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Relationship between perceptions of family-to-family support, general well-being, and psychological resilience of mothers with children with special needs

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Abstract

This study aimed to investigate the association between perceptions of family-to-family support and the general well-being and psychological resilience of mothers raising children with special needs. Employing a descriptive correlational research design, the study included mothers of children aged 0-18 residing in a city center in northeastern Türkiye. Data collection was conducted through face-to-face interviews using the Personal Information Form, Brief Psychological Resilience Scale, General Well-Being Scale Short Form, and Family-to-Family Support Perception Scale for Families of Disabled Children. The results revealed a positive and significant relationship between mothers' perceived level of family-to-family support and their psychological resilience (β=0.437, $p<0.01$). Furthermore, a positive relationship was observed between mothers' general well-being levels and perceived support (β=0.315, $p<0.05$). However, no significant relationship was found between general well-being levels and psychological resilience (β=0.189, $p>0.05$). These findings underscore the significant connections between perceived family-to-family support, general well-being, and psychological resilience among mothers of children with special needs. They suggest a critical need for developing enhanced social and psychological support mechanisms to alleviate the stress and difficulties experienced by these mothers.

Keywords: Children, general well-being, mothers, perception of support, psychological resilience, special needs

Introduction

Special need is a situation of experiencing problems due to physical or developmental functional impairment that prevents equal participation in social life. Children with special needs need different education, health, rehabilitation, devices, orthoses, prosthesis, environmental regulations or other social and economic services [1-3]. It is known that children with special needs have a significant impact on family order [1]. Children with special needs have needs that require special support to ensure their development. While parents assume the primary caregiving responsibilities, the additional challenges and stresses associated with caregiving, compounded by limited skills, resources, and support, introduce various stressors for parents and their families. Parents may also face risks such as impaired functioning, poor health, psychological distress, and reduced well-being and quality of life [2].

The concepts of well-being and psychological distress are interrelated and can be considered both overlapping and distinct constructs [3]. Well-being is defined as experiencing positive feelings and functioning effectively across physical, mental, emotional, and social domains [4]. Conversely, distress is characterized as a state of emotional suffering, often marked by symptoms of depression and related negative emotions [5]. Various factors, including meeting physical and psychological needs, influence family quality of life, well-being, and distress [6]. Individuals' personalities, attitudes, beliefs and resilience [2]; wider factors, including the home environment and immediate environment; also policies, norms and cultural beliefs [4]; and family support and resources [7] significantly influence family well-being and psychological distress. For these reasons,

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parents have to cope with many difficulties related to the needs of a child with a disability while trying to meet the needs and expectations of other family members [8]. This situation is closely related to the concept of psychological resilience [9], which is the capacity of families to manage their psychological, social and cultural resources in the face of negative experiences and the ability to overcome difficult situations by using these resources meaningfully. Psychological resilience refers to the ability and capacity to cope with life experiences that may lead to adverse outcomes, utilizing individual, family, and social resources to continue functioning and adapting effectively to these circumstances. This capacity and ability of the individual may change and develop over time and may be strengthened or increased by the individual, familial and social factors that the individual has [10].

The arrival of a child with special needs in a family often triggers feelings of personal inadequacy and disrupts the established order, leading to psychosocial challenges that reverberate throughout the entire household [11]. This new dynamic can stir up emotions of inadequacy and a sense of being overwhelmed, potentially causing disturbances in family dynamics and social interactions [11,12]. Research indicates that parents of children with developmental challenges requiring special education face markedly elevated levels of stress [13], enduring trait anxiety [14,15], depression [15-17], and feelings of hopelessness [11,15].

Parents of children with special needs require increased psychosocial support due to the challenges associated with their circumstances. Studies have shown that mothers' stress, anxiety and depression levels increase more than fathers [17-19]. Coping strategies and social as well as psychological support can effectively mitigate anxiety, stress, depression, and other psychosocial challenges experienced by families raising children with special needs [14,15,20]. It is stated that insufficient social support causes various psychological problems such as burnout and stress in parents [21,22], and adequate social support increases satisfaction with life [21,23]. Findings from a study indicated that parent-to-parent support programs tailored for parents of children with special needs enhanced their perceived support from more seasoned families accustomed to navigating similar challenges [12]. Similarly, other studies conducted with families of children with special needs also emphasized the importance and meaning of parent-to-parent support [24-26].

It is very important for families with children with special needs to be able to cope with social and psychological problems. The support perception of these families can positively affect their ability to cope with psychosocial problems. Studies endeavors should focus on fostering communal bonds among families raising children with special needs, encouraging social interaction, and assessing the types of support families seek from one another. Thus, the difficulties faced by individuals as parents of a child with special needs can be reduced and they can be enabled to use coping methods better [27]. Strengthening family-to-family support networks can increase mothers' overall well-being and support their psychological resilience. This study provides an important basis for the development of future intervention and support programs. No study has been found in the literature examining the relationship between family-to-family support perceptions, general well-being and psychological resilience of mothers with children with special needs. In this context, this study aimed to examine the relationship between family-to-family support perceptions, general well-being and psychological resilience of mothers with children with special needs.

Research question: What is the relationship between family-to-family support perceptions, general well-being and psychological resilience of mothers with children with special needs?

Material and Methods

Ethical Considerations

Before starting the study, approval (2024/30) was obtained from the ethics committee of a state university. Participants were informed about the study in accordance with the Declaration of Helsinki. Afterwards, their consent was obtained through the Informed Consent Form.

Study Design and Population

The study was conducted between 01 March- 31 May 2024 with a descriptive relationship-seeking research model. The population of the research consisted of 101 mothers with special needs children between the ages of 0-18, residing in a city center in the northeastern part of Türkiye. The study was completed with 71 mothers who could be reached by the full count method, without using the sample selection method, who had no communication barriers and who agreed to participate in the research. 70% of the universe was reached in the study.

Procedure

Data of the study; It was collected face to face with the Personal Information Form, Short Psychological Resilience Scale, General Well-Being Scale Short Form and Family-to-Family Support Perception Scale for Families of Disabled Children. Application of the forms was completed in approximately 15-20 minutes.

Personal Information Form: The form consists of a total of 13 questions that inquire about sociodemographic characteristics such as the mother's age, family type, education, employment and income status, number of children, and information about the disabled child's age, gender and accompanying diseases [14,27].

Brief Psychological Resilience Scale (BPRS): BPRS, developed by Smith et al. (2008), is used to evaluate the psychological resilience of individuals [28]. The scale was adapted into Turkish by Doğan (2015). The scale contains 6 items on a 5-point Likert scale. Responses range from 'Not at all suitable' (scored as 1) to 'Completely suitable' (scored as 5), with higher scores indicating greater psychological resilience. The internal consistency coefficient of the scale was previously reported as 0.83 [29], while in the current study, it was found to be 0.76.

General Well-Being Scale Short Form (GWBSSF): The GWBSSF is comprised of 14 items derived from a factor analysis

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conducted on the original 65-item General Well-Being Scale [30]. The scale was adapted from Odacı et al. (2021) adapted to Turkish culture. Responses range from 'Not at all true=1' to 'Always true=5'. The scores that can be obtained from the scale vary between 14 and 70. Factor analysis results showed that the scale had a single-factor structure. In previous reliability studies, the internal consistency coefficient of the scale was determined to be 0.84 [31]. In the present study, this coefficient was measured at 0.86, indicating strong internal consistency.

Family to Family Support Perception Scale for Families of Disabled Children (FSPS): The scale developed by Kürtüncü and Arslan (2022) consists of 4 sub-dimensions (Appreciation Support sub-dimension, Informational Support sub-dimension, Emotional Support sub-dimension and Togetherness Support sub-dimension) and 24 items. The scale is a form developed for families with disabled children. The scale utilized in this study is a four-point Likert type. All items are positively framed, and there are no reverse-scored items. The scores that can be obtained from the scale vary between 24 and 96. Responses range from 'strongly disagree (1)', to 'strongly agree (4)'. A higher score on the scale indicates higher perceived support. The reliability coefficient for the entire scale was previously determined as 0.94 [27]. In the current study, the reliability coefficient was found to be 0.96.

Statistical Analysis

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 26.0 for Windows. Normality of the data distribution was assessed based on Skewness and Kurtosis coefficients falling within the range of (-1) to (+1) [32]. Descriptive statistics were calculated to summarize continuous variables, providing measures such as numbers, percentages, means, and standard deviations (SD). Parametric tests were applied due to the normal distribution of the data. Comparisons of maternal characteristics with their scale scores were performed using the Independent Samples T Test and One-Way ANOVA test. Bonferroni posthoc analysis was employed to identify specific group differences when comparing more than two groups with equal variances. The relationship between variables was examined using Pearson correlation analysis. Moreover, Multiple Linear Regression analysis was applied using the enter method to assess the association between dependent and independent variables.

Results

Table 1 presents a comparative analysis of sociodemographic and select diagnostic characteristics of mothers and children with special needs alongside their average scale scores. In the study, the mean BPRS total score of the mothers was 19.01±3.88. Significant differences were observed in the mothers' BPRS total score averages based on family type and the child's diagnosis ($p<0.05$, $p<0.01$, respectively). As a result of the posthoc analysis made according to the child's diagnosis variable, it was determined that the BPRS total score averages were higher in mothers whose children were diagnosed with Down Syndrome (DS) than in those whose children were diagnosed with Cerebral Palsy (CP), Sipina Bifida (SB) and Autism Spectrum Disorder (ASD). No significant difference was found between the BPRS total score averages and other variables ($p>0.05$). In the study, the mothers' GWBSSF total score average was found to be 47.53±8.49. No significant difference was found between the GWBSSF total score average and the variables ($p>0.05$). In the study, the mothers' FSPS total score average was found to be 74.01±11.32. Significant differences were found in the FSPS total score average based on the variables of place of residence, family type, and birth order of the child with special needs ($p<0.01$, $p<0.01$, $p<0.05$, respectively). As a result of the posthoc analysis performed according to the child's birth order variable, it was determined that the FSPS total score averages of mothers of children with birth order three were higher than those of mothers of children with birth order four. No significant difference was found between FSPS total score averages and other variables ($p>0.05$, Table 1).

Table 1. Comparison of the sociodemographic characteristics of mothers with the scales mean scores (n= 71)

Variables			n (%)	BPRS Mean±SD	GWBSSF Mean±SD	FSPS Mean±SD
	Mean±SD	Min.-Max.				
Average age of mothers	39.32±7.95	(25-58)				
Average age of children	9.62±4.86	(1-18)				
Mother's educational status	Primary school graduate		38 (53.5)	19.44±3.67	47.92±7.48	76.36±11.48
	Middle school graduate		21 (29.6)	18.33±3.75	45.66±9.04	71.47±11.36
	High school graduate or above		12 (16.9)	18.83±4.83	49.58±10.50	71.00±9.80
Statistical analysis				F=.564	F=.894	F=1.815
				p=.571	p=.414	p=.171
Mother's working status	I am not working		64 (90.1)	18.87±3.95	47.64±8.50	74.31±11.17
	I am working		7 (9.9)	20.28±3.09	46.57±9.03	71.28±13.26
Statistical analysis				t=-.911	t=.314	t=.669
				p=.366	p=.754	p=.506

*Independent T test, **One-Way ANOVA, ***According to mother's own statements, [a]Bonferroni=3>4, [b]Bonferroni= 4>3,2,1

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Table 1. Comparison of the sociodemographic characteristics of mothers with the scales mean scores (n= 71)

Economic level* **	**Income is less than expenses**	18 (25.4)	19.55±3.38	46.94±8.91	75.50±12.53
	Income equals expenses	53 (74.6)	18.83±4.05	47.73±8.42	73.50±10.96
Statistical analysis			t=.682	t=-.339	t=.642
			p=.498	p=.735	p=.523
Residential area	**Village/district**	22 (31.0)	20.36±3.64	49.31±7.25	79.50±11.30
	Province	49 (69.0)	18.40±3.87	46.73±8.94	71.55±10.53
Statistical analysis			t=2.003	t=1.189	t=2.873
			p=.049	p=.239	**p=.005***
Family type	**Nuclear family**	54 (76.1)	18.51±4.05	46.77±8.19	71.87±10.20
	Extended family	17 (23.9)	20.58±2.82	49.94±9.20	80.82±12.29
Statistical analysis			t=-2.349	t=-1.347	t=-3.001
			p=.024*	p=.182	**p=.004***
Number of child	**1**	11 (15.5)	18.81±3.15	50.72±11.18	72.27±11.89
	2	20 (28.2)	18.15±4.38	43.50±7.47	71.75±7.25
	3	29 (40.8)	18.62±3.94	48.62±8.47	77.17±12.27
	4	11 (15.5)	21.81±2.27	48.81±4.87	71.54±13.59
Statistical analysis			F=2.498	F=2.400	F=1.296
			p=.067	p=.077	p=.283
Birth order of a child with special needs	**1[1]**	30 (42.3)	18.36±4.18	47.86±9.66	74.60±11.18
	2[2]	22 (31.0)	18.68±3.68	46.22±8.04	71.63±9.78
	3[3]	12 (16.9)	19.33±3.39	48.25±7.94	81.41±11.56
	4[4]	7 (9.9)	22.28±2.81	49.00±6.13	66.28±10.43
Statistical analysis			F=2.108	F=.278	F=3.480[a]
			p=.107	p=.841	**p=.021****
Receiving assistance in child care	**No**	41 (57.7)	18.85±3.65	46.09±7.65	72.41±11.43
	Yes	30 (42.3)	19.23±4.23	49.50±9.29	76.20±10.98
Statistical analysis			t=-.404	t=-1.689	t=-1.401
			p=.687	p=.096	p=.166
Child's gender	**Female**	38 (53.5)	18.60±3.70	46.31±8.19	71.63±9.57
	Male	33 (46.5)	19.48±4.08	48.93±8.73	76.75±12.64
Statistical analysis			t=-.951	t=-1.305	t=-1.939
			p=.345	p=.196	p=.057
The child's diagnosis	**Cerebral palsy[1]**	23 (32.4)	18.08±3.47	48.30±10.61	75.13±12.37
	Sipina bifida[2]	8 (11.3)	17.62±3.77	48.62±4.98	77.37±9.03
	Autism spectrum disorder[3]	8 (11.3)	16.25±4.13	44.75±7.10	70.87±3.18
	Down syndrome[4]	6 (8.5)	23.50±3.93	53.00±5.40	71.66±10.46
	Intellectual disability[5]	18 (25.4)	20.00±3.36	47.55±8.36	74.38±12.00
	Muscular atrophy[6]	8 (11.3)	20.25±2.81	42.87±6.22	71.50±15.51
Statistical analysis			F=3.960[b]	F=1.235	F=.425
			p=.003**	p=.089	p=.830
Comorbidity	**No**	26 (36.6)	19.69±2.79	47.65±8.65	72.73±14.23
	Yes	45 (63.4)	18.62±4.37	47.46±8.49	74.75±9.34
Statistical analysis			t=1.256	t=.089	t=-.649
			p=.214	p=.929	p=.520

*Independent T test, **One-Way ANOVA, ***According to mother's own statements, [a]Bonferroni=3>4, [b]Bonferroni= 4>3,2,1

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Table 2 shows the correlation between BPRS and GWBSSF and FSPS. There was a positive and statistically significant correlation (r=0.407, p<0.001) found between the BPRS and GWBSSF total scores. A statistically significant moderate positive correlation (r=0.307, p<0.01) was observed between GWBSSF and FSPS total scores, as indicated in Table 2.

Table 2. Inter-scale correlation coefficients

Variables		BPRS	GWBSSF	FSPS
BPRS	**r**	1		
	p	-		
GWBSSF	**r**	.407*	1	
	p	.000	-	
FSPS	**r**	.032	.307*	1
	p	.792	.009	-

*Pearson correlation, correlation is significant at the 0.01 level (2-tailed)

We conducted a multivariate linear regression analysis to predict the GWBSSF dependent variable using the independent variables BPRS and FSPS (Table 3). As a result of the analysis, a significant regression model was found, F (2, 68)=11.473, p<0.001, and 23% of the variance in the dependent variable (R^2adjusted=.23) was explained by the independent variables. Accordingly, BPRS predicts GWBSSF positively and significantly, (β=.398, t (68)=3.791, p<0.001, pr^2=.175). FSPS predicts GWBSSF positively and significantly, (β=.294, t (68)=2.806, p<0.01, pr^2=.104), (Table 3).

Table 3. Regression analysis between BPRS and FSPS with GWBSSF scale total score

Dependent variable	Independent variables	95.0 CI							
		B	**SE**	**β**	**t**	**p**	**Lower**	**Upper**	**Model fit**
GWBSSF	**Constant**	14.663	7.218	-	2.032	.046	.260	29.065	Adj.R^2=.230 F=11.473
	BPRS	.869	.229	.398	3.791	.000	.412	1.327	
	FSPS	.221	.079	.294	2.806	.007	.064	.378	

Adj.R^2: adjusted R square, B: partial regression coefficient, β: standard partial regression coefficient, 95% CI: 95% confidence interval

Discussion

This study explored the associations between perceived family-to-family support among mothers of children with special needs and their levels of general well-being and psychological resilience. Our findings show that mothers' perceived level of support has a significant impact on general well-being and psychological resilience. Specifically, higher levels of support increase general well-being, whereas lower levels of support are negatively associated with resilience. Research results emphasize the importance of support mechanisms to reduce the stress and difficulties experienced by mothers. In particular, strengthening family-to-family support networks can increase mothers' general well-being and support their psychological resilience [33].

According to the study results, it was determined that the BPRS total mean score was higher in mothers whose children were diagnosed with DS than in those whose children were diagnosed with CP, SB and ASD. In a study by Pastor-Cerezuela et al. (2021), moderate levels of resilience were observed among parents diagnosed with ASD, DS, and those whose children had typical development. The research highlighted higher parental stress within the ASD group compared to the DS group. Interestingly, this stress was predominantly associated with factors related to the child and the distinct characteristics of each disorder, as perceived by the parents. It was less influenced by demographic or social factors pertaining to the parents or families [34]. Pastor-Cerezuela et al. (2021) findings highlight the relationship between resilience and aspects of how children's diagnoses are perceived, children's unique characteristics, and the characteristics of each disorder [34]. In the current study, mothers with children diagnosed with DS had higher psychological resilience compared to children with other diagnoses, suggesting that these factors may be effective.

The study found that general well-being did not differ according to variables related to mothers or children. Psychiatrist Elisabeth Kübler-Ross introduced a framework suggesting five emotional stages experienced by terminally ill patients and those who have suffered loss: denial, anger, bargaining, depression, and acceptance [35]. This model, known as the Kübler-Ross grief model, can be insightful in understanding the reactions of mothers raising children with special needs. Families caring for children with special needs often encounter challenges in fully accepting their circumstances [36]. With the birth of a child with special needs and learning of this condition, all previously established balances in the family change. These changing balances impose new and often heavy responsibilities on each member of the

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family. Undoubtedly, most of these responsibilities fall on the mother [37]. Having a child is an important and difficult process for families, especially mothers. The birth of a child with special needs or the subsequent occurrence of this condition may cause problems for families [38]. Mothers who have a child with special needs may experience many negative emotions about not being able to have the child of their dreams. In this process, well-being levels may vary. Mothers' awareness of their negative emotions and acceptance of their emotions and current situation can positively affect their general well-being.

In the study, the mothers' total FSPS score average was 74.01±11.32. This finding shows that mothers' perception of family-to-family support is at a medium level. Supporting this finding, Şahin and Yılmaz (2023) reported in their study with mothers of disabled children that mothers perceived moderate levels of social support [39]. Mothers' roles in caring for their children may affect their levels of social relationships.

In the study, it was found that the perception of family-to-family support of mothers living in rural areas or districts was higher than that of mothers living in the province. It was found that mothers with extended families had higher perceptions of family-to-family support compared to mothers with nuclear families. No evidence regarding this finding has been found in the literature. The fact that social networks in rural areas/districts and extended families are more functional may be effective in obtaining these findings.

In the study, we found that mothers of children with birth order three had higher perceptions of family-to-family support than mothers of children with birth order four. No evidence regarding this finding has been found in the literature.

The study found that there was a positive and significant relationship between the family-to-family support perceptions, general well-being and psychological resilience of mothers with children with special needs. It was determined that psychological resilience positively and significantly affected general well-being. It was found that perceived support from family to family positively and significantly affected general well-being. In their study with mothers of disabled children, Tekinarslan and Tok (2023) reported that social support indirectly affects the subjective well-being of the mother positively by increasing psychological resilience [40]. This finding is similar to our study. The lowest score that can be obtained from the general well-being scale is 14 and the highest score is 70. Accordingly, it can be said that the mothers' general well-being score average (47.53±8.49) is at a medium level. It is predicted that mothers are generally doing well because they are adapting to their situation and perceive themselves to be socially supported. Similarly, Çetin (2018), in his study with families with disabled children, reports that there is a significant relationship between parents' acceptance of their disabled children and their level of social support [36].

Study Limitations

Study results cannot be generalized to the entire universe. Since the demographic characteristics of the mothers in the sample and the special needs levels of the children were not selected similarly, the participants were heterogeneously distributed in these respects. Another limitation is the small number of participants and data collected only through self-report scales.

Conclusion

The study results emphasize the need to understand the difficulties experienced by mothers with children with special needs and to strengthen social support mechanisms. As a result, the psychological resilience of mothers whose children are diagnosed with DS is higher than those whose children are diagnosed with CP, SB and ASD. General well-being does not differ according to variables related to mothers or children. Mothers' perceptions of family-to-family support are at a medium level. The general well-being of mothers is at a moderate level. Mothers living in rural areas or districts have higher perceptions of family-to-family support than mothers living in the provinces. Mothers with extended families have higher perceptions of family-to-family support compared to mothers with nuclear families. Mothers of children with birth order three have higher perceptions of family-to-family support than mothers of children with birth order four.

There is a relationship between the perception of family-to-family support, general well-being and psychological resilience of mothers with children with special needs. Psychological resilience positively affects general well-being. Perceived support from family to family positively affects general well-being. Considering that the psychological resilience of mothers and their perceived support from family to family positively affects their general well-being, it is thought that it is important to investigate the social support networks of mothers and increase the quality and quantity of these networks and the necessary interventions to increase the psychological resilience of mothers. In this regard, nurses have important roles in strengthening the social support perceptions of mothers with children with special needs. Since mothers living in the province have a lower perception of family-to-family support than mothers living in districts and rural areas, nurses can bring families together with social events; psychoeducation to increase the psychological resilience of mothers; They can carry out awareness-raising activities to prevent social prejudices against children and their families. It is also recommended that research be conducted to strengthen the psychological resilience of mothers with children with special needs and their family-to-family support networks.

Conflict of Interests
The authors declare that there is no conflict of interest in the study.

Financial Disclosure
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Ethical Approval
The Ordu University Research Ethics Committee approved the research. Ethics committee approval dated 2024 and numbered 30 was obtained.

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