ORIGINAL RESEARCH ARTICLE

Burden on Family Caregivers of Children with Autism Spectrum Disorder: A Cross-Sectional Study

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DOI: 10.55489/njcm.161120255276

ABSTRACT

Background: Children with Autism spectrum disorders need special care and understanding. This study aimed to assess burden and challenges faced by caregivers of children with ASD aged 2-10 years in Bhubaneswar, Odisha.

Materials and methods: A cross-sectional study conducted in Bhubaneswar, Odisha over two and half years. Data were collected from 12 autism therapy centres and schools. Caregiver Strain Questionnaire (CGSQ) with socio-demographic details of caregivers was used for assessment of challenges and experiences of caregivers.

Results: The mean age of mothers was 34.74 ± 3.40 years and the mean age of fathers was 40.02 ± 3.65 years. Highest level of strain as reported by caregivers was on subjective internalized subscale i.e. 3.07 ± 0.39 followed by objective strain subscale with mean score of 2.29 ± 0.46. Education, socio-economic status and family type were significantly associated with CGSQ score ($P<0.05$). Caregivers of children with autism spectrum disorder have significantly higher strain in low education levels, lower middle socio-economic status and nuclear families.

Conclusion: Caregivers experience a lot of challenges in parenting the child with ASD, so more educational and counselling sessions are needed to decrease their stress and improve the quality of life.

Keywords: ASD, Carers, Autism

ARTICLE INFO

Financial Support: None declared
Conflict of Interest: The authors have declared that no conflict of interests exists.
Received: 03-03-2025, **Accepted**: 16-09-2025, **Published**: 01-11-2025
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How to cite this article: Barik S, Pattanaik S, Patnaik L, Sarangi R. Burden on Family Caregivers of Children with Autism Spectrum Disorder: A Cross-Sectional Study. Natl J Community Med 2025;16(11):1076-1083.
DOI: 10.55489/njcm.161120255276

www.njcmindia.com | pISSN: 0976-3325 | eISSN: 2229-6816 | Published by Medsci Publications

INTRODUCTION

Autism spectrum disorders are highly heritable and complex pervasive neurodevelopmental disorders occurring in children. These are quite common and cause more disability than other childhood behavioural disorders. These disorders are a group comprising of deficits in social communication and repetitive sensory- motor behavior.[1] The group includes Autistic disorder, Asperger disorder, and Pervasive developmental disorder- Not Otherwise Specified (PDD-NOS).[2]

It is diagnosed at a mean age of 5 years though early warning signs can be observed in infancy.[3] It is commonly seen in males with a male to female ratio 4:1.[1] Earlier considered as a rare disorder, ASD is now well researched and recognised and the prevalence has been increasing.[4,5] Indian studies reveal an estimated prevalence of 0.1 to 1.4%.[6] The recognition of ASD dates back to 1943 when Leo Kanner first described about infantile autism. This disorder was recognized late in the 1980s and was categorized as infantile autism in DSM-III, then finally in DSM-5 various disorders like Asperger disorder, Autistic disorder, PDD-NOS were combined together as ASD.[7,8]

The etiopathogenesis of ASD is still uncertain with most accepted hypothesis being the interplay of genetic & environmental factors with genetics playing a major part. ASD present along a continuum of severity ranging from mild to very severe forms.[1,9,10] The children have deficit in social communication and social interaction along with repetitive behaviours and activities such as stereotyped speech, play and insistence on sameness. They have difficulty in social interaction and reciprocation and have decreased nonverbal communication.[11,12]

The children need special care and understanding as most of the times they are unable to function independently. It directly or indirectly causes various levels of difficulties for the caregivers or guardians.[13] These behaviour changes limit social participation and interfere with education, thus creating stress for caregivers.[1,14]

There is need of special provisions and treatment which creates mental as well as economic burden on the caregivers.[15] These children need early recognition and early interventions in order to make them adaptable to the environment and lead a normal life to whatever extent possible.[16] This study addresses a gap in understanding caregiver burden in India, where cultural and socioeconomic factors uniquely shape caregiving experiences. It aimed to assess burden and challenges faced by caregivers of children with ASD aged 2-10 years in Bhubaneswar Odisha.

METHODOLOGY

The study was a cross-sectional study conducted in Bhubaneswar, Odisha over a period of two years and six months between April 2020 to October 2022. Data were collected from 12 autism therapy centres and schools in Bhubaneswar city. Among the selected centres, 7 were categorised as Special Educational Needs School, while 5 were Autism therapy centres. among these 8 were non-governmental organizations, while 4 were government -run.

The inclusion criteria for this study comprised caregivers of children diagnosed with autism spectrum disorder (ASD), aged between 2-10 years, who were present at the centres on designated visiting days and provided informed consent to participate. Caregivers of children with other chronic illnesses or debilitating conditions, as well as those who declined participation, were excluded. Additionally, caregivers who expressed willingness to participate but were unable to complete the questionnaire due to limited knowledge or memory impairments were also excluded from the study.

The study was approved by the Institutional Ethical Committee IMS & SUM Hospital; Bhubaneswar vide letter no. Ref.no/DRI/IMS.SH/SOA/2021/039. The participants were explained about the purpose of the study and informed written consent was obtained before recruitment. The convenience sampling method was used to select participants, considering accessibility and feasibility within the study context. Among the 128 individuals approached, 87 gave their informed consent to participate in the study and the response rate in this study was approximately 68%. After establishing rapport with the participants, all questions were communicated in the local language to ensure clarity and understanding. Participants were assured of the confidentiality of both their identities and the data provided. Participation in the study was entirely voluntary, with no incentives or compensation offered for involvement.

Data collection tool: The schedule included a section on the socio-demographic characteristics of both the caregivers and the children with autism spectrum disorder (ASD). Data were collected on variables such as age, gender, religion, caste, family type, number of family members, educational attainment and occupation of both the participant and the head of the household, as well as the total family income. Additionally, a semi-structured questionnaire was utilized to assess the challenges and experiences faced by the caregivers. The Caregiver Strain Questionnaire (CGSQ) is a 21-item self-report tool designed for parents to evaluate the challenges of raising a child with special needs. Each question is scored on a scale from 1 (not at all a problem) to 5 (very much a problem). The questionnaire includes three subscales: Objective Strain, Subjective Internalized Strain, and Subjective Externalized Strain. Scores for each subscale are calculated by summing the responses to relevant items. The Objective Strain subscale captures parents' perceptions of the tangible effects on daily activities, employment, and financial responsibilities. The Subjective Internalized Strain subscale addresses internally felt emotions

such as sadness, fatigue, and concerns about the child's future. In contrast, the Subjective Externalized Strain subscale focuses on outward emotional responses like resentment, anger, and embarrassment. The Global Score is the sum of all three subscale scores.[17,18]

Following data collection, the dataset was reviewed for completeness before being entered and cleaned using Microsoft Excel. The cleaned data were then exported to IBM SPSS Statistics version 26 for analysis. Categorical variables were presented as frequencies and percentages. Continuous variables were summarized using either mean with standard deviation (SD) or median with interquartile range (IQR), along with 95% confidence intervals. To examine associations between categorical variables, the Chi-squared test and McNemar Chi-squared test were applied. For continuous variables, statistical tests such as the independent t-test, Mann-Whitney U test, and Kruskal-Wallis ANOVA were employed. A p-value of 0.05 or below was considered statistically significant.

RESULTS

Participant characteristics: The age of mothers ranged from 26 years to 42 years with a mean age of 34.74 ± 3.40 years and the age of fathers ranged from 34 years to 48 years with a mean age of 40.02 ± 3.65 years. Autistic children were between 4 to 9 years with a mean age of 5.63 ± 1.51 years. Majority of the participants belonged to Upper middle class (65.5%) followed by lower middle class (24.1%) and few were in upper class (10.3%). 72.4% were nuclear families and 27.6% were joint families. (Table-1) None of the respondents had a broken family.

Caregiver strain questionnaire (CGSQ): Highest level of strain as reported by caregiver was on subjective internalized subscale i.e. 3.07 ± 0.39 followed by objective strain subscale with mean score of 2.29 ± 0.46. Lowest strain was on subjective externalized strain with mean score of 1.15 ± 0.20. Among the objective strain mean score was maximum for the disruption of family activities (2.77 ± 0.817), then in decreasing order of scores the items of objective strain subscale were financial strain, missing work/duties, less attention to other family members, doing without things, time interruption, disruption of family routines, feeling isolated, disruption of family relationship, negative health effects and minimum score (1.28 ± 0.475) was for Child getting into trouble with the neighbours, the school, the community or law enforcement. Among the items in subjective internalised strain highest score was reported for worry about child's future with score of 4.11 ± 0.813 followed by being tired/strained, worrying about family's future, toll on family, feeling guilty and minimum score of feeling sad or unhappy (2.18 ± 0.883). Considering the different items in subjective externalized strain, highest score was for feeling embarrassed (1.41 ± 0.657) followed by showing anger towards the child and being resentful towards the child. The minimum score was given for how well did they relate to their child (1.00 ± 0.000) which was reverse coded and hence meant they related very well to their child. (Table-2)

The mean CGSQ scores were compared among participants divided into different categories on the basis of various sociodemographic variables. The total number of participants were 87.

Table 1: Sociodemographic and socioeconomic characteristics of Parents and their children with ASD

Variable	Parents (%)
Gender of Child	
Male	68 (78.2)
Female	19 (21.8)
Birth order	
1st	45 (51.7)
2nd	40 (46)
3 or more	2 (2.3)
Type of family	
Nuclear	63 (72.4)
Joint	24 (27.6)
Religion	
Hindu	83 (95.4)
Muslim	2 (2.3)
Christian	2 (2.3)
Socio economic status	
Upper	9 (10.3)
Upper middle	57 (65.5)
Lower middle	21 (24.1)

Table 2: Descriptive statistics for CGSQ

No.	Items	Mean ± SD
Objective strain subscale		2.29±0.469
Q1	Time interruption	2.48±0.963
Q2	Missed work/duties	2.70±1.069
Q3	Disrupted family routines	2.33±0.773
Q4	Doing without things	2.62±0.766
Q5	Negative health effects	1.55±0.660
Q6	Child getting into trouble with others	1.28±0.475
Q7	Financial strain	2.75±1.164
Q8	Less attention to other family members	2.66±0.819
Q9	Disrupt family relationships	1.78±0.784
Q10	Disrupt family activities	2.77±0.817
Q11	Feeling isolated	2.31±0.736
Subjective Internalized strain		3.07±0.394
Q12	Feeling sad or unhappy	2.18±0.883
Q16	Worried child's future	4.11±0.813
Q17	Worried family future	3.10±0.953
Q18	Feeling guilty	2.92±0.943
Q20	Tired or strained	3.16±0.938
Q21	Toll on family	2.99±0.982
Subjective Externalized strain		1.15±0.205
Q13	Feeling embarrassed	1.41±0.657
Q14	Relating to child[a]	1.00±0.000
Q15	Anger towards child	1.18±0.418
Q19	Resentful toward child	1.03±0.184
Global score		2.17±0.248

[a]Reverse-coded items

Table 3: CGSQ score among Participants according to sociodemographic variables (N=87)

Variables	Global score (Mean ± SD)	Objective strain (Mean ± SD)	Subjective Internalised strain (Mean ± SD)	Subjective Externalised strain (Mean ± SD)
Age of caregiver (Years)				
<30	48.20 ± 6.81	24.60 ± 5.75	18.70 ± 2.83	4.90 ± 0.99
≥30	48.35 ± 6.36	25.31 ± 5.11	18.44 ± 2.32	4.60 ± 0.79
P-value	0.92	0.68	0.74	0.34
Maternal age (Years)				
<30	48.11 ± 5.89	24.84 ± 4.92	18.65 ± 2.31	4.62 ± 0.78
≥30	48.72 ± 7.20	25.91 ± 5.56	18.16 ± 2.46	4.66 ± 0.90
P-value	0.93	0.35	0.34	0.96
Gender of Child				
Male	48.49 ± 6.93	25.34 ± 5.54	18.50 ± 2.47	4.65 ± 0.84
Female	47.79 ± 3.82	24.84 ± 3.57	18.37 ± 2.00	4.58 ± 0.76
P-value	0.98	0.95	0.95	0.79
Birth Order				
1st	48.38 ± 6.72	25.22 ± 5.37	18.51 ± 2.53	4.64 ± 0.83
2nd or more	48.29 ± 6.05	25.24 ± 4.98	18.43 ± 2.19	4.62 ± 0.82
P-value	0.96	0.98	0.87	0.94
Education				
Below Graduate	50.79 ± 6.83	26.72 ± 5.31	19.00 ± 2.57	5.07 ± 0.92
Graduate and above	47.10 ± 5.80	24.48 ± 4.94	18.21 ± 2.23	4.41 ± 0.67
P-value	**0.01**	0.056	0.14	**0**
Occupation				
Homemaker	48.15 ± 6.52	24.99 ± 5.23	18.44 ± 2.48	4.72 ± 0.85
Working	49.20 ± 5.74	26.40 ± 4.80	18.60 ± 1.76	4.20 ± 0.41
P-value	0.47	0.3	0.81	**0.01**
Family Type				
Nuclear	51.33 ± 6.42	27.42 ± 5.42	19.29 ± 2.27	4.63 ± 0.77
Joint	47.19 ± 6.01	24.40 ± 4.84	18.16 ± 2.34	4.63 ± 0.84
P-value	**0.001**	**0.01**	**0.04**	0.88
Sibling				
Yes	48.40 ± 6.33	25.35 ± 5.17	18.41 ± 2.34	4.64 ± 0.83
No	47.92 ± 6.90	24.50 ± 5.26	18.83 ± 2.58	4.58 ± 0.79
P-value	0.75	0.5	0.56	0.84
Number of Siblings				
0	47.92 ± 6.90	24.50 ± 5.26	18.83 ± 2.58	4.58 ± 0.79
1	48.28 ± 6.42	25.34 ± 5.27	18.32 ± 2.28	4.62 ± 0.84
2	48.80 ± 6.68	25.80 ± 4.32	18.20 ± 2.28	4.80 ± 0.44
3	51.50 ± 2.12	24.50 ± 6.36	22.00 ± 2.82	5.00 ± 1.41
P-value	0.79	0.89	0.23	0.71
Religion				
Hindu	48.55 ± 6.36	25.41 ± 5.13	18.49 ± 2.41	4.65 ± 0.83
Muslim	47.50 ± 4.95	25.00 ± 4.24	18.00 ± 1.41	4.50 ± 0.70
Christian	40.00 ± 1.41	18.00 ± 2.82	18.47 ± 2.36	4.00 ± 0.00
P-value	0.1	0.13	0.92	0.44
Caste				
General	48.07 ± 6.08	24.73 ± 4.95	18.69 ± 2.61	4.64 ± 0.71
OBC	48.25 ± 6.20	25.66 ± 5.10	18.03 ± 2.02	4.56 ± 0.94
SC	50.75 ± 8.98	26.63 ± 6.97	19.13 ± 2.41	5.00 ± 0.92
ST	46.00 ± 7.07	24.00 ± 5.65	18.00 ± 1.41	4.00 ± 0.00
P-value	0.78	0.64	0.54	0.19
SES Class				
Upper	46.67 ± 4.84	23.44 ± 4.18	18.89 ± 2.26	4.33 ± 0.50
Upper middle	47.14 ± 6.06	24.49 ± 5.01	18.14 ± 2.15	4.51 ± 0.84
Lower middle	52.29 ± 6.37	28.00 ± 5.12	19.19 ± 2.83	5.10 ± 0.70
P-value	**0.007**	**0.018**	0.379	**0.001**

*Independent t test, Mann-Whitney u test, Kruskal-Wallis test

Table 4: Regression Analysis of Factors Associated with Global Caregiver Strain Score

Variable	B	Std. Error	Beta	t	p-value
Age of caregiver	-0.075	0.290	-0.040	-0.259	0.797
Monthly income	0.023	0.077	-0.038	-0.298	0.766
Age of mother at childbirth	1.913	1.845	0.151	1.036	0.304
Type of family	-3.630	1.508	-0.256	-2.407	0.018
Education of caregiver	2.729	1.750	0.203	1.560	0.123

According to the age (in years) of the caregiver two categories were made- those aged less than 30 years and those more than equal to 30 years. The global score of caregivers ≥30 years (48.35 ± 6.36) was slightly greater than those aged <30 years (48.20 ± 6.81) the difference was not significant. The age of mother during the birth of the autistic child i.e., the maternal age was categorised into <30 years and ≥30 years. The global mean score for the first group was 48.11 ± 5.89 which was slightly less than that of the second group i.e.,48.72 ± 7.20 with no significant difference between the two. The mean global score for male child was 48.49 ± 6.93 which was slightly higher than the score for female child which had a score of 47.79 ± 3.82. this difference was not significant. Considering the birth order the score for first born child was 48.38 ± 6.72 whereas the score for second or higher birth order was 48.29 ± 6.05, the difference being not significant. According to the education status of caregivers/parents they were divided into two categories. One is below graduate with a global score of 50.79 ± 6.83 which is quite higher than the other group comprising of graduate and above with a mean score of 47.10 ± 5.80. this difference was found to be significant with a p-value of 0.01. Additionally, they exhibited significantly greater subjective externalised strain (*p = 0.00*), indicating higher levels of outwardly expressed stress. Considering the occupation of caregiver, majority were homemakers and had a mean score of 48.15 ± 6.52. Few were working and had a slightly higher mean score of 49.20 ± 5.74 but the difference between the two groups was not significant. (Table-3)

The caregiver strain was found to vary significantly with the type of family structure. Participants from nuclear families had significantly higher Global CGSQ scores (51.33 ± 6.42) compared to those from joint families (47.19 ± 6.01), with a p-value of 0.001. Similarly, objective strain was higher in caregivers from nuclear families (27.42 ± 5.42 vs. 24.40 ± 4.84; *p = 0.01*), and subjective internalised strain was also significantly greater (19.29 ± 2.27 vs. 18.16 ± 2.34; *p = 0.04*). No statistically significant difference was noted in subjective externalised strain between nuclear and joint family caregivers (*p = 0.88*). Caregivers in nuclear families experience significantly greater overall and internalised burden, likely due to limited intra-household support compared to joint family systems. The mean score for children having one or more sibling was 48.40 ± 6.33which was slightly higher than those with no sibling who had a mean score of 47.92 ± 6.90. Considering the number of siblings, with increase in number of siblings the burden score increased with highest score of 51.50 ± 2.12 in case of children with three siblings but the difference was not found to be significant. (Table-3)

While comparing the three sub-scores of objective strain, subjective internalised strain and subjective externalised strain in the three socio economic classes. The highest score was in the objective strain, highest score was found in the lower middle class (28.00 ± 5.12) followed by upper middle and the upper class. In the subjective internalized strain again, the lower middle class had highest score followed by the upper class and the upper middle class had the lowest score. In the subjective externalised strain also, the highest score was in the lower middle class followed by upper middle and upper class. The difference in scores was found to be significant in the objective strain (p-value 0.018) and the subjective externalized strain with p-value of 0.001. the difference in the scores of subjective internalized strain was not significant. (Table-3)

A multiple linear regression was performed to examine the effect of demographic and family characteristics on caregiver burden (Global CGSQ score). The predictors included age of caregiver, monthly income, age of mother at childbirth, type of family, and education of the caregiver. The overall model was statistically significant, F (5,81), p = 0.030, and explained 12.1% of the variance in CGSQ scores (Adjusted R^2 = 0.078).

Among all variables, **only type of family was a significant predictor** (B = -3.63, p = .018), indicating that caregivers from nuclear families experienced significantly more levels of strain. Other variables like age, income, education, and maternal age at childbirth were not statistically significant. (Table-4)

DISCUSSION

Children with ASD need lifelong support and are not able to work independently. This creates a burden on the parents and caregivers of the children which lead to mental stress, social difficulties, and financial burden.

All respondents in our study were mothers who came with their child to the autism therapy centres. In similar studies, it was observed that majority of caregivers were mothers; 78.02%[17],80.2%[19], 88.4%[20]. Majority of caregivers were graduates constituting 63.2% in our study. Similar finding was seen in studies by Kirby AV et al[21] and **Asahar SF** et al[19]. Hosseinpour A et al[22] showed that majority of mothers were studied up to secondary school. In our study, maximum were homemakers (82.8%). Similar finding was seen in study by Cetinbakis G et al[23]. Studies by Asahar SF et al[19] and Durán-Pacheco G et al[24] found that, homemakers were 28.4% and 29.4% respectively.

The mean age of the caregivers was 34.74 ± 3.4 years with age ranging from 26 to 42 years. In a study conducted by Cetinbakis G et al[23] the mean age was 38.11±6.51 years. In different studies the mean age of respondents varied 42.46 years[25], 41.4 years[26] and 35.77 years[19]. In our study the children were young between 2 to 9 years of age. 13.8% children were single child and rest children had one or more siblings. Cetinbekis G et al[23] found that, 22.6% children

were single child and Asahar SF et al[19] found 27.6% were single child. Some parents, after having a child diagnosed by ASD may not want to go for a second child but no correlation was found between caregiver burden and number of siblings. Most children (91%) in our study were born at term and around 9% were pre term. It has been seen various literatures that preterm birth is associated with a risk of ASD.[27,28] Purpura G et al[26] found around 19% preterm children their study.

A significant difference was observed between the objective strain (P=0.018) and subjective externalised strain (P=0.001) and thus the global strain (P=0.007) in the socio-economic classes with highest strain among the lower middle socio-economic class. The strain increased with decrease in the socioeconomic class. This difference can be due to less knowledge about the disease and financial constraints.

Caregiver strain or caregiver burden refers to the difficulties, demands, responsibilities and negative psychic consequences of caregiving for the child with special needs. The questionnaire used in our study that is caregiver strain questionnaire (CGSQ). This model has been used to assess the burden in parents/ caregivers with many disorders including Autism spectrum disorder.[29] Recent Indian studies have highlighted that caregivers of children with ASD experience significant emotional, social, and financial strain, often exacerbated by cultural stigma and lack of formal support systems.[30-32] Additionally, qualitative findings from India indicate that caregiving in autism is shaped by socio-cultural factors, which influence coping strategies and the level of perceived burden.[33,34] Some studies have used the CGSQ and it has been reported to be a valid and reliable tool to assess the caregiver strain. Also, few studies have validated it use for caregivers of children with ASD.[17,18]

In our study it was found that the highest score was for subjective internalised strain i.e., 3.07±0.394, followed by objective strain with mean score 2.29±0.469 and then the subjective externalised strain with mean 1.15±0.205. These findings were consistent with those in the study by Kirby et al[21] who reported greater internalised subjective caregiver strain with mean 3.14±1.02, followed by objective strain (2.39±0.85) or externalised subjective caregiver strain (1.62±0.58). Similar findings were also reported in the study by Jessica Bradshaw J et al[35] where the maximum score was reported for subjective internalised strain (3.26±0.87) followed by the objective strain and then the subjective externalised strain.

In our study the highest strain was for feeling worried for the child's future which was a part of subjective internalised subscale. The mean score was 4.11±0.813. Similarly study by Bradshaw J et al[35] also reported highest strain in this field. As most parents know that this disorder stays lifelong and the children cannot work independently, they feel quite worried about the child's future, about his/her employment and marriage etc. Slight variation was seen in the study by Yang R et al[18] who found more strain for interruption of personal time which is a part of objective subscale.

Among the items of objective strain subscale, the maximum strain was seen in disruption of family activities. This finding was slightly different from the studies by Bradshaw J et al[35] and Yang R et al[18] where maximum objective strain was for interruption of personal time. The lowest strain found in our study was for the child getting into trouble with the neighbours or other people around. This finding was consistent with those of Bradshaw J et al[35]. Slight variation was seen in the study by Yang et al[18] where lowest strain was for family suffering negative health effects.

In the subjective internalised strain we got the lowest strain in feeling sad or unhappy with the child's condition followed by feeling guilty. Slight variation was seen in the studies by Bradshaw J et al[35] and Yang et al[18] who found more strain in feeling guilty about the child's condition.

In the subjective externalised strain we found highest strain for feeling embarrassed (Mean = 1.41±0.65) followed by being angry at the child. Yang R et al[18]**.** reported that feeling embarrassment had strong factor loadings within the externalised subscale when applied to parents of children with ASD. The study by Bradshaw et al[35] got minimum strain for being resentful towards the child whereas study by Yang R et al[18] got minimum strain for being angry towards child followed by resentful towards the child. In our study minimum strain was found in relating to the child. This was reverse coded and meant that the caregivers could connect to and relate to their child very well. There could be a bias in answering this because parents love their child a lot and thus feel connected.

Higher strain was observed among caregivers who had education below graduate level with a mean score of 50.79±6.83 whereas for the graduate and above, the strain was less (Mean= 47.10±5.80) and the difference was significant. This was in contrast to the study by Bradshaw J et al[35] where they found no association between maternal education and the CGSQ strain.

There was higher strain for the nuclear families (Mean= 51.33 ± 6.42) as compared to joint families (Mean=47.19 ± 6.01), the probable explanation may be, in joint family's other members also taking care of children and hence decrease the burden on parents.

Subjective externalised strain was significantly higher among homemakers than working caregivers which may be contributed by the increased financial strain. Also, the subjective externalised strain was significantly higher in caregivers who were below

graduates. This may be due to less knowledge about the disorder which increased the stress and strain. Considering the family type, there was significantly higher objective strain as well as subjective internalised strain in nuclear families as compared to the joint families.

Limitations

This study has several limitations that warrant consideration. The use of convenience sampling may have introduced selection bias which limit the generalizability of findings to the broader population of caregivers. The relatively small sample size may have affected the reliability of observed associations. The exclusion of non-consenting individuals and those with memory impairments may not fully represent caregiver experiences. Additionally, the cross-sectional design precludes causal inference and limits the ability to observe changes over time. The self-reported data through the Caregiver Strain Questionnaire (CGSQ) may have introduced response bias.

Conclusion

Caregivers of children with autism spectrum disorder have increased burden and it is inversely associated with education levels, socio-economic status and nuclear families experienced more strain. These findings underscore the urgent need for culturally tailored interventions to alleviate caregiver burden in India. As the caregivers experience a lot of challenges in parenting the child with ASD, more educative and counselling sessions are needed to decrease their stress and improve the quality of life. Increased awareness and social support may help in decreasing the burden on caregivers. Policymakers should fund community-based ASD support programs, and healthcare providers should integrate caregiver counselling into therapy services.

Individual Authors' Contributions: SB, **SP**, **LP**, and **RS** were all equally involved in the conception and design of the study, data collection and interpretation, drafting of the manuscript, and final approval of the version to be published.

Availability of Data: Data are available upon reasonable request to the corresponding author.

Declaration of Non-use of Generative AI Tools: This article was prepared without the use of generative AI tools for analysis, or data generation. All findings and interpretations are based solely on the authors' independent work and expertise.

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