Original Article

Assessing the Impact of Coping Strategies and Resilience on Caregiver Burden in Parents of Children with Autism

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ABSTRACT

Objective: To examine the relationship between coping strategies, resilience, and caregiver burden in parents and caregivers of children with ASD.

Study Design: Cross-sectional study

Place and Duration of Study: This study was conducted at the Dr. Soetomo General Hospital and Airlangga University Hospital in Indonesia from September 2024 - January 2025.

Methods: This cross-sectional study involved parents and caregivers of children with ASD at Dr. Soetomo Hospital, Surabaya. Validated self-report questionnaires assessed coping strategies, resilience, and caregiver burden.

Results: Among 52 caregivers, 63.5% relied on emotion-focused coping, with avoidance as the most common strategy. Resilience scores ranged from 36 to 76, with higher scores indicating greater adaptability. Caregiver burden was high or very high in 40.2% of participants. Statistical analysis confirmed a significant relationship between coping strategy and caregiver burden ($p < 0.05$) and between resilience and caregiver burden ($p < 0.05$).

Conclusion: Emotion-focused coping, particularly avoidance, is associated with higher caregiver burden, whereas higher resilience correlates with lower burden. Encouraging problem-focused coping strategies and resilience-building interventions may help reduce caregiver burden in parents and caregivers of children with ASD.

Key Words: Coping Strategy, Resilience, Caregiver Burden, Autism Spectrum Disorder

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INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong condition marked by challenges in social interaction, communication, and repetitive behavior. Caring for a child with ASD places ongoing emotional and physical demands on parents, often leading to stress and reduced well-being. With prevalence now estimated at 1 in 100 children globally, the need for caregiver support is growing.[1,2] Compared to parents of neurotypical children, those caring for children with ASD report higher stress levels, driven by behavioral unpredictability, emotional regulation issues, and the constant need for supervision.[1,2]

Caregivers' ability to manage the demands of caring for children with ASD depends heavily on their coping strategies, typically categorized as problem-focused (addressing the stressor) or emotion-focused (managing emotional responses). These strategies influence caregiver resilience and overall well-being.[3,4] Caregiver burden includes both objective strain, such as disrupted routines and financial stress, and subjective distress, including emotional exhaustion. Ineffective coping can heighten psychological distress and increase the risk of burnout.[4,5] While prior research has explored the link between coping, resilience, and caregiver burden, findings remain inconsistent, particularly among caregivers of children with ASD. Understanding these mechanisms is crucial for developing targeted, effective support interventions.[3,4,5]

This study aims to examine the relationship between coping strategies, resilience, and caregiver burden in parents and caregivers of children with ASD. By identifying key factors contributing to caregiver burden, the findings may guide improvements in support services and intervention strategies for caregivers of children with ASD.

METHODS

Participants: This cross-sectional study included parents or caregivers of children with autism spectrum disorder (ASD) who visited the psychiatric outpatient

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clinic from September 2024 - January 2025. Eligible participants were parents or caregivers aged 20–60 years who lived in the same household as the child and provided direct care. All participants received detailed information about the study and provided written informed consent before participation. A total of 52 parents/caregivers met the inclusion criteria and were included in the study. Data were collected through self-administered questionnaires. This study was approved by our local Institutional Review Board (IRB).

Measures: Self-report questionnaires were used to collect sociodemographic and psychological data.

- Demographic Questionnaire: Developed by the researchers based on existing literature, this questionnaire collected information on parental/caregiver characteristics (age, gender, religion, education level, marital status, economic status, occupation, and major life challenges) and child characteristics (age, duration since diagnosis, duration of therapy, number of siblings, and level of independence).
- Ways of Coping Questionnaire (WCQ): The WCQ consists of 66 items rated on a Likert scale (0–3). Higher scores indicate more frequent use of coping behaviors in response to stress. The instrument has demonstrated strong reliability, with a Cronbach's alpha of 0.871.
- Connor-Davidson Resilience Scale (CD-RISC 25): Resilience was measured using the 25-item CD-RISC, which assesses resilience over the past month using a Likert scale. Total scores range from 0 to 100, with higher scores indicating greater resilience. The scale has been validated with a Cronbach's alpha of 0.85.
- Caregiver Burden Assessment (CBA): The CBA consists of 39 items measuring subjective and objective caregiver burden using a Likert scale. Higher scores indicate a greater burden. Reliability testing showed strong internal consistency, with Cronbach's alpha values of 0.936 for objective burden and 0.925 for subjective burden.

Statistical Analysis: Data were summarized using frequency distributions and presented in tables and diagrams. Statistical analyses were conducted using SPSS. The Kruskal-Wallis test was used to examine the relationship between coping strategies and caregiver burden, while the Spearman correlation test assessed the association between resilience and caregiver burden. A p-value of <0.05 was considered statistically significant for all analyses.

RESULTS

The majority of caregivers were women (92.3%) aged 31–40 years, with all participants married and most having a high school education (55.8%). Over two-thirds were housewives (67.3%), and 55.8% had two children. Nearly half (48.1%) received caregiving assistance, and most reported medium (44.2%) to high (28.8%) socioeconomic status. Health issues were minimal (92.3% reported none), though many experienced slights to moderate family (38.5% and 19.2%) and economic stress (42.3% and 36.5%). All had been caregiving for more than two years, with most children requiring full (63.5%) or partial (25.0%) assistance and having moderate autism (55.8%). Emotion-focused coping was more common (63.5%), especially avoidance (46.2%), while problem-focused strategies were used by 36.5%, mainly planful coping (23.1%). The average resilience score was 55.46 (SD ±12.79), indicating a moderate level of resilience.

The analysis revealed that while a portion of caregivers reported low levels of burden, 23.1% with very low and 30.8% with low objective burden, many experienced significant strain. High or very high objective burden was reported by 23% of participants, and subjective burden was rated as high or very high by 38.5%. Overall, 40.2% of caregivers experienced high to very high total caregiver burden (Table 1). Cross-tabulation showed that caregivers employing planful, confronting, or socially supportive coping strategies were more likely to report low burden levels. Conversely, those using emotion-focused strategies such as avoidance, positive reappraisal, or self-control tended to report higher burden. This association was statistically significant (p = 0.001), with a strong effect size (C = 0.776), highlighting the influence of coping style on caregiver well-being (Table 2).

Table No.1: Caregiver Burden Among Parents/ Caregivers of Children with ASD

Caregiver Burden	n	(%)
Objective Burden		
Very low	12	23.1
Low	16	30.8
Moderate	12	23.1
High	10	19.2
Very high	2	3.8
Subjective Burden		
Very low	7	13.5
Low	11	21.2
Moderate	14	26.9
High	7	13.5
Very high	13	25.0
Total Caregiver burden		
Very low	8	15.4
Low	11	21.2
Moderate	12	23.1
High	10	19.2
Very high	11	21.2

An inverse relationship was found between caregiver burden and resilience: caregivers with very low burden had a median resilience score of 51, while those with very high burden had a median of 44. This correlation was statistically significant (p = 0.001, Rs = –0.974), indicating that higher burden is associated with lower resilience. Resilience also varied significantly across coping strategies. The highest resilience scores were observed in caregivers who used seeking social support (mean = 71.8), while the lowest were among those using self-control (mean = 39). Caregivers using problem-focused coping strategies—such as planful coping and social support—tended to have higher resilience compared to those relying on emotion-focused strategies. This association was statistically significant (p = 0.001), and the Kruskal-Wallis test confirmed significant differences in resilience across coping types ($p < 0.05$) (Table 3).

Table No.2. Coping Strategies and Total Caregiver Burden Among Parents/Caregivers of Children with ASD

Coping Strategy	**Total Caregiver Burden**					
	Very Low	**Low**	**Moderate**	**High**	**Very High**	**Total**
Problem-focused coping (PFC)						
Planful	5(41.7%)	7(58.3%)				12
Confronting		2(100.0%)				2
Seeking Social	3(60.0%)	2(40.0%)				5
Emotion-focused coping (EFC)						
Self-control					2(100.0%)	2
Positive reappraisal			4(80.0%)	1(20.0%)		5
Avoidance			8(33.3%)	7(29.2%)	8(37.5%)	24
Positive reappraisal & Avoidance				2(100.0%)		2

Table No.3. Resilience Scores by Caregiver Burden Level and Coping Strategy

Category	**N**	**Mean Resilience**	**Median (min–max)**
Caregiver Burden Level			
Very Low	8	—	51 (40–55)
Low	11	—	53 (49–57)
Moderate	12	—	45 (37–51)
High	10	—	42 (36–49)
Very High	11	—	44 (38–49)
Coping Strategies			
Planful (PFC)	12	69.50	68 (62–76)
Confronting (PFC)	2	66.00	66 (65–67)
Seeking Social (PFC)	5	71.80	72 (64–76)
Self-control (EFC)	2	39.00	39 (39–39)
Positive Reappraisal (EFC)	5	54.80	56 (46–59)
Avoidance (EFC)	24	46.29	44 (37–59)
Positive Reappraisal & Avoidance	2	48.00	48 (47–49)

DISCUSSION

The findings of this study indicate that emotion-focused coping strategies were the most commonly used by parents and caregivers of children with ASD. Many caregivers opted for avoidance coping, a strategy that involves diverting attention away from stressors to reduce psychological and physical strain. Avoidance coping has been previously described as a mental and physical escape from perceived threats, which can help reduce immediate stress but may have both positive and negative consequences depending on the circumstances.[6] The study also found that 49.4% of caregivers had been aware of their child's ASD diagnosis for more than two years, and 63.5% of children required full-time assistance. Parents and caregivers frequently faced challenges such as explaining their child's condition to others, managing therapy costs, handling emotional outbursts, finding suitable schools, and worrying about their child's future. Emotion-focused coping strategies are often used when individuals perceive that they cannot change their circumstances. This aligns with previous research suggesting that emotion-focused coping is effective when dealing with stressors beyond one's control, while problem-focused coping is more beneficial when individuals can actively modify their environment.[7,8]

Resilience plays a key role in balancing protective and risk factors in caregiving. Low resilience reduces the ability to cope with stress, increasing caregiver burden. In this study, resilience scores ranged from 36 to 76, with higher scores reflecting greater adaptability. Caregivers with higher resilience levels reported lower perceived burden, even when providing intensive care.[9] This highlights the protective role of resilience in mitigating stress and maintaining psychological well-being.

Children with ASD often require intensive care, placing considerable strain on caregivers. In this study, 19.2% reported high and 3.8% very high objective burden, while subjective burden was high in 13.5% and very high in 25%. Overall, 40.2% experienced high to very high total burden. Key contributors included lack of social support, limited access to substitute caregivers, and economic constraints, which increased psychological stress and restricted access to services. Additionally, lower education levels were linked to greater burden, as caregivers with higher education may be better equipped to understand ASD and apply effective coping strategies.[3,10,11]

The Relationship Between Coping Strategies and Caregiver Burden: Caregiving is inherently challenging, especially for primary caregivers who lack formal training in managing chronic conditions like ASD. The stress of continuous caregiving is well documented, with Lazarus and Folkman describing coping as a process that helps individuals adapt to increasing stress levels. Effective coping strategies, whether problem-focused or emotion-focused, can play a protective role in reducing caregiving stress.[10-11]

This study found that 63.5% of caregivers relied on emotion-focused coping, particularly avoidance coping. While this approach may provide temporary relief, its excessive use can contribute to greater caregiver burden. Caregivers using self-control, positive reappraisal, avoidance, or a combination of positive reappraisal and avoidance reported moderate to very high levels of caregiver burden. These findings are consistent with previous studies, which reported that emotion-focused coping strategies, particularly escape-avoidance, were associated with higher psychological distress in caregivers and that greater caregiver burden was linked to the use of emotion-focused coping strategies.[12,13] In contrast, problem-focused coping strategies such as planful coping and seeking social support were linked to lower caregiver burden. Caregivers who actively sought solutions and social support were better able to manage stress, highlighting the importance of targeted interventions to promote adaptive coping strategies.

The Relationship Between Resilience and Caregiver Burden: Resilience is a crucial factor in caregiving, enabling individuals to adapt positively despite ongoing challenges. It is defined as the ability to recover from stress and adjust to difficult situations without experiencing long-term negative consequences.

This study found a significant inverse relationship between resilience and caregiver burden. Caregivers with very low burden had a median resilience score of 51, whereas those with very high burden had a median resilience score of 44. Statistical analysis confirmed that as caregiver burden increased, resilience decreased ($p < 0.05$, $Rs = -0.974$). These findings align with previous research which found that higher caregiver burden was associated with lower resilience and that caregivers with greater resilience experienced significantly lower burden. Resilience is shaped by internal and external factors, including family dynamics, social support, and cultural influences. The complexity of caregiving responsibilities also plays a role. Many caregivers in this study lacked substitute caregivers, social support, and financial stability, which contributed to increased stress. Additionally, longer caregiving durations were associated with higher burden levels, a finding consistent previous study which showed that caregivers who provided longer daily care experienced greater stress and exhaustion.[14,15,16]

CONCLUSION

This study found that emotion-focused coping was the dominant strategy used by parents and caregivers of children with ASD. Caregivers with low resilience were more likely to rely on emotion-focused coping, while those with high resilience tended to use problem-focused coping. The choice of coping strategy was significantly associated with caregiver burden, and higher resilience was linked to lower caregiver burden. These findings highlight the importance of enhancing resilience and promoting adaptive coping strategies to reduce caregiver burden.

Author's Contribution:

Concept & Design or acquisition of analysis or interpretation of data:	Pegi Karinda Pramadita, Izzatul Fithriyah
Drafting or Revising Critically:	Pegi Karinda Pramadita, Izzatul Fithriyah
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