


# Mental health of children with neurodevelopmental disorders during COVID-19: A brief report of family experiences from a low and middle income country

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## Abstract

COVID-19 has grossly impacted lives of people across the globe. In particular, children have also been affected due to closure of schools, therapy, and day care centers. Families have been challenged with new circumstances, and mental health professionals are coming up with novel ways to help these families who have children with mental health issues. This article describes experiences of families who have children with a diagnosed neurodevelopmental disorder with comorbid mental health difficulties and their ways of coping with the pandemic challenges. The series will throw light on ground level experiences of families during the pandemic, give insights into their ways of adapting, and brings out problem areas which healthcare professionals must work on, to design novel ways of care. The case series is novel and a similar report has probably not been presented from India or other low and middle income countries.

## Keywords

COVID-19, child mental health, neurodevelopmental disorders, coping, developmental delay, pandemic

## Introduction

COVID-19 has rapidly spread across the world, (“[As World Grapples With Coronavirus](#)”, n.d.; [MyGov.in](#), n.d.) causing psychosocial disturbances due to prolonged sudden lockdown and physical distancing (“[Coronavirus disease 2019](#)”, n.d.) which can affect the mental health of all, including

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children and adolescents, especially those with mental health disorders, comorbidities, and developmental disorders (Frankova, 2020; “School closures caused by Coronavirus (Covid-19)”, n.d.; Steinman, 2020). The financial burden on parents having a variable pay job, temporary loss of work, along with the stress of responsibilities, can have an impact on the mental health of children and adolescents. The pandemic has affected their learning and behavior and has made some vulnerable to violence and abuse (“COVID-19’s mental health effects by age”, n.d.; Golberstein et al., 2020; Lee, 2020; “Mental health and COVID-19”, n.d.; Singh et al., 2020).

Some families have coped with the pandemic, but there have been families with children exhibiting aggravated behavioral issues, anxiety symptoms, and difficulties coping indoors (Di Renzo et al., 2020; Stankovic et al., 2020). Disruption of therapy sessions, closure of schools, day care centers, and crèche, and parents having to work from home have impacted clinical progress, therapeutic support, and short-term outcomes in many children with neurodevelopmental disorders (NDD) like cerebral palsy, autism, and intellectual disability (Colizzi et al., 2020; “Stanford Medicine”, n.d.; “World Economic Forum”, n.d.). Many families have difficulty reaching out to mental health support systems, and teleconsultations have been challenging to use for therapy or follow-up in children with NDD (Ameis et al., 2020; McGowan et al., 2020; Singh et al., 2020).

## Methodology

This commentary summarizes the experiences of four families, who have a child with mental health and neurodevelopmental issues. These families were selected consecutively from a group of children with NDD who were already in follow-up with the author. Lockdown was initiated in India in the third week of March 2020. This study was conducted in June–July 2020, when India was 3 months into the lockdown. Those families who contacted the clinician for treatment follow-up during the lockdown were invited to participate and share their experiences. Families had to mention that they voluntarily consent to share their experiences in the Google form, after which they were given access to the form with questions. Four families of the 11 who were invited consented to participate. The treating team although had information on diagnosis and ongoing management of the children, sociodemographic details, child’s diagnosis, understanding of the concept of lockdown by the child, new onset behavioral issues, parent coping skills, and family support system during the pandemic were collected.

## Case presentation

### *Family 1*

Miss A, a 2½-year-old girl, lives in a nuclear family with her parents and older brother. She was diagnosed with attention deficit hyperactivity disorder (ADHD) (predominantly hyperactive) with mild global developmental delay and features of autism (sensory issues and repetitive behaviors). She was on melatonin and risperidone pharmacotherapy for her sleep and behavioral problems. She was in an individualized early intervention program since January 2020, which stopped when the lockdown was imposed in March. During the lockdown, no strategies seem to help her understand the need to stay indoors, and she insisted to be taken out, multiple times every day. She was hyperactive, more than her pre-lockdown state. Parents tried to maintain a routine by engaging her in timely activities like picture reading, writing, coloring, and structured play. However, due to her behavioral problems and time spent with the older sibling, her parents felt burnt out. Although there were no new onset behavioral problems in her, managing sensory issues, hyperactivity, and personal

care and hygiene was difficult. They felt a lack of support from the system. They were sensitized about teleconsultation but were unsure if it would work.

### *Family 2*

Miss B is a five-year-old girl, second born with an older brother. She was brought to India and is currently with her mother and grandparents for the treatment of her medical condition since January 2020. Her father and brother continue to live abroad. She was diagnosed to have acute myeloid leukemia and started on chemotherapy. She developed chemotherapy-associated posterior reversible encephalopathy syndrome (PRES) and had seizures and regression of speech. As sequelae to these events, she had behavioral issues such as irritability, frequent crying spells throughout the day, and sleep disturbances. She is on chemotherapeutic drugs along with aspirin, levetiracetam, and melatonin. Home-based behavioral management strategies were introduced, along with speech and language stimulation at home. Her sleep improved, and as she regained speech, her irritability gradually decreased. She also was on physiotherapy for PRES-induced quadriplegia.

Cognitively she is a girl with higher abilities. She understood the concept of lockdown. She freely discussed her thoughts about the virus and understood social distancing and the need to stay indoors. Due to her medical state, she was restricted to indoors even before the onset of the pandemic. Therefore, coping with the pandemic was easy and has not impacted her much. She maintains a routine with activities like physiotherapy, painting, craft, reading, and screen time. She has a supportive family system.

### *Family 3*

Master C is a 6-year-old boy who is the only child to graduate parents living in a joint family with paternal grandparents. He was diagnosed to have seizure disorder at 3 years of age and is on multiple antiepileptic medications. He also was diagnosed to have developmental delay with ADHD. He is on risperidone for his behavioral problems. He was attending a mainstream preschool in a remote village with no access to therapy. They practice home-based parent-mediated training programs along with once in 2-month reviews with the treating team. His seizures are not well controlled. He has intermittent behavioral worsening during the seizure episodes.

Ever since the pandemic began, keeping the child indoors has been a challenge for the family. Parents are unsure if he could understand the concept of lockdown. There are times when he insists on going out and has to be reminded repeatedly. During times when all their behavioral strategies fail, they give him screen time to engage him indoors. Mother tries to maintain a routine for him by engaging in structured play, writing, and schoolwork but frequently has to give in to television and phone. Parents do not report burnout. Although there were no major behavioral problems seen in the child due to lock down and disruption of school, temper tantrums, increased energy levels are new onset issues. He has learned self-help skills and can groom himself, which is a positive change reported by his mother. Pharmacotherapy includes levetiracetam, valproate, clonazepam, and risperidone, all of which were easily procured.

### *Family 4*

Master D is a 4-½-year-old male living in a nuclear family with his parents. He was diagnosed to have mild Autism Spectrum Disorder (ASD) and mild ADHD at 3 years of age. His cognitive abilities indicated that he had normal IQ scores, but he had delayed speech and language skills and deficits in

social skills. He was in a mainstream school with a home-based intervention plan. He had been making good progress even before the COVID-19 pandemic.

During the lockdown, although he understood the concept, he needed frequent reminders to stay indoors and lot of positive reinforcement. The pandemic allowed his parents to work with him vigorously. He was engaged with activities such as household chores, art and craft work, writing and reading, and structured play. They also practiced home-based therapy, guided by their therapist, with whom they followed up once every week. They have observed significant improvement in speech and communication skills. He is not on any medication. As father had to work for longer hours during the day and they had no social support, parents reported burnout. Mother was the primary caregiver at home. The child's screen time also was higher than usual.

Table 1 summarizes details of the child, working diagnosis, medical and psychiatric history, and parental mental health.

**Table 1.** Summary of clinical details, medical and psychiatric history and parental mental health.

Question	Family 1	Family 2	Family 3	Family 4
Index child age in years	Female 2 ½	Female 5	Male 6	Male 4 ½
Working diagnosis	Severe ADHD, cognitive delay, and autism features	Acute myeloid leukemia, chemotherapy-associated PRES, and had seizures and regression of speech	Seizure disorder, mild intellectual delay, and moderate to severe ADHD	Mild autism spectrum disorder with mild ADHD
Concept of lockdown, staying indoors, and behavioral issues	No understanding, difficult to manage, and worsened behavioral issues	Cognitively higher abilities, understood lockdown, and engaged well in routines and made progress	Unsure about his understanding about lockdown, behavioral strategies not working, and worsened behavioral issues	Understands lockdown but needs frequent reminders and reinforcement
Medication	Risperidone and melatonin	Chemotherapeutic drugs, levetiracetam, and melatonin	Levetiracetam, valproate, clonazepam, and risperidone	No
Taken regularly, procured easily?	Yes	Yes	Yes	Not applicable
Intervention before pandemic	Initiated therapy in January 2020 and was enrolled in individualized early intervention program	Home-based behavioral management strategies with speech and language stimulation	Home-based parent-mediated training programs along with once in two-month reviews with the treating team as family reside in a remote village with no access to therapy	Home-based therapy sessions

(continued)

**Table 1.** (continued)

Question	Family 1	Family 2	Family 3	Family 4
Type of family	Nuclear with older brother	Extended (during the pandemic)	Joint (paternal grandparents)	Nuclear
Parents education	Postgraduates	Postgraduates	Graduates	Graduates
Socioeconomic class	Lower middle	Upper middle	Lower middle	Upper middle
Parents read/utilized COVID19 related online material/ resources for maintaining good mental health of children	Unaware of such resources	Did not have the necessity	Unaware of such resources	Unaware of such resources
Ongoing online therapy/ interventions	No	No	No	No
Parents work from home	No	No	Father works 2–4 hours/day	Father works 6 hours/day
Parental mental health	Report burnout	Mother maintains a positive attitude to keep herself going and strong	Joint family system allows each caregiver to have “myself-time”	Parents report burnout
Screen time	Much more than usual	Slightly more than usual	Slightly more than usual	Slightly more than usual

Note. ADHD = attention deficit hyperactivity disorder; PRES = posterior reversible encephalopathy syndrome.

## Discussion and conclusion

The pandemic has impacted families in various ways. Coping of children with NDDs found in our series seem to be similar to findings from across the world. Although all families tried to maintain a routine and engage children, those with developmental delay have definite difficulty understanding the concept of lockdown, and staying indoors throughout the day was a challenge similar to other studies (McGowan et al., 2020; Nonweiler et al., 2020; Stankovic et al., 2020). Involving children in routine household chores, spending quality time is valuable similar to reports from other parts of the world (Colizzi et al., 2020; Narzisi, 2020; “REMEMBER’: Surviving the Pandemic with your Children!”, n.d.; Yarımkaya & Esentürk, 2020). Children with ASD may have rigidity and interest to maintain a routine, while those with ADHD need scheduled tasks to enhance attention and concentration (Cortese et al., 2020; Lai et al., 2014; McGowan et al., 2020). Therefore, introducing a consistent routine, making the day predictable, and introducing play-based activities at home may be useful, particularly in younger children with NDDs.

Two families reported burnout, possibly due to challenges in managing their child with multiple developmental and behavioral comorbidities, while work and child care needs. The extended family probably helped to share parenting tasks and helps avoid burnout. Burnout in families who have children with NDDs, anxiety, and disturbances in psychological well-being of parents has been frequently reported and is on the rise during the pandemic (Ardic, 2020; Colizzi et al., 2020; Di Renzo et al., 2020; Dykens, 2015; Ersoy et al., 2020; Nonweiler et al., 2020; Patel et al., 2020; Smile, 2020; Stankovic et al., 2020). Two families belonged to lower–middle socioeconomic class

while two belonged to the upper–middle socioeconomic class according to the modified Kuppuswamy classification for socioeconomic status in India (Table 1). One family lived in the rural area and three lived in urban area. None of the four families who were included reported financial difficulties during that phase of the pandemic. However, it is probably meaningful to say that the pandemic has potentially worsened the situation and increased risk for many families who are vulnerable to burnout.

While one family reported that they did not need to read material on child mental health and COVID-19, three families reported being unaware of the availability of such material online. The unawareness about online resources is possibly due to the lack of mental health literacy and digital literacy to seek resources online and read them. It is also possible that majority of families rely on television and newspapers for news and daily updates in which child mental health support is barely discussed. This digital divide has been reported from low and middle income countries as well as high-income countries (Kaku et al., 2021; Watts, 2020).

Increased screen time was commonly reported by all families, possibly because of the need to stay indoors and a higher risk for increased screen time, especially in those with ASD and ADHD (Montes, 2016; Slobodin et al., 2019). Availability of healthcare services and procuring medications are not challenging for any of the families.

Mental health professionals are trying novel ways to support these families. Many agencies have also published resources to help families manage children at home and handle behavioral issues (Barney et al., 2020; Cassidy et al., 2020; Cortese et al., 2020; Evans et al., 2020; McGowan et al., 2020; Smile, 2020). However, experts have projected that there will be a larger mental healthcare crisis post the pandemic (“As World Grapples With Coronavirus”, n.d.; Golberstein et al., 2020; Singh et al., 2020; World Economic Forum, n.d.). In particular, the mental health of children and adolescents is of concern considering the impact of the pandemic at multiple levels such as developmental age, comorbid medical conditions, behavioral comorbidities, and belonging to a lower socioeconomic group with greater risk for infection and lesser access to health care (Frankova, 2020; Singh et al., 2020). Many hospitals and therapy centers have resorted to telemedicine online services and consultations for families and particularly adolescents in India and across the world (Ameis et al., 2020; Colizzi et al., 2020; Frankova, 2020; Kaku et al., 2021; Singh et al., 2020). But families from low-income settings definitely will face the problems of the digital divide as discussed earlier.

We are also currently facing previously unknown situations like mass temporary unemployment, working from home, online homeschooling, rise in domestic violence, absolute lack of physical contact with friends/family, and restrictions within home space for prolonged periods (Colizzi et al., 2020; Di Renzo et al., 2020; Frankova, 2020; Kawabe et al., 2020; Parenteau et al., 2020). In parallel, fear of contracting the virus is still widely prevalent (Rajkumar, 2020; Roy et al., 2020; Singh et al., 2020). The impact of this stress and anxiety is unmeasurable at this point, and long-term implications are unknown. The downside of its effect on child and adolescent mental health is probably going to be a result of a combination of “public health crisis, social isolation, and economic recession” (“As World Grapples With Coronavirus”, n.d.; Golberstein et al., 2020; “Mental health and COVID-19”, n.d.; Witt et al., 2020). The need for indoor physical exercise, academic time, indoor hobbies, family time, storytelling, and other strategies cannot be stressed enough (Esentürk, 2020; “REMEMBER’: Surviving the Pandemic with your Children!, n.d.”; Yarımkaya & Esentürk, 2020). Parents must also plan strategies to prevent burnout, which will negatively impact children. Wherever feasible, tele-mental health services can be used. However, these services may not work for those living in remote/rural areas with a lack of resources. Community mental health services must come together to support children and adolescents with NDDs, who cannot access specialty services, for broader care until the pandemic cloud clears up.

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