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Parental Perceptions of the Impact of the COVID-19 Pandemic on the Sleep of Children With Neurodevelopmental Disorders

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Introduction: Little is known about the impact of the COVID-19 pandemic on sleep in schoolaged children with neurodevelopmental disorders. This study aimed to (1) determine and describe the

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impact of the COVID-19 pandemic, and (2) identify and describe contributing factors.

Method: Parents of children with neurodevelopmental disorders and insomnia symptoms ($n = 100$) were surveyed to determine if their child's sleep had changed because of the COVID-19 pandemic. Parents who reported changes were asked to describe how the pandemic influenced their child's sleep.

Results: Most parents (66%) reported the pandemic did not worsen their child's sleep, 30% stated their child's sleep had worsened, and 4% reported an improvement. Stress and anxiety about the pandemic, disrupted routines, and increased screen time were common parent-identified contributing factors.

Discussion: Health care providers should explore strategies to mitigate contributing factors, such as anxiety about the pandemic, disrupted routines, and increased screen time. J Pediatr Health Care. (2022) XX, 1–6

KEY WORDS

Sleep, COVID-19, neurodevelopmental disorders, children

INTRODUCTION

Rates of sleep disturbance in children with neurodevelopmental disorders (NDDs) may be as high as 80% (Corkum et al., 2014; Jan et al., 2008) and are associated with poorer daytime functioning and quality of life (Corkum et al., 2014; Jan et al., 2008; Kamara & Beauchaine, 2020). Changes in daily routines can have a negative impact on sleep habits, especially in children with NDDs who have distinct care needs (i.e., increased use of medications and higher use of specialist and nonspecialist health care services) and benefit

from routine and regularity (Arim et al., 2017; Corkum et al., 2020; Jan et al., 2008). Disruptions in care and routines can further exacerbate difficulties sleeping in children with NDDs.

The COVID-19 pandemic has disrupted children's day-to-day lives. By March 2020, stay-at-home orders implemented in Canada resulted in the transition to online schooling, cancellation of in-person activities (e.g., sports, after-school clubs, etc.), and reduced in-person contact.

In typically developing (TD) children, COVID-19 lockdown measures have been associated with worse sleep quality, increased difficulties falling asleep, nighttime awakenings, nightmares, and a shift to later bedtimes and waketimes (Becker et al., 2021; Cellini et al., 2021; Guo et al., 2021; Lavigne-Cerván et al., 2021; Lehmann et al., 2021). A Canadian-based study by Mackenzie et al. (2021) interviewed parents of Canadian TD children (aged 4 to 14 years old) who previously reported insomnia symptoms (i.e., chronic and frequent difficulties falling and staying asleep). They found worsening child sleep was influenced by increases in disrupted routines, anxiety, and screen time associated with the pandemic and resulting restrictions. Thus, while children's sleep duration may have increased during the pandemic (Moore et al., 2020), children's sleep quality may also be at risk.

Studies exploring the ramifications of COVID-19 lockdown measures on children and youth with NDDs also found shifting sleep/waketimes, worsening sleep quality, difficulties initiating/maintaining sleep, and anxiety at bedtime (Berard et al., 2021; Bruni et al., 2021; Ueda et al., 2021). No studies to date have explored the mechanisms of these changing sleep habits in children with NDDs.

In the current study, we asked parents participating in the *Better Nights, Better Days for Neurodevelopmental Disorders (BNBD-NDD)* program (Corkum et al., 2020; an e-health sleep behavioral intervention for parents of children with NDDs and insomnia symptoms) pan-Canadian randomized control trial about how their child's sleep may have changed during the pandemic at their baseline assessment. We aimed to (1) determine and describe the impact of the COVID-19 pandemic on sleep in school-aged children with NDDs and insomnia symptoms, and (2) describe factors that contributed to change in sleep habits.

METHODS

Participants

Participants were parents of school-aged (i.e., aged 4 to 12 years old) children with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Fetal Alcohol Spectrum Disorder (FASD), or Cerebral Palsy who met insomnia criteria and agreed to participate in the BNBD-NDD pan-Canadian RCT (Corkum et al., 2020). Participants were ineligible to participate in the RCT if (1) they bed-shared with their child and wanted to continue this practice, (2) were unable to read and speak English, (3) their child was unable to walk independently without a mobility device, (4) their child was diagnosed with

a significant mental and/or physical disorder that required hospitalization or residential care, or (5) their child was diagnosed with a sleep-related breathing disorder.

The Research Ethics Board of the IWK Health Center (REB no. 1024081) approved all study procedures. All participants provided informed consent online.

Procedure

Participants completed baseline assessments from April 2020 to March 2021 via the online platform, Research Electronic Data Capture tool (REDCap; Harris et al., 2019). In addition to parent/caregiver and child demographic information, baseline assessments assessed parental perception of the impact of COVID-19 on their child's sleep ("Has COVID-19 affected your child's sleep?"). Participants selected one of three responses: (1) *yes, for the better*, (2) *yes, for the worse*, or (3) *no change*. Participants who indicated a change in their child's sleep were asked to describe how the pandemic impacted their child's sleep in an open-ended text box.

Data Analysis

We analyzed quantitative data with the Statistical Package for Social Sciences (SPSS version 27.0; IBM Corp., Armonk, NY). Descriptive statistics summarized sample characteristics and changes in participants' perceptions of their child's sleep due to COVID-19.

We analyzed qualitative data using qualitative content analysis (Vaismoradi et al., 2013) and deductively coded parental responses based on codes previously developed to analyze changing sleep habits during COVID-19 in TD children (Mackenzie et al., 2021). No new codes were needed to fit the data. We used NVivo 12 (version 12; QSR International, Doncaster, Australia) to manage qualitative data. The first author (A. Pizzo) coded text box responses line-by-line. In consultation with the second author (E. Keys), codes were organized into themes. The senior author (P. Corkum) oversaw coding and theme development. We conducted consensus meetings between authors (A. Pizzo, E. Keys, and P. Corkum) to discuss theme development and maintain rigor.

RESULTS

Sample Characteristics

We obtained 100 parental reports (94 maternal reports and six paternal reports) on 100 children (25 female and 75 male). Parents' age ranged from 25 to 55 years. The mean age was 8.74 years old ($SD = 2.23$ years) for female children and 8.81 years old ($SD = 1.93$ years) for male children. Of children's NDD diagnoses, 70 had ADHD, 23 had ASD, two had CP, and 5 had FASD.

Quantitative Results

In terms of parental perceptions of changes in their child's sleep due to COVID-19, 30 parents reported sleep changed for the worse, 4 parents reported sleep changed for the better, and 66 parents reported no change. Tables 1 and 2

TABLE 1. Sample characteristics

Child diagnosis	Mean age of children in years (SD)	No. of children (% of total sample)	No. of female children (% based on diagnostic category)
ADHD	9.33 (1.79)	70 (70)	17 (24)
ASD	7.44 (1.96)	23 (23)	6 (26)
CP	8.75 (2.33)	2 (2)	0 (0)
FASD	7.26 (1.75)	5 (5)	2 (40)
Overall	8.80 (2.00)	100 (100)	25 (25)

Note. ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; CP, cerebral palsy; FASD, fetal alcohol spectrum disorder.

display sample characteristics and quantitative results for the entire sample and by diagnostic group.

Qualitative Results

Of the 34 participants who responded that their child's sleep had changed (either for the worse or better), 100% provided open-ended text responses that could be coded. Most parents who provided qualitative data were parents of youth with ADHD (21 worse sleep, 3 better sleep) (Table 2).

Worse sleep quality

Two themes described parental perceptions of the types of worsening sleep since the COVID-19 pandemic.

Theme 1: Difficulties falling or staying asleep

This theme reflects children's difficulties with falling or staying asleep such as waking up multiple times during the night, having nightmares, or waking up earlier than normal and not being able to fall back asleep.

“... Since COVID he is hard to get to bed and wakes up in the night with nightmares.” (Mother of 8-year-old child with FASD).

“... He is waking more frequently.” (Mother of 8-year-old child with ASD).

Theme 2: Shifting bedtime and waketime

Parents noticed a shift in their child's bedtime and waketime during the pandemic.

“... She has been going to bed much later now. About 2 hours later.” (Mother of 8-year-old child with ASD).

Mechanisms leading to worse sleep quality

Parents who perceived their child's sleep to be worse described two themes about mechanisms that lead to worsening sleep habits.

Theme 3: Increased anxiety, stress, and worry

Parents attributed difficulties falling/staying asleep to increased anxiety, worry, and stress during the pandemic.

“... My child has always had difficulty sleeping but since COVID she has been more anxious and refuses to go to bed even more often and stays up later than we would like; often staying up 'til between 3 and 5 a.m. before (she is) able to fall asleep or wakes at that time for the day.” (Mother of 8-year-old with ASD).

“... He can become very worried before bed and at the start of the isolation, was very anxious and worried. We found his dreams more stressful and talking in his sleep was more animated. Stress coming out during sleep.” (Mother of 7-year-old with ADHD).

Theme 4: Changes in routines

Parents emphasized that changes in daily routines due to COVID-19 led to less energy expended that resulted in difficulties falling/staying asleep.

“... My son requires a lot of intensive physical activity during the day to exhaust himself. Due to COVID-19, he is unable to participate in swimming, trampoline, in-person karate instruction, and other programs. He does not receive the same type of input from backyard play or riding his scooter. It is more difficult for him to fall asleep with the lack of outlets available.” (Mother of 6-year-old child with ADHD).

TABLE 2. Quantitative results

Child diagnosis	No. of participants with no change in sleep habits (% based on diagnostic category)	No. of participants in which sleep habits changed for the better (% based on diagnostic category)	No. of participants in which sleep habits changed for the worse (% based on diagnostic category)	Total
ADHD	46 (66)	3 (4)	21 (30)	70 (100)
ASD	15 (65)	0 (0)	8 (35)	23 (100)
CP	2 (100)	0 (0)	0 (0)	2 (100)
FASD	3 (60)	1 (20)	1 (20)	5 (100)
Overall	66 (66)	4 (4)	30 (30)	100 (100)

Note. ADHD = Attention-Deficit/Hyperactivity Disorder; ASD = Autism Spectrum Disorder; CP = Cerebral Palsy; FASD = Fetal Alcohol Spectrum

“... Since she is burning less energy throughout the day it is taking her longer to fall asleep.” (Mother of 9-year-old child with ADHD).

Some parents described that changes in routines (i.e., bedtime and daily) brought on by the pandemic contributed to shifting bedtimes and waketimes.

“... Later bedtime and different routine versus when she had a routine for school.” (Mother of 8-year-old child with ADHD).

Parents also described how changes in routines led to increasing bedtime resistance during the pandemic, which contributed to shifting bedtimes and waketimes.

“... Because his normal routine is not there I think that's why he wants to stay up later [and] fights to go to bed at his normal time.” (Mother of 7-year-old child with ADHD).

“... Goes to bed later, fights going to sleep almost every night and is very restless. Sleeps later than normal as all sense of routine is gone.” (Mother of 6-year-old child with ASD).

Parents reported that changes in routines increased screen time during the pandemic, ultimately leading to later bedtimes and waketimes.

“... Due to the lack of structure, but also in an attempt to allow him to maintain control over some facet of his day, he began staying up later, watching TV as he went to sleep, etc.” (Mother of 7-year-old child with ADHD).

“... The lack of routine in the spring–summer seasons made it harder for my son to keep a normal sleep schedule. He was using computers more for school and pleasure and he often slept in longer and then wanted to go to sleep later. He fought going to bed earlier.” (Mother of 11-year-old child with ADHD).

Improved sleep quality

We identified only one theme in responses by parents who noticed improved sleep quality in their child during the pandemic.

Theme 5: Improved sleep quality because of reduced extracurricular and school commitments

This theme captured children's ameliorated sleep routine and quality (i.e., fewer night wakings and an easier time falling asleep) that occurred throughout the pandemic. Parents ascribed their child's improved sleep quality to changes in routines (i.e., reduced extracurricular activities and school commitments), leading to less stress and better sleep.

“... We have been able to establish a better bedtime routine without the interference of sports and arriving home later in the evening.” (Mother of 12-year-old child with ADHD).

“... Since we've been in quarantine, my child does not have to get up early for school. This has been a huge relief for us, as she is able to wake naturally in the morning, and bedtime is less of a rush.” (Mother of 7-year-old child with FASD).

DISCUSSION

A notable proportion of parents (30%) described disrupted routines due to the pandemic as having a negative impact on their child's sleep, while a much smaller proportion (4%) described these disrupted routines as having a positive impact on their child's sleep and the majority reported no

change (66%). Increased anxiety/stress and changes in bedtime resistance and screen time due to disruptions in routines were common reasons parents ascribed to worsening sleep habits.

Previous reports assessing the impact of lockdown measures on sleep habits of children and adolescents with NDDs have found, similar to our findings, that 30% to 40% of the sample endorsed worsening sleep quality (Berard et al., 2021; Bruni et al., 2021; Ueda et al., 2021). Variations between studies are likely due to variability in how sleep was assessed and sample characteristics (e.g., ages, geographic location).

Interestingly, a Canadian-based study by Mackenzie et al. (2021) with TD children, who also had participated in BNBD, found that 40% of parents reported worse sleep quality in their children compared to 30% in our study. It is possible that children with NDDs might not have fared worse in the pandemic than TD children because parents of children with NDDs may be more likely to uphold daily routines, resulting in fewer disturbances at bedtime. Moreover, children in this study were actively experiencing symptoms of insomnia. Therefore, the pandemic may not have had as strong an effect on their sleep habits as they already had difficulties sleeping.

To our knowledge, this is the first study that attempted to describe factors that contributed to changes in sleep habits in children with NDDs during the COVID-19 pandemic. Our findings are consistent with Mackenzie et al. (2021) who conducted interviews with parents of TD children to determine how the pandemic influenced child sleep habits. Parents of children with NDDs and parents of TD children both emphasized that increased anxiety/stress and screen time lead to worsening sleep quality. Moreover, in both studies, some parents reported that disrupted routines led to worsened child sleep, whereas others stated the disruption associated with less stringent schedules improved child sleep.

Our findings have implications for families learning to navigate a world with COVID-19, which may include future waves of COVID-19 infections and/or other conditions that unexpectedly restrict children's day-to-day activities. The development of new routines (especially bedtime routines) during the treatment of sleep problems should be emphasized and maintained during any future periods of restricted activity, particularly in children with NDDs, as poor sleep can negatively impact daytime behaviors and optimal health and well-being of these children and their families. Moreover, mitigating anxiety, stress, and worry by offering effective treatments that can be conducted virtually (i.e., cognitive behavioral therapy; Gould et al., 2018; Kalvin et al., 2021; Wood et al., 2009) and supporting families to reduce or limit screen time during future waves of the pandemic or crises may also improve sleep habits in youth with NDDs undergoing treatment for sleep problems. Healthcare providers should be encouraged to work with families of children living with NDDs around strategies to build/maintain bedtime routines, mitigate stress/anxiety, and limit screen time during periods of restricted activity.

There are several limitations to the current study. Most participants were parents of children with ADHD or ASD rather than a heterogeneous group of NDDs. Therefore, we encourage other researchers to explore these themes with parents of children with other NDDs. All measures were dependent on parental reports, which may have been influenced by additional factors, such as parental stress. Participants completed the qualitative portion of the study online with an open-ended text box. While having parents describe changes in sleep using an open-ended text box increased the number of participants who provided data, it reduced the richness of the data. Future research using interviews as a data collection method would allow for in-depth exploration of experiences. Future studies would also benefit from recruiting more parents of children from under-represented NDDs, which may improve the understanding of how these findings extend to families with children with other NDDs. Finally, quantitatively assessing the longitudinal relationship between child sleep and the identified factors (i.e., change in routines and increased anxiety/stress) could help elucidate the relationship between these variables. This could inform the development and/or refinement of healthcare services tailored to the specific needs of this population during future waves of and/or the recovery from the COVID-19 pandemic.

In conclusion, while we found that the COVID-19 pandemic did not worsen the sleep of most children with NDDs already experiencing problems sleeping, it did have a negative impact on 30% of children and a positive impact on 4% of children. Parents who identified changes in their child's sleep habits attributed these changes to increased anxiety/stress and disrupted daily routines. Healthcare providers working with families of children with NDDs (especially ADHD and ASD) experiencing sleep problems should be aware of the potential impact that future waves of the pandemic or restrictions in day-to-day activities may have on their sleep. Supporting families of children with NDDs to find ways to maintain or increase routines could help buffer the impact of stress and mitigate or prevent the development of sleep disturbances and other negative impacts of new waves of COVID-19 or future crises in children with NDDs.

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