

Original Research Article

Disaster, disruption and disability- a multi-center parental survey of the mental health impact of COVID-19 pandemic on children with and without disabilities in India

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ABSTRACT

Background: The COVID-19 pandemic has impacted the pediatric population worldwide, with Children with developmental disabilities (CwDD) being particularly vulnerable. Data on the magnitude of the impact of the pandemic on children in India, particularly CwDD is much needed. The aim of the study was to explore parental perceptions of the impact of the COVID lockdown on daily behaviors and mental health outcomes of Typically developing children (TDC) compared to CwDD.

Methods: A cross-sectional survey was conducted on 708 parents of CwDD and TDC (age 2-18 years) in three centers in northern and western India, using an adapted version of the CoRonavIruS health and Impact Survey (CRISIS) questionnaire. Descriptive statistics, 2-sample t-tests, and linear regression models were analyzed.

Results: Opportunities to step out reduced equally for both CwDD and TDC ($p>0.05$), while social isolation was perceived more negatively ($p<0.001$) by TDC. Family's exposure to COVID was significantly lower ($p=0.01$) for CwDD, while financial stress due to COVID-19 was reported by both groups ($p>0.05$). Although composite scores for mental health during the pandemic were not significantly different between CwDD and TDC, parents reported worsening of children's mental health outcomes with 18.29% CwDD and 25.48% TDC as sad, 28.99% CwDD, and 32.03% TDC as anxious, 56.33% CwDD and 51.78% TDC as irritable and 40.47% CwDD and 38.08% TDC as distracted.

Conclusions: As per parental perceptions, mental health outcomes of CwDD and TDC have deteriorated similarly during the lockdown. However, the implications may be more severe for CwDD whose levels of independence, opportunities for participation, and mental health status were lower even pre-COVID.

Keywords: COVID-19, Developmental disabilities, Mental health, Survey, Parents, India

INTRODUCTION

The COVID-19 pandemic, with its attendant social distancing, physical restriction measures, and school

closures, has particularly affected children across the world, with the effects on children's mental health being most significant.¹ In March 2020, UNESCO estimated that 87% of the world's students would be affected by school

closure, restricting access to education, and causing disruptions in physical activity and social interactions.^{2,3} The lockdown created feelings of monotony and loneliness; children, in particular, stayed indoors and became restless; in some cases, even violent.⁴ Since then, multiple studies have reported the mental health impact on children globally, including increased anxiety, fear, stress, neglect, and violence.⁵⁻⁹ Further, increased screen-time with a range of electronic devices and television viewing led to sleep disturbances, altered behavior, irritability, and increased sedentary life.¹⁰

Children with developmental disabilities (CwDD) form a significant vulnerable population during the pandemic.¹ Apart from the risk posed by their disabilities, CwDD and their families faced barriers many times over in the pandemic due to the inaccessibility of therapy & intervention services, lack of appropriate information and safety advisories, loss of friendships, and the absence of structured environments and social life.^{11,12} In a study from the UK, the majority of young people with a history of mental illness said that the pandemic had worsened their condition.¹³ For caregivers, pandemic disruptions were also severe, ranging from financial anxiety, lack of services and unmet needs, health concerns, and child behavior problems, exacerbating parental burnout and stress.^{14,15}

In India, a lockdown on account of the COVID-19 pandemic was announced in March 2020. At the time of this study, all schools continued to remain closed, and most therapy services were either shut or offered only online. Multiple authors have commented on the detrimental psycho-social impact of the pandemic on children in India and specifically on CwDD.¹⁶⁻¹⁸ Additionally, Dhiman et al reported a high prevalence of depression and significant change in stress displayed by caregivers of CwDD during the COVID-19 outbreak.¹⁹ However, studies on caregivers' perception of how the COVID pandemic and lockdown has affected children, especially CwDD, are just emerging, with one parental survey reporting nearly half of their children with autism spectrum disorder as feeling anxious and hopeless.²⁰ The paucity of valid information is significant for three reasons: (a) As schools in India begin to reopen, the need for awareness of the impact of the prolonged lockdown on children's lives and mental health is critical for caregivers, school administration, and policy-makers; (b) CwDD are often overlooked and it is vital to highlight the influence of the pandemic on this vulnerable population; (c) The proper implementation of the New education policy 2020 will require an understanding of the psychosocial needs of children who are reentering schools after a prolonged period of enforced absenteeism.

This paper aims to understand the effect of the COVID lockdown on the behaviors and routines of children and how these changes played out in the mental health and emotional lives of children. Additional objectives are to explore the differential impact of the lockdown on

Typically developing children (TDC) compared to CwDD and examine risk and protective factors for mental health outcomes in children.

METHODS

Design

We conducted a cross-sectional exploratory online survey across three urban areas in western and northern India in August 2021, 18 months after the official COVID-19 lockdown throughout India in March 2020. The study was a collaborative effort of Ummeed Child Development Center, Mumbai, Latika Roy Foundation, Dehradun and Sethu Center for Child Development and Family Guidance, Goa- all not-for-profit Child development centers (CDCs) providing services for children with or at risk for developmental disabilities and their families.

Recruitment

Caregivers of TDC and CwDD aged 2-18 years residing in Mumbai, Dehradun and Goa were invited to participate in the study via emails, WhatsApp, and Facebook from the three CDCs in August 2021. Using a snowball sampling method, recipient caregivers were also encouraged to recruit other TD and DD children's caregivers. All participating caregivers were sent study information and opt-out instructions before providing access to login instructions.

Ethical considerations

All participants included in these analyses provided informed consent to participate before proceeding to the rest of the survey. Ethical approval (Ref. 23072021) was obtained from the Institutional Research Ethics Committee.

Measures

The survey instrument was developed to capture changes in various aspects of child behavioral health and lifestyle factors known to influence mental health. Questions were adapted from the CoRonaVirus health and Impact Survey (CRISIS) which was developed for use as an easy-to-implement and robust questionnaire covering key domains relevant to mental distress and resilience during the pandemic. These included health/exposure status to coronavirus, daily behaviors, life changes, emotional and mood changes, media consumption, and substance use.²⁰ The CRISIS questionnaire has been shown to have high construct validity and strong values for replication across various samples and settings, suggesting that the CRISIS questionnaire can be used in diverse settings.²¹

Adaptation and validation

The original CRISIS questionnaire was adapted to suit the Indian context and forward translated into three Indian

languages- Hindi, Marathi, and Konkani by two independent translators with proficiency in English and the Indian languages and back-translated into English. The research team validated the survey tool across a pilot sample of 7-10 caregivers per language.

Factor analysis

Exploratory factor analysis was conducted to explore underlying factors that would explain the correlation between the multiple items on the questionnaire. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.72, and Bartlett's test of sphericity was significant [$\chi^2(561) = 4285.498, p < 0.05$]. Overall, 58% variance was explained by the factor analysis. Five items were eliminated because they did not contribute to a single factor. Final, principal components analysis of the remaining 26 items, using varimax rotations, was conducted, with three factors explaining 26% of the variance. All items in this analysis had primary loadings over 0.5. The final six outcome variables determined by the factor analysis have been explained below:

Outcome variables

Daily behaviors

This composite variable (score range 3-12) was collated from 3 items, including the ability of the child to complete everyday activities, self-care activities, and entertain oneself for more than 20 minutes.

Opportunities for stepping out

The composite score included children's opportunities to go out to play and visit public places like parks/shops in terms of number of days per week (range 2-10).

Social stress of isolation

Responses to items about changes in quality of friendships during the lockdown, stress observed due to these changes, and distress due to the cancellation of important events because of the lockdown were combined to create a composite score (range 3-12).

Family's COVID exposure

This variable was a composite score (range 0-3) of three items- whether any parent or other family member had fallen ill physically or went into self-quarantine mode (with symptoms).

Financial distress

The financial implications of the lockdown were measured by responses about financial difficulties arising for the family on a Likert scale (1=not at all to 5=extremely), and yes/no responses about job loss of a caregiver/family

member, and reduced ability to earn, creating a composite score (range 4-8).

Mental health

This variable measured the health and wellbeing of the child on a series of 5 dimensions- mood, anxiety, restlessness, attention/concentration, and aggression/irritability. Item responses were provided on a five-point Likert scale and collated to create a continuous composite score (range 5-25).

Demographic variables

Demographic predictor variables included in the analysis are the age of the child, a pre-existing health condition, schooling during lockdown, education and income of the caregiver, family members in the household and media use.

Analysis

The statistical analysis was performed using STATA version 13. The internal consistency of scales to measure the validity of the main outcome variable, namely, mental health outcome within our sample was acceptable (Cronbach's $\alpha = 0.73$). Descriptive statistics were reported for all items constituting demographic and outcome variables. In the next step, a two-sample t-test was done to measure the differential implications on the main outcome variables by the diagnosis of the child i.e.; CwDD and TDC. Then, linear regression models were fitted to measure the association for each of the main outcome variables controlling for all the demographic predictor variables. Finally, a linear regression was specifically fitted to measure the association between the composite mental health outcome controlling for all the predictor demographic variables, including the other main outcome variables.

RESULTS

Sample

This study was conducted on primary caregivers of CwDD and TDC in Mumbai, Dehradun and Goa. The total number of survey respondents was 800; the respondents that did not give consent (N=33), did not meet location criteria (N=66), and did not meet the child's age criteria (N=14) were excluded from the study. The sample for this study consisted of 708 participants, 344 participants were primary caregivers of CwDD, and 364 participants were primary caregivers of TDC.

Demographic characteristics

Among CwDD, 111 (16%) were between 2.1-6 years, 145 (43%) between 6.1-12 years, and 88 (39%) children between 12.1-18 years. 77% of the CwDD identified as male, with autism spectrum disorder (ASD) as the most

common diagnosis (42%), and the majority (61%) did not have any pre-existing health conditions. 80% of primary caregivers were mothers, with 18% having a minimum of 12 years of education. Family income was above INR 50,000K per month for 36% of the families.

Among the TDC, 99 (27%) were between 2.1-6 years, 155 (42%) between 6.1-12 years and 110 (30%) children between 12.1-18 years. 57% of the TDC identified as male, the majority (72%) did not have any health conditions, followed by 15% having seasonal allergies. 76% of primary caregivers were mothers, with 21% having a minimum 12 years of education. Family income was above INR 50,000K per month for 58% of the families.

Demographic characteristics of both groups of CwDD and TDC are mentioned in Table 1.

Outcome variables

Daily behaviors

As per caregiver reports, the percentage of CwDD able to perform daily activities and self-care independently increased marginally from 7% (N=27) to 10% (N=35), while it decreased in TDC from 31% (N=115) to 25% (N=92) during the period of lockdown. In the same period, the number of CwDD able to entertain themselves independently increased from 37% (N=129) to 42% (N=145) and decreased marginally in TDC from 67% (N=246) to 59% (N=218). However, overall, caregivers of CwDD perceived their children (M=7.74, SD= 2.472) as significantly lower [$t(705)=9.765$, $p=0.000$] on their independence in everyday activities, self-care, and ability to entertain themselves than TDC (M=9.47, SD=2.187) (Table 2).

Regression analysis reveals an association between children's independence in everyday activities, self-care, and ability to entertain themselves with age (β coeff=0.14, $p<0.000$) and schooling (β coeff=1.339, $p<0.000$) during the lockdown, with older children and those with access to schooling being more independent (Table 4).

Opportunities for stepping out

Opportunities for stepping out to play and visiting public places reduced drastically for CwDD and TDC. The number of CwDD who did not step out to play at least once/week increased from 24% (N=84) before lockdown to 50% (N=174) during the lockdown, while the number of CwDD stepping out for play daily decreased from 28% (N=98) to 9% (N=34). The number of TDC who did not step out to play increased from 10% (N=37) to 46% (N=166), while the number of TDC stepping out to play daily decreased from 45.76% (N=162) to 11.30% (N=40). Before lockdown, 16% (N=58) of CwDD and 11% (N=39) of TDC did not visit public places even once a week, which increased to 66% (N=229) for CwDD and 72% (N=255) in TDC. However, no statistically significant differences

[$t(705)=0.401$, $p=0.688$] were noted between composite scores of CwDD and TDC during the study period (Table 2).

Reduction in the number of days going out to play or visit public places was associated with a pre-existing health condition (β coeff=-0.458, $p<0.001$) and more media use (β coeff=-0.663, $p<0.000$) (Table 4).

Social stress of isolation

As a result of the lockdown, relationships with friends changed for the worse for 15.65% (N=54) of CwDD and 32.6% (N=119) in TDC. The change in relationship was perceived as stressful in 40.29% (N=139) of CwDD and 63.29% (N=231) of TDC. Similarly, cancellation of events was perceived as stressful to some degree by approximately 72.17-77.81% of the children studied (Table 3).

The stress of social isolation was associated with attending online classes (β coeff=1.487, $p<0.000$) during the lockdown and more media use (β coeff=1.158, $p<0.000$), and perceived as significantly lower for CwDD when compared to TDC [$t(705)=7.219$, $p=0.000$] (Table 3).

Family's COVID exposure

During the lockdown, 33.9% (N=240) of the sample had some COVID exposure with family members of 10.2% (N=72) taken physically ill, 20% (N=142) of the caregivers put into self-quarantine, and extended family members of 12.5% (N=88) had COVID (Table 3).

The composite score for family's exposure to COVID was significantly lower [$t(705)=2.485$, $p=0.013$] for CwDD when compared to TDC (Table 4).

Financial distress

Financial problems resulting from COVID, ranging from moderate to extreme, were reported by caregivers in 46.09% of CwDD and 38.91% in TDC (Table 3). Lower levels of reported financial distress were associated with the child attending school and higher family income levels. However, differences in composite scores for financial stress due to the COVID pandemic as reported by caregivers of both groups of children were not statistically significant [$t(705)=7.188$, $p=0.000$] (Table 4).

Mental health

Before lockdown, caregivers reported 7.25% of CwDD and 3.56% of TDC as sad or unhappy, which increased to 18.29% in CwDD and 25.48% in TDC during the study period. Similarly, caregivers reported 17.39% of CwDD and 9.04% of TDC as anxious or nervous before lockdown, which increased to 28.99% in CwDD and 32.03% in TDC during the study period. In the same period, caregivers of 40.87% CwDD and 38.08% TDC perceived them as

moderately to very unfocused or distracted. The percentage of children whose caregivers perceived them as moderately to extremely irritable increased from 38.85% to 53.63% in CwDD and from 26.31% to 51.78% in TDC (Table 2).

Risk and resilience factors impacting mental health during the pandemic

Composite scores for mental health outcomes during the study period did not show any significant differences between CwDD and TDC [$t(705)=1.231$, $p=0.219$]. There was an inverse association between the age of the child (β coeff=-0.752, $p<0.031$) and composite mental health

outcome scores. An increase in media use was associated with the deterioration of mental health (β coeff=-1.516, $p<0.000$).

The composite mental health outcome score was also significantly associated with all the other outcome variables identified in the study except the family's COVID exposure.

Improvement in mental health during the pandemic was associated with higher scores on independence in daily behaviors and opportunities to play or visit public places. Deterioration of mental health was associated with social stress of isolation and financial distress (Table 5).

Table 1: Demographic characteristics.

Demographic variables		CwDD		TDC	
		N	%	N	%
Age of child (years)	2.1-6	111	16.69	99	27.2
	6.1-12	145	43.61	155	42.58
	12.1-18	88	39.7	110	30.22
Gender	Male	268	77.91	208	57.14
	Female	76	22.09	156	42.86
Place of residence	Mumbai	136	44.01	148	40.66
	Dehradun	98	31.72	86	23.63
	Goa	75	24.27	130	35.71
Diagnosis	Autism spectrum disorder	208	42.36		
	ADHD	35	7.13		
	Cerebral palsy	50	10.18		
	Down syndrome	26	5.3		
	GDD/intellectual disability	52	10.59		
	Learning disability	46	9.37		
	Speech disorder/others	74	15.07		
Health condition	Asthma/lung problems	6	1.6	12	3.17
	Epilepsy/seizures	33	8.78	4	1.06
	Hearing and vision problems	34	9.04	16	4.22
	Heart/kidney problems	6	1.59	3	0.79
	Immune disorder	9	2.39	4	1.06
	Seasonal allergies	49	13.03	59	15.56
	None of the above	230	61.17	275	72.56
Schooling during lockdown	Enrolled	277	80.52	326	89.81
	Not enrolled/does not attend	67	19.48	37	10.19
Access to therapy	No	127	36.69		
	Yes	217	63.31		
Income in INR	< 30,000	166	48.26	137	37.64
	30,000-50,000	54	15.70	52	14.29
	>50,000	124	36.05	175	48.08
Education level of primary caregiver	Till class 12	63	18.37	79	21.70
	Bachelors	123	35.86	101	27.75
	Masters/professional degree	157	45.77	184	50.65
Number of family members	5 or more	310	90.12	324	89.26
	7 or more	34	9.88	39	10.74
Media use other than school	No T.V./Media - < 1 hour	97	28.12	59	16.11
	1 - 3 hours	130	37.68	153	41.92
	4 - 6 hours	81	23.48	102	27.95
	> 6 hours	37	10.72	49	13.42

Note: CwDD- Children with developmental disabilities; TDC-Typically developing children.

Table 2: Impact of COVID lockdown on children.

Outcome variables		CwDD		TDC		t test at Baseline		CwDD		TDC		t test at endline			
		Before lockdown						After lockdown							
		N	%	N	%	t	P	N	%	N	%	t	P		
Daily behaviors						13.247	0.000*							9.807*	0.000
Independence in daily activities	Not applicable	102	29.57	32	8.77			79	22.9	26	7.12				
	Supervised	216	62.6	218	59.73			231	66.95	247	67.67				
	Independent	27	7.83	115	31.51			35	10.14	92	25.21				
Independence in self care	Not applicable	107	31.01	27	7.4			76	22.03	22	6.03				
	Supervised	155	44.93	131	35.89			174	50.43	137	37.54				
	Independent	83	24.06	207	56.71			95	27.54	206	56.44				
Entertaining oneself	Not applicable	62	17.97	16	4.38			44	12.75	20	5.48				
	Supervised	154	44.63	103	28.22			156	45.22	127	34.79				
	Independent	129	37.39	246	67.4			145	42.03	218	59.73				
Opportunities to step out						3.802	0.000*							0.401	0.688
Days of play	None	84	24.35	37	10.45			174	50.43	166	46.89				
	1 - 2 days	52	15.07	43	12.15			85	24.64	80	22.6				
	3 - 4 days	66	19.13	63	17.8			37	10.72	45	12.71				
	5 - 6 days	45	13.04	49	13.84			15	4.35	23	6.5				
	Daily	98	28.41	162	45.76			34	9.86	40	11.3				
Public place	None	58	16.81	39	11.02			229	66.38	255	72.03				
	1 - 2 days	155	44.93	179	50.56			81	23.48	79	22.32				
	3 - 4 days	71	20.58	80	22.6			21	6.09	9	2.54				
	5 - 6 days	29	8.41	31	8.76			7	2.03	4	1.13				
	Daily	32	9.28	25	7.06			7	2.03	7	1.98				
Mental health outcomes						9.166	0.000*							1.225	0.22
Mood	V/ Mod [†] unhappy	25	7.25	13	3.56			70	20.29	93	25.48				
	Neutral	89	25.8	46	12.6			87	25.22	70	19.18				
	V/ Mod happy	231	66.96	306	83.84			188	44.49	202	55.34				
Anxiety	V/ Mod anxious	60	17.39	33	9.04			100	28.99	117	32.06				
	Neutral	114	33.04	72	19.73			104	30.14	79	21.64				
	V/ Mod calm	171	49.57	260	71.23			141	40.87	169	46.3				
Restlessness	V ^{††} restless	45	13.05	42	11.51			85	24.64	84	23.02				
	Mod restless	111	32.17	82	22.47			96	27.83	93	25.48				
	SI/Not [‡] restless	189	54.78	241	66.02			164	47.54	188	51.51				
Attention	V/ Mod distracted	133	38.55	63	17.26			141	40.87	139	38.08				
	Neutral	55	15.94	53	14.52			50	14.49	57	15.62				
	V/ Mod attentive	157	45.51	249	68.22			154	44.64	169	46.3				
Anger/ Irritability	Very irritable	43	12.47	29	7.95			91	26.38	98	21.85				
	Mod irritable	91	26.38	67	18.36			94	27.25	91	24.93				
	SI/Not [‡] irritable	211	61.16	269	73.7			160	61.16	176	48.22				

*Significant at p value <0.05; **CwDD-children with developmental disabilities; TDC-typically developing children; [†]V/Mod- Very/Moderately; ⁺⁺Very; [‡]Slightly/Not

Table 3: Impact of COVID lockdown on children.

Dimensions		CwDD		TDC		t-test			
During lockdown		N	%	N	%	t	P		
Social stress of isolation									
Change in relationships with Friends	Worse	54	15.65	119	32.6	2.4747**	0.0136		
	About the same	98	28.41	126	34.52				
	Better	49	14.21	59	16.16				
	Not applicable/ No friends	144	41.74	61	16.71				
Stress associated with change in Friendships	Very	38	11.02	56	15.34				
	Moderately	47	13.62	66	18.08				
	Slightly or not at all	260	75.16	243	66.57				
Cancellation of Events	Very	61	17.68	86	23.57				
	Moderately	89	25.8	71	19.45				
	Slightly or not at all	195	56.53	208	56.98				
Family's COVID exposure									
Fallen physically sick		29	8.5	43	11.75			-1.331	0.1836
Put into self-quarantine with symptoms (Yes)		53	15.5	89	24.3				
Caregiver had COVID (Yes)		65	19.1	81	22.1				
Another member had COVID (Yes)		101	29.6	52	14.2				
Financial distress									
Degree of Financial Problems	Very	108	31.31	89	24.39	-1.331	0.1836		
	Moderately	51	14.78	53	14.52				
	Slightly or not at all	186	53.92	223	61.1				
Job loss of primary earner		19	5.6	13	3.5				
Job loss of another member		13	3.8	12	3.3				
Reduced ability to Earn money		36	10.7	40	10.9				

Note: *Significant at p value<0.05; CwDD- Children with developmental disabilities; TDC- Typically developing children.

Table 4: Multiple linear regression results: association between outcome variables with demographic variables as predictors.

Demographic variables	Everyday behaviour		Going out to play and visit public places		Social stress of Isolation		Financial Distress		Family's COVID exposure	
	β	P value	β	P value	β	P value	β	P value	β	P value
Child level variables										
Age	0.143	0.000*	-0.011	0.456	0.047	0.063	-0.030	0.017	-0.008	0.362
Pre HC++	-0.333	.067	-0.458	0.001*	-0.437	0.060	-0.169	0.148	0.000	0.998
Accessed Schooling	1.339	0.000*	0.197	0.279	1.487	0.000*	-0.418	0.006	0.050	0.643
More Media Use	0.538	0.001*	-0.663	0.000*	1.159	0.000*	0.230	0.034	0.116	0.135
Family level variables										
CG+ Education										
Bachelors	-0.216	0.394	-0.071	0.720	-0.290	0.371	-0.078	0.631	0.260	0.026
Masters	-0.285	0.318	-0.443	0.046	-0.306	0.402	-0.364	0.047	0.333	0.011
Specialised	-0.240	0.431	-0.160	0.498	-0.178	0.648	-0.102	0.602	0.348	0.013
Income level										
30k - 50k	0.435	0.091	-0.156	0.436	0.777	0.018	-0.774	0.000*	0.330	0.006
Above 50k	1.239	0.000*	0.254	0.128	0.666	0.016	-1.309	0.000*	0.111	0.262
Family members										
5-6 members	-0.175	0.336	-0.263	0.062	-0.092	0.692	0.130	0.266	0.144	0.086
> 6 members	0.174	0.534	-0.159	0.466	-0.453	0.207	-0.132	0.465	0.119	0.360

Note: *Significant at p value <0.05; CG- caregiver.

Table 5: Multiple linear regression results for composite of mental health outcomes.**

Variables	β (Std.Coeff.)	P value	95% CI	
Child level variables				
Age of the child	-0.075	0.031*	-0.143	-0.007
Had pre-existing health condition	-0.16	0.604	-0.766	0.446
Had schooling during lockdown	-0.209	0.611	-1.016	0.598
More media use	-1.516	0.000**	-2.097	-0.936
Family level variables				
Education of the caregiver				
Bachelors	-0.793	0.064	-1.632	0.046
Masters	-0.125	0.797	-1.074	0.825
Specialised	-0.409	0.425	-1.416	0.598
Income level of the caregiver				
30k-50k	-0.351	0.429	-1.223	0.521
Above 50k	-0.592	0.134	-1.366	0.182
No. of family members				
5-6 members	0.19	0.535	-0.411	0.791
More than 6 members	0.851	0.072	-0.076	1.778
Outcome variables				
Everyday behaviour	0.541	0.000**	0.415	0.667
Going out to play and visit public places	0.195	0.018**	0.033	0.358
Social stress of isolation	-0.367	0.000**	-0.467	-0.267
Financial distress	-0.344	0.001**	-0.541	-0.146
Family's COVID Exposure	-0.095	0.496	-0.368	0.178

*Significant at p value <0.05; **Composite of 5 dimensions- mood, anxiety, restlessness, attention/concentration, and aggression/irritability.

DISCUSSION

This study is one of the first in India to explore how the COVID pandemic and the long-drawn lockdown have affected the daily behavior and mental health of children, with particular emphasis on children with developmental disabilities.

In many ways, the results are not surprising. As expected, the situation was difficult for all children everywhere, irrespective of where they lived or their developmental status. Opportunities to step out, either to play or to visit public places, reduced significantly. Parents perceived that their children's friendships suffered, greatly exacerbating children's stress. Four out of ten families surveyed reported financial difficulties as a direct outcome of COVID.

Sadly, and again as expected, children from families from a higher socioeconomic background were far more likely to be enrolled in online services. Our study corroborates the findings from the Annual Status of Education Report (ASER) 2021 report that showed smartphone access, as a proxy of financial status, was a challenge in online education delivery.²²

However, a few interesting differences emerged between CwDD and TDC. Although overall, parents of CWD perceived their children to need more assistance during daily activities and self-care, they considered their children

to have made gains in their level of independence during the lockdown. Our finding suggests that possibly parents consciously utilized the lockdown period to address independent living skills in their CwDD, as has been reported in a study from Turkey.²³ Interestingly, families with CwDD reported significantly lower exposure to COVID. Our experience has been that families often view their disabled child as more vulnerable and more prone to infection in general. As a result, it is likely that they took Covid. protocols very seriously.

The stress around social isolation which parents reported for their CwDD was significantly lower than those reported for TD kids. While it is tempting to find this reassuring, we fear this may be due to disabled children just being more accustomed to limited opportunities for social engagement and participation. For them, lockdown restrictions may have felt like same-old, same-old.

In both groups of children in our study, mental health suffered during the COVID pandemic. One in four parents said their children seemed depressed, while close to one in three considered their children anxious during the lockdown. Other global studies found the reverse to be true: i.e.; depression was more common than anxiety.^{22,23}

Whichever order these mental health issues show up in, however, our figures are a considerable source of concern. In sheer magnitude, we are looking at huge numbers of children in crisis, but also in the context of a recent

UNICEF survey suggesting that India is one of the few countries where children are reluctant even to seek support.²⁴ Additionally, our findings concur with many similar studies in revealing that parents are significantly concerned about their children's increased levels of restlessness and inattention.^{2,6,11}

Globally, studies have suggested that CwDD bore the brunt of the pandemic, with indefinite closures of special schools, therapy services, and public spaces.²⁵⁻²⁷ However, our study findings do not reveal significantly varied outcomes between CwDD and those developing typically. We hypothesize that this could be due to multiple reasons. With parents and extended family-members forced to stay at home, increased opportunities for interaction between caregivers and children might have contributed to their participation and engagement during lockdown, and possibly warded off further deterioration of mental health.²⁰⁻²³

We also wonder whether closure of in-person schools and the absence of demands to socialize may also have been a protective factor for some CwDD, especially those with ASD.²⁸ Additionally, our findings are based on parent perceptions and not actual measurements of children's daily behaviors and mental health states. The changes due to the pandemic may have appeared starker to parents of TDC as compared to CwDD, who even during pre-COVID times had limited independence in daily behaviors, significantly fewer opportunities to step out and compromised mental health status.

Children spent significantly more time with media of all types during the lockdown. In our study, an increase in media use was a common factor associated with the increased stress of social isolation, reduced opportunities for stepping out, and deterioration in the mental health outcomes of children. Extant literature shows the complexity of the role that media, especially social media, has played in the lives of children and adolescents during the pandemic.²⁹ Exposure to frequent news reports and inappropriate, sometimes overwhelming, amounts of information on media combined with social isolation may have exacerbated anxiety in children and adolescents. Yet, paradoxically, social media may also have served as a coping mechanism to combat the isolation and boredom of school closures and reduced opportunities to step out.³⁰

The high percentage of families of CwDD in our study who faced financial distress (46.09%) should not be ignored. Given the prolonged nature of the pandemic, the addition of economic challenges added to the significant pre-existing caregiving burden of CwDD.³¹

Strengths and limitations

Ours was one of the few studies from the Indian sub-continent to provide data on both typically developing and developmentally disabled children's daily behaviors and their mental and emotional health as seen by the caregivers who know them best. Such data is crucial to throw light on

what is likely to be an unfortunate and enduring legacy of the pandemic and to enable policymakers, physicians, educationists, and caregivers to collaboratively make decisions that benefit all children.

The limitations of our study included the absence of validated tools to capture specific mental health outcomes. In addition, reliance on caregivers' perception of their children's daily behaviors and mental health and change during the pandemic are subject to recall bias and possible under or over-reporting. For example, adolescents may rate their mental health difficulties as higher than their parents; similarly, caregivers may not completely and accurately perceive the mental health status of CwDD, many of whom may have challenges in communication.

Furthermore, we conducted the study in August 2021, when lockdown was less stringent and re-opening measures were in place. Our findings may have been starker had the study been done earlier.

CONCLUSION

The implications of this study are multi-faceted. As schools have reopened in some parts of India, attendance has been low. Parents fearful about a 'third wave' cite children's vulnerability despite evidence that children are less susceptible and have milder symptoms if they are infected. Data from studies like ours that reveal the debilitating and far-reaching effects of social isolation may help parents make more informed decisions, while encouraging policymakers to accelerate vaccination policy for children. Special focus must be given to the challenges disabled children face, which may still be overlooked due to heightened fears of vulnerability in this segment. The pandemic has taught us valuable lessons: collective trauma requires swift action by caring adults in the community. More people need training in trauma-focused treatment practices to support children through similar crises. Last but not least: as parents and other caregivers are children's best hope for weathering life's storms, it's imperative to support caregiver mental health.

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