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Parenting stress levels among parents of autism children

¹ K Sushma Kiran, ² Dr. P Sreedevi, ³ Dr. G Swarupa Rani and ⁴ Dr. M Prasuna

¹ M.Sc. Research Scholar, Department of Human Development and Family Studies, College of Community Science, PJTSAU, Hyderabad, Telangana, India

² Scientist, CD component, All India Coordinated Research Project- Women in Agriculture, Rajendra Nagar, PJTSAU, Hyderabad, Telangana, India

³ Assistant Professor, Department of Human Development and Family Studies, College of Community Science, PJTSAU, Hyderabad, Telangana, India

⁴ Professor, Department of Extension Education and Communication Management, College of Community Science, PJTSAU, Hyderabad, Telangana, India

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Corresponding Author: K Sushma Kiran

Abstract

The study aimed to assess the levels of parenting stress among parents with autism children. A total of 120 parents (60 mothers and 60 fathers) in the age range of 20 – 50 years whose children are diagnosed with Autism were selected from the twin cities of Telangana state as sample through purposive sampling method. The data was collected by using Parenting stress index-short form (PSI-SF) developed by Abidin (1995). An ex-post facto research design was adopted for the study. The parental stress scale that measures the parental distress, parent child dysfunctional interactions and parental difficulty in dealing with the child. Frequencies and percentages were used to analyze the data. Findings of the study revealed that 38% of parents with ASD children experienced clinically significant levels of parenting stress followed by high levels (28%), average levels (22%) and only few (12%) of them had low levels. This suggest that parents need immediate intervention services to cope up effectively with their parenting stress.

Keywords: Autism spectrum disorder, parenting stress, autism children

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disability impacting social interactions and communication skills (American Psychiatric Association, 2013). Children with ASD exhibit various characteristics such as impaired communication, atypical or limited social functioning and repetitive or self-stimulatory behaviours. Prevalence of Autism has been on the rise. It is estimated globally that about 1 in 100 children has autism (Zeidan *et al.*, 2022) ^[22] and ET Health World report, 2023 also stated that approximately 18 million people in India have been diagnosed with autism among which boys affected 3 to 4 times more than girls. ASD symptoms vary widely across individuals, as they occur on a spectrum, resulting in different expressions and levels of severity.

The unique and unpredictable nature of each child's behaviour in autism adds multifaceted burdens to parents. The core ASD symptoms create challenges in bonding and understanding their child's needs. Managing challenging behaviours like self-injury, tantrums and disrupted eating habits adds to the stress among parents (Beighton and Wills, 2017) ^[2]. The magnitude of parental stress varies with age, education, occupation, support systems, severity levels and associated conditions of autistic children. Parenting stress is an adverse psychological reaction to the demands of being a

parent.

Parenting stress emerges from the challenges of parenthood and the perceived inadequacies towards resources to cope with those demands and also influenced by life events, environmental, sociological factors and the unique characteristics of the child. Studies revealed that parenting stress is higher in parents of autistic children when compared to children with other developmental disorders as well as parents of children with typical development (Muhammad *et al.*, 2020) ^[11]. Increased parenting stress can lead to adverse physical and mental health outcomes for both parents and children. The stress level of parents significantly impacts childcare functions and parent-child relationships (Mitchell *et al.*, 2018) ^[10]. Distressed parents often experienced strained emotional connections, reduced family activities, limited social and leisure opportunities and compromised mental and physical health. This can lead to diminished parent-child interactions, lower parental self-efficacy and poor quality of life.

Many studies revealed that parents of children with Autism Spectrum Disorder (ASD) had clinically significant (74.40%) levels of stress Gonal *et al.* (2023) ^[4]. Parents of ASD children experienced high levels of stress in their parental role and had the perception of having a difficult child (Operto *et al.*, 2021) ^[12]. Parents of children with

autism spectrum disorder (ASD) have been experiencing higher levels of stress and poorer physical health than parents than typically developing children (Padden and James, 2017).

Materials and Methods

Locale of the study

The present study was aimed to study the levels of parenting stress among parents with autism children. The study was carried out in Twin cities of Telangana State because these twin cities have a significant number of Autism centres and a large population of parents having children diagnosed with autism are available. From each city two centres were selected purposively for this study.

Sample Size

A total sample comprised of 120 parents of autistic children with 60 mothers and 60 fathers were selected for the study.

Tools used for the study

Parenting stress index-short form (PSI-SF) by Abidin (1995) was used. The scale has three dimensions and 36 items, the dimensions were parental distress, parent child dysfunctional interactions and difficult child.

Statistical Analysis

Frequency distribution and percentages were used to measure the levels of parenting stress.

Results and Discussion

Table 1 shows that above one third of parents with autism children had moderate levels (37%) of parental distress followed by high levels (34%) and only about thirty percent (29%) of them had low levels.

It implies that, majority of the parents quite often felt that they were trapped in managing their responsibilities and giving up much of their personal life to meet their child's needs, most of the times they unable to perform their roles and executive different tasks efficiently, not even able to think about new and different things in their life as earlier. They always worried about their future life, lost interest in spending time with their friends, neighbours and relatives and felt that they were being isolated and leading life without friends. Sometimes they also experienced excessive guilt that needs of their spouse are being neglected, due to this emotional distance and deterioration they had struggles in their marital relationships compared to previous healthy connections. Although, they were attending the parties occasionally but still not able to enjoy themselves in those gatherings. At times they also feel unhappy as they were not at all able to spent time to their personal life such as purchasing things like clothing, personal care and wellness products, Jewelry and gadgets etc. The reason might be due to stress from unmet expectations, challenging parenting demands and a lack of time and energy for personal and social activities due to having child with autism. These findings are in line with the study conducted by Lievore *et al.* (2024) ^[7] who reveled that parents often feel overwhelmed by the demands of parenting, which can affect their personal interests and social interactions. Similarly, Yesilkaya and Magallon-Neri (2024) ^[21] also revealed that parents of autism spectrum disorder children face higher

levels of stress due to the extreme challenges of parenting. Along with the above Lee *et al.* (2017) ^[6] found that parents of children with ASD had significantly higher scores of parental distresses.

Table 1: Distribution of parents of autism children based on parental distress component related to parenting stress (n1=60, n2=60, n=120)

S. No	Parental distress	Mother(n1)		Fathers (n2)		Total (n)	
		F	%	F	%	F	%
1	High	34	57	27	12	41	34
2	Moderate	18	30	26	43	44	37
3	Low	8	13	7	45	35	29
Total		60	100	60	100	120	100

Note: 'F' denotes frequency and '%' denotes percentage

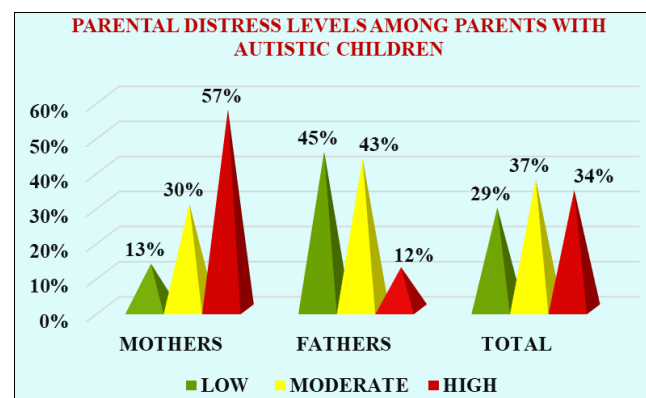


Fig 1: Levels of parental distress among parents with autism children

The above figure.1 also indicates that nearly sixty percent (57%) mothers had high levels of parenting distress followed by moderate (30%) and low levels (13%). Whereas, almost half (47%) of the fathers had low levels followed by moderate (43%) and high levels (12%). This reflects that parenting distress was more among mothers when compared to fathers of children with autism. The reason might be due traditional gender roles which defines mothers are primary caregivers and should take major responsibility towards care of the children in family despite of their personal and social life when compared to fathers. These findings are in line with Shahbaz *et al.* (2023) ^[14] who revealed that parents of children with ASD, particularly mothers, experienced high levels of stress. Along with this Ozturk *et al.* (2014) ^[13] and Solaiman *et al.* (2023) ^[16] also reported that mothers had high levels of stress than fathers due to less engaged in social life style.

Table 2 reveals that nearly half (48%) of the parents with autism children had moderate levels of parent-child dysfunctional interaction, about one fourth of them had low levels (27%) and high levels (25%). It indicates that majority of the parents of children with autism felt that they were incompetent or not very good at being a parent and their child does not like them or want to be close to them. Often they became helpless as they felt that their efforts towards caring for their child were not much appreciated. Many times, parents felt that their child was not up to their expectations and they were no longer as warm and close to them. They also felt that autism children took more time to

adjust to new things and were more unpredictable, displays repetitive behaviors intentionally which are bothered them a lot. At times they also felt that their child didn't seem to learn or smile as quickly or as much as most children and not gave minimum smile expected as parents. This might be due to prevalence of difficult behaviours in children lead them challenges in maintaining a positive relationship and usage of effective parenting practices and also difficulties in communication and emotional connection with their children. These findings are in line with studies conducted by Temelturk *et al.* (2021) ^[18] who reported that ASD was found to be an independent predictor for disordered relationship between children and their parents. Similarly Costa *et al.* (2019) ^[3] also revealed that parents of children with ASD interacted significantly less with their children which resulted in emotional difficulties in children. Along with the above Al-oran and Al- Sagarat 2021 ^[11]; Basri and Hashim 2019 also reported that parents with ASD experienced less satisfaction with their children.

Table 2: Distribution of parents based on parent- child dysfunctional interaction (PCDI) (n1=60, n2=60, n=120)

S. No	Parent-child dysfunctional interaction (PCDI)	Mothers(n1)		Fathers (n2)		Total (n)	
		F	%	F	%	F	%
1	High	24	38	6	10	30	25
2	Moderate	32	55	26	43	58	48
3	Low	4	7	28	47	32	27
Total		60	100	60	100	120	100

Note: 'F' denotes frequency and '%' denotes percentage

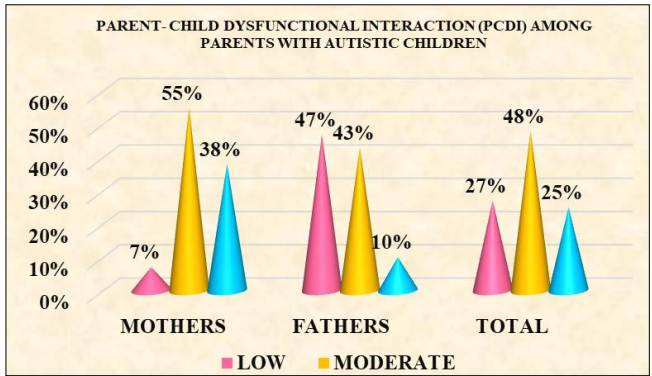


Fig 2: Levels of parent-child dysfunctional interaction among parents

It can also observed from the above figure 2 that above half of the mothers (55%) had moderate levels of parent child dysfunctional interactions followed by high (38%) and a meagre percent of them had low levels (7%). However, almost half (47%) of fathers had high levels of parent child-dysfunctional interactions followed moderate (43%) and low levels (10%). This indicates that parent child dysfunctional interaction was more among mothers than fathers. This might be due to greater involvement of

mothers in day-to-day caregiving, societal expectations and higher emotional investment in parenting responsibilities when compared to fathers. The current findings were on par with the study conducted by Loncarevic *et al.* (2024) ^[8] who found that mothers lacking psychological resources are sensitive to their child needs, feeling helpless and incompetent when interacting with their child. Similarly Hassam and Inam (2013) ^[5] also stated that mothers suffered more difficulties than fathers in the areas like social engagement, educational attainment of their children which affected the emotional bonding between mother and child. Table 3 states that nearly forty percent (38%) of parents with autism children displayed moderate levels followed by low levels (33%) and high levels (29%) of difficulty in managing the child. It implies that majority of the parents experienced stress due to dealing with difficult behaviours in autism children. They said that the child's disruptive behaviours like repetitiveness, refusing to listen, interrupting during conversations, being overly active and crying were bothering them a lot. They often experienced overwhelmed worries regarding their child's future life. They also felt hard in establishing the child's sleeping or eating schedules, getting their child to do something or stop doing something. At times, they perceived that their child was very moody, frustrated, highly reactive to things they disliked and get upset easily over the little things. Occasionally, they also felt that their child was more of a problem than they had expected and made more demands on them than most children. This could be lack of adequate training for parents to deal with different challenging behaviours like communication challenges, sensory sensitivities, behavioural issues, social interaction difficulties etc might made parents to become stressful. These findings are in line with the study Smith *et al.* (2014) ^[15] who found that parents frequently disclosed the challenges related to their kids encountered while carrying out day to day tasks such as eating, dressing, sleeping and using the toilet. In line with the above Operto *et al.* (2021) ^[12] also stated that parents of autism children experienced high levels of stress in their parental role and had the feeling of burnout due to having a difficult child. Zovko *et al.* (2023) ^[23] who found that their own ability to bear the responsibility of becoming parents (20%).

Table 3: Distribution of parents based on stress due to dealing with difficult child (n1=60, n2=60, n=120)

S. No	Parental stress in dealing with difficult child	Mothers (n1)		Fathers (n2)		Total (n)	
		F	%	F	%	F	%
1	High	28	47	7	12	35	29
2	Moderate	21	35	24	40	45	38
3	Low	11	18	29	48	40	33
Total		60	100	60	100	120	100

Note: 'F' denotes frequency and '%' denotes percentage

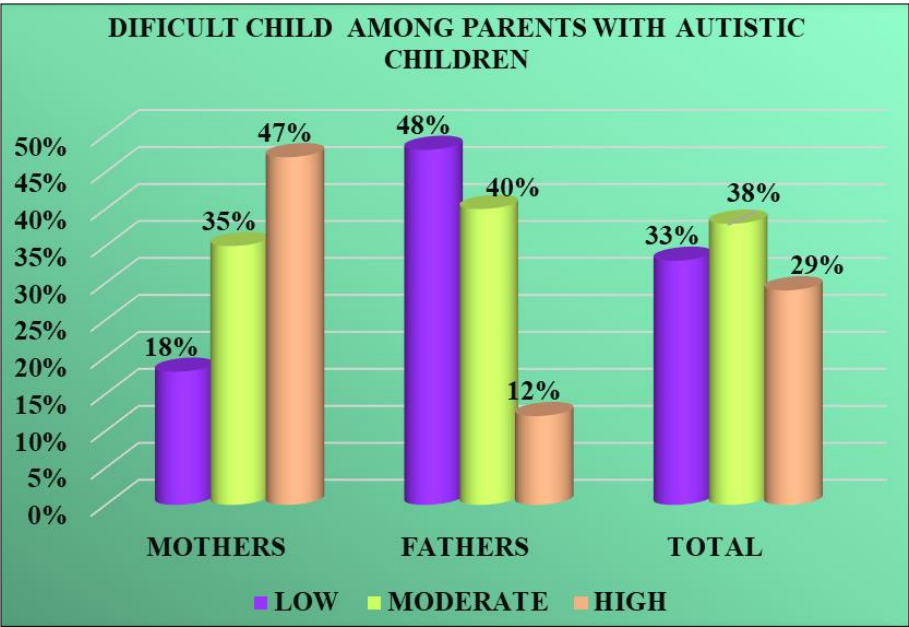


Fig 3: Levels of parental stress in dealing with difficult child

The figure 3. clearly depicts that almost half (47%) of the mothers with autism children had high levels of difficulty followed by moderate levels (35%) in managing the autism child and only very few (15%) of them had low levels of difficulty. In contrast, nearly half (48%) of fathers with autism children had low levels of difficulty followed by moderate (40%) and high levels (12%) of difficulty in managing difficult behaviours of autism children. This shows that mothers are facing more difficulties in managing the child when compared to fathers. This might be due to mothers are spending more time in dealing with child and taking care of their basic needs than the fathers. These findings are in line with the study by Zovko *et al.* (2023) [23] who found that majority of mothers expressed greater degrees of difficulty with their children's demanding behaviour (27%) and their own ability to bear the responsibility of becoming parents (20%).

Table 4 clearly depicts that nearly forty percent (38%) of parents with autism children had clinically significant levels of stress followed by high levels (28%). Only about one fifth (22%) of them had normal levels of stress and very few (12%) had low levels of parenting stress. This implies most of the parents of autistic children indicated high emotional burdens, experienced feelings of helplessness, loneliness, guilt about spouse neglect, inability to fulfil parental responsibilities, and excessive difficulties in controlling their child's disruptive behaviours, all of which negatively affected their emotional health and relationships with their families. The reason might be due to constant demands of caregiving, unresolved conflicts in parent-child relationships and emotional damage of balancing multiple responsibilities without adequate resources or coping mechanisms. These findings were in line with research conducted by Gonal *et al.* (2023) [4] who stated that majority of the parents of children with autism had clinically significant (74.40%) levels of stress. Although, Tripathi (2015) [20] also reported that majority of the parents (81% in the clinical range) were experiencing significant levels of stress. Similarly, Yesilkaya and Magallon-Neri (2024) [21] also reported that

parents who had difficulty in managing their emotions were more likely to experience parenting stress.

The above figure 4 illustrates that majority (67%) of mothers with autism children had clinically significant levels of parenting stress followed by high (17%), normal (13%) and only a negligible percent (3%) had low levels of parenting stress. Nonetheless, above one third percent (40%) of fathers with autism children had high levels of parenting stress followed by normal (32%), low levels (20%) and only a meagre (8%) percent of them had clinically significant levels of parenting stress. This indicates that when compared to fathers, more mothers of autism children experiencing greater parenting stress. This might be due to mothers are primary caregivers, were forced to stop working, and made career-related sacrifices, understanding the demands of raising a child with ASD and facing more frequent and intensive child-related challenges, feeling greater societal and self-imposed pressure to meet parenting expectations. These findings are in line with the study conducted by Shahbaz *et al.* (2023) [14] who found that parent of children with ASD, particularly mothers, experience high levels of stress when compared to fathers. Although (McStay *et al.* 2015; Soltanifar *et al.* 2015) [9, 17] also reported that mothers experience greater stress levels than fathers, which may be the result of greater involvement with the child. Similarly, Hassam and Inam (2013) also reported that mothers suffered more stress than fathers.

Table 4: Distribution of parents based on overall parenting stress levels (n1=30, n2=30, n=60)

S. No	Overall parenting stress levels	Mothers (n1)		Fathers (n2)		Total (n)	
		F	%	F	%	F	%
1	Clinically Significant	40	67	8	20	45	38
2	High	10	17	24	40	34	28
3	Normal	8	13	19	32	27	22
4	Low	2	3	12	20	14	12
Total		60	100	60	100	120	100

Note: 'F' denotes frequency and '%' denotes percentage

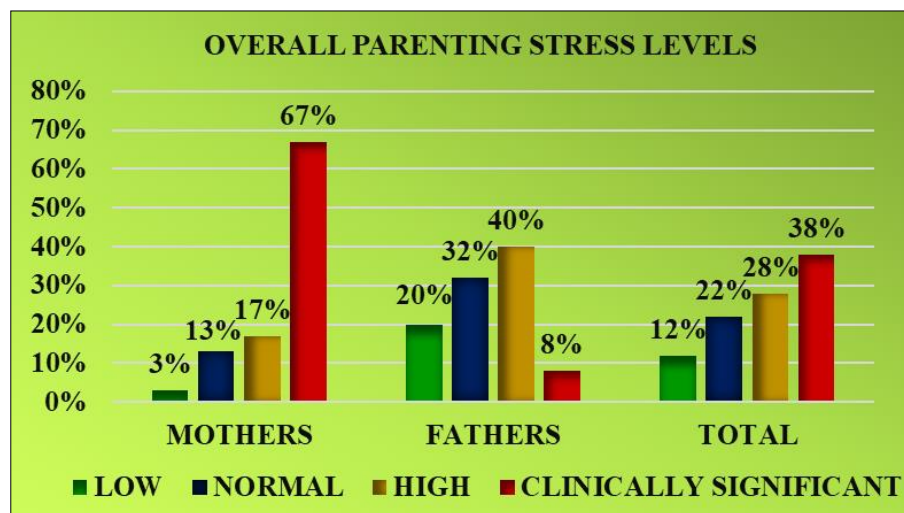


Fig 4: Overall parenting stress levels among parents

Conclusion

The study can be concluded that majority of parents experienced clinically significant to high levels of parenting stress. This suggests that parents with ASD children experienced more stress than other disabilities children. To reduce the parenting stress, parents need to adopt effective coping strategies to deal with their parenting stress. They should be oriented on nature of autism and how to deal with autism children and also specific needs of the autism children. Media should enforce on prevalence of parenting stress and its management. Parental associations and networks should be built and adequate counselling services must be given to reduce the stress in parents. The identification and understanding of the factors that contribute to parenting stress is necessary to effectively address the psychological needs of parents as part of any intervention program.

Future Scope

This study highlights how parents were experiencing stress in their parenting role. Policy makers, psychologists and educators should explore the underlying factors contributing to the elevated levels of parenting stress and plan appropriate interventions and support programs to reduce stress.

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Conflict of Interest

None.

References

1. Al-Oran HM, Al-Sagarat AY. Parenting stress of children with autistic disorder. *Open Access Library Journal*. 2016;3(7):1-10.
2. Beighton C, Wills J. Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration. *Journal of Intellectual Disabilities*. 2017;21(4):325-345.
3. Costa AP, Steffgen G, Vogele C. The role of alexithymia in parent-child interaction and in the emotional ability of children with autism spectrum disorder. *Autism Research*. 2019;12(3):458-468.
4. Gonal AM, Lata P. Stress factors in parents of children with autism spectrum disorder. *The Pharma Innovation Journal*. 2023;12(6):982-985.
5. Hassan K, Inam A. Factors contributing to stress among parents of children with autism. *Nurture*. 2013;7(1):1-8.
6. Lee J, Ong S, Lee V, Fairuz N. Parenting stress among Malaysian Parents of children with autism spectrum disorder (ASD). *Medicine and Health*. 2017;2(1):42-55.
7. Lievore R, Lanfranchi S, Mammarella IC. Parenting stress in autism: do children's characteristics still count more than stressors related to the COVID-19 pandemic? *Current Psychology*. 2024;43(3):2607-2617.
8. Loncarevic A, Maybery MT, Barbaro J, Dissanayake C, Green J, Hudry K, *et al*. Parent-child interactions may help to explain relations between parent characteristics and clinically observed child autistic behaviours. *Journal of Autism and Developmental Disorders*. 2023;1-15.
9. McStay R, Trembath D, Dissanayake C. Raising a child with autism: A developmental perspective on family adaptation. *Current Developmental Disorders Reports*. 2015;2(1):65-83.
10. Mitchell AE, Whittingham K, Steindl S, Kirby J. Feasibility and acceptability of a brief online self-compassion intervention for mothers of infants. *Archives of Women's Mental Health*. 2018;21(5):553-561.
11. Muhammad N, Baroi B, Rathi SR. Mental health of parents with and without autistic children: A comparative study. *Jagannath University Journal of Psychology*. 2020;10(1):21-32.
12. Operto FF, Pastorino GMG, Scuoppo C, Padovano C, Vivencio V, Pistola I, *et al*. Adaptive behaviour, Emotional/Behavioural problems and parental stress in children with Autism Spectrum Disorder. *Frontiers in Neuroscience*. 2021;15:751465.
13. Ozturk Y, Riccadonna S, Venuti P. Parenting dimensions in mothers and fathers of children with Autism Spectrum Disorders. *Research in Autism*

- Spectrum Disorders. 2014;8(10):1295-1306.
14. Shahbaz T, Khalid S, Ali A, Yaqoob S. Parenting Stress Among Parents of Children with Autism Spectrum Disorder. *Journal of Health and Rehabilitation Research*. 2023;3(2):724-729.
 15. Smith AL, Ronski M, Sevcik RA, Adamson LB, Barker RM. Parent stress and perceptions of language development: Comparing Down syndrome and other developmental disabilities. *Family Relations*. 2014;63(1):71-84.
 16. Solaiman MA, Morshed ASM, Morshed NM, Mullick MSI, Rahman M, Ahmed S. Psychological Distress and Perceived Burden Among Bangladeshi Parents of Children with Autism Spectrum Disorder: A Cross-sectional Study. *Psychological Studies*. 2023;68(3):319-325.
 17. Soltanifar A, Akbarzadeh F, Moharreri F, Soltanifar A, Ebrahimi A, Mokhber N, *et al.* Comparison of parental stress among mothers and fathers of children with autistic spectrum disorder in Iran. *Iranian Journal of Nursing and Midwifery Research*. 2015;20(1):93-98.
 18. Temelturk RD, Yurumez E, Uytun MC, Oztop DB. Parent-child interaction, parental attachment styles and parental alexithymia levels of children with ASD. *Research in Developmental Disabilities*. 2021;112:103922.
 19. The Economic Times. Panache. 18 million Indians. [Internet]. 2023 Apr 2 [cited 2023 Sep 10]. Available from: <https://economictimes.indiatimes.com/magazines/panache/18-million-indians>.
 20. Tripathi N. Parenting style and parent's level of stress having children with autistic spectrum disorder (CWASD): A study based on northern India. *Neuropsychiatry*. 2015;5(1):42-49.
 21. Yesilkaya M, Magallon-Neri E. Parental stress related to caring for a child with autism spectrum disorder and the benefit of mindfulness-based interventions for parental stress: A systematic review. *SAGE Open*. 2024;14(2):21582440241235033.
 22. Zeidan J, Fombonne E, Scora J, Ibrahim A, Durkin MS, Saxena S, *et al.* Global prevalence of autism: A systematic review update. *Autism Research*. 2022;15(5):778-790.
 23. Zovko M, Simlesa S, Olujic Tomazin M. Parenting stress, coping strategies and social support for mothers of preschool children with autism spectrum disorder in the Republic of Croatia. *Clinical Child Psychology and Psychiatry*. 2024;29(2):674-686.