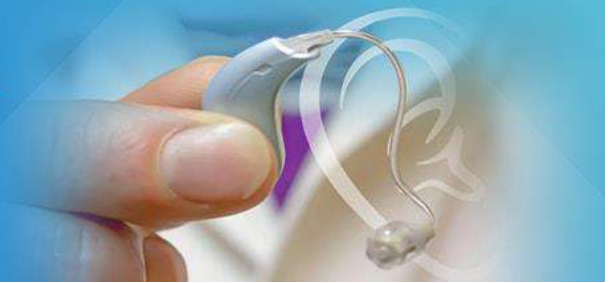


International Journal of Speech and Audiology



E-ISSN: 2710-3854
P-ISSN: 2710-3846
IJSA 2023; 4(1): 29-34
© 2023 IJSA
www.rehabilitationjournals.com
Received: 12-12-2022
Accepted: 28-01-2023

Balambigai N
M.ASLP, Assistant Professor,
Department of Speech Hearing
and Communication, National
Institute for Empowerment of
Persons with Multiple
Disabilities (NIEPMD),
Chennai, Tamil Nadu, India

Suruthilaya
Intern, B.ASLP,
Department of Speech Hearing
and Communication, National
Institute for Empowerment of
Persons with Multiple
Disabilities (NIEPMD),
Chennai, Tamil Nadu, India

Dr. Priya Kanagamuthu
M.B.B.S, M.S, Professor,
Department of ENT,
Chettinad Hospital and
Research Institute,
Kelambakkam, Tamil Nadu,
India

Correspondence
Dr. Priya Kanagamuthu
M.B.B.S, M.S, Professor,
Department of ENT,
Chettinad Hospital and
Research Institute,
Kelambakkam, Tamil Nadu,
India

The impact of the pandemic on children with autism spectrum disorder and their families

Balambigai N, Suruthilaya and Dr. Priya Kanagamuthu

Abstract

Introduction: The objective of the study was to understand the effects of pandemic on children with Autism spectrum disorder (ASD) and their families in India, the effectiveness of teletherapy, the parental stress levels and the sources of stress.

Methodology: A structured interview was conducted with 53 parents of children with ASD. The children were aged between 3.5-12 years. The responses were analyzed qualitatively and quantitatively.

Results: Parents reported a significant increase in problem behaviour, decline in social and emotional skills, but improvements in language skills. More than half the participants were attending teletherapy, and reported it to be beneficial, but one-third of the participants reported limited benefit due to difficulties in sustaining the child's attention. The majority of the parents reported high levels of stress, with the major sources of stress being children's behavioral problems, closure of schools and disruptions in therapeutic services.

Conclusion: Addressing the parental stress and making appropriate adaptations to teletherapy through a multi-disciplinary team is essential.

Keywords: COVID-19, autism spectrum disorder, parental stress, teletherapy, efficacy

1. Introduction

The outbreak of the novel COVID-19 has affected millions of people worldwide. With the onset of the pandemic and the lockdown restrictions, one of the most affected groups is the individuals with Autism Spectrum Disorder (ASD). ASD is a neuro-developmental disorder in which the individual exhibits restricted repetitive patterns of behavior and interest and deficits in social communication [1].

The pandemic has impacted the individuals with ASD in several ways. Firstly, due to school closures and lockdown restrictions, children have been isolated and restricted at home, resulting in insufficient social interaction [2]. Secondly, rehabilitation services and educational services aid children overcome their behavioural challenges and manage the symptoms of ASD. Unfortunately, the restrictions posed by the pandemic has impacted the access to in-person therapeutic services. Thirdly, Children with ASD demand a consistent environment and daily routine [3]. The pandemic on the other hand has brought significant and abrupt change in their daily routines, including lack of outdoor physical activities. As a result, children with ASD have been placed at a significant disadvantage and may be especially vulnerable during the lockdown period [2, 4, 5].

Earlier studies have also reported increased problem behaviors [4, 6-8] among children with ASD during the pandemic. In order to overcome the restrictions posed by the pandemic, the rehabilitation professionals have moved to providing therapeutic services using telecommunications, but their efficacy has been reported to be mixed in low resource countries [9].

Though a handful of studies have been conducted on the effect of Pandemic among children with ASD, to our knowledge none have particularly been conducted in India. With the high prevalence of ASD in India [10], it is important to understand the effect of pandemic among these vulnerable individuals. Also, due to school closures, several families have relocated away from cities, where in-person therapeutic services are scarce. As a result, even when lockdown restrictions were relaxed, these children did not have access to in-person services or hybrid services. Furthermore, telepractice is still in its infancy in India. Poor network connectivity in rural areas, unavailability of smart phones among parents, and limited knowledge of use of gadgets make telepractice difficult.

Taking all of these factors into account, it is critical to understand the effects of the pandemic and the effectiveness of telepractice for individuals with ASD in developing countries like India. This, in turn, will assist rehabilitation professionals in identifying gaps and making adaptations and modifications to improve the effectiveness of interventions and supporting children and families with ASD during the difficult times.

In addition, parents of children with ASD are on average more stressed than parents of typically developing children [11]. Support from friends has shown to help parents cope with stress and anxiety [12]. Pandemic, on the other hand, has disrupted parent interactions and support groups, resulting in greater stress among parents. Hence it is important to identify stress among parents and address them promptly as this in turn may affect the child with ASD and exacerbate their behavioral difficulties [8]. The aim of this study was threefold,

1. The impact of pandemic and the restrictions imposed in various domains among children with ASD in India.
2. The Therapeutic services offered and the effectiveness of teletherapy.
3. Parental stress levels and the sources of stress during the pandemic.

2. Methodology

Ethical clearance was obtained from the Institutional ethical committee (Reference No: IHEC-II/0183/22). To serve the purpose of the study, a viable and effective method of study was chosen to be a structured interview. A questionnaire was developed, with a focus group of Psychologist, Speech language pathologist, Special educator, Occupational therapist, and two parents of children with ASD. The questions were focused on the following domains: demographic details, impact of the pandemic, the challenges faced and changes experienced by children with ASD; therapeutic services, their effectiveness and challenges; and the parental stress during the pandemic. There were a total of 18 questions. The questionnaire was in a hybrid format, consisting of open-ended, closed-ended, and likert-scale

questions.

One hundred and ten participants with the clinical diagnosis of ASD from Chennai, India were contacted by telephone in January 2022, during the third wave in India. All the participants had a diagnosis of ASD based on the Indian scale for assessment of Autism (ISAA) from a clinical Psychologist with over 5 years of experience in ASD. There were no further sensory impairments in any of the children. A total of 53 parents of children with ASD volunteered to take part in the study, with a 48.18% participation rate. There were a total of 45 males and 8 females. Parents completed the informed consent forms through Google forms. Their participation was voluntary and information collected was kept confidential. The participants were interviewed over the telephone. And the interview took approximately 20 minutes to complete. The responses were recorded and analyzed both qualitatively and quantitatively. For quantitative analysis descriptive statistics was used.

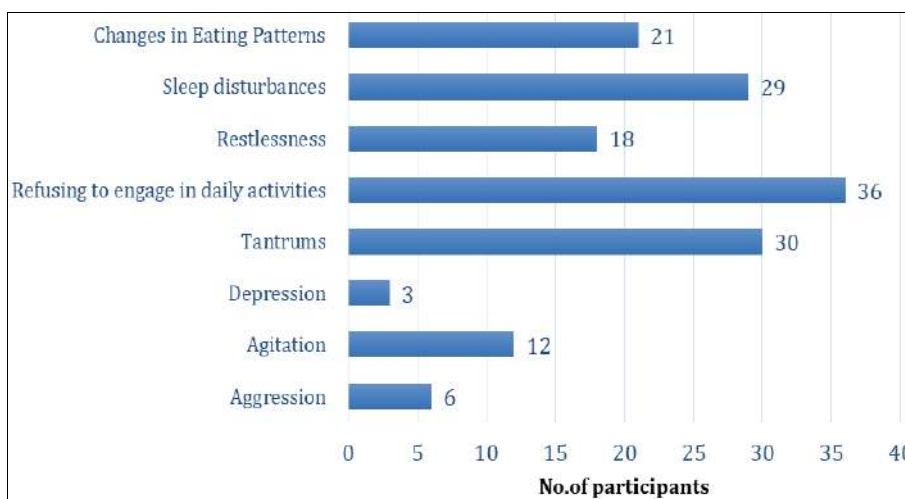
3. Results

3.1 Demographics

The children's ages ranged from 3.5 to 12 years, with an average age of 7.5 years. All the children were from Tamil Nadu, India, with Tamil as their home language. Most parents belonged to the middle and lower middle socio-economic class. Among the children, 52% were at single word level, 15% were at two-word level, 20% were at sentence level, and the others had no true words.

3.2 Effect of pandemic on children with ASD and their families

With regard to the effect of the pandemic, 49% of the parents reported very significant changes, 11% reported extreme changes, and close to one third of the parents (30%) reported a significant change in behavior, and the rest reported minimal to no changes. More than half the parents reported behavioral changes such as exhibiting tantrums, and refusing to engage in daily activities, followed by sleep disturbances, changes in eating patterns, restlessness, agitation, aggression, and depression (Graph:1).



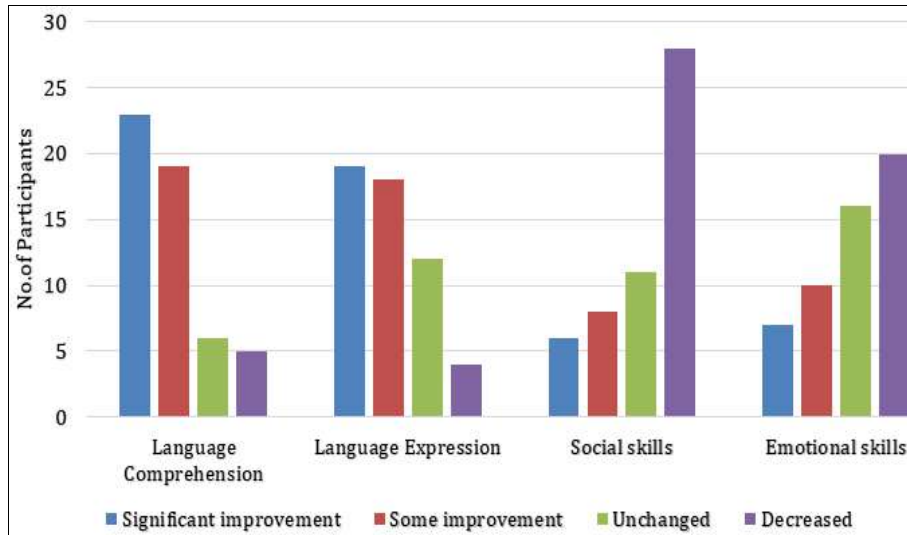
Graph 1: Behavioral changes during the pandemic

The majority of the parents reported significant improvements in language skills, but also a decrease in social and emotional skills (Graph:2). Understanding commands, and increase in vocabulary are some of the notable areas of improvements in children as reported by

parents. Some of the major challenges for the child as per parental reports were, lack of knowledge about the pandemic, lack of opportunities to socialize, suspension of therapeutic services, lack of outdoor activities, and changes in routine. Some of the major challenges reported by the

parent due to the lockdown restrictions were supporting therapeutic services for the child at home, having the child

stay indoors, engaging the child throughout the day, and lack of time to care for the child.

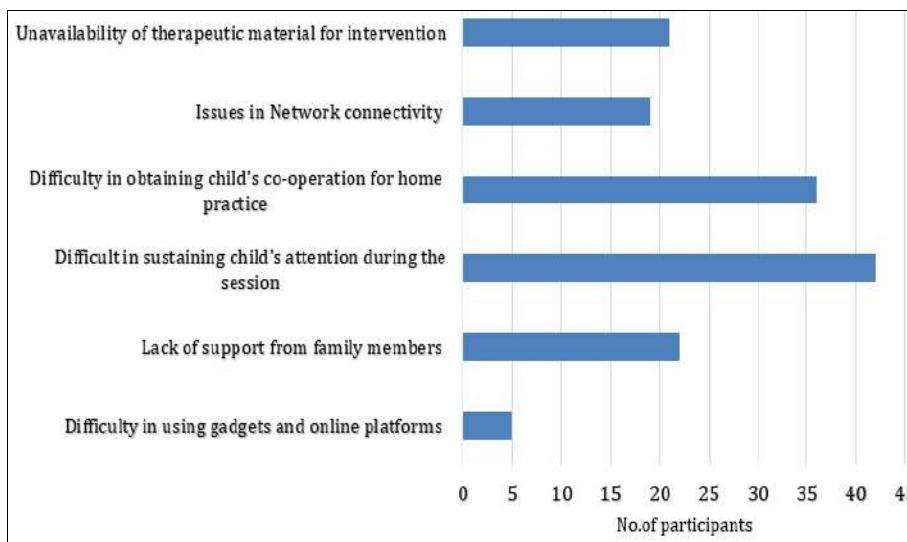


Graph 2: Impact of pandemic on children with ASD in various Domains

3.3 Therapeutic services

Among the parents interviewed, more than half of the children (61%) were receiving tele therapies provided by rehabilitation professionals, 15% of the parents reported to receive Parent-Mediated tele-intervention, and a small proportion reported to avail therapy face-to face (11%) and the rest reported of self -training the child at home. Among those who were receiving therapeutic services, more than half the parents (68%) reported telepractice to be highly beneficial, while 22% reported limited benefit and the rest reported no benefit from tele practice.

Among the benefits of telepractice, parents reported improvements in children’s communication skills, and increase in parental knowledge regarding therapies. Among the barriers to teletherapy, a large number of parents reported significant difficulties in getting the child’s attention/cooperation, both during the session, and after the session for home practice. Others also reported lack of support from family members and difficulty in using online platforms and gadgets. Most parents wanted the center to open up, and also allow provision for one-to-one therapy sessions and home-based interventions.

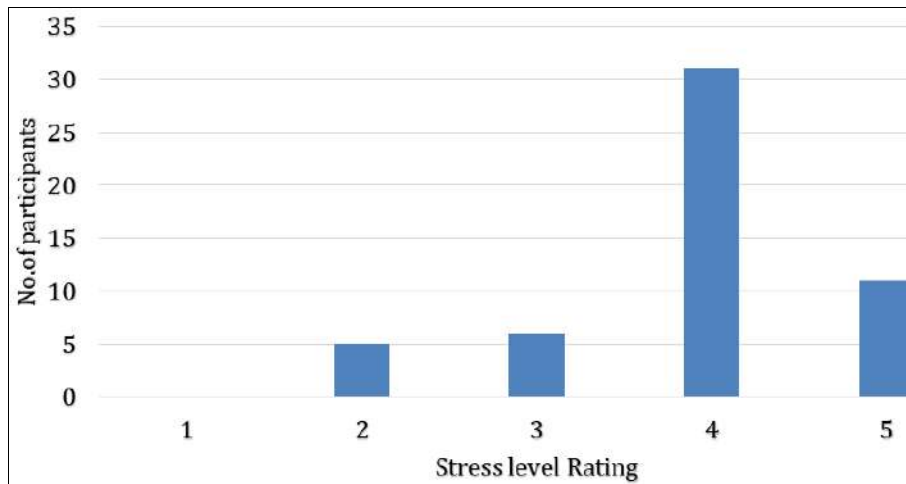


Graph 3: Barriers to Teletherapy

3.4 Stress among parents

Almost all of the parents reported high stress levels during the course of the pandemic. Parents were asked to rate their

stress levels on a scale of 0-5, 0 being not stressed at all and 5 being extremely stressed, and the results are represented in Graph 4.



Graph 4: Parental rating of Stress level during the pandemic

Some of the major sources of stress for parents were managing the child at home, and suspension of therapeutic services, followed by financial concerns, closure of schools, and stress due to work from home.

4. Discussion

Public health measures taken to mitigate Covid-19 included closure of schools and therapy services. Tasks like staying indoors throughout the day, suspension of face-to-face therapeutic services, along with drastic changes in routines, has had a significant impact on children with ASD and their families. With the third wave in India in January 2022, the therapeutic services were interrupted. The schools for children less than 6 years had remained closed from the onset of the pandemic in March 2020 till February 2022 in Tamil Nadu India. This prolonged school closure and intermittent therapeutic services has had a severe impact on children and families with ASD.

4.1 Effects of pandemic on children with ASD

The majority of parents in this study reported a significant negative impact, including an increase in problem behaviours such as tantrums, refusal to participate in everyday activities, restlessness and agitation. Similarly, during the Covid-19 Pandemic, children with ASD have been reported to exhibit an increase in distractibility, hyperactivity, stereotypic behaviour [7]; aggression, sleep disturbances [8]; and behavioral challenges [8]. Being restrained at home, children are prone to increased levels of anxiety which in turn can aggravate the symptoms of ASD. Also, changes in routine are known to cause an increase in challenging behavior, and aggression [13]. Furthermore, the majority of the parents in the current study reported increased levels of stress, which may also explain the increased behavioural difficulties reported among children [6].

Further, one of the common changes reported was sleep disturbances. Several of the previous studies have also reported sleep disturbances among children with ASD during the pandemic [4], and sleep disturbances are in turn associated with increased aggression, withdrawal, hyperactivity, anxiety, irritability [14], as well as problem behaviours [15]. Thus, sleep disruptions could explain the negative impact and behavioural issues reported by the parents.

In terms of changes observed in various domains, a greater

proportion of parents reported improvements in language skills. Their gains in the language domain could be attributed to therapist mediated intervention and professional assisted parental coaching of children at home. Similar improvements in communication skills have been reported among young children who received ABA-based treatment [7] during the pandemic and parent-based intervention using telepractice [16]. Children, on the other hand, demonstrated increased difficulties in social and emotional domains. These findings are consistent with the earlier study which reported improvements in the communication domain but not in the social domain among the children receiving parent-directed intervention [17]. This could be attributed to isolation due to pandemic and lack of social interaction, as well as changes in daily routines [18] and the difficulty in working on these skills via teletherapy. Some of the major challenges for the parents were engaging the child at home, having the child indoors, and lack of time, and dealing with the child's behavioral problems. These findings are consistent with previous research [19].

4.2 Therapeutic services

The majority of the parents interviewed received therapeutic services via telepractice, with only 10% receiving in-person services. Because of the pandemic's restrictions and lack of in-person services, and for the fear of infection most parents had opted for online sessions. The majority of the parents reported high parental satisfaction, significant progress in children and thus a greater acceptability of telepractice. The results are similar to therapist-assisted Parent-based intervention via telepractice [17, 20, 21] among children with ASD.

On the other hand, among the parents availing online therapeutic services, one third found it to be of limited to no significant benefit and the majority found it difficult to sustain the child's attention. Limited benefit from teletherapy due to the difficulty in holding children's attention, limitations in reinforcement, and lack of peer interaction has also been reported in earlier studies [5]. Children with ASD are known to have attention problems, and hence paying attention especially over the digital media, could be even more challenging. Furthermore, children with ASD who have additional cognitive deficits may benefit from the use of concrete materials and direct work with the therapist in a face-to-face session. Teletherapy also eliminates the beneficial face-to-face interaction with peers

that traditional treatments provide. Furthermore, the vital support the parents receive from direct parenting group contacts are also lacking in telepractice. All these factors may have contributed to limited benefit from teletherapy reported by a group of parents.

4.3 Parental stress

A vast number of studies have documented the increased stress among families with children with ASD [22]. The way parents handle stressful situations has an impact on their children's ability to control and cope with stress. Parental stress disrupts the caregiver system, leading to further emotional and behavioral issues in children [6]. The majority of the parents in the current study reported high levels of stress during the pandemic. Similar findings of increased parental stress, fear, anxiety and feeling of helplessness among parents of children with ASD have also been reported in the earlier studies during the pandemic [5, 23].

Hence, a multidisciplinary team must assess children with ASD and their families, and the sources of parental stress must be identified. Given the pandemic situation, families can be given recommendations that are specific, realistic, and attainable [24]. To avoid burnout, parents and caregivers must receive psychological support through online counseling. Similarly, to improve the quality of life for families, professionals can organize parent respite care and parent support groups via online modes to boost their spirits and reduce their burden.

It is important to identify children who do not significantly benefit from telepractice. Parent coaching interventions that teach parents how to interact, play, and communicate more effectively with their children would be extremely beneficial for preschool-aged and minimally verbal children. It is critical to provide written information to parents on how to support the child's communication at home, modifications to be made at home, and guidance to carry out intervention in a natural environment at home. Based on the needs of the child, video training material for parents may also be created. In the case of therapist-mediated intervention, the therapist must receive specialized telepractice training in order to make sessions appealing and tailored to the child's interests. Visual reinforcers may help with attention during teletherapy. Whenever possible, a hybrid approach to intervention should be provided.

With the pandemic continuing, it is critical to find ways to balance the need for therapeutic and educational intervention while protecting children from infection, as a prolonged lack of therapeutic services may exaggerate maladaptive behaviour and may also result in a loss of previously acquired skills. Hence parent mediated intervention must be encouraged for long-term positive outcomes. Telecommunication system including network connectivity and availability of devices must be strengthened in developing countries like India. Professionals must look out for signs of stress among the family, and the source of stress must be addressed.

Some of the limitations of the present study included a small sample size and lack of control group of typically developing children. The study findings are based on parental reports and due to the nature of the survey, the participants were self-selected. In addition, the Parent's psychological problems were not examined prior to the pandemic. In spite of these limitations, the study has helped us understand the needs of the children and families of

children with ASD.

5. Conclusion

To conclude, the pandemic has had a significant impact on children with ASD causing a significant increase in problem behaviours and on their families causing a significant increase in stress levels. The effectiveness of telepractice has been mixed. As the pandemic continues, it's critical for rehabilitation professionals to take these factors into consideration and support children with ASD and their families to improve their quality of life.

6. References

1. Tian J, Gao X, Yang L. Repetitive Restricted Behaviors in Autism Spectrum Disorder: From Mechanism to Development of Therapeutics. *Frontiers in Neuroscience*. 2022;16:780407.
2. Bellomo TR, Prasad S, Munzer T, Laventhal N. The impact of the COVID-19 pandemic on children with autism spectrum disorders. *Journal of Pediatric Rehabilitation Medicine*. 2020;13(3):349-354.
3. Hyman SL, Levy SE, Myers SM. Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics*. 2020;145(1):e20193447.
4. Türkoğlu S, Uçar HN, Çetin FH, Güler HA, Tezcan ME. The relationship between chronotype, sleep, and autism symptom severity in children with ASD in COVID-19 home confinement period. *Chronobiology International*. 2020;37(8):1207-1213.
5. White LC, Law JK, Daniels AM, Toroney J, Vernioia B, Xiao S, *et al*. Brief Report: Impact of COVID-19 on Individuals with ASD and their caregivers: A Perspective from the SPARK Cohort. *Journal of Autism and Developmental Disorders*. 2021;51:3766-3773.
6. Colizzi M, Sironi E, Antonini F, Ciceri ML, Bovo C, Zocante L. Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: an online parent survey. *Brain Sciences*. 2020;10(6):341.
7. Sergi L, Mingione E, Ricci MC, Cavallaro A, Russo F, Corrivetti G, *et al*. Autism, Therapy and COVID-19. *Pediatric Reports*. 2021;13:35-44.
8. Mutluer T, Doenyas C, Aslan Genc H. Behavioral Implications of the Covid-19 Process for Autism Spectrum Disorder, and Individuals' Comprehension of and Reactions to the Pandemic Conditions. *Frontiers in Psychiatry*. 2020;11:561882.
9. Samadi H, Samadi SA. Understanding Different Aspects of Caregiving for Individuals with Autism Spectrum Disorders (ASDs) a Narrative Review of the Literature. *Brain Sciences*. 2020;10(8):557.
10. Chauhan A, Sahu JK, Jaiswal N, Kumar K, Agarwal A, Kaur J, *et al*. Prevalence of autism spectrum disorder in Indian children: A systematic review and meta-analysis. *Neurology India*. 2019;67(1):100-104.
11. Hayes SA, Watson SL. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2013;43(3):629-642.
12. Drogomyretska K, Fox R, Colbert D. Brief report: stress and perceived social support in parents of children with ASD. *Journal of Autism and Developmental Disorders*. 2020;50(11):4176-4182.
13. Bull LE, Oliver C, Callaghan E, Woodcock KA.

- Increased Exposure to Rigid Routines can Lead to Increased Challenging Behavior Following Changes to Those Routines. *Journal of Autism and Developmental Disorders*. 2015;45(6):1569-1578.
14. Henderson JA, Barry TD, Bader SH, Jordan SS. The relation among sleep, routines, and externalizing behaviour in children with an autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2011;5(2):758-767.
 15. Lindor E, Sivaratnam C, May T, Stefanac N, Howells K, Rinehart N. Problem Behavior in Autism Spectrum Disorder: Considering Core Symptom Severity and Accompanying Sleep Disturbance. *Frontiers in Psychiatry*. 2019;10:487.
 16. Wilkes-Gillan S, Lincoln M. Parent-mediated intervention training delivered remotely for children with autism spectrum disorder (ASD) has preliminary evidence for parent intervention fidelity and improving parent knowledge and children's social behaviour and communication skills. *Australian occupational therapy journal*. 2018;65(3):245-246.
 17. Ingersoll B, Berger NI. Parent Engagement with a Telehealth-Based Parent-Mediated Intervention Program for Children with Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes. *Journal of medical Internet research*. 2015;17(10):e227.
 18. Baweja R, Brown SL, Edwards EM, Murray MJ. COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. 2022;52(1):473-482.
 19. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, *et al*. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet*. 2020;395(10227):912-920.
 20. Bearss K, Burrell TL, Challa SA, Postorino V, Gillespie SE, Crooks C, *et al*. Feasibility of Parent Training via Telehealth for Children with Autism Spectrum Disorder and Disruptive Behavior: A Demonstration Pilot. *Journal of autism and developmental disorders*. 2018;48(4):1020-1030.
 21. Parsons D, Cordier R, Vaz S, Lee HC. Parent-Mediated Intervention Training Delivered Remotely for Children with Autism Spectrum Disorder Living Outside of Urban Areas: Systematic Review. *Journal of medical Internet research*. 2017;19(8):e198.
 22. Bonis S. Stress and Parents of Children with Autism: A Review of Literature. *Issues in mental health nursing*. 2016;37(3):153-163.
 23. Dhiman S, Sahu PK, Reed WR, Ganesh GS, Goyal RK, Jain S. Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in developmental disabilities*. 2020;107:103790.
 24. Summers J, Baribeau D, Mockford M, Goldhopf L, Ambrozewicz P, Szatmari P, *et al*. Supporting Children with Neurodevelopmental Disorders During the COVID-19 Pandemic. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2021;60(1):2-6.