

## Research Article

# Influence of family support on parental care burden of autism spectrum disorder with parental acceptance as a mediator

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### Abstract

Parents of children with autism spectrum disorder (ASD) frequently struggle to maintain their mental health and wellbeing due to high levels of stress. This will result in an even heavier burden on parenting, therefore, it is very important to find a model to relieve the burden. The aim of this study is to find out whether parental acceptance can mediate family support with parental care burden for parents who have autistic children. The sample used in this study had as many as 33 parents. Path analysis is the data analysis technique employed in this investigation, with a significance value of 0.090 larger than 0.05, the direct effect analysis findings reveal that parental acceptance is not significantly impacted by family support; family support has a significant effect on parenting burden with a significance value of  $0.05 \leq 0.05$ ; and parental acceptance has a significant effect on parental care burden with a significance value of  $0.030 \leq 0.05$ . The results of the analysis on Sobel's analysis are known that the t value of the table of 2,036  $\geq$  t-statistic of 1,404 which means that the effect of family support on the burden of parental care can not be mediated by the parental acceptance variable.

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## Introduction

When families find out that their child has developmental problems or autism, their initial reaction can be disbelief, shock, sadness, disappointment, guilt, anger, or denial. It is undoubtedly difficult for parents to accept a diagnosis of autism in their children. If this condition persists for a long time, it will increase stress and present significant challenges in maintaining their mental health and well-being. Several studies by Cadman et al. (2012); Kirby et al. (2015); Cohrs and Leslie, (2017); Seymour et al. (2017) have highlighted the high level of caregiver pressure among these parents. Caregiver stress, commonly referred to as caregiver "burden," is the unfavorable attitude held by parents of special needs children. It encompasses various experiences that contribute to this tension, such as financial difficulties, disruption of routine, disruption of work and career, burnout, feelings of social isolation, anger, worry, and sadness. A range of emotions related to raising and caring for children with autism spectrum disorder (ASD) are also experienced by caregivers. These emotions include frustration, anxiety, restlessness, astonishment, helplessness, anger, sadness, annoyance, financial difficulties, the burden of parenting, confusion, sudden changes in schedules, and a shift in family priorities toward immediate goals rather than long-term goals (Bashir et al., 2014).

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According to Zarit et al. (1980), parental care burden refers to the stress experienced by caregivers, which causes adverse effects on their physical, emotional, and psychological well-being, social life, and financial situation of caring for their family members. According to Liu et al. (2020), the parental care burden includes various levels of stress experienced by caregivers while caring for family members or their loved ones, which occur from time to time. Hamilton, as cited in Liu et al. (2020), initially identified two types of parenting burden: subjective burden and objective burden. Subjective burden involves the caregiver's personal emotions and is generated during the parenting process, while objective burden refers to negative events or experiences encountered during parenting. Siegert et al. (2010) proposed three dimensions of parenting burden, namely: personal tension, role tension, and feelings of guilt. Personal tensions arise from caregivers and emerge throughout the parenting process, including emotions such as anger, embarrassment, discomfort, and other forms of distress. Role strain refers to the feelings of burden experienced by caregivers due to their children's increasing dependence on them, which causes disruption in the social life of the parents. Guilt is prevalent among caregivers, as they often experience guilt for not being able to provide adequate care or attention to their children because of the need to balance their time with work commitments.

As per Kyzar, Turnbull, Summers, and Gomez (2012), family support is a construct at the family unit level that has a reducing effect on adverse family conditions like stress or depression and a boosting effect on more favorable outcomes. According to Kirk (2003), when parents of children with special needs receive the support they require, it can help parents lessen negative perspectives in carrying out their responsibilities and produce favorable effects that, over time, can reduce stress and improve well-being, which has a positive impact on the quality of life in the family. The family's support can lessen the burden and stress of being a parent of a child with special needs; in this case, the support is able to lessen the psychological stress symptoms experienced by the parents, who in the event of a lack of family support, are more likely to experience high levels of anxiety and depression, low levels of emotional well-being, or issues with their mental health (Spence et al., 2014). As a result, family support helps foster positive mental health outcomes.

Family support can reduce the burden and stress of being a parent of a child with special needs; in this case, support can reduce symptoms of psychological stress experienced by parents, conversely, if there is no family support, they are more likely to experience high levels of anxiety and depression, low levels of emotional well-being, or problems with their mental health (Spence et al., 2014). Therefore, family support helps drive positive mental health outcomes.

On the other hand, as parents of children diagnosed with autism reach the acceptance stage, the burden of parenting also diminishes. Parents go through various psychological stages before reaching self-acceptance. The Kubler-Ross model (2005) suggests that individuals typically experience stages such as denial, anger, bargaining, depression, and eventually, acceptance. However, a process of acceptance known as "Resolution of diagnosis," wherein parents accept and adapt to their new reality, has been linked to improved parental well-being. Studies by Milshtein et al. (2010) and Sher-Censo et al. (2022) indicate that parents' resolution involves adjusting their internal expectations and perceptions to accommodate their child's neurodevelopmental disability. It also necessitates modifying parenting approaches accordingly. Internal representation refers to parents' beliefs, emotions, and understanding of their child's personality and behavior (Sher-Censo, 2017).

Parents' resolution of their child's autism diagnosis leads to enhanced stress management abilities, resulting in reduced psychological stress and depression, increased marital satisfaction, and seeking and receiving social support (Da Paz, 2018). Conversely, failure to accept a child's autism diagnosis is associated with lower levels of emotional support (Sheeran et al., 1997). Heredia-Alvarado and Chen (2017) discovered that positive factors like family support and the bond between mother and child play a significant role in the acceptance process. Parents often experience relief upon realizing that they are not alone within their community and can access support, thereby reducing self-blame (Chao, 2018). Hotez (2017) found a positive correlation between higher levels of resolution and perceived social support. Lopez et al. (2018) also noted that support influences the extent of parental involvement in caregiving.

## **Problem of Study**

Based on the description above, there is an interrelationship between family support, parental acceptance, and the burden of caring, and it has not been studied how the role of parental acceptance plays a role in the relationship between family support and the burden of caring for parents with children with autism. Therefore, this researcher raises the theme of the role of parental acceptance as the mediator in the relationship between family support and the burden of parenting

## **Method**

### **Design**

Quantitative research was the method used in this investigation. According to Creswell (2014), quantitative research is a method for testing objective theory by looking at the correlation between variables. This study employs a quantitative research design. Variables in this study can be measured using instruments, and the data can be analyzed using statistical procedures.

The independent variable in this study is family support. Friedman (2013) defines family support as the attitude and actions of family members toward accepting and supporting one another. It includes informational support, appraisal support, instrumental support, and emotional support. Family support is measured based on the perception that other family members are supportive and willing to provide assistance when needed.

The dependent variable is the parental care burden. Zarit et al. (1980) describe caregiver burden as the negative impact experienced by caregivers in terms of their physical, emotional, psychological well-being, social life, and financial situation while taking care of their family members.

The mediator variable is parental acceptance. According to Rohner et al. (2012), parental acceptance refers to the warmth, attention, affection, comfort, support, or love given by parents to their children as a form of acceptance. It serves as a mediator in understanding the relationship between family support and parental care burden.

### **Participant**

Participants in this study were 33 parents of elementary school students with autism syndrome aged between 7-13 years.

### **Data Collection Tool**

The instrument used in this study was developed by the researchers based on their respective constructs and arranged on a Likert scale with scale values ranging from 1 to 4. To ensure construct validity, the "experts review" method was employed, as recommended by Dimitrov (2012). The scale items were evaluated by a panel of experts to assess how well the items measure the intended constructs. The scale was presented to three reviewers who specialize in the fields of educational technology and measurement. Statements that obtained an agreement ratio of 80% were validated, while other statements were modified based on the feedback from the panel. and then statistically examined using an internal consistency approach, which involved connecting the item's total score with the scale's overall score.

The parental care burden scale is based on the concept proposed by Siegert et al. (2010) and comprises three dimensions: role tension, personal tension, and feelings of guilt. This scale is used to assess the level of burden experienced by mothers who are caring for their children. Out of the 26 items gathered, the study of item validity revealed 23 valid items.

The family support scale is based on Friedman's (2013) concept and includes four dimensions: informational support, instrumental support, appreciation support, and emotional support. The scale aims to measure the level of support received from family members. The results of the analysis of item validity found 18 valid items from the 23 items compiled.

The parental acceptance scale was compiled based on the Munandar & Robinson concept, consisting of five dimensions, namely: attention, affection, participating in children's activities, not expecting too much from children and not distinguishing children from others. Analisis validitas item mengungkapkan bahwa dari 26 item yang awalnya disusun, ditemukan 23 item yang valid.

Scale reliability test based on Cronbach's Alpha analysis. An instrument is said to be reliable if the minimum value obtained from the Cronbach Alpha reliability test is 0.6 and the maximum value obtained is close to 1 (Azwar, 2018).

**Table 1.** Cronbach alpha analysis results

No	Scale	Cronbach Alpha
1	Family Support	0.910
2	Parental Care Burden	0.936
3	Parental Acceptance	0.927

### Results

Before conducting a simple linear regression analysis to evaluate a hypothesis, it is essential to test the assumptions, including normality and linearity. The purpose of assumption tests in statistical analysis is to evaluate whether certain assumptions are met in the data. Two common assumptions include the normal distribution of data and the presence of a linear relationship between independent variables and the dependent variable.

By verifying these assumptions, researchers can ensure the validity of the regression analysis and make any necessary adjustments if the assumptions are not met.

The results of the normality test analysis used the Kolmogorov-Smirnov test. The family support variable shows a normal distribution with a significant value of 0.522 greater than 0.05. The parental care burden variable shows a normal distribution with a significant value of 0.282 greater than 0.05. The data for the parental acceptance variable exhibits a normal distribution, as indicated by a significance value of 0.383, which is greater than the commonly used threshold of 0.05. This suggests that there is no significant departure from normality in the distribution of the data for the parental acceptance variable.

**Table 2.** Normality test results

Variables	Significant	$\alpha$	Interpretation
Family Support	.522	0.05	Data is normally distributed
Parental Acceptance	.383		
Parental care burden	.282		

The linearity analysis results indicate that there is a linear relationship between family support and parental acceptance, as the significance value of 0.225 is greater than the threshold of 0.05. Similarly, the relationship between family support and parental care burden also shows a significance value of 0.447, which is greater than 0.05. Therefore, both variables can be considered to have a linear relationship. Additionally, the relationship between parental care burden and parental acceptance reveals a significance value of 0.475, which is also greater than 0.05, indicating a linear relationship between these variables.

**Table 3.** Linearity test results

Variables	Significant	$\alpha$	F score	Interpretation
Family support and Parental acceptance	0.225	0.05	1.515	Linear
Family support and Parental care burden	0.447		1.096	
Parental acceptance and Parental care burden	0.475		1.024	

The results of the simple linear regression analysis, specifically the direct effect test, indicate that there is no significant effect of family support on parental acceptance. The significance value for this effect is 0.09, which is greater than the predetermined threshold of 0.05. This suggests that the relationship between family support and parental acceptance is not statistically significant. For a comprehensive overview of the results, please refer to Table 4, which provides detailed information regarding the analysis.

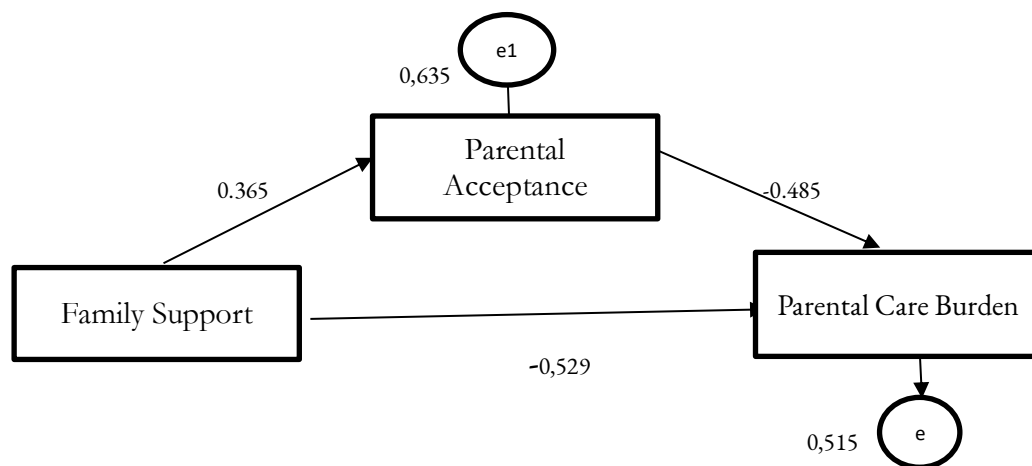
**Table 4.** Correlation of Family Support and Parental Acceptance

	Variable	Unstandardized Coefficients		Standardized Coefficients		t	Sig.
		B	Std. Error	Beta			
1	Family support	.365	.209	.300		1.750	.090

The results of the path analysis showed that there was a direct effect of family support on the parental care burden which indicated a significant value of 0.05 which was the same as the value of 0.05 and also revealed that there was a direct effect of parental acceptance on the parental care burden which indicated a significant value of 0.03 which was smaller than the value of 0.05. Complete results are listed in Table 5.

**Table 5.** Correlation of Family Support, Parental Acceptance and Child Care Burden

No	Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	Family support	-.529	.260	-.325	-2.038	.050
2	Parental acceptance	-.485	.213	-.362	-2.273	.030



**Figure 1.** Model Parental care burden

The model of parental care burden above can be explained that the influence of family support on parental acceptance is 0.365 with a significance of 0.09 so it is concluded that there is no influence on parent acceptance. The direct effect of parental acceptance on the parental care burden was -0.485 with  $p < 0.5$ , it can be concluded that there is an effect of parent acceptance upon the parental care burden. The negative effect can be expressed as the higher parental acceptance the lower parental care burden and vice versa. The effect of family support on the parent care burden is -0.529, the negative sign has the meaning of the higher family support, the lower parental care burden, and vice-versa.

Analysis of the role of parental acceptance as a mediator using Sobel's formula. The results of the Sobel test show that the t-statistic of 1.404 while the t-table value of 2.036. It can be concluded that the t-statistic is smaller than the t-table. Thus it can be concluded that parental acceptance does not function as a mediator in the influence of family support on the parental care burden.

### Discussion

The primary objective of this study is to investigate the role of parental acceptance as a mediator in the relationship between family support and parental care burden among parents who have children with autism

#### Effect of family support with parental care burden

Based on the analysis results, it was shown that family support significantly influences the parental care burden on parents who have autistic kids. The higher the family support, the lighter the caregiver's burden is perceived by the mother. The burden of parental care is a multidimensional stress that appears to a caregiver. It is the same when the burden is analogous to stress, Lazarus and Folkman (in Taylor, 1995) argued that each new event or environmental change will encourage individuals to make a primary assessment of the importance of the event, individuals then make secondary assessments, where secondary evaluation is an evaluation of the resources owned and whether there is social support. In this study parents who have autistic children make the main assessment about the event. When the primary

judgment feels negative, then the parents will make a secondary estimate of the external resources that they own as family support.

The burden of raising a child with special needs comprises a variety of burdens that are perceived, such as the physical burden of the parent's health, the psychological burden of their emotions, the stress of raising a kid with autism, the financial burden, and the social load, when the parents get family support in the form of financial assistance, emotional support form such as providing parenting assistance, attention then this will make the parents feel the burden to be light.

### **The effect of parent acceptance with caregiver burden**

Further analysis reveals a significant relationship between parental acceptance and caregiver burden in parents of children with autism. The findings indicate that as parental acceptance increases, the burden felt by caregivers decreases. In other words, when parents accept their child's condition and embrace it with understanding and support, caregivers experience a reduced sense of burden. This suggests that parental acceptance plays a crucial role in influencing the caregiver's perception of the burden of caring for a child with autism.

The proof of this hypothesis can be explained by the fact that the characteristics of parents who have reached the stage of accepting their children with autism are shown: parents no longer expect the child to reach conditions like normal children, parents have the ability to take wisdom from the problems they are experiencing with closer to God and show minimal behavior of anxiety, recognize the character and needs of the child, know the parenting strategy according to the specificity of the nature of children, regulate the demands of maturity / pressure on children's abilities, as well as give autism compliance according to ability. The aforementioned findings align with the results of the study conducted by Sagita et al. (2021).

Besides that, parents who have received children have had coping strategies that not only use emotional enhancers but also direct approach to the problem, for example placing children in therapeutic institutions, and parents begin to look for science to be able to care for children in a proper way. Based on this description, it can be inferred that the process of reaching the stage of acceptance will also reduce the burden of parenting, because the parenting burden on autistic children is a stressful condition in which emotional factors are more dominant. When parents are able to accept a child with special needs, it will ease the burden of nurturing.

### **Impact of family support on parental acceptance and the mediator's role**

Based on the results of research, it is known that family support does not significantly affect parent acceptance. These findings are inconsistent with the findings of Heredia-Alvarado and Chen (Heredia-Alvarado, 2017), that family support will affect parents' acceptance of their children diagnosed with autism.

There are several potential limitations or unproven aspects to consider regarding the hypothesis of the influence of family support on parental acceptance child diagnosed with autism, as well as the role of parental acceptance as a mediator in the effect of family support on parenting burden. Firstly, it is important to acknowledge that the study assumes that parents had already reached the stage of acceptance at the time of the research due to the long duration since the diagnosis. This assumption might not hold true for all parents, as the process of accepting a child's diagnosis of autism can vary greatly among individuals and families. Some parents may still be in the earlier stages of the acceptance process, such as experiencing rejection, anger, or bargaining, rather than reaching the final stage of acceptance. Additionally, research by Di Renzo et al. (2020) suggests that failure to accept a child's diagnosis of autism is associated with negative outcomes for parents, including higher distress, depression, and lower levels of emotional support. This indicates that the level of parental acceptance can have significant implications for parental well-being. Furthermore, Sagita et al. (2021) found that various factors influence parental acceptance, including education level, knowledge, age, occupation, household harmony, social support, economic conditions, ethnicity, interaction with experts, clarity of symptoms displayed by the child, and the presence of siblings. These findings suggest that internal factors of parents, such as their personal characteristics and circumstances, play a substantial role in influencing parental acceptance of a child with an autism diagnosis. Considering these various perspectives, it becomes apparent that internal factors of parents may have

a more significant influence on the acceptance of a child with an autism diagnosis, rather than solely relying on external factors like family support. Therefore, the hypothesis regarding the influence of family support on parental acceptance and the mediating role of parental acceptance on parenting burden remains unproven. To establish a statistical model where parental acceptance acts as a mediator, it is essential to demonstrate the significant direct influence of each variable in the model.

The unproven hypothesis of the influence of family support on parental acceptance in a child diagnosed with autism leads to the unproven role of parent acceptance as a mediator on the effect of parental support on the parental care burden. In a statistical model, a variable plays the role of mediator if the entire direct influence of each variable has a significant influence.

### Recommendations

Parents who have children diagnosed with developmental disorders with autism syndrome must have had a hard time accepting this fact. Disbelief, anger, blaming certain parties, confusion, and embarrassment are the initial responses that occur in parents and these conditions can cause stress. The behavior and emotions of children with autism syndrome also often stress parents. This condition results in an increasingly heavy burden by parents in raising children with autism. The step that parents of children with autism syndrome must take immediately is acceptance. In the process of reaching the acceptance stage, parents must carry out emotional coping strategies, where parents immediately learn to manage emotions, see the positive side of this problem, and find wisdom from this problem. Then continue to look for solutions to this problem, for example examinations, finding treatment solutions, and training for children, then parents will arrive at the stage where parents accept the child's condition.

For families, they must continue to support parents who have children with this developmental disorder, especially emotional support.

For future researchers who are interested in the same theme, it is recommended to examine subjects who are new to the diagnosis of natural developmental disorders by their children and increase the number of subjects so that the research results are more representative.

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