unemployed, 24.7% had lower income than expense. Of the children, 77.3% stated they were at the phase of reconciliation, acceptance and adaptation of their disability. Table 2 shows the correlation between the total scale score and the scores of its subscales.

The scales		BDI total scale score	
		r	p
WHOQOL	General health status	-0.416a	0.001**
	Physical health	-0.388a	0.001**
	Psychological dimension	-0.677a	0.001**
	Social relations	-0.588a	0.001**
	Environment	-0.343a	0.001**
Zarit Caregiver Burden Scale	Mental tension and disruption of private life	0.646b	0.001**
	Irritability, restriction	0.579b	0.001**
	Disruption of social relations	0.524b	0.001**
	Economic burden	0.433a	0.001**
	Dependency	0.397b	0.001**
	Zarit Total Score	0.638a	0.001**

Table 2. The correlation between the total scale score and the scores of its subscales. ar: Pearson correlation coefficient, br: Spearman correlation coefficient, \*\*: p<0.01.

There was a negative and statistically significant difference between the parents' scores from the BDI and the subscales of the WHOQOL ( $p < 0.01$ ). There was a positive and statistically significant difference between their scores from the BDI and the subscales of Zarit scale ( $p < 0.01$ ). As their depression level increases, their quality of life decreases and burden level increases. There was no negative correlation between the parents' scores from the subscales of WHOQOL and Zarit scale ( $p < 0.05$ ). This means as caregiver burden increases, the quality of life of the individual in question decreases. The univariate analysis of the subscales of WHOQOL and Zarit scale indicates that these are each a risk factor for the total BDI score. To show their multivariate effects, a linear regression (backward) analysis was made.

The summary of the model showing the degree of influence of the scores from the subscales of WHOQOL and Zarit scales at the end of five steps is given in Table 3. Therefore, ( $R^2 = 0.589$ ) scores from the subscales of WHOQOL and Zarit scales affect the level of depression at a rate of 58.9%. The effect of the subscales of WHOQOL and Zarit scales on the level of depression was tested using regression analysis and at the end of the five steps, a significant correlation was found between the mentioned variables ( $R^2 = 0.589$ ). The regression analysis showed that the general health status, mental tension and disruption of private life, disruption of social relations and attachment subscales had no significant effect on the model ( $p > 0.05$ ).

Model	R	R square	Corrected R square	Standard error
5	0.768	0.589	0.576	6.087

Table 3. Summary of the model.

Parents' total scores from the BDI and the affecting features are given in Table 4. The parents' scores from the BDI ranged between 0 and 39 and their depression level was found to be mild with a score of  $15.19 \pm 9.35$ . There were significant correlations between the parents' social security and child's feelings about the disability and the BDI ( $p < 0.05$ ,  $p < 0.01$ ).

Attributes	n	BDI scores		Test value (p)
		Mean	SD	
Child's age				
0-3 years	30	11.4	8.06	
4-6 years	51	15.04	9.26	F:2.240
7-12 years	85	16.47	9.2	e0.085
13-18 years	32	15.59	10.43	
Birth order				
1st child	57	14.46	9.46	
2nd child	82	15.29	9.44	F:0.396
3rd child	35	14.97	9.98	e0.756
≥ 4th child	24	16.92	8.1	
Having another child				
Yes	171	15.51	9.43	t:1.224
No	27	13.15	8.71	c0.223
Having other health problems				
Yes	48	16.02	9.84	t:0.705
No	150	14.93	9.21	c0.482

Age of parents			
18-25 years	9	15.22 ± 8.32	
25-35 years	64	14.06 ± 9.18	$\chi^2:1.328$
35-45 years	87	15.52 ± 9.48	f0.723
>45 years	32	16.34 ± 9.73	
Parental education level			
Low	89	15.96 ± 8.95	
Moderate	79	15.47 ± 9.76	F:1.883
High	30	12.2 ± 9.11	e0.115
Social security			
Yes	166	14.69 ± 9.67	t:-2.154
No	32	17.81 ± 7.03	c0.036
Income status			
Low	49	16.61 ± 8.21	
Moderate	134	15.16 ± 9.57	F:2.249
High	15	10.8 ± 10.09	e0.108
Chronic health problem			
Yes	35	16.4 ± 11.19	t:0.728
No	163	14.93 ± 8.93	c0.471
Family Structure			
Nuclear	166	15.05 ± 9.67	$\chi^2:2.199$
Extended	26	16.81 ± 7.83	f0.333
Other	6	12.17 ± 5.04	
Child's feelings about the disability			
Shock, denial, grief	18	22.83 ± 9.28	F:31.246
Guilt, indecision, anger, embarrassment	27	24.19 ± 8.59	e0.001**
Reconciliation, acceptance, adaptation	153	12.71 ± 7.97	1>3, 2>3

Table 4. Evaluation of the BDI scores and the affecting features. c: Student t-test, e: One-way ANOVA, f: Kruskal Wallis test, \*:  $p < 0.05$  \*\*:  $p < 0.01$ .

Evaluation of the WHOQOL subscales and total scores and the affecting features is provided in Table 5. Parents with children aged 0-3 years had higher scores from the psychological dimension and social relations subscales of WHOQOL compared to those with children aged 4-6 years and 7-12 years. Parents who had lower education level had higher scores from the environment subscale of the WHOQOL compared to those with higher education level. Regarding the child's feelings about the disability, children obtained higher scores from the physical health and social relations subscales compared to guilt, shock and reconciliation and higher scores from the psychological dimension compared to guilt and reconciliation.

The scores from the Zarit scale and its subscales and the affecting features are given in Table 6. Statistically significant outcomes were obtained between Zarit scale and child's age and all subscales, between birth order and economic burden, between having another child and economic and total scale score, between having another health problem and dependency and total scale score, between irritability and restriction subscales and all other subscales regarding child's feelings about the disability. There was a significant correlation between child's age and all subscales. This shows that parents take on care burden irrespective of the disabled child's age. Economic burden of the first child is more than that of the fourth child. Mental tension and disruption of private life, and irritability and restriction are more common in families with low income compared to families with higher income.

Subscales/ Attributes	n	General health status		Physical health		Psychological dimension		Social relations		Environment	
		Mv	Mv	Mv	Mv	Mv	Mv	Mv	Mv	Mv	Mv
Child's age											
0-3 years	30	60 ± 15.19	F:1.745	53.45 ± 12.35	F:1.116	69.72 ± 18.18	F:3.168	67.5 ± 20.1	F:4.819	60.73 ± 16.28	F:0.478
4-6 years	51	53.92 ± 22.01	e0.159	50.28 ± 13.59	e0.344	59.23 ± 16.04	e0.026*	49.84 ± 22.64	e0.003**	58.21 ± 18.48	e0.698
7-12 years	85	50.74 ± 20.26		49.12 ± 12.06		59.41 ± 16.59	1>2, 1>3	52.35 ± 22.11	1>2,1>3	56.69 ± 17.02	
13-18 years	32	54.3 ± 14.76		52.23 ± 11.82		61.72 ± 16.68		57.29 ± 20.38		58.79 ± 12.76	
Birth order											
1st child	57	53.07 ± 21.56	F:0.362	51.88 ± 13.36	F:0.493	62.5 ± 18.13	F:0.357	53.95 ± 24.4	F:0.212	58.88 ± 18.65	F:0.404
2nd child	82	55.03 ± 16.77	e0.781	50.74 ± 11.67	e0.688	61.59 ± 16.52	e0.784	55.39 ± 21.33	e0.888	58.88 ± 14.37	e0.750
3rd child	35	51.07 ± 18.03		49.29 ± 12.4		60.71 ± 17.01		53.1 ± 21.01		56.25 ± 16.18	
≥ 4th child	24	53.13 ± 24.52		48.81 ± 13.56		58.33 ± 16.39		57.29 ± 23.35		55.73 ± 19.86	
Having another child											
Yes	171	53.87 ± 19.33	t:0.618	50.23 ± 12.65	t:-0.985	60.82 ± 17.07	t:-1.004	54.48 ± 22.71	t:-0.498	58.04 ± 16.47	t:0.016
No	27	51.39 ± 20.02	c0.537	52.78 ± 11.35	c0.326	64.35 ± 16.44	c0.316	56.79 ± 19.89	c0.619	57.99 ± 17.98	c0.987
Having other health problems											
Yes	48	50.26 ± 19.03	t:-1.347	47.54 ± 12.35	t:-1.947	55.38 ± 16.01	t:-2.822	51.74 ± 22.93	t:-1.093	53.26 ± 13.83	t:-2.311
No	150	54.58 ± 19.45	c0.180	51.55 ± 12.42	c0.053	63.19 ± 16.91	c0.005**	55.78 ± 22.1	c0.276	59.56 ± 17.21	c0.022*
Age of parents											
18-25 years	9	51.39 ± 22.92		51.59 ± 17.42		62.04 ± 22.29		61.11 ± 24.3		50 ± 21.42	
25-35 years	64	55.08 ± 19.38	χ2:1.505	51.56 ± 12.48	χ2:1.418	62.96 ± 17.43	χ2:0.439	57.29 ± 23.45	χ2:2.529	59.13 ± 17.63	χ2:3.086
35-45 years	87	53.3 ± 19.3	f0.681	50.45 ± 11.54	f0.701	60.34 ± 16.38	f0.932	53.83 ± 21.18	f0.470	57.69 ± 15.42	f0.379
>45 years	32	51.97 ± 19.39		48.97 ± 13.62		60.53 ± 16.74		51.32 ± 22.56		58.88 ± 16.56	
Parental education level											
Low	89	52.53 ± 20.31	F:0.430	51.36 ± 14.34	F:0.413	60.07 ± 17.56	F:0.440	55.34 ± 23.28	F:0.064	54.39 ± 17.15	F:4.258
Moderate	79	53.32 ± 16.23	e0.652	49.64 ± 10.59	e0.663	62.13 ± 16.52	e0.644	54.11 ± 22.04	e0.938	60.32 ± 14.63	e0.015*
High	30	57.08 ± 24.05		50.71 ± 11.39		62.78 ± 16.77		55 ± 20.72		62.81 ± 18.25	1>3
Social security											
Yes	166	55.2 ± 18.32	t:2.791	50.69 ± 12.63	t:0.285	62.3 ± 17.29	t:1.896	55.32 ± 22.74	t:0.751	60.05 ± 15.95	t:4.038
No	32	44.92 ± 22.64	c0.006**	50 ± 11.9	c0.776	56.12 ± 14.51	c0.059	52.08 ± 20.08	c0.454	47.56 ± 16.45	c0.001**
Income status											
Low	49	44.64 ± 20.09	F:24.871	47.38 ± 12.54	F:10.362	52.38 ± 13.04	F:14.172	46.94 ± 21.83	F:7.397	44.52 ± 13.33	F:46.63
Moderate	134	53.73 ± 16.72	e0.001**	50.32 ± 11.88	e0.001**	63 ± 17.09	e0.001**	55.91 ± 21.6	e0.001**	60.4 ± 14.21	e0.001*
High	15	80.83 ± 13.25	1>2, 1>3, 2>3	63.33 ± 10.23	1>3	75.28 ± 13.68	1>2, 1>3, 2>3	70.56 ± 21.1	1>2, 1>3	81.04 ± 10.4	1>2,1>3
Chronic health problem											
Yes	35	50.36 ± 23.77	t:-1.069	53.67 ± 14.94	t:1.398	59.05 ± 18.09	t:-0.864	51.43 ± 23.7	t:-0.985	55.54 ± 17.65	t:-0.979
No	163	54.22 ± 18.33	c0.286	49.91 ± 11.84	c0.169	61.78 ± 16.76	c0.389	55.52 ± 22.01	c0.326	58.57 ± 16.42	c0.329

Family Structure											
Nuclear	166	54.07 ± 18.42	χ <sup>2</sup> :2.413	50.67 ± 12.45	χ <sup>2</sup> :0.039	61.55 ± 17.3	χ <sup>2</sup> :0.669	54.47 ± 22.54	χ <sup>2</sup> :0.056	59.24 ± 16.2	χ <sup>2</sup> :6.609
Extended	26	50 ± 22.36	f:0.299	50.14 ± 13.76	f:0.981	60.74 ± 14.77	f:0.716	56.09 ± 20.89	f:0.972	52.64 ± 18.28	f:0.037*
Other	6	54.17 ± 32.27		50 ± 9.04		56.94 ± 19.31		58.33 ± 25.28		47.92 ± 15.89	1>2
Child's feelings about the disability											
Shock, denial, grief	18	55.56 ± 18.3		56.75 ± 13.63		56.48 ± 14.24		56.48 ± 22.24		63.72 ± 13.18	
Guilt, indecision, anger, embarrassment	27	47.22 ± 14.84	F:2.551	43.65 ± 10.26	F:6.854	51.23 ± 11.43	F:11.597	39.81 ± 17.65	F:7.525	53.13 ± 14.16	F:2.264
			e:0.092		e:0.001**		e:0.001**		e:0.001**		e:0.107
Reconciliation, acceptance, adaptation	153	54.41 ± 20.1		51.07 ± 12.25	2>1, 2>3	63.64 ± 17.4	2>3	57.24 ± 22.14	2>1, 2>3	58.23 ± 17.23	

Table 5. Evaluation of the WHOQOL subscales and total scores and the affecting features. f: Kruskal Wallis Test, c: Student t-test, d: Mann Whitney U test, e: One-way ANOVA, \*: p<0.05, \*\*: p<0.01.

Mv	Mental tension and disruption of private life		Irritability, restriction		Disruption of social relations		Economic burden		Dependency		Zarit Scale Total Score	
	Mean ± SD	Test value (p)	Mean ± SD	Test value (p)	Mean ± SD	Test value (p)	Mean ± SD	Test value (p)	Mean ± SD	Test value (p)	Mean ± SD	Test value (p)
Child's age												
0-3 years	12.3 ± 5.04	χ <sup>2</sup> :8.610	5.2 ± 2.28	χ <sup>2</sup> :11.943	3.83 ± 1.26	χ <sup>2</sup> :12.553	11.67 ± 4.2	F:2.679	5.23 ± 2.71	χ <sup>2</sup> :15.049	38.23 ± 11.89	F:4.206
4-6 years	15.63 ± 5.96	f:0.035*	6.96 ± 3.03	f:0.008**	5.2 ± 2.09	f:0.006**	12.9 ± 3.75	e:0.048*	5.57 ± 2.51	f:0.002**	46.25 ± 14.81	e:0.007**
7-12 years	15.36 ± 5.76	1>3	7.19 ± 2.67	1>2, 1>3	5.18 ± 2.01	1>2,	13.73 ± 3.48	1>3	6.76 ± 2.64	1>3, 1>4, 2>4	48.22 ± 13.57	1>3, 1>4
13-18 years	16.16 ± 6.99		6.78 ± 3.03		4.97 ± 2.65	1>3	13.69 ± 3.32		7.25 ± 2.44		48.84 ± 15.56	
Birth order												
1st child	14.09 ± 5.9	χ <sup>2</sup> :5.216	6.56 ± 2.47	χ <sup>2</sup> :0.678	4.81 ± 2.12	χ <sup>2</sup> :2.084	12.35 ± 3.24	F:3.109	6.14 ± 2.86	χ <sup>2</sup> :0.455	43.95 ± 12.83	F:1.500
2nd child	14.95 ± 5.58	f:0.157	6.79 ± 2.87	f:0.878	4.79 ± 1.9	f:0.555	13.09 ± 3.55	e:0.028*	6.45 ± 2.6	f:0.929	46.07 ± 14.14	e:0.216
3rd child	15.43 ± 6.58		7.11 ± 3.3		5 ± 2.06		13.63 ± 4.13	1>4	6.2 ± 2.69		47.37 ± 15.63	
≥ 4th child	17.5 ± 6.46		6.63 ± 2.95		5.71 ± 2.65		14.96 ± 3.98		6.33 ± 2.57		51.13 ± 15.97	
Having another child												
Yes	15.43 ± 6.2	Z:-1.771	6.82 ± 2.93	Z:-0.568	5.02 ± 2.15	Z:-0.791 d:0.429	13.37 ± 3.78	t:2.045	6.37 ± 2.65	Z:-0.908	47.02 ± 14.89	t:2.498
No	12.96 ± 4.04	d:0.077	6.37 ± 2.17	d:0.570	4.48 ± 1.65		12.11 ± 2.82	c:0.047*	5.85 ± 2.84	d:0.364	41.78 ± 9.15	c:0.016*
Having other health problems												
Yes	16.77 ± 6.77	Z:-2.109	7.71 ± 2.97	Z:-2.612	5.5 ± 2.18	Z:-2.290	14.25 ± 3.43	t:2.298	6.63 ± 2.78	Z:-0.984	50.85 ± 14.83	t:2.562
No	14.56 ± 5.66	d:0.035*	6.46 ± 2.74	d:0.009**	4.77 ± 2.04	d:0.022*	12.86 ± 3.71	c:0.023*	6.2 ± 2.64	d:0.325	44.85 ± 13.92	c:0.011*
Age of parents												
18-25 years	13.67 ± 5.72	χ <sup>2</sup> :2.737	6.33 ± 2.69	χ <sup>2</sup> :1.634	4.89 ± 2.03	χ <sup>2</sup> :2.506	12.22 ± 4.02	χ <sup>2</sup> :2.400	5.56 ± 2.92	χ <sup>2</sup> :2.748	42.67 ± 14.64	χ <sup>2</sup> :2.707
25-35 years	14.39 ± 6.14	f:0.434	6.45 ± 2.58	f:0.652	4.69 ± 2.11	f:0.474	12.72 ± 3.34	f:0.494	5.94 ± 2.79	f:0.432	44.19 ± 13.56	f:0.439
35-45 years	15.57 ± 6.02		7.07 ± 3.01		5.02 ± 2.01		13.53 ± 3.64		6.6 ± 2.53		47.79 ± 14.27	
>45 years	15.53 ± 5.86		6.68 ± 2.93		5.21 ± 2.3		13.47 ± 4.25		6.42 ± 2.74		47.32 ± 15.65	
Parental education level												
Low	15.45 ± 6.12	χ <sup>2</sup> :2.188	6.9 ± 2.81	χ <sup>2</sup> :3.971	5.25 ± 2.27	χ <sup>2</sup> :3.411	13.3 ± 3.79	F:0.834	6.08 ± 2.72	χ <sup>2</sup> :1.187	46.98 ± 14.49	F:0.978

Moderate	15.22 ± 5.98	f0.335	6.96 ± 2.93	f0.137	4.75 ± 1.9	f0.182	13.38 ± 3.36	e0.436	6.52 ± 2.61	f0.552	46.82 ± 14.28	e0.378
High	13.73 ± 5.73		5.83 ± 2.57		4.57 ± 1.96		12.4 ± 4.17		6.4 ± 2.72		42.93 ± 14.06	
Social security												
Yes	15.11 ± 6.13	Z:-0.194	6.77 ± 2.81	Z:-0.098	4.92 ± 2.12	Z:-0.798	13.12 ± 3.7	t:-0.664	6.39 ± 2.67	Z:-1.100	46.31 ± 14.66	t:0.009
No	15.03 ± 5.43	d0.846	6.72 ± 3.02	d0.922	5.09 ± 1.99	d0.425	13.59 ± 3.64	c0.507	5.84 ± 2.65	d0.271	46.28 ± 12.76	c0.993
Income status												
Low	16.04 ± 5.38	χ <sup>2</sup> :8.535	7.51 ± 2.62	χ <sup>2</sup> :8.360	5.39 ± 2.08	χ <sup>2</sup> :5.416	13.8 ± 3.38	F:1.255	6.18 ± 2.74	χ <sup>2</sup> :1.540	48.92 ± 11.45	F:2.883 e0.068
Moderate	15.13 ± 6.21	f0.014*	6.64 ± 2.89	f0.015*	4.86 ± 2.11	f0.067	13.09 ± 3.83	e0.287	6.25 ± 2.68	f0.463	45.98 ± 15.36	
High	11.67 ± 5.16	1>3	5.4 ± 2.53	1>3	4.27 ± 1.79		12.2 ± 3.19		7.13 ± 2.36		40.67 ± 12.04	
Chronic health problem												
Yes	15.34 ± 6.16	Z:-0.192	6.57 ± 2.97	Z:-0.413	5.2 ± 2.17	Z:-0.919	12.37 ± 4.58	t:-1.223	6.14 ± 2.69	Z:-0.383	45.63 ± 15.91	t:-0.306
No	15.04 ± 5.99	d0.848	6.8 ± 2.82	d0.680	4.89 ± 2.08	d0.358	13.37 ± 3.46	c0.228	6.34 ± 2.67	d0.702	46.45 ± 14.03	c0.760
Family Structure												
Nuclear	15.02 ± 5.95	χ <sup>2</sup> :0.584	6.78 ± 2.93	χ <sup>2</sup> :0.147	4.9 ± 2.06	χ <sup>2</sup> :1.451	13.17 ± 3.64	χ <sup>2</sup> :0.699	6.28 ± 2.7	χ <sup>2</sup> :0.968	46.16 ± 14.43	χ <sup>2</sup> :0.889
Extended	14.85 ± 5.44	f0.747	6.77 ± 2.16	f0.929	4.92 ± 2.15	f0.484	13.04 ± 4.04	f0.705	6.19 ± 2.55	f0.616	45.77 ± 13.45	f0.641
Other	18.17 ± 9.75		6.33 ± 3.33		6.17 ± 2.86		14.5 ± 3.62		7.33 ± 2.5		52.5 ± 16.66	
Child's feelings about the disability												
Shock, denial, grief	17.67 ± 5.35	χ <sup>2</sup> :24.134	7.39 ± 2.45	χ <sup>2</sup> :16.907	5.5 ± 2.33	χ <sup>2</sup> :15.242	14.44 ± 3.48	F:5.033	7.11 ± 2.08	χ <sup>2</sup> :6.687	52.11 ± 11.27	F:12.498
Guilt, indecision, anger, embarrassment	19.85 ± 6.3	f0.001** 1>3, 2>3	8.78 ± 2.56	f0.001** 1>3	6.15 ± 1.88	f0.001** 1>3	14.85 ± 3.01	e0.007** 1>3	7.22 ± 3.03	f0.035* 1>3	56.85 ± 14.09	e0.001** 1>3, 2>3
Reconciliation, acceptance, adaptation	13.95 ± 5.54		6.33 ± 2.77		4.67 ± 2.03		12.76 ± 3.72		6.05 ± 2.63		43.76 ± 13.71	

**Table 6.** Evaluation of the Zarit's subscales and total scores and the affecting features. f: Kruskal Wallis Test, c: Student t-test, d: Mann Whitney U test, e: One-way ANOVA, \*: p<0.05, \*\*:p<0.01.

## Results and Discussion

According to a study conducted with families of disabled children in 2009, those families of the disabled children in the younger age group faced problems such as school selection and guidance, whereas the families of the disabled children in the older age groups faced such problems as future life and employment status of their children. Thus, families with disabled children in the older age groups had higher depression levels [9]. This study, however, found that while age did not affect the depression level of the families, having social security affected it and that depression level of the parents who had social security was low. Sen et al. found that the majority of families with disabled children (47%) had moderate and severe depression levels [20].

The study shows that the factors that affected the quality of life of the families were child's age and having social security. Parents with disabled children aged 3 years and under had higher scores from the psychological dimension and social relations subscales of the WHOQOL compared to those with disabled children aged 4 years and over. Thus, we can say that the parents with a child in the 0-3 age group have higher quality of life. As the children grow older, the problems that their families have to face increase too. It takes time for the families to accept the situation as the children grow older. The families may feel pressured by social structures and may be judged that they do not understand

their disabled child's needs. To avoid this, families may limit their social networks [21]. As the disabled children grow older, their families' social relations reduce, and so, they are affected mentally.

Significant correlations were found between having social security and income status and the subscales of the WHOQOL. Aktürk et al. [22]. found a negative correlation between economic status and anxiety levels of families. Thomas et al. found that parents with higher monthly income had higher quality of life even when they had a disabled child [23]. Şimşek et al. stated that families with disabled children had economic problems, they did not find time to get involved with their healthy children, thus their social and interpersonal relationships were greatly affected [24]. In addition, when they had to leave their jobs to take care of their disabled child, they faced economic problems with the loss of either mother's or father's income [20].

There were significant outcomes between all subscales of Zarit scale and child's age in this study. Roberts et al. discussed that a disabled child would need extra care in all areas of life and in this case, their families would take on more care burden [25]. Mothers of disabled children have the greatest care burden and experience higher depression and anxiety compared to other mothers with healthy children [26,27]. Sen et al. stated that care and treatment of disabled children cause financial difficulties to their families [20]. Economic burden brought by every disabled

child is considerably high and his/her care, treatment and education bring a greater economic burden to the family.

Consequently, in line with the literature, depression levels, quality of life and care burden of families with disabled children are affected by the child's age and the presence of social security. Taking into account parents' scores from BDI, their depression levels were found to be mild. Also, there were significant correlations between having social security and child's feelings about the disability and the BDI. Parents who had a disabled child in the 0-3 age group and had lower education level had higher quality of life scores than others. A significant correlation was found between having another child, income status, and child's age and the subscales of Zarit scale.

There was a positive and statistically significant difference between parents' scores from the BDI and the total scores from Zarit scale ( $p<0.01$ ). There was a negative and statistically significant difference between their scores from the subscale of WHOQOL and the total scores from Zarit scale ( $p<0.01$ ). The linear regression analysis (back ward) showed that the scores from the WHOQOL subscale and subscales of Zarit scale affected depression at a rate of 58.9%. Because there is interaction between the quality of life, family care burden and depression levels of parents, the importance of family centered care of disabled children in nursing is underlined.

## Conclusion

This study recommends nurses to assess these variables together since there is a positive correlation between caregiver burden and depression levels of parents with disabled children. Because there was a negative correlation between caregiver burden and quality of life of these parents, nurses should do applicable planning and help disabled children to sustain a better life and to reduce caregiver burden of their families.

Nurses should also develop care protocols, guidance and institutional policies and provide care with a family-centered approach to ensure care of disabled children since there is interaction between the quality of life, care burden and depression levels of the parents.

## Conflict of Interest

The authors declare no conflict of interest for this study.

## Financial Disclosure

No financial support was taken from any institution or entity for this study.

## Authors' contributions

Conception: GM, BM, PU; Design: GM, BM, PU; Data Collection: GM, BM, PU; Conducting research: GM, BM, PU; Statistical Analysis: GM, PU; Literature review: GM, BM, PU; Writing: GM, BM, PU; Critical Review: GM, BM, PU;

## References

1. Giulio PD, Philipov D, Jaschinski I. Families with disabled children in different European countries. *Fam Soc* 2014; 23: 1-47.
2. Yılmaz A. Eğitimde yeni gelişmeler 2012.
3. Coşkun HY. Özürlü birey ve ailesinin sosyal iletişim sürecinde karşılaştığı ve yaşadığı durumlar hakkında teorik ve ampirik bir çalışma, Yüksek lisans tezi. Selçuk Üniversitesi Sosyal Bilimler Enstitüsü Halkla İlişkiler Ve Tanıtım Anabilim Dalı Araştırma Yöntemleri Bilim Dalı, Konya. 2010.
4. Bilsin E. Engelli çocukların ailesine verilen hemşirelik bakımının aile gereksinimini karşılama düzeyine etkisinin incelenmesi yüksek lisans tezi, Ege Üniversitesi Sağlık Bilimleri Enstitüsü. 2012.
5. Özcanarlan F, Karataş H, Aydın D. Şanlıurfa ilinde engelli çocuğa sahip annelerin depresyon durumlarının belirlenmesi. *Harran Üniversitesi Tıp Fakültesi*. 2014; 11(2): 75-82.
6. Yılmaz Kurt F, Üzen Ş. Engelli çocuğu olan ailelerin gereksinimleri, engelli çocuklar ve hemşirelik yaklaşımı özel sayısı. *Dijital Akademi Türkiye Klinikleri* 2017; 3(3): 162-8.
7. Coşkun D. Fiziksel engelli çocuğu olan ebeveynlerde bakım yükünün ve aile işlevlerinin değerlendirilmesi, Yüksek lisans tezi, Atatürk Üniversitesi Sağlık Bilimleri Enstitüsü, Erzurum. 2013.
8. Turan Gürhopur FD, İşler Dalgıç A. Zihinsel yetersiz çocuğu olan ebeveynlerde aile yükü. *Psikiyatri Hemşireliği* 2016; 8(1): 9-16.
9. Tsai MS, Wnag HH. The relationship between caregiver's strain and social support among mothers with intellectually disabled children. *J Clin Nurs* 2009; 18(4).
10. Conk Z, Başbakkal Z, Balyılmaz H, et al. *Pediatric hemşireliği* Ankara: Akademisyen Tıp Kitapevi 2013.
11. Aktaş E. Fiziksel engelli çocuk ve ailesinin evde bakım gereksinimine, Işık Tutucu Araştırmaların Sistematik İncelemesi, Yüksek Lisans Tezi. Marmara Üniversitesi, Sağlık Bilimleri Enstitüsü İstanbul. 2010.
12. Beck AT, Ward CH, Mendelson, et al. An inventory for measuring depression. *Arch Gen Psychiatry* 1961; 4(6): 561-571.
13. Hisli N. Beck depresyon envanterinin üniversite öğrencileri için geçerliği ve güvenilirliği. *Psikoloji Dergisi* 1989; 7(23): 3-13.
14. Çivi S, Kutlu R, Çelik HH. Kanserli hasta yakınlarında depresyon ve yaşam kalitesini etkileyen faktörler. *Güllhane Týp Dergisi* 2011; 53(4): 248-253.
15. Durukan E, İlhan MN, Bumin MA, et al. 2 Hafta-18 aylık bebeği olan annelerde postpartum depresyon sıklığı ve yaşam kalitesi. *Balkan Med J* 2011; 28(4): 385-393.
16. Eser E, Fidaner H, Eser SY, et al. Whoqol-100 ve whoqol-bref'in psikometrik özellikleri. *Psikofarmakoloji (3P)* 1999; 7(2): 23-40.
17. Zarit S, Reeve K, Bach-Peterson J. Relatives of the impaired elderly: correlates of feeling of burden. *Gerontologist* 1980; 20(6): 649-655.



18. İnci HF, Erdem M. Bakım verme yükü ölçeği'nin türkçe'ye uyarlanması geçerlilik ve güvenilirliği. Atatürk Üniversitesi Hemşirelik Yüksekokulu 2008; 11(4): 85-95.
  19. Özlü A, Yıldız M, Aker T. Zarit bakıcı yük ölçeğinin şizofreni hasta yakınlarında geçerlilik ve güvenilirlik çalışması. Nöropsikiyatri Arşivi 2009; 46: 38-42.
  20. Sen E, Yurtsever S. Difficulties experienced by families with disabled children. J Spec Pediatr Nurs 2007; 12:4: 238-252.
  21. Leung S, Li-Tsang P. Quality of life of parents who have children with disabilities. Hong Kong J Occup Ther 2003; 13(1): 19-24.
  22. Akturk U, Aylaz R. An evaluation of anxiety in parents with disabled children and their coping strategies. Int J Caring Sci 2017; 10(1): 342.
  23. Thomas S, Shakman WL, Saraswathy K, et al. Parenting a child with metabolic diseases: Impact on health related quality of life of parents. Diabetes Metab Syndr 2017; 11(1): 25-29.
  24. Şimşek Eİ, Erel S, Şimşek T, et al. Factors related to the impact of chronically disabled children on their families. Pediatr Neurol 2014; 50(3): 255-261.
  25. Roberts K, Lawton D. Acknowledging the extra care parents give their disabled children. Child Care Hlth Dev 2002; 27(4).
  26. Yildirim A, Aşıl RH, Karakurt P. Effects of a nursing intervention program on the depression and perception of family functioning of mothers with intellectually disabled children. J Clin Nurs 2013; 22(1-2): 251-261.
  27. <https://static.ohu.edu.tr/uniweb/media/portallar/engelsizuniversite/duyurular/1345/diwnu3i5.pdf> Erişim.01.06.2020
- \*Correspondence to**  
Pelin Uymaz  
Alanya Alaaddin Keykubat University  
Alanya, Turkey  
Tel: 905357967195  
E-mail: [pelin.uymaz@alanya.edu.tr](mailto:pelin.uymaz@alanya.edu.tr)