

Autism Spectrum Disorder in the COVID 19 Era: New Challenges - New Solutions

This survey explored the support available and the effect of lockdown on children with autism spectrum disorder and their families in India and the United Kingdom. Our findings showed significant problems for children and families due to lockdown. App-based information delivered to parents with support showed encouraging feedback.

Keywords: Anxiety behavior, App-based support, Lockdown, Telehealth.

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During the coronavirus disease 2019 (COVID-19) lockdown, all face-to-face support and planned activities of children with ASD were interrupted. This brought a significant change of routine for them [1]. They reported higher levels of anxiety, reduced dispositional hope, and psychological well-being [2]. Information technologies have been an essential tool during these challenging times [3]. Studies have reported positive effects of parental empowerment with training and support using technological platforms [4]. We investigate the impact of lockdown on children with ASD and their families in India and the UK.

Parents of 45 children with a confirmed diagnosis of ASD - 15 from Cornwall, United Kingdom [mean (range) age, 11.06 (7.02-17.05) years] and 30 from Lucknow, India [mean (range) age, 5.2 (2.11- 8.07) years] participated in the survey. Children with confirmed ASD were identified from clinical records of the child development center in Lucknow and Cornwall. Consent was obtained and General Data Protection Regulation guidelines were followed during data collection and analysis.

A semi-structured survey was constructed. It included four variables: change in behavior (CIB), change in the routine (CIR), regression in skills (RIS), and parental stress (PS) (**Web Fig. 1**). The final survey was reviewed by an expert panel, and their suggestions were included before conducting the telephonic survey. Speech and language therapists in the UK and trained child psychologists in India conducted telephonic surveys in mid of April over two weeks. Each interview took approximately 45 minutes. All questions on CIB, CIR and RIS were rated on an 8-point scale ranging from 0 to 7 and for PS on a 5-point scale ranging from 0 to 4.

Nonparametric *t*-test, Pearson correlation and multivariate regression analysis were calculated to measure the difference, bivariate associations, and the impact of lockdown on the study variables.

The mean rank for CIR, PS and CIS were higher in the UK as compared to India, whereas there was no significant difference in CIB. CIR and CIB were reported for all children. All parents reported increased PS (**Table I**). There was a significant correlation of change in behavior score with change in routine score ($r=0.446$, $P<0.01$), regression in skills score

($r=0.750$, $P<0.01$) and parental stress score ($r=0.370$, $P<0.05$). Parental stress score also significantly correlated with change in routine ($r=0.535$, $P<0.01$) and with regression in skills ($r=0.375$, $P<0.05$). Regression in skill and change in routine scores were also significantly correlated ($r=0.410$, $P<0.01$).

Parents and families reported extra difficulties in managing adults with ASD [5,6]. In the UK, children with ASD are provided diagnosis based on NICE guidelines. Necessary support is provided through schools, along with parental courses offered by the local council. Additional help is available through pediatricians, speech and language, child and adolescent mental health services, occupational therapy, and support groups. In Lucknow, children were assessed by a multi-professional team. The diagnosis was confirmed using ADI-R. The families who enroll in the early intervention program were provided with a home program support app.

Disruption in routine due to lockdown affected the behavior of children with ASD [1]. Change in routine was positively and significantly correlated with change in behavior, regression in skills, and parental stress, similar to previous reports [5].

In Cornwall, the parents' interview explained a lack of support or contact because of the long waiting list of appointments with professionals before the pandemic, which worsened with the lockdown. Studies reported a lack of support for both autistic individuals and their family's post-diagnosis prior to lockdown [8,9].

The mainstay of autism treatment is parental training and environmental modification around the child [10]. This study identified a gap in empowering parents with resources post-diagnosis that they can access when required. The app model support has shown promise, but parents needed support,

Table I Impact of Lockdown on Children With Autism Spectrum Disorder and Their Families in India and United Kingdom

<i>Group</i>	<i>Mean rank (SD)</i>	<i>P value</i>
<i>Change in behavior</i>		
India	24.0 (10.49)	0.45
UK	20.9 (10.49)	
<i>Change in the routine</i>		
India	18.22 (4.44)	0.01
UK	32.57 (4.44)	
<i>Regression in skills</i>		
India	22.28 (2.84)	0.61
UK ^a	24.43 (2.84)	
<i>Parental stress</i>		
India	17.18 (6.30)	0.01
UK	34.63 (6.30)	

Number of families enrolled UK-15, India-30. Proportion of parents who reported changes in the variable during lockdown was 100% for all variables except ^a78.6% for regression in skills from UK.

despite using the app. Due to the lack of appropriate measures, we were unable to measure the psychometric of the survey. However, the finding of this study is based on the direct parent's experiences, which is a strength of the study. The result helped in re-establishing the important role of routine and structure in children with ASD (**Web Table I**).

In conclusion, COVID-19 lockdown brought an opportunity to reassess our services for children with ASD. Technology-mediated support showed encouraging feedback of being used in combination with clinical practice.

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Note: Additional material related to this study is available with the online version at www.indianpediatrics.net

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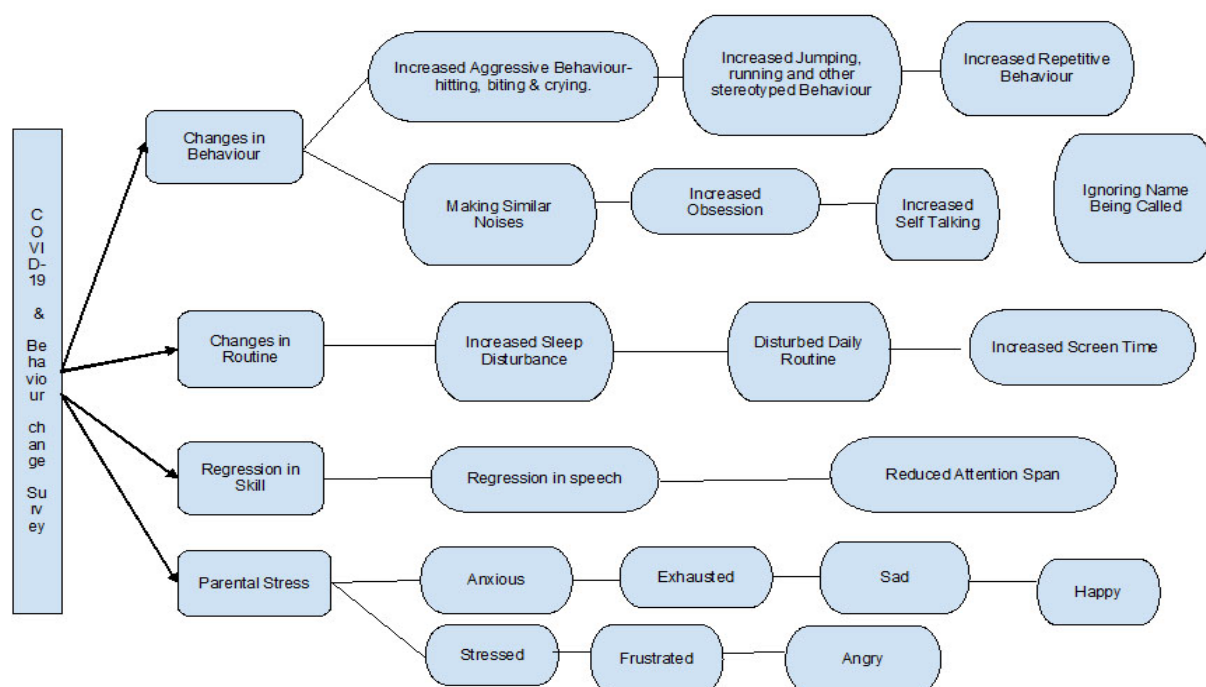
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REFERENCES

1. Colizzi M, Sironi E, Antonini F, et al. Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sci.* 2020;10:341.
2. Ersoy K, Altın B, Bayram SB, Güngörmüş OO. The comparison of impact of health anxiety on dispositional hope and psychological well-being of mothers who have children diagnosed with autism and mothers who have normal children in Covid-19 pandemic [Turkish]. *Sosyal Bilimler Araştırma Dergisi.* 2020;9:117-26.
3. Eshraghi AA, Li C, Alessandri M, et al. COVID-19: overcoming the challenges faced by individuals with autism and their families. *Lancet Psychiat.* 2020;7:481-83.
4. Lai MC, Anagnostou E, Wiznitzer M, et al. Evidence-based support for autistic people across the lifespan: Maximizing potential, minimizing barriers, and optimizing the person-environment fit. *Lancet Neurol.* 2020;19:434-51.
5. White LC, Law JK, Daniels AM, et al. Impact of COVID-19 on individuals with ASD and their caregivers: A perspective from the SPARK cohort. *J Autism Dev Disord.* 2021:1-8 [Epub ahead of print]
6. Singh S, Roy D, Sinha K, et al. Impact of COVID-19 and lockdown on mental health of children and adolescents: A narrative review with recommendations. *Psychiat Res.* 2020;293: 113429.
7. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *J Autism Dev Disord.* 2008;38:1278.
8. Crane L, Batty R, Adeyinka H, et al. Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *J Autism Dev Disord.* 2018;48:3761-72.
9. Jones L, Goddard L, Hill EL, et al. Experiences of receiving a diagnosis of autism spectrum disorder: a survey of adults in the United Kingdom. *J Autism Dev Disord.* 2014;44:3033-44.
10. Beaudoin AJ, Sébire G, Couture M. Parent training interventions for toddlers with autism spectrum disorder. *Autism Res Treat.* 2014;2014:839890.

Web Table I Learning Points From Parental Feedback to Improve Support for Children With Autism and Their Families

<i>Feedback from parents in the U.K.</i>	<i>Recommendations</i>
<ul style="list-style-type: none"> • Lack of contact/support post-diagnosis • Alternative methods of giving post-diagnosis information/recommendations as felt generic/overwhelming at the time • No contact during the waiting time and not able to access other services when on ASDAT pathway • Not knowing who to contact during the waitlist and after diagnosis. • Lack of peer support/families connected. 	<ul style="list-style-type: none"> • Amendment in a diagnostic letter to emphasize the family feedback meeting as an opportunity to support families along with discussing diagnosis. • Possible liaison with National Autism Society to discuss targeted opportunities for parents to connect each other/peer support • Rank information on diagnosis letter/prioritize and make clearer who families can contact and when, e.g. passionate about autism
<i>Feedback from parents in India</i>	<i>Recommendations</i>
<ul style="list-style-type: none"> • Clear and easy to understand information pre-and post-diagnosis • The app is very helpful; it helps parents to manage the child's problem at home • Provides training when the child is not cooperative • The app helped a lot during the lockdown and provided clarity • I was able to access information in my own time 	<ul style="list-style-type: none"> • More support on the application of information provided on the app. • Communication system with the organization to be in-build and recorded on the app



Web Fig. 1 Showing the variables and sub-dimensions studied in the survey.