

Psychosocial Impact of COVID-19 Pandemic on Parents of Children with Special Needs

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ABSTRACT

Objective: To determine the association of COVID-19-related psychosocial Impact in parents of children with special needs.

Study Design: Cross-sectional study.

Place and Duration of Study: Developmental-Behavioral Pediatrics Department, University of Child Health Sciences, The Children's Hospital, Lahore, Pakistan, from August to December 2021.

Methodology: A study sample of 213 parents of children (aged 1-16 years) with disabilities was recruited. The Perceived Stress Scale was administered.

Results: Most children 133(62.4%) with special needs were males with a mean age of 61.36±29.17 months. 91(42.7%) parents fear that either themselves or their family members could be affected by COVID-19. 75(35.2%) parents reported that their special needs child knew preventive measures for COVID-19. 147(69%) parents were facing social difficulties because of COVID-19. Income was negatively correlated with stress. Stress was more evident in parents who had a fear of the loss of a family member and who thought that disabled children needed more protection than their other children.

Conclusion: The COVID-19 pandemic had a negative effect on parents of children with special needs due to the restrictions imposed all over the country. One of the few factors that increased stress among parents of special needs children in COVID-19 were financial and social difficulties.

Keywords: COVID-19; Disabled children, Child, Preschool, Adolescent, Parents, Psychology.

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INTRODUCTION

The COVID-19 has profoundly affected the life around the globe. Isolation, contact restrictions and economic shutdown completely change the psychosocial environment in affected countries.^{1,2} A growing body of evidence shows that both the virus itself as well as the policies implemented by governments to minimize its spread disproportionately impact children with disability and their families.³

Even prior to the COVID-19 pandemic, children with special needs were at greater risk for difficulties accessing healthcare and performing instrumental activities of daily living.⁴ Their cognitive and intellectual disabilities limit their ability to comprehend the warnings issued to help them protect themselves from contracting and spreading the COVID-19 infection.⁵ The consequent closing of special schools, health centres and outdoor services in many hospitals meant difficulties in delivering therapy services in-person or virtually. Hence, after closing special education centres, therapists and teachers cannot provide appropriate therapy and education to children.^{6,7} Caring for children with special needs may

be more challenging for caregivers in this situation. Caregivers of individuals with intellectual disability (ID) reported significantly greater levels of anxiety and depression.⁸

Much research has been conducted on stress among adolescents, the working population and health professionals,^{9,10} however none has been conducted on stress among parents of children with special needs in Pakistan. Therefore, the present study aimed to determine the relationship of COVID-19-related characteristics with stress among parents of children with special needs.

METHODOLOGY

The cross-sectional study was conducted at the Developmental-Behavioral Pediatrics Department, University of Child Health Sciences-The Children's Hospital, Lahore, from August to December 2021, after approval from the IRB (Ref No. 2021-273-CHICH). The sample size was calculated through G-power analysis, with the prevalence of disability in Pakistan reported to be 15%.¹¹

Inclusion Criteria: Parents of children of either gender aged-16 years, presenting at the Outpatient Department with any disability (global developmental delay, intellectual disability, learning disorder, Down syndrome, autism spectrum disorder, social

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communication disorder, developmental language disorder, attention deficit hyperactivity disorder, hearing impaired and cerebral palsy) and needed special assistance were included.

Exclusion Criteria: Parents with a history of psychiatric illnesses were excluded. Parents of children who had chronic diseases like heart disease, celiac disease, gastrointestinal illness, etc., were also excluded.

Perceived stress scale (PSS) was used to measure perceived stress. It comprises ten items with a Likert response format that was answered on a scale ranging from 0 (never) to 4 (very often). There was reverse scoring in a few items of PSS. Individual scores on PSS can range from 0-40, with higher scores indicating higher perceived stress.¹² The reliability coefficient of the tool is 0.88.¹³

Parents whose children had already been diagnosed as having any disability by a multi-disciplinary team and were receiving rehabilitative, therapeutic services from the Department of Developmental-Behavioral Pediatrics were approached and enrolled in the study after the informed consent. Demographic form and Perceived stress scale were administered to the participants while maintaining confidentiality.

Statistical Package for Social Sciences (SPSS) version 25.0 was used for the data analysis. Quantitative variables were expressed as Mean±SD and qualitative variables were expressed as frequency and percentages. Correlation and regression analysis was done to determine the association and prediction of stress. The *p*-value of ≤0.05 was considered statistically significant.

RESULTS

Out of 213 children, 133(62.4%) special needs children were males, and 80(37.6%) were females, with a mean age of 61.36±29.17 months. Nearly half of the children (47.9%, n=102) were first-born. The mean age of the child at the time of diagnosis was 31.32±19.40 months. The mean income of the father was reported to be Pakistani currency 51957.74±4.22 Rs. 30(14%) of the participants had mental health issues in the family, and 57(26.8%) reported disability in the first-degree relatives. Nearly half of the parents 91(42.7%) feared that they or their family members could be affected by COVID-19, and 62(29.1%) had a fear of the loss of a family member. Most participants 147(69%) faced social difficulties because of COVID-19.

Table-I: Socio-demographic Characteristics of the participants (n=213)

Characteristics	n (%)
Gender	
Male	133(62.4)
Female	80(37.6)
Family System	
Nuclear	96(45.1)
Joint	117(54.9)
Mother's Education	
Matric	106(49.8)
Intermediate	23(10.8)
Bachlors	34(16.0)
Masters	40(18.8)
M.Phil	10(4.7)
Father's Education	
Matric	98(46.0)
Intermediate	20(9.4)
Bachlors	48(22.5)
Masters	39(18.3)
M.Phil	8(3.8)
Birth Order	
First born	102(47.9)
Middle born	55(25.8)
Last born	56(26.3)
Socio-Economic Status	
Low	83(39.0)
Middle	108(60.7)
High	22(10.3)
Any Mental Health Issues in the Family	
Yes	30(14.1)
No	183(85.9)
First Degree Relative with Disability	
Yes	57(26.8)
No	156(73.2)
Fear of Loss OF Family Members Due to COVID-19	
Yes	62(29.1)
No	151(70.9)
Fear of Being Affected from COVID-19	
Yes	91(42.7)
No	122(57.3)
Special Needs Child Knew Preventive Measures of COVID-19	
Yes	75(35.2)
No	138(64.8)
Parents Following the Advice Given by Therapist at Home for Child with Special Needs	
Yes	193(90.6)
No	20(9.4)
Parents are Protecting their Special Needs Child More than their other Children in COVID-19	
Yes	107(50.2)
No	106(49.8)
Parents Facing Social Difficulties Because of COVID-19	
Yes	147(69.0)
No	66(31.0)
Other Family Members Help In Taking Care of Special Needs Child	
Yes	132(62.0)
No	81(38.0)

The majority of the parents 193(90.6%) reported that they followed the advice given by the therapist at

Psychosocial Impact of COVID-19 Pandemic

home for their child with special needs, and 132(62%) reported that other family members also helped in taking care of this child (Table-I). Table-II shows that income ($r=-0.18, p<0.01$) was negatively correlated with stress. Fear of the loss of a family member ($r=-0.19, p<0.01$) and being affected by COVID-19 ($r=-0.17, p<0.05$) was positively correlated with stress. Parents protecting their special needs child compared to their other children was positively correlated with stress ($r=-0.38, p<0.01$). Multiple Regression (Enter Method) for COVID-related characteristics as Predictors of Stress is shown in the Table-III.

vious study reported that the majority of the children with behaviour disorders belonged to middle SES and were first-born.¹⁴ They also reported that 20.5% had mental illness in their family. An study showed the impact of COVID-19 on parents and reported that most parents belonged to low or middle-income groups.¹⁵

In this study, parents feared that they or their family members could be affected by COVID-19. Rahman *et al.* found that parents had a high level of worry regarding the possibility of their children getting infected.¹⁶ Another study reported that worry about the child's safety about being infected and the

Table-II: Descriptive Statistics and Correlations of COVID-19 related characteristics and Stress (n=213)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Age	-														
Gendera	-.08	-													
Family systemb	-.01	.06	-												
Income	-.12	-.05	-.19**	-											
Age at the time of diagnosis	.41**	-.07	.02	.08	-										
Any mental health issues in familyc	-.20**	-.05	-.09	.09	-.04	-									
First degree relative in family with disabilityc	-.07	-.08	-.04	.02	-.06	.27**	-								
Fear of loss of family members due to COVID-19c	-.05	.09	.08	-.15*	-.06	-.05	.03	-							
Fear of being affected from COVID-19c	-.13	-.02	.06	-.17*	-.12	.06	.10	.59**	-						
Special needs child knew preventive guidelines of COVID-19c	-.33**	.11	.12	-.15*	-.30**	.01	.18*	.09	.14*	-					
Parents are protecting special needs child more than other siblingsc	.19**	.08	-.02	.14*	.28**	-.14*	-.23**	-.00	-.03	-.17*	-				
Parents facing social difficulties because of COVID-19c	-.16*	-.04	.06	.07	-.16*	.18**	.18*	.09	.19**	.09	-.18**	-			
Parents following the advice given by therapist at home for child with special needsc	-.01	.02	.07	.04	.00	-.06	.09	.03	.12	.04	.07	.17*			
Other family members help in taking care of special needs childc	.09	.09	-.07	-.21**	.09	-.04	-.03	-.03	-.03	.11	.01	-.21**	-.02	-	
Perceived stress scale	.03	.08	.05	-.18**	-.19*	-.04	.09	-.19**	-.17*	.08	-.38**	-.05	.05	-.08	-
M	61.36	0.37	0.55	51957.74	31.32	0.86	0.73	0.71	0.57	0.65	0.49	0.31	0.09	0.38	19.73
SD	29.17	0.48	0.49	53344.22	19.40	0.34	0.44	0.45	0.49	0.48	0.50	0.46	0.29	0.49	4.20

a Male=0, female=1. bNuclear family system=0, joint family system=1. c Yes=0, No=1.* $p<0.05$. ** $p<0.01$.

DISCUSSION

The present study aimed to determine the relationship of COVID-19-related characteristics with stress in parents of special needs children.

Our study found that most of the children belonged to middle SES and were first-born. One fourth had a disability in first-degree relatives. A pre-

level of discomfort from the child's loss of care and assistance from specialists was between moderate to high degree. 82% of parents felt worried and anxious about the symptoms that might threaten their health and those around them.¹⁷

In the present study, parents reported that special needs children knew preventive measures for COVID-

Table-III: Multiple Regression (Enter Method) for COVID-related characteristics as Predictors of Stress (n=213)

Variables	Unit Measurement	Stress			t	p-value
		Unstandardized Coefficient		Standardized coefficient		
		B	Standard Error	Beta		
Constant		22.61	.72		31.48	<.001
Fear of loss of family members due to COVID 19	Categorical (0=yes,1=no)	-1.15	.72	-.13	-1.60	.110
Fear that you or your family members can be affected from this disease	Categorical (0=yes,1=no)	-.84	.68	-.09	-1.25	.214
Special needs child knew preventive measures of COVID-19	Categorical (0=yes, 1=no)	.37	.57	.04	.65	.516
Parents are protecting special needs child more than other siblings	Categorical (0=yes,1=no)	-3.27	.54	-.39***	-6.02	<.001
Parents facing social difficulties because of COVID-19	Categorical (0=yes,1=no)	-.71	.61	-.08	-1.17	.245
Parents following the advice given by therapist at home for child with special needs	Categorical (0=yes,1=no)	-.44	.92	-.03	-.48	.633
Other family members help in taking care of special needs child	Categorical (0=yes,1=no)	.20	.56	.02	.37	.714

19. In contrast, Abdelfattah *et al.*⁶ reported that 15.1% of parents responded that their children understood the meaning of social distancing. 17% of parents responded that their child knew how to maintain health safety conditions related to the prevention of coronavirus.

Parents protecting special needs children more than their other children were more affected. The presence of a sibling with a disability in the house compromised parents' abilities to meet the new demands of home-schooling for other children and to manage family stress.^{18,19}

The majority were facing social difficulties. In the study by Abdelfattah *et al.* 74.6% of the parents considered the lack of social meetings between their children and other children as a source of stress.⁶ Most parents reported that other family members helped take care of their special needs child. This is in contrast to a study done by Werner *et al.* who reported that families of individuals with disability had experienced lower social support during the COVID-19 pandemic.¹⁵

Income was negatively correlated with stress in relation to COVID-19, which means that parents whose income was less were more stressed. This was also found in a previous study which reported that parents whose family income was less than 5000 CNY had significantly higher anxiety level.²⁰

This study would help policymakers develop psychological interventions that minimize the negative impact of COVID-19 and help the vulnerable groups at higher risk of stress related to the pandemic. The study

also recommends providing guidance programs for distress during the pandemic.

LIMITATION OF STUDY

Parents of children with special needs were examined as a group, and no comparison was made according to disability type or severity. A longitudinal exploration of the study variables would help better understand the phenomenon.

CONCLUSION

The COVID-19 pandemic had a negative effect on parents of children with special needs due to the restrictions imposed all over the country. One of the few factors that increased stress among parents of special needs children in COVID-19 were financial and social difficulties. This was in addition to extra care of special needs children at home and fear of infection in children and other family members.

Conflict of Interest: None.

Authors Contribution

Following authors have made substantial contributions to the manuscript as under:

MN & SM: Data acquisition, data analysis, data interpretation, critical review, approval of the final version to be published.

AA: Study design, data interpretation, drafting the manuscript, critical review, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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