

Survey

Autism spectrum disorder and lockdown – a parental survey on communication and related aspects

Ms. Shruti Raja Venkat¹, Ms. Elakiya Elango², Ms. Maria J^{3*}

ABSTRACT

According to the National Institutes of Health, Autism Spectrum Disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Rehabilitation of a child diagnosed with Autism Spectrum Disorder requires the coordinated effort of a Multi - Disciplinary team. COVID- 19, the global pandemic that has caused a lock down which has affected the daily living and halted the provision and access to various Rehabilitation services. This study targets to tap on the communicational difficulty faced by children with Autism Spectrum Disorder and the awareness of tele practice among the parents of children with ASD. The study included 15 parents of children who were diagnosed with ASD and the results revealed that Lock down has hampered the child's communication and learning. Tele practice could be considered as a good alternative during this pandemic situation to support the child's communication.

Keywords: *Autism Spectrum Disorder, Pandemic, Tele therapy*

According to Ousley (2014) Autism spectrum disorder (ASD) is a behaviorally defined neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors. In the latest conceptualization of ASD, these two behavioral dimensions represent the core defining features of ASD, whereas associated dimensions, such as intellectual and language ability, provide a means for describing the ASD heterogeneity [1]. According to a study done by Laura Pérez-Crespo (2019) on the Temporal and Geographical Variability of Prevalence and Incidence of Autism Spectrum Disorder Diagnoses in Children in Catalonia, Spain, revealed that ASD prevalence of 1.23% in 2017, with 1.95% for boys and 0.46% (for girls, the highest prevalence being in 11- to 17-year-olds. The ASD diagnosis incidence increased from 0.07% in 2009 to 0.23% in 2017, with a higher increase in girls, and in children aged 2–5 years at the time of diagnosis [2]. According to a study done by Sunil Kumar Raina (2017) in India to identify the Prevalence of Autism Spectrum Disorder among Rural, Urban, and Tribal Children (1–10 Years of Age) and the results revealed that the prevalence

¹BASLP Students, Madras ENT Research Foundation-Institute of Speech and Hearing (P) Ltd-Chennai, India.

²BASLP Students, Madras ENT Research Foundation-Institute of Speech and Hearing (P) Ltd-Chennai, India.

³Assistant Professor, Madras ENT Research Foundation-Institute of Speech and Hearing (P) Ltd-Chennai, India.

*Responding Author

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Autism spectrum disorder and lockdown – a parental survey on communication and related aspects

rate was 0.15% in general and male sex and upper socioeconomic group of head of family/father had a higher risk of getting diagnosed as autism as compared to lower socioeconomic group[3]. The systematic review on the Prevalence of ASD in South Asia revealed the prevalence of 0.09% in India to 1.07% in Sri Lanka that indicates up to one in 93 children have ASD in this region. Alarming high prevalence (3%) was reported in Dhaka city [4]. Parents of children with Autism Spectrum Disorder experience unique challenges in terms of understanding the disorder, child's needs and managing the behaviors that is exhibited as well as increased parental stress. Thus, children with ASD require a constant rehabilitation support to assist the various needs of the child ranging from the sensory to the behavioral and communicational deficits that is persisting [5]. COVID-19 is the infectious disease caused by the most recently discovered coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China, in December 2019. COVID-19 is now a pandemic affecting many countries globally [6]. This has hampered the overall living and the various services that are provided. Tele practice is defined as “the application of telecommunications technology to deliver professional services at a distance by linking clinician to client, or clinician to clinician for assessment, intervention, and/or consultation” (American Speech-Language-Hearing Association [ASHA], 2005, p. 1). This will combine the use of modern technology and the traditional knowledge that is available to diagnose or treat a condition [7]. The current study focused on documenting the communicational challenges faced by the children with Autism Spectrum Disorder and how tele practice could act as a forum to improve the nature of the services rendered.

Aim:

1. To document the communicational challenges faced by the children with Autism Spectrum Disorder.
2. To tap on the awareness of tele practice and its effectiveness during the pandemic condition.

METHODOLOGY

Instrument

A self-rating questionnaire was prepared by reviewing the literature. The questionnaire was designed constituting three sections, in which section 1 covered the communication difficulties child presented, nature of the rehabilitation services the child attended and the progress that was encountered pre-lockdown. The second section of the questionnaire included questions related to the difficulties that was experienced during the lock down in terms of learning, adapting to new habits/ routines, teaching strategies adapted to make the child learn. This section also covered the parent's opinion about the tele therapy and the suggestions that they would like to provide to improve the quality of the services rendered. The expectations that parents have on attending online sessions post the lock down and the child's attitude towards attending face-to-face sessions after a long break were covered in the third section.

Participants

The questionnaire was subjected to content validation by four experienced Speech-Language Pathologists. The google forms were prepared and circulated to the parents of children who are diagnosed with Autism Spectrum Disorder. The data was collected by using both telephonic conversation and from the circulated google forms.

RESULTS AND DISCUSSION

15 Parents of Children with Autism Spectrum Disorder were included in the study. The children between the age range 4-10 years were included. Most of the children who were included in the study received the Rehabilitation services such as Speech Therapy, Behavioral Therapy and Occupational Therapy as a part of the special school they attended. The duration of which the children attended the rehabilitation services depended on the age at which the child was diagnosed with Autism Spectrum Disorder.

Pre – Lockdown

The results revealed that 80% (n=12) of the children spent the time with the mother before lockdown and remaining 20% (n=3) of children spent time with their grandparents. 33% (n=4) of children with ASD reported that both parents were working. 93% (n=14) of children with ASD were attending day care or special school before lockdown. 80% (n=12) of children spent less than 8 hours in the school but 20 % (n=3) of children spend more than 8 hours in school before the lockdown. Parents of 73% (n=11) of children reported that their children exhibited difficulty in socialization and 93% (n=14) of the parents also reported that their children benefitted from the speech therapy. The effectiveness of the Rehabilitation services attended could be observed in terms of increased sitting tolerance, improved attention and ability to sustain and maintain eye contact and the emergence of speech behaviors. The parents also reported the reduction of Temper tantrums and self-injurious behaviors that was very significant at the initial phases.

During Lockdown

46% (n=7) of parents reported that lockdown affect their child's learning and 26% (n=4) reported that their children did not exhibit a well-established verbal/Non-Verbal behavior during the lockdown. All the children (n=15) spent most of the time with the Mother during the lockdown. 73% (n=11) of the parents reported that they work from home during the pandemic but 20% (n=3) of parents reported that it was difficult to manage both their work and children.

Parents reported that 66% (n=10) of child increased the dependency of electronic gadgets such as TV, mobile and 20% (n=3) of children developed aversion to certain objects. 80% (n=12) of parents felt the child's daily routine was affected during the lockdown and 46% (n=7) of the parents reported that their children had difficulty to adapt new behaviors such as wearing mask, frequent hand wash, social distancing. The parents incorporated strategies such as using modelling, teaching, explaining and imitating to make child to understand and adapt to the novel essential habits. 46% (n=7) of parents had slight difficulty to control their child's behavior, 46% (n=7) of them could control their child's behavior with difficulty and 6% (n=1) reported of increased difficulty to control the child's behavior. 13% (n=2) of parents reported that the child's performance was better during the lockdown, 26% (n=4) reported that it had worsened during the lockdown and 46% (n=9) of parents reported of no significant difference in the performance that was seen in the child. All the parents (n=15) reported that they trained their children for better communication during lockdown. 66% (n=10) of parents reported that they practice incidental teaching and 33% (n=5) trained their children for one hour a day. 33% (n=5) of parents reported that they have sufficient training material at home to carry out the home training activities.

80% (n=12) of parents felt the importance and the necessity of Speech and Language Therapy that has to be provided and presumed during lockdown but only 13%(n=2) of

Autism spectrum disorder and lockdown – a parental survey on communication and related aspects

parents attempted to contact a Speech Language Pathologist. 86% (n=13) of parents reported that they incorporate language stimulation goals along with the daily routine to teach their children and 6% (n=1) used training materials provided by the therapist and 6% (n=1) used online resources like YouTube and online games to train their children.

80% (n=12) of the parents were aware about tele therapy but 20% (n=3) of children only attended teletherapy service. The children who were enrolled in teletherapy services attended 2 sessions per week on an average for 20-30 minutes each. Among the children who were attending Tele-therapy services (n=3) only 66% (n=2) of the children were able to concentrate throughout the complete session and looked forward to attend the sessions regularly. Parents also reported that teletherapy was effective and they were satisfied with teletherapy services that was rendered. 33% (n=5) of parents reported that they are willing to enroll their children to attend Tele-therapy. 80% (n=8) of parents preferred home-training plan and 20% (n=2) expected a weekly monitoring from the speech language pathologist.

Post – Lockdown

20% (n=3) of parents reported that they will prefer online sessions post-lockdown and still 80% (n=12) of parents would still prefer face to face sessions for their children. 73% (n=11) of the parents reported that their children will have difficulty in socializing with others post lockdown. 86% (n=13) of parents believe that their children would develop reluctance to attend routine therapy sessions post lockdown. 86% (n=13) of the parents also reported that lockdown has hampered the overall Quality of life of child with ASD.

CONCLUSION

Autism Spectrum Disorder is a Neurodevelopmental condition that affects the social interaction, communication with peers and is significantly characterized by the presence of stereotypic behaviors. Children diagnosed with ASD exhibit sensory and motoric difficulties which needs support from various Rehabilitation Professionals to improve the persisting difficulties and to bring about a holistic change in the child. It is equally important to attend the services regularly till the child attains self-sustenance. COVID-19 is a globally spread pandemic that has hampered the lives as well as the services that is vital due to the lockdown that it has imposed. This lockdown has brought up a halt to the traditional mode of service delivery which has also had a huge and noticeable impact on the children diagnosed with Autism Spectrum Disorder. This study has documented the difficulties that is faced by the parents of children with Autism Spectrum Disorder and it is very evident that the standstill of the rehabilitation services has not only affected the child's established verbal/Non-verbal behavior but has also added to one among the major cause of stress to these parents in addition to the lockdown. Parents of these children should use established home training programs or contact their therapist regularly when they are not aware about what has to be done when the Rehabilitation services are abruptly halted. Professionals of the various rehabilitation team and the parents has to practice and accept the New-normal ways like the use of Tele mode of services for consultation and providing therapeutic services. Though, India still needs improvisation and technological advancement in using Tele-mode as a service delivery forum to provide various services to different parts of the country uniformly, pandemic situations like COVID 19 could be considered as an experimental phase to try and practice such techniques for the betterment.

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Conflict of Interest

The author declared no conflict of interest.

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