



PERCEIVED CAREGIVING BURDEN AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background

Caring for a child with Autism Spectrum Disorder (ASD) may place considerable demands on mothers. Behavioral difficulties, communication problems, dependence on caregivers, treatment requirements and everyday caregiving responsibilities may influence maternal emotional, social and psychological well-being. Assessment of perceived caregiving burden is therefore important for identifying mothers who require additional support.

Objective

The study aimed to assess perceived caregiving burden among mothers of children with ASD and to examine its relationship with maternal knowledge regarding ASD.

Methods

A quantitative exploratory cross-sectional design was used among 200 mothers of children with ASD living in selected urban areas of Punjab. Participants were selected through purposive convenience sampling. Data were collected using a structured knowledge questionnaire and a perceived caregiving burden scale. Descriptive statistics and Pearson's correlation were used for analysis.

Results

The mean total perceived caregiving burden score was 58.41 ± 6.38 , with a mean percentage of 66.37%. Of the 200 mothers, 123 (61.5%) experienced moderate-to-severe burden and 77 (38.5%) experienced severe burden. No participant was classified as having mild-to-moderate or no/minimal burden.

The highest section-wise mean percentage was observed for overall caregiving burden (72.13%), followed by feelings while interacting with the child (71.34%) and child dependence on the caregiver (70.25%). The correlation between knowledge and perceived caregiving burden was very weak and positive ($r = 0.051$).

Conclusion

The findings demonstrate a substantial caregiving burden among mothers of children with ASD. Family-centered support, counselling, education, appropriate coping strategies and accessible support services are important components of comprehensive nursing care.

Keywords: Autism Spectrum Disorder, caregiver burden, mothers, caregiving, parental stress, nursing.

INTRODUCTION

Autism Spectrum Disorder affects not only the child but also the family system. Mothers frequently provide extensive assistance with communication, behaviour, education, therapy attendance and activities of daily living. The continuing nature of these responsibilities may influence emotional well-being, social participation and quality of life.

The present study was undertaken because the researcher assumed that mothers may experience feelings of being overburdened while caring for children with ASD. The study also aimed to identify possible solutions for reducing caregiving burden through guidelines based on identified deficit areas.

Perceived caregiving burden is a subjective experience related to the demands and consequences of providing care. In mothers of children with ASD, burden may be influenced by the child's level of dependence, behavioural difficulties, communication challenges and the amount of support available to the family.

The Health Belief Model was used as the conceptual framework for the original study. The framework included individual perceptions such as perceived susceptibility and perceived seriousness, modifying factors and factors influencing health-related behaviour.



REVIEW OF RELATED LITERATURE

Bozkurt, Uysal and Düzkeya (2019) conducted a descriptive cross-sectional study in Istanbul, Turkey, involving 131 parents of children with ASD. The study found moderate-to-high caregiving burden, with mothers reporting greater burden than fathers. Inadequate coping mechanisms, lower educational attainment and greater dependence of the child were associated with increased burden. The researchers recommended family support services and interventions to improve coping.

Turan, Çavuşoğlu and Özdemir (2019) studied 131 parents of children with ASD using the Caregiver Strain Index and Ways of Coping Questionnaire. Parents experienced considerable caregiving burden, particularly when children had limited autonomy in everyday activities. Poor coping mechanisms were associated with increased stress and caregiving burden.

Iadarola, Pérez-Ramos, Smith and colleagues (2018) studied 174 caregivers of children with ASD in the United States. The study identified substantial burden related to behavioural problems, sleep disturbances and daily caregiving demands. Mothers experienced elevated stress and poorer mental health, while greater social support was associated with lower perceived burden.

Bonis (2016) reviewed research on maternal mental health and caregiving burden among mothers of children with ASD. The review identified higher levels of stress, sadness, anxiety and emotional exhaustion. Caregiving responsibilities involving behavioural problems, communication challenges, therapy appointments and educational needs contributed to maternal strain. Lack of social support and concerns regarding the child's future were also associated with poorer maternal quality of life.

Dardas and Ahmad (2014) conducted a study among 184 parents in Jordan, including 114 mothers and 70 fathers. Mothers reported lower quality-of-life outcomes than fathers, while parents experienced high parental stress and poorer physical, psychological, social and environmental quality of life. Financial difficulties and lack of community support further increased caregiving challenges.

Rivard et al. (2014) examined factors associated with parenting stress among mothers of children with ASD. Greater behavioural difficulties, including aggression, hyperactivity and emotional outbursts, together with lower adaptive functioning, were associated with greater maternal stress and caregiving burden.

Recent studies in the reference database further demonstrate the continuing importance of caregiver burden. Barik et al. (2025) examined burden among family caregivers of children with ASD, while Sandilya and Singh (2025) investigated caregiver burden, parental stress, depression and anxiety among mothers of children with ASD.

MATERIALS AND METHODS

Research Design

A quantitative exploratory cross-sectional research design was used. This design enabled the researcher to assess knowledge and perceived caregiving burden among mothers at a single point in time.

Participants and Setting

The study was conducted in selected urban areas of Punjab among mothers of children with ASD aged 21 years to more than 30 years.

Sample and Sampling Technique

The sample consisted of 200 mothers. Sample size was determined using G*Power software, and purposive convenience sampling was used.

Data Collection Tools

The study used a structured knowledge questionnaire and a perceived caregiving burden scale. The caregiving burden measure included domains related to general feelings about caregiving, feelings related to caring for the child with autism, interaction with the child, impact on life, caregiving responsibilities and concerns, child dependence and overall caregiving burden.

Statistical Analysis

Descriptive statistics were used to summarize the distribution of knowledge and caregiving burden. Pearson's correlation coefficient was used to examine the relationship between knowledge and perceived caregiving burden.



RESULTS

Overall Caregiving Burden

Among 200 mothers, 123 (61.5%) had moderate-to-severe caregiving burden and 77 (38.5%) had severe caregiving burden. No mothers were classified as having mild-to-moderate or no/minimal burden.

Table 1. Distribution of Mothers According to Perceived Caregiving Burden

Level of caregiving burden	Frequency	Percentage
Severe burden	77	38.5%
Moderate-to-severe burden	123	61.5%
Mild-to-moderate burden	0	0%
No/minimal burden	0	0%
Total	200	100%

Mean Caregiving Burden

The mean total perceived caregiving burden score was 58.41 ± 6.38 , with a median of 59, a maximum score of 75, a minimum score of 41 and a range of 34. The mean percentage was 66.37%.

The highest mean percentage was observed for overall caregiving burden (72.13%), followed by feelings while interacting with the child (71.34%) and child dependence on the caregiver (70.25%).

Table 2. Section-Wise Perceived Caregiving Burden

Domain	Mean $\pm$ SD	Mean %
General feelings about caregiving	7.73 ± 1.69	64.42%
Feelings related to caring for child with autism	8.24 ± 2.32	68.67%
Feelings while interacting with child	11.42 ± 2.60	71.34%
Impact of caregiving on life	10.23 ± 3.01	63.91%
Caregiving responsibilities and concerns	15.10 ± 2.65	62.92%
Child's dependence on caregiver	2.81 ± 1.18	70.25%
Overall caregiving burden	2.89 ± 1.03	72.13%
Total perceived caregiving burden	58.41 ± 6.38	66.37%

Relationship Between Knowledge and Caregiving Burden

The mean knowledge score was 28.01 ± 6.11 , while the mean perceived caregiving burden score was 58.41 ± 6.38 . Pearson's correlation coefficient was $r = 0.051$, indicating a very weak positive relationship between knowledge and perceived caregiving burden.

This finding suggests that higher knowledge was not strongly associated with either increased or decreased caregiving burden in the present sample.

DISCUSSION

The present study demonstrated a considerable caregiving burden among mothers of children with ASD. More than three-fifths of mothers (61.5%) experienced moderate-to-severe burden and 38.5% experienced severe burden. Importantly, none of the participants fell into the mild-to-moderate or no/minimal burden categories. These findings are consistent with Bozkurt et al. (2019), who reported moderate-to-high caregiving burden among parents of children with ASD and higher burden among mothers. Their findings also indicated that inadequate coping, lower educational attainment and greater child dependence were related to increased burden.

The present findings are also supported by Turan et al. (2019), who found substantial caregiver strain, particularly when children had limited autonomy in daily activities. The authors emphasized the importance of social support and constructive coping strategies.

Iadarola et al. (2018) similarly identified behavioural problems, sleep disturbances and daily caregiving demands as important sources of caregiver burden, while social support was associated with lower perceived burden.

The section-wise findings of the present study are also important. Overall caregiving burden had the highest mean percentage (72.13%), followed by interaction with the child (71.34%) and child dependence (70.25%). This suggests that the emotional experience of caregiving and the child's dependence may represent particularly important areas for nursing assessment and intervention.



The weak correlation between knowledge and burden ($r = 0.051$) indicates that knowledge alone may not be sufficient to reduce caregiving burden. Caregiving burden is likely to be influenced by multiple factors, including child dependence, behavioural difficulties, coping, family support and practical caregiving demands. The literature reviewed in the study supports the importance of social support and coping interventions.

Nursing Implications

Nurses should assess caregiving burden as part of family-centred care for children with ASD. Education should be combined with practical support rather than being provided as information alone.

Nursing interventions may include:

- Individualized counselling for mothers.
- Education regarding ASD and behavioural management.
- Guidance regarding communication and interaction with the child.
- Promotion of positive coping strategies.
- Encouragement of family and social support.
- Referral to appropriate rehabilitation and developmental services.
- Identification of mothers requiring additional psychological or social support.
- Development of structured guidelines based on identified caregiver needs.

CONCLUSION

The study demonstrated a substantial perceived caregiving burden among mothers of children with ASD. The mean burden score was 58.41 ± 6.38 , with a mean percentage of 66.37%. A total of 61.5% of mothers experienced moderate-to-severe burden and 38.5% experienced severe burden.

The highest domain score was observed for overall caregiving burden, followed by feelings while interacting with the child and child dependence. The correlation between knowledge and perceived caregiving burden was very weak ($r = 0.051$).

The findings highlight the need for comprehensive, family-centred nursing interventions addressing not only maternal knowledge but also emotional well-being, coping, social support and practical caregiving needs.

REFERENCES

1. Barik, S., Pattanaik, S., Patnaik, L., & Sarangi, R. (2025). Burden on family caregivers of children with autism spectrum disorder: A cross-sectional study. *National Journal of Community Medicine*, 16(11), 1076–1083. <https://doi.org/10.55489/njcm.161120255276>
2. Bonis, S. (2016). Stress and parents of children with autism: A review of the literature. *Issues in Mental Health Nursing*. [Volume, issue, and page range to be verified.]
3. Bozkurt, G., Uysal, G., & Düzkaya, D. S. (2019). Examination of coping mechanisms and caregiving burden among parents of children with autism spectrum disorder. [Journal title, volume, issue, and page range to be verified.]
4. Dardas, L. A., & Ahmad, M. M. (2014). Quality of life among parents of children with autistic disorder: A sample from the Arab world. *Research in Developmental Disabilities*, 35(2), 278–287.
5. Dijkstra-de Neijs, L., Boeke, D. B., van Berckelaer-Onnes, I. A., Swaab, H., & Ester, W. A. (2024). Parental stress and quality of life in parents of young children with autism. *Child Psychiatry & Human Development*. <https://doi.org/10.1007/s10578-024-01693-3>
6. Fithriyah, I., & Carrasco, M. E. (2021). Caregiver burden and psychosocial factors in mothers with autism spectrum disorder children. *Biomolecular and Health Science Journal*, 4(2), 80–85. <https://doi.org/10.20473/bhsj.v4i2.28875>
7. Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism*, 17(4), 465–480. <https://doi.org/10.1177/1362361311416830>



8. Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, 65(1), 20–30.
9. Kaya, M., Akça, Ö. F., et al. (2024). Depression and parental distress among caregivers of autistic children: A serial mediator analysis. *BMC Psychology*, 12, Article 339. <https://doi.org/10.1186/s40359-024-01704-x>
10. Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609–1620. <https://doi.org/10.1007/s10803-013-2028-z>
11. Sandilya, R., & Singh, R. (2025). Caregiver burden, parental stress, depression and anxiety among mothers of autism spectrum disorder. *Indian Journal of Preventive and Social Medicine*, 56(3). [Page range to be verified.]
12. Turan, N., Çavuşoğlu, H., & Özdemir, A. (2019). Examination of care burden and stress coping styles of parents of children with autism spectrum disorder. *Journal of Pediatric Nursing*, 47, 142–147. <https://doi.org/10.1016/j.pedn.2019.05.005>

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