International Journal of Intellectual Disability

E-ISSN: 2710-3897 P-ISSN: 2710-3889 IJID 2024; 5(1): 06-11 © 2024 IJSA www.rehabilitationjournals.com/ intellectual-disability-Journal Received: 03-11-2023 Accepted: 10-12-2023

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Impact of lockdown COVID-19 on children with special needs and their parents at Tertiary Care Hospital

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Abstract

Introduction: The COVID-19 lockdown has brought about a sense of fear and anxiety around the world. This led to short-term as well as long-term psychosocial and mental health issues for children and their parents. The present study reports the challenges experienced by parents and children with special needs during COVID-19 pandemic in India.

Aim: To identify the impact of lockdown due to COVID-19 on special needs Children's communication, social interaction, and behaviors and also to identify the factors impacting their parents.

Methods and Materials: A cross-sectional study was conducted in SRM IST, Chennai. A questionnaire was developed and administered among 58 parents attending speech therapy. All statistical analysis was completed using (SPSS) version 24.

Results: The current study indicates that the impact of COVID-19 has brought about a major effect on children's behavioral (80.1%), communication (75.8%), and social (83.9%) abilities. The findings also indicate that the child's interaction skills were affected severely. Similarly, the effect on parents' social aspects (89%), Parent-Child Interaction (94.1), Psychological impacts (100%), and emotional aspects (96.4) are increased stress levels during the lockdown period.

Conclusion: The present study states that the impact of lockdown due to COVID-19 will be more on children with special needs as well as their parent's and caretakers' mental health, therefore there is a need to provide service for children with special needs in both face-to-face, as well as digital platforms.

Keywords: COVID-19, mental- health, communication, behavioural, lockdown

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 May17-2020, 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. 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, and organizations, who served as a source of information for them. This was a lifeline for many parents and helped to facilitate learning and teaching. National lockdowns lead 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 have an impact on these children's future development. Therefore there was a need to study the impact of the lockdown period on (i) children with special need, their communication, interaction. behavior. and emotion: social (ii) parents/caretakers' communication and interaction with their children, stress, emotion, and adaptation to the situation; finally to find the need of professional support.

Methodology

A cross-sectional study was conducted in SRM IST, Chennai; where 58 participants were involved in the study. 1.1 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 sub-sections, which contained closed-ended questions. The first sub-section was related to a child's behavioral changes during the lockdown period and consisted of 10 questions, which covered speech and communication aspects (Q. 1 to Q.4) covers about Behaviour, Emotional and Psychological Aspects, (Q.5 to Q.7) covers about Communication Aspects, and were (Q.8 to Q.10) covers about Social Interaction Aspects. The second subsection was related to the impact on parents during this period parents and had 11 questions covering the social aspect (Q.11 & 12) Parent-Child Interaction (Q.13 to Q.15) Psychosocial aspect (Q.16 to Q.18) and Emotional aspect (Q.19 to Q.21). The questionnaire was developed in English and validated by a speech-language pathologist who had more than five years of experience. The response of the parents was documented and scored according to the 5-point Likert rating scale, where the options included 0- indicating 'No', 1- indicating 'Yes', 2- indicating 'mild severity', 3indicating 'moderate severity', and 4- indicating 'severe severity'.

Participant Recruitment and Survey Dissemination

The participants involved in this study were 58 parents of children with Cerebral palsy, ADHD, Intellectual disability, and Autism who were attending speech therapy regularly at the tertiary care hospital unit. The participants were parents of children who attended therapy regularly. 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.

Respondents' data were analyzed and summarized by using the Chi-Square test, mean (standard deviation) for numeric data, and frequency (percent) using (SPSS) version 24.

Results

All 58 participants gave their consent of voluntary participation and completed the questionnaire through the interview method via telephonic survey mode in a tertiary hospital. All 21 closed-ended questions in the questionnaire were responded to by the participants during the survey, which was further analyzed.

Child-Related

The impact of the lockdown due to COVID-19 on children with special needs has majorly affected their communication, social interaction, behavior, and emotional abilities in their daily routines. On evaluating using the developed questionnaire among the children who attended speech therapy regularly at SRM IST, the results obtained indicated that the majority of the parents faced drastic negative impact on the behavioral patterns of their children which consequently affected their social ability.

The below tabular column (Table-1) indicates the presence and absence of effect impacting the child indicated by yes (with a score of 1) or no (with a score of 0) respectively, followed by the graphical representation of the results as reported by the parent (Figure-1). The severity score of the effect impacting the child reported by the parents, indicating yes with a score of 1 is provided with the graphical representation in figure 2.

 Table 1: Child-related questions indicating behavior, psychological, emotional, social interaction, and speech and communication aspects (all the descriptions need to be modified)

Child	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
	Percent (%)									
0		1.7								
1	100	98.3	100	100	100	100	100	100	100	100

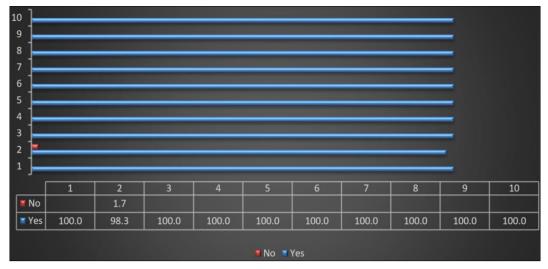


Fig 1: Indicating the effect of Children's Behavioral, Emotional, Psychological, Speech, Communication Aspects, and social interaction.

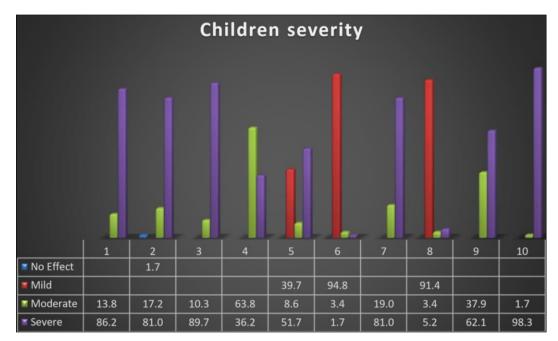


Fig 2: Indicating the severity effect of Children's Behavioral, Emotional, Psychological, Speech, Communication Aspects, and social interaction.

The questions mainly involved concerns related to the Child's behavior, emotional, psychological, speech, and communication aspects. The first, second, third, and fourth questions include the aggressive behavioral pattern (86.2%), behavioral variation (81.0%), behavioral impact (89.7%), and ability to cooperate (63.8%) respectively during the lockdown period were evaluated, where the majority of the participants found their children were severely affected and fewer were moderately affected.

The fifth, sixth, and seventh question includes the change in communicative interaction (51.7%) reported severely affected, in deterioration in communication skills (94.8%) reported mildly affected, and in the ability of the child to follow the commands and instruction (81%) reported severely affected, respectively.

The eighth, ninth, and tenth question includes the changes in play behavior (91.4%) reported mild impact, in the ability to perform daily activities (62.1%), and in the changes in social interaction in the home setting (98.3%) reported severely affected, respectively.

2.2 Parent-Related Questions

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 behavior, psychological, emotional, social interaction, and speech and communication aspects when administered using the developed questionnaire among 58 participants with the age group of 21-60 years including both males and females.

The below tabular column (Table 2) represents the presence and absence of impact on parents indicated by yes (with a score of 1) and no (with a score of 0) respectively, followed by the graphical representation of the results reported by the parents (Figure-3). The effect of severity on the parents or caregivers of children with special needs who indicated yes (with a score of 1) is provided with a graphical representation in Figure 4.

Table 2: Parent-related questions indicating behavior, psychological, emotional, social interaction, and speech and communication aspects.

Parent	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11
	Percent (%)	Percent									
		(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
0		1.7								10.8	
1	100	98.3	100	100	100	100	100	100	100	89.2	100

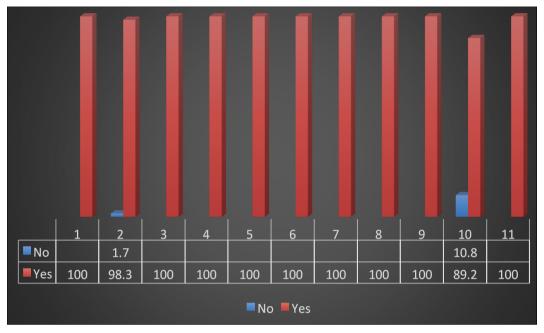


Fig 3: Indicating the effect of parent's Behavioral, Emotional, Psychological, Speech, and Communication Aspects.

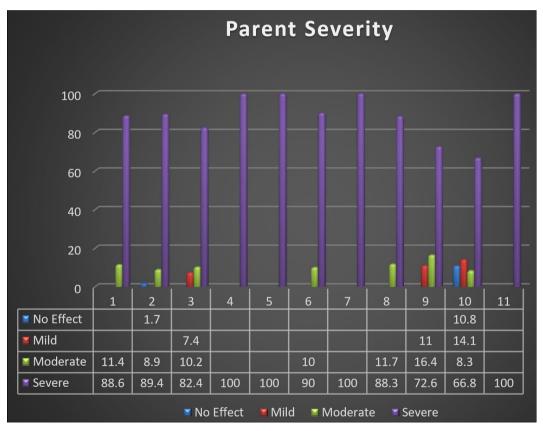


Fig 4: Indicating the severity effect of parent's Behavioral, Emotional, Psychological, Speech, and Communication Aspects.

The values of parent-related questions and their graphical representation depict the results for the second sub-section of the questionnaire i.e. 11 parent-related questions which were evaluated among 58 participants. The questions mainly

involved concerns related to Parental stress, Parent-child interaction, and Emotional aspects.

The first and second questions are regarding the social aspects, i.e. first question relates to, the balance between the

daily chores and their Child's behavior (88.6%) reported that they are severely affected, and where the second question relates to providing equal opportunity (89.4%) reported that it is severely affected and (1.7%) reported that there is no effect.

The third, fourth, and fifth questions are regarding the parent-child interaction, i.e. third question relates to teaching new skills (82.4%) reported that they were severely affected, the fourth question relates to prioritizing the time to teach their child (100%) reported that they are severely affected and the fifth question relates to usage of varied teaching method and how they comforted their child with special needs (100%) reported that they are severely affected.

The sixth, seventh, and eighth questions regarding the psychological impact on parents, i.e. the sixth question relates to an increase in their anxiety level due to their Child's behavior (90%) reported they're severely affected and (10%) reported they are moderately affected, the seventh question relates to the response of other family members to the Child's behavioral management (100%) reported that they're severely affected and the eighth question relates to parents temper management (88.3%) reported that they're severely affected and (11.7%) reported they are moderately affected, was most of the parents reported to have a severe impact on their mental health.

The ninth, tenth, and eleventh questions regarding the emotional aspect, i.e. the ninth question relates to time spent with their special child and their siblings (72.6%) reported severely affected, the tenth question relates to prioritizing the time to teach their child (66.8%) reported severely affected, (8.3%) reported moderately affected, (14.1%) reported mildly affected and (10.8%) reported no effect in this and the eleventh question relates to support of family members in managing the daily routines and their special child (100%) reported they were severely affected.

Discussion

The present study addresses the impact of lockdown due to COVID-19 on special needs

Children's communication, social interaction, and behaviors 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 behavior and dyadic interaction and it also has an impact on interaction. The findings of this study indicate that the Child's behavioral 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 behaviors 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 in 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. 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. 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 carers' takers' 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, 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-toface 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 a smaller sample size and to understand more about the impact of COVID-19 on special needs children along with their parent's stress and behavioral 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.

Acknowledgment

We want to acknowledge Dr. D. Balakrishnan, BSc MBBS MS DLO Ph.D., ENT Surgeon & HOD Audiology and Speech-Language Pathology, SRM Medical College, SRM Institute of Science and Technology, Dr. A. Sundaram Dean (Medical), SRM Medical College, SRM Institute of Science and Technology and Mr. Arunachalam, MPH.

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.

Funding

No grants or other financial support was obtained for this study.

Conflict of Interest

The authors declare that they have no conflict of interest.

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