

Impact of Lockdown COVID-19 on Children with Special Needs and their Parents at Tertiary Care Hospital

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Introduction

Today each one of us, to be precise the entire world has become a victim of COVID-19. Because of this deadly virus, the entire world is in an uncertain situation. The whole world is under tremendous pressure and each country is finding new ways to fight with Coronavirus (CoV). To control this situation our country, India decided to go for the first Lockdown in May-17-2020, where only the emergency services were ON in the country, as a result, people had to be isolated at home. Later the lockdown was relaxed step by step in each state, but unfortunately, the number of COVID-19 cases was increasing and the lockdown period was extended. Thus lockdown has affected all aspects of human life. This has made a metamorphosis in the daily routine of individuals, including children with special needs and their families who had regular therapeutic support before the lockdown period. The office of the Registrar General Census Commissioner of India in 2011 reported the percentage of the special population; that includes, intellectual disability (10.3%), speech impairment (7.5%), and hearing impairment (5.8%) of the total population. Coping up with normal children during this lockdown period is a great challenge for parents, and an extra challenging effort for parents who have children with special needs, for instance, a child with Autism may often have difficulties with communication and may have a harder time understanding the rapidly changing situation or environment. Additionally, they may struggle with expressing their feelings and require strict adherence to daily routines, and develop maladaptive behaviors such as self-aggressions or acute anxiety when that is not possible [1,2]. The same may apply to children with other developmental disabilities such as children with cerebral palsy, intellectual disability, and/or communication disorders who are dependent on professional support. Therapeutic support and proper guidance need to be delivered time-sensitively and appropriately for such children's development. Before the pandemic, parents with special needs children had the support of caregivers, teachers, speech language pathologists, Clinical psychologists, and organizations, who served as a source of information and guidance for them. This was a lifeline for many parents and helped to facilitate learning and teaching [3,4]. National lockdown led to the loss of access to networks of support, leaving them vulnerable to isolation, also many of these children may not be able to understand the situation and may find it very difficult to adapt to the restrictions. This increased strain and stress on the parents due to this pandemic situation brought about thoughts and concerns about how their children will cope with their routines. There is a high possibility that this may impact these children's future development [5,6]. Therefore, there was a need to study the impact of the lockdown period on (i) children with special need's communication, social interaction, behaviour, and emotion; (ii) parents/caretakers' communication and interaction with their children, stress, emotion, and adaptation to the situation; finally, to find the alternative options to provide professional support to them and their families [7-9].

Methodology

A cross-sectional study with purposive sampling was conducted in SRM IST, Chennai; where 58 parents of children with special needs attending speech and language therapy in the Department participated in the study.

Development and validation of the survey questionnaire

For the study, a self-rating questionnaire was developed to administer to the parents of children who attended therapy regularly. The Questionnaire consisted of 21 questions that addressed the challenges faced by the children with special needs and their parents during the lockdown period.

The questionnaire consisted of two sections, which contained closed-ended questions. The first section was related to the impact of the pandemic on children with special needs, which consisted of 10 questions, in that Q. 1 to Q.4 - covered the changes in behavioural aspect of the child (aggressive behavior, stubbornness, screaming or defiance, irritable and restless, and uncooperativeness), Q.5 to Q.7 - Communication aspects (decrease in communicative interaction, deterioration in communication ability and changes in following instructions or commands), Q.8 to Q.10 - Psychosocial aspects (impact on carrying out their earlier routines independently, changes in his play behaviours and social interactions with family members). The second section, the impact of pandemic on parents were discussed which consisted of 11 questions to identify the impact of lockdown on parents of these children, in that Q.1 & 4 dealt about emotional aspect parent and family (losing temper often while managing the child increase in stress level, other family members difficulty in handling the child and bond between mother and child), Q.5 to Q.8 - Parent-Child Interaction (able to plan and provide opportunities to interact with his/her sibling or family members, able to teach the child learn something new, use appropriate and different strategies to make him/her feel comfortable and not able to provide specific time to maintain the behaviours taught in the therapy sessions), and Q.9 to Q.11 - Psychosocial aspect in daily routines (impact on daily routines due to change in child's behaviour not able to spend equal time with other sibling of the child and support from spouse or other family members to manage the child during difficult period).

The questionnaire was developed in English and Tamil and the content was validated by three speech language pathologists who had more than five years of experience. The questionnaire included a 5-point Likert rating scale, where the options included 0- 4, where '0'

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indicated 'No', 1- indicated 'Yes' 2- indicated 'mild severity', 3- indicated 'moderate severity', and 4- indicated 'severe severity'.

Participant recruitment and data collection

The participants involved in this study were 58 parents of children with Cerebral palsy (15.5%), ADHD (27.5), Intellectual disability (6.8%), and Autism (50%) who were attending speech therapy regularly at the tertiary care hospital unit. The parents of children who attended therapy regularly were participants. At the same time, parents of children who had medical or psychological problems were excluded from this study. Before the administration of the questionnaire, the aim of the study was explained in detail to the participants, and consent was obtained. The same was administered individually by the researcher to the parents using an interview method via a Smartphone.

SPSS Version 24 was used for data coding and analysis. Quantitative data were expressed in percentages using frequency and descriptive analysis.

Results

The current study aimed to explore the impact of lockdown on the behavioural aspect Communication aspects and Psychosocial aspects of children with special needs and also on their parents/caretaker's emotional aspect, parent-child/family interaction, and psychosocial aspects in daily routines. A total of 126 parents were contacted and only 58 parents consented to participate and responded to the questionnaire giving the study a response rate of 46%. The average age of the participants was years with 42 (41%) females and 48 (59%) males. More than 90% of the parents were from low socioeconomic groups.

The results have been presented under two sub headings 1. Parents perspective on their child's behavioural aspect, Communication aspects, and Psychosocial aspects, and 2. Parent's self-perspective concerning their emotional aspect, parent-child/family interaction, and psychosocial aspects in daily routines.

Parent's perspective of their children's behaviour:

Analysis indicates that all the three domains of child with special needs were affected during the lockdown. Figure 1 shows that only 1.8% parents reported that they did not observe and stubbornness or screaming behaviour during this period in their children.

Figure 2 depicts the perception of parents on the severity of the

impact on the various abilities of their child with special needs.

With reference to the behavioral aspects, 81% - 86.2% of parents reported that the behaviors like aggression, stubbornness, and irritability had increased while the ability to cooperate was moderately impacted (63.8%) in their children. According to the parents there was mild (39.7%) to severe (51.7%) impact on their basic communication interaction. Similarly, they reported that there was mild (94.8%) deterioration in their communication skills. While their children's ability to follow instructions and commands was affected severely (81%). Regarding the psychosocial aspects it was reported that the children's ability to carry out independently their basic routines was mildly affected (91.4%), while they observed moderate to severe impact on play (37.9% and 62.1% respectively) and socialization (98.3%) behaviors (Figure 2).

Parents self -perspective on the impact of lockdown on them

The majority of the parents faced drastic negative impacts on the behavioural patterns of their children which consequently affected their social ability. As the COVID-19 situation persists, precautions and guidelines suggest the isolation of individuals at home as a safety measure which in turn has affected the quality of life. Parents and caretakers with special needs children experienced difficulty adapting to the situation, which brought about stress and emotional variation in them. There was significant variation observed in the emotional, parentchild/family interaction, and psychosocial aspects in daily routines.

The below graphical representation Figure 3 represents the presence and absence of impact on parents. It can be observed that 1.7% reported that there was no increase in stress or anxiety during this period and 10.8% felt that the bond between them was same as earlier to lockdown.

The impact of severity analysis is presented in Figure 4. There was severe impact on their various emotional aspects like losing temper (88.6%), increase in stress/anxiety (89.4%), felt increased difficulty in handling the children's behavioral tantrums (82.4%).

With reference to parent-child interaction, 100% of the parents felt that they were not able to plan and provide opportunity to their children to interact with their sibling /other family members and also to not able to use different strategies or methods to make their child feel comfortable.

About 90% expressed that they were not able teach new skills to their

100 90 80 70 60 50 40 30 20 10 0 2 3 4 5 6 7 8 9 10 No 1.7 100 98.3 100 100 100 100 100 100 100 Ves No Yes

Figure 1: Percentage of types of responses obtained for the presence or absence of the lockdown impact on children with special needs.

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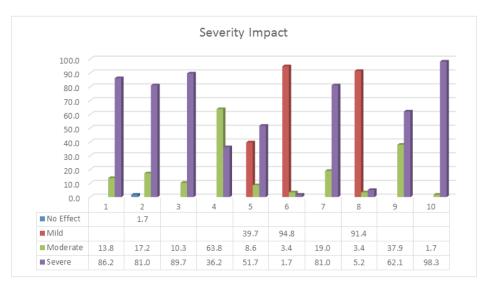


Figure 2: Indicating the severity effect on children's behavioral, Communication and Psychosocial aspects.

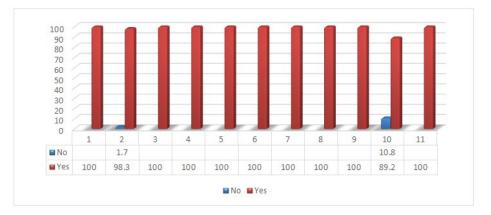


Figure 3: Percentage of types of responses obtained for the presence or absence of the lockdown impact.

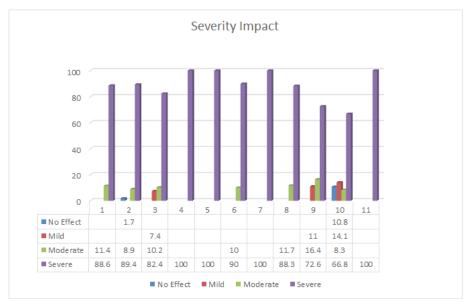


Figure 4: Indicating the severity effect of parent's emotional, parent-child/family interaction, and psychosocial aspects in daily routines.

children. Approximately 88.3% to provide specific time to maintain the skills developed in the therapy session prior to the lockdown.

Analysis of psychosocial aspects of daily routines showed that their daily routine was affected moderate to severely (16.4% and 72.6% respectively) due to changes in child's behavior during this lockdown period. Approximately 66.8% felt that they were not able to spend equal time with their other children as attending to special need child's needs took away maximum of their time. It was striking to observe that 100% of them said that they got little support from their spouse or other family members.

Discussion

The present study addresses the impact of lockdown due to COVID-19 on special needs Children's communication, social interaction, and behaviours and also identifies the factors impacting their parents. It is a major concern since parental stress is a most important part of both parent and child behaviour and dyadic interaction (Crnic et al.2005) and it also has an impact on interaction (Strauss et al.2012). The findings of this study indicate that the Child's behavioural aspects referring to aggressiveness, stubbornness, and irritability were severely affected and the uncooperativeness, child's speech and communication aspects referring to communication interaction, following of commands and communication skills, and also socialization refers to the daily routine, socializing abilities and play behaviours were severely affected as reported by the parents.

Neece et al. (2012), stated that families have been valuing more time together. This may have helped to enhance positive parental-child relationships and interaction. On evaluating parents' results outcome suggests that social aspects referring to daily routine activities and opportunities to interact with other family members and siblings were severely affected, and the parent-child interaction aspect referring to factors such as helping the child to learn new activities and maintaining an already learned skill in therapy sessions before the lockdown was reported to be severely affected by parents, similarly the use of the different methods to teach their children was reported to be severely affected. In psychological aspects, parents reported having a severe effect in referring to factors such as stress and anxiety faced by them, difficulty in controlling the temper tantrum of their child, and themselves finding difficulty in managing their temper. Finally, the emotional aspects referring to factors such as spending equal time with their other children are severely affected, as well as the bond between them and their special child along with receiving support and help from family members was reported to have a severe effect. Therefore, this impact on children may make it difficult for the therapist to show a significant improvement in their therapy treatment post-COVID- 19 lockdown release, as the children were completely under break for more than a year due to the lockdown. It is also important to note that an extended period of the outbreak was not associated with a change in depression score among the general population (Wang, Pan, et al., 2020; Wang, Hu et al., 2020). Parents of children with special needs face unique challenges in family, and social life and are tarnished in society because of their children's disability and also Behavioural issues are very common in this population (Martin et al., 2019; Vadivelan et al., 2020). This was supported by the findings that the strain and stress levels were higher in parents.

Conclusion

Although the rate of COVID-19 infection risk among children is low, the stress faced by children with special needs poses their condition

as highly vulnerable. Many studies have been conducted to analyze the impact of COVID-19 and lockdown on children Therefore the present study concludes that the impact will be more on children with special needs as well as their parent's and caretakers' mental health. There is a need to enhance children with special needs services by using both faces to face, as well as digital platforms. For this initiation collaborative network of parents, speech language pathologists, psychiatrists, psychologists, paediatricians, social workers, and NGOs is required. There is a need for 'tele-mental health comradeship' that can be accessible to the public at a large scale. It should also be economically affordable to avoid further effects on children with special needs and their parent's mental health.

Limitations

The present study includes a few limitations. This study was completely based on subjective responses and data was obtained through the telephonic interview, whereas face-to-face interviews could provide more appropriate results. A relationship between COVID-19 and the psychological outcome is difficult to record because of the cross-sectional nature of the study and also due to COVID-19 for some participants in itself may have contributed to levels of mental health symptoms, and this was not controlled. The study has not categorized the severity of the child's disability separately; rather it investigated all types of severity. This study also includes smaller sample size and to understand more about the impact of COVID-19 on special needs children along with their parent's stress and behavioural impact, a similar study can be done with a larger population. These aspects should be focused on in future studies.

Ethical considerations

The research behind this manuscript did involve human subjects (online survey design) and all procedures were approved by the SRM Institute of Science and Technology. Appropriate consent language was included in communicating with subjects and no requirement of documentation of informed consent was assumed since the study was considered "no more than minimal risk" to participants. Respondents were provided with a description of the study and were assured of the confidentiality of their information and informed any support required would be provided through teletherapy wherever possible.

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Authors contribution

All authors conceived of the study, participated in its design and coordination, performed the statistical analysis, collection, and interpretation of the data, and drafted the manuscript. All authors read and approved the final manuscript.

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Conflict of Interest:

The authors declare that they have no conflict of interest.

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