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Occupational Disruption: The Influence of the COVID-19 Pandemic on the Behavioral Inflexibility and Anxiety of Autistic Children

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Occupational Disruption: The Influence of the COVID-19 Pandemic on the Behavioral Inflexibility and Anxiety of Autistic Children

Abstract

Background: The COVID-19 pandemic caused unprecedented changes to the lives of many. The aim of this paper was to understand how the COVID-19 pandemic impacted behavioral inflexibility (BI) and anxiety among autistic children and how autistic children and their families have adapted to COVID-19-related routine changes.

Methods: This sequential mixed-method study included two phases. During the first phase, parents of autistic children (N = 48) completed an online survey consisting of the Behavioral Inflexibility Scale (BIS) and the Parent-Rated Anxiety Scale – Autism Spectrum Disorder (PRAS-ASD). During the second phase, a subset of parents (parents of adolescents, N = 11) was invited to participate in a virtual focus-group.

Results: The parents reported a wide range of BI during the pandemic (BIS $M = 2.03$, $SD = 1.02$, range = 0.21 – 3.86). Child BI was a significant predictor of anxiety ($t[40] = 5.56$, $p < .0001$). From the focus groups, 155 codes were organized into four themes, two of which are discussed in this paper: child client factors that have changed during the pandemic and changes to family routines.

Conclusions: In this preliminary study, the parents identified problematic BI and anxiety among their autistic children. The outcomes of this small-scale study indicate that some of the changes to routines brought about by the pandemic may be helpful for autistic children after the pandemic restrictions have ended. We provide a unique perspective on how to leverage occupational changes that resulted from the COVID-19 pandemic to aid autistics during non-pandemic times.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

autism, COVID-19, behavioral inflexibility, anxiety

Cover Page Footnote

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Credentials Display

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The worldwide Coronavirus (COVID-19) pandemic in 2020 ignited an unprecedented challenge for many autistic individuals and their families (Gillespie-Smith et al., 2021; White et al., 2021). Typical daily routines were instantly altered as families could no longer rely on familiar occupations, such as attending school, eating out at a restaurant, or socializing with peers and family because of the lockdowns and business closures (Cassidy et al., 2020b). Occupations changed drastically: scheduled events were canceled, many people shifted to working remotely, and most people were forced to wear a face mask when in public. These changes were especially difficult for autistic children, who often insist on sameness, have strict rigidity in daily routines (Sethi et al., 2019), and may experience additional anxiety when their routines are disrupted (Cassidy et al., 2020b). The focus of this study was to describe the behavioral inflexibilities (BIs) and anxiety of autistic children during the COVID-19 pandemic.

BI and Anxiety in Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by differences in social processing, sensory processing, and a preference for consistency in daily routines (Autism Self Advocacy Network, n.d.). An insistence on sameness and consistency in daily routines can be conceptualized as a characteristic of BI. BI is defined as rigid patterns of behavior that contrast with the need to be adaptable to changing environmental demands (Lecavalier et al., 2020). BI is a common characteristic in autistic children (Bodfish et al., 2021; Lecavalier et al., 2020), with higher ratings reported relative to neurotypical children (Bodfish et al., 2021) and children with Fragile X Syndrome and Down Syndrome (Harrop et al., 2021). In descriptions of child BI, parents of autistic children have noted that changes to routines can cause an increase in problematic inflexible behaviors (Sethi et al., 2019). Therefore, it is plausible that changes to normal routines during the pandemic may have been especially problematic for autistic children and their families.

BI in ASD has been found to associate with a magnitude of other behaviors, including cognitive flexibility (Miller et al., 2015), rumination (Gotham et al., 2014), play style (Honey et al., 2012), and increased impairments in daily life (Ben-Sasson et al., 2008). BI and anxiety in ASD appear to be closely related (Duvekot et al., 2018). Anxiety is a common co-occurring condition of ASD, with prevalence estimates ranging up to 84% (see Vasa & Mazurek, 2015 for a review). Co-occurring anxiety in ASD worsens core ASD symptom severity (Mazefsky & White, 2014) and is associated with greater emotional dysregulation (Swain et al., 2015). Autistic individuals with co-occurring anxiety have increased health care and psychotropic medication use (Maddox et al., 2018), decreased intervention efficacy, and reduced engagement with treatment (Kerns et al., 2016). Anxiety during adolescence is predictive of later psychiatric diagnoses and suicidal ideation in young adulthood (Cassidy et al., 2020a). Further, reports of anxiety in ASD have increased during the COVID-19 pandemic (Chen et al., 2020; Guessoum et al., 2020; Tso & Park, 2020). For example, disruptions to daily routines and lockdown measures have led to higher anxiety levels among autistic populations than in neurotypical (NT) populations (Esentürk, 2020). Pre-pandemic, parents of autistic children reported that increases in inflexible behaviors tended to cause higher anxiety levels for themselves and their children (Sethi et al., 2019). Therein, it is reasonable to assume that the COVID-19 pandemic caused a problematic increase in both BI and anxiety in the autistic population, which may negatively impact the quality of life for both the autistic child and their family.

The growing body of literature indicates that changes to occupational performance associated with the COVID-19 pandemic have negatively impacted the mental health of autistic individuals (White et al., 2021) and their families (Gillespie-Smith et al., 2021). Given this and the associations between BI, anxiety,

and well-being (Boulter et al., 2014; Jenkinson et al., 2020), we sought to examine the impact and effects of the COVID-19 pandemic on the mental health and occupational performance of autistic youth. In this sequential mixed-method study, our research questions were:

1. How has the COVID-19 pandemic impacted BI and anxiety in autistic children?
2. How have autistic children and their families adapted to COVID-19-related routine changes?

We hypothesized a strong relationship between child BI and anxiety. We also hypothesized that parents would report unique challenges associated with their child’s BI as a result of the COVID-19 pandemic; however, we also anticipated that some components of the pandemic (such as more opportunities to stay at home, time to sleep in) might alleviate some children’s anxiety.

Method

Research Design

Guided by an interpretative phenomenological analysis framework (IPA; Smith et al., 2009), this sequential explanatory mixed-method study was designed to gather quantitative and qualitative information from parents of autistic children to discover the impact of the COVID-19 pandemic on child BI, anxiety, and daily occupations. IPA researchers are interested in how participants make sense of their individual experiences. IPA methods are well-suited for studying events as they are lived in real time (Finlay, 2013). The Institutional Review Board of The University of North Carolina at Chapel Hill approved all research procedures.

Participants and Procedures

Autistic children and their primary caregivers were recruited from the more extensive Project BIDD study (Jones et al., 2021; Lecavalier et al., 2020), and data were collected from June 2020 to October 2020. During the original study, participants’ autism diagnoses were verified by the administration of the Autism Diagnostic Observation Schedule – Second edition (ADOS-2; Lord et al., 2012). All of the parents of autistic children from two of the original sites (The University of North Carolina at Chapel Hill and The Ohio State University) were invited to participate. Forty-seven of the 140 (34%) agreed to participate and completed the survey, which included several quantitative measures (described below). Afterward, a subset of parents of autistic children ($n = 11$) was invited to complete a virtual focus group with two or three other parent participants. Participant demographics are reported in Table 1.

Table 1
Demographics

	Survey	Focus Group
Total N	47	11
Parent Participants		
Female Gender	46 (98%)	11 (100%)
Parent Race		
White	35 (74.45%)	10 (90.91%)
Asian	1 (2.12%)	0
Black	7 (14.89%)	0
Bi-racial	2 (4.26%)	0
AI/NA/AN	2 (4.26%)	1 (9.09%)
Parent Hispanic/Latino	2 (4.26%)	0
Average Parent Age (years)	43.04 (6.04)	44.82
Income		

< 20,000	2 (3.33%)	0
20,001–40,000	8 (17.02%)	2 (18.18%)
40,001–60,000	3 (6.38%)	1 (9.09%)
60,001–90,000	12 (2.55%)	4 (36.36%)
90,000+	22 (46.81%)	4 (36.36%)
Child Information		
Child ABIQ	90.64 (23.34)	
Average Child Age (years)	9.51 (3.67)	
Diagnosed with ADHD	15	
Diagnosed with Anxiety Disorder	15	
Diagnosed with Depressive Disorder	4	
Diagnosed with Bipolar Disorder	1	
BIS Average*	2.03 (1.03)	1.77 (0.84)
PRAS-ASD Average*±	1.21 (0.62)	1.22 (0.68)
ADOS Comparison score	6.96 (1.94)	
Received Occupational Therapy before the Pandemic	5	
Received Occupational Therapy during the Pandemic	2	

Note. AI = American Indian, NA = Native American, AN = Alaskan Native, BIS = Behavioral Inflexibility Scale, BIS-CI = Behavioral Inflexibility Scale – Clinical Interview, PRAS-ASD = Parent Rated Anxiety Scale – Autism Spectrum Disorder, ABIQ = abbreviated intelligence quotient, ADHD = attention deficit hyperactivity disorder.

*The score for this measure is calculated as the mean of the individual items

± Based on the 24 item PRAS-ASD Scale.

Phase 1

Parents were sent a link to a Qualtrics survey that described the study and asked for their consent to participate. After providing consent, the parents completed study surveys that included the following measures: the Behavioral Inflexibility Scale (BIS) (Lecavalier et al., 2020), the Parent-rated Anxiety Scale-Autism Spectrum Disorder (PRAS-ASD) (Scahill et al., 2019), and a brief demographic survey. The brief demographic survey was completed by the caregiver and included self-reported child and caregiver race, family income, and child diagnoses. This demographic information was used to characterize our participants (see Table 1). The survey ended with questions about interest and consent to participate in subsequent phases of the study. The participants were able self-select whether or not to be contacted regarding the next steps of the study.

Phase 2

A subset of parents who expressed interest was invited to participate in one of three semi-structured focus group interviews conducted via a HIPAA-compliant online video platform (e.g., Webex). Parents were invited to participate in a focus group if their child was 10–17 years of age, had an ASD diagnosis, and indicated their interest in Phase 2 through the Qualtrics surveys. Of the 32 eligible participants, all were invited, and 11 (34%) chose to participate. We limited these focus groups to only parents of adolescents because we believed the cancelation of social events may have uniquely challenged autistic adolescents, who may have been more likely to have their primary sources of social experiences be activities that were canceled because of the pandemic. Further, anxiety rates among autistic children typically peak in adolescence (Lecavalier, 2006); therefore, we anticipated that parents of this especially vulnerable group would offer unique insights into autistic experiences during the pandemic. In addition, limitations in funding and award duration prevented us from interviewing all 32 interested parents. These focus groups were designed to have only three or four parents, given that smaller focus groups tend to be preferred for virtual interviews (Griffith et al., 2020; Turney & Pocknee, 2005).

Each focus group had two facilitators. The first facilitator served as the primary facilitator and asked questions of parents. The second took notes and was responsible for asking follow-up questions at the end of the interview. The first author, with a Ph.D. in occupational therapy, and the second author, a research assistant, served as primary and secondary facilitators, respectively, for all focus groups. The focus groups lasted 80 min on average, and topics of focus included family occupations during the COVID-19 pandemic, changes to routines, child BI, and anxiety.

Measures

The BIS

The BIS is a 38-item parent-reported rating measure of behavioral inflexibility for children 3–18 years of age (Lecavalier et al., 2020). The BIS was developed through an iterative process, outlined in detail in Lecavalier et al. (2020), and measures everyday BI from behaviors present in the home (e.g., inflexibility in food choices at mealtimes) and at school (e.g., transitioning between activities) to those in the community (e.g., families limit community outings). Caregivers rate items on a 6-point scale ranging from 0, *not at all a problem*, to 5, *very severe or extreme problem* (Lecavalier et al., 2020). Scores range from 0 to 228, and a higher score indicates more BI. The measure is relatively new; in the original sample of autistic children, the average BIS score was 83.9 ($SD = 38.6$; Lecavalier et al., 2020). The BIS has high reliability ($\alpha = 0.97$). Sample items include “my child is rule-driven or rule-bound” and “my child wants to complete specific routines or rituals.”

PRAS-ASD

The PRAS-ASD (Scahill et al., 2019) is a 25-item parent-reported scale of child anxiety for children 5–17 years of age. Items are rated on a 3-point scale (0 = *not present*; 1 = *present sometimes, not a real problem*; 2 = *often present and a problem*; 3 = *very frequent and a major problem*). Scores range from 0 to 75, and a higher score indicates more anxiety. In the original sample, the average PRAS-ASD total score was 31 ($SD = 15.6$; Scahill et al., 2019). The scale has shown excellent test-retest reliability ($r = 0.88$), strong convergent validity with related measures, such as the SCARED (Birmaher et al., 1999) ($p = 0.83$; Scahill et al., 2019) and the Aberrant Behavior Checklist Irritability subscale (Kaat et al., 2014) ($p = 0.59$; Scahill et al., 2019), and strong divergent validity for unrelated constructs, such as social communication as measured by the Social Communication Questionnaire (Chandler et al., 2007) ($p = 0.33$; Scahill et al., 2019). In our study, a clerical error resulted in only 24 items of the scale being presented to parents. To account for this error, we imputed the missing score (see Data Analysis for details).

Stanford-Binet Intelligence Scales – Fifth Edition (SB-5)

The abbreviated version of the Stanford-Binet Intelligence Test, Fifth Edition (SB-5; Roid, 2003) was administered to all of the participants during a previous research visit (described in more detail in Jones et al., 2021) to determine verbal, nonverbal, and general IQ for all participants. To assess verbal knowledge, the participants completed the vocabulary subtest. To assess nonverbal fluid reasoning, the participants completed the object series/matrices subtest. Raw scores for these subtests were summed and standardized to create abbreviated intelligence quotient scores.

Brief Demographic Survey (BDS)

Parents also completed a brief demographic survey that included information about caregiver gender, sociodemographic status, activity participation, and therapeutic services. The survey results are described in the following sections and presented in Table 1.

Data Analysis

Quantitative Analysis

Descriptive statistics were calculated from data obtained in Phase One to characterize our sample. Linear regression was used to examine the relationship between the BIS and anxiety among the autistic children with complete data in both measures ($n = 44$).

To correct for the missing PRAS-ASD item not shown to parents, we used multiple imputations (Rubin, 1987) to estimate that item. A two-level (one level for subject and one level for time-point) normal imputation model was fit for the missing PRAS-ASD item based on data from the SB-V, from the present study, and the PRAS-ASD and BIS items drawn from the present study and the original BIDD study (Bodfish et al., 2021; Jones et al., 2021). This allowed for within-participant correlation on the PRAS-ASD item across study visits. The missing PRAS-ASD item from this study was imputed 10 times based on this imputation model. Results were pooled across the 10 imputations, producing a single set of results using standard pooling rules for multiple imputations (Barnard & Rubin, 1999; Rubin, 1987). The multiple imputation and results pooling was implemented using the *mice* R package (van Buuren & Groothuis-Oudshoorn, 2011).

Qualitative Analysis

To analyze the qualitative data derived from Phase 3, we first transcribed each focus group transcript verbatim. Transcription was performed by undergraduate research assistants supervised by the last author (CH). Next, coders independently and iteratively coded each transcript using NVivo 12. The first author (AD) served as the master coder and resolved any disagreements in coding. The principles of IPA (Smith et al., 2009) guided the coding process. After reading transcripts multiple times, coders identified meaningful segments of text and provided information about the phenomenon of interest.

In the initial round of coding, four independent coders generated 155 codes. These iterative codes were continually checked against previous codes, and any new codes were recorded in a memo. The master coder then removed all duplicate codes and met with team members to discuss discrepancies. Once complete agreement was reached, a particular code was given to a segment of text. This process of reduction resulted in 130 codes. Afterward, the master coder organized these codes into two themes and sub-themes according to data analysis strategies discussed in Krueger and Casey (2015). Emergent themes were clustered to identify the relationships between themes. The iterative process continued where the master coder returned to the interview texts and re-read through each transcript, ensuring that the themes applied. Lastly, cross-case analysis identified convergent and divergent themes.

Results

Forty-seven parents completed the survey. Four themes emerged from the data. For brevity, two of those themes are included in this paper. The first theme was a change in child factors, specifically anxiety, inflexibility, and individual knowledge, as a result of the COVID-19 pandemic. The second theme was changes to family routines that, paradoxically, both supported and restricted occupational participation among autistics.

Child Factors That Have Changed During the Pandemic

Anxiety

In the PRAS-ASD, the parents reported that their autistic child demonstrated symptoms of anxiety during the COVID-19 pandemic ($M = 1.21$, $SD = 0.62$; see Table 1). This was explained in further detail during the focus groups when the parents noted how their child's anxiety changed during the COVID-19

pandemic. In one particularly challenging moment, one participant’s child accompanied her in a store. “He came in, and he was all nervous and he was like right behind me, stuck to me like glue, and I’m like ‘what is wrong,’ and he says ‘I’m afraid I’m going to get coronavirus in here.’” Children also frequently worried about their loved ones catching COVID-19. For example, when one mother felt ill, she went to lay down. Her child “got upset because he thought [she] had COVID and was going to die.” Several of the parents noted their child’s anxious behaviors were quite different from behaviors observed pre-pandemic. As one parent noted, her son’s BI shifted from worrying about their next activities to “talking to us about worrying, and worrying about us separating, um, so we’ve had a shift from being anxious [before the pandemic] about unexpected things outside of our family, to being anxious about things inside of our family.”

Table 2*Code Concept with Semantic and Text Examples*

Code Concept	Semantic code example	Quote example	Number of coded segments
Child factors changing during the pandemic	Child behavioral inflexibility impacting function	But she was really upset about that and we called the teacher and I said, ‘When you say that you can take notes, is that your gentle way of saying, of suggesting, take out paper and take notes now? Or, does that mean it really doesn’t matter.’ Because for RS, she needs to hear, “yes, I need notes or no, it doesn’t matter.” She’s given the choice, then she’s going to say, ‘I can remember it’ and honestly, she can right now.	27
	General anxiety	He works himself up for no reason just, just because he knows that he feeds off my energy, you know, and if he knows that he gets worked up, I’ll get worked up.	69
	Child anxiety about COVID	[He] had some OCD in the past about, um, getting sick and the handwashing and with making sure that, um, and I think he even said yesterday, “Mom I touched-I think I rubbed my nose with my hand and touched my snot, do I need to wash my hands?” There was extra fear about a virus.	24
Changes to child routines	Missing usual activities	It’s been kinda trapped and wanting to do the favorite things that we can’t do and so seeing a lot more inflexibility, uh, and some of those behaviors a little bit so. But ordinarily, she’d be a little fish [swimming in the community pool]	23
	Missing social engagement	I think I kind of alluded to earlier... he doesn’t usually seek that out, so I am usually, I find myself saying, “oh, have you checked in with so-and-so and have you guys messaged lately?” And once I remind him, “oh I’ll go do that!” And actually, um, one of his very good friends is kind of the same way, doesn’t really reach out a lot either, so it was kind of a lot of the time it was his mom and I texting saying let’s set up a time for them to facetime for today. And then they would have a great time once we set that up and they would go do it.	6

At the onset of the pandemic, many of the parents initially struggled to help their child cope with anxiety-provoking experiences.

I don't think I handled it as, as good as I should of, but I really didn't know how to react . . . coming out of the gate, I really couldn't comfort him because I didn't know what to say and I'm not going to lie to him and say to him 'it's all going to be okay.'

As the parents and children learned more about the pandemic, anxiety decreased for some children. "When we looked into it and explained to him how we could, you know, be safer and the masks and . . . staying home most of the time. Now that he understands it, I guess he realizes that knowledge is power." For some, however, increased knowledge of COVID-19 only heightened their anxieties. One participant's child demonstrated increased anxious and obsessive-compulsive disorder (OCD) behaviors after learning more about the pandemic. "It's been hard for me to tease out how much of that is the same type of OCD he had a year ago, before there was extra fear about the virus." Clearly, the more this participant learned about the coronavirus, the more he grew concerned about the effects the virus would have on himself and his family.

Over time, the parents and children developed strategies to help alleviate anxiety. Frequently, the parents focused on how they presented information. One parent noted, "we can talk through things and kind of present it in a logical manner of this is what happened and this is why. He has a lot of anxiety over things he doesn't understand." The parents also spent a lot of time searching for information to communicate clearly with their child. "We did a lot of reading up, you know, because we didn't know either." Finding accurate information about the pandemic became a priority for families. When reading alone was insufficient, the parents called on experts for help. "The doctor called and did a little Zoom meeting with him and just answered some of his questions, and after that, he's not scared of it anymore, he's just more relaxed." Timely access to accurate information was an important factor that the parents used to reduce child anxiety. Other parents focused on presenting a limited amount of information. "I was kind of guarded with how much information to share because he catastrophizes. He just makes it all extreme, and so I don't want to share that much with him." Ultimately, the parents developed individualized and empathetic communication methods to help their child understand the complexities of the unfolding pandemic.

Inflexibility

The parents reported a wide range of BI during the pandemic in both the BIS survey (BIS $M = 2.03$, $SD = 1.02$, range = 0.21 – 3.86; see Table 1) and in the focus groups. Child BI, as explained by the BIS, was a significant predictor of child anxiety ($t[40] = 5.56$, $p < .0001$).

In our focus groups, the families shared how, in many cases, their child's BI had changed during the pandemic. Some of the parents described how the pandemic allowed them to maintain consistency in their child's routine, thereby reducing some problematic inflexible behaviors and leading to what they believed to be a surprising decrease in child anxiety. As one parent noted:

The side effect of this is reducing anxiety because she's in her favorite place, she's at home, and she gets to stay there, and mom's not dragging her out to do something . . . for her, the benefit was just being able to live life in her most favorite way, which is at home and what she calls her safe place and doing her most favorite things with mom and her brother.

Many of the parents were able to create inclusive and comforting spaces at home to decrease problematic BI.

However, for some families, the impact of the pandemic on child routines was more problematic. As the parents negotiated their own stressors of online education, therapy, and changing work situations,

they described how it was difficult to provide novel situations for their child in the wake of the pandemic. In turn, they described how environmental consistency led to a decrease in BI in the home but an increase in problematic BI when novel situations emerged. In one case, a mother discussed her son’s challenges with uncertain situations. When he asked questions, she could not explain what would happen in a new environment, and she described how she “can’t not answer him because it doesn’t calm the anxiety, so that’s [his BI behaviors] way worse than what I remember it being.” Ultimately, uncertainty about what the next day or week would hold meant it was difficult for many families to plan learning opportunities. “It is always an adjustment to try and figure out what we are going to be doing with school this week, because it seems to change every day.” However, when possible, the parents leveraged this uncertainty to support their child. As one parent noted, “his behavioral inflexibility has been forced to improve. We’ve always tried to make a point to do things like not always having to do things at the same time every day.” Because of the emerging pandemic situations, children were often forced to change their BI and, in turn, learn new skills.

Learning New Skills

In the focus groups, the parents reported that the pandemic provided opportunities for autistic children to develop new skills. For some, the fact that fewer people were out in the community meant that new skills could be practiced. With fewer people on the road, one family spent time learning to drive. For others, the fact that education shifted to online classrooms required students to practice new skills, such as typing and taking turns on Zoom. In addition, the shift to education in the home provided families with more opportunities to foster daily living skills. For example, one parent described teaching her child “to do laundry and . . . talking more about food and talking more about nutrition . . . about the kitchen and safety.” The parents leveraged their understanding and acceptance of their child to create an inclusive environment that fostered their child’s growth.

The pandemic also provided space for autistic children to succeed. One parent shared how her involvement in her child’s education changed.

My child made progress academically, like I have never seen him make progress before because now they can’t push me away through the schools, I have to be part of his learning, so I now know what he knows, I know what he doesn’t know, I know what kind of like I’m like hey, should he know decimals, he doesn’t know whole numbers completely like yes, he can count, but they say oh it’s for exposure, so I know how much of his education is BS... all of these skills umm that really weren’t transferring because of the generalization issue were happening.

The increased involvement of the parents in their child’s daily routines provided ample space for families to learn new ways of reducing their child’s anxiety, limiting their problematic BI, and enabling their success in the school environment.

Changes to Family Routines

Family and child routines changed significantly during the COVID-19 pandemic. In our study, sleep problems were a frequent challenge for autistic children and their families. In the focus groups, the parents discussed how their child’s sleep routines were often difficult to manage before the pandemic. However, because the pandemic allowed families to change sleep routines, for many children, sleep routines improved. “So, he can sleep later, he can get up and, in a less pressured way, um, get his day

started.” Another parent noted that “now he doesn’t have to get up that early, so things are a lot better in that respect because he would argue and take forever in the morning before.”

Because of BI, the parents reported that some of the children insisted on maintaining pre-pandemic routines. For example, a mother reported her child “still puts on a school uniform for school . . . and I’m like, ‘why are you wearing a school uniform’ and I was like, ‘you don’t have to get dressed in a uniform when you’re at home’.”

For some families, activities were positively impacted because more family members could be present at home. Two mothers shared that their husbands were now working from home, which meant that their husbands could be more involved in their children’s routines. As one mother noted, “my husband, so we’re in the house more together, and so I have him, he’s got my back.”

Caregivers also reported new and meaningful occupations and ways to build relationships with their autistic children. One family noted that their child’s previous occupations were primarily indoors. However, the pandemic encouraged them to include more outdoor activities into their family’s routines. “My husband and my daughter have been able to have, like, a backyard campout.” Families developed new routines. One mom noted that she and her daughter had a daily dance party. “We were all just kind of like, no, let’s just dance party the day away.”

Discussion

This sequential mixed-method study sought to understand how the COVID-19 pandemic impacted BI and anxiety in autistic children and how autistic children and their families adapted to COVID-19-related routine changes. Our findings build on previous research (Majoko & Dudu, 2020; White et al., 2021) and highlight the challenges autistic children faced during the COVID-19 pandemic. In particular, we bring into focus the important role of BI in families’ daily routines.

We found that BI levels in our study were mainly similar to our previous research; our parents reported similar levels of BI to other autistic samples when measured via the BIS (Bodfish et al., 2021; Lecavalier et al., 2020). However, qualitatively, the parents shared stories of the changing nature of their child’s BI as a result of the COVID-19 pandemic, which contrasted with those pre-pandemic (Sethi et al., 2019). This finding is particularly interesting given that previous research has reported an increase in other problematic behaviors of autistic children during the COVID-19 pandemic (White et al., 2009). While our respondents reported some cases of problematic behaviors, they primarily reported improvements in their child’s inflexibilities. This somewhat paradoxical finding is partly explained by the parents’ descriptions of creating what we call inclusive neurodivergent-affirming spaces. One feature of BI is a preference for consistency during daily occupations, and the pandemic allowed some families to create that preferred consistency in their child’s routines and environments. Ultimately, this points to the complexity of supporting autistic children and their families. Occupational therapists should support these families by helping them create routines that affirm the autistics’ ways of processing the world (i.e., consistency) while also helping the child with those still persistent problematic behaviors.

Research has shown that the uncertainty of the pandemic has been problematic for the mental health of autistic adults (Cassidy et al., 2020b), which is particularly problematic given that autistic individuals are known to have high rates of mental health comorbidities (Asbury et al., 2020; Jenkinson et al., 2020; Taylor et al., 2020). Our results contextualize the centrality of anxiety in the lives of children on the autism spectrum during COVID-19 and suggest that anxiety may also be related to intense uncertainty for children on the spectrum. Ever-shifting transitions, unclear information, and routine

adaptations make uncertain times like the pandemic especially problematic. Occupational therapists have a long history of helping autistic children cope with challenging situations (Case-Smith & Arbesman, 2008; Tomchek et al., 2010). As occupational therapists are on the front lines during moments of crisis, it is imperative we develop clear and effective ways to provide timely information to families.

Importantly, the COVID-19 pandemic provided space for many children and their families to develop different abilities. For some families, the pandemic provided flexibility, which enabled them to leverage their autistic child's strengths and preferences to teach new skills. For several families, the fact that their child could sleep past their usual school wake-up time meant that their child was more rested, better emotionally regulated, and more able to learn previously unknown skills. Based on our findings, we believe there is strong evidence for using strengths-based therapeutic approaches aimed at minimizing systematic barriers that prevent autistic children from being successful. These approaches are in line with a growing call for occupational therapists to use neurodivergent-affirming practices with autistic children (Dallman et al., n.d.; Kornblau & Robertson, 2021) and suggest that radical changes to routines and occupations may promote well-being for autistic children and their families. We recognize that such changes are difficult in the context of the systematic barriers (e.g., educational systems with strict class start times) that have existed for long periods; yet, we believe the pandemic provided a unique case study of how some extreme changes to occupations may, in fact, be supportive for autistic children.

This study highlights how BI may impact the lives of autistic children and their families during the COVID-19 pandemic and other unexpected circumstances. Occupational therapists can serve autistic families by providing needed information about uncertain circumstances. In addition, the COVID-19 pandemic has provided occupational therapists with a unique opportunity to learn about supports for autistic children. Most notably, occupational therapists must ensure parents have access to educational and therapeutic environments during virtual and in-person learning.

Limitations

Future efforts should also seek to obtain self-reported experiences from autistic children themselves. It is imperative that occupational therapists leverage this opportunity to learn from the pandemic and develop assessments and interventions to help autistic children and their families in future times of uncertainty.

Conclusion

During the COVID-19 pandemic, preliminary results from our small-scale study suggest that some autistic children experienced an unprecedented time characterized by disrupted routines, unclear information about the virus and our role in containing its spread, and evolving occupational performance. Because our sample was small and limited, readers should be cautious in interpreting these results. Future qualitative research studies are needed to provide further support for these findings. However, if other studies verify these findings, we believe these results suggest that autistic children may need additional supports during future ever-changing situations.

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