



The Impact of the Pandemic on Children with Autism in Bangalore

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Abstract

The COVID-19 pandemic and resultant lockdown disrupted life for the entire population. This disruption has been particularly stressful for the autism-population, who need structure and routine to regulate their daily lives. This paper uses case vignettes from an early intervention centre to highlight the challenges faced by children on the autism spectrum. Observations suggest that the disruptions in routine and therapy services led to increased sleep difficulties, behavioural challenges and also affected the language development of these children. Some suggestions to ameliorate the situation are discussed and the need to take this learning forward is underscored.

Keywords: COVID-19, Pandemic, Autism Spectrum Disorders, Special Education

1. Introduction

On the 11th of March 2020, WHO characterized the outbreak of COVID-19 as a pandemic. The Karnataka Government responded by ordering the closure of all educational institutions. This was soon followed by a nationwide lockdown. This unanticipated predicament left everyone high and dry - providers did not have the means to provide service and the recipients had to learn to cope

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in the ways they could. With the parents working from home, the stress of work had to be handled along with the burden of home management. Parents had to contend with multiple roles of housemaid, cook, teacher, playmate and parent even as they attended office meetings. This scenario was particularly hard on parents of children with special needs as they had the additional responsibility of assuming the role of therapists.

Patrick et al (2020) carried out a national survey in the US to ascertain the impact of the pandemic on parenting, typically of developing children. They found that 27% of the parents reported worsening of their mental health with 14% reporting worsening of their children's behavioural difficulties. The impact on families with special needs is of a greater magnitude than those with typically developing children. This can be seen from the results of a survey carried out in Italy (Colizzi et al, 2020) among parents of children with Autism Spectrum Disorder (ASD) during the pandemic, where 93.9% reported increased difficulties in carrying out daily activities. In this same survey, 41.5% of the parents reported facing more frequent behavioural difficulties. The true extent of the impact will probably be clear only after intervention centres and special schools reopen. Closer home, a survey carried out by a premier institution in Bangalore found that 34% of the parents reported new-onset behavioural challenges among their children with ASD (submitted, under review). While this looks like a smaller number in comparison to the Italian data, it must be remembered that this online survey could only tap into the computer literate, English speaking population.

Autism Spectrum Disorder is a disorder characterised by impairments in communication, social interaction and restricted, repetitive thinking and behaviours (DSM5). It affects 1 in 54 individuals today (Maenner et al., 2020). The diagnosis of the disorder is based on multiple features, however, two features – impairment in social interaction and inflexible adherence to routine – are particularly relevant in the lockdown scenario.

The objective of this paper is to outline my field experiences and observations on how this pandemic has affected young children on the autism spectrum, a population for which I frequently provide services to. Using a narrative approach, case vignettes have been

recounted to highlight the challenges faced by children with autism spectrum disorder. These case vignettes are of all those children who came in for consultation to the early intervention centre during the period of November 2020 to December 2020. I have broadly divided the case vignettes into two groups - those who had received a diagnosis prior to the start of the pandemic and those with no previous diagnosis, and came into the intervention center seeking a diagnosis. The challenges faced by the parents during the lockdown have been briefly outlined in the case vignettes, followed by a summary. Some suggestions for ameliorating the challenges have been made based on the best practices in autism intervention.

2. Children with a diagnosis prior to the start of the pandemic

Young children with a diagnosis of ASD or those who have been deemed to be at risk for developing ASD were enrolled in a one on one early intervention. These children attended sessions at the center several times a week, along with intensive intervention sessions with their parent at home. Some of these children also attended preschool programs in the time they were undergoing intervention. The disruption brought in by the pandemic, in their regular routines threw up several challenges which impacted both their intervention and their development.

C, a child with severe ASD features was diagnosed at the early age of 17 months and had been in the early intervention program for nearly 6 months before the start of the lockdown. The child's sleep disorder had been brought under control with some substantial effort by the mother. The measures adopted to improve the sleep difficulties included increased physical activity like long walks and play sessions in the park every evening. Due to the lockdown and the ensuing home confinement, keeping C engaged became increasingly difficult for the mother. The reduced physical activity meant that the mother was finding it difficult to get the child to sleep at a reasonable hour in the night. The child's biological clock reversed and he started sleeping during the day, while staying awake most of the night. His behaviour became difficult, he was cranky and the mother could not carry out any therapy. This resulted in a complete stagnation of progress in his development.

K had been diagnosed as being at risk for autism at the age of 19 months in the month of February. He had been enrolled into the early intervention program and his mother had been trained to work intensively with him. However, his centre-based intervention came to a standstill within a few weeks of enrolment. This put tremendous pressure on the parent to work with him at home on her own. Having had little exposure to hands-on training during intervention, the mother was finding it difficult to make sense of the intervention activities she was asked to carry out. K's development suffered and he does not appear to have made the kind of progress that he might have had, had he received the centre-based intervention.

Ag, three and half years old at the time of the lockdown, had been receiving early intervention therapy for over five months. His hyperactivity had been brought under control with intensive, structured teaching and he had been coming to the centre five times a week. He had also shown considerable improvement in his sitting tolerance and communication skills while coming to the centre for therapy. The prolonged break on account of the lockdown and closure of intervention sessions, brought his progress to a standstill. Currently, he appears to have lost his ability to sit and attend to tasks with an increase in hyperactivity.

3. Children with no prior diagnosis

Behavioural challenges in very young children sometimes go unnoticed as family members consider it to be characteristic of their young age. Often, the first concerns about the child's development arise when preschools report the difficulties that they face with the child's behaviour. Interestingly, the disrupted routine and the amount of time spent in close quarters with their children, has made some parents aware of the differences in their child's development, leading to them reach out to professionals for a diagnosis.

Ab, a 2.5-year-old child had delayed language skills. But due to his young age and routine of going to preschool, his behaviour was managed and his marginally delayed language did not alarm his parents. The parents after a discussion with the paediatrician had

taken the “wait and watch” approach. However, once lockdown occurred, his routine was completely disrupted. There was no school to go to and his parents were working from home. The nanny who came in to look after him for a few hours a day was also asked to stay away since parents decided to isolate themselves socially. These changes impacted Ab’s behaviour negatively. Without anyone keeping him actively engaged, he became more hyperactive, cranky and difficult to manage.

H, 2.5 years old, had a regular routine at home with his homemaker mother. He had some speech development and the parents did not face any challenges with his behaviour. In the period the lockdown was in effect, H’s regular routine was disrupted. His visits to the market and the park were stopped and he was confined to the house. Socialization outside of his home was stopped. The mother had less time to engage him as she no longer had her house help coming in. Parents found that he had started withdrawing into himself and that instances of verbal utterances had gradually reduced, leading them to seek help from a developmental paediatrician.

Xy, another previously undiagnosed child, had marginally delayed language development but the parents were not overly concerned as he was behaviourally manageable. As both parents were working, the child spent part of the day in a daycare centre and another part with grandparents. The daycare centre was shut during the lockdown and the child was with parents and grandparents all day. They started finding it difficult to keep him engaged and his behavioural challenges increased. Along with this they also found that he was also not sleeping in the night and his language skills regressed.

4. Discussion

These case vignettes illustrate the difficulties that children with autism spectrum disorder (ASD) have in coping with changes in their routine. These children are slow to adapt and this influences their behaviour and development in times of sudden change. Gioia et al. (2002) have reported inflexibility in behaviour as a significant part of the executive function profile of children with ASD, hence,

rendering them susceptible to changes in their routines. The lack of predictability, brought on by the changes, increases anxiety levels and results in acute behavioural challenges. As can be noted from the cases outlined, the disruption to their routine has had a tremendous impact. Even those parents who were hitherto unaware about their child's problems, came to recognise and become aware of the developmental difficulties when the routine was disrupted along with the pandemic related increased parent-child interaction time.

The key themes that have emerged from these case vignettes highlight the following domains of impact of the pandemic and provide pointers to areas of service that must be strengthened to provide better care for children with ASD.

4.1. Sleep

Children on the autism spectrum have a higher prevalence of sleep problems and this impacts not just their functioning but also the mental health of the parents (Devnani & Hegde, 2015). One primary suggestion given to parents of children with sleep disorders is to establish a regular routine and follow sleep hygiene. Turkoglu et al. (2020) have reported that children confined to their homes during the pandemic reported higher levels of sleep problems than when they were not confined.

4.2. Hyperactivity

Manning et al.(2020), reporting on a survey conducted during the pandemic reported higher levels of stress among parents associated with the difficulty in keeping their children engaged while attending to their work. The dual roles thrust on parents of having to work from home and at the same time monitor their children through the day resulted in the child being left free for long durations. Due to their executive function difficulties, most children on the spectrum cannot occupy themselves gainfully and need adult intervention to do so. Moreover, being confined indoors for long hours meant that the children were not getting enough opportunity to exercise and expend some of their energy in parks and other outdoor spaces.

4.3. Social Interaction

Social interaction is one of the domains that are severely affected in ASD but the impairments do not always become apparent until social demands exceed developmental levels. The restrictions on social interactions during the lockdown meant that there were no demands on the child. It resulted in fewer opportunities for children to practice their social skills leading to further difficulties.

The lack of social demands could lead to impairments going unnoticed for a longer duration. There could be a section of the special needs population who have as yet not been diagnosed because of lack of exposure to social situations like preschools and social events outside of home.

4.4. Language Development

Delayed language development is generally the primary reason why parents seek help for their autistic child (DeGiacomo & Fombonne, 1998). These delays are often detected in preschools either by the preschool teachers or when parents compare their children with their classmates. With schools closed, this avenue of possible early detection has been lost. There is a likelihood of some children who are going to face substantial delays in their diagnosis. Delayed start of intervention leads to worsening of the associated behavioural difficulties.

4.5. Aggression

Children with autism are prone to anger and aggression and parents report that one frequent trigger for this is a change in routine (Ho et al, 2012). Maintaining the routine that the child was accustomed to, proved to be particularly challenging for parents during the pandemic.

The stress of being cooped up in close quarters leading to an increase in spousal abuse has been widely discussed in the media (Maji et al., 2021) but the levels of aggression against and among children with ASD has not been investigated. Surveys and future clinical data might be of use to understand this. Encouraging the formation of support groups can be an avenue that professionals should explore to reach out to families who may otherwise hesitate to talk about aggression and abuse.

Protocols for support services for children with ASD need to keep the following items in view -

1. **Disciplined Routine:** Maintain a routine regardless of the situation. Fix a regular timetable for waking up and carrying out daily activities. This not only keeps the children calmer, it will also help them to keep learning. This routine needs to be set and enforced by the parent as the child may lack the necessary skills to do it.
2. **Sleep Hygiene:** Have a regular sleep time for the child. Ensure that the child does calming activities in the evening and avoid playing on the phone/tablet. Dim the lights in house an hour before bedtime. Give the child a warm bath and make sure he finishes his last meal at least an hour and a half before bedtime (Malow et al, 2013).
3. **Teaching Independence:** Utilizing this time productively to make the child more independent with work through the use of visual schedules will go a long way in helping the child. Several intervention centres are offering online parental support which can enable them to learn the necessary techniques to carry this out.
4. **Visual Communication:** Use visual cards for communication and behaviour control. Children on the autism spectrum always respond to visuals better than they respond to verbal communication. Visuals can be used for communication and to proactively help the child learn how to behave (Meadan et al., 2011). It will be worthwhile to remember that using visual cards for a child on the spectrum is no different than a child with visual impairment using spectacles.
5. **Social Stories:** Visually illustrated social stories will help control the child's anxiety. Social stories help the child understand what to expect and how to behave in a given scenario (Gray & Garand, 1993). This ensures predictability and will reduce any behavioural challenges that may occur.
6. **Self-Care:** It might be hard for parents to take time out for themselves but they must try. They can always give the

child free access to what they like during the time the parent does activities he or she likes. For example, allowing the child to play in the sand while they watch a movie or do yoga.

7. **Involve the child in household chores:** There is always something the child can participate in when you are busy with household chores. Keep him engaged, whether it is to put the clothes in the washing machine, shell peas or to hand you the clothes pegs as you hang up the washing. Or maybe he could wipe the dishes dry as you wash them. No matter what age or level the child is at, there could be an activity that he could participate in.
8. **Bonding:** This could be the ideal time to bond with the child and spend time just playing with him. Play need not necessarily be constructive, it could be something he enjoys, like rolling around on the bed, jumping on a trampoline or swinging.
9. **Reach to other parents:** Reaching out to other parents is a good way to de-stress. Technology can enable us to stay in touch with people who are facing similar challenges and just venting out the day's frustrations can make things easier for both the parent and the child.

The pandemic has resulted in major upheavals among families across India, particularly those with children on the autism spectrum, struggling to cope in the absence of support services. Baweja et al. (2021) have highlighted pandemic-related impact on individuals with ASD in the United States arising from disruptions caused by educational changes, alterations in home and leisure routines and changes in access to mental and physical health services. Closer home, in the case vignettes discussed in this study, it is obvious that the disruption in schedules was associated with an increase in behavioural challenges and sleep problems. This emphasizes a need for protocols for emergency situations where a well-maintained routine for children on the autism spectrum can be ensured. It has also highlighted the burden that most families have to bear in the absence of adequate help and more importantly,

highlights the need for more respite centres equipped to handle individuals on the autism spectrum.

Confinement at home and disrupted schedules have also brought to fore the behavioural difficulties of some previously undiagnosed children, leading parents to seek a diagnosis. However, there could still be some children going undiagnosed as their social and communication difficulties go unnoticed due to their social isolation. With support from professionals and with the help of autism-friendly strategies, parents can be helped to cope better with the situation. These strategies not only help in lockdown situations but also during any other disasters or emergency situations. Hence, steps need to be taken for developing special protocols in the mental health services, to tide over such disruptions and for the ongoing skills development for individuals and development within systems to better respond to needs of the ASD population.

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