

# Modelling The Impact of Caregiving Burden on Psychological Distress with the Mediating Role of Social Support Among Mothers of Children with Autism Spectrum Disorder

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## ABSTRACT

**Objective:** The study aims to investigate the relationship between caregiving burden, social support, and psychological distress among mothers of children with autism spectrum disorder (ASD). It specifically examines the mediating role of social support in the linkage between caregiving burden and psychological distress.

**Methods and Materials:** This cross-sectional study utilized Structural Equation Modeling (SEM) to analyze data from a sample of mothers of children with ASD. Key variables included caregiving burden, perceived social support, and psychological distress measured with standardized tools. The statistical analysis was conducted using SPSS-26 for preliminary data handling and descriptive statistics, while AMOS-22 was utilized for the SEM analysis to explore the relationships between caregiving burden, perceived social support, and psychological distress among the participants.

**Findings:** Results indicated that caregiving burden significantly predicts psychological distress ( $\beta = 0.19, p < 0.001$ ), and social support plays a crucial mediating role in this relationship. Higher levels of perceived social support were found to significantly mitigate the impact of caregiving burden on psychological distress ( $\beta = -0.37$  for social support to distress, and  $\beta = -0.43$  for burden to support,  $p < 0.001$  for both). The model fit indices (CFI = 0.95, TLI = 0.94, RMSEA = 0.06) confirmed a good fit for the SEM model.

**Conclusion:** The study shows the significant impact of caregiving burden on psychological distress among mothers of children with ASD. More importantly, it indicates the critical role of social support as a buffer in this relationship.

**Keywords:** Psychological distress, social support, Autism spectrum disorder, Caregiving burden.

## 1. Introduction

Autism spectrum disorder is a pervasive developmental disability that affects the individual's nervous and biological systems throughout life. This disorder impacts a child's ability to communicate and socialize with others and includes repetitive behaviors, interests, and activities. It causes disruptions in social and occupational functions. Autism spectrum disorder is defined as a single disorder including autism, Asperger's syndrome, childhood disintegrative disorder, and other unspecified developmental disorders. To diagnose autism spectrum disorder, a child must consistently show deficits in two areas: social interaction and communication, and restricted interests or repetitive behaviors (American Psychiatric Association, 2022). Caring for children with autism results in emotional consequences for parents, especially mothers, disrupting family systems. Parents of children with developmental delays experience increased levels of psychological distress, with mothers continually bearing the heavy burden of caring for a disabled child and experiencing more stress (Lee et al., 2024; Wei, 2023). Mothers of children with autism spectrum disorder show higher stress levels compared to mothers of children with other disabilities and generally exhibit higher levels of psychological distress than the general population (Millaku, 2023; Rezaei et al., 2023). Disruptive and abnormal child behaviors are a primary source of stress for parents of children with autism spectrum disorder, especially mothers. Studies have shown that these mothers experience more stress and concern than with other chronic illnesses (Chen et al., 2020; Dąbrowska & Pisula, 2010). Various individual, familial, and social factors can exacerbate the psychological distress of these mothers, negatively impacting their children.

One of these factors is the caregiving burden. Caregiving burden is defined as a persistent problem, stress, or negative experiences resulting from providing care (Ng et al., 2021). Increased pressure on caregivers leads to family isolation, loss of hope for social support, disruption in family relationships, inadequate patient care, and eventual patient abandonment. Approximately 70% of caregivers face two major problems: patient care and treatment issues and adapting to caregiving responsibilities. This caregiving pressure is a significant problem for the patient and their family, often leading to considerable health-related issues. Since caregiving pressure is not considered a disease and is hidden in nature, both the patient and caregiver suffer. They

desperately need social support and understanding (Kuhlthau et al., 2014).

Research has shown that social support mediates and moderates the effect of parental stress of children with autism spectrum disorder on satisfaction and mental health (Ghanimi et al., 2018; Jadidi et al., 2017; Lu et al., 2018) and that when parents perceive greater social support, family adaptation increases, and parental stress decreases (Lu et al., 2018; Meral & Cavkaytar, 2012). Social support obtained from others leads to improved physical and mental health (Rodda & Estes, 2018; Schertz et al., 2013). The most important predictors of perceived social support are sources of social support, including family, friends, or others (Meral & Cavkaytar, 2012). Family support, compared to friends and acquaintances, has a greater effect on resilience against problems. Parents of exceptional children, due to the high stress experienced from their child's presence, need more support from others than typical individuals (Ghanimi et al., 2018; Jadidi et al., 2017). The social support these parents receive evokes feelings of being important, respected, valued, cared for, and loved (Watson et al., 2019) and acts as a support system to cope with the stress of having a disabled child, leading to increased resilience and psychological toughness. Additionally, perceived social support from the family is associated with lower levels of psychological helplessness among family members (Lu et al., 2018).

Therefore, the current research was conducted with the aim of modeling the psychological distress of mothers of autistic children based on caregiving burden with the mediation of perceived social support.

## 2. Methods and Materials

### 2.1. Study Design and Participants

The current research is applied in purpose and quantitative in data collection. It employs a descriptive correlational research design, conducted using the Structural Equation Modeling (SEM) method. The population of this study comprises all mothers of children with autism spectrum disorder in Tehran in the year 2020, with the required sample size estimated at 354 based on Kline's suggestion, selected via convenience sampling. Inclusion criteria include having a child with autism spectrum disorder, a minimum educational qualification of a high school diploma, being aged between 25 to 50 years, not suffering from evident mental and physical disorders, not

being divorced, and giving informed consent. The exclusion criterion is the non-completion of questionnaires.

Initially, with a list of autism centers, their contact numbers, and addresses, researchers contacted the centers to explain the research objectives and requested cooperation from school authorities. Finally, Tehran Autism Center and a clinic for children with special disorders agreed to cooperate. The questionnaires were converted into electronic formats, and the researcher, in an explanatory session, detailed the research objectives and the principle of confidentiality to the center authorities, requesting them to distribute the questionnaires to mothers of children with autism spectrum disorder, considering COVID-19 pandemic restrictions.

## 2.2. Measures

### 2.2.1. Psychological Distress

This scale, developed by Kessler et al. (2002) in both 10-item and 6-item versions, is used for identifying mental disorders in the general population. Questions in these forms are rated on a Likert scale from 'never' to 'always' and from 0 to 40. The 10-item version does not target a specific psychological disorder but overall assesses the level of anxiety and depression symptoms experienced in recent weeks. Scores are based on the Likert scale from 'never' (0) to 'always' (4), with the total score being the sum of all item scores, ranging from 0 to 40. Higher scores indicate greater psychological distress and vice versa. Yaghubi (2016) in his research titled "Study of the Psychometric Properties of the 10-Item Version of the Kessler Psychological Distress Scale" found its reliability and validity to be 0.84. Cronbach's alpha coefficient calculated in Yaghubi (2016) study for this questionnaire was estimated to be above 0.70 (Yaghubi, 2016).

### 2.2.2. Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) was developed by Gregory D. Zimet, Nancy W. Dahlem, Sara G. Zimet, and Gordon K. Farley in 1988. This tool is designed to measure perceived social support from three sources: family, friends, and significant others. The MSPSS consists of 12 items, divided equally among the three subscales, each containing 4 items. Respondents rate each item on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (very strongly agree). The scores for each subscale are summed to provide a total score, with

higher scores indicating greater perceived social support. The MSPSS has demonstrated strong reliability and validity across various populations and contexts, as confirmed by numerous studies (Jadidi et al., 2017).

### 2.2.3. Caregiver Burden

The 24-item questionnaire was developed by Novak and Guest in 1989. It includes five subscales: Time-Dependent Caregiver Burden (reflecting the time spent on daily caregiving: 5 items (1 to 5)), Developmental Caregiver Burden (burden during different developmental periods of the caregiver's life, like adolescence, due to caregiving: 5 items (6 to 10)), Physical Caregiver Burden (physical stress and weariness from caregiving: 4 items (11 to 14)), Social Caregiver Burden (burden affecting the caregiver's social life during caregiving: 5 items (15 to 19)), Emotional Caregiver Burden (burden impacting the caregiver's emotions and feelings: 5 items (20 to 24)). Responses are measured on a 5-point Likert scale (from 'completely false' to 'completely true'). This questionnaire has good reliability, with Cronbach's alpha coefficients for the subscales reported between 0.69 and 0.87, and an overall Cronbach's alpha of 0.80 (Gaston-Johansson et al., 2004). In the research by Abbasi et al. (2013) for assessing the questionnaire's reliability, internal consistency method was used, and in a preliminary study with a sample of 20 caregivers of cancer patients, the overall alpha coefficient was 0.90, and the alpha coefficients for the subscales ranged from 0.76 to 0.82. For validity, content validity was applied, and the questionnaire was reviewed for relevance, clarity, and simplicity by ten faculty members, yielding scores of 91.8% for relevance, 90.2% for clarity, and 93.6% for simplicity, with an overall CVI of 91.86% (Shafizadeh et al., 2020).

## 2.3. Data analysis

For data analysis, both descriptive and inferential statistical methods were used. The descriptive statistics included tables, charts, mean, and standard deviation. The inferential statistics employed Pearson's correlation coefficient, path analysis, and structural equation modeling, with the final data analysis conducted using SPSS-26 and AMOS-22 software.

## 3. Findings and Results

The majority of the participants were in the age range of 30 to 40 years (45.2%). In terms of educational attainment

and employment status, a higher percentage of mothers of children with autism spectrum disorders in the sample group had a bachelor's degree (35.3%) and were self-employed (39.3%). For most mothers in the sample group, the first

child was diagnosed with autism spectrum disorders (59%). Economically and socially, the majority of the sample group's families were at a middle level (55.9%).

**Table 1**

*Descriptive Statistics of Research Variables*

Variable	Mean	Standard Deviation	Minimum Score	Maximum Score
Total Caregiving Burden Score	83.73	17.15	25	120
Components of Caregiving Burden				
Time-Dependent Caregiving Burden	17.19	4.04	5	25
Developmental Caregiving Burden	15.15	4.79	5	25
Physical Caregiving Burden	14.73	4.52	4	20
Social Caregiving Burden	17.26	5.82	6	24
Emotional Caregiving Burden	19.40	6.87	5	25
Total Perceived Social Support Score	41.03	11.12	14	60
Components of Perceived Social Support				
Perceived Support from Family	14.69	3.89	5	20
Perceived Support from Significant Others	12.19	4.04	4	20
Perceived Support from Friends	14.15	3.79	5	20
Psychological Distress	24.30	6.43	5	40

The **Table 1** presents descriptive statistics for various research variables. The total caregiving burden score among the study participants was found to be 83.73 with a standard deviation of 17.15, ranging from a minimum of 25 to a maximum of 120. Breaking down the caregiving burden into its components, time-dependent caregiving burden scored an average of 17.19 (SD = 4.04), developmental caregiving burden averaged 15.15 (SD = 4.79), physical caregiving burden was 14.73 (SD = 4.52), social caregiving burden stood at 17.26 (SD = 5.82), and emotional caregiving burden

scored the highest with an average of 19.40 (SD = 6.87). The total perceived social support score averaged at 41.03 (SD = 11.12), with the perceived support from family being the highest at 14.69 (SD = 3.89), followed by support from friends at 14.15 (SD = 3.79), and the lowest from significant others at 12.19 (SD = 4.04). Lastly, the psychological distress among the participants was reported to have an average score of 24.30 with a standard deviation of 6.43, the scores ranging between 5 and 40.

**Table 2**

*Correlation Coefficients Between Research Variables*

Endogenous Variables	Perceived Social Support (r, p)	Psychological Distress (r, p)
Total Caregiving Burden	-0.49, 0.001	0.34, 0.001
Components of Caregiving Burden		
Time-Dependent Caregiving Burden	-0.31, 0.001	0.27, 0.001
Developmental Caregiving Burden	-0.26, 0.001	0.24, 0.001
Physical Caregiving Burden	-0.52, 0.001	0.32, 0.001
Social Caregiving Burden	-0.48, 0.001	0.36, 0.001
Emotional Caregiving Burden	-0.50, 0.001	0.34, 0.001
Total Perceived Social Support	1, -	-0.46, 0.001
Components of Perceived Social Support		
Perceived Support from Family	0.69, 0.001	-0.49, 0.001
Perceived Support from Significant Others	0.58, 0.001	-0.32, 0.001
Perceived Support from Friends	0.66, 0.001	-0.31, 0.001
Psychological Distress	-0.46, 0.001	1, -

The **Table 2** data reveals the correlation coefficients and significance levels between various research variables for

mothers of children with autism spectrum disorder. The total caregiving burden showed a significant negative correlation

with perceived social support ( $r = -0.49, p = 0.001$ ) and a positive correlation with psychological distress ( $r = 0.34, p = 0.001$ ). Specifically, the emotional caregiving burden had a notable negative correlation with perceived social support ( $r = -0.50, p = 0.001$ ) and a positive correlation with psychological distress ( $r = 0.34, p = 0.001$ ). The total perceived social support was negatively correlated with psychological distress ( $r = -0.46, p = 0.001$ ). Regarding the components of perceived social support, support from family had the strongest negative correlation with psychological distress ( $r = -0.49, p = 0.001$ ), followed by support from friends ( $r = -0.31, p = 0.001$ ) and significant others ( $r = -0.32, p = 0.001$ ). These correlations indicate a significant relationship between the caregiving burden, perceived social support, and psychological distress among the study participants.

In conducting our Structural Equation Modeling (SEM) analysis, we meticulously verified various critical assumptions to ensure the robustness and validity of our

findings. Firstly, we checked for linearity and multicollinearity among the variables. The Variance Inflation Factor (VIF) values ranged from 1.05 to 1.42, well below the threshold of 5, suggesting no multicollinearity issues. Secondly, we assessed the normality of the data; skewness and kurtosis values for all variables were within the acceptable range of -2 to +2, indicating normal distribution. The model fit was evaluated using several fit indices: The Comparative Fit Index (CFI) was 0.95, the Tucker-Lewis Index (TLI) was 0.94, and the Root Mean Square Error of Approximation (RMSEA) was 0.06, all of which fall within the recommended values, indicating a good model fit. Additionally, we conducted a confirmatory factor analysis (CFA) to ascertain the measurement model's validity, with all factor loadings being significant ( $p < 0.001$ ). These assessments collectively validate the assumptions underlying our SEM analysis, providing confidence in the reliability and validity of the results derived from our structural model.

**Table 3**

*Parameters of Direct Relationships Between Variables in the Tested Final Model*

Path	Unstandardized Coefficient (B)	Standardized Coefficient (β)	Standard Error	Lower Limit	Upper Limit	p
Caregiving Burden to Psychological Distress	0.40	0.19	0.08	0.119	0.412	0.001
Social Support to Psychological Distress	-0.71	-0.37	0.03	-0.298	-0.619	0.001
Caregiving Burden to Social Support	-0.88	-0.43	0.02	-0.359	-0.713	0.001

Based on the data in Table 3, the relationships between the variables in the tested final model are reported as follows: The path from caregiving burden to psychological distress showed a standardized beta coefficient ( $\beta$ ) of 0.19 with a significance level ( $p$ ) of 0.001. The path from social support to psychological distress had a negative standardized beta coefficient of -0.37 with a significance level of 0.001.

Lastly, the path from caregiving burden to social support also showed a negative standardized beta coefficient of -0.43 with a significance level of 0.001. These beta values and p-values indicate significant relationships between caregiving burden, social support, and psychological distress within the final tested model.

**Table 4**

*Estimation of Indirect Paths in the Model Using Bootstrap*

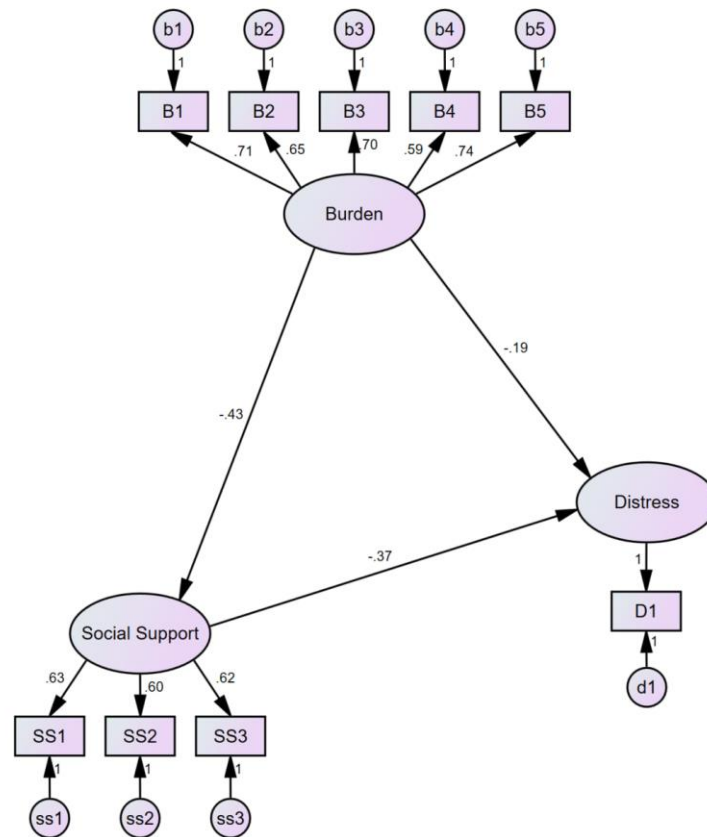
Path	Unstandardized Direct Coefficient (B)	Standardized Indirect Coefficient (β)	Standard Error	Lower Bound	Upper Bound	p
Caregiving Burden to Psychological Distress through Social Support	-0.33	-0.16	0.04	-0.110	-0.356	0.001

The data from Table 4 indicates that in the model estimating the indirect path from caregiving burden to psychological distress through social support, the standardized indirect coefficient ( $\beta$ ) is -0.16, with a p-value

of 0.001. This significant beta value suggests that social support plays a mediating role in the relationship between caregiving burden and psychological distress.

Figure 1

Final Model with Beta Coefficients



#### 4. Discussion and Conclusion

The results indicated that the direct path coefficient from caregiving burden to perceived social support among mothers of children with autism spectrum disorder is negative and significant. Additionally, while perceived social support maintained its effect on reducing the psychological distress of these mothers, it also played a mediating role, transforming the positive effect of caregiving burden on mothers' psychological distress into a negative one.

These findings are consistent with the results of prior research (Ghanimi et al., 2018; Jadidi et al., 2017; Lu et al., 2018; Meral & Cavkaytar, 2012; Rodda & Estes, 2018; Schertz et al., 2013; Watson et al., 2019).

In explaining the direct relationship between caregiving burden and the psychological distress of mothers of children with autism spectrum disorder, it can be said that each child with autism spectrum disorder has a unique cognitive, behavioral, sensory, emotional, motivational, and social status (Kuhlthau et al., 2014; Ng et al., 2021). These children

typically face fundamental difficulties in social interaction, understanding social cues, forming interpersonal relationships, eye contact, joining peer groups, engaging in symbolic play, shared attention, imitation, and communication skills (Lu et al., 2018). Therefore, due to these challenges, parents, particularly mothers, must allocate more time for caregiving and bear greater cognitive, social, and emotional responsibility compared to parents of typically developing children. Consequently, these parents are exposed to stress, psychological harm, and numerous challenges. In these families, mothers experience more stress than fathers because they spend more time caring for their child and face greater psychological stress due to the cognitive, social, and emotional conditions of these children (Rodda & Estes, 2018; Schertz et al., 2013). These stresses can lead to feelings of anger, irritation, guilt, loneliness, despair, and psychological tension in the mother (Mello et al., 2022; Taghvaei et al., 2019). Moreover, research in this field has shown that parents of children with autism spectrum disorders report higher levels of stress and severe symptoms of psychological pathology compared to parents

of typically developing children (Taghvaei et al., 2019). Generally, caregiving for a child with autism presents numerous challenges for the caregiver, potentially causing stress and negative physical and psychological effects.

In elucidating the mediating role of perceived social support in the relationship between caregiving burden and psychological distress, it can be said that one of the factors explaining the significant correlation between caregiving burden and psychological distress is the lack of adequate social support for these caregivers. One of the main reasons for the psychological distress of these mothers is the absence of social support and a reduced communication network. The lack of a supportive network is a key factor in increasing caregiving pressure and inadequate adaptation to children with autism spectrum disorder. If the family's support networks, including relatives, friends, and the children's educational team, weaken, the mother will experience greater caregiving burden. Conversely, strengthening these connections and support networks will play an effective role in better and more effective adaptation of the mother and in reducing psychological burden and caregiving stress (Ng et al., 2021). Social support not only facilitates and promotes health behaviors but also reduces life's stressful events and encourages the achievement of personal goals, recognized as a strong coping force for successfully and easily confronting stressful situations (Jadidi et al., 2017).

## 5. Suggestions and Limitations

This study, while insightful, has certain limitations that must be acknowledged. Firstly, its cross-sectional design limits the ability to infer causality among the studied variables. The sample was restricted to mothers of children with autism spectrum disorder, which may limit the generalizability of the findings to other populations or caregivers of children with different conditions. Additionally, the reliance on self-reported measures might introduce response bias, as participants may provide socially desirable responses or may not accurately recall past experiences. Lastly, the study was conducted within a specific cultural and social context, which might influence the generalizability of the findings across different cultural settings.

Future research could address the limitations of this study by adopting a longitudinal design to better understand the causal relationships between caregiving burden, social support, and psychological distress. It would also be beneficial to include a more diverse sample, encompassing

fathers, other caregivers, and families dealing with various developmental disorders, to enhance the generalizability of the findings. Incorporating objective measures or third-party assessments could provide a more comprehensive understanding and help mitigate the biases associated with self-reported data. Additionally, exploring these variables in different cultural contexts would provide deeper insights into the cultural dynamics that influence caregiving experiences.

The findings of this study have important implications for practice, particularly for mental health professionals and policymakers. The significant role of social support in mitigating the psychological distress of caregivers suggests the need for developing and implementing support systems and interventions targeted at caregivers of children with autism spectrum disorder. This could include community-based support groups, counseling services, and respite care. The study also highlights the importance of training and resources for healthcare professionals to better support these caregivers. Policymakers should consider integrating caregiver support into healthcare policies and ensuring accessible mental health services for these families. Furthermore, raising public awareness about the challenges faced by these caregivers could foster a more supportive and inclusive community environment.

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## Declaration of Interest

The authors of this article declared no conflict of interest.

## Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

## Transparency of Data

In accordance with the principles of transparency and open research, we declare that all data and materials used in this study are available upon request.

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### Authors' Contributions

All authors equally contributed in this article.

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