

Caregivers of Adolescents with Neurodevelopmental Disabilities: Resilience and Psychosocial Adjustment

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Introduction

Caring for an adolescent with a neurodevelopmental disability has been associated with increased burden due to the often-challenging nature of the symptoms associated with these disabilities (Barker et al., 2011). Despite increased responsibilities, many caregivers report positive life-outcomes after taking on the caregiving role. Caregiver resilience, described as the ability of an individual to thrive in the face of adversity, may represent one factor, which promotes positive adjustment (Connor & Davidson, 2003).

The purpose of the current study was to investigate caregiver resilience as a mediator between burden, and perceived social support among Korean parental caregivers of adolescents with a neurodevelopmental disability.

Methods

Participants

- 165 caregivers of adolescents with a neurodevelopmental disability
 - n = 83 Intellectual Disability (ID), n = 43 Developmental Disability (DD), and n = 39 Autism Spectrum Disorder (ASD)
 - 81% participants women
 - Participant age: $M = 47.5$; $SD = 6.0$
 - Child with disability age: $M = 18.5$; $SD = 1.5$

Procedure:

- Teachers of children with these disabilities approached caregivers of students to complete the study survey.
- IV: Burden Assessment Scale (BAS)** is a 19-item self-report measure of caregiver burden.
- M: Connor-Davidson Resilience Scale (CD-RISC)** is a 10-item self-report measure of caregiver resilience, or ability to positively adapt when faced with an adverse situation.
- D: Multi-Dimensional Perceived Social Support Scale (MPSS)** is a 12-item self-report measure of perceived social support adequacy.

Data Analysis

- Bootstrapping analyses (5,000 samples, 95% CI) were conducted to investigate the mediating effect of resilience between caregiver burden and social support. Caregiver gender, age, time spent caregiving, income, and disability type were controlled for.

Results

- Pearson correlations revealed that all variables were significantly inter-correlated ($p < .01$) (Table 1).

Table 1. Correlations and Descriptive Statistics Between Variables

	Mean	SD	1	2	3
1. Burden	25.19	12.55	-		
2. Resilience	25.10	7.58	-.37**	-	
3. Social Support	48.27	15.17	-.37**	.54**	-

$N = 165$, ** $p < .01$

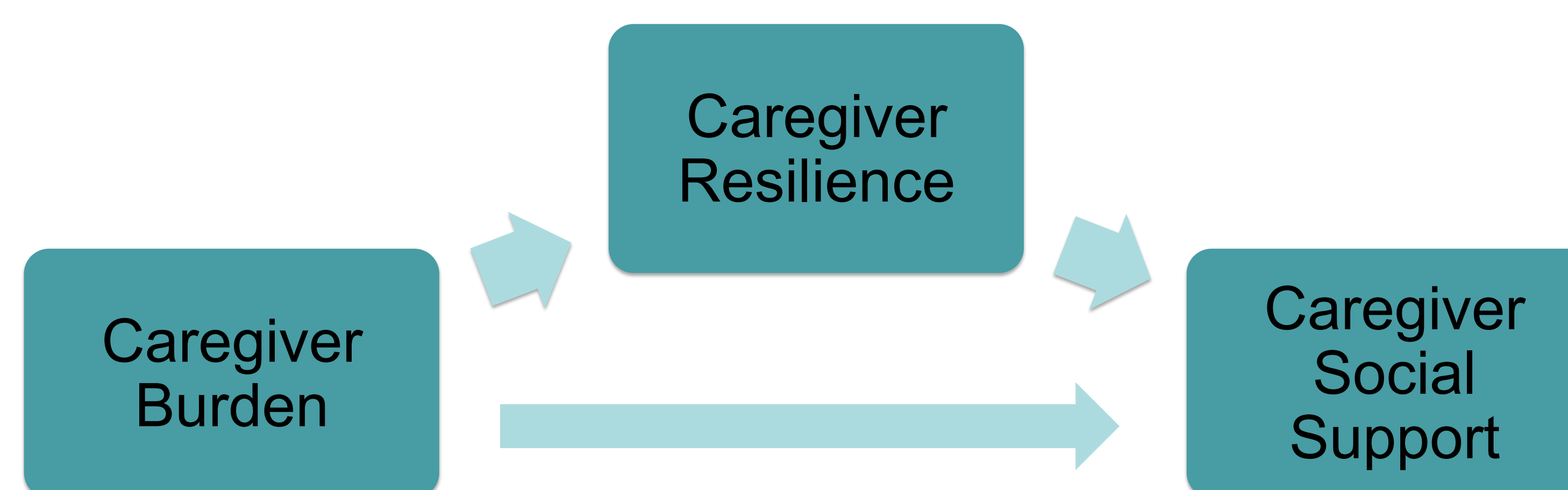


Table 2. Mediation Analysis

Relationship	Variable	Coefficient	SE	CI	F	R ²
IV – DV					7.16	0.21
	Burden (IV)**	-.39	1.00	-.58, -.20		
IV – M					6.58	0.20
	Burden (IV)**	-.21	.05	-.31, -.11		
IV – M – DV					13.77	0.38
	Burden (IV)*	-.20	.09	-.37, -.02		
	Resilience (M)**	.91	.14	.64, 1.19		

$N = 165$, * $p < .05$, ** $p < .01$

- The mediation analysis investigating the relationship between caregiver burden and perceived social support indicated resilience as a significant partial mediator improving the explained variance in social support from 21% to 38%, *indirect effect* $CI = -.32$ to $-.10$, $p < .001$ (Table 2).
- The partial mediating effect was confirmed by a significant Sobel test, $Z = -3.59$, $p < .001$.
- No significant moderation effects were found.

Major Findings

Caregiver resilience was a significant partial mediator between caregiver burden and perceived social support among parental caregivers of adolescents with a neurodevelopmental disability. These results suggest that when caregivers higher in resilience are faced with burden, they may be more likely to seek or recognize positive resources such as social support. Thus, resilience may play a protective role against the negative effects of caregiver burden to promote more positive adaptation. While many factors that contribute to caregiver burden are outside of the caregiver's control, resilience may represent internal, external, and transactional resources that may be modified to improve psychosocial adjustment of the caregiver and care recipient.

Limitations & Implications

There were a few limitations associated with this study. First, the present sample represents solely Korean maternal caregivers. Therefore, the results may not generalize to caregivers from other cultural and demographic backgrounds. It will be important for future research to compare the results of the present study with a Western sample of caregivers to investigate cross cultural conditions. Additionally, individuals with neurodevelopmental disabilities represents a diverse group of conditions, and thus may present with a wide range of characteristics and severity. Within group differences were not investigated in the present study due to limited sample size. Lastly, future research should seek to further clarify the relationships demonstrated in this study using longitudinal designs to identify causal factors. Despite these limitations, the present results are consistent with resilience theory and the idea that interventions to foster resilience among caregivers could increase resources to support psychosocial adjustment.

Overall, higher levels of caregiver resilience partially mediated the relationship between burden and perceived social support among caregivers. Clinically, this study highlights the importance of employing interventions to increase resilience among caregivers to navigate available social support resources, and in turn the use of these resources.