

**NAVIGATING SENSORY PROCESSING CHALLENGES DURING THE  
COVID-19 PANDEMIC**

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the  
requirements for the degree of Master of Science in Occupational Therapy

by

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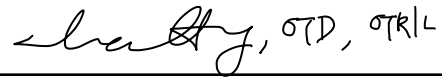
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## Certification of Approval

I certify that I have read Navigating Sensory Processing Challenges During the Covid-19 Pandemic by Kyleigh Beatty, Bennett Callado, Alyzah Dalnay, Jacklyn Liu, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

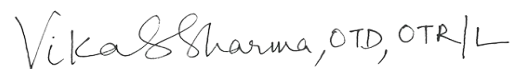


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## Abstract

**Purpose.** The current study explored the lived experiences of caregivers and families of children with sensory processing difficulties during the coronavirus disease (COVID-19) pandemic. We hypothesized that caregivers of children with sensory processing difficulties would report a greater difficulty addressing their child's sensory processing needs due to COVID-19 closures and restrictions.

**Design.** A mixed-methods study was conducted through an online survey distributed through social media. The demographics questionnaire asked 32 participants about their child's diagnosis, age, gender, and ethnicity. The caregiver questionnaire measured how family life and routines were affected during the COVID-19 pandemic over various domains.

**Results.** Statistical and qualitative data analysis revealed that 93.8% of participants experienced increased challenges meeting their child's sensory processing needs due to the COVID-19 pandemic across various domains, and that 58.6% of participants felt the education and home program provided to them was not sufficient.

**Implications.** The findings of this study add to previous research that examined the lived experience of parents and caregivers with children with sensory processing difficulties. We suggest improved caregiver education and resources from occupational therapy practitioners to help these families navigate the new normal. Future research can address ways occupational therapy practitioners can help families meet the needs identified by this study.

*Keywords:* pediatric occupational therapy, sensory processing difficulties, caregiver lived experiences, COVID-19 pandemic, survey research

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### **Navigating Sensory Processing Challenges During the COVID-19 Pandemic**

Many children receiving occupational therapy (OT) services have difficulty registering sensory input from their environment, also known as sensory processing and integration (Reynolds et al., 2017). Children who experience sensory processing difficulties are unable to appropriately respond to their environmental stimuli which impact their developmental skills for everyday routines, social participation and play. According to Schaff et al. (2014), engagement in client-centered sensory integration (SI) interventions in sensory gyms or OT clinics have been shown to improve a child's ability to process sensory stimuli, set and achieve goals, perform functional self-care tasks, and socialize with others. However, due to the COVID-19 pandemic, many of these sensory gyms and OT clinics were closed or only allowed for limited access. Additionally, many of the community playgrounds and sports programs that families sought as integral sources of sensory input were also put on hold. While OT sensory recommendations usually consist of a combination of a sensory gym and community experiences, families were left with little to no outside sources of sensory input for their children with sensory needs.

As of yet, there has been no research published to assess the need for adapted SI interventions and additional family support due to the constraints adopted to mitigate the COVID-19 pandemic. However, even before the pandemic posed an issue, there has been a functional need to provide home-based and caregiver-directed interventions, as many functional difficulties in sensory processing occur in the home. According to Miller-Kuhaneck and Watling (2018), the OT field has made limited contributions towards the importance of providing home-based interventions or parent training and education

related to their child's sensory needs. Additionally, most SI interventions have certain environmental demands that will need to be addressed when adapting an SI experience to the home (American Occupational Therapy Association [AOTA], 2014). Given that most SI interventions take place in the home and under the parents' direction, it has become increasingly important to understand these lived experiences in order to improve recommendations, parent education, and environmental adaptations for more effective SI interventions.

This research aimed to understand how the families of children with sensory processing difficulties have been affected during the COVID-19 pandemic as well as to gain caregiver perspective on providing home interventions for children with sensory processing difficulties during this time. This research takes the first step towards questioning existing practice in light of the COVID-19 pandemic, and also provides insight into the ways in which occupational therapy can be more meaningful and beneficial for families with a child who has sensory processing difficulties.

### **Literature Review**

#### **Family Experiences of Raising a Child with SI Difficulties**

In order to provide caregivers with specific SI interventions, relevant caregiver education, and appropriate recommendations for environmental adaptations, OT practitioners must familiarize themselves with a family's experience of raising a child with SI difficulties. In a qualitative, exploratory study by Scotch (2017), various struggles in family dynamics were identified within families that had a child with sensory processing disorder (SPD). A few of these struggles included recurring conflict between parents, revolving life around a schedule, living with increased stress, balancing attention



among all family members, and developing and maintaining social relationships with others. Chiu (2013) explored the experiences of mothers raising a child with SPD, and similarly found mothers struggled with juggling their dual roles as working mothers while also tending to their children's needs during homework after school. It was reported that the majority of the time spent between mom and child was occupied with completing the child's homework, which increased nervousness in the mother. The survey results of Fletcher et al.'s (2019) study provided further insight into what sensory challenges children with SPD have, as well as strategies to manage their behavior. Some children were reported to have abnormal gait, clumsy behavior, or offensive behavior towards other people around them. The main strategies shared in this study were using comfort objects or therapy pets, going out at a time when there are fewer crowds or when the caregiver has more energy for watching their child, and being prepared for what to expect in the situation or event. These strategies were credited with being able to help with regulating the unpredictability of their child from the environment and to support the child's safety and enjoyment in activities they find meaningful.

According to the research identified, the daily routines of families of children with sensory-related behaviors are impacted. Schaaf et al. (2011) identified that parents accommodated their child's sensory needs by driving two cars to family outings in case their child needs to go home early, and tailored vacuuming schedules around their child with auditory sensitivity. Parents also experienced guilt for a variety of reasons: the lack of attention they are providing to other siblings, the lack of socialization the parents can experience with peers, or the inability to participate in outings as a married couple because of challenges to find appropriate childcare (Schaaf et al., 2011). Another

difficulty identified was children with SPD could demonstrate avoiding behaviors to tactile input from their clothing. These findings established the need to anticipate the child's needs in the environment to minimize risks and to be "2 steps ahead," as stated by a parent in Schaaf et al.'s study.

Given the shared experiences that these studies have explored with families and meeting their child's sensory needs, there is a need for healthcare professionals to apply a family-centered service for parents of children living with SPDs (Chiu, 2013). Offering and applying family-centered service can help to relieve stressors and social isolation while providing a form of social support. These studies suggest the need for healthcare professionals to teach caregivers how to better engage with their child with SPD, as this could decrease stress and tension in the family.

### **Parent Education and Coaching**

Regarding parent-implemented SI interventions in the home, parent education is essential for positive outcomes in child functional improvement (Miller-Kuhaneck & Watling, 2018). While a child can show promising results through a session with an OT practitioner, caregivers and parents must be involved in the ongoing follow through and treatment of their child's natural environment. Through 1-on-1 sessions, the OT practitioner can mimic the environments that a child will experience throughout their day but it will not be the same as the natural environment. Thus, caregiver education is important in noting how to tackle these situations and develop strategies that work best with their child. Additionally, there seems to be a lack of parent knowledge regarding their child's sensory processing/integration difficulties. In a study by Kumar and Nagalakshmi (2019), 77 parents/caregivers were asked about their knowledge of their

child's diagnosis. Only 34.08% of parents were aware that their child needed SI therapy. On the other hand, 50.9% of parents were unaware of their child's sensory problems, and 15.2% were unsure.

Further, Vertes et al. (2018) explored research that looks at parents' experiences of observing their child during their sensory motor therapy and after receiving information regarding their child's participation in the sensory motor group. This qualitative study found three overarching themes: parent support, the benefit of observation, and knowledge. Parents reported they felt they could better understand their child's difficulties with sensory input and how they could help them through observation. Parents also stated that observation allowed them to feel better equipped to reinforce therapy at home in order to help and meet their child's sensory needs. Similarly, being knowledgeable enabled parents to better understand SPD and apply various therapeutic tools. Pfeiffer et al. (2017) similarly found that parents reiterated the importance of being prepared to adapt to their child's sensory needs. They were able to establish strategies to prevent or enable their child's participation in the environment and society. Findings from these studies support the rationale for parent education and demonstrate how beneficial it can be in order to apply and carry over knowledge parents learned in sessions to their homes to better assist their children. There is a need for therapy to not only be applied when children are seen in sessions by their OT practitioners, but also in the home and community. Therefore, parents should be educated on how to properly care for their child outside of therapy. While the need for parent education is clear, the OT profession has made a limited contribution to providing parent education and training (Miller-Kuhaneck & Watling, 2018). Preliminary studies on the efficacy of providing

training and education for parents indicate that it can result in positive outcomes for the child and family—even after fairly minimal hours of education time. Since the most SI interventions are currently taking place in the home under the parents' direction, caregiver education is now more important than ever.

### **Environmental Supports and Adaptations**

According to the OT practice framework, a child's environment should encompass physical, cultural, social, temporal, and virtual conditions (AOTA, 2014). Reynolds et al. (2017) have indicated that a child's environment can improve or diminish a child's ability to learn and participate in meaningful daily activities. Additionally, Pfeiffer et al. (2017) suggest that the strategies parents use to enable their child's participation in society relies heavily on environmental modifications. One of these strategies involves ensuring that their chosen activity occurs in a sensory enriched environment. This includes swings at the parks, foam pits at the gym for deep touch, the feeling of resistance of water in swimming, and darkness in movie theaters (Pfeiffer et al., 2017). Another modification parents learned in this study is to be adaptable to their child's needs. This includes taking tags off of clothes, dimming the lights, and reducing noise in the environment.

Traditionally, an OT will make recommendations for accommodations or modifications based on assessment results, activity analysis, and observation (Reynolds et al., 2017). The child is typically included in the process of deciding which environments to assess whenever possible. Additionally, many SI traditionally prescribed or implemented by an OT have specific environmental demands that cannot be met in today's climate. Currently, many of these modifications are taking place within the home

due to the COVID-19 pandemic. Being indoors creates a challenge for both the child and parents/caregivers who are looking for creative ways to get and provide that sensory input. In Sahoo and Senapati's (2014) study, a sensory diet that included outdoor play and SI techniques was shown to be more effective than SI interventions alone. The experimental group, which consisted of both outdoor play and SI techniques, had a mean score difference between pre- to posttest of 16 compared to the mean score difference of 6.58 of the control group with only SI interventions. This indicates a need for practitioners to find ways that outdoor play activities can be replicated in the home. Some environmental modifications that have shown to be helpful in the home with specific sensory dysfunctions include altered seating (ball chairs, air cushions, rocker chairs), compression clothing, fidget toys, weighted tools, use of headphones, visors, sunglasses, study carrels, light covers, and sound proofing (Reynolds et al., 2017). These environmental modifications should be used and prescribed with caution. As with other aspects of sensory integration, there is currently a lack of research regarding the effectiveness of specific environmental modifications.

### **Statement of Purpose**

The purpose of our study was to gain a deeper understanding of the lived experiences of families of children with sensory processing difficulties that have since been affected by the COVID-19 pandemic. By surveying this population of caregivers, we aimed to gain a new understanding of the experiences of families with children with sensory processing difficulties and specify the challenges they have faced in adapting to the new contextual and environmental restraints of the COVID-19 pandemic. We hypothesized that caregivers of children with sensory processing difficulties would report

a greater difficulty addressing their child's sensory processing needs during the COVID-19 pandemic. Furthermore, we predicted that caregivers of children with sensory processing difficulties would indicate a greater need for education and programming from their OT during this time. The COVID-19 pandemic has made it more apparent that there is a need to better equip and educate parents to be able to adapt and address their child's sensory processing needs and understand the needs for adaptive SI interventions. For our outcomes, we hope to obtain improved knowledge on the current sensory needs that are needed in the home due to the closure of external resources and gain a deeper understanding about families' lived experiences during the COVID-19 pandemic. One of the aims of this study was to develop a foundation for improving how OT practitioners may better educate and therefore empower families to care for their child with sensory needs to succeed in any environmental or pandemic context.

### **Theoretical Framework**

Two theoretical frameworks may be applied when considering families of children with sensory processing difficulties and their experience with navigating sensory difficulties during the COVID-19 pandemic. First, the SI framework is integral in understanding difficulties in development, behavior, and family function that are common for children and families of children with sensory processing difficulties. Second, the person-environment-occupational performance (PEOP) model explores the intrinsic factors of the children and families, their occupations, and environmental variables that have been affected by the changing environment and context brought upon by the COVID-19 pandemic. These implications will be important when considering the effective and permanent changes that this pandemic will leave.

### **Sensory Integration**

A child with a sensory processing difficulty may require assistance from an OT practitioner to help them process and integrate different sensory functions such as visual, hearing, vestibular, taste, smell, proprioceptive, touch, interoception, pain, and/or sensitivity to temperature and pressure (AOTA, 2014). The concept of SI originated from the works of A. Jean Ayres (Parham & Mailloux, 2014) and was based on the idea that the function of the brain is connected with the child's ability to develop, learn, interact, and engage successfully in daily occupations. Abdel Karim and Mohammed (2015) conducted a study that described how atypical sensory reactions could be partly due to poor sensory integration in the nervous system. This leads to impairments in attention, arousal, and abnormal self-stimulatory behaviors. In order for the body to learn how to adapt, organize sensory information, and regulate itself, adequate sensory stimulation is necessary during the critical developmental stages of a child's life. Lack of proper sensory input impacts a child's ability to function optimally and can even cause the brain to malfunction.

### **Person-Environment-Occupation-Performance**

To further examine our approach to understanding the challenges these families' faced during the COVID-19 pandemic, the PEOP model can assist in exploring what is affecting the family, whether it includes psychological or physiological issues, environmental features, including social support or physical environment, or challenges within the roles of the family, including the tasks they have. This theoretical framework emphasizes the complexity of person-occupation-environment relationships and describes how a person's occupation, behaviors, and the context of one's environment is very much

interconnected (Cole & Tuffano, 2020). This is a client-centered model, which means it examines everything meaningful and important to the client, including activities the person wants and needs to do (AOTA, 2020). Through this model, we can approach how the interactions of the person and environment will support or hinder occupational performance (Baum et al., 2015).

The four crucial variables of the PEO model—personal factors, environment factors, occupations, and occupational performance—can all affect performance (Cole & Tuffano, 2020). We examined the personal factors that could have hindered or supported the life-altering changes that the COVID-19 pandemic brought to the families of children with sensory processing difficulties. Additionally, with the closures of schools, clinics, and playgrounds due to the COVID-19 pandemic, there was a need to research and understand how these changed environmental factors impacted caregiver success in addressing their child's sensory processing needs. The PEO model allows us to see how the person, environment, and their chosen occupation can influence the performance and participation.

## **Methodology**

### **Participants**

The participants for this study consisted of 32 caregivers of children that have sensory processing difficulties (N=32). The child diagnoses included 71.9% with SPD, 53.1% with autism spectrum disorder, 28.1% attention deficit hyperactivity disorder, 21.9% with developmental delays, and 24.8% with other disorders which included disruptive mood dysregulation disorder, anxiety, reflexes integration, dyspraxia, attachment disorder, cerebral palsy, and speech and language disorder. Child age



categories included 9 children in the 0–5 range, 16 children in the elementary school age group, 3 children in the junior high school age group, and 4 children in the high school age group. Regarding gender, 23 children were male, 8 children were female, and 1 preferred not to disclose. The majority of participants (26) identified as White or Caucasian, 2 identified as Hispanic or Latino, 2 identified as Asian or Pacific Islander, 1 identified as multiracial or biracial, and 1 identified as Indian. We recruited participants through the distribution of an online Google Forms survey which was posted on various Facebook groups and online support groups for parents and caregivers of children with sensory processing difficulties. Participants were eligible if they agreed to the informed consent form, were a caregiver of a child (age 0–18) with sensory processing difficulties, and were at least 18 years of age. See Table 1 for our full participant demographic information.

### **Measures**

The demographics section of the questionnaire consisted of four questions that asked participants about their child’s current diagnosis, age, gender, and ethnicity. For the child’s diagnosis, four diagnoses were listed, and there was an option to write in a response. The child’s age was reported using four different age categories which included 0-5, elementary, junior high, and high school. Gender categories included male, female, nonbinary, and an option if they preferred not to disclose. Ethnicity categories included Asian or Pacific Islander, Black or African American, Hispanic or Latino, Alaskan native, Native American, White or Caucasian, multiracial or biracial, and an option to write in a response. See Appendix for the complete demographics questionnaire. The caregiver questionnaire contained 17 questions, including two open-ended questions. The

survey addressed the impact of daily life routines (such as attention, socialization, hygiene, grooming, feeding, bathing, toileting, and their child's arousal level) during the COVID-19 pandemic. Questions also addressed how caregivers have coped with or addressed these challenges in the home over the course of the COVID-19 pandemic (such as dedicating more time to address the child's needs, whether they purchased additional play equipment, if they utilized online resources, etc.). Finally, the questionnaire asked how equipped or educated the caregivers felt to address these needs, and if education on sensory integration or ideas for at home activities would have helped these caregivers or if it could help them in the future. Quantitative items in the survey were either yes/no responses, multiple responses, and/or included an option to write in a response. See Appendix for the complete caregiver questionnaire.

### **Procedure**

The survey assessed caregiver knowledge on sensory techniques used in the home, and how the COVID-19 pandemic has affected their child's sensory needs. Survey links were posted through different discussion and support groups on Facebook and Instagram starting April 22, 2021 and were live until June 3rd, 2021. We reposted survey threads to prevent it from being lost into old threads and keep it relevant.

Participants accessed the online link to our Google Forms survey. All participants received an informed consent form. If participants agreed to the informed consent by typing the phrase "I agree," they were prompted to the demographics questionnaire where they were first asked about their child's diagnosis, age, gender, and ethnicity. Following the demographics questionnaire, participants answered the multiple-choice questions

within the caregiver questionnaire. Finally, participants were prompted to answer the final two open-ended questions of the caregiver questionnaire.

### **Data Analysis**

The survey consisted of a mixed methods design including both quantitative and qualitative data collection. Quantitative data from multiple choice style questions was analyzed into percentages and qualitative data gathered from the open-ended questions was coded and extracted for themes. Content analysis was used on data collected from the open-ended questions to identify relevant themes and issues. We blinded ourselves to the identity of respondents to eliminate bias as much as possible. We focused on recognizing patterns within the survey responses. After initial reading, we then identified a handful of themes; these themes are presented in the following results section with quotes from the responses of the caregivers. The results of this study can improve the ways in which OT practice can better educate and prepare families to address their children's sensory needs within their natural family and home environment.

## **Results**

### **Quantitative Data**

Preliminary analysis indicated that the data of this study met the assumption of normality through the central limit theorem ( $N > 30$ ). Results of this study supported the hypothesis that caregivers of children with sensory processing difficulties experienced disruptions in services as well as increased challenges in meeting their child's sensory processing needs due to the COVID-19 pandemic. 93.8% of participants indicated that their services were disrupted, and 93.8% of participants indicated that they experienced increased challenges in meeting their child's sensory processing needs. Of the

participants, 62.5% also responded that they personally felt equipped to meet the sensory processing needs of their child. Finally, 58.6% of participants felt the education and home program provided to them by their OT did not sufficiently prepare them to address their child's sensory processing needs at home. Table 2 displays the responses and percentages for each of the multiple-choice survey questions as well as the four yes/no questions on the caregiver questionnaire.

Quantitative data from this study indicate that participants had to adapt to various specified changes due to the COVID-19 pandemic. These major changes included the transition to online learning (75%), the closure of playgrounds (68.8%), the closure of community recreation areas (65.6%), the disruption of OT services (40.6%), and other changes (18.8%). Responses indicate that children from this sample face challenges in their everyday routine, such as: difficulty paying attention and focusing on tasks (81.3%), lack of social interaction (81.3%), impacted educational success (75%), lowered self-esteem (50%), participation in their self-care routine (46.9%), and difficulty with arousal (low = 40.6%, high = 37.5%). Responses also indicate that challenges that the family has experienced includes maintaining family routines (87.1%), increased stress among family members including sibling and marital relationships (87.1%), caregiver burnout (77.4%), impact on parent's work schedule or parent's engagement (67.1%), and lack of support from child's service providers (54.8%), among others.

Quantitative data from this study also indicate that various supports were employed to help the caregiver, the family, and the child with sensory processing difficulties during this time. Results indicated that personal strengths (68.8%), online parent support groups (53.1%), family (46.9%), extended family (31.3%), and religion or

spirituality (15.6%), and others (9.3%) helped them through this difficult time.

Participants also indicated a variety of actions that were required to address their child's additional sensory challenges: purchasing additional play equipment for sensory input (81.3%), dedicating more time to address their child's needs (75%), and utilizing online resources to come up with home activities (53.1%). Finally, participants indicated what additional resources would have helped them to better adapt to their child's sensory processing needs during a pandemic. The most favored responses included ideas for home activities (83.9%), and education on sensory integration (67.7%), among other responses.

### **Qualitative Data**

The first open-ended item was, "If comfortable, please share a story or an example of when your child's sensory processing needs were clearly impacted by the COVID-19 pandemic and how this interfered with their daily routine." The second open-ended item was, "What tools as a parent did you use to help your child in the above situation?" See Appendix 1 for the full caregiver questionnaire. Each of the two open-ended items from the caregiver needs survey were optional to respond to, and they each had 16 responses out of the total number of 32 participants. Codes from the responses were first identified, and these codes were then categorized into six common themes.

#### ***How a Child's Sensory Processing Needs were Impacted by the COVID-19 Pandemic***

The question on sharing a story or an example on the change of the child's sensory processing needs and how this impacted their daily routine was coded into: (a) social skills and lack of socialization, (b) difficulty with activities of daily living (ADLs)—dressing, feeding, sleeping, grooming, etc. (including wearing a face

mask/covering), (c) self-esteem/depression/emotional dysregulation, (d) increase in problems with attention and fidgeting, (e) difficulty adapting to change, and (f) heightened sensitivity to sensory input.

**Social skills and lack of socialization.** The most common issue raised by 9 out of 17 respondents was a decrease in social skills and a lack of socialization. Some caregivers described how having to social-distance added to the barrier of social interaction skills and opportunities their children face. One participant wrote, “he lost a very important year of building social skills, which he already tracked behind in.” This describes the extra process some children with social challenges need in order to have more experience in communicating appropriately with peers or those in their communities.

**Difficulty performing activities of daily living.** The next most common theme raised by 7 respondents concerning impacted child sensory needs during the COVID-19 pandemic was a new or worsened difficulty performing ADLs. Participants indicated that many children faced new difficulties with completing ADLs such as dressing, feeding, sleeping, and grooming. Included in this category is a new ADL that was identified during the COVID-19 pandemic—donning and wearing a mask in public. Some participants reported that they started noticing that their child began, “refusing to get dressed” and “waking up at night again.”

**Self-esteem, depression, and emotional dysregulation.** Another common theme that many participants noticed with their child with sensory processing needs was a decrease in self-esteem, and an increase in depression and emotional dysregulation. One participant noted that, “there were a lot of meltdowns, emotional dysregulation, [and] just

unhappy kids.” Similarly, another participant noted that they, “saw more outbursts, meltdowns, and a dislike for daycare.” In one extreme case, a participant noted that their son’s self-esteem became really low and he began, “wishing he was dead and writing ‘I hate school’ on his arms.” Another participant reported that their child, “became very irritable and got angry and upset a lot faster” during the COVID-19 pandemic. These emotional disturbances led some caregivers to make modifications; one parent reported that many times they, “chose to not have him participate in these [online school lessons] because he would become so upset.”

**Increase in problems with attention and fidgeting.** Participants also indicated that many children with sensory processing difficulties faced an increase in problems with attention and fidgeting during the COVID-19 pandemic. One parent reported that their child has been, “more fidgety than usual,” and another noted that their child has displayed, “difficulty with maintaining attention for learning.” Similarly, another participant reported that: “During distance learning, my child had the need to constantly be pounding on the table or touching the caretaker. He was consistently distracted by the screen and the need to continuously touch the iPad.”

While maintaining attention during online learning was clearly a common issue for many of the children in this sample, it appears to have been a similar problem when moving to telehealth. One participant noted that, “Moving to telehealth OT sessions failed. He couldn’t sit through the session. Home was too much of a distraction.”

**Difficulty adapting to change.** Some participants emphasized that their child with sensory processing difficulties had a more difficult time adapting to the major changes that the COVID-19 pandemic brought on. One caregiver reported, “We tried our

best to prepare our son for this new change, but it was very challenging for him to adapt. It was an abrupt change to his routine.” Another participant noted that their child, “cannot process the changes going on around him and people dying.”

**Heightened sensitivity to sensory input.** Some parents identified that the COVID-19 pandemic brought upon some unexpected “acute sensory reactions.” Sensory sensitivities identified ranged from children being “auditorily overwhelm[ed],” to “proprioceptive seeking through hitting, tapping, ripping, kicking.” Many caregivers expressed distress when attempting to mitigate their children’s new sensory sensitivities, with one participant identifying that:

[my child] would wake up screaming and crying because anything touching her skin would hurt. I couldn’t even hold her to calm her down because even me touching her would hurt. It was like that until she started occupational therapy.

With the disruption in the schedule and not being able to go to therapy, she started waking up at night again.

### ***Tools Used by Caregivers to Address Child’s Impacted Sensory Processing Needs***

The question of what kind of tools the caregivers used to address their child’s impacted sensory needs was asked to understand what kind of modifications or adaptations caregivers used as a response to their concerns from previous questions. We coded the participants answers to this open-ended question into use of equipment, toys, electronic devices, and arts and crafts; outdoor or active activities, heavy work, and/or physical touch; priming techniques and verbal prompts or praise; socialization; mindfulness, grounding, and behavioral techniques; and established and/or modified routines.



**Use of equipment, toys, electronic devices, and arts and crafts.** The most common theme, one that was identified 19 times, was the need to use extra equipment. Being in their homes for most of their days reflected this change, therefore caregivers addressed their child's sensory needs with "sensory toys," "alternative clothing," and a "calming box." One caregiver identified a way to assist in the child's attention in table top activities by placing a "silicone makeup cleaning pad within his reach as an appropriate place to touch . . . to limit the interaction or constant need for touch." Other equipment identified from other caregivers included electronics and media like "hand washing timers, "iPad," and "YouTube videos."

**Outdoor or active activities, heavy work, and/or physical touch.** The next most common technique identified was the use of physical activities and the outdoors to address their child's sensory needs. As identified with a couple of caregivers, some of these activities included the use of equipment like "swings, trampoline, blanket wraps" and "weighted blankets." Some caregivers reported that they generally just "started trying to do or find more active activities." While another caregiver specified that they "took her to the lake where she could play in the sand." A few parents identified the role and purpose to these activities by stating "physical activity to alert for work and support self-regulation," "heavy work activity before daycare," and "heavy work during breaks or before beginning asynchronous learning."

**Priming techniques and verbal prompts or praise.** Caregivers also reported that this technique was used as a method to address their child's sensory needs. Two caregivers describe explaining to their child how the day would look, with one caregiver reporting, "talking to him every morning about how drop off would go" and the other

giving “information about schedules and expectations.” Two other caregivers devoted time to create dialogue between them and their child by “talking to her” and “giving consistent praise.”

**Socialization.** As stated previously, socialization was one of the biggest problems identified during the height of the COVID-19 pandemic. The main way to address this issue was through virtual meetups. One of the caregivers “started trying to let him FaceTime or video chat with his one friend he has had since kindergarten.” Other caregivers identified family as their main source of socialization. They reported that “he benefits from a twin that tends to make friends easily otherwise it would have been very hard to have anyone to reach out to for this socialization.” This same caregiver was able to find a “small pod of friends” to engage their child in socialization.

**Mindfulness, grounding, and behavioral techniques.** Another identified theme was the use of mindfulness and grounding techniques. One caregiver identified the practice of “mindfulness, grounding sensory strategies, and calming strategies to prepare for bed/reduce anxiety.” Other caregivers identified strategies in changed behavior for the child and themselves. For the child, one caregiver created “behavior modification strategies and working in desensitization of masks.” As for the caregivers themselves, one stated “just by managing our own reactions and behavior helped.”

**Established and/or modified routines.** With the change caused by the COVID-19 pandemic, caregivers had to establish new or modify existing daily routines. Some caregivers stated generally that they “made our own routines,” while others caregivers identified specific things that they have added like “letting her sleep in bed with me” or “buying lots of individual smaller packets of food where possible for his use only.” This

theme was identified in summary of all the previous techniques/themes that the parents reported. One caregiver stated that “at the time we knew very little,” and used new equipment and implemented heavy physical work in a trial-and-error fashion to meet their child’s sensory needs.

### **Discussion**

Through this research project we hoped to obtain improved knowledge on the lived experiences and challenges of children with SPD, and their families, during the COVID-19 pandemic. The hypothesis of this study stated that caregivers of children with sensory processing difficulties would report a greater difficulty addressing their child’s sensory processing needs during the COVID-19 pandemic. A secondary hypothesis stated that caregivers of children with sensory processing difficulties would indicate a greater need for education and programming from their OT during this time. The results of this study support the hypothesis and support the prediction.

While research on the lived experiences of children and families with sensory processing difficulties is limited, previous research indicated that the societal changes brought about by the COVID-19 pandemic would be a disruption and difficulty in the lives of these children, as well as their family members and caregivers. Results from this study indicate that a majority of families with children with sensory processing difficulties experienced some type of disruption (in services, etc.) during the COVID-19 pandemic, which caused a difficulty in meeting their child’s sensory processing needs. Contrary to the preliminary hypothesis, many caregivers from this study indicate that they felt equipped to handle the increase in difficulties. The majority of caregivers felt

that the education and home program provided to them by their OT was not sufficient in meeting their child's sensory processing needs during the COVID-19 pandemic.

Furthermore, qualitative research from this study sheds light on the lived experiences of those caring for children with sensory processing difficulties during this time. These results indicate how sensory processing needs were impacted by the COVID-19 pandemic including an impact on ADLs, socialization, emotional regulation, attention, as well as adapting to change. These results also indicate the ways in which caregivers adjusted or assisted their child through these difficulties. These include the use of equipment and toys, the use of prompting and praising, socializing with others, engaging in physical activities, establishing or modifying a routine, as well as through the use of mindfulness and grounding techniques. When looked at together, these results display the common difficulties that these families faced during the pandemic, and also the similar ways in which these families coped with these difficulties.

### **Strengths**

One strength of the present study is that it researched a phenomenon that had not yet been studied. To date, there has been little research in OT on the lived experiences of parents or caregivers of children with sensory processing difficulties. Furthermore, there have been no published studies looking at how this experience was impacted by the COVID-19 pandemic. This study sheds light on the ways children with sensory processing difficulties were impacted by the pandemic, and how caregivers and family were impacted as well. Another strength of the present study is that it consisted of an adequately sized sample, to allow for normalization of the data ( $N = 32$ ). Having an adequately sized sample allows more space for the generalizability of the findings from

this study. This sample size can serve as a hypothesis-generating study that can support the call for a greater study to be conducted to address the needs reported by families.

Finally, the present study included both quantitative and qualitative data analysis. Quantitative data allows for variations in representing the percentage of families experiencing their services being disrupted due to the COVID-19 pandemic, adequacy in fulfilling their child's sensory needs, and statistical variations relating to the most common disruptions shared by families. Quantitative data highlights common areas that the majority of families could be experiencing all at once. Further, qualitative data takes into account personal testimonies that families have been able to share. Subjectivity of caregivers' personal accounts highlights individual narratives but also assess the quality and characteristics of the response in relation to other reports. A mixed method design gives us comprehensive data from both an inductive and deductive point of view and allows more depth to support the statistical analyses.

### **Limitations**

One limitation of the present study is that it did not control for bias as a confounding variable to the results. The digital advertising and Google Forms survey website link were posted on open forums that were designed for parents, caregivers, and families of children with sensory processing difficulties. It is possible that the caregivers who responded to the Google Forms survey were the parents that felt strongest about the impact of the COVID-19 pandemic on their child, on them, and/or on their family. In this way, the survey responses in the present study might reflect more of the negative experiences faced by the sample of the overall caregiver population. Or, conversely, it might reflect a sample that wanted to relay that the COVID-19 pandemic did not

negatively impact their child's sensory processing difficulties, as reflected by two participants that noted they did not have increased challenges in meeting their child's sensory processing needs. One participant out of the sample of the 32 caregivers further indicated that their child, "thrived at home during the pandemic in many ways." The caregiver goes on to explain that while their child experienced less sensory disturbances, they are aware that their child "lost a very important year of building social skills, which he already tracked behind in." Examples like this show that although some children with sensory processing difficulties might have had less sensory distractions throughout the pandemic, the isolation that they most likely experienced did not adequately prepare them for life post-pandemic.

Another limitation of the current study is that it relied on caregiver reports for diagnosis of sensory processing or sensory integration difficulties. By relying on caregiver reports for their child's diagnosis, it is possible that caregivers may lack the ability to assess areas of strengths and weaknesses in relation to sensory integration difficulties. Without direct observation from an OT practitioner, caregivers report what they perceive as areas of concern. However, areas of age-appropriate development and deficits may truly be assessed from a clinical point of view to identify underlying causes of sensory integration difficulties that may not be recognized from an individual with a non-clinical lens.

### **Clinical Significance**

Clinicians can use this information to further identify effective SI interventions to use with their patients as an integral part of therapy. An important factor OT practitioners must recognize is that home programs/activities may not generalize to the home due to

lack of parent education, recommendation, and available resources. As much as caregivers have tried to mimic sensory activities and provide sensory input, a child's behavior is different in their natural environment. This is something to consider when creating home-programs or providing advice for caregivers who struggle with their child at home.

Furthermore, OT practitioner need to take into consideration that treatment and interventions must involve the entire family. Our survey identified that 87.1% of caregivers reported having increased stress on family members, including siblings and marital relationships, and that they had trouble maintaining family routines. Therefore, building a strong occupational profile and recognizing the system perspective on family occupations are important. The involvement of family members and family dynamics are central to OT as they are the support system for the child and influence the child's environment and identity.

The next step is to identify the strengths and barriers the child and family possess from the occupational profile. In doing so, OT practitioners can develop creative ways to use the families' strengths to address their barriers. This can start with proper caregiver education on their child's sensory difficulties and needs. One way to provide proper education is to assess the caregivers' literacy levels and make sure OT practitioners educate at that level or below for accurate and efficient learning. According to health education literature, people prefer materials written below their literacy abilities (Bastable et al., 2020). OT practitioners can ask for confirmation that they are understood by the caregivers to ensure they are effectively communicating with the client. This will

allow caregivers to feel supported and respected enough to reach out when help is needed.

Further, other clinical implications that can be derived from this study are creating proper just right challenges that parents can use in their home program. Parents have reported that their child has been removed from the classroom and isolated at home due to the COVID-19 pandemic. For instance, one parent stated: “he has been excluded and his self-esteem is really low.” By providing families with more ways to create home interventions and techniques to address their child’s sensory needs, OT practitioners can help parents integrate interventions centered around the just right challenge within their home. Starting with interventions that children can easily master within their natural environment to help boost a child’s self-esteem in their performance and their self-esteem when transitioning to self-efficacy skills in relation to ADLs. Parents can use this information to apply and use effective sensory based techniques in their home.

### **Conclusion**

During the COVID-19 pandemic, the changes to daily routines and physical environment brought increased challenges for children with sensory processing difficulties and their families. Caregivers identified the need for more education about sensory integration and in-home activities that can empower them to adapt the home program interventions within any context. The results suggest there is a gap between the way in which OT practitioners have educated caregivers on home programs and what may be feasible and effective in the context of the COVID-19 pandemic. Our findings underscore the need to provide interventions that are family-centered, as well as to better educate caregivers’ understanding of sensory based interventions. With these



considerations, caregivers can adapt OT-based strategies within their constantly changing environment.

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**Appendix****Caregiver Questionnaire**

1. What is your child's diagnosis? (click all that apply)
  - a. Autism Spectrum Disorder (ASD)
  - b. Attention Deficit Hyperactivity Disorder (ADHD)
  - c. Sensory Processing Disorder (SPD)
  - d. Developmental delays
  - e. Other: \_\_\_\_\_
2. How old is your child?
  - a. 0-5
  - b. Elementary
  - c. Jr high
  - d. High school
3. Gender
  - a. Male
  - b. Female
  - c. Nonbinary
  - d. Prefer not to disclose
  - e. Other
4. Ethnicity
  - a. Asian or Pacific Islander
  - b. Black or African American
  - c. Hispanic or Latino
  - d. Alaskan Native
  - e. Native American
  - f. White or Caucasian
  - g. Multiracial or Biracial
  - h. Other: \_\_\_\_\_
5. Were your services disrupted due to the COVID-19 pandemic?
  - a. Yes
  - b. No
6. Have you experienced increased challenges in meeting your child's sensory processing needs due to the COVID-19 pandemic?
  - a. Yes
  - b. No
7. What changes have you had to adapt to due to the COVID-19 pandemic? (click all that apply)
  - a. Disruption of OT service
  - b. Transition to telehealth appointments

- c. Transition to online learning
  - d. Closures of sensory gyms
  - e. Closures of playgrounds
  - f. Closure of sports/community recreation programs
  - g. Other: \_\_\_\_\_
8. What challenges has your child faced in their everyday routines due to the COVID-19 pandemic? (click all that apply)
- a. Maintain attention/focus to tasks
  - b. Participate in their self-care routine (click all that apply below)
    - i. Hygiene/grooming
    - ii. Dressing
    - iii. Feeding
    - iv. Bathing
    - v. Toileting
  - c. Maintain appropriate arousal level to go about their everyday routines
    - i. Low arousal (seems withdrawn from environment and activities)
    - ii. High arousal (hyper-active)
  - d. Lack of social interaction
  - e. Lowered self-esteem
  - f. Impacted relationship with caregiver
  - g. Impacted relationship with family members
  - h. Impacted educational success
  - i. Other: \_\_\_\_\_
9. What challenges has your child faced specific to maintaining precautions due to the COVID-19 pandemic? (click all that apply)
- a. Wearing of facial covering or mask
  - b. Social distancing of 6ft from others
  - c. Maintaining hand hygiene
  - d. Keeping hands to themselves and avoiding contact with high touch surfaces
  - e. Covering cough or sneeze
  - f. Other: \_\_\_\_\_
10. What challenges has your family experienced in trying to meet the needs of your child with sensory processing disorder during the COVID-19 pandemic? (click all that apply)
- a. Focus shifted away from other family members
  - b. Impact on parent's work schedule or engagement
  - c. Maintaining family routine
  - d. Caregiver burnout
  - e. Financial impact from additional support or services

- f. Increased stress among family members including sibling & marital relationships
  - g. Lack of support from child's usual service providers (therapists, teachers, aides, etc.)
  - h. Other: \_\_\_\_\_
11. What helped you and your family get through this difficult time?
- a. Personal strengths
  - b. Family supports
  - c. Extended family supports
  - d. Online parent support groups
  - e. Additional services
  - f. Religion or spirituality
  - g. Other: \_\_\_\_\_
12. What have you done to address your child's additional sensory challenges during the COVID-19 pandemic? (click all that apply)
- a. Dedicate more time to address child's needs from self
  - b. Dedicate more time to address child's needs by bringing in extra caregiver
  - c. Purchase of additional play equipment for sensory input
  - d. Utilize online resources to come up with home activities
  - e. Other: \_\_\_\_\_
13. Do you feel equipped to meet the sensory processing needs of your child?
- a. Yes
  - b. No
14. What additional resources can help you to better adapt to your child's sensory processing needs during this pandemic?
- a. Education on sensory integration
  - b. Ideas for at home activities
  - c. Other: \_\_\_\_\_
15. If comfortable, please share a story or an example of when your child's sensory processing needs were clearly impacted by the COVID-19 pandemic and how this interfered with their daily routine.
- a. Option for comment
16. What tools as a parent did you use to help your child in the above situation?
- a. Option for comment

**Table 1**

*Participant Demographics*

<b>Measure</b>	<b>Item</b>	<b>Count</b>	<b>Percentage</b>
Diagnosis	Autism Spectrum Disorder (ASD)	17	53.1%
	Attention Deficit Hyperactivity Disorder (ADHD)	9	28.1%
	Sensory Processing Disorder (SPD)	23	71.9%
	Developmental Delays	7	21.9%
	Other	8	25%
Age Category	0-5	9	28.1%
	Elementary	16	50%
	Junior High	3	9.4%
	High School	4	12.5%
Gender	Male	23	71.9%
	Female	8	25%
	Non-binary	0	0%
	Prefer not to disclose	1	3.1%
	Other	0	0%
Ethnicity	Asian or Pacific Islander	2	6.3%
	Black or African American	0	0%
	Hispanic or Latino	2	6.3%
	Alaskan Native	0	0%
	White or Caucasian	25	78.1%
	Multiracial or Biracial	1	3.1%
	Other	2	6.3%



**Table 2**

*Caregiver Questionnaire Responses*

Measure	Item	Count	Percentage
Were your services disrupted due to the COVID-19 pandemic?	Yes	30	93.8%
	No	2	6.3%
Have you experienced increased challenges in meeting your child’s sensory processing needs due to the COVID-19 pandemic?	Yes	30	93.8%
	No	2	6.3%
What changes have you had to adapt to due to the COVID-19 pandemic? (Click all that apply)	Disruption of OT services	13	40.6%
	Transition to telehealth appointments	12	37.5%
	Transition to online learning	24	75%
	Closure of sensory gyms	6	18.8%
	Closure of playgrounds	22	68.8%
	Closure of sports/community rec.	21	65.6%
	Other	6	18.8%
What challenges has your child faced in their everyday routines due to the COVID-19 pandemic? (click all that apply)	Maintain attention/focus to tasks	26	81.3%
	Participate in self-care routine	15	46.9%
	Hygiene/grooming	11	34.4%
	Dressing	11	34.4%
	Feeding	8	25%
	Bathing	5	15.6%
	Toileting	11	34.4%
	Maintain appropriate arousal level	11	34.4%
	Low arousal	13	40.6%
	High arousal	12	37.5%
	Lack of social interaction	26	81.3%
	Lowered self-esteem	16	50%
	Impacted relationship with caregiver	7	21.9%
	Impacted relationship with family	14	43.8%
Impacted educational success	24	75%	

What challenges has your child faced specific to maintaining precautions due to the COVID-19 pandemic? (click all that apply)	Wearing of facial covering or mask	17	53.1%
	Social distancing of 6ft from others	20	62.5%
	Maintaining hand hygiene	17	53.1%
	Keeping hands to self/avoid surfaces	24	75%
	Covering cough or sneeze	17	53.1%
	Other	2	6.3%
What challenges has your family experienced in trying to meet the needs of your child with sensory processing disorder during the COVID-19 pandemic? (click all that apply)	Shifted focus away from other family	13	41.9%
	Impact on parent work schedule	21	67.7%
	Maintaining family routines	27	87.1%
	Caregiver burnout	24	77.4%
	Financial impact from add. support	10	32.3%
	Increased stress among family members	27	87.1%
	Lack of support from service providers	17	54.8%
	Other	1	3.2%
What helped you and your family get through this difficult time?	Personal strengths	22	68.8%
	Family supports	15	46.9%
	Extending family supports	10	31.3%
	Online parent support groups	17	53.1%
	Additional services	1	3.1%
	Religion or spirituality	5	15.6%
	Other	3	9.3%
What have you done to address your child's additional sensory challenges during the COVID-19 pandemic? (click all that apply)	More time addressing child needs (self)	24	75%
	More time add. Child needs (extra help)	5	15.6%
	Purchase additional play equipment	26	81.3%
	Utilize online resources for activities	17	53.1%
	Other	4	12.4%
Do you feel equipped to meet the sensory processing needs of your child?	Yes	20	62.5%
	No	12	37.5%

Do you feel that the education and home program provided to you by your OT has sufficiently prepared you to address your child's sensory processing needs at home?	Yes	12	41.4%
	No	17	58.6%
What additional resources can help you to better adapt to your child's sensory processing needs during this pandemic?	Education on sensory integration	21	67.7%
	Ideas for at-home activities	26	83.9%
	Other	4	12.8%