

## Stress and coping strategies in parents of children with special needs

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### Abstract

**Objectives:** To identify the stress level and commonly used coping strategies of parents having children with special needs.

**Method:** The correlational study was conducted from January to April 2019 in Lahore, Pakistan, and comprised parents of special children from three special schools of the city. Data was collected using the Coping Strategies Inventory and the Perceived Stress Scale. Data was analysed using SPSS 24.

**Results:** Of the 150 children, 98(65%) were aged <10 years. Among the parents, 108(65.5%) faced moderate stress, 8(4.8%) faced low stress and 34(20.6%) faced high level of stress. Mean score was the highest for cognitive restructuring as the coping strategy  $14.95 \pm 2.87$ , followed by problem-solving  $14.81 \pm 2.98$ . There was a significant negative correlation of stress with cognitive restructuring ( $p < 0.01$ ), positive link with problem-focused engagement ( $p < 0.05$ ), positive correlation with self-criticism ( $p < 0.001$ ), social withdrawal ( $p < 0.01$ ), and emotion-focussed disengagement ( $p < 0.001$ ). High level of stress was positively associated with high level of disengagement ( $p < 0.05$ ).

**Conclusion:** Parents were found to be using more positive and practical strategies to cope with stress induced by taking care of children with special needs.

**Keywords:** Stress, Children with special needs, Coping strategies. (JPMA 71: 1369; 2021)

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### Introduction

The childbirth is generally associated with feelings of joy, but parents who have children with special needs (SNs) face many challenges in bringing up their children.<sup>1</sup> They face stress in managing the behaviours and needs of their children, and the overall family life changes while dealing with different needs of children with SNs. Long-term burden means stress often spreads across every aspect of life and may even lead the person to show non-functional responses.<sup>2,3</sup> Studies<sup>1-4</sup> emphasise the need to understand the beliefs of parents about their child's disability as their belief system guides them to take necessary actions about the management of such children.

To deal with the stress induced by children with SNs, parents apply and exercise a variety of techniques and coping mechanisms. Many child factors, like diagnosis, age, gender and functioning level, and parental factors, like socio-economic status (SES), education, family size and system, contribute towards selection and execution of a coping mechanism. Each family has its own set of coping strategies to manage the stress. Not all strategies help all parents as they have diverse personalities and characteristics. Being the primary care-taker and by virtue of spending more time with the child, mothers play the

most important role in managing such children. Nurses work with mothers so they should focus on guiding the mothers about the coping strategies which may help manage the stress.<sup>5</sup>

According to a study,<sup>6</sup> parents of SN children have a heightened level of stress compared to parents of typically developing children as these parents face an extra level of stress while dealing with child's diverse and challenging needs. Therefore, they feel overburdened and face more challenges in handling daily-life problems. Parents' stress also affects their own well-being, health and child's adjustment.

Another study<sup>7</sup> found that parents with SN children with cognitive delay face more stress compared to other disabilities. There are many other factors which can be a predictor of stress in parents, like low level of mother's education, fathers' poor health, poverty and less social support.<sup>8</sup>

A study identified strategies, including seeking guidance and help from others, sharing with friends, dependence on positive sources found in families, thinking about one day at a time, trying to learn the vocabulary about the child's disability, learning to handle natural feeling of rage, frustration and bitterness, keeping their outlook positive, finding the related and helpful management problems, accepting the situation and feeling responsibility for their child and identifying the fact that they are not alone in this endeavour.<sup>8,9</sup>

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Parents' interpersonal relationship, their financial adjustments and their professional growth together influence their adjustment in terms of handling their SN child.<sup>7</sup> Parents use different coping strategies, such as developing and maintaining a healthy relationship with their child, giving equal love to the child and developing a close relationship with the family.<sup>8,10</sup> The current study was planned to identify the stress level and commonly used coping strategies of parents having SN children.

## Subjects and Methods

The correlational study was conducted from January to April 2019 in Lahore, Pakistan, and comprised parents of SN children from three special schools of the city; Amin Maktab, Rising Sun and Shadaab School. After approval from the ethics review board of the University of Management and Technology, Lahore, the sample was calculated using OpenEpi calculator<sup>11</sup> with significant level 5% at 95% confidence interval (CI). The sample was raised using purposive sampling technique, and due to disproportionate sample distribution, SN categories were not classified and all available participants were included. To control confounding factors, parents of children with physical disability and medical history / deficiency were excluded, and so were parents with more than one child with SN.

After written informed consent from the parents, data was collected using the Coping Strategies Inventory (CSI)<sup>12</sup> and the Perceived Stress Scale (PSS).<sup>13</sup> The CSI is 32-item inventory comprising 14 subscales, including 8 primaries, 4 secondary and 2 tertiaries. High scores indicate more use of that particular coping technique.<sup>12</sup> PSS is a 10-item scale designed to assess perceived stress of participants. High scores demonstrate more stress. The scores were categorised into a low 0-13, moderate 14-26 and high 27-40 level of stress. Both CSI and PSS were translated into Urdu to make them comprehensible for parents. We followed following procedures of translation; (i) translation, (ii) back translation, (iii) piloting, (iv) revising items and (v) testing items (try-out). Alpha coefficient for both scales were observed as .88 and .82 respectively.

Data was analysed using SPSS 24. Frequencies, percentages were used to express correlation analyses of the data.

## Results

Of the 150 children, 55(36.6%) were from Amin Maktab, 50(33.3%) from Rising Sun and 45(30%) were from Shadaab School. Overall, 98(65%) children were aged <10 years (Table-1).

**Table-1:** Descriptive characteristics of the sample.

Characteristics	f	%
<b>1- Age (Child) years</b>		
<10	98	65%
11- 20	52	35%
<b>2- Disability</b>		
Mild	37	23%
Moderate	68	45%
Sever	45	30%
<b>3- Family System</b>		
Joint	68	45%
Nuclear	82	55%
<b>4- Birth Order</b>		
First Born	59	39%
Middle Born	58	39%
Last Born	33	22%
<b>5- Father Occupation</b>		
Job	90	61%
Business	28	19%
Labour	32	20%

**Table-2:** Correlation between perceived stress and coping strategies.

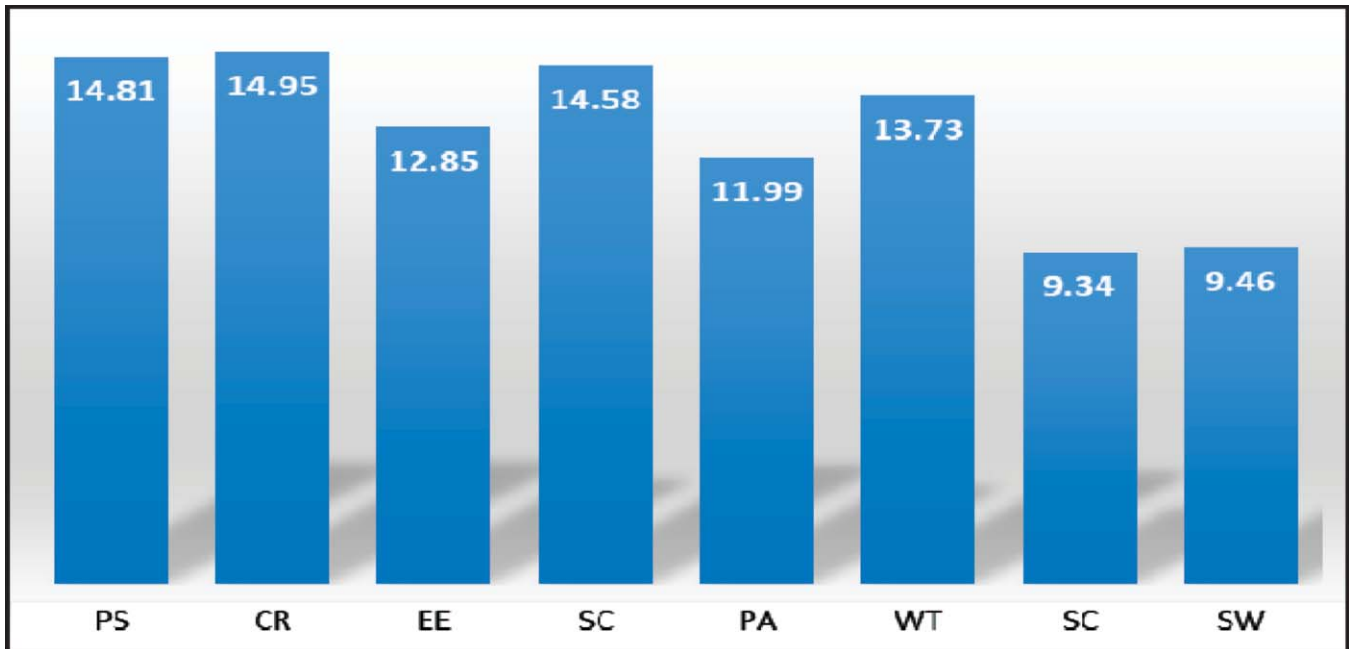
Measures	Stress	M	SD	Alpha
<b>Primary Coping Strategies</b>				
Problems Solving	-.161	14.81	2.98	.857
Cognitive restructuring	-.263**	14.95	2.87	.853
Express emotions	-.014	12.85	3.26	.855
Social contact	-.092	14.58	3.35	.858
Problem avoidance	.078	11.99	3.16	.851
Wishful thinking	.133	13.73	2.54	.851
Self-criticism	.455***	9.34	4.24	.852
Social withdrawal	.270**	9.46	3.73	.854
<b>Secondary Coping Strategies</b>				
Problem-focused Engagement	-.237**	29.86	5.15	.851
Emotion-focused Engagement	-.046	27.47	5.66	.854
Problem-focused Disengagement	.143	25.65	5.17	.838
Emotion-focused Disengagement	.431***	18.84	6.87	.850
<b>Tertiary Coping Strategies</b>				
Engagement	-.178	57.33	8.27	.843
Disengagement	-.369**	44.44	9.97	.840

Note: \*p<.05, \*\*p<.01, \*\*\*p<.001, M: Mean, SD: Standard deviation.

Among the parents, 108(65.5%) faced moderate stress, 8(4.8%) faced low stress and 34(20.6%) faced high level of stress.

The three most commonly used coping strategies by parents were cognitive restructuring (CR), problem-solving (PS), and social contact (SC) (Table-2; Figure).

There was a significant negative correlation between the level of stress and CR, and significant positive correlation between coping strategy of self-criticism (SCT) and social



PS: Problem solving, CR: Cognitive restructuring, EE: Express emotions, SC: Social contact, PA: Problem avoidance, WT: Wishful thinking, SCT: Self-criticism, SW: Social withdrawal.

**Figure:** Mean scores on coping strategies.

withdrawal (SW) and parents; perceived stress ( $p < 0.05$ ). There was positive correlation between level of stress and emotion-focussed disengagement ( $p < 0.05$ ) and a negative correlation between the level of stress and problem-focussed engagement ( $p < 0.05$ ). Finally, there was a positive correlation between parents' level of stress and disengagement ( $p < 0.05$ ).

## Discussion

More than 20% parents were found to have high level of stress, demonstrate that taking care of SN children is a stressful task. This supplements earlier findings.<sup>14</sup> Such a high prevalence of stress could be due to the way it is perceived as a challenge. It is evident that parents who perceive the presence of disability in their family as a challenge experience lower level of stress. On the other hand, parents who perceive the child's disability as a burden or some sort of tension face a high level of stress and they mostly blame themselves for the child's disability.<sup>15</sup> The present study also found that there was a significant positive correlation between the coping SCT and SW strategies and parents perceived stress. Previously,<sup>16</sup> it was found that parents indulge in self-criticism, avoidance, denial, self-blame and, consequently, socially withdraw. Another reason could be insufficient economic, social and emotional support parents receive from their surroundings. In a society like Pakistan, an SN child is tagged with pity and stigma. Further, these

children also face patronising behaviour, over-protection, distrust, hostility, anxiety, fear and horror.<sup>17</sup>

Another finding was a negative correlation between the level of stress and problem-focused engagement. Parents are more prone to using emotion-focussed engagement rather than problem-focussed, but, on the contrary, a study<sup>18</sup> found that parents prefer problem-focussed engagement. Surprisingly, the present study showed that most common strategies parents used were PS, CR and SC. One study<sup>19</sup> also identified social support, PS and the regulation of emotions as the commonly used coping strategies. In addition, the current study also found that parents' high level of stress led to emotion-focussed disengagement in which they did not engage in activities that can lead to logical problem-solving. This finding seems to be in line with a past study.<sup>20</sup>

A study<sup>21</sup> found that 74% of parents adapt to their child's disability, and 26% use inappropriate coping strategies. Also, 7% parents used poor coping strategies. But in the present study, the majority of parents used negative and emotion-focussed strategies. It is very crucial to understand the parents' selection of coping strategies, as this understanding may correctly guide psycho-education training programmes for parents with SN children.<sup>22</sup>

The current study has limitations. Only three special

schools in a single city formed the study sample. Future studies should include all the districts of Punjab and compare the stress levels and coping strategies parents use to manage their stress in different settings. The family-professional relationship is very important in managing SN children. Mothers need to work with professionals to understand the condition of their child. By consulting with the professionals, mothers' health may improve and they may be in a better position to manage the whole family.<sup>10</sup>

## Conclusions

Parents of children with SN faced high stress. Parents who faced a high level of stress used SCT as a coping strategy, which is a negative strategy. Parents were found to be using both appropriate and inappropriate coping strategies.

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**Conflict of Interest:** None.

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## References

- Zablotsky B, Black LI, Maenner MJ, Schieve LA, Danielson ML, Bitsko RH, et al. Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009-2017. *Pediatrics* 2019;144:e20190811. doi: 10.1542/peds.2019-0811.
- Auerbach E, Perry H, Chafouelas SM. Stress: Familycaregivers of children with disabilities. Storrs, CT: UConn Collaboratory on School and Child Health. [Online] 2019 [Cited 2021 March 03]. Available from URL: <https://bureaubulletin.files.wordpress.com/2020/01/collaboratory-on-school-and-child-health-brief-related-to-stress-and-family-caregivers-of-children-with-disabilities-november-2019-.pdf>
- King G, Baxter D, Rosenbaum P, Zwaigenbaum L, Bates A. Belief Systems of Families of Children with Autism Spectrum Disorders or Down Syndrome. *Dev Disabilities* 2009;24:50-64. Doi: 10.1177/1088357608329173
- Siklos S, Kerns KA. Assessing need for social support in parents of children with autism and Down syndrome. *J Autism Dev Disord* 2006;36:921-33. doi: 10.1007/s10803-006-0129-7.
- Hockenberry MJ, Wilson D. Wong's nursing care of infants and children, 8th ed. Missouri, USA: Elsevier Mosby Company; 2007.
- Margalit M, Kleitman T. Mothers' stress, resilience and Early Intervention. *Eur J Spec Needs Educ* 2006;21:269-83. doi: 10.1080/08856250600810682
- Shin JY, Nhan NV. Predictors of parenting stress among Vietnamese mothers of young children with and without cognitive delay. *J Intellect Dev Disabil* 2009;34:17-26. doi: 10.1080/13668250802690914.
- Twoy R, Connolly PM, Novak JM. Coping strategies used by parents of children with autism. *J Am Acad Nurse Pract* 2007;19:251-60. doi: 10.1111/j.1745-7599.2007.00222.x.
- Pasana MR. Adjustment mechanism of parents of children with autism spectrum disorder: Basis for an intervention scheme. Eulogio Amang Rodriguez Institute of Science and Technology. 2011.
- Sivberg B. Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children. *Int J Circumpolar Health* 2002;61(Suppl 2):36-50. doi: 10.3402/ijch.v61i0.17501.
- Dean AG, Sullivan KM, Soe MM. OpenEpi: Open Source Epidemiologic Statistics for Public Health, Version 3.01. [Online] 2013 [Cited 2020 October 17]. Available from URL: [https://www.openepi.com/Menu/OE\\_Menu.htm](https://www.openepi.com/Menu/OE_Menu.htm)
- Tobin DL. User Manual for The Coping Strategies Inventory. [Online] 2001 [Cited 2019 February 21]. Available from URL: [https://www.academia.edu/30133319/User\\_Manual\\_for\\_the\\_COPIPING\\_STRATEGIES\\_INVENTORY](https://www.academia.edu/30133319/User_Manual_for_the_COPIPING_STRATEGIES_INVENTORY)
- Cohen S, Kamarck T, Mermelstein R. A Global Measure of Perceived Stress. *J Health Soc Behav* 1983;24:385-96. doi: 10.2307/2136404
- Feizi A, Najmi B, Salesi A, Chorami M, Hoveidafar R. Parenting stress among mothers of children with different physical, mental, and psychological problems. *J Res Med Sci* 2014;19:145-52.
- Waisbren SE, Rones M, Read CY, Marsden D, Levy HL. Brief report: Predictors of parenting stress among parents of children with biochemical genetic disorders. *J Pediatr Psychol* 2004;29:565-70. doi: 10.1093/jpepsy/jsh058.
- Picci RL, Oliva F, Trivelli F, Carezana C, Zuffranieri M, Ostacoli L, et al. Emotional burden and coping strategies of parents of children with rare diseases. *J Child Fam Stud* 2015;24:514-22. doi: 10.1007/s10826-013-9864-5
- Barton L. The struggle for citizenship: the case of disabled people. *Disabil Soc* 1993;8:235-48. doi: 10.1080/02674649366780251
- Bawalsah JA. Stress and coping strategies in parents of children with physical, mental, and hearing disabilities in Jordan. *Int J Educ* 2016;8:e8811. doi: 10.5296/ije.v8i1.8811
- Smith PM. You Are Not Alone: For Parents When They Learn That Their Child Has a Disability, 3rd ed. [Online] 2014 [Cited 2021 March 03]. Available from URL: [https://www.parentcenterhub.org/wp-content/uploads/repo\\_items/notalone.pdf](https://www.parentcenterhub.org/wp-content/uploads/repo_items/notalone.pdf)
- Woodman AC, Hauser-Cram P. The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *J Intellect Disabil Res* 2013;57:513-30. doi: 10.1111/j.1365-2788.2012.01555.
- Farheen A, Dixit S, Bansal SB, Yesikar V. Coping strategies in families with mentally retarded children. *Indian J Pract Doctor* 2008;5:11-2.
- Singer GH, Ethridge BL, Aldana SI. Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis. *Ment Retard Dev Disabil Res Rev* 2007;13:357-69. doi: 10.1002/mrdd.20175.