

Families With Children With Neurodevelopmental Disorders During COVID-19: A Scoping Review

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Abstract

Objective Prolonged home isolation may lead to long-term negative consequences for both children and caregivers' psychological wellbeing, especially in families with children with neurodevelopmental disorders. Therefore, a scoping review was conducted to identify challenges faced by caregivers of children with neurodevelopmental disorders during the coronavirus disease 2019 (COVID-19) pandemic and to consolidate parenting interventions and guidelines. **Methods** A systematic search was conducted on Embase, PsycInfo, PubMed, Scopus, and LitCovid. All article types published between December 2019 and November 2020 which reported on intervention guidelines and experiences of families with children with neurodevelopmental disorders during the COVID-19 pandemic were included. Qualitative themes, quantitative data, and article summaries were charted, and a thematic analysis was conducted. **Results** Twenty-nine articles were included in the review. Three themes were generated: (a) behavioral issues and health concerns, (b) disruptions of lifelines and daily routines, and (c) existing programs, models, and guidelines to support families. Additionally, a list of caregiver strategies such as scheduling regular online consultations, maintaining online therapy, educating a child on COVID-19, and preventive behaviors, creating a structured daily schedule and reinforcement system, and selecting child-appropriate activities was consolidated. **Conclusion** This review revealed a lack of evidence-based studies and articles on children with other neurodevelopmental disorders apart from autism and attention-deficit hyperactivity disorder. It also places emphasis on the importance of telehealth services as major lifelines to parents during this pandemic and urges healthcare organizations to provide funding to increase telehealth services to afflicted families.

Key words: ADHD; attention; autism spectrum; COVID-19; healthcare services and utilization; hyperactivity; parenting.

Introduction

The unprecedented scale of the novel coronavirus disease 2019 (COVID-19) has led to the swift

implementation of disease containment measures, such as social distancing, home quarantine, and closures of schools and nonessential businesses, by

governments worldwide. Although this is effective in mitigating the spread of the virus, the disruption of services, limited social contacts, and worsening economic situations, together with existing anxieties related to COVID-19, are jeopardizing the mental health of the general population (Mazza et al., 2020).

Extended periods of quarantine present psychological issues that persist over time, such as posttraumatic stress symptoms, anger, depression, low mood, irritability, and emotional exhaustion (Brooks et al., 2020). On top of this, home quarantine presents another array of problems and parenting stress for caregivers or parents with young children and adolescents. Increased time at home has also seen a rise in screen time among children, which can lead to psychosocial disorders, such as lowered self-esteem or internet addiction (Grechyna, 2020). Prolonged physical isolation from peers, extended family members, and community networks have heightened loneliness among children (Loades et al., 2020), which also increases their vulnerability to depression, stress, anxiety, avoidance behavior, and posttraumatic stress disorder (Liu et al., 2020). The disruption of daily routine poses an even greater problem for children with neurodevelopmental disabilities as established routines promote stability and allow the child to know what is expected of them. Therefore, sudden changes in routine, and the child's inability to adapt and comprehend the changes may result in heightened anxiety, frustration, and emotional breakdowns, especially in children with autism (Kawabe et al., 2020; Kong, 2020). Additionally, the closure of schools, and special education and rehabilitative centers may result in a "COVID-19 slide," where children display patterns of learning loss and skills development impediment (Kuhfeld & Tarasawa, 2020). Despite the switch to an online platform, children from low socioeconomic backgrounds or with neurodevelopmental and learning disorders may struggle to adapt due to lack of resources or decreased ability to participate consistently with virtual instruction. This increases the risk of them falling further behind in terms of learning and skills development and may disrupt months of educational and rehabilitative efforts. Although pediatric cases are low and clinical evidence remains inconclusive on the risk of infection among children, home quarantine and full-time childcare have been a major collateral concerns for parents, especially for families of children with neurodevelopmental disorders (Fontanesi et al., 2020).

Despite home quarantine being the perfect opportunity for personal growth and family bonding, the risk of trauma, the uncertainty of the future, detachment, and the sense of loss of time and security may instead increase the risk of violence and mental health issues for both parents and children (Fontanesi et al., 2020).

This is especially so for families with children with neurodevelopmental disorders, in which parents are already experiencing elevated levels of stress compared with parents of typical children or children with other chronic diseases (Hoffman et al., 2009). Therefore, children with disabilities are reportedly at an increased risk of domestic maltreatment (Seppälä et al., 2020). For instance, parents of children with attention-deficit hyperactivity disorder (ADHD) tend to exhibit more ineffective and less positive or warm parenting compared with parents of children without ADHD (Johnston & Mash, 2001), and this risk may increase during the pandemic due to heightened family tensions. Furthermore, children with neurodevelopmental disorders who receive regular care from primary care settings are not able to get timely and professional care from home settings (Zhang et al., 2020). Parents who are not expected to be domain experts are therefore forced to undertake educational responsibilities and manage their children's emotional and behavioral problems single-handedly. Lockdown regulations and concerns about older family members contracting the virus may also deter them from receiving support from extended family members. These barriers may inevitably contribute to increased parenting stress and burden, and may further exacerbate both parents' and children's psychological wellbeing and worsen the children's behavioral problems (Zhang et al., 2020). Therefore, this pandemic poses a greater threat to families with children with neurodevelopmental disorders as they encounter additional challenges due to functional limitations, changes in daily routine, and the abrupt termination of regular support.

Although efforts to develop pharmaceutical interventions for COVID-19 are under way, additional support and guidelines for families with children with neurodevelopmental disorders are needed to forestall psychopathological trajectories in this already vulnerable population. In this review, individuals aged 18 years and below were considered children. Current studies focused heavily either on the epidemiology and clinical characteristics of COVID-19 among children to generate guidelines for pediatric healthcare providers (de Rojas et al., 2020; Duke et al., 2020) or on the mental health of adolescents and their families (Fegert et al., 2020; Loades et al., 2020). However, scant attention is being paid to the challenges faced by families with children with neurodevelopmental disorders. Although general parenting recommendations have been issued by the World Health Organization (WHO) to promote positive family wellbeing during home quarantine (World Health Organization, 2020), families with children with neurodevelopmental disorders face unique behavioral challenges which are not taken into consideration. Therefore, this scoping

review aims to identify challenges faced by parents of children with neurodevelopmental disorders during the COVID-19 pandemic and to consolidate interventions, guidelines, and parenting strategies for these families.

Materials and Methods

Study Design

A scoping review design was adopted as it is a transparent and rigorous approach to examine the extent, range, and nature of research activity in a topic area, and to identify research gaps especially for novel topics that have not been reviewed comprehensively (Arksey & O'Malley, 2005). Scoping reviews generally include a wide variety of publication types and study designs beyond empirical evidence (Munn et al., 2018; Pham et al., 2014). Due to the novelty of the COVID-19 pandemic and scarce amount of literature available, a scoping review design is appropriate to provide an overview of existing literature and to map out the indefinite contents related to the COVID-19 pandemic through an iterative exploration and analysis. Arksey and O'Malley's (2005) five-stage framework which include: (a) identifying the research question, (b) identifying relevant studies, (c) study selection, (d) charting the data, and (e) collating, summarizing, and reporting the results, was used to conduct the scoping review. This review aims to answer the following research question: what are the challenges faced by parents of children with neurodevelopmental disorders during the COVID-19 pandemic, and what available interventions or guidelines are there for these parents?

The review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews statement (Tricco et al., 2018) (Supplementary Material 1).

Search Strategy

A systematic electronic search for English language articles was conducted on five databases (Embase, PsycInfo, PubMed, Scopus, and LitCovid) from December 2019 to November 5, 2020. The cutoff date for the electronic search was derived from the first reported case of COVID-19, which was in December 2019. The search strategies were drafted in consultation with experienced librarian, and further refined and reviewed through team discussions with the librarian and two reviewers (S.S. and E.D.N.). Generated keywords were related to the concept of parenting and pandemics, such as parent, family, caregiver, child, COVID-19, pandemic, lockdown, and quarantine. Due to the scarcity of available COVID-19 literature, the search terms remained broad and specific disability-related keywords were not included.

Combinations of keywords, Booleans, and subject headings were further refined to optimize the search results for each database. A hand search of bibliographies of relevant articles was also conducted. A detailed search strategy is provided in [Supplementary Material 2](#).

Study Selection

The current scoping review included all types of articles published in peer-reviewed scientific journals, such as empirical studies with qualitative, quantitative or mixed methods approaches, editorials, commentaries, special reviews, brief reports, and letters to editor. Articles were included if they were published in English and mentioned parenting experiences, or proposed intervention models and guidelines for parents with children with neurodevelopmental disorders specifically during the COVID-19 period. Empirical studies that included both or either parent- or child-reported outcomes were included. According to the Diagnostic and Statistical Manual of Mental Disorders 5th edition (American Psychiatric Association, 2015), neurodevelopmental disorders are a group of conditions with onset during the developmental period and are characterized by developmental deficits that lead to impairments of social, personal, academic, or occupational functioning. Such disorders include the autism spectrum disorder (ASD), ADHD, learning disorders, motor disorders, communication disorders, and intellectual disabilities. Unpublished articles or articles on the epidemiology or clinical characteristics of children with COVID-19, familial clusters or transmission, or guidelines for healthcare professionals, were excluded. Studies were also excluded if the child's age was above 18 years old.

The library search was executed by a reviewer (E.D.N.), and the Endnote X9 program (Clarivate Analytics, Philadelphia, PA) was used to import articles and remove duplicates. Title and abstracts were screened for relevance by two reviewers independently and shortlisted articles were then assessed for full-text eligibility before being included in the review. Any discrepancies in the screening of eligibility were resolved by clarification with the other authors.

Charting the Data

Crucial information from the included articles (i.e., author's name, year, country of origin, publication type, aim of article, sample characteristics [number of participants, children's age, gender, type of disorder], method of data collection, outcome measures [if applicable], and main findings [qualitative themes and sub-themes, quantitative data—survey percentages, narrative summary]) was collated and charted onto a document that was modified consistently as new data emerged. Modifications made included the separate

categorization of peer-reviewed articles from other article types (e.g., editorials, commentary, special articles), and the listing of children's type of diagnosis as a standalone header. These were done to provide readers a clearer overview of available findings without having to sieve through clustered information. The chart draft was piloted on three random articles by two reviewers (S.S. and E.D.N.). After minor revisions, the chart was used independently by the two reviewers (S.S. and E.D.N.) to gather information from the included articles narratively. Any discrepancies were clarified with the rest of the team.

Collating, Summarizing, and Reporting the Results

After the extraction of text findings from the included articles, the findings were separated, grouped, abstracted, and categorized into themes and subthemes by two reviewers (S.S. and E.D.N.) independently. The level of agreement between both reviewers was 80%. Disagreements between reviewers were resolved through discussions and consultations with other team members until a consensus was reached. A thematic analysis was conducted using Braun and Clark's framework (Braun & Clarke, 2006). Different concepts were highlighted using a manual color-coding method that generated the initial codes. Similar codes were then collated and organized into themes and subthemes. Prominent themes from the reviewers' individual analysis were selected, relabeled, and finalized after a comprehensive review and discussion between both reviewers.

Results

Characteristics of the Articles

The initial search yielded 1,019 articles, and 374 duplicates were removed. Then, 645 article titles and abstracts were screened for relevance. The full texts of 40 articles were then screened for eligibility, and 29 were included in the review (Figure 1).

All articles were published in the year 2020: 15 from Europe (mainly Italy), 5 from Asia, eight from North America (United States and Canada), and 1 from Africa (Zimbabwe). Fifteen articles specifically focused on families with children with ASD, four focused on families with children with ADHD, nine were on neurodevelopmental disorders in general, and one on intellectual developmental disorder. There were seven quantitative studies and five qualitative studies, encapsulating a total of 499 adolescent self-reports and 1,789 parent-reports on the impacts of COVID-19 on family life, the children's (aged 3–18 years) wellbeing, behavioral symptoms, and adaptation. The remaining seventeen articles were brief reports, letter to editors, commentaries, and special

articles that highlighted the potential challenges faced by families with children with neurodevelopmental disorders, or proposed diagnostic and intervention models, and guidelines for such families. The details and references of the included articles are presented in [Supplementary Materials 3 and 4](#), respectively.

Three themes (behavioral issues and health concerns, disruptions of lifelines and daily routine, and existing programs, models, and guidelines to support families) and a consolidated list of strategies for parents were generated. The themes "behavioral issues and health concerns" and, "disruptions of lifelines and daily routine" highlighted the parenting challenges faced during the COVID-19 pandemic, whereas "existing programs, models, and guidelines to support families" and the list of parenting strategies provided an overview of existing familial support and consolidated recommendations.

Behavioral Issues and Health Concerns

Surveys revealed that most families with children with neurodevelopmental disorders found it more challenging to manage their children's behaviors and daily activities during the COVID-19 pandemic compared with the pre-COVID period (Colizzi et al., 2020; degli Espinosa et al., 2020; McGrath, 2020). A study from the United Kingdom found that in comparison to neurotypical controls, children with neurodevelopmental disorders had a higher prevalence of emotional symptoms, increased conduct problems, and decreased prosocial behaviors during the early stages of the pandemic (Nonweiler et al., 2020).

According to a clinician, children's and parents' moods, and children's study time are predictors of ADHD behavior during home quarantine (McGrath, 2020). In a China-based study, certain ADHD behaviors had significantly worsened during the pandemic, especially anger management, ability to adhere to routines, and on-task attention (Zhang et al., 2020). However, most parents reported an improvement or sustained levels of their children's ability to listen to instructions, maintain neatness, quietness, not interrupting adults, and better eating and sleeping behaviors (Zhang et al., 2020). Similarly, in Ireland, adolescents with ADHD reportedly had better moods and behaviors since school closure, and those on optimized medication were doing well (McGrath, 2020). But contrary to Zhang et al.'s study (2020), poorer sleep hygiene was reported by McGrath (2020). Adolescents with ADHD also experienced greater difficulty with remote learning than adolescents without ADHD, but both groups did not differ in terms of self-rated positive and negative affect, and concentration difficulties (Becker et al., 2020). Parents were also less confident in managing and supporting remote learning for their children with ADHD (Becker et al., 2020).

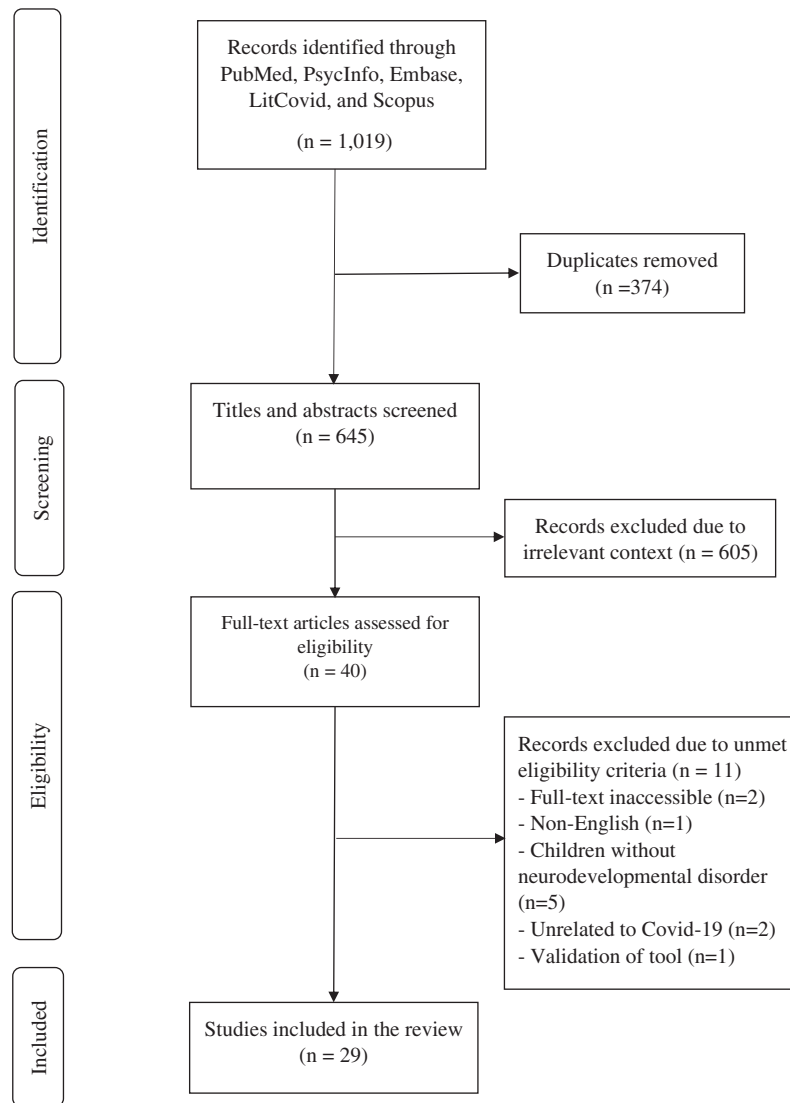


Figure 1. PRISMA flow diagram.

On the other hand, as compared with the pre-COVID-19 period, parents of children with ASD reported an increase in intensity and frequency of behavior problems (Colizzi et al., 2020). Parent-reported behavioral problems were also higher among parents of children with ASD than those of children without ASD (Amorim et al., 2020). Primary causes of behavioral changes were attributed to anxiety, irritability, obsession, hostility, and impulsivity (Amorim et al., 2020).

The frequency and intensity of behavior problems were predicted by preexisting behavior problems, younger child's age, married households, and a lack of school support during the lockdown. Additionally, parents of children with ASD struggled to manage their children's free time, structured activities, autonomies, and mealtimes (Colizzi et al., 2020), and also encountered a lack of structure and child's lack of

motivation due to free access to reinforcers (degli Espinosa et al., 2020). According to one mother:

The management of G became very difficult. All his routines and perception of time had been disrupted. G, who was never interested in playing, became satiated with technology and was constantly searching for food, becoming very anxious during mealtimes. (degli Espinosa et al., 2020)

Lockdown and quarantine measures also posed other health issues for children with neurodevelopmental disorders such as increased sedentary lifestyle, impaired diet, weight gain, sleep disorders, and addiction to technological devices that may lead to poor sleep hygiene (degli Espinosa et al., 2020; Esentürk, 2020; McGrath, 2020; Turkoglu et al., 2020). Therefore, in Esentürk's study (2020), parents advocated the importance of physical activities during this stay home period as these will benefit their children's physical health, build their social skills, prevent

technology addiction, reduce stress and anxiety, and instill relaxed and calm feelings in their children.

Disruptions of Lifelines and Daily Routine

The highly infectious COVID-19 virus has caused nationwide lockdowns in various countries, which led to the abrupt suspension of clinical, rehabilitative, and special education services that are crucial in meeting the unique needs of children with neurodevelopmental disorders. As these children are losing a main component of their support system, they may be at increased risks of social withdrawal, isolation, and stagnations or regressions of skills or milestones (Eshraghi et al., 2020; Kong, 2020; Trabacca & Russo, 2020). In addition to routine disruption, children with ASD may have difficulty comprehending the rapidly changing situation (Cahapay et al., 2020; Eshraghi et al., 2020; Kong, 2020; Majoko et al., 2020). Coupled with their inability to communicate and express themselves effectively, their limited understanding of the situation may elicit major emotional upheaval, unnecessary anxiety, and maladaptive behaviors, such as frustration and self-aggression (Kawabe et al., 2020; Kong, 2020; McGrath, 2020). In two qualitative studies (Cahapay et al., 2020; Majoko et al., 2020), parents described how they introduced their children to the new social norm, and one parent commented:

They cannot easily comprehend new normal, so I take extra effort to let them understand the situation. . . I allowed him to drive around the city and told him that almost all establishments are close because of a disease (Cahapay et al., 2020).

Meanwhile, nationwide lockdowns have also led to loss of income, support networks, access to specialists and school support for parents, which contributed to worry, anxiety, stress, distress, frustration, and feeling overwhelmed (Amorim et al., 2020; Asbury et al., 2020; Eshraghi et al., 2020; Fazzi & Galli, 2020; Neece et al., 2020; Trabacca & Russo, 2020). A study from India revealed higher prevalence of depression, anxiety, and stress symptoms among caregivers of children with special needs during COVID-19 as compared with pre-COVID-19, and these were associated with reduced use and lower perceived efficacy of telehealth rehabilitation (Dhiman et al., 2020). A study from Italy revealed that majority of parents of children with ASD reported a need for in-home and center-based healthcare support, whereas parental, peer, and community support were the least needed support (Colizzi et al., 2020). In another study pertaining to children's physical activities during the pandemic (Esentürk, 2020), parents of children with ASD explicitly mentioned the need for more family education and training, professional support and guidance, and information on how to encourage children to engage in physical activity.

However, in qualitative studies (Cahapay et al., 2020; Majoko et al., 2020; Neece et al., 2020), parents mentioned a silver lining during isolation and lockdown, as more family members are at home and involved in home education. One parent commented "we congregate when she throws tantrums. None of us is guaranteed of calming her down. . ." (Majoko et al., 2020). Moreover, with restricted access to formal education, some parents saw this as an opportunity to teach their children life skills:

With a child with autism in your home, patience is a virtue. I teach my child basic things like cooking rice, washing dishes, and sweeping the floor. This is the right time to learn the essentials of life.

Parents also reported an improvement in family relationships, enhanced self-efficacy in parenting and better communication with their child (Asbury et al., 2020; Neece et al., 2020). Some were heartened by their child's developmental gains during quarantine (Neece et al., 2020). A collaborative community culture also manifested during the lockdown as families of children with autism provided support and exchanged parenting tips (Cahapay et al., 2020; Majoko et al., 2020).

Existing Programs, Models, and Guidelines to Support Families

Continuity of care for families with children with neurodevelopmental disabilities during the pandemic was emphasized in most articles (Aishworiya et al., 2020; Fazzi & Galli, 2020; Smile et al., 2020), which led to the proposal of a few telehealth interventions and diagnostic frameworks or programs (Camden & Silva, 2020; Narzisi, 2020b; Provenzi et al., 2020; Summers et al., 2020). Such programs challenge healthcare providers to improvise and reimagine service delivery with virtual platforms that may not necessarily require new initiatives and funding (Smile et al., 2020).

Camden and Silva (2020) proposed a Viewing, Information, Relationship, Technology, Unique, Access, and Legal guideline for clinicians implementing telehealth programs. Narzisi (2020b) shared two potential telemedicine working models for diagnosis and intervention. The diagnosis model included two stages: pre-specialistic consultation and specialistic assessment. The pre-specialistic consultation involved the submission of parent-report questionnaires and various videos of their child's playing scenarios and behaviors, whereas the specialistic assessment involved video call assessments of the child conducted over four days. On the other hand, the intervention model comprised of recommended online session schedules for children of different age groups (Narzisi, 2020b). Only two studies evaluated families' responses to telehealth programs (Provenzi et al., 2020; Summers et al., 2020). Provenzi et al. (2020)

evaluated a telehealth program (Engaging with Families in Online Rehabilitation of Children during the Epidemic) for families of children with neurodevelopmental disabilities in Italy. The program included case-specific tailored telehealth sessions focused on parental support and child rehabilitation. After 6 weeks, 80% of parents reported child growth and development, 40% found it effective, and the majority reported increased feelings of self-relevance, engagement, perceived support, and recognition (Provenzi et al., 2020). Meanwhile, the “COVID-19 Neurodevelopmental Disorders Clinic” program was a home-based virtual consultation comprising of a multidisciplinary team that adopted a strictly solution-based approach for referrals that were motivated by the COVID-19 situation (Summers et al., 2020). The program was well-received by parents, without major issues in virtual format and technology. However, it required more parent-centered counseling and support, as well as support for implementing strategies (Summers et al., 2020). Although telehealth programs were well-received by most families, issues such as poor internet connection, web literacy gaps, interruption of sessions, and difficulty with following instructions ensued (Camden, 2020; Provenzi et al., 2020).

Consolidated Strategies for Caregivers

Based on the thematic analysis, parenting tips and suggestions for families with children with neurodevelopmental disorders from ten articles were consolidated into five key points and summarized in [Table I](#).

Schedule Regular Online Consultations

Regular online consultations are essential for coaching and equipping parents with child management strategies in terms of effective communication, developing daily schedules, and selecting and implementing appropriate activities (degli Espinosa et al., 2020; Narzisi, 2020a). Medical updates through online consultations are also necessary for better disease management and allow healthcare providers to instruct and support parents effectively.

Maintain Online Therapy

Although online therapy for children with ASD can be challenging, it is the only one which is flexible, cost-efficient, and provides individualized therapy during a pandemic (Eshraghi et al., 2020). For high functioning children, online therapy can provide them a safe place to talk, check their moods, and reduce anxiety (Narzisi, 2020a).

Educate the Child on COVID-19 and Preventive Behaviors

In order to mitigate a child’s stress and reduce unnecessary anxiety, a top priority would be to provide the

child with critical information about the COVID-19 pandemic and explain why he or she has to stay home (Glasper, 2020; Kawabe et al., 2020; Narzisi, 2020a). Educating children on preventive behaviors such as regular hand washing, maintaining social distancing, and wearing masks can give them a sense of control over the risk of infection, which may allay their fears and worries (Kawabe et al., 2020; Kong, 2020).

Create a Structured Daily Schedule and Reinforcement System

A consistent home schedule will subsequently become the new norm and help children with the adjustment period as well as reinforce positive dietary and sleep patterns (Cortese et al., 2020; Kong, 2020). For families with children with ASD, household reinforcement systems may help less vocal children to engage in parent-led activities and instructions (degli Espinosa et al., 2020). This may be done using a token reinforcement system which allows a child to earn a token when they provide an appropriate response, which can then be exchanged for other rewards. Additionally, activity-based reinforcement system allows a child to engage in an instructional activity for a set amount of time, and subsequently allows them more reinforcement time (degli Espinosa et al., 2020).

Select Child-Appropriate Activities

Child-appropriate activities can be classified into independent activities without adult support, household chores, table-top discrete teaching, and adult-led or shared activities (degli Espinosa et al., 2020). Shared activities between a parent and a child such as encouraging a child to share his or her special interests (e.g., trains and maps) can also facilitate communication and bonding (Narzisi, 2020a). It is also important to note that children with ASD may have issues with certain types of play due to sensory issues or preferences for structured activities. Therefore, the child’s preference needs to be considered during the selection of activities (Narzisi, 2020a). Physical activities or exercises should also be incorporated into the daily schedule to avoid an overly sedentary lifestyle that may lead to other potential issues (e.g., weight gain, video game addiction; Esentürk, 2020).

Discussion

This review highlighted the challenges and needs of families with children with neurodevelopmental disorders, specifically ASD and ADHD, during the COVID-19 pandemic. It also aggregated available parenting tips for this vulnerable group. Due to limited literature on pandemic, some evidence-based comparisons were drawn from post-disaster studies.

Table I. Parenting Tips for Families With Children With Neurodevelopmental Disorders

Parenting tip	Description	Relevant articles
Schedule regular online consultations	– Maintain close correspondence with children’s educators and therapists through texts, emails, or video calls for regular updates, medical advices, parent training, and as a form of support	degli Espinosa et al. (2020), Fazzi & Galli (2020), Kawabe et al. (2020), Narzisi, (2020a), and Trabacca & Russo (2020)
Maintain online therapy	- Continue to seek and maintain therapy for the child through telehealth - Ensure a proper verification and security of video conferencing applications, good bandwidth, and create a private therapeutic setting	Eshraghi et al. (2020), Fazzi & Galli (2020), McGrath (2020), and Narzisi (2020a)
Educate the child on COVID-19 and preventive behaviors	- Provide the child with critical information about the COVID-19 pandemic and explain why he or she has to stay home - Educate the child on preventive behaviors such as regular hand washing, hand sanitizing, maintaining social distancing, and wearing masks - Make use of positive reinforcers that are easy to relate to (e.g., to protect grandpa), use simple and clear language, use visual cues, storyboards, social stories, or conceptual mapping to impart skills (usually obtainable from therapists or online resources)	Glasper (2020), Kawabe et al. (2020), Kong (2020), Narzisi (2020a), and Tarbox et al. (2020)
Create a structured daily schedule and reinforcement system	- Establish a new home routine and schedule specific times for study, play, meals, and sleep - Use whiteboards or visual daily calendars together with verbal communication - Use household reinforcement systems (e.g., token exchange)	Cortese et al. (2020), degli Espinosa et al. (2020), Kawabe et al., (2020), Kong, (2020), Narzisi (2020a), and Tarbox et al. (2020)
Select child-appropriate activities	- Select activities based on long-term learning objectives for the child - Activities can be independent without parent support, household chores, table-top discrete teaching, or shared activities between parent and child. - Important to include physical activities or exercises	degli Espinosa et al. (2020), Narzisi (2020a), and Esentürk (2020)

Behavioral and Emotional Regulation During Crises

During home quarantine, key parenting challenges revolve around the behavioral and emotional regulations of children. Interestingly, children with ADHD had decreased challenging or disruptive behaviors, whereas children with ASD had increased intensity and frequency of challenging behaviors. However, both groups had problems with routine adherence, and anger and mood regulation. Similarly, studies have found an increase in internalizing problems and disorders, such as posttraumatic stress symptoms among children with neurodevelopmental disorders after natural disasters (Lochman et al., 2017; Rubens et al., 2013). Disaster or crises exposure may contribute to heightened stress-response systems among these children, causing elevated aggression and irritability in response to relatively mild interpersonal provocation (Lochman et al., 2017). Moreover, the adaptive behaviors of children with ASD in terms of communication, daily living, and motor skills are severely affected after a natural disaster, and only immediate and intensive post-disaster behavioral interventions are able to aid in partial recoveries of adaptive functioning

(Valenti et al., 2012). Therefore, it is crucial for parents to maintain or seek professional help and therapy during this COVID-19 crisis in order to prevent regression of their child’s skills and behaviors.

Overcoming Disruptions

Although Colizzi et al.’s study (2020) reported that most parents were still receiving help from private therapists, there is a major lack in medical healthcare support for their children, especially for those who require medication and constant physical monitoring. For parents who are bringing their child for physical consultations, it is hard for them to adhere to public social distancing measures as most children with neurodevelopmental disorders require higher assistance and supervision due to possible disruptive behaviors (Eshraghi et al., 2020; Fazzi & Galli, 2020). Although this is not in line with current policies, parents and caregivers should be allowed to remain with their children during health checkups to ensure efficient processes (Eshraghi et al., 2020). Moreover, children with ASD may also be hypersensitive and unwilling to wear masks in public (Eshraghi et al., 2020; Kawabe et al., 2020). Hence, the development of a home-based

COVID-19 testing kit would also be ideal, especially for families with children with ASD (Eshraghi et al., 2020).

Parents had specifically requested for more in-home and center-based healthcare support, but due to home quarantine measures and strained healthcare resources from the overwhelming cases of COVID-19 patients, physical support may not be sustainable. However, medication guidelines issued by the European ADHD Guidelines Group (Cortese, Asherson, et al., 2020; Cortese et al., 2020) and the use of telehealth can be useful alternatives to encourage parenting self-efficacy and educate parents in managing and monitoring their child's symptoms at home. Prior to the COVID-19 pandemic, certain home-based behavioral therapies for families with children with neurodevelopmental disorders such as applied behavioral analysis and behavioral parent training were ongoing; these are now possibly curtailed to various extents during the pandemic. These home-based therapies or caregiver trainings that usually involve home visits or face-to-face interactions with a therapist are beneficial in improving children's cognitive and social skills, compliance, reducing aggressive behaviors, and enhancing relationship with parents and siblings. They also promote parenting confidence and parental psychological wellbeing, increase family empowerment, and decrease family chaos (Grindle et al., 2009; Pfiffner & Haack, 2014). In recent years, the adaptation of such therapies, parent trainings, and professional consultations through telehealth has produced equally favorable outcomes while creating more cost-effective and easily accessible support for parents (Alkhalifah & Aldhalaan, 2018; Lindgren et al., 2016; Spencer et al., 2020; Sutherland et al., 2018; Vismara et al., 2013). Therefore, during the COVID-19 pandemic, the use of telehealth care is critical in supporting families and children with neurodevelopmental disorders.

Recommended Parenting Strategies

Although the WHO has issued advocacies for parents and children during confinement, such as having one-on-one time, staying positive, creating a daily routine, avoiding bad behaviors and habits, keeping calm and managing stress, and being honest and supportive when talking about COVID-19, no details were provided on how to execute these actions and specialized parenting tips for families with special needs children were unavailable (World Health Organization, 2020). Hence, healthcare professionals ought to also educate parents on the 'how', instead of only listing the "what" to do, via online consultations or trainings. Parental communication with children about the COVID-19 situation should be prioritized as parents often have the misconception that avoiding discussions about stressful feelings or situations would

protect their children from distress when the contrary holds true (Dalton et al., 2020). Apart from using simple and age appropriate language to explain about the pandemic, visuals should be used to educate on the best hygiene practices to provide the child with a sense of control over the situation as well (Kawabe et al., 2020).

Another major parental need is the creation of daily schedules which their children can adhere to. Previous studies have demonstrated the effectiveness of activity schedules in reducing challenging behaviors among children with ASD (Lequia et al., 2012). Since children may have difficulties processing and retaining verbal information, activity schedules incorporating photographs, line drawings, and videos have been used to increase the predictability of the daily schedules, and promote self-regulation and management (Lequia et al., 2012). In order to increase schedule adherence and activity participation, reinforcement systems are also often implemented. Token systems are a robust and effective method in enhancing social behaviors, reducing disruptive behaviors and food refusals among children with ASD (Matson & Boisjoli, 2009), and improving behavioral performance in children with ADHD (Luman et al., 2005). It is also noteworthy that children with neurodevelopmental disorders have aberrant sensitivity to reinforcement or decreased social motivation (Kohls et al., 2013; Luman et al., 2010). Thus, it is essential to consider the types of reinforcements used, such as using small but immediate rewards instead of larger, delayed rewards (Luman et al., 2005). However, there is conflicting evidence on the function or dysfunction of the reward circuitry among children with neurodevelopmental disorders (Kohls et al., 2013; Luman et al., 2005), which suggests a trial and error approach, and a need for further research.

Last, healthcare professionals ought to guide parents on selecting appropriate activities which can be included in the daily schedules. Prior to COVID-19, children with neurodevelopmental disorders often engaged in sedentary behaviors such as watching television and playing video games (Jasem & Delpont, 2019; Memari et al., 2015). Only 10% of children with ASD (usually boys and younger aged children) engaged in physical activities (Memari et al., 2015), and these numbers may fall further during home quarantine. Although evidence has highlighted the benefits of physical or sensorimotor activities in improving thought problems, social problems, and aggressive behaviors among children with neurodevelopmental disorders (Kim, 2018; Yarımkaya & Esentürk, 2020; Zang, 2019), barriers to the parental enforcement of home-based physical activities were the lack of knowledge, time, resources and facilities to conduct such activities (Esentürk, 2020; Jasem & Delpont, 2019;

Memari et al., 2015). Therefore, therapists and healthcare providers should guide and provide adequate resources for parents to implement simple physical activities within the home setting to engage their children during the pandemic. Additionally, considering a child's preferred play activity is essential for activity planning. Children with ASD are more inclined to solitary play (Memari et al., 2015) and have stronger affinity for activities that incite strong and distinct sensory feedback, and repetitive motions. Pretend play, and arts and crafts were less favored (Doody & Jana Mertz, 2013). Conversely, children with ADHD preferred to have play partners, engage in exploratory play, and need continuous changes in games. Games with rules and educational games were the least favorite (Jasem & Delpport, 2019). Play preferences are also subjected to each child's personality. Hence, collaborative efforts between parents and therapists are needed to tailor daily activity schedules to meet a child's needs.

Limitations and Future Implications

A major limitation of this review is the paucity of evidence-based studies on the COVID-19 pandemic which prevented deeper insight into the situations of families with children with neurodevelopmental disorders. Moreover, despite the aim to consolidate information on families with children with neurodevelopmental disorders in general, eligible articles only focused on more common disorders such as ASD and ADHD. In order to provide timely support, there is an urgent need for more scientific and anecdotal research on interventions and experiences of families with children with neurodevelopmental disorders, especially those with learning, motor, communication disorders, or intellectual disabilities.

This scoping review identified research gaps pertaining to the challenges faced by families with children with neurodevelopmental disorders, such as the lack of adequate support for parents to manage their children at home. Although piloted telehealth programs showed potential effectiveness and user satisfaction, further revisions and testing of models are needed prior to adoption by clinicians. Overall, joint effort from policymakers, researchers, and clinicians are needed to implement standardized medical guidelines and protocols, provide additional parenting guidance, and develop supportive interventions for such families that are already at a heightened vulnerability for psychological disorders.

Conclusion

The findings from this review reiterate the significant behavioral and emotional issues faced by families with children with neurodevelopmental disorders during

the COVID-19 pandemic primarily due to routine disruption. Suggestions for parents and caregivers to manage and overcome these challenges include the maintenance of child therapy and regular parent-provider correspondences through telehealth services to discuss behavior plans and schedules. The potential for long-term negative psychological impact of home quarantine and isolation on both special needs children and parents or caregivers should serve as an impetus for healthcare organizations to allocate more funds to make telehealth more widely available to affected families and for more supportive intervention research catered to this vulnerable group.

Supplementary Data

Supplementary data can be found at: <https://academic.oup.com/jpepsy>.

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The remaining references are given in Supplementary Material 4.