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RESEARCH ARTICLE

The Relations of Social Support and Well-Being in Mothers of Children with Special Needs During The COVID-19 Pandemic: The Mediating Role of Caregiving Burden

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ABSTRACT

This study explores the relationship between social support and well-being in mothers of children with special needs during the COVID-19 pandemic with a specific focus on the mediating role of caregiving burden. The research investigates the challenges faced by families with special needs children, particularly mothers, due to the pandemic-related closure of schools and rehabilitation centers. The closure has intensified the caregiving burden on mothers, requiring full-time support for their children at home. Existing literature suggests a significant impact on the psychological well-being of families with special needs children, emphasizing the need for attention to this vulnerable group during the pandemic. The study formulates hypotheses related to the negative correlation between family support and caregiving burden, the negative correlation between caregiving burden and psychological well-being, and the positive correlation between family support and psychological well-being. Additionally, it hypothesizes that caregiving burden mediates the relationship between family support and psychological well-being. Using a relational research approach, the study employs a quantitative method to analyze data collected from 321 participants. The demographic information of the participants, including age, working condition, marital status, and the type of disability of their children, is presented. Data collection instruments include a Sociodemographic Information Form, Family Support Scale, Caregiving Burden Scale, and Psychological Well-being Scale. Results indicated a positive relationship between family support and psychological well-being, as well as a negative relationship between caregiving burden and psychological well-being. The mediation analysis confirmed that caregiving burden significantly partially mediates the relationship between family support and psychological well-being. The findings highlighted the crucial role of family support in enhancing the psychological well-being of mothers with special needs children. Additionally, the study emphasized the negative impact of increased caregiving burden on psychological well-being. These results contribute to the understanding of the challenges faced by families with special needs children during the COVID-19 pandemic and underscore the importance of targeted interventions to support this vulnerable group. Future research may explore strategies to involve fathers in the caregiving process and further enhance maternal mental health.

Disasters and significant historical events such as wars impact individuals and families on a national or international level. In this context, the COVID-19 pandemic that started in 2019 and led to social isolation has been particularly challenging for families of children with special needs despite affecting all families with children (Asbury et al., 2021; Lee & Kim, 2020). Parents of children with special needs, who already face more physical, social, and emotional challenges compared to parents of typically developing children (Jones

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& Frederickson, 2010), have been further vulnerable due to the problems brought by the pandemic (Park & Nam, 2019). Global quarantine measures resulting in the closure of schools and rehabilitation centers during the COVID-19 pandemic have forced millions of children with special needs to stay at home for months (Wang et al., 2020). The closure of rehabilitation institutions providing necessary support for children with special needs has particularly burdened mothers, requiring them to provide full-time support to their children (Lučić et al., 2020).

Research conducted during the COVID-19 pandemic has highlighted the significant impact of both pre-existing stress factors related to the needs of children with special needs and stress factors arising from pandemic-related restrictions on the psychological health and well-being of families (Alhuzimi, 2021; Grumi et al., 2021; Rose et al., 2020). These studies have emphasized the importance of focusing on factors affecting the psychological well-being of children with special needs and their mothers, who constitute a significant risk group during the COVID-19 period. Psychological well-being is a dynamic construct sensitive to current social and economic conditions (Cummins, 2005). The new economic and social situations arising with the COVID-19 pandemic inevitably impact the psychological well-being of mothers with children with special needs (Embregts et al., 2021; Özmete & Melike, 2023; Rogers et al., 2021). Increased behavioral problems in children with special needs due to restricted educational rights and socialization opportunities during the pandemic have led to elevated stress levels in mothers (Neece et al., 2020), increased caregiving burden (Rogers et al., 2021), and decreased perceptions of self-competence (Cameron, 2020). Additionally, mothers' anxiety levels have increased due to the added responsibilities during the pandemic, distancing from their social circles, coping with economic difficulties, and not being able to allocate sufficient time for themselves (Asbury et al., 2020; Drogomyretska et al., 2020; Manning et al., 2020; Marchetti et al., 2020). The relevant literature revealed that caregiving burden (Arvidsdotter et al., 2016; Chafouleas & Iovino, 2021; Iovino et al., 2021) and perceived social support (Dickinson et al., 2023; Ekas et al., 2010; Hasting et al., 2002; Ren et al., 2020) were among the main factors influencing the mental health and well-being of mothers of children with special needs during the COVID-19 period.

Perceived social support is a broad concept that expresses individuals' satisfaction with being respected, supported, and understood in social life (Norris & Kaniasty, 1996). Especially in stressful and anxiety-inducing situations, receiving support from family, friends, and acquaintances has been a significant factor contributing to individuals' psychological health (Zhou et al., 2013). A study has shown that perceived social support among mothers with children with special needs plays a partial mediating role in the relationship between the burden of raising a child with a disability and depression, anxiety, and stress (Carlson & Miller, 2017). These results indicated that experiencing less social connection and support associated with the increased family burden due to disability was linked to increased reporting of stress, depression, and anxiety (Carlson & Miller, 2017). Another study conducted with parents of children with special needs during the COVID-19 period has also shown that perceived social support positively influenced the psychological well-being of these parents (Ren et al., 2020).

As aforementioned above, perceived social support positively influences the well-being of mothers of children with special needs. Social support is critical in the face of challenges when raising a child with special needs (Armstrong et al., 2005). In situations where social support is lacking, the caregiving burden on parents has increased (Carlson & Miller, 2017; Werner, 2022). Caregiving burden refers to the challenges, restrictions, and difficulties children with special needs and their families have faced in various aspects of their lives (Stoneman, 2005). This study aims to determine the mediating role of perceived caregiving burden in the relationship between perceived family support and the psychological well-being of mothers of children with special needs during the COVID-19 pandemic.

The hypotheses of the research are as follows:
H1: Family support is negatively correlated with caregiving burden.
H2: Caregiving burden is negatively correlated with psychological well-being.
H3: Family support is positively correlated with psychological well-being.
H4: Caregiving burden mediates the relationship between family support and psychological well-being.

Methodology

This research is relational research, one of the quantitative research methods that reveals the relationships between variables. Relational research determines the degree of relationship between two or more variables (Fraenkel et al., 2015). This study examined the mediating role of caregiving burden in the relationship between social support and psychological well-being.

The Study Group

The study group for the research was reached by a convenient sampling method. Since it was thought that the data of the participants with 5% or more missing data in the data set could cause problems in terms of reliability and affect validity, the data of the participants with missing data higher than 5% were excluded and this study was conducted with only 321 mothers who have children with special needs. The ages of the participants ranged between 18 and 60, with 243 (75.70%) participants aged between 25 and 44, 69 (21.50%) between 45 and 60, and 9 (2.80%) between 18 and 24. While 256 (80.70%) of the mothers who participated in the study were not working, seven (2.20%) lost their jobs during the pandemic. While 299 (93.10%) of the participant mothers were married, 22 (6.90%) were divorced. According to the type of disability of the participant mothers' children, the number of participants with autism was 47 (14.60%), 51 (15.90%) with intellectual disability, 38 (11.80%) with learning disability, 80 (24.90%) with hearing and visual disability, 49 (15.30%) with Down Syndrome, 39 (12.10%) with physical disability, and 17 (5.30%) with multiple disabilities. The demographic information of the participants is presented in more detail in Table 1.

Table 1. The Demographic Information (N = 321)

	n	%		*n*	%
Age			**Geographical Region**		
18-24	9	2.8	Mediterranean	64	19.9
25-44	243	75.7	Eastern Anatolia	22	6.9
45-60	69	21.5	Central Anatolia	63	19.6
Working Condition			Southeast Anatolia	27	8.4
Public employee	28	8.7	Black Sea	47	14.6
Private sector employee	30	9.3	Marmara	52	16.2
Not working	256	80.7	Aegean	46	14.3
Job loss in a pandemic	7	2.2	**Residential Units**		
Marital Status			Village	59	18.4
Married	299	93.1	District	135	42.1
Divorced	22	6.9	Province	44	13.7
Child's Type of Disability			Metropolitan	83	25.9
Autism	47	14.6	**Income**		
Intellectual Deficiency	51	15.9	Under 3000 TL	188	58.6
Learning Disabilities	38	11.8	3000 TL -7000 TL	105	32.7
Hearing/Sight	80	24.9	Over 7000 TL	28	8.7
Down Syndrome	49	15.3	**Diagnosis of COVID-19**		
Physical Disability	39	12.1	Yes	72	22.4
Multiple Disabilities	17	5.3	No	249	77.6

Data Collection Instruments

Sociodemographic Information Form

The sociodemographic information form prepared by the researchers included questions about the participant's age, employment status, marital status, type of disability of the child, geographical region and residential unit, economic status, and whether the participant was diagnosed with COVID-19.

Family Support Scale

Kaner (2003) developed the scale for parents of children with disabilities. The scale consists of five sub-dimensions: social cohesion support, information support, emotional support and care support, close relationship support, and financial support. The scale has a total of 31 items, including nine items in the emotional support dimension, eight in the information support dimension, five in the care support dimension, six in the close relationship support dimension, and three in the financial support dimension. An example of scale items is “There is someone who will give me information about my child's education”. The items of the scale are answered on a three-point Likert scale as 1=never, 2=sometimes, and 3=always. The lowest score on the scale is 31, and the highest score is 69. High scores on the scale indicate that parents have sufficient support areas to meet the needs of their children with disabilities.

In contrast, low scores indicate they do not receive enough support and experience deprivation. It was analyzed that the total variance explained by the scale was approximately 61%. In addition, when the scale has inter-factor relationships, a total score can be obtained from the scale. In the context of the criterion validity of the scale, the relationship between the scale and perceived social support was examined, and it was seen that there was a significantly high relationship (Kaner, 2003). In the context of psychometric analysis, the internal consistency coefficient was examined, and the internal consistency Cronbach α coefficient of the scale was analyzed as .95. For this study, the Cronbach α value was calculated as .96.

Caregiving Burden Scale

The 22-item scale developed by Zarit et al. (1980) and adapted into Turkish by İnci and Erdem (2008) was analyzed to have a three-factor structure, and a unidimensional structure was proposed as a result of the analyses (İnci & Erdem, 2008). The scale item “Would you want someone else to care for your relative?” can be an example. A 4-point Likert-type scale was used for scoring the scale: 0=never, 1=rarely, 2=sometimes, 3=quite often, 4=almost always. The lowest score that can be obtained from the scale is 0, and the highest score is 88. A high score on the scale indicates that the caregiving burden is high. The total variance explained by this scale structure was analyzed as 53.55%. When the reliability analyses were examined, the internal consistency coefficient of the scale was examined with Cronbach α and found to be .95. In addition, it was examined with the test-retest technique, and the reliability coefficient was analyzed as .90 (İnci & Erdem, 2008). For the current study, Cronbach's α reliability value was calculated as .90.

Psychological Well-Being Scale

The original form of the scale adapted into Turkish by Telef (2013) was developed by Diener et al. (2010). As a result of the validity studies of the scale, it was analyzed that its eight-item structure was unidimensional, and the total variance it explained was approximately 42% (Telef, 2013). The item “My social relationships are supportive and satisfying” can be given as an example of the items of the scale. In scoring the items of the scale, a 7-point scale was used with 1=strongly disagree and 7=strongly agree. The lowest score that can be obtained from the scale is eight, and the highest score is 56. A high score on the scale indicates a high level of psychological well-being, and a low score indicates a low level of psychological well-being. Within the scope of criterion-related validity studies, the relationship between well-being and need satisfaction was examined, and it was found that there were significant positive relationships between both scales (Telef, 2013). In the reliability analysis of the scale, the internal consistency coefficient was examined, and Cronbach's alpha coefficient was calculated as .80. For this study, the Cronbach α reliability value was calculated as .91.

Data Analysis

The data were obtained by reaching the participants both online and in person in April 2022 after the approval of the ethics committee of Hacettepe University. Moreover, the informed consent form was given to the participants, and they were informed in detail that they could leave at any stage of the research process and about their other rights and conditions. The data collection process was carried out by the researchers. SPPS v26 was used for data analysis, and PROCESS macro (Model 4) was used to test the mediation model (Hayes, 2018). To determine data normality, kurtosis and skewness values, linearity, and variance homogeneity were examined (Abu-Bader & Jones, 2021). As a result of the normality analysis, skewness values were found to be between - .35 and .15, and kurtosis values were found to be between - .74 and -.60. In addition, it was observed that there were significant relationships between predictor, mediator and predicted variables. VIF and tolerance values were found to be .85 and 1.18. These results revealed that the assumptions of mediation analysis were met (Abu-Bader & Jones, 2021; Byrne, 2013; Field, 2016). The study determined family support as the predictor variable, care burden as the mediator variable, and psychological well-being as the predicted variable.

Results

Table 2. Reliability, descriptive statistics, and correlation values (N= 321)

	1	2	3	α	*M*	*SD*	Skewness	Kurtosis
1. Family support	-			.96	69.31	15.19	-.35	-.74
2. Caregiving burden	-.39**	-		.90	56.27	15.67	.16	-.60
3. Psychological Well-being	.32**	-.24**	-	.91	36.18	12.21	-.47	-.65

Note. α: Cronbach's Alpha. $^{**}p$<.01.

The results of the descriptive, correlation and reliability values of the data are presented in Table 2. As shown in Table 2, there was a positive and significant relationship between psychological well-being and family support (r = .32, p < .01). At the same time, there was a negative and significant relationship with care burden (r = -.24, p < .01). In addition, there was a negative and significant relationship between burden of care and family support (r = -.39, p < .01). In particular, to clarify the uncertainty of multicollinearity, the correlation coefficient between the variables was examined and it was seen that there was not a high level of relationship. Thus, since there was no multicollinearity problem, the mediation analysis can be conducted (Tabachnick & Fidell, 2013). As a result, the regression-based mediation test results suggested by Hayes (2018) are presented in Table 3.

Tablo 3. Mediation Analysis Results

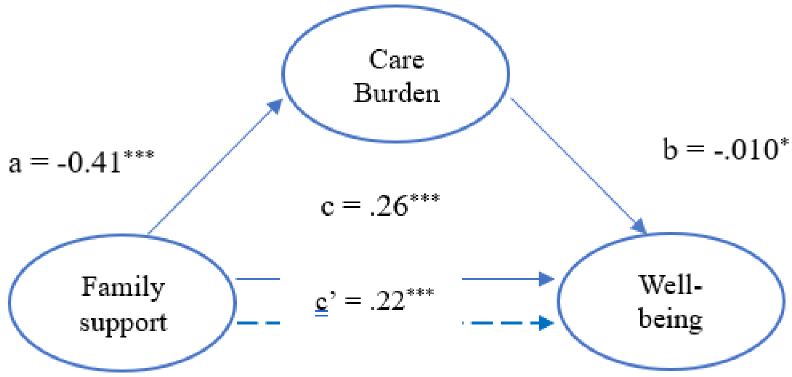
Effects	Coefficient	*SE*	*t*	*p*	95% CI (LL-UL)	
Direct effect	.22	.05	4.72	<.001	.13	.31
Indirect effect	.04	.02			.002	.09
Total effect	.26	.04	6.03	<.001	.17	.34

Note. SE: Standart Error, LL: Lower Limit, UL: Upper Limit, CI: Confident Interval.

According to the results of the study, psychological well-being was positively associated with family support (β =.26, p<.001, total effect) and negatively associated with caregiving burden (β=-.01, p<.05). In addition, there was a significant negative relationship between caregiving burden and family support (β=-.41, p<.001). The mediation analysis showed that caregiving burden was a significant mediator between family support and psychological well-being (β =.22, p <.001, direct effect). In contrast, the confidence interval for the indirect effect did not include zero (β =.04, *SH* =.02, 95% CI=.002-.09). In other words, when care burden was not included in the analysis, the level of care burden partially mediated the relationship between family support levels and psychological well-being levels, as a one-unit increase in family support caused a 0.22-unit increase in psychological well-being levels. These results showed that psychological well-being increases as family support increases, but the psychological well-being of mothers with children with special needs is negatively affected due to their high care burden.

When the mediation effect of care burden on the relationship between family support and psychological well-being was examined, the following model emerges (Figure 1), and it was seen that the indirect effect was significant. Since the mediation effect was significant and the relationship between family support and well-being level was significant, it was seen that the caregiving burden had a partial mediation effect. The caregiving burden decreases the relationship between family support and well-being (c'=.22, p<.001). Table 3 also showed that the level of indirect effect was significant (p<.001).

Figure 1. Mediation Model



Discussion, Conclusion and Limitations

This research encompasses significant findings regarding the caregiving burdens and psychological well-being of mothers of children with special needs. According to the research results, increased family support corresponds to improved psychological well-being. However, the high caregiving burden experienced by mothers of children with special needs adversely affects their psychological well-being. The first hypothesis of the research, indicating the positive impact of family support on perceived caregiving burden, has been confirmed. As family support increases, the perceived caregiving burden decreases. This finding is consistent with previous studies that suggested receiving sufficient support from the environment reduces the caregiving burden for parents of children with special needs (Sivrikaya & Tekinarslan, 2013; Varona et al., 2007). It aligns with previous findings associating maternal stress, maladaptive behavior, and low social support with caregiving burden (Estes et al., 2013).

The second hypothesis, stating that the caregiving burden significantly negatively impacts psychological well-being, has also been confirmed in the current study. As the caregiving burden of mothers with children with special needs increases, their levels of psychological well-being decrease. This result is consistent with studies conducted outside Türkiye indicating high stress levels for mothers of children with special needs (Boztepe et al., 2019; Çetinbakış et al., 2020). Gobrial (2018), in a study with Egyptian mothers, found that an autism diagnosis negatively affected mothers' social lives and mental health, while the caregiving burden increased the risk of stigmatization for both mothers and children. Children with special needs may experience behavioral regression and comprehensive problems due to the inability to access daily school education, rehabilitation training, personalized interventions, and treatments during the COVID-19 pandemic. This situation imposes multiple responsibilities on the caregiver parent, potentially increasing parenting stress and leading to mental health problems (Chen et al., 2020).

The current study has validated the third hypothesis, indicating family support's vivacious and significant impact on psychological well-being. Previous research has reported that social support is a crucial factor in enhancing the coping abilities of parents with children who have special needs (Ekas et al., 2010; Hasting et al., 2002). Furthermore, the parents of children with autism experienced adverse mental health outcomes when they received less family support (Benson & Kersh, 2011). Insufficient social support has been linked to various psychological problems in parents (Duygun & Sezgin, 2003; Karadağ, 2009), while perceived adequate social support has been reported to increase parental life satisfaction (Deniz et al., 2009; Wulffaert, 2009). From a different perspective, receiving professional guidance, interacting with peer groups, extended family members, parent groups with similar concerns, and online communities (e.g., Facebook) have been identified as protective solid factors against parenting stress (Illias et al., 2018). These resources support mental health by assisting parents in coping with stressors (Lowell et al., 2012). Studies have also demonstrated a significant relationship between receiving social support from family and increased enjoyment of life and optimism among mothers, indicating improved mental health and decreased negative emotions (Al-Kandari et al., 2017; Çetinbakış et al., 2018). Additionally, Chen et al. (2020) reported a significant relationship between parental psychological well-being and family support, a sub-dimension of social support, in a study examining various factors affecting the psychological status of families with children with special needs during the COVID-19 pandemic.

The fourth hypothesis, indicating that the caregiving burden mediates the relationship between family support and psychological well-being, has been observed in the current study. Mothers are most affected by the caregiving burden created in the family due to having a child with special needs (Hodge et al., 2011), and the caregiving burden has been reported to lead to certain discomforts in mothers (Sarı, 2007). While no studies have been found that examine family support, caregiving burden, and psychological well-being together, some studies have reported that social support predicts caregiving burden (Ghosh & Greenberg, 2012; Gönültaş, 2017), and the caregiving burden is more prominent in mothers (Pozo et al., 2014) and affects their psychological well-being.

Mothers in families of children with special needs tend to experience more psychological distress than fathers (Foody et al., 2015; Vilaseca et al., 2014), and they also bear a more significant caregiving burden (Roper et al., 2014). Especially during the pandemic, parents of children with special needs had to seek help and support from others to address caregiving issues (Ren et al., 2020). The increased time spent at home by children with special needs during this period, the increased caregiving burden on mothers due to taking on more responsibilities, and the insufficient family support due to measures taken may have adverse effects on the psychological well-being of mothers. The issue of caregiving burden is also related to cultural norms, where mothers often identify themselves with the caregiver role due to societal expectations, leading them to sacrifice personal lives for the sake of the family (Wang et al., 2018). Therefore, the caregiving burden usually falls on mothers rather than fathers. Women, especially during the pandemic, have stayed more at home to take care of their children with disabilities (Vilanova et al., 2022). In this regard, future studies may focus on involving fathers in the caregiving process, in addition to supporting maternal mental health.

Although the valuable insights provided by this study, there are several limitations that need to be acknowledged. Firstly, the research employed a cross-sectional design, limiting the ability to establish causal relationships among variables. Therefore, the extent of associations between variables should be considered as a priori and it is important to supplement with longitudinal studies which would offer a more comprehensive understanding of how social support, caregiving burden, and psychological well-being evolve over time, particularly amidst dynamic circumstances like the COVID-19 pandemic. Furthermore, the study sample was limited to mothers, neglecting the perspectives of fathers or other caregivers. Investigating the role of fathers and examining family dynamics in caregiving could offer a more holistic understanding of the support needs and well-being of families with special needs children. Lastly, the study was conducted in a specific cultural context, and the findings may not be generalizable to other cultural contexts. Future research should aim to explore these relationships across diverse populations to enhance the applicability of findings.

Despite these limitations, the findings of this study carry significant implications for practice and policy. Firstly, the study underscores the importance of providing targeted support interventions for mothers of children with special needs, especially during crises like the COVID-19 pandemic. Mental health professionals and policymakers should prioritize the development and implementation of support programs aimed at alleviating caregiving burden and enhancing social support networks for these mothers. Such interventions could include peer support groups, respite care services, and accessible mental health resources tailored to the unique needs of this population. Moreover, the study highlights the need for studies based on gender-sensitive approaches that recognize the disproportionate caregiving responsibilities shouldered by mothers and seek to involve fathers more actively in caregiving tasks and support processes. Strengthening familial support systems and promoting gender equity in caregiving roles could contribute to improving the overall well-being of families with special needs children. Finally, the study underscores the importance of fostering inclusive and supportive environments within communities and educational institutions to reduce the stigma associated with disabilities and promote social inclusion for children with special needs and their families. By addressing these implications, mental health professionals, educators, and policymakers can work collaboratively to enhance the well-being and resilience of families facing the challenges of raising children with special needs.

Author Note: This study is based on the doctoral dissertation of the first author.

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